Care and Outcomes for Older Adults with Advanced Chronic Kidney Disease

Helen, Tam-Tham

doctoral thesis

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Care and Outcomes for Older Adults with Advanced Chronic Kidney Disease

by

Helen Tam-Tham

A THESIS
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Abstract

The prevalence of older adults with advanced chronic kidney disease (CKD) is increasing globally, although optimal treatment remains uncertain. We examined in this thesis survival outcomes for older adults with kidney failure treated and not treated with dialysis. We also sought to identify barriers and facilitators to optimal conservative (non-dialysis) care for older adults with kidney failure managed by primary care physicians.

We conducted three studies: a population-based retrospective cohort study using administrative and laboratory data to compare survival outcomes between dialysis and non-dialysis treatment; a qualitative descriptive study to explore primary care physician experiences when providing conservative care to older adults with kidney failure; and a cross-sectional population-based survey study within Alberta, Canada, to quantify results from the previous qualitative study. These last two studies formed a sequential exploratory mixed methods program of work to identify barriers and facilitators to community-based conservative care.

We found that compared to non-dialysis care, dialysis was associated with a reduced risk of all-cause mortality but only within the first three years following onset of kidney failure.

Conservative care for older adults is commonly provided by primary care physicians; however, they face substantial barriers to optimal care. Primary care physicians also expressed a need for resources including telephone access to nephrology or conservative care expertise, better access to conservative care clinics, and improved ability to appropriately co-manage patients with nephrologists.

Research in conservative care has previously focused on patients with advanced CKD referred to nephrology. However, conservative care and outcomes among older adults not referred to...
nephrology is largely unknown. This thesis examined clinical care and outcomes through a wider perspective. To foster clinical impact we worked closely from conceptualization to dissemination stages with key stakeholders in Alberta including the Southern Alberta Conservative Management Program, the Conservative Kidney Management Pathway Steering Committee, the Kidney Health Strategic Clinical Network, and the Alberta College of Family Physicians. Our findings contributed to development of a conservative kidney management clinical care pathway and province-wide telephone access for primary care physicians to directly contact nephrologists and conservative care specialists.
Preface

Stemming from the program of study outlined in this thesis, the following manuscripts have been published or are ready to be submitted to peer-reviewed journals. For each of the papers, Helen Tam-Than led the study design, manuscript writing, data analysis, and interpretation. Each stage was conducted with guidance from her thesis committee (Drs. Brenda Hemmelgarn, Kathryn King-Shier, Robert Quinn, Chandra Thomas, and Karen Fruetel) and other co-authors. All authors listed below contributed important intellectual content and provided critical review of the manuscripts.

**Tam-Than H**, Quinn RR, Weaver RG, Zhang J, Thomas CM, King-Shier KM, Fruetel K, James MT, Manns BJ, Tonelli M, Murtagh F, Hemmelgarn BR. *Comparison of Survival among Older Adults with Kidney Failure Treated versus Not Treated with Chronic Dialysis: A Propensity Score Matched Cohort Study.* This study is based in part on data provided by Alberta Health and Alberta Health Services. The interpretation and conclusions contained herein are those of the researchers and do not necessarily represent the views of the Government of Alberta or Alberta Health Services. Neither the Government of Alberta nor, Alberta Health or Alberta Health Services express any opinion in relation to this study.


**Tam-Than H**, Hemmelgarn BR, Campbell DT, Thomas CM, Fruetel K, Quinn RR, King-Shier KM. *Primary Care Physicians’ Perceived Barriers, Facilitators, and Strategies to Enhance...*

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~To my grandparents Yu Lian Zou and Ye Ping Gao
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<tbody>
<tr>
<td>ACEi</td>
<td>Angiotensin-Converting Enzyme inhibitor</td>
</tr>
<tr>
<td>ARB</td>
<td>Angiotensin-Receptor Blocker</td>
</tr>
<tr>
<td>CKD</td>
<td>Chronic Kidney Disease</td>
</tr>
<tr>
<td>CKD-EPI</td>
<td>Chronic Kidney Disease Epidemiology Collaboration</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence Interval</td>
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<tr>
<td>COREQ</td>
<td>Consolidated criteria for reporting qualitative health research</td>
</tr>
<tr>
<td>eGFR</td>
<td>estimated Glomerular Filtration Rate</td>
</tr>
<tr>
<td>HR</td>
<td>Hazard Ratio</td>
</tr>
<tr>
<td>ICD</td>
<td>International Classification of Diseases</td>
</tr>
<tr>
<td>IQR</td>
<td>Interquartile Range</td>
</tr>
<tr>
<td>PCP</td>
<td>Primary Care Physician</td>
</tr>
<tr>
<td>PS</td>
<td>Propensity Score</td>
</tr>
<tr>
<td>RECORD</td>
<td>REporting of studies Conducted using Observational Routinely-collected health Data</td>
</tr>
<tr>
<td>RRT</td>
<td>Renal Replacement Therapy</td>
</tr>
<tr>
<td>SD</td>
<td>Standard Deviation</td>
</tr>
<tr>
<td>STROBE</td>
<td>STrengthening the Reporting of OBservational studies in Epidemiology</td>
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</table>
Epigraph

“It is not death that the very old tell me they fear.

It is what happens short of death –
losing their hearing, their memory, their best friends, their way of life.”

- Atul Gawande

Being Mortal: Medicine and What Matters in the End
CHAPTER ONE:
AN INTRODUCTION TO TREATMENT DECISION-MAKING AND CONSERVATIVE NON-DIALYSIS CARE AMONG OLDER ADULTS WITH ADVANCED CKD
1.1 Overview

1.1.1 Overview and statement of the problem

Chronic kidney disease (CKD) and progression to kidney failure is prevalent among older adults and associated with high morbidity, mortality, and health care costs (1). While older adults with kidney failure have the highest rates of dialysis initiation (2), their survival and functional outcomes following dialysis initiation remains poor (3). Evidence-based treatment of kidney failure among older adults remains elusive as randomized controlled trials comparing effectiveness of dialysis to non-dialysis care are currently not available (4). We compared as part of this thesis the survival outcomes for older adults with kidney failure treated and not treated with dialysis (5).

International clinical practice guidelines in nephrology support conservative non-dialysis care as a treatment option for patients with kidney failure (6). These guidelines also support formalized comprehensive conservative care programs that encompass coordinated end-of-life care for patients and their families via primary care and/or specialist care. Although these programs should include multiple components including symptom and pain management, psychological and spiritual care, and bereavement support, these programs are underdeveloped and highly variable in many areas across the globe (1,7,8).

Previous work suggests that many older adults with kidney failure are not treated with renal replacement therapy (9) and not managed by specialists (10,11), indicating that it is common for older adults with kidney failure to be managed in the primary care setting. We therefore sought as part of this thesis to conduct a descriptive investigation of care for older adults with kidney failure in the primary care setting.
In summary, we conducted three studies as part of this thesis to inform prognosis and conservative care for older adults with kidney failure in Alberta. We derived a cohort from routinely collected data of older adults with kidney failure that permitted us to compare survival between patients treated and not treated with chronic dialysis. We also conducted a qualitative descriptive study where we interviewed primary care physicians caring for the population of interest to understand their perspectives on care. We subsequently used these findings to carry out a census survey of primary care physicians in Alberta to quantify barriers and facilitators to conservative care among older adults with kidney failure.

1.1.2 Aligning our research objectives with the KDIGO Chronic Care Model

We draw on principles of the CKD Chronic Care Model (12) that is endorsed by international guidelines (Kidney Disease Improving Global Outcomes) (6) to promote optimal care and improved outcomes for older adults with kidney failure. This CKD Chronic Care Model hence embeds this thesis within a larger context of CKD care. It highlights multiple principles for achieving optimal care and outcomes, including needs for: 1) self-management support and 2) decision support, and improvements in 3) delivery system design and 4) clinical information systems. We draw on two of these principles (decision support and delivery system design) to advance evidence for supporting treatment decision-making, and to generate knowledge for enhancing the quality of conservative care delivery.

1.1.3 Overview of research objectives

1. To compare survival among older adults with kidney failure treated and not treated with chronic dialysis (chapter 2)
2. To describe primary care physicians’ perspectives on conservative management of older adults with kidney failure (chapter 4)

3. To survey primary care physicians caring for older adults with kidney failure and examine the magnitude of key barriers and facilitators to conservative care (chapter 5)

1.2 Background

1.2.1 CKD in older adults

CKD is defined by abnormalities of kidney structure or function (i.e. estimated glomerular filtration rate (eGFR) <60 mL/min/1.73m² or at least one marker of kidney damage), that persists for ≥3 months with implications on health (6). CKD is common with substantial impact on public health. It is associated with increased morbidity, mortality, and health care costs (6,13–15). Approximately 13% of adults and >30% aged ≥65 years have CKD in Canada (16); these estimates are similar in the United States (17). The definition of older adults referred in this thesis is broad though generally focuses on age ≥65 years.

Development of kidney failure, defined by eGFR <15 mL/min/1.73m² (with presentation of symptoms generally by eGFR <10 mL/min/1.73m²), places an increased burden on the patient and the health care system. This is particularly relevant for older adults given the impact of kidney failure on quality of life and health care costs (18–20). Age has been shown to be a key modifier in the association between kidney failure and death (21). Treatment-decisions among older adults are complicated by their limited life expectancy, substantial burdens relating to symptom management and comorbidities, and poor health outcomes. Hence, older adults with kidney failure are a vulnerable and high-risk group that we will focus on in this thesis.
1.2.2 Treatment options for kidney failure

Renal replacement therapy options for kidney failure include dialysis (hemodialysis or peritoneal dialysis) or kidney transplant. Another treatment option is conservative (non-dialysis) care without renal replacement therapy. The majority of older adults with kidney failure are not candidates for kidney transplant due to their burden of comorbidities. Hence, their primary treatment options are chronic dialysis (22,23) and conservative care (9). Hemodialysis involves a machine with a dialyser that functions to remove waste and excess water from the blood, and is usually performed in-center three times a week (24). Peritoneal dialysis involves filling the peritoneal cavity inside the abdomen with dialysis fluid to remove excess water and waste, and is performed by the patient in their home (24).

Approximately 80% of patients age ≥80 years on dialysis are frail (25). Frailty is defined as a condition with multiple body impairments contributing to reduced resiliency and increased vulnerability to stress (26). There are a series of clinical considerations that inform whether frail and older adults may pursue dialysis (27). The clinical considerations of dialysis include impacts of treatment on quality of life and modality-specific needs. Hemodialysis has issues related to transport needs, vascular access, and time to recovery from each treatment. Peritoneal dialysis considerations include patient ability to learn dialysis procedures, availability of social support, and needs for assistance to perform dialysis (26). Although survival outcomes are reportedly similar between hemodialysis and peritoneal dialysis modalities (23), use of hemodialysis compared to peritoneal dialysis increases with age; over 90% of older adults initiating dialysis are treated with hemodialysis (23).
More than 50% of incident kidney failure patients treated with chronic dialysis in 2012 were aged \( \geq 65 \) years, a rate that has doubled since 1993 (2). The incidence of chronic dialysis in Canada is highest among older patients aged \( \geq 75 \) years (2), with similar results in the United States (28,29). Possible explanations for the increase in dialysis initiation among older adults include the rise in prevalence of CKD, availability of access to dialysis, and increasing life expectancy (29,30). There are, however, a subset of older patients including those with a high burden of comorbidity and functional impairment who may choose to forgo dialysis altogether.

### 1.2.3 Conservative non-dialysis management

The terminology surrounding non-dialysis care for patients with advanced CKD can be inconsistent (7,31,32). Kidney failure not treated with renal replacement therapy has been referred to as non-dialysis care, conservative care, comprehensive conservative care, supportive care, and palliative care; their definitions further are not always clearly defined (31). Palliative care is internationally considered an approach that aims to improve quality of life for patients and their families with serious illness (33,34). Palliative care aims to prevent and relieve suffering via early identification and management of issues related to physical, psychosocial, and spiritual well-being (33,34). Some patients and health care providers in the field of nephrology and other specialities prefer the term supportive care compared to palliative care (33,35). We, however, use palliative care and supportive care interchangeably in this thesis. Palliative care can be provided throughout the CKD disease trajectory. It is not limited to end-of-life care and can be provided concurrently with dialysis or as part of a comprehensive conservative care program (31) (figure 1.1).
Systematic reviews have found that palliative care programs involving multidisciplinary care teams for patients with various terminal diseases can help foster family/caregiver satisfaction with patient care (36). Palliative care programs are associated with improvements in patient quality of life, symptom control, enhanced advance care planning, lower health care use (37), and promote continuity of care (38). Hence, palliative care needs to be more fully integrated in the management of patients with kidney failure (22), regardless of dialysis or non-dialysis care.

For every patient who initiates renal replacement therapy there is approximately one patient with kidney failure who does not (9,31,39). Older adults with kidney failure in particular are less likely to be treated with dialysis compared to their younger counterparts (9). Conservative care is the treatment option for patients who decide not to pursue renal replacement therapy (6,40). There are three general conservative care populations among patients with advanced CKD: 1) choice-restricted conservative care, 2) unrecognized G5 CKD, and 3) comprehensive conservative care (33). Choice-restricted conservative care is not provided by patient choice; patients in this category are managed without dialysis due to limitation of resources or other factors that prevent access to renal replacement therapy (33). Unrecognized G5 CKD refers to patients not treated with renal replacement therapy, although it is also not by choice given that their CKD has not been identified (33).

On the other hand, comprehensive conservative care provides the full extent of conservative care. Comprehensive conservative care is chosen by the patient or is medically advised by their health care provider. This form of care can be structured as comprehensive programs involving multiple dimensions of pharmacological and non-pharmacological care, including active medical management and components of palliative care. It focuses on optimizing quality of life by
emphasising on slowing decline of kidney function (e.g. via blood pressure control), treating complications and symptoms, and may also include advance care planning, psychological support, and education for patients and their family members (6,31) (figure 1.1).

We use conservative care and non-dialysis care synonymously in this thesis, and refer broadly to care without dialysis that is chosen by the patient or health care provider. It is currently unknown the extent that comprehensive conservative care dimensions are implemented in care of older adults with kidney failure. Nephrologists (e.g. in renal units) in the United Kingdom for example manage many conservative care patients with variation in scope and organization (7). The provision of conservative care however is even less clear in the primary care setting. Understanding provision of community-based conservative care is especially important as a portion of patients (up to 40% of patients aged ≥75 years with eGFR <15 mL/min/1.73m²) are not referred to a nephrologist (11). We focused on conservative care chosen by the patient and/or their health care provider, although we recognize there are various pathways to kidney failure not treated with dialysis.

1.2.4 Symptom burden of kidney failure

The decision to pursue dialysis or not is complex, and is complicated by the symptom burden of kidney failure. The burden of symptoms experienced by patients with advanced CKD is high regardless of whether patients are treated or not treated with dialysis (41–45). Patients not on dialysis have a symptom burden that is analogous to patients with terminal cancer or end-stage heart failure (43,46). The most commonly reported symptoms include fatigue, pruritus, and drowsiness. Dyspnea, edema, and pain are also common among non-dialysis patients (43). The number of symptoms on average is high among non-dialysis patients, ranging from 7 to 17, with
increasing symptom burden and severity at the end-of-life (47). Patients on dialysis also experience a high symptom burden with common symptoms including pain, fatigue, pruritus, and constipation (42). Dialysis patients (and their providers) therefore have identified symptom management and pruritus specifically as a research priority (48).

1.2.5 Burden of multiple comorbidities among older adults with advanced CKD
Multimorbidity (with at least one additional chronic disease) is also common among older adults with advanced CKD (49), and has implications on the decision whether to initiate dialysis or not (50). Concordant comorbidities that share a similar pathophysiological pathway with CKD include diabetes and cardiovascular diseases, while discordant comorbidities that do not share a similar pathophysiological pathway include depression, chronic pain, dementia, and cancer (50,51). Older patients with multimorbidity and polypharmacy in particular have increased treatment burden and complexities of self-management that impact their quality of life (50).

Previous studies have shown that older patients (≥80 years) on dialysis have a high burden of comorbidities (29). Almost 30% of them have four or more chronic diseases (29), with common comorbidities including congestive heart failure (almost 50%), ischemic heart disease (over 30%), and diabetes (almost 30%) (29). Older patients (≥55 years) on hemodialysis have been found to also have moderate to severe cognitive impairment (up to 70%) (52). Some single-centred studies report similar burdens of comorbidity for dialysis and non-dialysis patients (53–55). Other studies meanwhile report that non-dialysis patients have more functional impairment, are more likely to have diabetes (56), and have a higher overall burden of comorbidity (57); ischemic heart disease is one of the most common comorbidities among non-dialysis patients (from 30% to 50%) (58–60). Treatment decision-making is therefore complicated among older
patients with advanced CKD who generally have a high burden of comorbidity, regardless of dialysis or non-dialysis care.

1.2.6 Clinical outcomes among older adults with kidney failure on dialysis

There is evidence to suggest that clinical outcomes are poor among older adults with kidney failure on dialysis. Older dialysis patients experience a high risk of falls (3), with incidence rates for falls ranging from one to two falls per person-year among dialysis patients age ≥65 years (61,62). Older patients on dialysis also experience a high risk of functional decline (3). A Canadian prospective study found that 37% of patients age ≥80 years experienced functional decline resulting in loss of independence by six months following dialysis initiation (63). The findings are similar in the United States for long-term care residents initiating dialysis (64). More than 50% of older adults on dialysis in fact require support with at least one activity of daily living (65).

Compared to conservative care, older adults (≥70 years) initiating dialysis experience an increased risk of hospitalization (53,66) and emergency department visits (67) from dialysis initiation to end-of-life. Some older adults on dialysis are reported to experience intensive procedures at the end of life including mechanical ventilation, feeding tube placement, and cardiopulmonary resuscitation (68–70). Approximately 6% of older adults (age ≥65) on dialysis receive in-hospital cardiopulmonary resuscitation (69). Older adults (age ≥67 years) that have the highest intensity of care around the time of dialysis initiation, compared to patients who initiated dialysis in the outpatient setting, are more likely to undergo subsequent intensive procedures, are less likely to discontinue dialysis before death, and have a shorter median survival (around six months versus about two years for outpatient dialysis initiation) (72). Survival has reportedly
improved over time among older patients (aged ≥65 years) on dialysis although it is still limited as the mean life expectancy after initiating dialysis ranges from two to five years (71). Survival outcomes further worsen among dialysis patients with increasing number of comorbid conditions (29).

Nevertheless, there is evidence to suggest that dialysis initiation continues to be increasing among older adults with kidney failure despite poor outcomes (29). We acknowledge that treatment decisions are complex, value-laden, and dynamic. An understanding of the effectiveness of chronic dialysis compared to conservative care would therefore help patients and their providers make informed treatment decisions. Unfortunately, we have limited research available to inform prognosis and optimal provision of care for older adults with kidney failure, particularly in relation to non-dialysis care in the community.

In summary, deciding whether to pursue dialysis or conservative care is complicated by a number of factors including symptom burden, multimorbidity, and risk of poor outcomes. However, head-to-head comparisons of patient outcomes comparing dialysis to non-dialysis care are limited and are vulnerable to methodological issues that we will explore later in this chapter.

### 1.2.7 Shared decision-making

Clinical practice guidelines recommend a shared decision-making approach when helping older adults with kidney failure decide to pursue dialysis or not (74). A shared decision-making approach draws on a balance of principles based on both autonomy and paternalism (75). Autonomy-focused decision-making respects individual freedom of choice, but can be overwhelming or even distressing for frail older adults (75). Paternalism on the other hand depends on clinicians to make medical decisions, and to act in their patients’ best interests (76).
The physician, however, is not always able to determine the optimal treatment decision for their patient without their input. Patients hence lose an opportunity to select treatment options that appropriately reflects their personal values and circumstances. Allocation of treatments by clinicians consequently could be biased and inequitably based on patient characteristics such as age, sex, and socioeconomic status. This can result in patient dissatisfaction or even regret in their treatment pursuits (73). Sixty percent of patients with advanced CKD from Alberta in 2008 reported that they regretted starting dialysis (73), and approximately half of the patients indicated that dialysis initiation was largely attributable to encouragement by their physicians (73). The pendulum of treatment decision-making for patients with terminal diseases has swung from one extreme (paternalism) to another (patient autonomy) over the past forty years (76). We are now shifting towards a shared decision-making approach that balances enhanced patient autonomy with disclosure of information (e.g. prognosis, disease trajectory, benefits and harms of dialysis versus non-dialysis care) and physician recommendations to support patient and family-centered outcomes. Shared treatment decision-making to pursue dialysis or not can be made across health care settings from primary care to tertiary care contexts.

1.2.8 CKD management in the primary care setting

Based on work from the Alberta Kidney Disease Network, the majority (almost 98%) of older adults in Alberta with earlier stages of CKD are managed by primary care physicians (10). Primary care physicians are important health care providers for patients with CKD, as they are often the first point of contact in the health care system. They also play an important role throughout the spectrum of care spanning from prevention and early identification of the disease to timely referral and coordination of specialist care (77).
There are potential barriers that primary care physicians face when providing care for patients with advanced CKD, barriers that may be addressed by interventions requiring behaviour change. A framework that is useful for examining behavioural change among health care providers is the Theoretical Domains Framework (78). This framework was developed from a synthesis of the literature on behavioural change, and is valuable for providing practical directions for the design of future interventions and policies (79). Primary care physicians can face a number of challenges when trying to provide optimal care for patients with CKD. These challenges relate to the following domains of the framework: 1) their knowledge; 2) environmental context and resources; 3) professional role and identity; and 4) beliefs about their capabilities. These four domains have been identified in the literature as potential barriers to CKD care among primary care physicians.

Firstly, previous work suggests that primary care physicians may experience knowledge gaps including their understanding of CKD (77), ability to identify earlier stages of the disease (80), understanding of risk factors of kidney disease (e.g. race and family history) (81), and how to treat disease complications (82). Secondly, they may face challenges related to availability of resources to facilitate their management of patients with advanced CKD in the community. They may be practicing in the context of primary care physician shortages (77), competing demands (83), time limitations (84), and limited access to nephrologists in rural settings (82). Thirdly, primary care physicians may experience challenges in communicating with nephrologists (82). They may have unclear referral guidelines and lack of clarity on co-management of patients (82). There are also challenges to sharing information related to a patient in a timely manner, and uncertainty of their role after referral. For example, they may have unclear responsibilities in
relation to screening and care management of comorbidities such as hypertension, diabetes, and lipid management (82,85). Lastly, they may experience challenges in their perceived abilities and that includes confidence in their ability to slow disease progression (85).

Primary care-based disease management of CKD has been shown to improve patient care and outcomes in spite of the aforementioned barriers. A program involving eGFR reporting, patient education, nutritional consultation, and medication support improved identification and management of patients with CKD (86). Another complex intervention including professional education, informatics, and financial incentives in primary care practices improved appropriateness of prescribing among patients with CKD (87). Shared models of care between primary and secondary care with nephrology can also be effective for supporting patients with stable renal function and lower their risk of renal replacement therapy or death (88).

Older patients with advanced CKD however bring a different and potentially unique set of challenges and opportunities when presented to primary care physicians. Hole et al (2016) indicated that evidence is generally available to understand care of patients with kidney failure who are referred to nephrology (89). Studies of older adults with kidney failure who are not referred to nephrology however are limited. There are many reasons why these patients may not be referred, including patient wishes and presence of comorbidities. Regardless, they represent a particularly vulnerable population with limited information on their care needs. We considered primary care physician perspectives for patients that were referred and hence co-managed with nephrologists, as well as patients that were not referred and hence managed solely by primary care physicians (chapter 3 and 4). We employed the Theoretical Domains Framework as a foundation for understanding primary care practice (78). We used this framework to inform
development of a survey to examine barriers and facilitators to conservative care in the primary care setting (chapter 5).

1.2.9 Methodological issues arising from comparisons of clinical outcomes

Evidence of clinical outcomes for older adults with kidney failure treated and not treated with dialysis is limited to observational studies. These studies are usually from small single-centers with mixed results and limited generalizability. Some studies report a statistically significant difference in median survival between dialysis and non-dialysis care (53,59), although others do not (54,56). These observational studies are prone to a number of potential biases that may distort estimates of the exposure-outcome relationship including treatment-selection bias, immortal time bias, and lead-time bias.

Treatment selection bias

One of the issues in previous studies is treatment-selection bias (90). Treatment-selection bias, or confounding by indication, is defined by systematic differences in baseline characteristics between dialysis and non-dialysis patients when estimating the effect of dialysis on survival outcomes (90). A propensity score approach is one method that can be used to address treatment-selection bias when estimating the effect of dialysis on survival using observational data (90).

A propensity score represents a patient’s conditional probability of being in a particular treatment group due to their observed or measured baseline characteristics (5). It is calculated using a logistic regression model (5). Patients with similar propensity scores have a similar distribution of baseline characteristics (91) and can be used to control for treatment-selection bias via matching, stratification, or adjustment in regression modelling (5). Matching patients by propensity score is most commonly used as it has been shown to be more effective in creating
balance in baseline characteristics between treated and untreated groups (92). We therefore used propensity score-matched methods to address treatment-selection bias (chapter 2).

An advantage of propensity score analysis is that treatment-selection bias is accounted for in the study design stage, and the estimated propensity scores are derived independent from outcome data (e.g. death) (91). This reduces the risk of biased estimates of the exposure-outcome relationship (91). Matching patients on the propensity score helps to ensure that estimates of the association between the exposure and outcome are based on comparable treatment groups (91). It is also advantageous to use propensity score methods when the outcome is rare and there are many covariates to consider with a limited sample size (5).

There are still limitations that need to be acknowledged. The study design with the propensity score approach is observational, and residual confounding or unmeasured confounding can still occur (5). Use of propensity scores in observational studies via matching generally reduces the sample size by excluding patients that cannot be matched, and those excluded may have values at the highest or lowest segments of the propensity score distribution (5). Generalizability is hence limited to patients with baseline characteristics included in the study.

*Immortal time bias*

Another methodological issue when comparing dialysis and non-dialysis care is immortal time or survivorship bias (93). This bias occurs when the time between study entry and enrolment into the treatment group or exposure is immortal and ignored (e.g. not accounting for the time prior to dialysis initiation). Ignoring this time period provides the dialysis group with an artificial survival advantage compared to the non-dialysis group. The dialysis group excludes high-risk
patients who did not survive until time of dialysis initiation, and this introduces a bias when estimating the exposure-outcome relationship.

Previous studies comparing survival between dialysis and non-dialysis care have generally not accounted for immortal time bias. Immortal time bias can be addressed primarily by three approaches. The first approach to addressing immortal time bias is to match alive and non-dialysis patients with dialysis patients at the time they are exposed (i.e. dialysis initiation). This approach addresses immortal time as the non-dialysis patients similarly survive to time of dialysis initiation. The second approach is to use a time-varying exposure variable that captures a change in treatment status. Patients are in the non-dialysis group until they initiate dialysis, with non-dialysis and dialysis periods of time categorized separately. Finally, a third approach to reducing immortal time bias is the use of a mandatory survival period prior to study entry based on an empirical assessment of the data. This approach excludes patients with very early mortality within an assigned period of time.

Assigning a survival period (third approach) is less desirable than use of the matching approach (first approach) or a time-varying exposure (second approach). The third approach is less accurate in capturing the duration of immortal time for patients treated with dialysis and excludes early deaths. We therefore used a time-varying exposure as the primary approach to address immortal time bias, as this approach maximizes our sample size including all dialysis and non-dialysis patients. We also incorporated in a sensitivity analysis the approach that matches alive and non-dialysis patients with dialysis patients at the time they are exposed (chapter 2).

*Lead-time bias*
Lead-time bias is another methodological issue that is common when comparing survival for dialysis and non-dialysis patients (94). Lead-time in our study is the time prior to kidney failure requiring dialysis. It is from the identification date of kidney failure based on screening to the presentation date of clinical indications for dialysis. Lead-time bias gives an inaccurate illusion of longer survival simply due to earlier detection of kidney failure, despite no difference from dialysis or non-dialysis care on survival outcomes (95). Lead-time bias in our study is primarily due to variability in establishing the level of kidney function among non-dialysis patients. Non-dialysis patients with more lead-time will appear to survive longer due to their residual kidney function than other non-dialysis patients with less lead-time.

Lead-time is ideally addressed in the context of kidney failure using clinical information (e.g. patient symptoms) to similarly establish an indication for dialysis initiation in both dialysis and non-dialysis groups. We aimed to address lead-time bias in this thesis by using a consistent definition of sustained kidney failure for dialysis and non-dialysis groups, namely by setting a 90-day criterion from a series of eGFR measurements <10 mL/min/1.73m² to define the start of follow-up.

We are not aware of previous work comparing survival for older adults with kidney failure treated and not treated with dialysis using a population-based cohort and propensity score matching to address treatment-selection bias. Investigations of lead-time and immortal time biases also have not been rigorously examined.

1.3 Thesis outline

The chapters in this manuscript-based thesis include a report of three studies with specific research questions formatted for publication in a peer-reviewed journal. The chapters aim to
inform outcomes pertinent to treatment decision-making and optimize conservative care for older adults with kidney failure residing in the community (figure 1.2).

We conducted as part of this thesis a population-based cohort study using linked administrative and laboratory data in Alberta from 2002 to 2012 (chapter 2). We compared survival outcomes for older adults treated and not treated with chronic dialysis, while aiming to address common methodological challenges including treatment-selection, lead-time, and immortal time biases. We also assessed the potential for effect modification by age and level of comorbidity, and conducted a series of sensitivity analyses to evaluate the robustness of our findings.

We also investigated a growing yet relatively under-studied population in this thesis: older adults with kidney failure managed or co-managed by primary care physicians in the community. We describe in chapter 3 the mixed methods study protocol and approach for integration of the qualitative and quantitative studies. We present in chapter 4 the results of our qualitative study of primary care physicians in southern Alberta, and their perspectives on conservative care for older adults with kidney failure. We identified through an inductive thematic approach major barriers, facilitators, and strategies for enhancing conservative care in the community.

We present in chapter 5 the results of our survey of primary care physicians in Alberta to quantify the magnitude of reported barriers and facilitators to enhancing conservative care. We mapped these barriers and facilitators to the Theoretical Domains Framework, and assessed potential demographic and clinical characteristics associated with key barriers to optimal conservative care in the community.
Finally, we discuss the findings of the overall thesis in chapter 6. We summarize the findings of this program of study including its strengths and limitations. We discuss the implications of these findings on clinical practice and areas warranting future investigation. The findings from this body of work can ultimately be used to inform shared treatment decision-making, inform provision of care for older adults with kidney failure in the community, and identify future interventions to improve quality of care for this older patient population.
Figure 1.1 Relationship between conservative care and supportive or palliative care for patients with advanced CKD
Supporting treatment decision-making and conservative care in the community could improve quality of care among older adults with kidney failure.

Major limitations exist in previous comparisons of survival between dialysis and non-dialysis care.

Lack of research to inform provision of conservative care in the primary care setting.

Chapter 2: Retrospective cohort study to address methodological issues comparing survival among older adults with kidney failure.

Chapter 3: Exploratory sequential mixed methods study design.

Chapter 4: Qualitative study to describe barriers and facilitators to conservative care in primary care.

Chapter 5: Population-based survey to examine magnitude of barriers and facilitators to conservative care in primary care.

Figure 1.2 Thesis overview
CHAPTER TWO:
COMPARISON OF SURVIVAL AMONG OLDER ADULTS WITH KIDNEY FAILURE TREATED VERSUS NOT TREATED WITH CHRONIC DIALYSIS: A PROPENSITY SCORE MATCHED COHORT STUDY

This chapter will be submitted as:

Tam-Tham H, Quinn RR, Weaver RG, Zhang J, Thomas CM, King-Shier KM, Fruetel K, James MT, Manns BJ, Tonelli M, Murtagh F, Hemmelgarn BR. Comparison of Survival among Older Adults with Kidney Failure Treated versus Not Treated with Chronic Dialysis: A Propensity Score Matched Cohort Study.
2.1 Abstract

Background: Previous comparisons of survival between dialysis and non-dialysis care for older patients with kidney failure are limited to those managed by nephrologists, and are vulnerable to lead-time and immortal time biases.

Objective: To compare time to all-cause mortality among older adults with kidney failure treated versus not treated with chronic dialysis.

Methods: We did a population-based retrospective cohort study using linked administrative and laboratory data to identify adults aged ≥65 years in Alberta, Canada, with chronic kidney failure from May 15, 2002 to December 31, 2012. Chronic kidney failure was defined by ≥2 consecutive outpatient estimated glomerular filtration rate (eGFR) measurements of <10 mL/min/1.73m², ≥90 days apart. We used Cox regression with propensity score matching to account for baseline differences in demographics and comorbidities between dialysis and non-dialysis groups.

Results: 838 patients met cohort inclusion criteria, with 396 (47.3%) included in the final propensity score matched cohort (mean age 80.4; 44.7% male; mean eGFR 7.8 mL/min/1.73m²). Compared to non-dialysis, dialysis was associated with a lower risk of death within the first 3 years of follow-up (hazard ratio [HR] 0.55; 95% CI 0.41 to 0.74, p-value <0.001). Dialysis was no longer associated with improved survival (HR 2.30; 95% CI 1.11 to 4.81, p = 0.026 for dialysis compared to non-dialysis care) after 3 years of follow-up. The results were robust in a number of sensitivity analyses (e.g. excluding patients with late referral to a nephrologist).
Conclusions: Among older adults with similar characteristics treated and not treated with chronic dialysis, dialysis was associated with improved survival up to 3 years after reaching kidney failure. These findings provide information to support shared treatment decision-making.
2.2 Background

Age modifies the treatment and outcomes of advanced chronic kidney disease (CKD). Compared to their younger counterparts, older adults with kidney failure experience higher levels of morbidity (25,65,94) and mortality (96). Older adults are also more likely to die than progress to initiate chronic renal replacement therapy (9,21,96). The majority of older adults with advanced CKD nevertheless receives or prepares to receive renal replacement therapy (97), with nearly 30% of patients initiating dialysis treatment in Canada aged ≥75 years (24). Complicating treatment decision-making, the life expectancy of this population is limited with or without dialysis, and the impact of dialysis on survival is not clear (98).

The decision to initiate dialysis is complex and includes quality of life considerations and the impact of treatment on patients and their families (99), although evidence to support the potential for dialysis to decrease the risk of death among older adults is limited. A recent systematic review reported similar 1-year survival among older adults with kidney failure regardless of whether they received dialysis or not (100). This review, however, was based on heterogeneous studies with small numbers of patients (particularly in non-dialysis groups) who were managed by nephrology teams. There were also considerable differences in baseline characteristics (e.g. age, diabetes, other comorbidities) between those treated and not treated with dialysis, with potential for lead-time and immortal time biases (55,66,89,100).

Given the limited evidence regarding survival comparisons in this patient population, we sought to compare time to all-cause mortality for dialysis and non-dialysis care among older adults with kidney failure who had similar baseline demographic and comorbidity characteristics. We
addressed the risk of lead-time bias by using a consistent definition of sustained kidney failure for both groups, and the risk of immortal time bias using a time-varying exposure.

2.3 Methods

2.3.1 Study population and cohort definition

We did a retrospective cohort study using population-based laboratory and administrative data from Alberta, Canada (101). We linked provincial administrative and laboratory data using unique Alberta Personal Health Numbers to assemble a study cohort of Alberta residents that were ≥65 years of age and identified as having kidney failure between May 15, 2002 and December 31, 2012. The study end date was December 31, 2013 to allow for at least 1 year of follow-up.

We defined kidney failure by ≥2 consecutive outpatient estimated glomerular filtration rate (eGFR) measurements of <10 mL/min/1.73m², calculated using the CKD-EPI (Chronic Kidney Disease Epidemiology Collaboration) equation (102), at least 90 days apart. We used the first eGFR after the 90-day period to define the index date for patients (regardless of treatment status) to prevent lead-time bias (figure 2.1). We chose eGFR <10 mL/min/1.73m² to define kidney failure as it reflects a level of kidney function at which patients and providers would have made a decision whether to pursue chronic dialysis or not. Others have previously used similar definitions of kidney failure (53–55,59,96).

We excluded patients who died on their index date as well as those treated with chronic dialysis prior to or on the index date. Patients receiving a kidney transplant at any time during the study period were excluded as they likely represent a healthier population (103) and would not be considered for non-dialysis care (104).
2.3.2 Definition of exposure

The exposure of interest was treatment with chronic dialysis. We identified incident chronic dialysis cases (hemodialysis or peritoneal dialysis) from the provincial dialysis registries, which include information on all patients treated with chronic dialysis in Alberta (105). We excluded periods of dialysis lasting less than 90 days followed by recovery of kidney function, whereas patients were included if they died within 90 days and the intent of the treatment (established by review of electronic medical records) was chronic dialysis. We supplemented these cases with additional cases of chronic dialysis identified from physicians’ claims using similar criteria. We used a time-varying exposure variable to characterize treatment status during follow-up to avoid immortal time bias (93).

2.3.3 Outcome

The outcome of interest was all-cause mortality, as determined from Alberta Health Registry and Alberta Vital Statistics data. We followed patients from their index date to their date of death, out-migration from the province, or study end date (December 31, 2013).

2.3.4 Measurement of covariates

We identified baseline characteristics at the index date. Demographic characteristics included age, sex, and First Nations status based on the Federal Indian Act (106), identified from the Alberta Health Registry file. We used the Canadian Census (data from 2001, 2006, and 2011 nearest to the index date) (107) with the Statistics Canada Postal Code Conversion File (108) to determine rural location of residence, defined by a population size of <1000 or density <400 individuals per square km outside a metropolitan area (108).
We identified diabetes (109) and hypertension (110) from hospital discharge records and physician claims using validated algorithms. We identified other comorbidities based on the Deyo classification of Charlson comorbidities (dementia; cerebrovascular disease; myocardial infarction; congestive heart failure; peripheral vascular disease; chronic obstructive pulmonary disease; mild liver disease; moderate and severe liver disease; peptic ulcer disease; rheumatologic disease; paraplegia and hemiplegia; and cancer) using validated International Classification of Diseases (ICD), Ninth Revision and ICD-10 coding algorithms from physician claims and hospitalization data, respectively (111). At least one diagnostic code identified up to three years prior to cohort entry was used to identify these comorbidities.

We defined angiotensin-converting enzyme inhibitors (ACEi), angiotensin-receptor blockers (ARB), and statin use as at least one prescription for these medications (as recorded in the Alberta Health drug file) within the year prior to index date. We categorized albuminuria in accordance with international guidelines, based on the most recent outpatient measurement within two years prior to the index date. Albuminuria was categorized as normal/mild, moderate, severe, or unmeasured, with the following types of measurement in descending order of preference: albumin to creatinine ratio (<3; 3 to 30; >30 mg/mmol or <30; 30 to 300; >300 mg/g), protein creatinine ratio (<15; 15 to 50; >50 mg/mmol or <150; 150 to 500; >500 mg/g), and urine dipstick (negative or trace; 1+; ≥2+) (6). We defined rapid progression of eGFR as a >5 mL/min/1.73m² decline per year based on eGFR values within three years prior to the index date (6,112).
2.3.5 Statistical analysis

We matched patients by propensity score to control for treatment-selection bias, a method that is commonly used to create balance in relevant baseline characteristics between treated and untreated groups (92). All variables listed in table 2.1 were used to create the propensity score. We matched dialysis and non-dialysis patients one-to-one on the propensity score without replacement in the primary analysis. We used the logit of the propensity for non-dialysis care (113), and matched patients using a nearest-neighbor matching technique within a caliper width equal to 0.2 of the standard deviation of the logit of the estimated propensity score. This approach has been shown to provide an optimal balance of prognostic variables (114). We then used standardized differences to compare baseline characteristics between dialysis and non-dialysis groups (90). We assessed the distribution of covariates in the two groups to determine whether the propensity score model had been adequately specified using cumulative density plots and quantile-quantile plots (115).

We used Kaplan-Meier survival curves in the propensity score matched sample to estimate the overall survival for the two groups. We used Cox proportional hazards models, with robust standard errors clustered by matched pairs to account for the propensity score matched sample (116,117), to examine the exposure-outcome relationship incorporating survival and censoring information (118). We assessed the proportional hazards assumption both graphically and using Schoenfeld residuals (119). The proportional hazards assumption was violated when using the entire period of follow-up. We hence examined the hazard ratio (HR) for each 1-year increase in follow-up time to identify two discrete time periods where hazards were proportional between treatment groups, namely 0 to 3 years and ≥3 years (figure S1). The estimates for both time
periods were derived from one overall model including the time-varying exposure. We also dealt with a violation of the proportional hazards assumption by accounting for change in baseline eGFR with time as an interaction term (as a time-dependent rather than time-varying covariate) in the model. Finally, we used interaction terms to assess for potential effect modification by age (categories 65 to 75; 75 to 85; and ≥85 years) (9,21) and level of comorbidity using the Charlson Comorbidity Index (score <7 versus ≥7) (54,120).

We conducted a number of sensitivity analyses to assess the robustness of the findings. We used the full cohort defined by ≥2 consecutive outpatient eGFR measurements of <10 mL/min/1.73m² at least 90 days apart to conduct Cox regression analysis, modelling exposure as a time-varying covariate to examine the effect of dialysis on mortality after accounting for baseline covariates (and for change in baseline eGFR with time as an interaction term). We included patients seen and not seen by a nephrologist in the primary analysis, as the decision whether to pursue chronic dialysis or not could take place in the primary or secondary care setting. We limited analysis to patients seen by a nephrologist (before or after index date) in a sensitivity analysis to reproduce the results of prior studies, and to examine the exposure-outcome relationship due to potential differences in care (i.e. excluding non-dialysis care provided exclusively in the primary care setting). We also limited analysis to patients with >90 days between their first nephrology visit and initiation of dialysis to remove the potential bias of late referrals (121).

We also matched (with replacement) patients who were treated with dialysis with non-dialysis patients who were alive at the same time, as measured by the duration from the original index date to dialysis initiation (as an alternative way to address immortal time bias). The new index date for the dialysis group was the date of dialysis initiation, while the index date for the non-
dialysis group was the original index date plus the length of immortal time of their matched
dialysis counterpart. Finally, we explored the exposure-outcome relationship in varying levels of
eGFR thresholds for defining kidney failure (i.e. <12 and <15 mL/min/1.73m²) in full and
propensity-matched cohorts. Also, among patients with eGFR measurements post-index date, we
descriptively examined eGFR decline post-index from index date to time of dialysis initiation
(and to the last eGFR measurement in the non-dialysis group).

The investigators had full access to the database population used to create the study population.
Statistical analyses were conducted with Stata 14 (122) and SAS version 9.4 (123) software. We
used the REporting of studies Conducted using Observational Routinely-collected health Data
(RECORD) statement as the reporting framework (124). Ethical approval and waiver of patient
consent was granted from the Conjoint Health Research Ethics Review Board at the University
of Calgary.

2.4 Results

2.4.1 Patient characteristics

We identified 5,238 Alberta residents aged ≥65 years with kidney failure defined by sustained
eGFR <10 mL/min/1.73m². Following exclusion of patients who initiated dialysis on or before
the index date, those who died on index date, and those with a prior kidney transplant, the final
study cohort included 838 older adults (figure 2.2); 500 (59.7%) received chronic dialysis and
338 (40.3%) did not. The baseline characteristics of patients who initiated dialysis were different
from those who did not prior to matching (table 2.1). Compared to older adults not treated with
dialysis, those treated with dialysis were more likely to be male, younger, prescribed ACEi/ARB
and statins, and generally had less comorbidity (including dementia, cerebrovascular disease, chronic obstructive pulmonary disease, and metastatic solid tumor).

2.4.2 Patient characteristics after propensity matching

From the full cohort, 198 (39.6%) adults who received chronic dialysis were matched on their propensity score to 198 (58.6%) adults who did not receive dialysis. The balance of covariates between the two groups improved after propensity score matching (table 2.1). The mean standardized differences in covariates decreased from 22.5% (range 0.2 to 99.9%) before matching to 2.8% (0.0 to 9.1%) after matching, achieving balance across all included covariates. The propensity-matched dialysis and non-dialysis groups were more similar in their propensity scores compared to the groups in the full cohort (figures S2 and S3). The median duration between the index date and dialysis initiation was 111 (IQR 49, 279) days. The mean age of the matched cohort was 80.4 (SD 6.5) years, 44.7% were male, and mean eGFR was 7.8 (SD 1.4) mL/min/1.73m². Seventy-four (18.7%) patients in the matched cohort had a high level of comorbidity (Charlson Comorbidity Index ≥7). Eighteen (9.1%) non-dialysis patients had not seen a nephrologist, while 12 (6.1%) dialysis patients were referred late to nephrology (≤90 days) prior to dialysis initiation. 157 (80.9%) dialysis patients were treated with hemodialysis as their initial modality (versus peritoneal dialysis).

2.4.3 Hazard ratio of all-cause mortality

154 (77.8%) patients in the non-dialysis group (median follow-up 1.0 years, IQR 0.4, 2.1 years) and 134 (67.7%) in the dialysis group (median follow-up 2.5 years, IQR 1.5, 4.3 years) died. Compared to older adults with similar characteristics and not treated with dialysis, treatment with dialysis was associated with a lower risk of all-cause mortality in the first 3 years of follow-up.
(HR 0.55; 95% CI 0.41-0.74, p-value <0.001, figure 2.3 and table 2.2). After the first 3 years of follow-up we found that dialysis no longer conferred a reduction in risk of all-cause mortality (HR 2.30; 95% CI 1.11 to 4.81, p = 0.026, figure 2.3 and table 2.2), although the number of patients was small. 26 patients in the non-dialysis group were alive (i.e. were at risk of death at the third year of follow-up) compared to 88 in the dialysis group at the start of this second time period. Non-dialysis patients surviving past 3 years had a median decline in eGFR that was minimal at -0.34 (IQR -0.92, 0.20) mL/min/1.73m² compared to -2.2 (IQR -3.8, -0.48) mL/min/1.73m² in the dialysis group prior to dialysis initiation. For both time periods, there was no evidence of effect modification by age (p = 0.32 and p = 0.81, respectively) or level of comorbidity (p = 0.37 and p = 0.95, respectively).

2.4.4 Sensitivity analyses

To assess the robustness of the findings we did several sensitivity analyses for the two time periods of follow-up (0 to 3 years and ≥3 years; table 2.2). The results were similar when we used the full cohort with exposure as a time-varying covariate (not using the propensity score). We also obtained similar results when we excluded patients referred late to a nephrologist, those who were never referred to a nephrologist, as well as those with improved kidney function post-cohort entry. Results from analyses using an alternative method of addressing immortal time bias (matching alive and non-dialysis patients to comparable patients when dialysis treatment began) also resulted in similar exposure-outcome relationships for both time periods.

We also explored two alternative definitions of kidney failure with sustained (at least 90 days) eGFR <12 and <15 mL/min/1.73m². Higher levels of kidney function used to define kidney failure showed a survival advantage of dialysis observed in the <12 mL/min/1.73m² cohort, while
no survival benefit was observed in the <15 mL/min/1.73m² cohort (table S1). These results were robust in Cox regression analysis using the full cohorts. Similar to our primary analysis of kidney failure defined by eGFR <10 mL/min/1.73m², the increased risk of death for dialysis compared with non-dialysis care was also observed after 3 years of follow-up for both alternative definitions of kidney failure (table S1). We found that a greater proportion of patients with kidney failure defined by higher levels of kidney function (<12 and <15 mL/min/1.73m²) initiated dialysis in-hospital (table S2). Further, a greater proportion of patients treated with dialysis among the higher eGFR thresholds had a rapid eGFR decline post-index but prior to dialysis initiation (table S3).

2.5 Discussion

In this population-based cohort study of older adults we found that dialysis was associated with a lower risk of death during the first 3 years following kidney failure, relative to those not treated with chronic dialysis. This relationship was not modified by age or comorbidity. However, the reduction in risk of death was no longer evident after 3 years of follow-up. These results were robust in a number of sensitivity analyses including the exclusion of patients that were late or never referred to a nephrologist, patients with improved kidney function, and when using an alternative method of addressing immortal time in the dialysis group. Findings were attenuated at higher levels of eGFR (i.e. <15 mL/min/1.73m²).

Results from previous observational studies are inconsistent (89). Some studies have shown a survival advantage associated with dialysis care (125,126), though other studies report an attenuated or null association among patients with greater comorbidity, older age, or after adjustment in multivariate analysis (54,55,57,66,127,128). Further, these studies are limited in
generalizability to settings managed by nephrologists and thus would not include non-dialysis patients with kidney failure who were not referred to nephrologists (11,129). Prior studies are also limited in how important biases including lead-time and immortal time biases were addressed (100), which could substantially influence survival results particularly in the study of patients with shortened life expectancy. Lead-time gives an illusion of survival benefit when diagnosis is identified prior to its usual clinical presentation (e.g. the duration from diagnosis of kidney failure by screening compared to the usual timing of diagnosis by clinical presentation) (95). Lead-time bias is particularly noteworthy among patients in the non-dialysis group, as bias may arise from their identification prior to the date at which they would hypothetically initiate dialysis. Immortal time, on the other hand, may bias the measurement of survival times in patients who go on to receive dialysis compared to those who never receive dialysis, i.e. the duration from diagnosis to dialysis initiation (93).

Similar to our findings, Verberne et al. (55) reported an almost 40% reduction in risk of death (from treatment decision) for those treated with dialysis compared with conservative care. The result from their subgroup analysis was contrary to our results, as older patients aged ≥80 years no longer experienced a reduction in risk of death. Their analysis, however, was vulnerable to treatment-selection bias (from patients that are differentially selected for dialysis versus non-dialysis) (130), and limited in power due to small sample size.

We attempted to address lead-time bias by setting a 90-day criterion to define the index date; however, the small number of patients who survived past 3 years of follow-up demonstrates the limitations of using an algorithm based solely on eGFR to accurately identify patients with life-threatening kidney failure. The eGFR progression among non-dialysis patients after cohort entry
was relatively stable compared to the dialysis group, and hence they may be a healthier group compared to their dialysis counterpart. Also, by relying on eGFR measurements, we may have misdiagnosed patients with large muscle mass who survived without dialysis (131).

Our definition of kidney failure was consistent with international guidelines that recommend dialysis initiation based on clinical presentation (e.g. development of symptoms) typically with eGFR 5 to 10 mL/min/1.73m² (6). A 2016 survey of nephrologists and primary care providers reported they are comfortable discussing non-dialysis care, though they also expressed that lack of outcome data was a barrier to recommending conservative care management (132). The decision to initiate dialysis includes patient suitability and other considerations such as quality of life considerations and patient wishes. We acknowledge that survival is only one, albeit an important, prognostic component of the shared decision-making process (40,133).

Our results have implications for decision-making about dialysis initiation for older adults with kidney failure. Support of treatment decision-making for older adults with kidney failure requires close monitoring of their clinical information (e.g. indicators for dialysis) as well as their individualized goals, expected prognosis, and benefits and harms of dialysis (23,134). Although dialysis may reduce risk of death, dialysis may also negatively impact quality of life and the burdens related to dialysis including potential for infections and vascular access issues need to be considered (47). Compared to non-dialysis care, dialysis patients may have higher rates of hospitalization, spend more time in hospital (53), and have a higher likelihood of death in-hospital (versus at home or in-hospice) (53,66). They may also have a lower likelihood of having advance care planning and palliative care compared to their non-dialysis counterparts (66). Hence, the survival information generated from this study can be used to educate patients and
providers to optimize treatment decision-making when communicated in the context of the potential negative impacts of dialysis on quality of life.

Our study has a number of strengths including its population-based design in a setting with universal access to health care and duration of follow-up. Also, our study was strengthened by its methodological rigor in addressing treatment-selection, lead, and immortal time biases in the examination of survival between dialysis and non-dialysis care groups.

Nevertheless, the results from our study need to be considered in the context of its limitations. We cannot exclude the potential for residual confounding given its observational design; we were unable to account for potential confounders at baseline including indication for dialysis initiation, frailty, and physical, functional, cognitive, and symptomatic status. However, we were able to identify clinically important demographic and comorbid covariates and demonstrate a meaningful balance of these characteristics between the matched dialysis and non-dialysis groups. While the feasibility of a randomized control trial remains to be determined, carefully designed observational studies may be our only option. As propensity scores were calculated using baseline covariates, a longer duration of time after the index date suggests potential for more differences to accrue between dialysis and non-dialysis groups. Hence, residual confounding based on events that happen between the index date and the true time of treatment decision should be acknowledged, as small differences were observed in the rate of eGFR progression post-index. However, the median duration between the index date and dialysis initiation date was only 111 days (75% initiated dialysis within 1-year), limiting the potential for major differences to accrue.
We were also unable to adjust for potential differences in care for the dialysis and non-dialysis patients (e.g. disease management, supportive care, and end-of-life care). Variations in care may exist for patients managed by specialty conservative care teams (e.g. comprehensive conservative care clinics), general nephrology, and primary care (7). We were however able to account for common drug treatments that included the use of ACEi, ARB, and statins. We further obtained similar results in sensitivity analysis excluding non-dialysis patients not managed by nephrology (before or after index date, i.e. managed solely by primary care). Finally, we did not ascertain cause of death. Cause of death may be related to uremia (45), dialysis withdrawal (135,136), or other causes. As dialysis withdrawal is increasing among older adults initiating dialysis (135), information on dialysis withdrawal would help inform the burden of dialysis impacting quality of life and outweighing potential benefits including reduced risk of death (137).

In conclusion, we found that dialysis was associated with a reduced risk of death compared to non-dialysis within the first 3 years following onset of kidney failure among older adults. The association between dialysis initiation and quality of life or health benefit overall for older adults remains to be determined. These findings can be used to support shared clinical decision-making within nephrology and primary care settings when managing older adults with kidney failure. Future prospective studies are required to identify older patients that benefit from dialysis initiation in terms of not only survival, but also quality of life.
Table 2.1 Baseline characteristics of older adults with kidney failure by dialysis versus non-dialysis care in entire cohort and after propensity score matching

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Entire cohort (N=838)</th>
<th>After propensity score matching (N=396)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dialysis N=500</td>
<td>Non-dialysis N=338</td>
</tr>
<tr>
<td>Male</td>
<td>273 (54.6)</td>
<td>134 (39.6)</td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>76.3 (6.4)</td>
<td>83.2 (7.2)</td>
</tr>
<tr>
<td>Age in years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>65 to &lt;75</td>
<td>228 (45.6)</td>
<td>45 (13.3)</td>
</tr>
<tr>
<td>75 to &lt;85</td>
<td>220 (44.0)</td>
<td>143 (42.3)</td>
</tr>
<tr>
<td>≥85</td>
<td>52 (10.4)</td>
<td>150 (44.4)</td>
</tr>
<tr>
<td>Rural location of residence</td>
<td>101 (20.2)</td>
<td>48 (14.2)</td>
</tr>
<tr>
<td>First Nations status</td>
<td>15 (3.0)</td>
<td>7 (2.1)</td>
</tr>
<tr>
<td>Mean eGFR at index (SD)</td>
<td>7.8 (1.4)</td>
<td>7.7 (1.6)</td>
</tr>
<tr>
<td>Index eGFR (mL/min/1.73m²) category</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;4</td>
<td>7 (1.4)</td>
<td>9 (2.7)</td>
</tr>
<tr>
<td>4 to &lt;6</td>
<td>37 (7.4)</td>
<td>38 (11.2)</td>
</tr>
<tr>
<td>6 to &lt;8</td>
<td>226 (45.2)</td>
<td>113 (33.4)</td>
</tr>
<tr>
<td>8 to &lt;10</td>
<td>230 (46.0)</td>
<td>178 (52.7)</td>
</tr>
<tr>
<td>Mean (SD) progression of eGFR per year</td>
<td>-5.8 (5.0)</td>
<td>-5.8 (6.7)</td>
</tr>
<tr>
<td>Rapid decline of eGFR per year prior to index (&gt;5 mL/min/1.73m² per year)</td>
<td>231 (46.2)</td>
<td>143 (42.3)</td>
</tr>
<tr>
<td>Medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ACEi/ARBs</td>
<td>365 (73.0)</td>
<td>181 (53.6)</td>
</tr>
<tr>
<td>Statins</td>
<td>301 (60.2)</td>
<td>131 (38.8)</td>
</tr>
<tr>
<td>Proteinuria category</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Normal or mild</td>
<td>21 (4.2)</td>
<td>36 (10.4)</td>
</tr>
<tr>
<td>Moderate</td>
<td>43 (8.6)</td>
<td>36 (10.7)</td>
</tr>
<tr>
<td>Severe</td>
<td>334 (66.8)</td>
<td>193 (57.1)</td>
</tr>
<tr>
<td>Unmeasured</td>
<td>102 (20.4)</td>
<td>74 (21.9)</td>
</tr>
<tr>
<td>Comorbidities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia</td>
<td>26 (5.2)</td>
<td>82 (24.3)</td>
</tr>
<tr>
<td>Characteristic</td>
<td>Entire cohort (N=838)</td>
<td></td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>-----------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td></td>
<td>Dialysis N=500</td>
<td>Non-dialysis N=338</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>48 (9.6)</td>
<td>62 (18.3)</td>
</tr>
<tr>
<td>Myocardial infarction</td>
<td>74 (14.8)</td>
<td>68 (20.1)</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>143 (28.6)</td>
<td>141 (41.7)</td>
</tr>
<tr>
<td>Peripheral vascular disease</td>
<td>73 (14.6)</td>
<td>39 (11.5)</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>132 (26.4)</td>
<td>116 (34.3)</td>
</tr>
<tr>
<td>Mild liver disease</td>
<td>12 (2.4)</td>
<td>2 (0.6)</td>
</tr>
<tr>
<td>Moderate/severe liver disease</td>
<td>1 (0.2)</td>
<td>2 (0.6)</td>
</tr>
<tr>
<td>Peptic ulcer disease</td>
<td>32 (6.4)</td>
<td>23 (6.8)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>273 (54.6)</td>
<td>173 (51.2)</td>
</tr>
<tr>
<td>Hypertension</td>
<td>482 (96.4)</td>
<td>309 (91.4)</td>
</tr>
<tr>
<td>Rheumatologic disease</td>
<td>15 (3.0)</td>
<td>7 (2.1)</td>
</tr>
<tr>
<td>Para/hemiplegia</td>
<td>9 (1.6)</td>
<td>1 (0.3)</td>
</tr>
<tr>
<td>Cancer</td>
<td>78 (15.6)</td>
<td>69 (20.4)</td>
</tr>
<tr>
<td>Metastatic solid tumor</td>
<td>4 (0.8)</td>
<td>16 (4.7)</td>
</tr>
<tr>
<td>Days between first and index eGFR,</td>
<td>102 (93,116)</td>
<td>107 (95,123)</td>
</tr>
<tr>
<td>median (IQR)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

N(%) reported unless indicated otherwise.
SD = standard deviation; IQR = interquartile range; eGFR = estimated glomerular filtration rate in mL/min/1.73m²; ACEi = angiotensin-converting enzyme inhibitors; ARB = angiotensin-receptor blockers
Table 2.2 Hazard ratios of mortality from primary and sensitivity analyses for dialysis versus non-dialysis care, by years of follow-up from onset of kidney failure defined with sustained eGFR <10 mL/min/1.73m

<table>
<thead>
<tr>
<th>PS-matched cohort</th>
<th>Dialysis</th>
<th>Non-dialysis</th>
<th>N</th>
<th>0 to 3 years</th>
<th>≥3 years</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>HR</td>
<td>95% CI</td>
</tr>
<tr>
<td>Kidney failure as sustained eGFR &lt;10 mL/min/1.73m</td>
<td>198</td>
<td>198</td>
<td>396</td>
<td>0.55</td>
<td>0.41-0.74</td>
</tr>
<tr>
<td>Exclude late referral to nephrologist</td>
<td>182</td>
<td>182</td>
<td>364</td>
<td>0.53</td>
<td>0.39-0.73</td>
</tr>
<tr>
<td>Exclude non-referral to nephrologist</td>
<td>186</td>
<td>186</td>
<td>372</td>
<td>0.60</td>
<td>0.44-0.81</td>
</tr>
<tr>
<td>Exclude improved kidney function post-cohort entry</td>
<td>193</td>
<td>193</td>
<td>386</td>
<td>0.49</td>
<td>0.36-0.68</td>
</tr>
<tr>
<td>Match non-dialysis with dialysis patients when treatment began(^{1})</td>
<td>298</td>
<td>298</td>
<td>596</td>
<td>0.38</td>
<td>0.31-0.46</td>
</tr>
<tr>
<td>Full cohort (not PS-matched)</td>
<td>500</td>
<td>338</td>
<td>838</td>
<td>0.56</td>
<td>0.45-0.71</td>
</tr>
</tbody>
</table>

N = number of people; HR = Hazard ratio; CI = Confidence Interval; eGFR = estimated glomerular filtration rate; PS = propensity score; \(^{1}\) matching with replacement
Figure 2.1 Retrospective cohort study design
Alberta Health Registry with residents age ≥18 years between April 1, 1994 and March 31, 2015
N=4,764,659

<table>
<thead>
<tr>
<th>Excluded:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- No outpatient creatinine measurements (N=1,713,840)</td>
</tr>
<tr>
<td>- Without at least two consecutive and sustained eGFR values &lt;10ml/min/1.73m² for at least 90 days (N=3,023,358)</td>
</tr>
<tr>
<td>- With index date on or after January 1, 2013 (N=1,731)</td>
</tr>
<tr>
<td>- Age &lt;65 on index date (N=592)</td>
</tr>
</tbody>
</table>

N=5,238

<table>
<thead>
<tr>
<th>Excluded:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Chronic dialysis started on or before index date (N=4282)</td>
</tr>
<tr>
<td>Death on index date (N=2)</td>
</tr>
<tr>
<td>Kidney transplant recipient at any time during the study period (N=116)</td>
</tr>
</tbody>
</table>

N=838 adults aged ≥65 years with kidney failure
(N=198 propensity score matched pairs)

**Figure 2.2** Cohort formation of older adults with kidney failure
Figure 2.3 Kaplan-Meier survival curves for propensity score matched dialysis versus non-dialysis care, with kidney failure defined by sustained eGFR <10 mL/min/1.73m². Note: the use of a time-varying exposure allowed patients to switch from non-dialysis to dialysis care.
Table S1 Hazard ratios of mortality from sensitivity analyses for dialysis versus non-dialysis care, by years of follow-up from onset of kidney failure defined with higher eGFR thresholds of <12 and <15 mL/min/1.73m

<table>
<thead>
<tr>
<th>PS-matched cohort</th>
<th>Dialysis</th>
<th>Non-dialysis</th>
<th>N</th>
<th>0 to 3 years</th>
<th></th>
<th>≥3 years</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney failure as sustained eGFR &lt;12 mL/min/1.73m</td>
<td>402</td>
<td>402</td>
<td>804</td>
<td>0.79</td>
<td>0.63-0.99</td>
<td>0.039</td>
<td>1.72</td>
</tr>
<tr>
<td>Exclude late referral to nephrologist</td>
<td>349</td>
<td>349</td>
<td>698</td>
<td>0.78</td>
<td>0.60-1.00</td>
<td>0.053</td>
<td>1.46</td>
</tr>
<tr>
<td>Exclude non-referral to nephrologist</td>
<td>338</td>
<td>338</td>
<td>676</td>
<td>0.79</td>
<td>0.61-1.02</td>
<td>0.065</td>
<td>1.61</td>
</tr>
<tr>
<td>Full cohort (not PS-matched)</td>
<td>863</td>
<td>714</td>
<td>1577</td>
<td>0.78</td>
<td>0.64-0.90</td>
<td>0.002</td>
<td>1.66</td>
</tr>
<tr>
<td>Kidney failure as sustained eGFR &lt;15 mL/min/1.73m</td>
<td>741</td>
<td>741</td>
<td>1482</td>
<td>1.25</td>
<td>1.05-1.49</td>
<td>0.011</td>
<td>1.57</td>
</tr>
<tr>
<td>Exclude late referrals</td>
<td>717</td>
<td>717</td>
<td>1434</td>
<td>1.18</td>
<td>0.99-1.41</td>
<td>0.068</td>
<td>1.48</td>
</tr>
<tr>
<td>Exclude non-referred</td>
<td>731</td>
<td>731</td>
<td>1462</td>
<td>1.18</td>
<td>0.99-1.41</td>
<td>0.059</td>
<td>1.58</td>
</tr>
<tr>
<td>Full cohort (not PS-matched)</td>
<td>1313</td>
<td>1616</td>
<td>2929</td>
<td>0.99</td>
<td>0.86-1.13</td>
<td>0.861</td>
<td>1.50</td>
</tr>
</tbody>
</table>

N = number of people; HR = Hazard ratio; CI = Confidence Interval; eGFR = estimated glomerular filtration rate; PS = propensity score; matching with replacement
**Table S2** In-hospital dialysis start by cohort

<table>
<thead>
<tr>
<th>PS-matched cohort</th>
<th>Matched pairs</th>
<th>In-hospital dialysis start</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sustained eGFR &lt;10 mL/min/1.73m²</td>
<td>198</td>
<td>67 (33.8)</td>
</tr>
<tr>
<td>Sustained eGFR &lt;12 mL/min/1.73m²</td>
<td>402</td>
<td>145 (36.1)</td>
</tr>
<tr>
<td>Sustained eGFR &lt;15 mL/min/1.73m²</td>
<td>741</td>
<td>323 (43.6)</td>
</tr>
</tbody>
</table>

N(%); eGFR = estimated glomerular filtration rate; PS = propensity score
Table S3 eGFR progression from 0 to 3 years of follow-up post-index date by cohort

<table>
<thead>
<tr>
<th>PS-matched cohort</th>
<th>Matched pairs</th>
<th>Index eGFR, median (IQR)</th>
<th>Most recent eGFR prior to dialysis start, median (IQR)</th>
<th>eGFR progression per year, median (IQR)</th>
<th>Rapid decline post-index</th>
<th>Normal or no decline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sustained eGFR &lt;10</td>
<td>198</td>
<td>7.9 (7.0,8.9)</td>
<td>6.7 (5.6,7.8)</td>
<td>-2.3 (-4.3,-0.6)</td>
<td>73 (36.9)</td>
<td>46 (23.2)</td>
</tr>
<tr>
<td>Sustained eGFR &lt;12</td>
<td>402</td>
<td>9.9 (8.6,10.8)</td>
<td>7.4 (6.2,8.7)</td>
<td>-3.2 (-6.8,-1.4)</td>
<td>111 (27.6)</td>
<td>62 (15.4)</td>
</tr>
<tr>
<td>Sustained eGFR &lt;15</td>
<td>741</td>
<td>12.2 (10.4,13.5)</td>
<td>8.0 (6.5,10.1)</td>
<td>-3.7 (-7.4,-1.5)</td>
<td>240 (32.4)</td>
<td>99 (13.4)</td>
</tr>
</tbody>
</table>

N(%), unless otherwise stated; eGFR = estimated glomerular filtration rate in mL/min/1.73m²; rapid decline is >5 mL/min/1.73m² per year; normal or no decline is <1 mL/min/1.73m² per year
Figure S1 Hazard ratio for each 1-year increase in follow-up time used to identify two discrete time periods where hazards were proportional between propensity score matched treatment groups: 0 to 3 years and ≥3 years.
Figure S2 Cohort before propensity matching from full cohort (propensity of non-dialysis care)
Figure S3 Cohort after propensity matching (propensity of non-dialysis care)
CHAPTER THREE:

PRIMARY CARE PHYSICIANS’ PERCEIVED BARRIERS AND FACILITATORS TO CONSERVATIVE CARE FOR OLDER ADULTS WITH CHRONIC KIDNEY DISEASE: DESIGN OF A MIXED METHODS STUDY

Our study described in chapter two was aimed at informing survival outcomes among older adults with kidney failure treated and not treated with dialysis. A clarification of prognosis can support patients and their health care providers make a more informed decision to initiate dialysis or not. Primary care physicians play an important role in supporting their patients to make treatment decisions and in providing their conservative care. However, their experiences including barriers and facilitators to optimal conservative care in the community setting is largely unknown. By clarifying the provision of community-based conservative care for older adults with kidney failure, we conducted a mixed methods study involving both qualitative and quantitative approaches.

We describe in this chapter the methodological details of a sequential exploratory mixed methods study design. We used this protocol to explore and further elucidate conservative care in the community setting. Findings from the qualitative strand are described in chapter 4, while results from the quantitative strand and integration of the two strands are described in chapter 5.

This chapter is published as:

3.1 Abstract

Background: Guideline committees have identified the need for research to inform the provision of conservative care for older adults with stage 5 chronic kidney disease (CKD) who have a high burden of comorbidity or functional impairment. We will use both qualitative and quantitative methodologies to provide a comprehensive understanding of barriers and facilitators to care for these patients in primary care.

Objectives: Our objectives are to: 1) interview primary care physicians to determine their perspectives of conservative care for older adults with stage 5 CKD, and 2) survey primary care physicians to determine the prevalence of key barriers and facilitators to provision of conservative care for older adults with stage 5 CKD.

Design: A sequential exploratory mixed methods design; the first phase of the study will involve fundamental qualitative description and the second phase will be a cross-sectional population-based survey.

Setting: Alberta, Canada.

Participants: Primary care physicians with experience providing care for older adults with stage 5 CKD not planning on initiating dialysis.

Methods: The first objective will be achieved by undertaking interviews with primary care physicians from southern Alberta. Participants will be selected purposively to include physicians with a range of characteristics (e.g. age, gender, and location of clinical practice). Interviews will be recorded, transcribed verbatim, and analyzed using conventional content analysis to generate themes. The second objective will be achieved by undertaking a population-based survey of
primary care physicians in Alberta. The questionnaire will be developed based on findings from the qualitative interviews and pilot tested for face and content validity. Physicians will be provided multiple options to complete the questionnaire including mail, fax, and online methods. Descriptive statistics and associations between demographic factors and barriers and facilitators to care will be analyzed using regression models.

Limitations: A potential limitation of this mixed methods study is its cross-sectional nature.

Conclusions: This work will inform development of clinical resources and tools for care of older adults with stage 5 CKD, to address barriers and enable facilitators to community-based conservative care.
3.2 Background

There is a large proportion of older adults with stage 5 chronic kidney disease (CKD) not treated with renal replacement therapy. In Alberta, Canada, 51% of people with stage 5 CKD not treated with renal replacement therapy are aged 75 years and older (11). Individuals with stage 5 CKD often live with multiple morbidities and poor life expectancy. Conservative management is a non-dialysis treatment option that is chosen by patients or is medically advised (33). It encompasses a planned holistic patient-centered approach including interventions to delay CKD progression, symptom management, advance care planning, psychological support, and family support (33). Clinical practice guidelines suggest that this management strategy should include a comprehensive program with coordinated end-of-life care for patients and their families via primary or specialist care (6). Nevertheless, there is a need to optimize the provision of conservative care in this particularly vulnerable older adult population with stage 5 CKD, as these programs are underdeveloped in many locations (1). Previous research on the provision of conservative management programs have identified variations in renal unit specific guidelines and the availability of dedicated conservative care staff and training (7).

Approximately 40% of patients with stage 5 CKD not treated with renal replacement therapy have not been seen by a nephrologist within a two year period (11). Hence, conservative care is often provided by primary care physicians, many independently without consultation from nephrology, who are also the first points of contact with the healthcare system for the majority of day-to-day healthcare needs. However, providing conservative care in the primary care setting is complex and incompletely understood. By understanding barriers and facilitators to community-based conservative management by primary care physicians, potential interventions can be
developed to support the development, accessibility, and quality of conservative management programs where they are needed. The research objectives in this program of study aim to yield information that can be integrated into routine decision-making processes for professionals who care for older adults with stage 5 CKD. The first objective is to describe primary care physicians’ perceived key barriers, facilitators, and strategies to enhancing conservative care for older adults with Stage 5 CKD. The second objective is to determine the prevalence of key barriers and facilitators to conservative care gathered from the first objective.

3.3 Methods

3.3.1 Mixed methods study design

Mixed methods research involves: identification of a specific mixed method research design; data collection and analysis of qualitative and quantitative data; integration of the two forms of data; and assignment of prioritization to either or both forms of data (138). A sequential exploratory mixed methods design (figure 3.1), a two-phase study design, will be conducted for the purposes of this study. The first phase of the study will involve qualitative description using interviews to understand and describe primary care physicians’ perspectives of care for older adults (aged 75 years and greater) with stage 5 CKD (eGFR less than 15mL/min/1.73m² for at least three months) not on dialysis in the primary care setting. A subsequent quantitative phase (phase 2) will be designed to quantify and describe the magnitude of barriers and facilitators to conservative care. The survey will be used to also examine the relationship between demographic and clinical practice characteristics and barriers and facilitators to care. The quantitative phase will involve questionnaire design, testing, and administration. The qualitative and quantitative phases are assigned equal priority and the two phases will be integrated sequentially (i.e. the quantitative phase will build on the qualitative phase). A study in the field
of nephrology using a similar type of design has been previously reported (139). Ethical approval of this mixed methods study has been obtained from the Conjoint Health Research Ethics Board at the University of Calgary.

3.3.2 Phase 1: qualitative interviews

Qualitative paradigm

Primary care physicians’ perspectives of barriers and facilitators to caring for older adults with stage 5 CKD are complex, and incorporate individual views and experiences of diagnosis, treatment, and referral. Hence, the nature of this research question encompasses multiple truths and rich perspectives. These multiple perspectives are best captured through the collection of data in the natural setting or context where the participants experience the barriers and facilitators (140). Ultimately, the qualitative paradigm is ideal for this component of the research, as it allows for a comprehensive and nuanced account of the problem under study. Fundamental qualitative description (141) will be employed to develop a comprehensive summary of barriers and facilitators experienced by physicians when providing care to older adults with stage 5 CKD.

Participant Selection and Recruitment

Using a snowball sampling approach, key stakeholders or opinion leaders in areas of family medicine, seniors’ health, and kidney disease will be asked to identify primary care physicians with experience caring for older adults with stage 5 CKD in the community. Eligible participants will include physicians who: currently practice in the primary care setting; have at least one year of experience as a primary care physician; and have experience caring for patients 75 years or older with stage 5 CKD in the past year. Consenting physicians will be interviewed in-person or
via telephone, based on their preference. Participants will also be asked to recommend other providers who meet the eligibility criteria.

**Data collection**

Participants will be asked to provide basic information regarding demographics and practice characteristics. An interview guide has already been developed based on a review of the literature and discussion with the research team, including key decision makers. The broad introduction question, probing questions, and closing question will be pilot tested with three primary care physicians (see appendix A for interview guide). The interview guide considered barriers, facilitators, and strategies regarding the following overarching topics: stage 5 CKD diagnosis and assessment, care management, and resource use. One interviewer (HT) will conduct the interviews to ensure consistency in interview style and structure. Participant recruitment will cease when theoretical saturation is reached (i.e. when new information or concepts no longer emerge from additional interviews). All interviews will be audio-recorded and then transcribed verbatim by a professional transcriptionist.

During the semi-structured interviews, providers will be asked about their perspectives on caring for the population of interest. The probing questions are designed to help interviewees think about barriers they experience regarding diagnosis, care management, and referral decisions, should these topics not develop spontaneously. Participants may also be asked about potential strategies or facilitators they could employ to address their challenges. All participants will be asked the broad introductory and closing questions, with probing questions used only when necessary. Field notes will also be documented on the participants’ responses to interview questions, which may inform data analysis and subsequent conduct of interviews.
Qualitative analysis

Perceptions relating to diagnosis and management decision-making will be identified and categorized using conventional content analysis (142), a method of interpreting interview data with the goal of describing the phenomenon of interest. The steps for conventional content analysis include: 1) achieving immersion by first reading the interview data in its entirety to acquire an overall sense of the phenomenon; 2) reading interviews word by word and highlighting words that capture key concepts that become codes; 3) documenting initial impressions, thoughts, and interpretation; 4) developing codes; and 5) sorting codes that are related to each other into themes and sub-themes. Definitions will be developed for existing codes, themes, and sub-themes, and exemplars of these will be reported in the findings. Coding will be conducted in triplicate (i.e. there will be three independent researchers coding each of the manuscripts) and then reviewed with the research team.

The process will be reflexive and interactive as continual data collection and data analysis will shape each other (141). For example, code titles or definitions identified based on the first interview may be modified based on data collected during the second interview, and new codes may be added requiring recoding of the first interview transcript. Codes will be generated from the interview data and they will be systematically applied to identify themes and patterns; results from the qualitative phase of this mixed methods study has been published elsewhere (143). These results will facilitate item generation for survey development in the next study phase, as the codes, themes, and subthemes will directly form the variables of interest in the questionnaire (phase 2).
3.3.3 Phase 2: quantitative survey

Participant selection

The sampling frame for this population-based survey will include all primary care physicians from the College of Physicians and Surgeons of Alberta, a provincial regulatory body of medical practice for physicians (144). Employing a series of screening questions on the cover letter of the questionnaire, physicians will be asked to complete the questionnaire only if they recall ever having experience providing care to people 75 years or greater with an eGFR of less than 15mL/min/1.73m². Providers will be invited to participate via mail, fax, and online methods.

Questionnaire Development and Administration

Based on results from the qualitative phase of the study, the questionnaire will obtain more information about barriers and facilitators to provision of care for older adults with stage 5 CKD in the community, and will include a combination of multiple choice, Likert scales, and open-ended responses. The questionnaire is likely to reflect diagnosis, management, and referral decision-making components of care for older patients with stage 5 CKD. Potentially sensitive items focused on personal attributes and clinical practice settings will be situated at the end of the questionnaire and will include: the respondent’s age; gender; practice interests (e.g. care of the elderly) (145); years practicing in this specialty; time allocated for clinical practice; and practice in an urban or rural area based on population. Previous studies have demonstrated that personal attributes and practice environments are key predictors of behavior among primary care physicians (146). The questionnaire will be developed in two steps: item identification and preliminary development of the questionnaire, and questionnaire refinement.

Item identification and preliminary development of the questionnaire
Potential items for inclusion in the questionnaire will be informed via a literature review and interviews from phase 1. Hence, addressing the qualitative objective will provide specific items relating to primary care for the patient population of interest, which will be categorized into different domains according to the Theoretical Domains Framework (78,147). The Theoretical Domains Framework provides a strategy for assessing problems related to implementation of clinical practice guidelines, and provides a foundation for intervention development. It has been validated and demonstrated to be useful over a range of different healthcare systems, containing the following 14 domains that may influence behavior and provides a comprehensive structure for categorizing barriers and facilitators to care: knowledge; skills; social/professional role and identity; beliefs and capabilities; optimism; beliefs about consequences; reinforcement; intentions; goals; memory, attention and decision processes; environmental context and resources; social influences; emotion; and behavioral regulation. All domains of the framework will be reviewed for inclusion during this stage based on their relevance to the research objective.

Refining the questionnaire

Face validity (i.e. extent to which the questionnaire appears to be measuring the intended information) and content validity (i.e. extent to which questionnaire has enough coverage of the content area, or sufficient number of questions for each domain) (148) will be assessed. At least three primary care physicians, nephrologists, and health services researchers (n=9) will independently review the questionnaire for face and content validity, to evaluate the merit (e.g. relevance and quality) of each item, to identify unnecessary or ambiguous questions (to assess clarity, relevance, flow, and wording), and to determine whether respondents will interpret the
questions appropriately and consistently (to assess interpretation) (149). The length of time required to complete the questionnaire will also be measured.

Survey administration

Approximately 4,500 primary care physicians will be contacted through information publicly available from the College of Physicians and Surgeons of Alberta (145). Potential participants will be recruited via: mail, fax, and online methods. The first contact will be a survey package that includes a personalized cover letter with screening questions to ensure only eligible physicians complete the questionnaire, a succinct questionnaire, a return fax number and email address, and an online survey as another option for completing the survey. Based on a modified Dillman approach (150), the first reminder with the same information (via fax) will be sent one week, the second reminder three weeks (mail), and the third reminder four weeks (fax) after the initial contact for non-responders.

Quantitative analysis

Questionnaire responses will be reported using descriptive statistics on the proportion of key barriers and facilitators perceived by primary care physicians in Alberta. Associations between demographic and practice characteristics and outcome variables (e.g. self-reported familiarity and use of comprehensive conservative programs) will be analyzed using regression models with backward elimination techniques. Based on a sample size calculation, a sample size of 371 eligible respondents will produce a 95% confidence interval equal to the sample proportion plus or minus 0.05 when the estimated proportion is 0.50. At the interpretation stage, the extent to which the quantitative results extend the initial qualitative findings will be discussed.
3.3.4 Dissemination

Employing an integrated knowledge translation approach, decision makers (leaders in primary care as well as the renal programs) have been involved in the development of study design, including interview and survey questions. Results from this mixed methods study will be published in peer-reviewed scientific journals, published in provincial and local newsletters targeted to primary care providers, and presented at national and international conferences to audiences in the areas of nephrology, family medicine, and geriatrics. In collaboration with key stakeholders of providers in the conservative care of patients with stage 5 CKD, the findings of this study will be used to inform the development of clinical practice tools, and resources, including a provincial conservative kidney management clinical care pathway as a standardized informational tool to implement clinical practice guidelines and best practices in renal care, for health care providers, patients, and their family members.

3.4 Discussion

The focus of this study is on investigating a growing, yet relatively under-studied, population of older adults with stage 5 CKD managed by primary care physicians in the community. To our knowledge, this is the first study of primary care physicians’ perspective in Canada, and will address key areas that have not been previously investigated: barriers and facilitators primary care physicians experience when providing care for this older patient population and the prevalence of challenges and enablers to conservative care experienced by these providers. Data and results from this work will inform the provision of care by health care providers for older adults with stage 5 CKD in the community, increase the awareness of provincial renal conservative care clinics and other related initiatives such as an online conservative kidney management pathway, and support the development of a collaborative network of healthcare
providers and researchers focused on improving the conservative care processes, outcomes, and future areas of investigation.

A potential limitation of this mixed methods study is its cross-sectional nature. We do not anticipate opinions about barriers and facilitators to care to evolve substantially over time, though further investigation is warranted following intervention strategies to improve conservative care. Also, we focus on older adults with stage 5 CKD to provide a clearly defined patient population, and acknowledge that younger adults may undergo conservative care as well. This specific subgroup of patient may present a challenge in recruitment, as not all providers will have the required experience.

This study protocol presents a rigorous yet feasible mixed methods study design that offers a valuable opportunity to obtain in-depth, rich data to explore perspectives of conservative care in the primary care setting (e.g. via purposive sampling to ensure diverse participation, and triplicate coding and to ensure data quality). It also provides an opportunity to examine the magnitude of potential challenges and solutions reported by providers caring for this patient population (e.g. via a census survey based on a validated data collection approach, and descriptive and statistical analytical approaches). Results based on this survey will likely be generalizable to other Canadian and similar contexts internationally with universal health care. Ultimately, this province-wide study will incorporate an integrated knowledge translation approach to ensure its clinical relevance, identify future interventions, and support quality of care by providers for older adults with chronic kidney failure residing in the community.
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<tr>
<th>Phase</th>
<th>Procedure</th>
<th>Product</th>
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<tr>
<td><strong>Phase 1:</strong> Qualitative data collection</td>
<td>• Identify and conduct in-depth interviews with a purposive sample of PCPs</td>
<td>• Text data from interview transcripts</td>
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<td></td>
<td>• Qualitative conventional content analysis (142)</td>
<td>• Codes and themes</td>
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<td></td>
<td>• Develop questionnaire based on qualitative results</td>
<td>• Report results in accordance to COREQ (151)</td>
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<td></td>
<td>• Evaluate questionnaire for face and content validity by PCPs, nephrologists, and health services researchers</td>
<td>• Questionnaire for quantitative phase</td>
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<tr>
<td>Integration</td>
<td>• Develop questionnaire based on qualitative results</td>
<td>• Categorical data from survey</td>
</tr>
<tr>
<td><strong>Phase 2:</strong> Quantitative data collection</td>
<td>• Administer questionnaire to PCPs in Alberta</td>
<td>• Descriptive statistics</td>
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<td></td>
<td>• Describe the proportion of key barriers and facilitators reported by PCPs</td>
<td>• Associations between participant characteristics and barriers and facilitators to care</td>
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<td>• Examine associations between demographic/practice characteristics with barriers and facilitators to care</td>
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<td>• Interpretation and explanation of quantitative and qualitative results</td>
<td>• Discussion, implications</td>
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<td></td>
<td>• In collaboration with decision makers and end-users, determine evidence-based clinical practice tools to enhance provision of conservative care</td>
<td>• Report results in accordance to STROBE (152)</td>
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<td></td>
<td>• Development of clinical practice tools and resources for health care providers, patients, and their family members</td>
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**Figure 3.1** The mixed methods study design
CHAPTER FOUR:

PRIMARY CARE PHYSICIANS’ PERCEIVED BARRIERS, FACILITATORS, AND STRATEGIES TO ENHANCE CONSERVATIVE CARE FOR OLDER ADULTS WITH CHRONIC KIDNEY DISEASE: A QUALITATIVE DESCRIPTIVE STUDY

We described in the previous chapter our mixed methods study design protocol, including the integration of the qualitative and quantitative stands. We describe in this chapter findings stemming specifically from the qualitative strand, which aims to provide an in-depth exploration of primary care physicians’ perspectives when caring for older adults with kidney failure whom are managed conservatively without dialysis.

This chapter was published as:

4.1 Abstract

Background: Although primary care physicians (PCPs) are often responsible for the routine care of older adults with chronic kidney disease (CKD), there is a paucity of evidence regarding their perspectives and practice of conservative (non-dialysis) care. We undertook a qualitative study to describe barriers, facilitators, and strategies to enhance conservative, non-dialysis, CKD care by PCPs in the community.

Methods: Semi-structured telephone and face-to-face interviews were conducted with PCPs from Alberta, Canada. Participants were identified using a snowball sampling strategy and purposively sampled based on sex, age, and rural/urban location of clinical practice. Eligible participants had managed at least 1 patient ≥75 years with Stage 5 CKD (estimated glomerular filtration rate (eGFR) <15mL/min/1.73m², not on dialysis) in the prior year. Participant recruitment ceased when data saturation was reached. Transcripts were analyzed thematically using conventional content analysis.

Results: Twenty-seven PCPs were interviewed. The majority were male (15/27), were aged 40-60 years (15/27), and practiced in primary care for >20 years (14/27). Perceived barriers to conservative CKD care included: managing expectations of kidney failure for patients and their families; dealing with the complexity of medical management of patients requiring conservative care; and challenges associated with managing patients jointly with specialists. Factors that facilitated conservative CKD care included: establishing patient/family expectations early; preserving continuity of care; and utilizing a multidisciplinary team approach. Suggested strategies for improving conservative care included having: direct telephone access to clinicians...
familiar with conservative care; treatment decision aids for patients and their families; and a conservative care clinical pathway to guide management.

Conclusions: PCPs identified important barriers and facilitators to conservative care for their older patients with Stage 5 CKD. Further investigation of potential strategies that address barriers and enable facilitators is required to improve the quality of conservative care for older adults in the community.
4.2 Introduction

The prevalence of Stage 5 chronic kidney disease (CKD), defined as an estimated glomerular filtration rate (eGFR) of less than 15mL/min/1.73m$^2$ for at least three months (9), is increasing among older adults, in particular. A sub-group of these patients may not receive dialysis and are managed conservatively without renal replacement therapy (dialysis or transplantation), often exclusively by primary care physicians (PCPs) (11).

Clinical practice guidelines indicate that conservative care is an important treatment option for older adults age ≥75 years with Stage 5 CKD, especially those who are frail or have multiple comorbidities (74). Despite these guidelines, comprehensive conservative care programs, including coordinated end-of-life care (6), remain underdeveloped in many locations (1). In 2012-2013, the majority (51%) of patients with Stage 5 CKD not on renal replacement therapy were aged ≥75 years in Alberta, Canada (11). Approximately 40% of these patients were managed independently by their PCPs without consultation from a nephrologist. Whether these PCPs had adequate resources and support to manage these patients is unknown.

Given the unique aspects of caring for patients with Stage 5 CKD and the paucity of evidence about PCPs’ experience (i.e. facilitators and barriers to conservative care), particularly in the North American context, we undertook this qualitative study to describe PCPs’ perceptions of key barriers, facilitators, and strategies to enhance conservative care for older adults with Stage 5 CKD residing in the community.

4.3 Subjects and methods

We used fundamental qualitative description (141) to develop a comprehensive summary of barriers and facilitators experienced by PCPs when providing care to older adults with Stage 5
CKD managed conservatively without renal replacement therapy. We used the consolidated criteria for reporting qualitative health research (COREQ) as the reporting framework (151).

4.3.1 Participant selection

Participants were identified using a snowball sampling strategy and purposively sampled (153) with maximum variation between PCPs based on sex, age, and rural/urban location of clinical practice. Using the snowball sampling approach, we initially contacted individuals (key stakeholders) from family medicine, seniors’ health, and nephrology via email, and asked them to recommend PCPs who potentially met the following eligibility criteria: (1) currently practicing in primary care in southern Alberta with at least one year of experience, and (2) experience managing patients ≥75 years with Stage 5 CKD in the prior 12 months. Recommended PCPs were subsequently invited via email, fax and/or telephone to participate in the study. To ensure representation and perspectives of physicians practicing in rural areas, all rural PCPs within southern Alberta that fulfilled the inclusion criteria were also invited to participate. Finally, each potential participant was asked to recommend other potential participants. The University of Calgary Conjoint Health Research Ethics Board provided Certification of Institutional Ethics Review.

4.3.2 Data collection

Individual semi-structured interviews were conducted at a time and by means (i.e. telephone, face-to-face) that were convenient for each of the participants. An interview guide was developed based on a review of the literature and in consultation with the research team (appendix A). Participants were asked to provide their practice characteristics at the beginning of the interview to inform subsequent probing questions. Participants were also asked to provide
basic demographic information at the end of the interview. The same person conducted all interviews (HT) between January and April 2015. Participant recruitment ceased when data saturation was reached (i.e. when no new concepts emerged from additional interviews) (154). Interviews were audio-recorded and then transcribed verbatim. Field notes were recorded at the time of the interview and used to inform data analysis and subsequent interviews.

4.3.3 Analysis

Conventional qualitative content analysis (142) was used. This is a method of examining qualitative interview data with the goal of creating a rich description of the phenomenon of interest. The research team members first read the interview data in its entirety to acquire an overall sense of the phenomena of interest. Words that captured key concepts were highlighted to create codes. Initial impressions, thoughts, and interpretations were noted. Related codes were categorized into themes and subthemes. The process was reflexive and iterative as continual data collection and data analysis shaped each other (e.g. analysis conducted between interviews influenced subsequent interviews) (141). HT and two research associates conducted the coding in triplicate. The themes were achieved through a series of discussions with the research team.

4.4 Results

All but one of the interviews was conducted via telephone. Two hundred and twenty PCPs were approached to participate, of whom 45 PCPs responded. Of those that responded, 27 were included, 13 were not eligible, 3 declined participation, and 2 responded after data collection had been completed. Saturation was reached during the 24th interview. However, three more interviews were completed to confirm no new concepts would emerge. Those that declined
participation did so primarily due to clinical commitment and lack of time. The duration of interviews was approximately 30 minutes.

The majority of participants were male (15/27), age 40-60 years of age (15/27), with more than 20 years of primary care experience (14/27), and practiced in a medium/large population centre (18/27) (table 4.1). One-third of the participants reported having a practice interest in geriatrics or care of the elderly, and approximately 75% of participants managed less than five patients in the population of interest in the past 12 months. Overall, 59% of participants indicated that their elderly conservative care patients were co-managed with nephrologists.

We categorized PCPs perceptions into three predominant barriers and three facilitators to providing conservative care for older adults with non-dialysis Stage 5 CKD (table 4.2). We also identified three potential strategies to enhancing conservative care.

4.4.1 Barriers

Managing patient and family expectations of chronic kidney failure

PCPs identified factors that impacted their ability to manage patient and family expectations of chronic kidney failure including uncertainty of prognosis, fostering acceptance of kidney disease severity, and misperceptions about dialysis.

Uncertainty of prognosis

Some PCPs found it challenging to help patients and their family members plan and manage expectations of Stage 5 CKD, particularly as it related to the uncertainty of the patient’s life expectancy. Participants indicated that there was a lack of tools that they could use to help predict survival for these older frail adults managed conservatively. This posed a challenge for
PCPs, given the difficulties to help patients and their family members make treatment decisions about renal replacement therapy, and establish the appropriate expectations of this disease. For example, one PCP said:

*I think getting a sense of how much time they have left is hard. I think the challenges for many of us, is how do we make the best estimate of life remaining? I mean there aren’t very good tools in the context of frailty when it comes to getting a really good sense of what to tell families.*

**Fostering acceptance of kidney disease severity**

Some participants indicated that managing the patients and family members’ expectations of kidney failure could be challenging, and that education tools would help foster their patient and family members’ acceptance of kidney disease severity. Participants indicated that it is often difficult to help patients and their family members understand the severity of this disease, given that many patients are asymptomatic. For example, some participants believed that patients/family members lacked understanding and acceptance that the disease could cause death and that aggressive intervention would not improve survival or quality of life:

*[It] took her and her family quite a bit of time to acknowledge that the situation was palliative... And when she went to hospice...Neither of them really seemed to have the insight into the severity of her illness, or that she was going to die from this.*

**Misperceptions of dialysis**

Participants believed that some patients and family members have false conceptions about what dialysis treatment will and will not do to improve survival and symptoms. Further, some PCPs
perceived that patients and their families may not be making rational decisions regarding their kidney disease, that dialysis may be perceived as a life-preserving therapy despite the patient’s poor prognosis. For example, one PCP shared this experience: “[The husband] wants [the patient] to have dialysis. She doesn’t want it. It doesn’t make sense...She’s been stable for quite a while. She has lots of comorbidities.” Hence, PCPs perceived these notions to be misperceptions of dialysis. The disparity between expectations and reality required considerable effort to help patients, and their family members, make informed treatment decisions.

**Complexity of medical management of patients requiring conservative care**

Various factors impacted PCPs’ ability to provide optimal medical management, including their ability to provide best practices in renal care and their ability to integrate multidisciplinary health professionals.

*Ability to provide best practices in renal care*

Symptom management was identified as being challenging and in particular, the ability to manage common symptoms such as pruritus, edema, and dyspnea. Initiation of new medications and renal dose-adjusting existing medications was identified as being problematic. Some PCPs indicated that they were unsure about the intensity and focus of care (e.g. target blood pressure, and treatment of mineral bone disease). PCPs also indicated that their older patients with CKD had multiple comorbid medical conditions, and that navigating the complexity of managing multi-morbidity was challenging. For example, a PCP shared the challenges related to this complicated and resource intensive patient population:

*I would say the challenge is they’re patients who have numerous comorbidities. There’s time challenges for us with a busy office. They are patients who take a lot of time. They
often are on numerous medications, they require a lot of blood work for monitoring, and they often have a high rate of hospital admissions for whether it’s their renal problem or it’s the diabetes, or there’s congestive heart failure, or pneumonia.

**Integrating multidisciplinary health professionals**

PCPs generally did not utilize palliative care services that were available (e.g. physician and home care consultations). There is universal health care coverage with access to palliative care services by all residents in Canada, where those services are provided. However, palliative care services were generally not perceived to be relevant for this patient population (palliative care was recognized as a resource for cancer patients). For example, one PCP acknowledged this oversight: “We have a palliative care team in the community here, [but] we tend to involve them here in more in things like cancer and recently in heart failure. But with renal impairment it’s not being something that’s been in my radar as such.”

PCPs also reported a lack of awareness of renal conservative care resources. Participants indicated that awareness of comprehensive conservative care programs and understanding of other relevant resources available to them locally would enhance their provision of care. Finally, PCPs reported difficulty providing optimal care for patients managed conservatively due to variation in renal-specific expertise among health professionals involved in their care (e.g. care aids in assisted living facilities, home care nurses, and palliative care nurses).

**Challenges associated with managing patients jointly with specialists**

*Negotiating healthcare provider roles and responsibilities*
Some participants expressed challenges co-managing their patients with nephrologists, including lack of role clarity and lack of communication. The extent of PCP involvement in co-management depended on individual physician preferences, and therefore needed to be tailored to each patient’s individual providers. For example a PCP expressed their need to establish a co-management system in a manner that meets their expectations: “Sometimes I think it takes an effort from the family or the primary care physician to actually liaise with the [renal] clinic...to establish who does what and how do we do things.”

PCPs indicated that clear communication of roles and responsibilities are required to ensure optimal patient care; hence, communication with nephrology was also a barrier to conservative care. Some PCPs preferred to be informed when there are any changes in medications, tests, referrals, and the patient’s clinical status. For example, one PCP expressed their dissatisfaction when they were not informed by the nephrologist of their patient’s death: “The disappointing thing was that once I made that phone call [to the nephrologist], I never got any documentation or phone calls back from that service, and I had to find out by reading in the newspaper that she had died.”

4.4.2 Facilitators

While there are many barriers to providing renal conservative care, PCPs also identified key facilitators that could help them in their practice. These facilitators fell into three major themes.
Establishing patient and family expectations of chronic kidney failure early

The establishment of patient and family expectations of kidney failure was facilitated via discussions regarding resuscitation status and determination of the appropriateness of a conservative care approach.

Employing discussions regarding resuscitation status

Some participants indicated that resuscitation status discussions were an integral part of the initial stages with patient and family members to establish their expectations of kidney failure; for example, a PCP expressed that “I think if you try to set the expectations fairly quickly, then you know that certainly helps.” Participants contended that these discussions prompted patient and family members to share their values and preferences, which in turn facilitated discussion about a clear treatment path.

Determining appropriateness of conservative care approach

The physician’s clinical assessment of the patient as a whole was important for determining whether the patient was appropriate for dialysis or non-dialysis care. PCPs identified that once a patient has been deemed less appropriate for dialysis, then they are cared for with a palliative care approach (which may or may not involve palliative care services); for example, one participant remarked that “…the bottom line is I do figure that if people have chosen not to go on dialysis that it is a palliative situation.” Hence, reaching the treatment decision as a care team involving the patient, family, and physician was important for providing optimal care.
**Preserving continuity of care**

PCPs valued the preservation of continuity of care with direct access to designated primary care providers, minimization of unnecessary intervention or burdens of healthcare, and developing their patient and family’s trust and confidence in conservative care.

*Enabling patients’ direct access to designated primary care providers*

The preservation of continuity of care was key to the PCPs’ decision whether or not to refer their patients to a nephrologist. This also influenced their level of personal involvement in patient care and patterns of referral. Hence, some PCPs provided their patients with direct access to their own care (e.g. providing the patient/family member with their cell phone number). For example, one participant explained their approach to enabling patients’ direct access to primary care providers:

“I have a built-in protocol with how the team functions with the patient and the family. So I always have one family member designated as the contact individual...then I identify one team member as the primary contact person as well, so sometimes that’s me.”

*Minimizing unnecessary interventions*

Participants expressed concern about the burden placed on patients if they were required to visit a nephrologist. For example, a PCP explained that the burdens included the patients’ time, cost of transportation, and enduring invasive examinations: “*It would have just been a burden to send [the patient] to another specialist, and explain all the story and inevitably the [nephrologist] says ‘oh let’s do a couple of extra investigations’...for some of these older people, it’s a marathon process.*”

*Developing patient and family’s trust and confidence in conservative care*
The patient and family’s trust and confidence in the health care team were key facilitators of conservative care. This was achieved in many ways (e.g. through time, patience, and demonstrating that the providers actually cared for the patient and their family), for example, one participant expressed:

_Sometimes...if you just gave them time, if you just show them that you really, really care, they go to all the quality of the physician and nurses, then they start to trust you, then they actually start to actually listen to what you’re saying, and then we can have good discussions. So a lot of people will sort of turn around the initial ‘no, I want this, this, this, and that.’_

**Utilizing a multidisciplinary team approach**

*Leveraging renal-specific competencies of nephrologists and allied health professionals*

Participants expressed the importance of having a strong multidisciplinary team, both within and outside of their medical clinics, and with both generalists and those with renal-specific expertise. For example, a PCP expressed that having a multidisciplinary team was their practice standard:

*“It usually involves a multiple health professional team as well as the patient and their family. It rarely is just a patient-physician relationship.”* Having these team members enabled PCPs to feel more confident and supported in the care of the patient and their family.

**Strategies to enhance conservative care**

PCPs identified the following potential strategies for enhancing conservative care, which included having: telephone access to clinicians familiar with conservative care, treatment
decision aids for patients and their families, and a conservative care clinical pathway to guide management.

**Telephone access and treatment decision aids**

To obtain the necessary advice and guidance without formal referral, some participants highlighted the value of telephone access to conservative care clinicians (e.g. nurse clinicians or nephrologists) to improve patient care. They indicated that having a discussion with such a clinician was both efficient and important. For example, one PCP indicated “it would make more sense for me as a non-palliative care doctor to be able to quickly access with a phone call somebody who has that information in their head right away.” Further, some PCPs suggested the value of educational resources for patients and their family, such as treatment decision aids for symptom management, to support the PCP in their “approach to... verbalize what the options are, what the pros and cons are, and what the realistic expectations are.”

**A conservative care clinical pathway**

When probed whether a conservative care clinical pathway would aid in community-based conservative care, some PCPs welcomed the idea: “just to get that learning out there and to have a readily available tool to go ‘okay, for this symptom I’ll do this and for these symptoms I’ll do that,’ it would be helpful.”

**4.5 Discussion**

In this qualitative study, we found that PCPs identified conservative care of older adults with non-dialysis Stage 5 CKD as a complex process with several potential barriers and facilitators to care. The barriers to conservative care were multidimensional and encompassed challenges to more effective management of patient/family expectations, optimization of medical
management, and co-management. Overarching key facilitators to community-based
conservative care included the early establishment of patient/family expectations, sustaining
continuity of care, and incorporating a multidisciplinary care team.

Although the perspectives of PCPs on conservative care for older adults with Stage 5 CKD have
not previously been examined in North America, they were recently explored as part of a study
on PCPs’ view on managing advanced CKD in the United Kingdom (155). There were some
similarities with the findings of our study. Regarding patients with advanced CKD, they reported
challenges related to managing multiple comorbidities, a lack of awareness of conservative care
programs, and difficulty negotiating healthcare provider roles and responsibilities. However, we
focused on older adult patients with chronic kidney failure not planning to initiate dialysis while
residing in Canada, a country with universal health care coverage with access to palliative care
by all residents in locations where it is provided (156). This is a particularly vulnerable patient
population that is the focus of clinical practice guidelines (74) and makes up a large and growing
proportion of patients with advanced CKD (11). We identified a number of unique themes that
contribute to the literature regarding conservative care delivery by PCPs for this older adult
population, including barriers related to providing certainty of prognosis, patient/family
unrealistic understandings of dialysis, and challenges PCPs experience in their ability to deliver
best practices in renal care.

Similar to other studies of earlier stages of CKD (82,85), we identified challenges in co-
management of conservative care of older adult patients. Previous work has similarly indicated
that co-management challenges were due to communication issues and a lack of clarity in the
PCPs’ role once the patient is under the nephrologists’ care (82). A potential solution may be
standardization of roles and responsibilities regarding specific aspects of screening and care, which can be tailored to individual PCP and nephrologist preferences via direct communication. Also, periodic clinical status reports from the nephrologist to the PCP may improve the clarity of communication.

A key strength of our study was the inclusion of PCPs from rural and urban settings, from a variety of settings including supportive living facilities, and with experiences co-managing and not co-managing their patients with nephrologists. In-depth data were collected via individual interviews rather than focus groups to accommodate scheduling and travelling restrictions of study participants; telephone interviews provide a valuable source of information when it is not possible to have direct access to participants (157). Data saturation from a purposive sample of PCPs with a range of demographic characteristics supports the transferability of these findings to PCPs across Canada. Credibility of the study was established through the debriefing of codes and themes with the research team, where questions were posed about the research process and findings to provide additional perspectives on analysis and interpretation. Also, similar findings from previous studies help to triangulate findings from this study. The rigorous data analysis process involving a team and consensus-building approach supports the dependability and confirmability of our findings.

Some potential limitations should be considered. By using a qualitative design, we did not intend to make statistically representative associations, but aimed to use rich data to explore this phenomenon in depth. Interviews were conducted on a single occasion. However, it is unlikely that participants’ perspectives of conservative care would change overtime. Finally, although we asked about provision of care to a clearly defined patient group aged ≥ 75 years not treated with
renal replacement therapy, and the majority of patients treated with conservative care are older adults (11), conservative care can also be an appropriate treatment option for younger patients with chronic kidney failure.

According to international clinical practice guidelines, key components of a comprehensive conservative care program involve: interventions to delay progression of kidney disease and minimize risk of adverse events or complications; shared decision-making; active symptom management; detailed communication including advance care planning; psychological support; social and family support; and cultural and spiritual domains of care (33). Future work is required to examine how these components of care are being provided in the primary care setting. Further research is also necessary to identify core outcomes important to patients, families, and providers to determine targets for optimal patient care.

In conclusion, we qualitatively demonstrated that PCPs perceive barriers and facilitators to their provision of conservative care for older adults with Stage 5 CKD not on dialysis, related to the complex components of care for this patient population. Potential strategies by renal programs in partnership with PCPs to enhance the quality of conservative care in the community, including telephone access to renal conservative care clinicians, education tools to aid in patient treatment decision-making, and a renal conservative care clinical pathway, may enhance the care for this patient population.
Table 4.1 Demographic characteristics of interview participants (n=27)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>15</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>Less than 40</td>
<td>2</td>
</tr>
<tr>
<td>40 to 60</td>
<td>15</td>
</tr>
<tr>
<td>Greater than 60</td>
<td>10</td>
</tr>
<tr>
<td>Duration of clinical practice in primary care (years)</td>
<td></td>
</tr>
<tr>
<td>Less than 10</td>
<td>5</td>
</tr>
<tr>
<td>10 to 20</td>
<td>8</td>
</tr>
<tr>
<td>More than 20</td>
<td>14</td>
</tr>
<tr>
<td>Practice interest in geriatrics or care of the elderly*</td>
<td>9</td>
</tr>
<tr>
<td>Number of patients in target population managed within the last 12 months**</td>
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</tr>
<tr>
<td>Less than 5</td>
<td>20</td>
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<tr>
<td>5 to 25</td>
<td>6</td>
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<tr>
<td>More than 25</td>
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</tr>
<tr>
<td>Population size and density of main clinical practice</td>
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</tr>
<tr>
<td>Large and medium population centres</td>
<td>18</td>
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<tr>
<td>Small population centres and rural areas</td>
<td>8</td>
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<tr>
<td>Both</td>
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</tr>
<tr>
<td>Setting of main clinical practice</td>
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<tr>
<td>Outpatient clinic</td>
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<tr>
<td>Continuing care facility</td>
<td>2</td>
</tr>
<tr>
<td>Both</td>
<td>3</td>
</tr>
<tr>
<td>Time dedicated to clinical practice</td>
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</tr>
<tr>
<td>Less than 25%</td>
<td>2</td>
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<tr>
<td>25 to 50%</td>
<td>4</td>
</tr>
<tr>
<td>More than 50%</td>
<td>21</td>
</tr>
<tr>
<td>Member of a Primary Care Network</td>
<td>25</td>
</tr>
<tr>
<td>Co-management</td>
<td>16</td>
</tr>
</tbody>
</table>

*Based on special practice interests reported by the College of Physicians and Surgeons of Alberta

**Patients age ≥75 years with eGFR ≤15mL/min/1.73m²

Urban area: a population of at least 1,000 and a density of 400 or more people per square kilometer (158)

Large population centre: consisting of a population of 100,000 and over

Medium population centre: consisting of a population of between 30,000 and 99,999

Small population centre: consisting of a population of between 1,000 and 29,999

Rural area: all territory outside an urban area

Continuing care facility: lodge, assisted living facility, or long-term care facility

Co-management: both the primary care physician and the nephrologist are involved in the care management of this patient population
Table 4.2 Primary Care Physicians’ Perceived Barriers and Facilitators of Conservative Care for Older Adults with Chronic Kidney Failure in the Community

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Facilitators</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Managing patient and family expectations of chronic kidney failure</em></td>
<td><em>Establishing patient and family expectations of chronic kidney failure early</em></td>
</tr>
<tr>
<td>• Uncertainty of prognosis</td>
<td>• Employing discussions regarding resuscitation status</td>
</tr>
<tr>
<td>• Fostering acceptance of kidney disease severity</td>
<td>• Determining appropriateness of conservative care approach</td>
</tr>
<tr>
<td>• Misperceptions of dialysis</td>
<td></td>
</tr>
<tr>
<td><em>Complexity of medical management of patients requiring conservative care</em></td>
<td><em>Preserving continuity of care</em></td>
</tr>
<tr>
<td>• Ability to provide best practices in renal care</td>
<td>• Enabling patients’ direct access to designated primary care providers</td>
</tr>
<tr>
<td>• Integrating multidisciplinary health professionals</td>
<td>• Minimizing unnecessary interventions</td>
</tr>
<tr>
<td></td>
<td>• Developing patient and family’s trust and confidence in conservative care</td>
</tr>
<tr>
<td><em>Challenges associated with managing patients jointly with specialists</em></td>
<td><em>Utilizing a multidisciplinary team approach</em></td>
</tr>
<tr>
<td>• Negotiating healthcare provider roles and responsibilities</td>
<td>• Leveraging renal-specific competencies of nephrologists and allied health professionals</td>
</tr>
</tbody>
</table>
CHAPTER FIVE:
PREVALENCE OF BARRIERS AND FACILITATORS TO ENHANCING
CONSERVATIVE KIDNEY MANAGEMENT FOR OLDER ADULTS IN THE
PRIMARY CARE SETTING

We described in chapter 4 findings from an inductive qualitative study of barriers and facilitators to conservative care. We integrate in this chapter those findings into the development and administration of a questionnaire to examine the magnitude of barriers and facilitators to conservative kidney care as experienced by primary care physicians across the province of Alberta. Identifying the prevalence of needs reported by primary care physicians can support the implementation of interventions to address key challenges and enable facilitators to optimize community-based conservative care.

This chapter was published as:

5.1 Abstract

Background and objectives: Conservative management of adults with stage 5 chronic kidney disease (CKD, eGFR <15mL/min/1.73m²) is increasingly being provided in the primary care setting. We aimed to examine perceived barriers and facilitators for conservative management of older adults by primary care physicians.

Design, setting, and participants: In 2015, we conducted a cross-sectional population-based survey of all primary care physicians in Alberta, Canada. Eligible participants had experience caring for adults aged ≥75 years with stage 5 CKD not planning on initiating dialysis.

Questionnaire items were based on a qualitative descriptive study, informed by the Behavior Change Wheel, and tested for face and content validity. Physicians were contacted via postal mail and/or fax, based on a modified Dillman method.

Results: Four hundred and nine eligible primary care physicians completed the questionnaire (9.6% response rate). The majority of respondents were male (61.6%), aged 40-60 years (62.6%), and practiced in a large/medium population centre (68.0%). The most common barrier to providing conservative care in the primary care setting was the inability to access support to maintain patients in the home setting (39.1% [95% CI: 34.6-43.6%] of respondents). The second most common barrier was working with non-physician providers with limited kidney-specific clinical expertise (32.3% [95% CI: 28.0-36.7%]). Primary care physicians indicated that the two most common strategies that would enhance their ability to provide conservative management would be the ability to use the telephone to contact a nephrologist or clinical staff from the conservative care clinic (86.9% [95% CI: 83.7-90.0%] and 85.6% [95% CI: 82.4-88.9%] respectively).
Conclusions: We identified important areas to inform clinical programs to reduce barriers and enhance facilitators to improve primary care physicians’ provision of conservative kidney care. In particular, primary care physicians require additional resources for maintaining patients in their home and telephone access to nephrologists and conservative care specialists.
5.2 Introduction

International clinical practice guidelines recommend that patients with an estimated glomerular filtration rate (eGFR) of less than 30mL/min/1.73m² be referred to a nephrologist (6). However, in the interest of patient-centered care, referral may not always be necessary nor will it always be a feasible option. For instance, the majority of patients with stage 5 chronic kidney disease (CKD, eGFR <15mL/min/1.73m² or G5 category in CKD) (6) that are managed without renal replacement therapy (i.e. conservative care) are older people (age 75 years and greater) (11), and their routine care is often provided by primary care physicians without seeing a nephrologist (11).

There are distinct conservative care populations: conservative kidney care, choice-restrict conservative care, and unrecognized G5 CKD (33). In this study, we focus on conservative kidney care, non-dialysis management that is chosen or is medically advised. Ideally, conservative kidney management involves a multidisciplinary team that provides symptom management, advance care planning, and psychological support (33). Although primary care physicians are key healthcare providers for conservative care for older adults with kidney disease, there is a paucity of research regarding the barriers and facilitators of their clinical practice.

This study was part of a sequential and exploratory mixed methods study (159). The findings reported from a prior qualitative descriptive study identified barriers and strategies to enhancing conservative care by primary care physicians (143). These findings directly contributed to the development of the questionnaire examined in this paper. In the prior study, we found that primary care physicians’ perceived barriers to care included management of patient/family
expectations, the complexity of medical management and especially challenges regarding the management of multi-morbidity, and challenges arising from co-management of patients with specialists. Respondents suggested that direct telephone access to conservative care experts, treatment-decision aids, and a conservative care clinical pathway would be helpful to them. Building on this prior work, we sought to determine the prevalence of perceived barriers and facilitators to improving primary care physicians’ ability to conservatively manage older adults with stage 5 CKD who were not planning to initiate dialysis.

5.3 Methods

5.3.1 Study participants
We undertook a population-based cross-sectional survey of all primary care physicians (4521 family physicians or general practitioners) registered with the provincial regulatory College of Physicians and Surgeons of Alberta, Canada (144). Physicians were eligible for the study if they self-reported having provided care for adults aged 75 years or older with stage 5 CKD, and did not intend to initiate dialysis.

5.3.2 Questionnaire development and administration
Details regarding questionnaire development and survey administration are reported elsewhere (160). In brief, the questionnaire (appendix B) included 32 questions. The major sections of the questionnaire focused on barriers to conservative care, facilitators to improving care, and demographic and clinical practice characteristics. Questionnaire items were informed by interviews with primary care physicians who had experience caring for the population of interest (143) and the Behavior Change Wheel (147). The Behavior Change Wheel incorporates a theoretical system with three components for understanding behavior, namely Capacity,
Opportunity, and Motivation (termed the ‘COM-B system’), and the Theoretical Domains Framework for behavioral change and implementation research (78). All domains of the framework were reviewed and three were identified as the most relevant COM-B components: psychological capability (knowledge skills), physical opportunity (opportunity afforded by the environment, e.g. resources), and reflective motivation (reflective processes involving plans/actions due to beliefs about positive/negative outcome expectations) (79). Four nephrologists, one geriatrician, three primary care physicians, and 14 health services researchers evaluated the questionnaire for face and content validity (149). The feedback received from the evaluations comprised of minor modifications that were incorporated, which improved the clarity and organization of the questionnaire.

Following receipt of ethical approval from the Conjoint Health Research Ethics Board at the University of Calgary, primary care physicians were contacted between September and October 2015, based on contact information available from the provincial regulatory College of Physicians and Surgeons of Alberta. Using a modified Dillman method (150) with a sequential mixed-mode approach (161), these physicians were contacted and expected to respond via mail, fax, and/or online methods. Based on previously conducted surveys among physicians in the Canadian setting, a mixed-mode of data collection was deemed to be important for increasing the response rate, particularly when involving mailing methods (162–164). A mixed-mode of data collection compensates for weaknesses of each mode alone, e.g. to reduce costs, improve timeliness of responses, and reduce selection bias due to mode of data collection (161). Up to three personal reminders were provided to non-responders. Data collection was open for a period of nine weeks. Questionnaire responses were confidential with implied consent.
5.3.3 Analysis

Descriptive statistics were used to report on the proportion of barriers and facilitators perceived by respondents to be particularly important in their provision of conservative care. Open-ended responses were analyzed by three researchers using conventional qualitative content analysis (142). We compared major barriers and facilitators using two-sample tests of proportions with outcomes collapsed as: never/rarely/sometimes a barrier versus likely/definitely a barrier, and definitely not/likely not/maybe a facilitator versus likely/definitely a facilitator. Finally, employing complete-case analysis, associations between demographic/clinical practice characteristics and major barriers and facilitators were explored using modified Poisson regression with robust error variance (165), outcomes were collapsed as: never/rarely a barrier versus sometimes/likely/definitely a barrier, and definitely not/likely not a facilitator versus maybe/likely/definitely a facilitator. We employed a backwards elimination technique, manually excluding terms with p-value $\geq 0.05$. Based on a sample size calculation, we estimated that a sample of 371 eligible respondents would generate a 95% confidence interval equal to the sample proportion of each outcome (e.g. ability to access resources from the conservative clinic as a barrier to care) plus or minus 0.05 when the estimated proportion of each outcome is 0.50. All statistical analyses were conducted using Stata 11.2 (166).

5.4 Results

Four hundred and nine primary care physicians were eligible and responded to the survey, representing 9.6% of all primary care physicians in the province (figure 5.1). Of the 55 participants that were not eligible for the study, two were no longer in clinical practice, one was on sabbatical, one was retired, and one was not a primary care physician. The remainder did not have experience providing care for patients with the demographic and clinical characteristics...
specified for this survey. Overall, the majority of the respondents were male (61.6%), age 40 to 60 years (62.6%), practiced in a large/medium population centre (68.0%), had extensive experience practicing in the primary care setting (i.e. 49.1% had greater than 20 years of experience in primary care), and 91.4% dedicated more than 50% of their time to their clinical practice compared to research or administrative duties. In general, respondents had similar demographic and clinical characteristics to the overall population of primary care physicians in Alberta (table 5.1).

5.4.1 Barriers to Conservative Care

Thirty-nine percent of respondents (95% CI: 34.6-43.6%) indicated that their ability to access support to maintain the patient in their home setting and to avoid transitions of care was often/always a barrier to conservative care (i.e. the most prevalent barrier to care, figure 5.2). Approximately a third of respondents indicated that the following items were often/always a barrier: the extent to which they were able to select medications and adjust their dosages (31.0%, 95% CI: 26.7-35.2%); know when to discontinue preventative measures (30.0%, 95% CI: 25.7-34.2%); and help patients/their family understand the risk/benefits of treatment options (26.5%, 95% CI: 22.4-30.6%). Also, about a third of respondents indicated that the following items were often/always a barrier: the extent to which they were able to work with healthcare providers without renal expertise (32.3%, 95% CI: 28.0-36.7%) and access resources from the conservative management clinic (29.8%, 95% CI: 25.4-34.1%) (figure 5.2).

5.4.2 Facilitators for Enhancing Conservative Care

The major facilitators that respondents believed would likely/definitely enhance conservative care were their ability to contact a nephrologist by telephone (86.9%, 95% CI: 83.7-90.0%),
ability to contact clinical staff from the conservative management clinic by telephone (85.6%, 95% CI: 82.4-88.9%), and ability to co-manage patients with nephrologists in a manner meeting the primary care physicians’ expectations (85.4%, 95% CI: 82.2-88.7%) (figure 5.3). Eighty-two percent of respondents (95% CI: 78.0-85.2%) indicated that improved access to conservative clinic services, 77.7% (95% CI: 73.8-81.5%) indicated that their ability to access educational resources to support treatment decision-making for patients (and their family), and 76.2% (95% CI: 72.3-80.2%) indicated that improved access to palliative care would likely or definitely enhance conservative care. The clinic mentioned above refers to a dedicated conservative management clinic in Alberta, which provides a novel and multidisciplinary program for patients who decide not to include dialysis in their treatment plan (167).

5.4.3 Open-ended responses
Themes generated from the open-ended responses, along with their exemplar quotations, are provided in table 5.2. Respondents reported educational barriers and challenges having access to and collaborating with non-physician healthcare providers. The continuing medical education programs currently do not focus on conservative kidney management, and primary care physicians generally lacked personal knowledge and experience caring for the patient population of interest. As one physician indicated, “[there is a] barrier just because of my limited knowledge/experience”. In particular, respondents reported they were unaware of the conservative management clinic, and they had a lack of knowledge about education and support resources for patients and their families. One respondent suggested such support for patients could be a priority: “I think having more educational resources for patients would help most.
Once the initial decision [to pursue conservative care] is made, it is not as difficult to deal with issues as they arise”.

Challenges to accessing and working with other healthcare providers included difficulties related to communication with other providers (e.g. CKD clinic nurses, nephrologists, and cardiologists), long wait times for a nephrology appointment, and issues specific to respondents who practice in rural settings. Respondents suggested potential strategies for improving care including improvements to their knowledge and education related to conservative kidney management, improved access to nephrology and palliative care services, and having access to adequate resources for avoiding transitions of care (i.e. their ability to access support to maintain the patient in their home setting).

5.4.4 Associations between respondent characteristics and barriers/facilitators to enhancing care

We found associations between respondent characteristics and the ability to access support to maintain the patient at home, the most prevalent barrier to care (table 5.3). Primary care physicians practicing in a metropolitan zone (versus non-metropolitan zone), being female and younger than 40 years of age, having more than 10 years of primary care experience, spending less than 25% of their time in clinical practice compared to research or administrative duties, and having less than 25% of their patients aged 75 years or older were more likely to experience the barrier.

For the second most commonly reported barrier, working with healthcare providers with limited renal expertise, the only respondent characteristics associated with the barrier were female sex and not having a clinical practice interest in the elderly. Females were more likely to experience
the barrier, while respondents with a clinical practice interest in the elderly were less likely to experience the barrier. No associations were identified between demographic/clinical characteristics and the ability to contact clinical staff from the conservative care clinic by telephone as a potential facilitator to care, or the ability to access an online conservative care clinical pathway as a facilitator to care.

5.5 Discussion
We report findings of a population-based survey to examine the frequency of barriers experienced by primary care physicians when conservatively managing older adults with stage 5 CKD, and the potential strategies they perceive to improve conservative patient care. Many of the barriers and strategies examined were found to be important areas for improving care, including their knowledge skills, the opportunities obtained from their environment, and their expectations of co-management with nephrology. The most prevalent barrier to conservative kidney care was their ability to access support for maintaining their patients at home, followed by their ability to work with non-physician healthcare providers (e.g. care aids and home care nurses) who have limited renal-specific clinical expertise. Other barriers related to their knowledge skills, such as the extent to which they were able to select medications and adjust their dosages, were also common. The strategies most commonly reported as facilitators for improving care were the ability to have telephone contact for advice from nephrologists or conservative management clinical staff.

The major barrier to conservative kidney care, the primary care physicians’ ability to access support to maintain the patient at home, was a broad survey item intended to capture issues related to the prevention of transitions of care from the home setting. It encompassed the ability
to prevent hospitalizations, maintain functional independence, delay long-term or supportive care admissions, and enable death in the home setting. Prior studies have demonstrated the importance patients place on being able to be cared for and remain in their own homes. Patients are willing to trade seven months of life expectancy to reduce admissions to the hospital (168) and many patients prefer to die at home (36.1%) or in an inpatient hospice (28.8%), rather than an acute care hospital (73). Although a previous study reported that conservative care (when compared to dialysis treatment) reduces hospitalization and increases likelihood of death at home or in a hospice (53), conservative management was examined in a setting managed by nephrologists.

We found that primary care physicians practicing in metropolitan zones compared to non-metropolitan zones were more likely to report that their ability to maintain the patient at home was a barrier to conservative care, consistent with previous research. Studies examining older adults treated with renal replacement therapy found that those living in predominately metropolitan areas had a higher likelihood of hospitalizations, intensive care unit admissions, interventional procedures during the last month of their lives (70), and were more likely to die in the hospital (169).

As reported in the prior qualitative study (143), a facilitator of conservative care was to establish patient/family expectations of stage 5 CKD early, and this is supported by discussions on resuscitation status. Hence, a potential explanation for the challenge in maintaining the conservatively managed patient at home may be due to the lack of advance care planning. Advance care planning is an ongoing formal process of communication between the patient, family, and healthcare provider regarding the patient’s end-of-life care goals and treatment
preferences, should the patient lose the ability to speak for themselves (170,171). Although advance care planning is associated with reduced hospitalization and increased death in a location preferred by the patient (172–174), previous work has illustrated that advance care planning is not systematically integrated into the care of stage 5 CKD patients (73). In addition to advance care planning, community-based complex interventions may address this chief barrier to conservative care. Based on a systematic review of randomized controlled trials, complex health and social interventions involving an interdisciplinary team can help to maintain physical function and independence among older adults (175).

Top strategies preferred by primary care physicians for improving conservative management were direct telephone access to nephrologists and conservative management clinical staff members. Telephone consultations have been identified as an important tool for rural primary care physicians and specialists (176–178) to obtain advice on routine management and for organizing semi-urgent or urgent referrals (176). We found that primary care physicians supported telephone consultations from other providers within the conservative care clinic, regardless of whether they practiced in a rural or urban setting. There are, however, potential issues that may arise from the use of telephone consultations including reduced ability to develop trust between providers, the extent to which specialists can provide advice without seeing the patient, and the accuracy of advice and impact on patient outcomes (176,179,180).

Some limitations should be considered when interpreting the results of our study. We were not able to determine the true denominator of eligible physicians from the physician listing provided; the reported response rate is considered to be a conservative estimate as we anticipate that only a subset and yet unknown proportion of physicians would meet the eligibility criteria of our study.
Although the response rate was relatively low, respondent characteristics were similar to the overall population minimizing the potential for response bias. The modified Dillman method employed in this study provided a practical guideline for improving the response rate, though future work is needed to examine strategies for improving the trend of lower response rates among primary care physicians (181–185).

In order to reduce time required to complete the questionnaire, ensure feasibility for practicing primary care physicians, and direct future areas of research, the questionnaire items were intentionally broad and only examined a selection of key sources of behavior. Although conservative care is increasingly provided by nephrology within Alberta (via only one dedicated conservative care clinic and as part of pre-dialysis programs in the province), a large proportion of non-dialysis care is still not provided by nephrology (11). Hence, conservative care is not well established as compared to other settings (7), and barriers and facilitators reported by primary care physicians in this paper are likely to be generalizable to similar settings where established conservative care practices are minimal. It is also important to note that our study was focused on a specific age group with stage 5 CKD, though older adults comprise of the majority of patients managed conservatively (11).

In conclusion, we identified important barriers and strategies and examined the extent to which primary care physicians consider them to be important in the care of older adults with stage 5 CKD not planning to initiate dialysis. Future work is needed to address the following common areas of concern to improve conservative kidney management. There is a need to enhance access to support for maintaining the patient in the home setting to avoid transitions of care, which could be accomplished in part through advance care planning. There is also a need to provide a
broad spectrum of educational support for patients, family members, and primary care providers. Furthermore, there is a need to increase telephone access by primary care physicians for direct and timely communication with nephrologists and experts in conservative kidney care.
### Table 5.1 Demographic and clinical characteristics of survey respondents and all primary care physicians in Alberta

<table>
<thead>
<tr>
<th>Characteristic, n (%)</th>
<th>Respondents n=409</th>
<th>All primary care physicians in AB n=4521</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>252 (61.6)</td>
<td>2609 (57.7)</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;40</td>
<td>102 (24.9)</td>
<td></td>
</tr>
<tr>
<td>40 to 60</td>
<td>256 (62.6)</td>
<td></td>
</tr>
<tr>
<td>&gt;65</td>
<td>45 (11.0)</td>
<td></td>
</tr>
<tr>
<td>No response</td>
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</tr>
<tr>
<td><strong>Years practicing in primary care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;10</td>
<td>127 (31.1)</td>
<td>1932 (42.7)</td>
</tr>
<tr>
<td>10 to 20</td>
<td>81 (19.8)</td>
<td>1169 (25.9)</td>
</tr>
<tr>
<td>&gt;20</td>
<td>201 (49.1)</td>
<td>1420 (31.4)</td>
</tr>
<tr>
<td><strong>Percentage of time in clinical practice</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;25</td>
<td>17 (4.2)</td>
<td></td>
</tr>
<tr>
<td>25 to 50</td>
<td>13 (3.2)</td>
<td></td>
</tr>
<tr>
<td>&gt;50</td>
<td>374 (91.4)</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td>5 (1.2)</td>
<td></td>
</tr>
<tr>
<td><strong>Location of main clinical practice</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>North Zone</td>
<td>48 (11.7)</td>
<td>344 (7.6)</td>
</tr>
<tr>
<td>Edmonton Zone</td>
<td>95 (23.2)</td>
<td>1509 (33.4)</td>
</tr>
<tr>
<td>Central Zone</td>
<td>54 (13.2)</td>
<td>434 (9.6)</td>
</tr>
<tr>
<td>Calgary Zone</td>
<td>163 (39.9)</td>
<td>1927 (42.6)</td>
</tr>
<tr>
<td>South Zone</td>
<td>49 (12.0)</td>
<td>307 (6.8)</td>
</tr>
<tr>
<td><strong>Population size of main clinical practice</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Large/medium</td>
<td>278 (68.0)</td>
<td>3464 (76.6)</td>
</tr>
<tr>
<td>Small/rural</td>
<td>131 (32.0)</td>
<td>1057 (23.4)</td>
</tr>
<tr>
<td><strong>Practice interest in geriatrics or care of the elderly</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>258 (63.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Percentage of patients aged ≥75 years</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;25</td>
<td>141 (34.5)</td>
<td></td>
</tr>
<tr>
<td>25 to 50</td>
<td>175 (42.8)</td>
<td></td>
</tr>
<tr>
<td>&gt;50</td>
<td>88 (21.5)</td>
<td></td>
</tr>
<tr>
<td>No response</td>
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<td></td>
</tr>
<tr>
<td><strong>Referral of patients to nephrology</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td>237 (57.9)</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>152 (37.20)</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>17 (4.2)</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td>3 (0.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Referral of patients to palliative care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td>47 (11.5)</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>230 (56.2)</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>127 (31.1)</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td>5 (1.2)</td>
<td></td>
</tr>
</tbody>
</table>
Note. Practice interest in the care of the elderly or geriatrics were based on clinical practice interests reported by respondents and the College of Physicians and Surgeons of Alberta. Medium/large population centre: consisting of a population of greater than 30,000 people; small population centre/rural area: consisting of a population less than 29,999 people. Referral questions based on patients age ≥75 years with eGFR ≤15mL/min/1.73m² not planning on initiating dialysis.
<table>
<thead>
<tr>
<th>Barriers to Conservative Care</th>
<th>Exemplar quotation</th>
</tr>
</thead>
</table>
| **Educational barriers**                                                                       | “Barrier just because of my limited knowledge/experience.”  
“It [has] been an issue especially dealing with adults with cardiac risk factors as to when to stop the NSAIDs [nonsteroidal anti-inflammatory drugs] especially ASA [acetylsalicylic acid] or the statins. How does one strike the balance?”  
“This subject is not target[ed] very well and having information on how to manage symptoms if patients choose to not pursue dialysis would be helpful.” |
| Lack of awareness of Conservative Management Clinic                                             | “Did not know conservative clinic existed. Need to promote the palliative nephrology clinic.”  
“Never heard of the palliative nephrology clinic.”  
“Patients are sometimes surprised that they have the right to refuse treatment”  
“I think having more educational resources for patients would help most. Once the initial decision is made, it is not as difficult to deal with issues as they arise.” |
| Deficiencies in education and support for patients and their families                           |                                                                                                                                              |
| **Challenges having access to and collaborating with health care providers**                    | “CKD [chronic kidney disease] Clinic nurses have presented a significant barrier to care as they often counteract the discussions I have had with patients, their families and the homecare aids and nurses. They typically seem unable to accept that a patient has declined dialysis.”  
“Communication between health providers is often a barrier – with suboptimal communication regarding what has been done, what is planned”  
“Biggest barrier – wait times! AHS [Alberta Health Services, a provincial health authority] needs to hire more nephrologists.” |
| Travel and resource challenges specific to rural settings | “Long wait times to see nephrologists.”
“Consultant appointments are too far out and unavailable when I need them.”
“Only sometimes a trouble due to rural location and distance to dialysis center for consult with nephrology, even if conservative management”
“Barrier to centralized services tend to be a problem in rural communities”
“Limited resources for care at home in rural areas.” |

<table>
<thead>
<tr>
<th>Facilitators for Improving Conservative Care</th>
<th>Enhancing conservative management-related knowledge</th>
</tr>
</thead>
</table>
| Need for continued education and clear guidelines | “Would be helpful to know when/why a nephrologist would treat a CKD/ESRD [end-stage renal disease] patient with conservative/palliative care, rather than choose dialysis. This might help inform future discussion with these patients prior to referral to nephrologist.”
“Provision of information about available services.”
“I would really appreciate some educational resources for families and patients and myself.” |

<table>
<thead>
<tr>
<th>Improving access to nephrology and palliative care services</th>
<th></th>
</tr>
</thead>
</table>
| Improving communication and co-management with nephrology | “I just want to be able to call someone for advice and not feel like I am wasting their time. I want a nephrologist to want to help me because I am in the trenches.”
“Shared care is essential especially given the workload of these patients. Not ‘my’ patient and not ‘your patient’. Our patient!”
“Timely access and phone availability for consultation from 0800 to 2000H is important.” |
| Better access to palliative support | “Palliative care in rural areas I find hard to access.”
“Insufficient after hours (palliative) nephrology resources and palliative physician resources overall.” |
Providing adequate resources to avoid transitions of care

Need more support to keep patients at home

“Multi-system disease often requires considerable resources to keep patients in outpatient/home setting”

“Home care services in [a small population centre] is very poor… they say that are too busy to provide additional services for seniors. Often patients end up in ER [emergency room] and/or hospital when early intervention could prevent this. Palliative care in this region is also poor. I have taken it on myself to do home visits, etc. to help people at home as long as the patient and family are comfortable.”
Table 5.3 Association between respondent characteristics and perceived ability to access support for maintaining patients at home as a barrier to conservative care

<table>
<thead>
<tr>
<th>Demographic/clinical characteristic (n=392)</th>
<th>Unadjusted RR (95% CI)</th>
<th>Full model RR (95% CI)</th>
<th>Reduced model RR (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
<td>0.03</td>
</tr>
<tr>
<td>Female</td>
<td>1.19 (1.06-1.33)</td>
<td>1.13 (1.01-1.27)</td>
<td>1.14 (1.01-1.28)</td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;40</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
<td>0.01</td>
</tr>
<tr>
<td>≥40</td>
<td>0.89 (0.79-1.01)</td>
<td>0.76 (0.62-0.92)</td>
<td>0.76 (0.62-0.93)</td>
<td></td>
</tr>
<tr>
<td>Years in primary care (years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;10</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
<td>0.04</td>
</tr>
<tr>
<td>≥10</td>
<td>1.00 (0.88-1.14)</td>
<td>1.25 (1.02-1.52)</td>
<td>1.22 (1.06-1.39)</td>
<td></td>
</tr>
<tr>
<td>Provincial zone</td>
<td></td>
<td></td>
<td></td>
<td>0.004</td>
</tr>
<tr>
<td>Non-metropolitan zone</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Metropolitan zone</td>
<td>1.22 (1.06-1.40)</td>
<td>1.17 (0.98-1.39)</td>
<td>1.23 (1.01-1.51)</td>
<td></td>
</tr>
<tr>
<td>Population size</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Small/rural</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Large/medium</td>
<td>1.18 (1.02-1.36)</td>
<td>1.07 (0.90-1.28)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percentage of time in clinical practice</td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>&lt;25</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>≥25</td>
<td>0.77 (0.67-0.88)</td>
<td>0.76 (0.66-0.88)</td>
<td>0.76 (0.78-0.98)</td>
<td></td>
</tr>
<tr>
<td>Clinical practice interest in the elderly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Reference</td>
<td>Reference</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.95 (0.89-1.00)</td>
<td>0.97 (0.91-1.03)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percentage of patients aged ≥75 years</td>
<td></td>
<td></td>
<td></td>
<td>0.03</td>
</tr>
<tr>
<td>&lt;25</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>≥25</td>
<td>0.87 (0.77-0.97)</td>
<td>0.89 (0.79-1.00)</td>
<td>0.88 (0.79-0.98)</td>
<td></td>
</tr>
</tbody>
</table>

Note. N/S: non-significance. Non-metropolitan zone: North, Central, and South zones; metropolitan zone: Calgary and Edmonton zones according to Alberta Health Services, the health authority for Alberta, Canada. Medium/large population centre: consisting of a population of greater than 30,000 people; small population centre/rural area: consisting of a population less than 29,999 people. Practice interest in the care of the elderly or geriatrics were based on clinical practice interests reported by respondents and the College of Physicians and Surgeons of Alberta. Outcomes: sometimes/often/always a barrier compared to never/rarely a barrier (reference). Analysis conducted using modified Poisson regression, with robust error variance.
Figure 5.1 Flow diagram of survey respondents
Figure 5.2 Reported frequency of barriers to conservative care
Figure 5.3 Reported frequency of facilitators for enhancing conservative care
CHAPTER SIX: SUMMARY
6.1 Summary of key findings

Comparative studies on dialysis versus non-dialysis care, and research on conservative care specifically, are international priorities to improving care and outcomes for older adults with kidney failure. Our program of study was conducted to provide a better understanding of dialysis effectiveness compared to non-dialysis care among older adults with kidney failure. We also aimed to determine the resource needs of primary care physicians managing this patient population. We ultimately sought from this work to provide evidence to inform CKD programs and primary care physicians to enhance conservative care delivery so that they can best meet the needs of older adults with kidney failure.

6.1.1 Comparing treatment options in relation to survival

A major component of treatment decision-making for older adults with kidney failure requires us to understand outcomes including survival for patients treated versus not treated with chronic dialysis (hemodialysis or peritoneal dialysis). We found in our propensity score matched study among older adults (age ≥65 years) with kidney failure that dialysis was associated with a reduction in the risk of all-cause early mortality within the first three years following onset of kidney failure. The survival advantage, however, was no longer evident beyond three years. Other relevant outcomes including quality of life were not assessed.

6.1.2 Provision of conservative care in the primary care setting

Provision of conservative care by primary care physicians for older adults with kidney failure has been identified as a gap in the literature (89). We hence aimed to examine barriers and facilitators to conservative care in the community. We found in our mixed methods study that
there are three overarching challenges that primary care physicians encountered when aiming to provide optimal conservative care for their patients with kidney failure.

The first major challenge experienced by primary care physicians was an understanding of what patient and families can expect in their disease trajectory. Primary care physicians reported that they did not have the appropriate prognostic tools to support their patients and their family. It is particularly challenging when patients and their family have difficulty accepting the diagnosis and had unrealistic expectations of what dialysis may offer for their survival and quality of life. The second challenge that primary care physicians identified was the complexities of managing conservative care patients. They acknowledged that they did not have sufficient capacity both in terms of their knowledge and resources available to ensure optimal care. The third major challenge was inherent to co-management between primary care physicians and nephrologists that hindered effective working relationships.

We also learned about effective strategies that supported conservative care in the community. Primary care physicians reported that discussing advance care planning helped them establish appropriate patient and family expectations and that it provided a framework for medical management. We also found other useful strategies. These strategies included identifying a central point of contact (providing direct access to designated primary care providers, e.g. with the primary care physician’s telephone number) and preventing unnecessary interventions or transitions in care. Finally, we found that primary care physicians who collaborated effectively with their multidisciplinary team were better able to provide optimal conservative care.
Approximately 85% of primary care physicians reported in our survey their need for provider-to-provider telephone consultation. Consultation via telephone access with a nephrologist or conservative care specialist would enhance their ability to deliver conservative care for their patients. Telephone consultation strategies were the most commonly reported methods for enhancing conservative care in the community.

We found that approximately 40% of primary care physicians experienced challenges in maintaining their patients in their home setting. This was reportedly the most common barrier to providing conservative care in the primary care setting. We found that about one third of primary care physicians had major gaps in their knowledge both in treatment decision-making and in providing medical care for non-dialysis patients. Approximately one third of multidisciplinary team members lacked training in CKD care hindering effective community-based conservative care. These results suggest that there are networks of excellence in managing conservative care and major gaps in capacity within the primary care setting when managing conservative care patients. The magnitude of barriers to care identified from our qualitative study were experienced consistently across the province.

6.2 Clinical implications and complexities of treatment decision-making

Shared treatment decision-making has been coined as the pinnacle of patient-centre care (186). It is a process involving at a minimum the patient and their health care provider. This process aims to inform the patient of the anticipated treatment benefits and harms, and to align the treatment decision within the context of the patient’s goals and preferences (134,186). At the crux of the informed decision-making process is the need for further evidence regarding potential survival
benefits of dialysis compared to conservative care. This is what we aimed to address in this thesis.

6.2.1 Informing treatment decision-making and certainty of prognosis

We (143), and others (132,187,188), have found that health care providers face uncertainties regarding outcomes for older adults with kidney failure, and as a result also face uncertainty with respect to treatment decision-making. Clinicians have consistently expressed the need to better understand survival outcomes for dialysis and non-dialysis care among comparable groups of patients (7,187). For the subgroup of older adults with kidney failure with a similar likelihood of dialysis, the findings we reported in this thesis have important implications for informing decision-making where there is substantial equipoise or uncertainty regarding their risk of death.

We found in our population-based study that dialysis reduced the risk of early mortality following onset of kidney failure regardless of level of comorbidity. We also found that this survival advantage was no longer evident after a longer period of follow-up. These findings need to be interpreted in the context of fundamental principles suggested by clinical practice guidelines emphasizing patient-centred care (74,134). A patient-centered care approach focuses on individualized care and the importance of engaging patients, families, and their health care providers in a shared decision-making process. This process should be informed by patient goals, preferences, prognosis, and benefits and harms of dialysis compared to conservative care. We hence acknowledge that survival is only one, albeit important, prognostic component of treatment decision-making.
We found that dialysis reduced the risk of early mortality, although dialysis can be burdensome and can significantly impact quality of life. Patients tend to prefer treatments that are generally less invasive (188). A systematic synthesis of qualitative studies found that older patients with advanced CKD valued maintaining their lifestyle, and deemed clinical outcomes (e.g. survival) to be less important compared to the impact of treatment on their lifestyle. Older patients generally did not want any disruptions to their usual activities (e.g. social events) or to their ability to carry out personal responsibilities (e.g. caring for their grandchildren) (189). CKD patients not exclusive to older adults have indicated that they are more likely to choose dialysis (hemodialysis or peritoneal dialysis) versus conservative care when dialysis increased survival. Even CKD patients not limited to older adults indicated that they would prefer conservative care and were willing to trade a considerable amount of life expectancy if dialysis negatively impacted their quality of life, such as increased hospitalization visits or restricted abilities to travel (168).

6.2.2 Primary care provider needs for maintaining patients in their home

Older adults including patients with kidney failure generally prefer to reside in their home as long as possible (190). Shifting the focus from providing health care in a medical setting to the home setting is a pan-Canadian priority. This priority aligns with patient preferences, the aging population with chronic disease, and improvements in technology; it is also generally considered to be more cost-effective (190). We aimed to align this thesis with the national priority and hence to engage and support primary care physicians in managing patients with kidney failure residing in the community.
We found from our survey (129) that the top challenge primary care physicians faced when providing community-based conservative care was their inability to access support to maintain their patients at home. This challenge was particularly a barrier among primary care physicians practicing in major urban settings. The difficulty in maintaining patients at home reflects challenges primary care physicians may encounter amidst efforts to prevent transitions of care from the home setting. This may encompass prevention of unnecessary hospitalizations, delaying admissions to long-term care, and enabling death at home. Patients treated with renal replacement therapy and residing in major urban centres (versus rural areas) have been shown similarly in previous work to have a higher likelihood of hospitalization, admission to intensive care units, interventional procedures at end-of-life (70), and death in-hospital (169). Patients with kidney failure however generally prefer to die at home or in-hospice rather than in-hospital (191). Many home care interventions for patients with CKD unfortunately are focused on patients on dialysis (192), while home care interventions specifically for conservatively managed patients are required. Other interventions such as advance care planning may help enable patient preferences to remain their receipt of health care needs in the community.

6.2.3 Establishing effective management of patient and family expectations

Advance care planning involves the patient, their family, and health care providers. It aims to facilitate understanding of patient goals and preferences at their end-of-life (171,191). There is evidence to suggest that advance care planning can reduce hospitalization and increase patient-preferred locations of death (172–174).
We found as part of this thesis that advance care planning was an integral part of the treatment decision-making process, and instrumental in establishing patient and family expectations (143). We found that avoiding these potentially difficult discussions may result in longer-term challenges in conservative care management if patient/family expectations are not established appropriately. The issues linked to not discussing advance care planning, including decline in disease progression and end-of-life care, has also been expressed among nephrologists and clinical nurse specialists (187).

Implementation of advance care planning among CKD patients and their families will hence help facilitate treatment decision-making and support conservative care management. Previous work has indicated that patients prefer their nephrologists to lead advance care planning decisions. Primary care physicians also have an important role in leading these discussions, and in relaying patient values and preferences to nephrologists (193,194). Training in end-of-life conversations among nephrologists to address system-barriers to treatment decision-making has also been proposed (195).

6.2.4 Optimizing medical management, co-management, and continuity of care

We found, based on results from our mixed methods study, that there is ambiguity in how co-management is operationalized between primary care physicians and nephrologists (143). This ambiguity may hinder effective patient care. A number of strategies could be employed to improve provider satisfaction and ultimately patient outcomes including clarity of provider roles and responsibilities specific to aspects of care (e.g. on screening and medical care), tailored co-
management practices meeting provider needs, and strategies for more direct communication between providers.

We found, based on our interviews and survey (129,143), that primary care physicians identified direct telephone access to nephrologists and conservative care experts as a potential strategy for obtaining the necessary information to improve conservative care in the community. Telephone consultations may fill primary care physician gaps in knowledge on medical management. We found this need expressed by primary care physicians from both urban and rural settings. Direct telephone access for primary care physicians to contact nephrologists and clinical staff from conservative care programs would provide an ideal opportunity to improve a number of reported barriers. Telephone consultations may improve provider communication, set tailored expectations between providers, and support effectively co-managed patients. Telephone communication may also prevent unnecessary patient referrals and help sustain continuity of patient care to optimize community-based conservative care.

Future work is required, however, to examine potential challenges associated with telephone consultations. Previous studies have highlighted issues with telephone consultations, including inability to develop a trusting relationship between providers and the inability to provide meaningful advice without seeing the patient (176,179,180).

6.2.5 Educational tools to aid in patient treatment decision-making

We found that there was a need for decision aids to support patients and their providers across primary to tertiary care settings. This was demonstrated in our interview and survey findings (129,143), and is consistent with other studies (187). Patient decision aids are tools that are
designed to facilitate discussions on difficult treatment decisions (e.g. dialysis versus non-dialysis care). They facilitate decisions that are more congruent with patient values and preferences to enable a shared decision-making approach (196). Decision aids alone, however, cannot replace basic communication skills for engaging patients in decision-making (197), although they have been shown to help patients feel better informed and clearer about their values. (198). Patient decision aids are hence a promising area of future study. They can help ensure a patient’s decision of care is in alignment with not only their preference but also their prognosis especially when incorporating outcomes important to them including survival, hospital-free survival, cognitive function, quality of life, and location of care and death (31,199). At least three new decision aid tools are currently in testing phases to support decisions to initiate dialysis or not (196).

6.3 Strengths and limitations

6.3.1 Strengths

Our program of work has a number of strengths including the examination of a patient population with a paucity of evidence to guide care, namely older adults with kidney failure managed in the primary care setting. We conducted a series of studies stemming from key stakeholder needs in nephrology. We conducted a methodologically rigorous survival comparison of dialysis versus non-dialysis treatment for older adults with kidney failure. Our study had strengths including the use of a population-based design in a setting with universal access to health care and long duration of follow-up (approximately 10 years). Our study was also strengthened by its methodological rigor in addressing substantial epidemiologic issues
associated with longitudinal observation data and survival analyses: treatment-selection, lead-time, and immortal time biases.

There were also strengths pertaining to our examination of patient care in the primary care setting. We employed an established mixed method study design to examine conservative care in the community using findings from the qualitative strand to develop a survey to evaluate barriers and facilitators to conservative care for older adults in the community. We employed in the qualitative descriptive study a purposive sampling approach. This approach enabled exploration of participant perspectives from a variety of clinical and geographic settings until data saturation, to enhance transferability of study findings. We strengthened the response rate in our survey by adopting the modified Dillman method that is considered the gold standard for survey administration. We categorized the questionnaire items based on the Theoretical Domains Framework, to promote uptake of survey findings and facilitate their mapping to a diversity of recognized interventions to remove barriers and enhance facilitators to conservative care. All studies were reported in accordance with standard reporting frameworks, and written for a clinical target audience.

6.3.2 Limitations

There are also limitations that should be considered when interpreting our findings. Our study comparing survival among older adults treated and not treated with dialysis was observational in nature. We lacked information given the data sources on decisions impacting dialysis initiation, including frailty and presence of symptoms. There is hence a potential for residual confounding that can distort the exposure-outcome relationship. We however identified and adjusted for other
clinically important demographic and comorbid covariates to demonstrate a meaningful balance of these characteristics between the dialysis and non-dialysis groups.

We also acknowledge potential for remaining lead-time bias (in the non-dialysis group), demonstrated by the small number of non-dialysis survivors observed three years after our defined onset of kidney failure. Results from follow-up after three years could be related to a potentially healthier non-dialysis group at the start of follow-up. This subgroup of non-dialysis survivors had slow progression in their rate of decline in kidney function that was below 10 mL/min/1.73m². We recognize that the rate of progression in kidney function may be attributable to underlying cause of kidney disease that we were not able to account for, such as ischemic nephropathy (200) versus rapidly progressive glomerulonephritis (201). Nevertheless, we aimed to overcome lead-time bias at the study design phase with a 90-day sustained eGFR <10 mL/min/1.73m² criterion to approximate patients eligible of dialysis and non-dialysis care. This eGFR threshold was in accordance with previous studies and clinical practice guidelines, and a stage when many patients start to experience symptoms requiring decision to pursue dialysis or not. We also acknowledge potential for misclassification bias from early deaths among patients intending to be treated with dialysis, but who were classified in the non-dialysis group.

Our mixed methods study was limited in its cross-sectional nature and in our focus exclusively on the perspectives of primary care physicians. We however intended on capturing current participant perspectives, and did not anticipate their perspectives to change extensively through a short period of time. Also, the interview and survey studies were conducted in advance of (and in collaboration with) implementation of an open-access provincial conservative kidney
management clinical pathway (www.ckmcare.com). We chose to focus on primary care physicians given their role in providing community-based care that includes continuing care services (e.g. home care, supportive living, and long-term care).

This program of study overall focused on a relatively narrow population of patients with kidney failure in Alberta: older patients aged ≥65 years with lower levels of eGFR <15 mL/min/1.73m². This well-defined population draws on the extensive literature within geriatric nephrology examining treatment decision-making and conservative care. We recognize, however, that conservative care among younger patients with advanced CKD is another area requiring further investigation. Our findings from these population-based studies including patients and providers across the province are likely generalizable to other settings with universal health care coverage and access to dialysis and conservative care.

6.4 Knowledge translation

We employed an integrated knowledge translation plan to enhance uptake of our findings through a collaborative endeavour between researchers and knowledge users (202). Study investigators represented key stakeholders in geriatrics, conservative kidney management, and general nephrology. The results from our study comparing survival of patients treated and not treated with dialysis were presented at national and international conferences in the fields of nephrology, palliative care, geriatrics, and gerontology. We will submit a manuscript from this work to a peer-reviewed journal targeting clinicians to increase understanding of survival differences among treatment options to support evidence-informed decision-making.
We also collaborated with a variety of key stakeholders including the Conservative Kidney Management Steering Committee, the Southern Alberta Conservative Management Program, the Alberta College of Family Physicians, the Alberta Health Services Kidney Health Strategic Clinical Network, the Department Family Medicine, and the University of Calgary Divisions of Geriatrics and Palliative Care for survey development and dissemination of survey results. Our dissemination strategies (table 6.1) included interactive small group presentations, poster presentations, and publications in clinical nephrology peer-reviewed journals. We aimed to structure the activities according to the audience to promote implementation of the survey findings or to exchange information/awareness pertaining to barriers and facilitators to conservative CKD care in the community.

We also developed a one-page infographic to disseminate survey results and increase awareness of new and established conservative and palliative care resources (appendix C). We developed the infographic in collaboration with our Graphic Design Specialist and Knowledge Translation Broker. We pilot-tested the infographic with study investigators, key stakeholders, and collaborators. Provincial primary care physician organizations (the Alberta College of Family Physicians and the Alberta Medical Association) distributed the infographic via e-newsletters and social media platforms.

Our integrated knowledge translation approach helped our survey findings contribute to development of province-wide telephone access for primary care physicians to directly contact nephrologists and conservative care specialists when needed. Our survey findings have also
informed 13 other interventions being developed by the Conservative Kidney Management Steering Committee, a provincial committee of multidisciplinary stakeholders.

6.5 Future directions

6.5.1 Intention to pursue dialysis when comparing dialysis to non-dialysis care

Our study comparing survival among dialysis and non-dialysis patients inspires a series of potential future directions that require additional investigation to further elucidate the exposure-outcome relationship. Our study focused on comparing non-dialysis care to the receipt of dialysis treatment, while the intent of dialysis was beyond the scope of this study. Validated data regarding permanent vascular access for hemodialysis and insertion of peritoneal dialysis catheter without subsequent dialysis treatments are not available to examine dialysis intent on survival outcomes (203). We however acknowledge that some older patients may not initiate dialysis after incident fistula creation (204). Future work examining survival outcomes among dialysis and non-dialysis care from an intention-to-treat perspective hence would be informative, particularly in observational retrospective and prospective longitudinal data.

Guidelines from the Renal Physicians Association recommend considering a time-limited trial of dialysis for patients who have an uncertain prognosis, or in situations where consensus on dialysis versus conservative care cannot be made (74). Time-limited trials of dialysis range from 1 to 3 months among patients with kidney failure (205). We included in our study all dialysis patients, and were not able to determine whether the intent was for a time-limited period. Future work examining potential outcomes of patients with a time-limited trial of dialysis (among those
who continued with dialysis care versus patients who withdrew from dialysis) would further inform treatment decision-making.

6.5.2 Methodological issues pertaining to survival comparisons

Other areas that require further investigation stemming from our survival comparison study are the methodological considerations inherent in this area of research. We, and others (55,66), have identified conservatively managed patients surviving beyond 3 years. Their survival may be attributed to extended periods of lead-time (among people who do go on to experience clinical presentations of kidney failure), or misclassification due to inaccuracies in eGFR measurements from factors such as muscle mass (among people who never go on to experience clinical presentations of kidney failure). Further research estimating lengths of lead-time among non-dialysis patients using eGFR and other routinely collected data requires further investigation. The extent of inaccuracies using eGFR to measure kidney function among older adults with kidney failure also warrants future research.

6.5.3 Other clinical outcomes when comparing dialysis and non-dialysis care

We focused on survival outcomes among dialysis and non-dialysis patients. Other important outcomes that require future research include health resource utilization (e.g. hospitalization, emergency room visits, and palliative care services) and quality of life. There is information on the predictors of survival for older adults on dialysis, although studies investigating predictors of mortality for older patients managed with conservative care are lacking (47,206). Future research is needed to differentiate patients with kidney failure that will benefit from dialysis compared to
patients with systemic multi-organ dysfunction in addition to kidney failure that would likely benefit from a conservative care approach (29).

**6.5.4 Unidentified advanced CKD patients**

We examined provision of care by primary care physicians including patients not referred to nephrology. This topic has been identified by Hole et al (89) as an area with a paucity of research. Another area requiring further research relates to patients that have not been identified by either primary care or nephrology as having advanced CKD. Our survival comparison study was limited to use of administrative data that only captured patients in contact with the health care system (e.g. patients with serum creatinine measurements). We may have missed some non-dialysis kidney failure cases who do not regularly have contact with health care providers, such as more vulnerable populations including people who live in remote areas, are homeless, and those without health care insurance. We estimate based on previous work (207) that approximately 80% of older adults in Alberta will have at least one serum creatinine measurement. The availability of universal healthcare in Canada removes barriers of access to the health care system due to financial issues, and this improves the quality of the administrative data used in our study. Future work exploring the magnitude and characteristics of non-dialysis patients without laboratory tests despite having kidney failure would be informative to examine this potentially more at-risk population.

**6.5.5 Theoretical Domains Framework: future interventions**

We examined in our survey study three major behavioural domains as barriers to conservative care in the primary care setting: knowledge skills; opportunities afforded by the environment;
and reflective processes involving plans/actions due to beliefs about outcome expectations. There are, however, nine other domains that should be explored as potential barriers to care including their skills, social/professional role and identity, and social influences (208). Information on barriers to care that were gained from our study could inform areas for future interventions to address the challenges that primary care physicians typically encounter. Interventions may be informed by the Theoretical Domains Framework and mapped to the Behavior Change Wheel. Domains of interventions may involve enabling, training, and environmental restructuring (78).

It is important to understand the provider’s perspective on caring for older patients with kidney failure, although it is also critical to gain understanding from the patient and their family caregiver’s perspective. Future work should explore the views of older patients living with advanced CKD cared for in the primary care setting to inform their needs and provision of services for this patient population.

6.5.6 Chronic care model: other pillars informing the conservative care pathway

This thesis draws from principles that are broadly outlined in the CKD chronic care model: 1) information required to inform shared treatment-decision making processes and 2) knowledge needed to enhance the quality of conservative care delivery. Other principles requiring further investigation and improvements in the field of conservative care include: information systems (e.g. development of conservative care registries); self-management and development of personal skills (e.g. how to slow CKD progression and manage symptoms); and creating supportive environments in the community (e.g. legitimatizing conservative care as a treatment modality among patients, families, providers, and policy makers).
6.6 Conclusions

Research on conservative care has previously focused on patients with advanced CKD that are referred to nephrology and related CKD services. Conservative care among patients that are not referred however is largely unknown. We examined clinical care and outcomes through a wider perspective with implications from primary to tertiary care contexts and their intersecting points of care. We found that dialysis compared to non-dialysis care may prevent early mortality among older adults within the first three years from onset of kidney failure. The survival-related findings inform a prognostic component of treatment decision-making. It can be used to support clinical practice guidelines and contribute to patient decision aids. We also found that opportunities exist to promote optimal conservative care by primary care physicians. Future interventions implemented in partnership with nephrology and primary care organizations that address knowledge, resources, and co-management are urgently required to reduce barriers and enhance facilitators to optimize conservative care in the community.
Table 6.1 Knowledge translation activities from mixed methods study on barriers and facilitators to conservative care

<table>
<thead>
<tr>
<th>#</th>
<th>Strategy and location</th>
<th>Date</th>
<th>Knowledge Translation audience</th>
<th>Knowledge Translation goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Teleconference, presentation and discussion of study</td>
<td>Jan 26, 2016</td>
<td>Conservative Kidney Management Steering Committee Meeting (22 knowledge-users)</td>
<td>To generate awareness to support development of conservative care clinical pathway (knowledge implementation)</td>
</tr>
<tr>
<td>2</td>
<td>Interactive small group presentation and discussion in the Alberta Health Services North Tower, Calgary, Alberta</td>
<td>Jan 26, 2016</td>
<td>Kidney Health Strategic Clinical Network Leadership Meeting (7 provincial policy and decision-makers)</td>
<td>To impart current knowledge of the conservative care program and seek support for its improvement (knowledge implementation)</td>
</tr>
<tr>
<td>3</td>
<td>Interactive small group presentation and discussion with opinion leaders, Sheldon Chumir Health Centre, Calgary, Alberta</td>
<td>Mar 1, 2016</td>
<td>Alberta Health Services, Renal End of Life Meeting (10 knowledge-users)</td>
<td>To transfer study findings to improve conservative care management by the clinic (knowledge implementation)</td>
</tr>
<tr>
<td>4</td>
<td>Teleconference, presentation and discussion of study</td>
<td>Mar 16, 2016</td>
<td>Alberta Health Services, Palliative / End of Life Care Meeting (7 policy and decision-makers)</td>
<td>To increase awareness of study findings to improve palliative care utilization (knowledge implementation)</td>
</tr>
<tr>
<td>5</td>
<td>Brief didactic information presentation, Health Sciences Centre, Theatre 3, Calgary, Alberta</td>
<td>Mar 15, 2016</td>
<td>Three Minute Thesis Competition, 25 general audience members</td>
<td>To generate interest based on findings from mixed methods study on enhancing conservative kidney management in the primary care setting</td>
</tr>
<tr>
<td>6</td>
<td>Interactive small group presentation and discussion</td>
<td>Mar 31, 2016 and April 14, 2016</td>
<td>Interdisciplinary Chronic Disease Collaboration (about 30 knowledge users, researchers, and trainees from Calgary and Edmonton)</td>
<td>To generate awareness, inform research methods, and facilitate learning (knowledge exchange).</td>
</tr>
<tr>
<td>#</td>
<td>Strategy and location</td>
<td>Date</td>
<td>Knowledge Translation audience</td>
<td>Knowledge Translation goal</td>
</tr>
<tr>
<td>----</td>
<td>------------------------------------------</td>
<td>--------------</td>
<td>------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>7</td>
<td>Poster presentation, Calgary, Alberta</td>
<td>April 7, 2016</td>
<td>Roy and Vi Baay/Tina Haworth Cardiovascular Research Day (knowledge users, researchers, and trainees)</td>
<td>To impart current knowledge of the conservative care management (knowledge exchange).</td>
</tr>
<tr>
<td>8</td>
<td>Poster presentation in Halifax, Nova Scotia</td>
<td>May 12, 2016</td>
<td>Canadian Society of Nephrology Annual General Meeting (decision makers, nephrology providers and researchers)</td>
<td>To impart current knowledge of the conservative care management (knowledge exchange).</td>
</tr>
<tr>
<td>9</td>
<td>Peer-reviewed publication</td>
<td>July 2016</td>
<td>Clinical Journal of the America Society of Nephrology journal (decision makers, knowledge users, nephrology providers and researchers)</td>
<td>To impart current knowledge of the conservative care management (knowledge exchange).</td>
</tr>
<tr>
<td>10</td>
<td>Infographic</td>
<td>October 2016</td>
<td>E-Newsletters: Alberta Medical Association, and Alberta College of Family Physicians, UC Department of Family Medicine (decision makers, knowledge users, providers)</td>
<td>To impart current knowledge of the conservative care management (knowledge exchange).</td>
</tr>
</tbody>
</table>
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APPENDIX A: INTERVIEW GUIDE

Broad introduction question:
• I would like to learn about your experience caring for older adults (age 75 years and greater) with severe CKD (eGFR <15mL/min/1.73m²). What was your experience like?

Probing questions on diagnosis and assessment:
• Are there any specific issues or challenges that you encountered with diagnosis or assessment of older adults with severe CKD?
  o Why is that challenging? Are there any specific issues? Can you give me an example? How do you deal with these challenges?

Probing questions on care management:
• Are there any challenges in caring for older adults with severe CKD in the community? These may be related to the patient, their caregivers, and/or the family involved in their care.
  o How do you deal with these challenges?
• Are there any challenges with symptom control?
  o Are there any challenges in managing nausea? Fatigue? Itching?
  o Are there any resources, tools, or strategies that help with treating these symptoms?
• Are there any challenges in managing pain?
  o Are there any resources, tools, or strategies that help with pain control?
• Are there any resources, tools, or strategies in general that you find helpful when caring for older adults with severe CKD?
• Do you have any suggestions that may help address the challenges that you identified or help improve care in the future for older adults with severe CKD by primary care in the community?
• (If they mentioned use of specialty services such as nephrology or palliative care in management of the elderly with severe kidney disease): You mentioned that you use nephrology services, how do you use them to help you manage these patients? How do you use palliative care services to help you management these patients?

Probing questions on resource use:
• What resources and services do you access to care for older adults with severe CKD?
• Hypothetically, in an ideal world with unlimited resources, what kind of services would be available or what improvements could be made to help you care of older patients with severe CKD?
• Are you aware that nephrology has a conservative care program that assists in the care of patients with severe kidney failure who do not want to initiate dialysis?

Closing question:
Is there anything else you would like to add relating to caring for older adults with severe CKD?
APPENDIX B: QUESTIONNAIRE

Supporting Primary Care Physicians in the Care of Older Adults with Chronic Kidney Disease, Not on Dialysis

Throughout this survey, please consider your patient(s) with all of these characteristics:
• severe CKD (eGFR <15mL/min/1.73m²)
• not planning on starting dialysis (conservative/palliative care)
• age ≥75 years

A. Have any of the following been a barrier to you when providing care for your patient(s) meeting the above characteristics? A barrier delays or interferes with your patient care.

<table>
<thead>
<tr>
<th>Your ability to:</th>
<th>Never a barrier</th>
<th>Rarely a barrier</th>
<th>Sometimes a barrier</th>
<th>Often a barrier</th>
<th>Always a barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Help the patient and/or their family understand the risks and benefits of dialysis versus no dialysis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Understand the progression of CKD when patients are not planning on starting dialysis</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>3. Manage the patient’s symptoms (e.g. pain, shortness of breath, and pruritus)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>4. Select medications and adjust dosage of medications (e.g. pain medications and antibiotics)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>5. Know when to discontinue preventative measures (e.g. ASA and statins)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>6. Work with non-physician healthcare providers (e.g. care aids and home care nurses) who have limited renal-specific clinical expertise</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>7. Access support to maintain the patient in their home setting to avoid transitions of care</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>8. Access resources from the AHS Conservative/Palliative Nephrology Clinic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Co-manage a specific patient with a nephrologist in a manner that meets your expectations</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>10. Do you have further comments regarding barriers to conservative/palliative care for older adults?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

162
B. Would the following *enhance* your provision of care for your patient(s) meeting the characteristics?

<table>
<thead>
<tr>
<th></th>
<th>Definitely would not enhance</th>
<th>Likely would not enhance</th>
<th>Might enhance</th>
<th>Likely would enhance</th>
<th>Definitely would enhance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Educational resources for patients and their families to make dialysis versus non-dialysis treatment decisions</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>2.</td>
<td>Access to AHS Palliative Care Services (i.e. physician and/or home care)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>3.</td>
<td>Access to resources from the AHS Conservative/Palliative Nephrology Clinic</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>4.</td>
<td>Ability to contact clinical staff from the AHS Conservative/Palliative Nephrology Clinic by telephone</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>5.</td>
<td>Ability to contact a nephrologist by phone for advice</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>6.</td>
<td>Ability to contact a nephrologist by email or other electronic methods for advice</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>7.</td>
<td>Co-management of a specific patient with a nephrologist in a manner that meets your expectations</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>8.</td>
<td>Access to a conservative/palliative care online clinical pathway to guide care</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>9.</td>
<td>Do you currently refer patients meeting the characteristics to a nephrologist?</td>
<td>O Never O Sometimes O Always</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Do you currently refer patients meeting the characteristics to AHS Palliative Care Services?</td>
<td>O Never O Sometimes O Always</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Do you have further comments regarding supports to enhance conservative/palliative care for older adults?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
C. Please select the responses that best represent you.

1. What is your main type of clinical practice setting?
   - Outpatient clinics (e.g. private offices and/or teaching clinics)
   - Continuing care facilities (e.g. assisted living and long-term care)
   - Other: __________________________

2. Your main clinical practice is a part of which AHS zone?
   - North
   - Edmonton
   - Central
   - Calgary
   - South

3. What is the population size of the city/town of your main clinical practice?
   - Small population center or rural area (< 29,999 people)
   - Large or medium population center (≥ 30,000 people)

4. How many years have you practiced as a primary care physician?
   - < 10 years
   - 10 to 20 years
   - > 20 years

5. In the last 12 months, what percentage of your time at work was dedicated to clinical practice (compared to research and administration)?
   - < 25%
   - 25 to 50%
   - > 50%

6. Do you have a clinical practice interest in the care of the elderly or geriatric patients?
   - Yes
   - No

7. What percentage of your patients are aged ≥75 years?
   - < 25%
   - 25 to 50%
   - > 50%

8. What is your sex?
   - Male
   - Female

9. What is your age?
   - < 40 years
   - 40 to 65 years
   - > 65 years
APPENDIX C: INFOGRAPHIC ON CONSERVATIVE NON-DIALYSIS CARE

CONSERVATIVE NON-DIALYSIS KIDNEY CARE

Our survey of primary care doctors in Alberta identified resources needed to assist you in the care of older patients with stage 5 chronic kidney disease, who are not planning to start dialysis.

Percent who said the following resources are needed:

- **85%** Telephone access to a nephrologist or conservative care specialist
- **75%** Palliative care services
- **70%** Conservative kidney care online clinical pathway
- **40%** More resources for maintaining patients at home
- **30%** Improved ability to work with non-physician providers without kidney-specific clinical knowledge and skills

We listened, the following consult services are available to help you care for your conservative kidney patients:

**Telephone access to conservative kidney care specialists:**
- **Southern Alberta:** 1-403-955-6534
- **Urgent Consults – Northern Alberta RAAPID:** 1-800-282-9911

**Palliative care services in Alberta:**
- myhealth.alberta.ca/Palliative-Care

**Conservative kidney care online clinical pathway:**
- www.ckmcare.com

For more information, contact Dr. Brenda Hemmelgarn at Brenda.Hemmelgarn@ualberta.ca. Division of Nephrology, University of Calgary.
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Helen

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to: Helen Tam-Tham

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Helen

Helen Tam-Tham, MSc

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From: Helen Tam-Tham
Sent: June 28, 2017 9:58 AM

To: Brenda Hemmelgarn (AHS), Bob Quinn (Mac), Robert Weaver, Hanxia Zhang, Chandra Thomas, Kathryn King-Shier, Kent Fruetel (AHS), Matthew Thomas James, Braden Manns (AHS), Marcello Tonelli, fliss.murtagh@ukol.ac
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Wed 8/28/2017 9:59 AM

To: Helen Tam-Tham

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Marcello Tonelli MD SM MSc FRCPC

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Please let me know if you have any questions.

Best regards,

Helen

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Helen Tam-Tham, MSc

Graduate Candidate in the Department of Community Health Sciences
Cumming School of Medicine, University of Calgary
Health Sciences Centre, Room 6125
3330 Hospital Drive NW
Calgary, AB, T2N 4N1
403-210-6861 | E-mail: helen.tam-tham@ucalgary.ca

https://outlook.office.com/owa/?resm=ucalgary.ca&path=mymailbox
Re: Please respond with your permission

Rob Quinn
Wed 8/28/2017 10:24 AM
To: Helen Tam-Tham

Fine with me.
Rob

On Wed, Jun 28, 2017 at 9:58 AM, Helen Tam-Tham wrote:

Dear co-authors,

Would you please respond to this email indicating that you provide permission for including the following manuscript in my thesis? Please respond to this email with your written permission by July 12, 2017.

Citation of the manuscript included in the thesis:
- Tam-Tham H, Quinn RR, Weaver RG, Zhang J, Thomas CM, King-Shier KM, Fruetel K, James MT, Manns BJ, Tonelli M, Murtagh F, Hemmelgarn BR. Comparison of Survival among Older Adults with Kidney Failure Treated versus Not Treated with Chronic Dialysis: A Propensity Score Matched Cohort Study

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Please let me know if you have any questions.

Best regards,

Helen

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Rob Quinn, MD PhD FRCP

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RE: Please respond with your permission

Robert Weaver  
Wed 6/28/2017 10:04 AM

To: Helen Tam-Tham

Hi Helen,

Yes, I give my permission.

Thanks,

Rob

From: Helen Tam-Tham
Sent: June 28-17 9:59 AM

To: Bronca Hemmelgarn (HHS), Rob Quinn-Rob, Robert Weaver, Jingao Zhang, Chandra Thomas, Kathryn King-Shier; 
Matthew Tonelli (AMS), Helen Tam-Tham, Rob A. Manns (AMS); Marianna Tonelli (AMS)

Subject: Please respond with your permission

Dear co-authors,

Would you please respond to this email indicating that you provide permission for including the following manuscript in my thesis? Please respond to this email with your written permission by July 12, 2017.

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1. Tam-Tham H, Quinn RR, Weaver RG, Zhang J, Thomas CM, King-Shier KM, Fruetel K, James MT, Manns BJ, 
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Please let me know if you have any questions.

Best regards,

Helen

---

Helen Tam-Tham, MSc

PhD Candidate in the Department of Community Health Sciences
Cumming School of Medicine, University of Calgary

https://outlook.office.com/owa/?resim=ucalgary.ca&path=mailbox
Re: Please respond with your permission

Dear Helen,

No problem and I hope your defence went well,

best wishes,

Fliss

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From: Helen Tam-Tham, MSc
Sent: 30 June 2017 17:45
To: Murtagh, Felicity
Subject: Re: Please respond with your permission

Dear Dr Murtagh,

Thank you again for your invaluable contributions to this study.

Please let me know if you have any questions regarding this permission to include the manuscript as part of my thesis.

With much gratitude,

Helen

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Helen Tam-Tham, MSc