Living Well Without Dialysis: Patients' and Healthcare Professionals' Evaluation of the Innovative, Online Conservative Kidney Management Pathway

By

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Abstract

Introduction

Conservative kidney management (CKM) is a non-dialysis treatment option for older end-stage kidney disease (ESKD) patients with multiple comorbidities and poor functional status. For such patients who are unlikely to benefit from dialysis, Alberta recently launched a CKM Pathway that standardizes CKM and focuses on preserving kidney function, managing ESKD symptoms and offering holistic psychosocial support to patients and families. The CKM Pathway was introduced in four kidney clinics through a guided implementation process with staff engagement and education. An evaluation was undertaken to assess the CKM Pathway in improving CKM through quantitative and qualitative measures. The focus of this thesis is on the qualitative evaluation of the CKM Pathway from the perspectives of patients/families and healthcare providers.

Methods

A qualitative descriptive design was used. Patients and healthcare providers at four kidney clinics in Edmonton and Red Deer participated. Individual in-depth interviews with CKM patients/families and semi-structured focus groups with staff were conducted, recorded and transcribed verbatim. Thematic analysis was done using line-by-line coding.

Results

Ten patient/family interviews with 16 participants and five focus groups with 25 healthcare providers were conducted across the four kidney clinics. Three patient/family themes were identified. The CKM Pathway: a) supported facilitated decision-making; b) provided effective CKM patient resources; and c) promoted patient-centered care.

From the staff focus groups, three related themes were identified. The CKM Pathway: a) improved kidney clinic processes and patient care; b) addressed a gap in CKM resources; and c) facilitated shared care with community- based healthcare providers.

Conclusion

Themes show overlap between patients/families' and healthcare providers' evaluation of the CKM Pathway. Kidney clinic staff piloting the CKM Pathway felt it provided evidence-based, standardized care and CKM patients felt supported with the pathway's tools and resources. Both felt the CKM Pathway facilitated patient-centered CKM by engaging primary care providers as partners. Future studies should evaluate the CKM Pathway from the community care providers' perspective.

Preface

(Mandatory due to research ethics approval)

This thesis is an original work by Syed Hussain. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Evaluating Key Stakeholders’ Experiences with the Conservative Kidney Management Pathway”, No. Pro00069527, Date 06/30/2017

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List of abbreviations

ACP - Advance care planning

AHS - Alberta Health Services

CKD - Chronic kidney disease

CKM - Conservative kidney management

EGFR – Estimated Glomerular Filteration Rate

ESKD - End stage kidney disease

PDA - Patient decision aid

RIC - Renal insufficiency clinic

GP - General practitioner

KSCRG - Kidney Supportive Care Research Group

NARP - Northern Alberta Renal Program

SDM - Shared Decision-making

TDF - Theoretical Domains Framework

Chapter 1: Introduction

1.1 Background

1.1.1 Chronic Kidney Disease in Older patients

The world population is getting older in nearly all countries of the world [1] and this is especially true for more developed nations like the United States where the percentage of seniors has increased steadily from 9% to 15% between 1960 and 2014 [2] and in Canada, where there are now more seniors than children [3]. Accompanying the myriad of changes brought on by an increasingly older population is the rise in prevalence and incidence of chronic kidney disease (CKD) [4-7]. End-stage kidney disease (ESKD) is the advanced version of CKD and is defined as an estimated glomerular filtration rate (GFR) of <15 ml/min [8-9]. While the incidence, but not the prevalence, of ESKD seems to have stabilized in many developed countries in recent years [10], people aged 65 or over continue to bear an increasing burden of this disease [11]. Not surprisingly , older patients, particularly those in the 75 and older age group, are also increasingly starting renal replacement therapy (RRT) in wealthier countries across the globe. In the UK, renal registry data from 2015 showed that both RRT-incident and prevalence rates were the highest in the 75-79 age group [12].

While dialysis is life-saving for the majority of patients with kidney failure, the literature suggests that, in subsets of the frail elderly population that have multiple comorbidities and poor functional status, dialysis may have limited value [13]. Frailty may be defined as a heightened state of vulnerability due to loss of functional, cognitive, and physiologic reserve. Frail individuals have an increased susceptibility to stressors and a diminished ability to regain homeostasis following a stressor event [14]. Frailty is a consequence of age-associated decline in multiple physiological systems that become less functional with cellular and molecular damage over time. The accumulation of deficits in multiple physiological systems, such as haematological, endocrine, and skeletal muscle systems, is more likely to precipitate frailty as opposed to abnormalities in any particular system [15]. The presence of frailty is associated with poor outcomes including falls, hospitalizations, care home admissions, and mortality as established by several large prospective cohort studies [16-18]. Older adults with CKD are more likely to be frail, with reported prevalence rates of frailty >60%, compared to 11% in the general older adult population [19]. Studies in CKD populations have also demonstrated similar associations between frailty and increased hospitalizations and mortality [20]. Because of the higher prevalence of frailty among older adults with CKD and the association of frailty with adverse outcomes in patients with ESKD [21], frailty is an important factor to consider in a holistic shared decision-making process when patients are exploring their RRT options. Increasing age is another independent risk factor for higher mortality in RRT patients and patients over 75 years of age with high comorbidity and diabetes get no significant survival advantage with dialysis [22]. One recent study reported that 30% of a group of older adults in their 80s who started hemodialysis died within three months [23]. Initiating dialysis can lead to decreased life satisfaction in the frail elderly [24], and is associated with accelerated functional decline [25], increased dependence [26], more time spent in the hospital and higher rates of hospitalizations [27].

Non-dialysis care of kidney failure has long been around, delivered and recognized under various titles including maximal conservative management, renal supportive care and palliative care [28]. The prevalence and use of these various terms underscored the need for a clear and detailed definition. This definition was recently developed by the Kidney Disease Improving Global Outcomes (KDIGO) group through a consensus-building conference with an international representation from experts in the field [29] and is now widely accepted. Conservative kidney management (CKM) has become the popular term for this type of non-dialysis management of kidney failure .

1.1.2 Defining CKM

Briefly, the KDIGO definition of CKM is non-dialytic care characterized by the preservation of kidney function, mitigation of CKD complications, and active assessment and management of symptoms [29]. Further, it includes the following important components: shared decision-making; advanced care planning; offering of psychological, social, and family support; and addressing cultural and spiritual domains of care [29].

A recommendation from the KDIGO conference was to consider CKM as a viable treatment alternative for patients unlikely to benefit from dialysis [29]. There is limited evidence from Canada and Australia to suggest that the number of patients who received CKM is similar to that of patients treated with dialysis [30, 31]. Older stage 5 CKD patients (age ≥75 years old) may make up the majority of those managed with CKM and their routine care may be provided largely by community-based family physicians [32]. Patients in the CKM population can be distinguished as: those who have actively chosen CKM; those who are restricted to CKM because of limited availability and access to RRT; and those in whom stage 5 CKD is present but unrecognized [33].

Survival on CKM has been a question of interest and studies have looked at this, often in comparison with dialysis. A recent review has summarized the available evidence [28]. It is important to note that comparing survival on CKM versus dialysis is challenging because of an inherent bias- healthier, more fit patients tend to choose dialysis and more frail, comorbid patients are advised and opt for CKM [28]. In addition, the CKM population is heterogeneous with at least three groups of patients: those suitable for dialysis who choose not to receive it; those with high comorbidity who are not advised for dialysis and therefore choose CKM; and those who lack capacity and may not be offered dialysis [28]. The survival rates between these group is likely to be different, irrespective of their CKM choice. Keeping that in mind, recent evidence comes from a study following 155 CKM patients over a period of 18 years where mean survival was 21.2 months [34]. This study also followed a group of patients on dialysis whose overall mean survival was significantly longer (67.1 months), but -importantly- for patients >75 years old, the survival advantage of dialysis was non-significant at only 4 months when corrected for age, high comorbidity, and diabetes [34]. This finding has generally been reflected in other studies as well [28].

Symptom burden on CKM is another question of interest. At least six studies have looked at symptom burden with patients on CKM and the number of symptoms range from 6.8 to 17 per individual patient [28]. There is a noted increase in symptom burden in the month prior to death [35]. A longitudinal study following patients on CKM and dialysis for up to 3 years found that CKM patients maintained their quality of life which was not the case for those who started dialysis [36]. There is also evidence to support that with appropriate CKM, patients can have stable or improved symptoms and quality of life [37].

1.1.3 Shared decision-making in CKM

An important element of CKM is supporting patients through a shared decision-making (SDM) process so that patients make a values-based, evidence-informed decision between dialysis and CKM in light of their personal context. SDM is a core component of patient-centered care defined as an interactive process involving the patient, their family members, and the healthcare team to reach a consensus on a treatment choice that incorporates the best available evidence with the explicitly discussed values and preferences of the patient [38]. The healthcare team explains the clinical situation to the patient and patient-identified stakeholders and helps them understand their options based on benefits and risks. The patient is then given the opportunity to reflect on their choices and share their values, wishes, goals and concerns if they so wish. Time is given for questions and discussion with family and the healthcare team. With some decisions, the benefits and harms of the available treatment options aren’t clear and SDM with guidance from healthcare teams is especially applicable in clinical decision-making that involves choosing between more than one reasonable option [39]. In the context of ESKD, a shift in demographics has been noted with patients being older, frailer, and having comorbid conditions [40] and it is not always clear that dialysis will offer either a survival or quality of life advantage to such patients. SDM is widely recommended in the nephrology community, but has yet to be routinely incorporated into discussions with patients making treatment choices [38]. A recent qualitative study of older patients on dialysis documented that patients end up on dialysis not fully informed of their options, feeling like they had no choice, uncertain about what to expect, and reporting poor satisfaction with their decision [41]. To improve SDM, patient decision aids (PDAs) have been shown to be effective; they increase patient participation and understanding, enhance values-choice concordance, and reduce decisional conflict [38]. A number of PDAs exist to help patients navigate RRT and transplant choices but only until recently, few addressed CKM specifically [38]. Two recently developed PDAs that compare CKM versus dialysis in patient-specific contexts include the CKM-PDA and the Ottawa PDA. The CKM-PDA is unique as an online web-based tool and is available as part of the CKM Pathway [42].

1.1.4 The Conservative Kidney Management Pathway

The Kidney Supportive Care Research Group (KSCRG), in collaboration with the Kidney Health Strategic Clinical Network (SCN) TM launched an innovative, online CKM Pathway in September, 2016 [42]. The pathway is a program of care designed to help healthcare providers who provide CKM and patients who receive CKM- it is a holistic care package in the form of a clinical pathway.

A) What are clinical pathways?

Clinical pathways are document-based tools that aim to align clinical practice with the best-available evidence for the management of specific medical conditions [43]. They offer structured processes and specific recommendations with the aim of optimizing patient outcomes and improving efficiency. A systematic review of 27 studies using clinical pathways and involving 11,398 participants showed that, compared to usual care, clinical pathways can reduce in-hospital complications, length of patient stay, and hospital costs, and improve documentation of patient records [43]. The CKM Pathway is the first of its kind- developed as an online, comprehensive clinical pathway. It is built in accordance with the KDIGO definition and incorporates the best-available evidence for the provision of high-quality CKM. It is this CKM Pathway that is the focus of evaluation in this thesis.

B) Meaning of the term 'CKM Pathway'

In this thesis, I use the CKM Pathway as a broad and loose term to refer to the pathway's various components and resources, including the provision of care. When taken together, it may be more intuitive to view the CKM Pathway as a structured program of care. Unless stated otherwise, the use of the term 'the CKM Pathway' is meant as a program of care that includes all of the components, resources and care processes of the pathway taken together. I also use 'the CKM Pathway' and 'the pathway' interchangeably and to refer to the same CKM Pathway.

C) Components and resources of the CKM Pathway

The three components to the CKM Pathway include web, print, and process components. The web and print components refer to the tools and resources provided by the CKM Pathway. The process components refer to the actual care process of the CKM Pathway (ie. the enactment of care procedures and the provision of CKM based on the CKM Pathway's guiding principles and symptom management strategies). These three components are separated out for explanatory purposes but are not meant to be viewed as entirely distinct or exclusive of one another. Rather, they overlap and the boundaries between them are blurred. For example, the CKM Pathway website, which is a web component of the pathway, houses many of the patient resources in electronic versions. These same patient resources also exist in hard copy in the CKM Patient Booklet (a print component) given to patients in the clinics.

Web components - The web components are the resources and tools of the CKM Pathway which are part and parcel of the pathway's website (CKMcare.com). The website is itself a resource and tool of the CKM Pathway. It is a subset of, and thus is not synonymous with, the CKM Pathway. The CKM

Pathway term refers to the web components, the print resource copies, and the actual care processes of CKM outlined by the pathway taken together.

The pathway's website offers palliative and end-of-life symptom management guidelines as well as the PDA tool to help clinicians and patients decide between dialysis and CKM. The website is not just simply an electronic storehouse for the pathway's resources. Rather, it is designed as an interactive tool to be used in the clinic where clinicians can provide input and get results tailored for the specific patient they are seeing. While many of the resources on the website are printable and thus translatable to a print component, some tools and features of the CKM Pathway website are not and this interactive aspect of the website is one example. Similarly, the PDA is also not translatable to a physical component version. The PDA displays tailored and prognostic information using complex algorithms based on patient responses to its 9 questions - thus a hard copy version is not available.

In addition to being a tool for healthcare providers, the website also has a patient portal with resources for patients and families. Similar to how the hard copy resources of the pathway were divided into a category for providers and a category for patients, the website is laid out separating patient resources and healthcare providers resources. The resources in the patient portal are designed as patient-friendly, accessible versions mirroring the resources available to healthcare providers.

Print components - The print components include any and all hard-copy materials and reading resources designed and available through the CKM Pathway website. The CKM Pathway's print materials (many of which are available as electronic versions on the pathway's website as well) can be divided into two broad categories- resources for patients and resources for healthcare providers. The bulk of the CKM Pathway's patient education materials are collected together in a comprehensive CKM Patient booklet and this would be considered a print component of the CKM Pathway. Another patient resource is the 'Considering CKM Pamphlet' which would also be a print component of the CKM Pathway commonly used in clinics when patients are in the decision-making process. Lastly, the CKM Pathway has symptom management resources with tips and strategies designed especially for patients and families and in hard-copy, these would also be considered print components of the pathway. These resources are available and accessible via the website, but in practice, are more commonly given as printouts to patients in clinics.

The print components for healthcare providers would be any hard-copy resources of the pathway that are used in the provision of CKM. All of the pathway's resources and tools for providers are available on the website. Examples include the print versions of symptom management guidelines and algorithms for healthcare providers or the template letter sent to family physicians of new CKM patients.

Process components - The process components refers to the actual care process associated with the CKM Pathway- that is, the provision of CKM based directly or indirectly on the CKM Pathway's guidelines, tools and/or resources. It includes the learning/training process involved on part of the healthcare providers and the changes in clinical practice and environment that result from implementing the pathway as a program. The process components of the CKM Pathway include the care of those patients who have not officially chosen CKM or dialysis but still have low GFRs that warrant management with CKM principles. These patients may be in the decision-making stage or in the pre-decision stage.

D) Meaning to the terms 'Launch and Implementation of the CKM Pathway'

A pair of common terms used throughout this thesis with respect of the CKM Pathway is 'launch' and 'implementation'. The launch of the CKM Pathway refers to the day the CKM Pathway, with its website, resources, and tools, was officially live and introduced to the kidney clinics' staff of the four clinic sites involved in the implementation. The implementation of the CKM Pathway refers to the process associated with the clinic staff becoming familiar with and utilizing the CKM Pathway, its tools and its resources, to adapt their care processes and deliver CKM. This implementation also includes the education/training and support provided by the KSCRG to clinic staff in the form of hands-on workshops, information sessions and monthly meetings.

To summarize the above definitions, the CKM Pathway may be best viewed as a comprehensive care program with the web, print, and process components defined and described above. It was this comprehensive care program that was evaluated from the patient and provider perspective.

E) Background on the development of the CKM Pathway

The development of CKM Pathway was guided by extensive end-user and stakeholder engagement, including patients and families, across Alberta through the use of World Cafe methods for facilitating large group conversations [44]. The focus of these sessions was on identifying the barriers, enablers, and opportunities to providing high-quality care for patients who choose CKM to manage their ESKD. Feedback from these sessions were analyzed through the Theoretical Domains Framework (TDF) [unpublished work in draft stage], organized according to themes, and implementation strategies were generated to integrate the suggestions into the design of the CKM Pathway.

Built on the definitional framework provided by KDIGO, the CKM Pathway tools, resources and website **(www.ckmcare.com)** address the key components of quality CKM and aim to provide sustainable, standardized, evidence-based care for patients with advanced chronic kidney disease unlikely to benefit from dialysis [45]. In keeping with the feedback received through the multidisciplinary world cafes, the CKM Pathway website is designed uniquely for the entire spectrum of healthcare professionals, ranging from specialists and family doctors to community nurses and homecare workers. This is in acknowledgement that CKM is currently occurring and should be supported at all levels of healthcare delivery with multidisciplinary teams of providers working in a variety of contexts. This may include home care staff working in a long-term care setting or a physician/nurse team in a remote rural setting. The CKM Pathway's tools and resources- the detailed informational material for patients and providers, guidelines and stepwise algorithms for the management of both general CKD and specific symptoms in kidney failure- aim to support CKM across the healthcare spectrum .

1.1.5 Evaluating the CKM Pathway

With the launch of the CKM Pathway as a program in September of 2016, an evaluation was undertaken simultaneously to assess the performance of the pathway in the kidney clinic setting. The evaluation was designed with both quantitative and qualitative components. The overall aim of the project was to determine how the care of CKM patients changed with the launch of the CKM Pathway and to identify the components of the CKM Pathway where there were opportunities for improvement. The objective with the quantitative evaluation was to do a pre- and post-pathway launch comparison of key quality indicators of CKM to quantify the impact of the pathway. The objective with the qualitative study was to seek input directly from stakeholders on what was working well with CKM using the pathway and where improvements could be made. This thesis will address the qualitative study evaluating the CKM Pathway.

The key stakeholders for CKM were identified as the patients on the pathway/their family caregivers and healthcare providers involved in delivering conservative care using the pathway. These two groups were approached for the qualitative evaluation not only because they, taken together, represented the majority of those impacted by the pathway but also because we recognized they may have different perspectives. We anticipated and were interested in getting the diverse input from participants who were either providing or receiving care using this clinical pathway. Patients' and family care providers' experiences with and attitudes towards the pathway could be complementary to or conflicting with that of the healthcare providers. Equally important, patients and healthcare providers were in unique positions to speak to aspects of the pathway that the other could not, at least directly, relate to. For example, to do a comprehensive evaluation, we wanted feedback on the clinical guidelines of the pathway for which staff, but not patients, were specifically probed. On the other hand, while staff could offer their input on the effectiveness of symptom management strategies, patients and family members were best placed to answer what strategies they used and how helpful they found them. In that sense, we were interested in feedback on parts of the pathway that both staff and patients could speak to as well as feedback on aspects that were associated uniquely with each group.

My overarching aim was to evaluate the CKM Pathway through the experiences of key stakeholders (patients, families, and healthcare providers). Specifically, the objectives were: 1) determine the impact of the CKM Pathway on the care of patients receiving CKM; 2) determine the impact of the CKM Pathway on the operations of the kidney clinics and the healthcare providers providing CKM.

Chapter 2: Methods

A qualitative study was designed and undertaken in four kidney clinics across Edmonton and Red Deer, collectively part of the Northern Alberta Renal Program (NARP). These clinics operate in the context of a large, multi-level, provincial healthcare system under a single umbrella organization, Alberta Health Services. Two of the three Edmonton clinics are located in urban, tertiary care hospitals with the remaining Edmonton clinic being in a community hospital. The Red Deer clinic is located in a rural community hospital. The clinics are staffed by multidisciplinary healthcare teams including nurses with specialized training in renal medicine. These clinics offer consultative service to a catchment area of approximately 2 million people in northern and central Alberta [46] and see the entire spectrum of CKD and ESKD patients, including many patients on dialysis. During the course of this study, these four clinics engaged in a guided implementation process to utilize the newly launched Conservative Kidney Management (CKM) Pathway to provide routine care for their patients on CKM. The aim of this study was to understand the experiences of key stakeholders with the CKM Pathway and to help evaluate the CKM Pathway in meeting patient and provider needs and in providing quality CKM. To generate a comprehensive evaluation on the state, successes, and struggles of the CKM Pathway, both healthcare provider and patient/family perspectives were sought. Frontline healthcare providers working in these clinics and delivering CKM were invited to participate through focus groups scheduled at each of these four clinics. Patient/family perspectives were sought through individual interviews conducted with patients and/or family members visiting these clinics for CKM. This qualitative study was part of a larger mixed method study and aimed to supplement the results from the quantitative evaluation of the pathway.

2.1 Study Design

2.1.1 Choosing a qualitative research approach

A qualitative research approach was chosen to answer the research question and complement the quantitative evaluation of the pathway already underway. As Al-Busaidi explains, the question is not which approach is better; but rather which approach is more appropriate for the research question at hand [47]. She cites Patton who outlines a number of research questions appropriate for qualitative study, which include questions about people's experiences. One of the main strengths of qualitative research is that it is fundamentally humanistic and person-centered. This allows researchers to form closer relationships with research participants than other conventional forms of inquiry such as surveys [48]. From this standpoint, qualitative researchers are better positioned to explore, understand and describe the behaviour, feelings, and experiences of people in ways that are purposeful and useful [49-50]. Although traditionally rooted in the social sciences, qualitative research has been increasingly applied and accepted as valuable in healthcare. In particular, with its emphasis on understanding meanings and experiences, qualitative research can be especially applicable in projects aiming for quality assessment and quality improvement [51]. With the aim of this study being to explore and gather the experiences of patients and providers with the CKM Pathway and evaluate the pathway as described in section 1.1.3, a qualitative research study was felt to be a critical component of the overall evaluation framework.

2.1.2 Qualitative methods

There are a myriad of qualitative methods available to researchers to guide clinical research [52]. As much as qualitative research allows for creativity and innovation, the requirements for rigour, consistency and integrity have necessitated the development of methods with various philosophical underpinnings [53]. Qualitative methods help create a systematic approach to the collection, organization, interpretation, and presentation of qualitative data and they anchor the 'work' of qualitative research within diverse philosophical perspectives. Highly popular methods in qualitative research are grounded theory and ethnography, both of which were initially considered as potential methods for this study. Grounded theory is described as a rigorous, constant-comparison method that aims to build theoretical explanations of particular phenomena in the context of complex social situations [48]. While this study did examine the phenomena of providing and/or receiving CKM with the pathway, the aim was not as ambitious as to develop a theory to delineate the complex psychological processes taking place behind CKM decision-making or to predict the dynamics or changes in patient-provider relationships with the launch of the pathway. For this reason, grounded theory was not used.

With ethnography traditionally going back to the work of anthropologists studying remote populations, the focus is on developing an understanding of people and processes through a cultural lens [53]. The definition of culture in this context is taken to mean an implicit relationship or link between individuals due to shared knowledge, experiences, or understandings. The appeal in considering this method for this study came from the sense that the subjects under proposed study - the patients and the healthcare providers- shared a ‘culture’ of living with or managing ESKD on a day-to-day basis. However, to do justice to the ethnography, significant observational data would be required and getting an intimate insider-look for the patient part of the population being studied was anticipated to be difficult on account of their aging, multi-morbid, frail conditions so this method was not pursued.

2.1.2 Qualitative description method

The method ultimately selected was qualitative description as it was felt to best resonate with the aims and objectives of this study. In 2000, qualitative description was described by Sandelowski in an attempt to name and thereby legitimize a method that many researchers were using but misclaiming as some other qualitative method [54]. She recognized qualitative description as already prevalent in healthcare disciplines and traced its philosophical roots to naturalistic inquiry. From that origin, qualitative description aims to study phenomena in as natural a state as possible and as a consequence, is less likely to be framed within some deliberately chosen abstract framework asdone in other methods like grounded theory. For the purposes of this study, the key goal was to evaluate the pathway from the experiences of the patients and the providers and to that end, there was no special pull towards any specific framework or philosophical orientation other than to achieve our purpose. The appeal for this method also arose from its key defining characteristic that study data and findings, which are necessarily interpretive to some extent, stay close to the original data and are much less transformed by interpretation than in other qualitative methods [55]. This license was tremendously useful in that it enabled us to analyze, retain and map the findings to specific aspects of the pathway that we hoped to evaluate without placing undue pressure to transform data beyond that. Having the leeway and the flexibility afforded by this method helped us avoid what Sandelowski called “methodological acrobatics” when researchers feel obligated to name their study a certain method even when their findings don’t reflect it [54].

A systematic review of qualitative descriptive studies outlined common characteristics of this group of studies [56]. We chose this study design because some of these characteristics fit well with our study purposes. For example, data collection strategies commonly include semi-structured individual interviews and/or focus groups [57]. The fact that qualitative descriptive studies can involve both techniques was particularly applicable for our dichotomous population of patients and care providers. Focus groups enabled us to reach a large number of providers from the kidney clinics while individual interviews engaged patients who might have felt intimidated in the presence of providers. Also, due to their physical and health status, the logistics of gathering patients together for focus groups would have been extremely difficult and overly burdensome for them. Sampling techniques employed in qualitative descriptive studies are typically variations of purposeful sampling, [54] which was necessary in our study context as our participants were limited to patients and providers who had experience with the new CKM Pathway.

2.1.4 Research team and roles

This thesis is the product of my own work but it is based on, and would not be possible without the work we undertook as part of a research team led by Dr. Sara Davison (MD, MHSc, FRCPC). It is my intention with this section to acknowledge the different contributions of the team members and clarifying their roles. Our research team consisted of the individuals involved in the design, conduct, analysis and writing up of this study. This included the principal investigator (SND) who is a nephrologist and Professor of Medicine, a clinical nurse educator (BAW), myself as a graduate student (SH) and two undergraduate summer students (SS and AK). Team composition was three female members to two male members. The entire team was involved and had a role in the design and conduct of the study. The interview and focus group facilitator guides were developed by the team in collaboration with a knowledge management consultant. All focus groups and seven of 10 interviews were conducted by pairing an experienced clinician (SND and BAW) with one or more of the students (myself and the two summer students). The final three interviews were conducted by the students. The students were largely responsible for the initial coding and analysis after training and direction had been provided by SND. The focus group results were assessed by all three students, working independently but collaborating and consulting with the principal investigator during weekly team meetings . The patient interview data, however, was analyzed by myself, in consultation with SND and using the framework and understanding that was established in the focus group data analysis. The writing, in the form of this thesis, was done by myself with iterative critiques and feedback from my thesis committee members.

2.1.5 Researcher reflexivity

In keeping with the recommendations of standard qualitative research reporting guidelines such as the COREQ (58) which I utilized (as described later in section 2.3.3.), I was advised by my committee members to write on my own background and perspectives as I present this research. My background is in biological sciences and qualitative research is a new venture. In that sense, I felt more comfortable with the choice of qualitative description for this study as opposed to one of the more theoretically-involved methods. The mindset I came with into this study was about quality assessment and improvement. It was about the experience of and getting feedback from patients and healthcare providers on the CKM Pathway and throughout the analysis, I strived to pick up on those bits of data that helped me expound on that. In no way did I come into study with the intention to change or re-present the experiences and feedback of participants as something other than what they were. Rather, as is the goal of qualitative description and to achieve my purposes of quality assessment and improvement, I attempted to remain ‘data-near’ so that the findings in large part were representative of participant views and could be used to enhance CKM delivery. On data collection, it is also relevant to mention that the team lead was the clinician/researcher behind the development of the CKM Pathway. The staff members participating in the focus groups were aware of this while patients weren’t informed directly about this and didn’t associate the researcher directly with their care. All participants were told to share what they felt was important and that it would not impact them negatively in any way. Still, to counter the effect of the researcher’s presence, we scheduled both focus groups as well as patient interviews with and without the lead researcher and results did not significantly differ.

2.2 Data collection

2.2.1 Research population and inclusion criteria

The participants of interest for this project were CKM patients and the kidney clinic staff directly responsible for their care at the four clinics implementing the CKM Pathway. Patient inclusion criteria were: had chosen CKM or had used the CKM Pathway’s patient decision aid; over the age of 65; and physically and mentally capable of being interviewed in English or have a supportive family member that could respond on their behalf. Staff inclusion criteria were: had to be a current staff member at one of the four clinics in the NARP program; and had to be familiar with and have a direct role in the provision of CKM to patients. As such, doctors, nurses, dietitians, social workers, and clinical administrative assistants were eligible to participate.

2.2.2 Participant recruitment

The kidney clinic nurses, upon request from the study team, identified suitable patients on their caseload and discussed the opportunity of this study. Nurses used their professional judgement in determining suitability based on the patient's physical, emotional and cognitive health state as well as their disease trajectory. Those patients identified as suitable were introduced to the study by the nurses during routine clinic appointments and offered a chance to participate. Patients/family care providers who were interested in being interviewed were then contacted by the research team by phone and provided additional information including that the study was voluntary, confidential and altruistic in that it will improve the care for future patients. Of the patients contacted, four refused to participate. One patient did not speak English, two were not interested, and one was not cognitively alert enough to participate. For those patients/families who agreed, a mutually-convenient time and location for the interviews was agreed upon over the phone.

For staff recruitment, a multi-pronged strategy was employed utilizing focus group posters and a recruitment email sent to clinic staff to inform them about the opportunity to participate. The support of a clinic manager was enlisted to help spread the word and an ideal date was chosen for each clinic in consultation with the manager to maximize staff presence. On the focus group days, posters were posted in the respective clinics to remind staff about time and location. To enhance attendance, focus groups were held inside or as close to the clinics as logistically possible.

2.2.3 Patient Interviews

Semi-structured face to face or phone interviews were conducted with patients on the CKM Pathway and/or their family caregivers using an open-ended question format. Signed informed consent was obtained at the start of the interview. All interviews were audio-recorded, transcribed, and along with any field notes taken, analyzed using thematic analysis nested in a qualitative descriptive design. The interviews were conducted either in patients' homes or in the clinic with the exception of two that were done over the phone. They were arranged at a time convenient for patients and lasted approximately 40 minutes on average (range: 28 minutes - 63 minutes). Seven of the 10 interviews were conducted by an expert interviewer (SND or BAW) along with a pair of student trainees. As part of the planned training regimen, the students were given pre-interview coaching. Gradually, students were encouraged to take on an increasingly active role in facilitating and leading the interviews as their skills expanded under direct supervision and the final three interviews were conducted by students upon being satisfactorily trained to do so. All transcripts of interviews were reviewed by S.N.D for quality control.

2.2.4 Staff focus groups

A semi-structured focus group conducted with staff members was arranged at each of the four clinics involved in CKM Pathway implementation with the exception of the University of Alberta Hospital Clinic, where two focus groups were planned several weeks apart to accommodate the larger number of staff members. Prior to the focus groups, a working draft of the focus group questions was circulated to the clinic staff to give them a chance to reflect and gather their preliminary thoughts on the topics. At the commencement of each focus group, staff were re-informed about of the research aims and purpose, their rights to privacy and confidentiality as well as the voluntary nature of their participation. Informed consents were obtained from all focus group participants. The focus groups were led and moderated by an experienced facilitator from the CKM team (SND or BAW) and lasted 1 hour 40 minutes on average (range: 1 hour 32 minutes - 1 hour 58 minutes). As with the patient interviews, all focus groups were audio-recorded, transcribed, and along with any field notes taken, analyzed using thematic analysis nested in a qualitative descriptive design. Immediately following each focus group, a debrief session was scheduled among the research team to discuss the organization of the focus groups, the questions posed and the responses from the audience. Based on these discussions, any needed change to the focus group strategy was decided and implemented for the next scheduled focus group.

2.2.5 Facilitator guides

Facilitator guides were created for both patient interviews and staff focus groups and are attached in the appendix. The questions for each guide were developed by the research team under the supervision of S.N.D, an experienced investigator in qualitative methods and bioethics, in collaboration with an independent knowledge management consultant from Alberta Health Services (AHS) experienced in developing and conducting healthcare-related interviews. The questions were developed through an iterative process over several consultations and team-meetings cycling through multiple revisions and drafts. All questions were designed as open-ended to allow patients and staff flexibility in their responses and prompting questions were predetermined and available to interviewers to utilize when necessary. Broadly speaking, the patient interview guide was organized into three major sections that covered the three components of the pathway: a 'patient education materials' section covering the print component; a 'CKM Pathway website' section covering the web component; and an 'impact on care experience' section covering the process component. The focus group facilitator guide was modified to have four specific sections so as to cover the components of the pathway in more detail. The four sections included: symptom guidelines, patient resources, impact on clinical practice and community engagement. 'Symptom guidelines' and 'patient resources' overlap the web and print components of the pathway and 'impact on clinical practice' and 'community engagement' are part of the process component of the pathway.

2.2.6 What data we were collecting and why

Among the topics we were seeking specific feedback on were the major components and tools of the pathway. These included the online web interface, the patient education materials and symptom handouts, and the various clinical guidelines and end-of-life algorithms for healthcare providers. One concrete output desired from this research was directions from patients/families and healthcare providers on which components of the CKM Pathway met their needs, which parts fell short, and how to potentially improve the pathway.

The related topic of patient education through the use of new pathway materials was also something we were interested in. We wanted to know how patients fared in terms of learning about their disease and symptom management on the pathway. In addition, because a key part of CKM is the decision to be conservative, we were interested in the decision-making process that patients engaged in. This entailed learning about the different treatment options available and utilizing pathway supports to make a decision regarding their care pathway, whether dialysis or CKM. To get feedback on this, we asked patients to talk about their reasons for choosing CKM and to describe what that process was like using the CKM Pathway. For staff, we asked them to describe the response of patients in receiving and utilizing pathway materials and decisional supports to make decisions relating to CKM.

Based on their ability to speak to different topics from different angles, we tailored a unique set of questions in the facilitator guides for both the patients and the healthcare providers. Specifically for patients, we were interested in what they had to say about their interactions with the kidney clinic and their experiences with seeking care in local settings such as with their family doctor or with other community healthcare workers as applicable. The CKM pathway was designed as an open access clinical tool as much for primary care as for specialty clinics. As a step on the pathway, a formal CKM letter is sent from the kidney clinic to advise a patient's family doctor once the patient makes the decision to be cared for conservatively. We wanted to ask patients about their interactions with and the role their family physicians were playing in the patient's care.

For the staff, we asked them for feedback on both the clinical CKM guidelines as well as the CKM Pathway materials designed for patients. Because the CKM Pathway was expected to make an impact on various aspects of clinical practice, we were interested in asking staff about how they integrated the CKM Pathway in their day-to-day routine. This included the interactions between clinic staff and colleagues, including nephrologists, and the dynamics of the inter-professional relationships that were impacted with the implementation of the CKM Pathway. Similarly, recognizing that the CKM Pathway was built with a community focus and has a structured approach to integrating community resources, we were interested in how staff were interacting with other community care providers as partners in healthcare and CKM delivery.

2.2.6 Ethics

This study was approved by the Human Research Ethics Board of the University of Alberta (Ethics ID: Pro00069527) and was conducted between April 2017 and March 2018. Relevant operational and administrative approvals were obtained from Alberta Health Services (AHS) to access and interview patients in the four NARP kidney clinics. Covenant Health Operational/Administrative Approval was also needed and obtained to access one of the NARP clinics located on Covenant Health property.

2.3 Data analysis

2.3.1 Guiding approach

The approach taken for data analysis was guided by Jodi Aronson work's on a pragmatic thematic analysis [59] where she describes a number of stepwise procedures. The first step of data analysis required taking transcribed conversations from interviews and focus groups and generating a list of 'patterns of experiences`. For the next step, a full scan of the data set was conducted and all related data were classified according to their specific pattern. When this was complete, the third step involved pooling related patterns of experiences and generating sub-themes that are ideas or topics that speak to the pool of related patterns. Aronson says the aim with themes is to present a comprehensive picture of the data set they represent and this is facilitated by undertaking rigorous study to develop familiarity with the data set and experimenting with linking ideas together. An important part of the analysis process is to get feedback from interviewees as patterns of experiences are being identified which either can be done during interviews or after transcription. We did this through a process of rolling data-analysis whereby the first interview findings were used to inform the subsequent interviews and feedback was collected on emerging patterns of experiences and themes.

2.3.2 The process

As the interviews were being conducted and completed, an independent transcriptionist was contracted. Words and phrases that sounded confusing or ambiguous on the recordings were marked during transcriptions for special attention. The transcripts were then cross-checked against the recordings for accuracy by the research team. Phrases or words that were confusing or unclear on the recording were deliberated upon and a team-based conclusion was reached regarding their meaning in the majority of cases. In some cases, group chatter on the recording did not allow for this. Once transcripts were finalized, they were printed with large margins and double-spaced to allow for memos, notes and codes. Multiple readings were done and inductive line-by-line coding of data was initiated by the research team members independently of one another. Transcripts were reviewed by at least two independent team members. Regular team meetings were held to share thoughts and approaches to looking at certain passages, amalgamate and clean-up code lists, and discuss emerging patterns and themes. As pattern lists were generated, an electronic database was created using Google Sheets to collate all patterns and memos along with the relevant quotations and context from the interview transcripts. This step to duplicate the analysis and create an electronic version of codes was taken primarily to enable easier sharing and consolidation of work between team members. An additional benefit was greater immersion into the data, a recommendation of good qualitative analysis [60], and a re-evaluation of the codes as they were entered into the spreadsheet. As part of a rolling data-analysis approach, we modified questions in the facilitator guides following a focus group to explore new emerging ideas in subsequent focus groups. We continued data collection until saturation was reached and presented our initial focus group findings to the kidney clinic staff to get feedback on the themes that were emerging from the analysis. Our approach with the interviews was to get feedback by asking patients to expand on their experiences as they were identified.

2.3.3 Data Reporting

The presentation of findings was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) which is a 32-item checklist that helps to standardize the reporting of qualitative research [58]. The checklist consists of three domains which are (i) research team and reflexivity, (ii) study design and (iii) analysis and reporting. Each of these three domains has two or more sub-domains which researchers are directed to speak to. For the first domain, researchers are asked to report on the personal characteristics of the team members and the nature of the relationship with the participants. For the second domain, researchers are invited to discuss their underlying theoretical framework, participant selection, research setting, and data collection. For the final domain, guidance is provided on the conducting and reporting of data analysis.

2.3.4 Rigour in qualitative description

Rigour is well emphasized and important in all qualitative methods but can be even more so in qualitative description which is sometimes criticized for being less theory-driven or aiming for surface-level descriptions and minimally-interpretive analysis [54]. While data-near analysis allows us to remain close to the participants views, it can introduce subjectivity in the analysis. To enhance rigour, Milne and Oberle discuss four important concepts that are authenticity, credibility, criticality and integrity [61]. Authenticity and credibility are closely related and discussed as pairs; the same goes for criticality and integrity. Authenticity is enabling and respecting participants' voices which lends to credibility if participants perspectives are successfully portrayed in the reporting. For this study, our consent forms and pre-interview introductions gave participants free license to talk about issues and encouraged them to share with the incentive that quick turn-around improvements could be made. As part of the study design, facilitator guides remained fluid and amenable to changes as data collection progressed to allow in-depth examination of emerging themes and this promoted richness and variation in the data. These strategies served to enhance authenticity and credibility was achieved by keeping in mind the focus of this study which was to evaluate the pathway through accurate representation of patient and provider experiences. For criticality and integrity, the aim is to reflect constantly on the researcher's personal viewpoints and perspectives and be mindful of how these can impact or bias research findings. In practice, this translates to a critical appraisal of all research decisions made, keeping the context of the researchers in mind. For our team, the decision to alternate the lead interviewers (SND and BAW) with different pair combinations of students (SH, SS, AK) across focus groups and patient interviews helped to recognize and account for intra-team variation as a result of individual researcher viewpoints and perspectives. In addition, the decision to contract out the transcriptioning to an independent, third-party expert added a layer of external integrity to the data collection and allowed the researchers to take a step back to renew focus.

2.3.5 Triangulation of Patient and Healthcare provider findings to enhance credibility

One of the aims of this research project was to compare and contrast the results from patients and providers to enhance our confidence in the findings. This is referred to as triangulation in qualitative research and adds to credibility. Triangulation will be used in the discussion chapter (Chapter 5) after the presentation of results in Chapters 3 and 4. What follows is a description of credibility and triangulation.

The qualitative method chosen to underpin this study was qualitative description. While described as less theory-driven than other qualitative methods, the importance of ensuring rigour is no less stressed. Among the four important concepts discussed by Milne and Oberle on the topic of rigour in qualitative description is credibility [61]. Credibility is also one of the four criteria proposed by Guba to establish trustworthiness in qualitative studies in general [62]. Credibility is defined by Oxford dictionaries as 'the quality of being trusted and believed in' and trustworthiness is an important synonym [63]. Being trustworthy and credible is an important goal for any research if it is to be accepted in the academic and public realms and thereby able to make an impact, contribute to change, advance a field, or otherwise achieve its purpose. It can be argued that credibility and trustworthiness are even more important to establish in qualitative research which is prone to critique from the positivistic paradigm [64]. There are a number of strategies for establishing credibility in qualitative research including prolonged engagement, member-checking and triangulation, as discussed by Lincoln and Guba [65]. Our focus in this discussion will be on the use of triangulation to look at our findings.

Triangulation in qualitative research refers to ideas that multiple sources of data or the use of multiple methods to arrive at convergent findings adds credibility to a study's conclusions and make them less vulnerable to errors [66]. Triangulation is an important technique for strengthening qualitative analysis and increasing its credibility. In this study, the use of individual patient interviews and healthcare provider focus groups allows for an ideal situation to look at the evaluation of the CKM Pathway using triangulation. There are four distinct types of triangulations identified in the literature: method triangulation, investigator triangulation, theory triangulation, and data source triangulation [66-67]. Carter and colleagues describe the different types of triangulation and explore the use of focus groups and in-depth interviews in studies to promote triangulation and increase confidence in the findings [68].

Method triangulation

A popular and common type of triangulation is method triangulation which involves using different methods to collect data on the given phenomenon of interest. An example would be to collect data via recording a formal interview with a participant while keeping mental observations of participant behaviour to document as field notes [69]. Method triangulation, also referred to as 'methodological triangulation', can be of two types [70]. If a study involves using at least one quantitative and one qualitative method for data collection, it can be thought of as 'across method'. If it uses multiple methods that are either just qualitative or just quantitative, it is referred to as 'within method'.

Data source triangulation

Similar to method triangulation is data source triangulation where the participants are recruited from different groups to talk about the same phenomenon from their own unique perspectives. Using different types or groups of participants can allow for the corroboration of findings [66]. Data source is particularly applicable in scenarios where a service is being provided and there are providers and recipients of the service. This allows for a comparison of what each group valued as important, relevant or impactful.

Investigator triangulation and theory triangulation

Investigator triangulation means using more than one investigator to see if they are arriving at the same conclusions. It could also be to determine if a researcher's presence or absence is having an impact on the study's data collection. It has been identified in the literature as being used to reduce researcher bias. Theory triangulation involves examining and scrutinizing the data collected for a study using different theoretical perspectives - for example, doing both content analysis and phenomenological analysis on a single data set to compare the findings.

The approach we used is a hybrid of method and data source triangulation. We used both interviews and focus groups as two major methods of data collection. We collected data from both patients and providers providing data source triangulation. Patton suggests that when doing triangulation, one may use the different types or sources of data to 'provide cross-data validity checks' [66] thereby enhancing the validity and 'truth' of the findings.

Chapter 3: Patient Interview Results

Ten interviews were done with 16 patient/family member participants. All patient participants were over 70 years of age, white, had ESKD (eGFRs lower than 15) and had chosen CKM. Six of the 16 participants (37.5%) were male. One patient/family member diad lived in a small rural town, the rest lived in the Edmonton area. Three primary themes, broken down further into several subthemes, were identified [Figure 1]. The first theme was 'supported facilitated decision-making'. It related to the experience of patients in making the CKM decision and the support they received from staff and the pathway's PDA. The second theme was 'provided effective CKM patient resources' . The third theme was 'promoted patient-centered CKM'. It described how the pathway improved care by increasing collaboration between community-based family physicians and the kidney clinics.

3.1 Supported facilitated decision-making

3.1.1 Enabled early treatment discussions

The CKM pathway supported shared decision-making between patients and healthcare providers in part by facilitating early treatment discussions. Patients and families said the kidney clinic staff started probing the treatment discussion early in their care and gradually provided information in bite-size chunks.

> ***"They had always kind of introduced us a little bit to that [CKM] direction from the moment we started with the team."***

Using the pathway and the PDA, the staff were able to provide patients with information in a planned, step-by-step fashion that made it easy for patients to process and understand.

3.1.2 Helped patients realize they had a choice

One of the points stressed by the CKM Pathway's PDA was that patients had a choice. Patients said that kidney clinic staff talked to them about the home and hospital dialysis options, but also told them about the CKM alternative that involved no dialysis.

> ***"she [nurse] told us about the three choices of what we would do in the event things get worse, and it was home, hospital or conservative... "***

Sometimes, patients and families came into treatment discussions with the preconceived notion that dialysis was a foregone, inevitable conclusion. They were unaware that there was another possible alternative.

> ***"I know, before they gave us this we really were thinking dialysis, we always thought one day it would happen and they showed us everything."***

Patients and family members described that through the use of the pathway's decisional supports, they not only learned that dialysis was a choice not appropriate for everyone, they were able to contextualize their options and felt comfortable with choosing CKM even when they had initial opposing expectations.

3.1.3 Empowered patients to explore their options

Patients appreciated knowing they had a choice in the selection of their treatment. As a result, they felt encouraged to explore actively their treatment options before making a decision. In one case, a patient and his family member attended hemodialysis and peritoneal dialysis classes to learn about the options, even when the patient was leaning towards choosing CKM. Attending the classes helped the patient reaffirm for himself that he did not want to go on dialysis and he felt more comfortable with CKM. Another patient reported that he became focused on reviewing all his treatment options before choosing to commit to any one approach:

"Now, we didn't go off the deep end about anything [i.e. available options] but just tried to get a general take on everything and I wanted to look after myself the best I could."

3.1.4 Provided patients with useful prognostic information

The CKM Pathway's PDA supported facilitated decision-making by providing patients with useful prognostic information. During the interviews, patients demonstrated confidence in their decision and showed they understood the benefits, or lack thereof, of dialysis in the context of their health conditions. Patients shared the insight that being of advanced age with various chronic conditions meant that dialysis may not offer them years of survival. One 85 year old patient recalled being told by his kidney team that his age was a factor that can affect his success on dialysis.

"They said that probably for a person my age it would be better if I didn't [start dialysis]..."

Based on their education using the CKM Pathway's PDA with clinic staff, patients were aware that any survival advantage offered to them via dialysis would not result in a tremendous prolonging of life.

"...it is not going to make a huge difference either way, [on] the time he has left" - Family member

One patient put a qualifier on his choice for CKM by saying if the survival advantage on dialysis was greater, the burden associated with dialysis would have been worth taking on. In this patient's opinion, the extension of life was not commensurate with the time and trouble that would be involved.

"It doesn't give you a long enough benefit for the trouble that's involved."

3.1.5 Helped patients reflect on their values

The pathway's PDA helped patients and families reflect upon the foreseeable impact of their decision, reconcile their options with their values, and make a treatment choice accordingly. For example, patients were not only educated about the time commitment needed for dialysis, but asked to consider what that burden meant to them based on their own preferences and values.

One value patients focused on with the help of the PDA was maintaining quality of life. Patients showed they were well-informed about the potential impacts of dialysis on their daily life and they had a strong interest in mitigating any detriment to their quality of life.

> ***"I am 84, I have had a better life than most people, and I would hate to be sitting there getting blood taken…"***

Patients also desired minimizing travel related to their healthcare. Starting hospital dialysis meant coming into clinic three times a week. Patients said that this high frequency of clinic visits and the travel associated with it would be very demanding and tiresome.

> ***"That, actually for me, I think I would consider to be very tiring and I am tired enough as it is."***

Patients considered the burden on their family members as a factor in their decision. One patient felt that the constant travel and regular visits would be a strain on her children, who actively volunteered their time and participated in her care.

> ***"To have to go every second day yet, that would be a strain not only on me but on my family. "***

Having control of their time was also extremely important for these patients who recognized using the PDA that dialysis would give them equal survival or only a minimal survival advantage compared to CKM. On the other hand, CKM offered more time. A patient went through the calculation of doing

3 dialysis sessions for 4 hours each per week during the interview and said he didn't want to spend those 12 hours of his life in the hospital every week when the advantage was negligible.

"You're giving 12 hours of your life to go to the hospital... "

In the case of one patient who lived in a remote community outside of Edmonton, dialysis was even less favourable because of the added travel time. In addition, this patient valued being able to travel for leisure and vacations.

"My wife and I love to travel and we travelled a lot but we still would like to..."

The PDA helped such patients visualize the impact of choosing dialysis or CKM on their quality of life and their values.

3.1.6 Eliminated decisional conflict

Patients had high satisfaction with their CKM choice. They did not report decisional conflict after choosing between CKM and dialysis using the PDA.

"I am very happy with the [CKM] treatment I am getting. "

"It has been extremely good."

Patients not only learned they had a choice, they felt empowered to make a CKM decision and were comfortable with their choice.

"INTERVIEWER: Are you comfortable with your decision? PATIENT: Oh sure!"

Patients also took comfort in the fact that if they wanted to or were unsatisfied with their choice, their care or their symptomatic condition at any point in the future, they had the option of starting dialysis.

"Well I seem to be doing fine now and like I said, I do have the opportunity of taking dialysis at a later date if I wish."

Having this option seemed more like a psychological need rather than something patients would actually act on, as patients interviewed showed no inclination of changing their CKM decision.

3.2 Provided effective CKM patient resources

3.2.1 Resources that were accessible, patient-friendly and useful as a reference

When patients and families explored CKM as a treatment option and learned about managing their kidney disease, they engaged with the pathway's patient resources and found them effective because they were simply written and easy to understand. The resources included the comprehensive CKM booklet, the online website, and the individual symptom management handouts that patients received during clinics. Patients and families were largely happy with the CKM patient materials and expressed no concern about the reading level or word choice.

"I think it is perfect for somebody…like dad doesn't seem to have any problems understanding it."

"It was an easy read. I am not the smartest person but I could read it and understand it and found it very helpful."

"They [CKM resources] are very interesting actually and helpful."

On account of being accessible, some patients described reading the CKM booklet cover to cover multiple times, in the interests of educating and familiarizing themselves with information related to their care. These patients wanted and valued the information in the booklets, and found it relevant and appropriate.

"I brought them [CKM patient resources] home, read them about three times just to make sure I would remember…"

" I go cover to cover [reading the CKM booklet]."

There was variation in how patients and families engaged with the CKM resources. While some patients preferred reading resources cover to cover, others utilized them as a reference when they needed information. Their approach was to look through the resources and read up on the specific topics they were interested in, such as symptoms or diet.

"I would just try to reference points when we did receive it."

"So I have refereed back to it for some of the diet and things like that..."

A useful reference for patients and families was the CKM Pathway patient portal, which was designed with patient partners. In many instances, the patients themselves were not using computers anymore but family members had utilized the website in some capacity.

"I did [access the website] when I was reading up on everything and I was trying to get as much information as I could."

Patients and families described the CKM booklet as a comprehensive CKM resource, which was useful both as an educational tool and a reference. Whether patients had read the CKM booklet multiple times or used it as a reference, they and their family members agreed that these CKM resources were useful supplements to have access to.

"...it is a great supplement because we can refer to it"

3.2.2 Helped patients explain their choice to others

Patients and families found the CKM patient resources educational not only for themselves but those in their social circles. These resources spread awareness of CKM by helping patients explain their CKM choice to others.

"I think it really defined [CKM] and it has been easier for me to explain to others what it has been. "

"I went over it with my children. They took the books, they actually read them too."

Having a formal, sharable resource legitimized this care option when patients' discussed their choice with others, particularly with those who were familiar only with dialysis and who tried to question a patient's decision. In this sense, one patient and family member felt the CKM resources helped preserve patient autonomy by helping them to defend their decision.

Sometimes, the CKM Pathway resources helped family members' understanding independent of the patients. In one case, a patient did not want any part in learning about his disease, was in denial about the severity of it and did not want to discuss it with his kids. The patient's daughter was able to use the patient portal of the CKM website and patient booklet to learn about her dad`s disease and develop a better understanding of CKM.

"There were so many things I didn't know and by reading all of that, I feel like I have a full understanding of what is happening."

As a result of this increased understanding of CKM, the patient's daughter was able to play a more active role as a supporting care-giver.

3.2.3 Served as clinic aids and reminders

CKM patient resources served as effective clinic aids and reminders. Some patients reported that during appointments, clinic staff were taking time to walk through some of the patient materials with them directly and patients found this helpful.

> ***"Yeah it's very good. I think one of the nurses kind of went through it in one of our interviews, and it's laid out very well."***

Reviewing resources in clinics helped orient patients to the important sections that were relevant for them and gave them the opportunity to ask questions.

Having CKM patient resources to take home was beneficial, as it allowed them to read up on what was discussed in the clinic, refresh their memories, further answer their questions, and helped them decide who to talk to about specific concerns or questions.

> ***"I think we need something to take home. Sometimes it is a little hard to absorb all the knowledge that they are passing on so I read the book so I can coordinate between them…makes it a little clearer."***

> ***"[Interviewer:] Do you have some questions for us? [Patient:] Not really, the book answered all of my questions."***

> ***"We were able to use that information to decide if that was something I should be talking to [the kidney nurse] or his GP about... It helped with that. "***

3.2.4 Supported disease and symptom management

In addition to building awareness and serving as reminders, patients felt the resources were helpful, or would be helpful, in their disease and symptom management. Patients interviewed were at different stages in their disease trajectory and had different degrees of symptom burden.

"He has been fortunate that he has had very few symptoms until he just got a little bit closer to what he is now."

"I have the itchy problem, all of the time, even now at 10 I still have itchy problems..."

Those patients who were early on in their disease trajectory and were doing well symptomatically used the resources to focus on preservation of kidney function. They valued information relating to symptom management and anticipated using more of the CKM booklet as their disease progressed.

"...at this point, the parts that we mainly used are things that cover how to maintain things with diet."

"But it looks to be a really good resources to turn to so if we do start having issues, I'm sure we will refer to it."

When patients did start having trouble with symptoms, they found that they could use the CKM booklet to learn symptom management strategies to try at home before going on to medication.

"It gave us some suggestions about what might be some other alternatives without medications that we could maybe try first."

An important aim of the CKM philosophy is minimizing prescriptions and patients were aware of this. Patients and their caregivers were able to follow the approach outlined by CKM resources and started with non-medicated ways to alleviate symptoms.

"Most of them I have implemented, soft sheets and that type of thing for bedding...the loose clothing and what kind of detergents..."

Sometimes, patients contacted kidney clinic staff directly who guided patients based on the recommendations provided in the CKM patient resources.

“So as far as all of these tips, he has done all of those things...probably from the consult with [Nurse]”

A family member shared an example of the CKM booklet being helpful with symptom management in the case of a patient experiencing significant itchiness. The patient had attempted different creams and pills to little avail.

“One of the worst was that he was so itchy he could hardly stand himself. ”

The patient’s daughter was able to use the information in the booklet to make the connection between his itch and his diet.

“I went through the book and realized it had something to do with what he was eating.”

She then offered to take charge of his diet and was able to promptly alleviate the patient’s itch within a week. She described her own surprise at the dramatic change she saw and attributed it in part to the information she accessed in the CKM patient resources.

3.2.5 Helped with knowing what to expect

The CKM Pathway resources supported patients with knowing what to expect. Patients and families felt the website and print resources were helpful with clarifying the unknown and helping to normalize symptoms. This provided comfort as families and patients could foresee the challenges that may arise, prepare in advance accordingly and react better in the event of an emergency.

“Everything from the signs and symptoms that he would have...it really defined for me the expectations I should have from it ”

These resources confirmed the patient experience in terms of their symptoms and define the boundaries of what was ‘normal’.

"It did kind of talk about these kinds of things, the itchiness, the tiredness, the trouble sleeping... so it does confirm the things that he is experiencing"

Feedback: Suggestions for Improving CKM Pathway resources

Patients and families, as well as healthcare providers, provided feedback for improving CKM Pathway resources and highlighted specific challenges (Appendix F). A couple of patients and families talked about sections in the pathway's resources that could be improved for clarity and offered suggestions on improving readability. One elderly lady who cared for her husband with kidney disease raised her concern that she wasn't sure on what she should do in the event of an emergency involving her husband.

"I don't quite understand how we can access…say if we needed help?"

She said that reading the crisis section of the booklet did not answer her questions sufficiently. She was worried if her husband was to fall, she would not be able pick him up. She wanted to know who she should call, whether EMS, the kidney clinic or some other provider. Her current crisis plan was not clear about who to call and she wanted it more explicitly laid out what she need to do to get help.

Another family member, while praising the CKM booklet as being accessible in terms of reading level, suggested that the length of the booklet may be a barrier for some patients. She offered that if certain headings, topics or sections descriptions could be highlighted or designed with a color-code scheme, it may facilitate easier navigation of the information in the book and helps users to easily lookup and reference sections they were interested in.

"If there are portions that dad could see in here that were highlighted...he could gain the knowledge he wants but the rest could be a discussion in detail."

3.3 Promoted patient-centered CKM

3.3.1 Engaged family physicians as desired by patients

Patients and families felt the CKM Pathway promoted patient-centered CKM by engaging primary care as partners. Patients expressed interest in having their family physicians informed about and involved in their CKM.

> ***"I would like to see him [Family Doctor] take the lead and be able to use the kidney clinic as a resource."***

The CKM Pathway facilitated this through routine communication from the kidney clinic to a patient's family physician when the patient started CKM or made changes to the care plan.

> ***"[Nurse] actually had sent an email to his GP with the [CKM Pathway] website... "***

Having their family physicians involved gave patients more choice and autonomy with regards to where they received CKM and who provided it.

3.3.2 Facilitated coordinated, timely, community-based care

The CKM Pathway helped reduce patient reliance on kidney clinics and improved access to CKM in the community setting. The pathway provided family physicians clear guidelines for referring patients to home care/palliative care services and a streamlined process to make referrals. This improved timely access to community resources as engaged family physicians were responsive to the needs of their CKM patients. One patient reported that when her condition deteriorated and she decided with the kidney clinic to involve palliative care, her family physician who was onboard with the CKM philosophy and supporting her care on the CKM Pathway, made the referral immediately. As a result, this patient saw a timely and seamless transition to palliative care.

"At that point he did right away and the next day [Palliative care] showed up at the door."

For some patients, access to the kidney clinic was limited because of the associated burden of travel. Additionally, while phone access was available, kidney clinics were not open on weekends and patients normally had appointments scheduled every three months. This made accessing kidney clinics for urgent, acute care impractical.

"I have an appointment in July but coming over here today I am wondering if maybe I might have to cancel it."

"I think once in a while the thing that we go with is that the clinic is not open on the weekends."

On the other hand, patients could access their family doctor on a more short-term and flexible schedule, which was more congruent with the needs of this older, multi-morbid group of patients. If a patient had a sudden symptom crisis, it could mean more timely access to care by their family physician. Family physicians who were informed about CKM via the pathway were able to work collaboratively with the kidney clinics and support patients in the community setting.

" [The kidney clinic and the family physician] were both paralleling his care."

"We've had very good support between home care, the renal clinic, and [the family physician]..."

3.3.3 Improved working relationships between healthcare providers

The pathway helped kidney clinics and community providers improve working relationships and divide roles and responsibilities. For example, one patient and family member shared how their family physician was monitoring the patient's monthly blood reports and was in communication with the providers at the kidney clinics to ensure that levels were within normal range for their shared CKM patient.

“[Family doctor] is doing a great job of it right now. I know that she and [nephrologist] correspond…”

In the case of another patient, the family doctor prescribed medication that she thought were safe for kidneys. However, through the communication channels established by the CKM pathway, the patient’s pharmacist was aware of the patient’s CKM decision and felt it appropriate for the medication to be reviewed by the nephrologist at the kidney clinic. The nephrologist felt there was a better alternative to the medication prescribed by the doctor and the pharmacist was able to inform the patient of the respective change.

“[Family doctor] has prescribed things she thought were safe for the kidney and then [pharmacist] would say [the nephrologist] would actually like her to use something else.”

A couple of patients talked about strong working relationship between their family physician, nephrologist and pharmacist that formed a safety net for patients on the CKM Pathway. The pathway’s guidelines helped provide a standard and brought the various healthcare team members on the same page.

“They have this flow, the triad.”

Patients and their caregivers relied on this triad of providers when they had questions and felt comfort in knowing that their providers were informed by the CKM Pathway.

“I am very good about phoning [the nephrologist] or [family physician] or our pharmacist because she has here a long time too.”

Using the pathway helped protect patients from treatments and medications incongruent with their kidney disease or choice for CKM.

Chapter 3: Summary of findings

Patients and families evaluated the pathway as supporting facilitated decision-making by firstly helping them realize that they had a choice. As a result, patients felt empowered to explore their options between hemodialysis, peritoneal dialysis , and CKM. After choosing CKM through shared decision-making and the use of the PDA, patients reported they were highly satisfied with their choice of the CKM pathway. They had the opportunity to reflect upon and reconcile their choice with their values. As a result of the education on modality choice, patients demonstrated a strong understanding of why they chose CKM over dialysis, including the fact that CKM allowed them the option of doing dialysis in the future if they wished.

Patients felt the CKM patient resources were accessible and patient-friendly. They were able to read, extract and understand the information they wanted regarding their care. The resources helped build awareness of CKM not only for themselves, but also among their family members and friends. The resources helped patients throughout their illness trajectory with different symptoms, starting with non-pharmacological strategies they could try at home before getting a prescription.

Patients also felt that the CKM Pathway promoted patient-centered care by encouraging and facilitating collaboration between the kidney clinics and family physicians. Even though all patients tremendously valued and appreciated the kidney clinic services, they expressed interest in greater involvement of their family physician in their care. More involved family physicians meant safer, more coordinated care for CKM patients. For example, having the triad between the family physician, the pharmacist, and the nephrologist served as a safety net for patients and helped keep a check on the medications prescribed to patients. The increased participation of family physicians facilitated by the pathway also helped to provide timely access to community services such as palliative care.

Chapter 4: Healthcare Provider Focus Group Results

Five focus groups were conducted in the four kidney clinics implementing the CKM Pathway. Focus group sizes ranged from seven to ten participants and a total of 25 participants attended. Focus group composition was mixed and included nephrologists (n=7), nurses (n=13), social workers (n=2), dieticians (n=2), and administrative staff (n=1). Three themes, and several subthemes, were identified. Healthcare providers said the CKM Pathway: improved kidney clinic processes and patient care; provided useful CKM resources; and facilitated shared care with community providers.

4.1 Improved kidney clinic processes and patient care

4.1.1 Increased collaboration and trust between clinic staff

Staff viewed the CKM Pathway as improving the way nephrologists, nurses and other support staff collaborated to care for their patients. Nurses were taking the lead in learning, referencing and operationalizing use of the CKM pathway in clinics based on the training and support they received through the implementation process. Nursing staff said that when it came to the management of patients, they were able to use the CKM Pathway guidelines and recommendations and present options for nephrologists to consider.

"We ... go through these recommendations and present them to the nephrologist to see if they are open to trying them."

"I will say to them, do you want to initiate tramadol as needed as per the CKM guideline?"

Nephrologists, for their part, were open and receptive to the CKM Pathway-based suggestions from nurses. Nephrologists said they relied upon and trusted the nurses to guide them as per the appropriate recommendations of the pathway.

> *"So, these guys have been doing it, as you know, in slapping a hand and saying "hey look, it is time to think about this and that and stuff..."*

> *"We are guided by them largely so they may be using the pathway and then telling us what to do "*

Nephrologists were comfortable with nurses guiding patient care based on the CKM Pathway and this encouraged nursing staff to perform within their full scope of practice and gave them more independence in supporting their patients.

> *"The nephrologists have been great to basically let us have free reign, and make suggestions, and within their own privy, decide what is useful."*

'Free reign' meant nurses felt comfortable and confident bringing up the pathway's recommendation as valid options.

> *"And that reflects that our physicians are really comfortable with letting us do our own thing and letting us have our nursing scope."*

Having their own 'nursing scope' meant nurses could work independently with their patients following the CKM Pathway. They could start the decision-making process using the PDA with their patients or when patients had already chosen CKM and had symptom concerns, nurses could respond with non-pharmacological management strategies using the pathway's symptom guidelines. For prescriptions, nurses could work with the nephrologist or the patient's community physician to initiate the treatment plan. One staff member described the pathway supporting patients as follows:

“...With a CKM patient you are trying to actually relieve their symptoms with these recommendations and then educate them on what to do if this doesn’t work and what the next step would be.”

Nurses said that if a nephrologist was not involved or engaged, nurses’ use of the pathway was limited. When the time came to involve nephrologists, staff said that the majority of nephrologists were open, accepting and cooperative.

“In order for us to use the CKM pathway, at the end of the day we can’t just do things on our own.”

“Generally speaking, I would say the majority [of nephrologists] do.”

Sometimes, nephrologists were hesitant in addressing patient issues that they had previously left for primary care, for example, itchiness and pain management.

“one of [Nurse]’s patients that needed a prescription for itchiness ...and we didn’t know who would be the prescribing doctor because our doctors don’t normally prescribe for those prescriptions.”

“I can sympathize with that when they say “I don’t want to treat it because we have never treated pain”.”

However, as a result of their trust in the CKM Pathway, many nephrologists chose to accept expanded responsibilities and support CKM patient management based on the pathway’s guidelines. This was especially important when some patients did not have an identified or active family doctor. Nursing staff said that sometimes it took a bit of explaining and familiarizing with CKM to get nephrologists involved in prescribing for symptoms.

"Most of them are open to addressing the symptoms, it is just familiarizing them with it..."

Nurses led the implementation and use of the pathway in clinics and nephrologists supported them by taking on new prescribing roles for CKM patients.

4.1.2 Facilitated staff professional development

Staff appreciated the CKM Pathway in part because learning to use it helped them become better healthcare providers. For example, an important part of the CKM Pathway is Advance Care Planning (ACP) and it was a feature that resonated with many staff members.

"I think that probably the biggest and for me the most useful feature of conservative care is the advanced care planning and making sure that you have these discussions with patients in a timely fashion to decide what they want to do."

A couple of nurses shared that attending the ACP training session as part of the pathway's implementation helped them improve their skills as communicators and facilitators.

"When we took the ACP and became ACP facilitators, yes we were trained to have those conversations but that made us better nurses period."

The implementation process included monthly meetings and a series of full-day, hands-on, interactive workshops. These were occasions where staff from all four clinics came together and were immersed in collectively learning about the CKM Pathway. These training sessions also helped staff adopt language and terminology that was more CKM-focused, which had a positive impact on patients.

"The language really helps and I think last year, talking about it so much, it is really starting to fill in."

"We are way more confident about it and you can see it in the patients who choose it."

The CKM Pathway training also helped staff feel more prepared to have difficult and uncomfortable conversations such as end of life planning. As one staff member pointed out, it was an important change in their culture of practice that they themselves were thinking about the topic of death, realizing the importance of having this discussion with their patients, and feeling prepared to lead it.

"I think we are starting to think more about what a good death is...what that end-stage looks like. I am less afraid of that and more willing to look at that with them."

4.1.3 Provided an effective CKM-specific PDA to facilitate decision-making

Staff said that pathway improved kidney clinic practice and patient care in how it supported patient decision making. The CKM-PDA was an integral part of the CKM Pathway that was effective in helping patients make treatment choices. In some cases, staff found that using the PDA could help patients and families overcome cultural pressures, resist temptations for an overly aggressive treatment approach, and make decisions in contrast to their initial expectations but in line with their goals, values and contexts.

"I think the PDA is the best thing in the whole pathway."

"Again, it was a complete 180. Then [Nephrologist] was able to go in with all of the information. It was a very positive outcome."

Staff appreciated that it was accessible online and could be completed in real-time with patients in clinics. They valued that it was especially tailored to their advanced CKD patients who were frail and multi-morbid. Staff said that patients and families found the PDA questions relevant to their personal contexts and applicable in their decision-making process.

"And I think they did because they could see the questions I was asking for the decision aid really related to their dad."

Staff appreciated the pictographs on the PDA, which helped patients and families visualize the benefits and harms of their choices. Staff said the pictures were able to get through to patients and their families in a way that words could not, especially when English was not their first language. The PDA pictographs depicting survival and time spent in hospitals based on treatment choice were particularly eye-opening for patients and families.

"All of those pictographs really hit home with them "

"To see how much time, the survival piece is huge and the amount of time this poor man was going to be spending in hospital and clinic."

Use of the PDA to make treatment decisions made the subsequent care planning with patients easier, as illustrated by the following comment from a nephrologist.

"Every nurse I follow who used it always had very positive feedback about using that tool and following them into see the patients you get a sense of "whew" and then it is easier to follow with their plan then"

4.1.4 Enhanced personalized symptom management

Keeping patients free of severe symptoms was an explicit goal of the pathway. This emphasis on symptom management encouraged staff to get better reporting of symptoms from their patients and respond when symptoms were present.

“You are always saying “call me with new or worsening symptoms.””

“...now I have got this boatload of resources to actually do something about these symptoms...”

Nurses were also increasingly approaching nephrologists to initiate appropriate interventions whenever patients reported severe symptoms (ESAS > 7).

“We might be becoming more of a pest, I don’t know if you have noticed that, but if we get a symptom that is on a ESAS that is seven or above, for example itchiness, we might be bothering you more frequently to try to get that symptom down...We are trying to help the patients feel better.”

Staff said that the pathway’s educational resources helped patients develop better awareness of their disease and CKM, patients sought help more readily with regards to managing their symptoms.

“Because they are aware now that these symptoms are related to their kidney disease so who do they call? ”

To achieve better symptom management, the pathway also helped staff combat a passive or apathetic approach that some patients had with regards to their symptoms. Sometimes, a bit of compassionate encouragement and convincing helped motivate patients to tackle their symptoms or blood targets. The CKM Pathway provided numerous management options for any given symptom which nurses could use to personalize care for their patients.

“And she said absolutely, whereas before that, she was “I don’t want to control my potassium.””

If a patient had an itch concern but did not like using creams, the conversation was about trying other tips on the CKM patient handout or deciding to try medications as the next step on the pathway. For a patient that worried about their pill burden, the discussion was about comparing the trouble of taking another pill with the expected benefit of relieving a particular symptom. Having the arsenal of symptom management options through the pathway's guidelines also helped staff treat some symptom crises in the community and prevent unnecessary hospitalizations for CKM patients.

"You know, when we look back a couple years ago we would have said, "Go to emergency". We very rarely say that now, especially to a conservative patient."

The above quote suggests that, since having access to the tools and resources of the pathway, staff noted a difference in their abilities to tackle symptom crises and keep patients out of emergency rooms.

Feedback: Challenges with time constraints

Clinic staff said that using the CKM Pathway and the PDA led to more time spent on individual patient appointments. The pathway promoted active symptom management which required a personalized approach that involved educating the patient, going through recommendations and determining the next steps in the course of treatment. Conversations were more sensitive and management was more personalized. If patients had multiple symptoms they wanted addressed, that added to the time.

"I think that is something that came up...definitely, conservative care takes a long time."

"Because with a CKM patient you are trying to actually relieve their symptoms with these recommendations and then educate them on what to do if this doesn't work and what the next step would be."

The decision-making stage also required time as patients needed to actively participate when choosing CKM. Staff said that CKM discussions could uncover any number of patient issues that needed to be explored and dealt with. Advanced care planning and planning a good death were also common yet difficult discussions that required time. Furthermore, staff shared prior experience outside of the CKM Pathway where discussions could be complicated by pressures from or disagreements between family members who may not support the patient's choice.

"You get talking about end of life and you don't have homecare yet but you are struggling but you don't want it ...okay. There is so much going on there"

" I think sometimes that family members can be barriers depending on if they have got the same sort of opinion about the care as the patient themselves."

Use of the PDA could sometimes cut time and help patients and families resolve conflict by showing them comparative data on how the various options would impact outcomes. More time spent with CKM patients created time pressures as staff were not previously allocating as much time for CKM. This affected the care of other CKD patients. Staff said while they strove to provide equal, high-quality care to all their patients, sometimes they couldn't get all of their planned CKM discussions or appointments completed in the time they allotted.

"I am passionate, obviously, about conservative care but I have to deliver that same best care to the rest of my people."

"Well I think it is a barrier though, because you are not able to do...every single piece that you want to in your period of time that you have."

Nurses also suggested that there was a bit of a learning curve with using the web-based CKM Pathway real-time in clinic and data collection for the quantitative part of the evaluation also took time. Staff anticipated using the pathway more as they became more familiar with the pathway's resources and guidelines.

> ***"Hopefully, like we said, as we get more familiar with it we will learn it bit by bit and use it online more."***

There was shared optimism that continued use of the pathway would decrease the time burden some staff were facing. Nurses wanted to be able to internalize CKM guidelines, so that they could use the pathway for quick references as needed, without feeling the time pressure.

> ***"So, it would be nice for me to, and I have read through all of that but they are not in my brain yet so maybe something like that would be amazing"***

4.2 Addressed a gap in CKM resources

4.2.1 Provided useful CKM resources that were easy to integrate in clinics

Staff said that the CKM Pathway provided resources that filled a long-standing resource gap, specifically for CKM patients.

> ***"When you look back to now it is just incredible. That is what we wanted so many years ago is something to give them."***

Prior to the pathway, staff felt there was a paucity of resources to guide or support CKM patients. One nurse shared that a patient family member even sent her links to resources from Australia to share with patients because they did not have much.

> ***"She sent me information that she found helpful that was from Australia and she said "you should share this with your other patients" because we had nothing, it was kind of embarrassing actually."***

With the pathway's resources and tools, staff found a systematic approach to follow with CKM patients. The pathway provided something concrete and staff were able to respond effectively to patient symptom concerns, whereas previously they would be uncertain. Staff also appreciated that what they were sharing with their patients was standardized across the four kidney clinics in Northern Alberta.

"Now we have something to access and resources to use instead of just figuring it out as we go along."

" it is important that, if nothing else, that this whole CKM and PDA has given us an opportunity to really give them something concrete. It is not just- you are not getting dialysis…."

"It is always nice... to have... something that is going to be standardized among all of us that we are suggesting the same things."

Kidney clinic staff appreciated the pathway's patient resources as being easy to integrate in clinic. There were three types of patient materials that staff reported using routinely in clinic. One was a small two-page pamphlet titled 'Considering CKM'. The second type of patient resource was the individual CKM symptom relief handouts on the various symptoms addressed on the CKM Pathway. The third type of patient resource was the CKM booklet, which was a comprehensive 62-page guide on CKM and living well with chronic kidney disease. It included all of the individual symptom handouts as well as the information available on the online patient portal of the CKM website. Staff reported that the shorter, simpler patient resources such as the pamphlet and single page symptom handouts came in handy as they were easier to cover in the clinics. Patients also appreciated them because they were short, concise and easy to read.

"I use the concerning CKM pamphlet a lot. I really like that and patients seem to like it because it is short, concise, and it is to the point."

"Like when we hand it out, the patients like them because they can read it."

Staff found these resources helpful as they provided taking points for overall CKM as well as specific symptom management. When patients and families reported symptom concerns, having printed copies on hand enabled staff to quickly grab the respective handout to share in clinic.

"I use it as I am going through talking about CKM in the clinic. "

"If you have a patient that has nausea or breathlessness or something, it does give you some other talking points to work on with those."

"Go grab a sheet if they are having a particular symptom and hand that to family if they are asking us or we cover that ourselves if it is our particular patient who is having that."

Most staff members had a routine of discussing the handout in addition to letting the patients keep a copy. One nurse shared that based on the patient and their symptom severity, she would tailor what points she chose to mention and discuss as not all points were applicable in a given patient's context.

"...but just handing it to the patient isn't adequate, you need to discuss it with them."

"And I mean, if I am going to discuss it I am probably not going to go through every single option down ... I might choose 3 or 4 different ones that I know based on their things that they like to do and that kind of stuff. "

Discussion of the handout in clinic was important to counter the reality that some patients would not be inclined to read it and might miss out on beneficial tips they could try. In addition to not reading, patients could also misunderstand what they read or how they were suppose to use them.

“It is worth going through [the handout] because you are never sure where they are at with the things they are doing. ”

One nurse shared the case of one patient who took home the CKM booklet, read it cover to cover and was overwhelmed by what she read about the final stages of kidney failure when GFRs fall into single digits. The CKM booklet, in an attempt to be comprehensive, provides a snapshot of the final months and weeks of life of a CKD patient that frightened this lady. The nurse took this as a learning opportunity and a reminder to herself for the importance of clarifying the purpose to patients when handing them resources and explaining how to use them.

“ So that I took to heart ...[that] I will say this is something that you can reference when you need it. ”

Patients appreciated having something concrete to take home as a reminder of the clinic discussion. In addition, the physical copies of the materials served as useful aids for family members who had questions or were looking for ways to help the patient.

“Again, this is something concrete that they can take home with them for further discussion because quite often it will be one child with a parent or the patient by themselves.”

“[If] they forget what the advice was, they can just review it at home.”

Staff were finding them helpful to the extent that they were sharing these with their other non-conservative patients as well.

“ I even use them for my non-conservative patients- they are awesome!”

In addition to the print resources, the online resources also came in handy for patients and families to learn about CKM. Staff shared in one instance, a patient’s relative used the CKM Pathway’s patient portal to view the different resources available that she could use to learn more about CKM.

" One of [Nurse]’s patients, the sister went on the website and looked it over and was excited to see what was on there."

4.2.2 Provided guidelines that standardized best-evidence practice

Symptom guidelines were part of the resources provided by the CKM Pathway. Nephrologists, and nurses reviewed the CKM guidelines and reported no concerns with the clinical content and step-wise organization of algorithms. They agreed with the use of guidelines in aiding clinical decision-making and felt that CKM guidelines were a good way to deliver consistent care.

“I actually logged on online and looked at all of them [Guidelines]...”

“I am biased towards this but I think it is a very good way to deliver consistent care.”

Many nephrologists and nurses shared that they tried to align their practice to be consistent with the pathway’s guidelines. One nephrologist commented that he would pick a medication suggested by the guideline over what he would have traditionally preferred. This was in the interest of promoting a standard level of care that was consistent across providers.

“I am someone who in general follows guidelines.”

“If there is a particular medication that I favor and it is not the same as in the pathway,...for the sake of consistency I would want to continue with the pathway.”

When it came to routine management, nurses reported that they were following the guidelines and recommendations of the CKM Pathway in a step-by-step fashion. Using these helped make clinical work easier and it was an incentive for staff to continue using guidelines.

“At the moment, when we are making decisions based on pathway guidelines it is easier.”

“I am certainly using all of the symptom management…so ...like in terms of what the pathway indicates.”

Staff shared that they followed the recommended pathway approach going from non-pharmacological management to low-dose medication to gradual titration and escalation to stronger drugs as needed. The nurses found this approach of the pathway to be sensible and easy to follow.

“For me, we start at the non-medicated...so the cetaphil and all of that”

If a patient was already familiar with the tips and had attempted them to little avail, that would be the indication for the nurses to move to the next step on the pathway, involving pharmacological management and the nephrologist for prescription. Having the pathway’s guidelines helped them know exactly what the next step in treatment would be. When medications became necessary for a symptomatic patient under distress, nurses would look at what, if anything, has been prescribed before and then systematically work from there based on guidelines.

“We tend to go through the other options and do the handout stuff and the things that we can do first and then we will look at what is already prescribed and kind of work from there into the more, you know fluid management or whatever.”

Staff said that using the CKM guidelines enabled them to expand their knowledge base and learn different ways to manage symptoms. They were more comfortable in attempting new interventions for managing symptoms like pruritus, as well as avoiding practices that were not recommended anymore, such as the use of statins for patients as they neared the end of life.

“It certainly has given us more information in terms of different ways to manage symptoms. Maybe more specific in terms of the algorithms.”

“We had started to use low-dose gabapentin which we probably didn’t before.”

“I think there have been some extra things that I, you know I might not have used for things like pruritus control and etc.”

As an example of adherence to pathway guidelines and recommendations, one nurse shared that she differentiated CKM patients from other CKD patients and modified blood work targets appropriately for her CKM patients only when the patient started experiencing target-associated symptoms.

“I treat my blood work targets the same for everybody but with my CKM patients I start to treat it when they are symptomatic.”

Some of the nursing staff also shared that the web-based resources were easily accessible and said navigating the website to access guidelines and symptom algorithms online was straight-forward. One nephrologist said that he particularly valued the methods for pain control that were described on the pathway’s website and nursing staff also appreciated having that access.

“There is also, it is pretty quick to get to I mean, when you just go in and click on the algorithms.”

“I think some of the stuff that is actually quite useful is some of the ancillary methods for pain control that are on there. ”

“I just wanted to say too, I really appreciate the framework that you guys are building and the many things that we can access ourselves as far as information goes.”

Feedback: Suggestions for Improving CKM Pathway resources

One suggestion staff had with regards to improving patient materials was to make them available in more languages. Many of the patients at these clinics were non-native English speakers. Staff identified that some of the most common languages that they encounter were Punjabi, Cantonese, Tagalog, and Arabic.

"We need some non-English ones."

With respect to the CKM Pathway guidelines, some staff members felt the appropriate process flow could be more detailed and instructional. For example, one dietician said she was unsure whether she should be calling a CKM patient whose phosphorus levels were abnormal for symptom assessment or if it was the nurse's responsibility to inform the patient and then recruit the dietician for help in management.

"Does that mean that the nurse calls and assesses symptoms and then refers to me to deal with the diet or am I now doing that conversation to assess all that symptoms at that point?"

One suggestion to improve guidelines was to create a quick facts sheet that covered how certain blood work targets and symptoms were interconnected across guidelines. This came from a nurse who had done in-depth review of the guidelines for managing her patients' symptoms. She had created a list of these subtle points extracted from the pathway's guidelines to know when to treat a certain target to help relieve a seemingly unrelated symptom complaint.

"I actually wrote it out on a sticky note on my desk, about what certain parameters, phosphorous, anemia, what have you, contribute to certain symptoms."

She felt that while these points were in the guidelines, they may require careful reading and attention-to-detail to pick up as it involved making connections across the different guidelines. Having them in one document may help make symptom management more effective. A related suggestion was to create a visual that linked various blood targets and health indicators with the associated symptoms they can precipitate. While staff felt such a resource would help them in remembering, if it is kept simple enough, it would also be used as an educational tool for patients.

4.3 Facilitated shared care with community providers

4.3.1 Increased communication and awareness

One of the aims of the kidney clinics was to enhance partnerships with community healthcare providers, including primary care, home care, long-term care, and palliative care to improve CKM patient care. One nephrologist said that when a patient decided on CKM, she would call the primary care provider, inform them of their patients' decision to be on CKM and not have dialysis, and request the provider to collaborate as an active partner.

"You know like, I am hoping you will be my partner in managing this."

Staff said the CKM Pathway facilitated shared CKM between kidney clinics and community providers, in part by increasing communication and awareness of CKM among family physicians. In the case of one patient, staff described that the family physician was becoming better informed about CKM through the pathway's resources that the patient was sharing.

"She has taken that and actually has let her GP look at it and her GP is looking at it."

Staff described that they were also doing their part in educating their community peers with regards to CKM on the pathway. They were reaching out to the various outlets of community care services and helping the providers help their patients.

“So we are reaching out into the home care, with palliative care, educators there, with the NP and just offering any sort of support.”

Staff felt the pathway was the appropriate resource to share when community providers asked for more information or materials they could reference.

“it goes back to the resource thing...I think that we do have that resource to show them.”

Staff gave examples of referencing the pathway directly when speaking with different teams of community care partners. For example, when patients were transitioning to end-of-life care and the kidney clinics thought it appropriate to engage palliative services, they would speak to the homecare team managing the patient.

“If somebody is on homecare, we have connected with the homecare coordinator and said this person is on the pathway, has chosen conservative treatment, and they are symptomatic. Can we do the connection to the palliative care resource nurse?”

Staff said that CKM pathway was gradually gaining more attention from community providers. As more conversations were happening with kidney staff referencing the pathway, providers were learning and discussing more CKM. As one participant said.

“Some of the home care nurses, the palliative care nurses, are starting to talk about the pathway so that is coming.”

This increased awareness of the CKM pathway was helping to improve shared care between providers which meant more timely, coordinated and reliable care, especially for patients who wanted their care managed in the community setting as much as possible.

4.3.2 Enhancing clinical expertise in family physicians

Staff said the CKM pathway helped engage family physicians who were important partners when kidney clinics needed to access referral services for their CKM patients. If family physicians were not accessible or identified, some nephrologists would act as their primary care physician but this practice was not sustainable. The pathway enabled scenarios where family physicians were aware and responsive:

> ***"I can phone the GP and say…I need your help to engage palliative home care"***

Staff shared examples where the CKM Pathway website and phone contact with kidney clinics was able to guide family physicians to independently manage CKM patients right up to their death. The pathway helped enhance that capacity in community providers to care for patients that couldn't regularly access kidney clinics because of poor health or other logistical reasons. One nurse shared her experience of working with physicians to coordinate care for two CKM patients in long-term care:

> ***"Both of my patients, I don't have too many on the pathway, have been in long term care and that works beautifully."***

She said that she was able to talk with the physicians managing these patients over the phone and directed them to the website and pathway resources. As a result, the primary care physicians were largely able to handle the patients' kidney care independently of the kidney clinic.

> ***"The GPs in long term care –I have had two... they are doing most of it [CKM], all of it practically."***

Another example was with regards to a patient who had chosen not to attend appointments in the kidney clinic but instead follow their CKM with their family physician. Nursing staff said that the family physician was able to provide CKM to this patient using the kidney clinic and the online pathway as a resource. As a nurse participant said:

> ***"I have one and the GP is fairly involved... I still talk to him a bit but ...he [the patient] doesn't come in and doesn't want to, and the GP is really a big partner in this."***

The family doctor was able to work with the kidney clinic and use the CKM Pathway tools and resources to familiarize themselves with CKM and build their capacity. They were able to care for the patient in the community setting, in accordance with the patient's wishes and preferences.

Chapter 4 Summary of findings

Healthcare providers reported the CKM Pathway improved kidney clinic processes by enhancing trust and collaboration between staff members. Nursing staff felt supported, practiced within their own scope and approached nephrologists with pathway recommendations to manage symptoms. Nephrologists increased their prescribing roles to support CKM patients as they became more familiar with the pathway. Staff said the pathway helped them personalize care and the implementation and training on the CKM Pathway made them better healthcare providers overall. The pathway's PDA helped patient decision-making but using the pathway did mean more time invested in CKM. Staff anticipated becoming more efficient with the pathway with continued use.

Providers also evaluated the resources of the CKM Pathway as filling an important gap, and said the use of guidelines facilitated ease and enhanced their practice with new options for symptom management. The pathway's patient materials were easy to use in clinics and beneficial for patients. Staff even used them for non-CKM patients. Staff made some recommendations for improvement of patient and provider resources.

Staff reported that the pathway facilitated increased communication with and more awareness of CKM among community providers. In particular, staff found the pathway helpful in engaging family physicians and building their capacity to co-manage CKM patients in the community.

Chapter 5: Discussion and Conclusion

The objective of this thesis was to evaluate, using qualitative description, the CKM Pathway from the perspective of key stakeholders. We targeted two distinct groups: a) CKM patients/ family members; and b) healthcare providers from four kidney clinics providing CKM using the new pathway. Findings show overlap in their evaluation of the pathway. Patients reported that the pathway supported their decision-making, helped them access effective resources, and promoted patient-centered care. The healthcare providers reported that the CKM pathway improved kidney clinic processes to better support patients, provided resources to standardize CKM, and facilitated shared care with community partners.

These findings are discussed within the context of the published literature under three sections: 5.1) shared decision-making; 5.2) CKM Pathway resources; and 5.3) facilitating patient-centered care.

5.1 Shared decision-making

Patients reported high satisfaction with the shared decision-making process using the CKM Pathway. Patients were well-informed with no decisional conflict. They felt empowered to explore their treatment options before choosing CKM. This is in contrast to most dialysis patients who start dialysis feeling that they did not have a choice [41]. In keeping with the literature, patients on the CKM Pathway described their choice for CKM as choosing quality of life over an uncertain survival advantage and did not view it as choosing life over death [36, 71]. Patients had a more evidence-informed understanding that survival with CKM and dialysis in their circumstances was likely comparable as corroborated by a recent review. 89 studies published between 1976 and 2014 reported survival data on a combined count of 294,921 older patients with ESKD [72]. Although there was a significant lack of studies covering CKM patients (724 patients or 0.2% of the total patients), authors found that 1-year survival of CKM patients was 70.6% (95% CI 63.3-78.0%) which was comparable to 1-year survival on hemodialysis (78.4% (95% CI 75.2-81.6)) and 1-year survival on peritoneal dialysis (77.9% (95% CI 73.8-81.9)). Patients' consistent understanding of the risks and benefits of dialysis and CKM suggests that staff using the pathway had a structured approach to educating patients and were providing standardized information, leading to well-informed decisions. Healthcare providers attributed the patients' understanding of their prognosis with dialysis versus CKM to the CKM Pathway's PDA.

Staff reported that they were able to effectively educate patients using the CKM Pathway and engage comfortably in shared decision-making using the PDA. A large United Kingdom study, the Conservative Kidney Management Assessment of Practice Patterns Study (CKMAPPS), looked at the state of care of older patients with ESKD who had to decide between CKM and dialysis. The CKMAPPS was unlike the present study in that no specific CKM program, intervention, website, or standardized resources were evaluated. As in our study, staff in the CKMAPPS felt they had facilitated informed decision-making for their patients [73]. However, the CKMAPPS found that patients did not appear to have a consistent or accurate understanding of what dialysis could offer in terms of survival. Patients also did not appreciate the impact of hemodialysis on their quality of life. The authors said that this inconsistency was likely influenced by the information provided to patients by staff who worked at different units with various degrees of commitment to and stages of development of a CKM treatment option. The study highlighted the need and importance of a standardized pathway for CKM that is evidence-based with accessible patient resources, and the need for specialized CKM training for staff. The CKM Pathway seems to fill the gap in decision-making identified in the CKMAPPS by facilitating a more consistent and evidence-informed understanding of the benefits,harms, and impact of dialysis versus CKM.

Another key finding of the CKMAPPS [73] was the need for better staff education and training to facilitate shared decision-making and end-of-life conservations. The study highlighted that good communication skills were an essential requirement to working with older CKD patients. Staff in our study also commented on the need for additional training to support conversations around CKM.

ACP workshops were part of CKM pathway implementation, rated highly by staff and identified as helping them become better facilitators of difficult CKM conversations. ACP has long been recognized as essential in the care of older ESKD patients [74,75] but patients, both on dialysis and CKM, still report not having a discussion about future plans with care providers [76]. ACP is an integral component of the CKM pathway. As part of the implementation, full-day collaborative training events helped staff develop better language and terminology to use with patients. Hands-on practice helped them feel more prepared to have those difficult conversations around planning a good death.

The nursing staff led the operationalization of the CKM Pathway by delivering CKM in clinics with the majority of nephrologists supporting their work. Nurses reported that working relationships and trust improved with their nephrologists. This is similar to the findings from the Canadian Collaborative Group for the Prevention of Renal and Cardiovascular Endpoints Trial (CanPREVENT), a study on managing CKD in nurse-led, physician-supported clinics [77]. It also reported good collaboration and improved teamwork between nurses and physicians, highlighting that structured initiatives can encourage better collegiality between staff.

Staff also reported an increased focus on symptom management. Nephrologists, in order to better support their nursing staff, expanded their roles by prescribing for common symptoms. Studies have shown that early coordinated focus on symptom management of CKD patients with targeted education improves outcomes [78]. ESKD patients sometimes report a high symptom burden [79**]** so active symptom management is critical and was facilitated effectively by the CKM Pathway.

5.2 CKM Pathway resources

We sought feedback on the CKM resources as they were an essential component of the CKM Pathway, unevaluated prior to this study, and patient resources are increasingly recognized as an integral part of modern healthcare [80]. Both patients and healthcare providers had similar positive feedback. Staff reported that the patient resources were easily integrated into clinical care: they were able to use them frequently and readily whenever patients reported symptoms. Healthcare providers said that patients valued the resources for their educational benefit and for reviewing what clinic staff had discussed during their appointments. Likewise, patients also reported that healthcare providers used the CKM materials during clinics to facilitate conversations with patients. Patients said they needed these resources to take home as reminders. Research has shown that quality patient education resources improve patient outcomes [81]. CKM patients described the pathway resources as accessible in terms of reading level and some reported reading through them multiple times. It is acknowledged that print resources must be developed in accordance with the literacy levels of target audiences [82] and patients felt the CKM Pathway achieved this. Studies show that CKD is associated with substantial cognitive decline [83]. Staff acknowledged that their patients had memory and comprehension challenges and required specialized teaching. Staffs' and patients' use of the CKM Pathway resources for building CKM knowledge and capacity suggests the resources are accessible and appropriate for the needs of this patient population.

One staff member described an instance where a patient reading through the entire CKM booklet became overwhelmed. As a result, we probed the patients we interviewed about whether they experienced similar thoughts. We did not find this among the patients we interviewed, suggesting it was not a regular occurence. Most patients did not find the information in the CKM booklet as stressful. Rather, patients and caregivers described using the book as a valuable reference. The vast majority of what patients and providers provided as evaluations of the pathway resources were positive and complimentary. The implication is that the design of the patient resources on the CKM Pathway was appropriate, acceptable and useful from the perspective of two groups of key stakeholders. Evaluating the pathway's resources from the perspective of community providers is also necessary and will be undertaken in the near future.

5.3 Facilitating patient-centered care

A parallel between patient and healthcare provider evaluations was in the way the pathway was perceived to impact in the community. The third theme in the patient results, ‘promoting patient-centered care’, was similar to the provider theme, ‘facilitating shared care with community providers’. Patient-centredness is a dimension of quality healthcare in Canada and is the idea of being considerate and responsive to patient preferences when delivering care [84]. Patients felt that the CKM Pathway engaged their family physicians in their CKM. Patients welcomed having their family physicians take on a larger role in their CKM because as their disease progressed, it became more difficult to attend kidney clinics. Patients highlighted travel as a barrier to seeking care. This is a common concern for patients with ESKD [85]. More informed family physicians meant that patients could rely on them and in turn not be as dependent on the hospital-based kidney clinics. This improved overall satisfaction with and access to care for those patients who preferred care from their family doctor because they were too ill to attend the kidney clinics. Staff described caring for patients who could not make it routinely to clinic and who relied exclusively on community-based care. Healthcare providers evaluated the pathway as improving the connection between the kidney clinics and community healthcare providers, particularly with family physicians, to facilitate community-based care that was on par with the care that kidney clinics were providing.

Patients noted that the formal letters sent to their family physicians when they chose to be on the CKM Pathway also helped engage their doctors. The online CKM Pathway platform allowed family physicians to access CKM resources and better support their patients. Nursing staff also felt that after pathway implementation, there was more communication as they knew more to relay to family physicians. All participants felt that the pathway served as a central resource to direct community providers to. Although none of the patients we interviewed were being managed exclusively by their family physician, there were examples provided by nursing staff where family physicians were doing all of the CKM, guided and supported by the CKM Pathway with additional support provided as needed by the kidney clinics via telephone. Studies looking at the management of advanced CKD and providing CKM in primary care are sparse but one qualitative study found that family physicians were willing to support or lead CKM for their patients, under the guidance of kidney clinics [86].

5.4 Limitations

This study has a number of limitations. Because of its qualitative nature, the findings are not necessarily generalizable to other conservatively managed patients or other kidney clinics. There was a training component associated with the implementation of the pathway involving 3 full-day workshops and monthly teleconference meetings with kidney clinic staff over a 12 month period. Clinic administration was fully cooperative and staff felt supported in their training, which contributed to the positive results of this study.

The patients interviewed for this study were proposed as potential candidates by their clinic nurses and their suitability reflected their functional and cognitive status and their illness trajectory. This may have led to sicker patients not being given equal opportunity although nurses did forward names of suitable family caregivers in cases where the patient was deceased, too sick or otherwise not able to participate. Patient perspectives were the focus of this study and family members provided support. Patient and family perceptions may differ and this was not systematically examined.

Interviews were done once with each patient/family and provided snapshots of their experience and opinions which may change over time. Since all patients were recruited from the clinics, we got patients who were predominantly reliant on the kidney clinics. We did not get patients who were primarily managed in the community. While we heard from staff about such patients, none of our participants fit that category. This will be the focus of future work to gain a broader perspective on the pathway's resources and evaluate how family physicians are interacting with the CKM Pathway to deliver care for their patients. All patients were also white and this lack of diversity may not represent all voices of older individuals with ESKD in Alberta. Finally, because the pathway was implemented about 8 months prior to commencing the qualitative evaluation, some staff members did not have many opportunities to familiarize themselves with all the pathway's various components. Waiting longer before conducting the evaluation may have given staff more opportunities to experiment with the pathway and add to their evaluations.

5.5 Conclusion and Future Directions

The findings from this study suggest that the CKM Pathway helped improve the decision-making and care of patients with ESKD who were unlikely to benefit from dialysis. Kidney clinic staff evaluating the CKM Pathway felt it improved kidney clinic processes and facilitated better care through the CKM Pathway's tools and resources. Patients also found the CKM resources accessible and were satisfied with their decision for CKM and their care using the CKM Pathway in kidney clinic settings. These findings corroborate and complement each other. It increases confidence in the content and structure of the CKM Pathway as being stakeholder-friendly. Both patients and providers reported the CKM Pathway played a role in facilitating patient-centered, shared CKM between community providers and kidney clinics and in engaging primary care as a partner in the provision of CKM. They shared that there was gradual and increasing awareness of the CKM Pathway among family physicians and other community providers. Future work should assess and evaluate the pathway from the community provider perspective, especially primary care physicians. An engagement strategy and implementation protocol should be developed to formally introduce the pathway in the community setting and provide the necessary education and training to get providers comfortable and familiar with the CKM Pathway. Studies can then seek feedback from primary care partners utilizing the pathway. Additionally, future work with CKM patients should seek to recruit from the community setting to assess how the CKM Pathway may be operating outside of hospital-based kidney clinics. The results from such studies will help inform the continued development, spread and scale of the CKM Pathway across Alberta and beyond.

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Appendix

A) Facilitator guide for Focus Groups

FOCUS GROUP FACILITATOR GUIDE: CKM AND PDA

Time	Question	Start Time/ Finish Time	Comment/ Observations
10:00 am (10 mins)	Welcome ▪ Introductions ▪ Consent forms ▪ Discuss goals of focus group ▪ Briefly outline the plan for the next 2 hours		
SECTION 1 – CKM GUIDELINES (17 MINUTES) **OBJECTIVE:** EVALUATE USABILITY AND HELPFULNESS OF CKM GUIDELINES FROM PROVIDER'S PERSPECTIVE (BARRIERS AND FACILITATORS)			
10:10 am (1 mins)	Q0. Temperature Check: How comfortable are you with the guidelines? a. Very comfortable b. Somewhat comfortable c. Not very comfortable d. Other		
10:11 am (10 mins)	Q1A. Tell us about - which components you are using and not using? Prompts: Why? ● Symptom management and algorithms ● Medication ● CKD guidelines ● Using as needed: *Have you added to your practice something recommended by the guidelines that you didn't do before?* ● *How do you know when to supplement your practice with the guideline recommendations?*		

	● When would you decide not to use the guidelines? – Could you give some examples? Prompts: ● Difficult to use in clinic setting ● Navigation issues ● Too much information: *How can we make information more manageable (one-pager guidelines)?*		
10:21 am (7 mins)	Q1B. What could be improved?		
Section 2 – CKM patient Education Materials (12 minutes) **Objective:** Evaluate CKM patient education materials from the provider's perspective			
10:28 am (4 mins)	Q2. In what ways are the materials meeting the needs and preferences of patients/families? – Do you have examples?		
10:32 am (2 mins)	Q3A. In what ways are the materials NOT meeting the needs and preferences of patients/families? – Do you have some examples? Prompts: ● Patient stories ● *Crisis plan: Feedback on a one-pager with a CKM blurb and an interactive component explaining patient choice for the green sleeve*		
10:34 am (3 mins)	Q3B. What could be improved? Prompts: ● Language ● Too much information		
10:37 am (3 mins)	Q4. How difficult or easy is it for you to use the patient education materials? Why? Prompts: ● Patient literacy ● Time strain		
Section 3 – Delivery of CKM Care (10 Minutes)			

OBJECTIVE: ASSESS FACTORS THAT ENABLE USE OF THE CKM PATHWAY TO CARE FOR PATIENTS			
10:40 am (5 mins)	Q5A. In your clinical setting- what factors encourage you to use the CKM pathway? ● Resources in own practice/clinic ○ *How do nurses prioritize information to internalize?* ● Support from your colleagues (*Nurse autonomy vs. physician disengagement*) ● Philosophy ● Time strain/usability in clinical setting ● User friendliness		
10:45 am (5 mins)	Q5B. Conversely – what factors discourage or get in your way of using the CKM pathway? Prompts: ● Time strain/usability in clinical setting ● User friendliness ● Accuracy		
SECTION 4 – COMMUNITY ENGAGEMENT (15 MINUTES) **OBJECTIVE:** ASSESS HOW THE INTERACTION BETWEEN DIFFERENT CARE TEAMS AND COMMUNITY CARE PROVIDERS HAS BEEN IMPACTED			
10:50 am (13 mins)	Q6. How has the pathway affected your interactions and engagement with: a. Patients and families; *Does pathway address non-kidney death?* b. Community; *Suggestions for building community knowledge and capacity?* c. Palliative Care; *Do you find palliative care taking ownership of patients?* d. GP; *Do you think pathway would meet GP needs to provide CKM care?* Prompt:		

	- How has interaction evolved since first implementing pathway? - *Can you see the pathway resolve GP and RIC clinic roles?*		
11:03 am (2 mins)	Q7. Blank Card - Any other comments or additional information- that you think might be helpful? - *Has CKM team been effective in communication?*		
11:05 am	**5 minute Break (8-10 Minutes)**		
Section 5 – PDA questions (35 Minutes) **Objective:** Assess the PDA using IPDAS criteria: Choice-Made Attributes 1.Knowledge 2. Accurate Risk Prediction 3. Informed Value-Based choice			
11:15 am (9 mins)	INTRODUCTION/ WELCOME BACK Q8. What are most important information pieces and the least important info pieces you use in the PDA? What is missing? Prompts: - Are there any pieces that should be tossed? - What are you doing with long answer pieces? - How well does the PDA describe the prognostic outcomes and treatment options - Do you have any patient stories?		
11:24 am (3 mins)	Q9. What concerns do you have regarding biases, if any, in the PDA? Prompts: - With respect to probabilities - With respect to treatments - With respect to values		

11:27 am (5 mins)	Q10. Are there any values that particularly resonate with your patient and their families? Which ones & why? Prompts: ● Hospitalization, Surgery, Control of time, Travel		
11:32 am (3 mins)	Q11. Are there any values that are missing or should be added? Prompts: ● *How can this be incorporated?*		
11:35 am (10 mins)	Q12.For patients having to make a decision - what has been most helpful and least helpful in the PDA for the decision-making process? Prompts: ● Did the PDA help resolve any decision-making challenges? – would someone have an example to share? ● *Has PDA given patient a voice in decision making; how?* ● Does anyone have an example of where it failed or it actually complicated the decision-making process?		
11:45 am (5 mins)	Q13.Overall- how user-friendly is the CKM-PDA tool? Prompts: ● Visuals, Relevance of content, Length/detail ● *What would help PDA use in clinic, given time constraints?* ● *Is it a valuable use of your time?*		
11:50 am (10 mins)	▪ Wrap Up & Thank you ▪ Consent Reminder ▪ Questions ▪ Next Steps		

B) Facilitator guide for CKM Patient Interview

<table>
<tr><td colspan="3">CKM PATIENT INTERVIEW QUESTIONS
<i>To gain an understanding of barriers and facilitators experienced by patients on the CKM pathway and their families in managing their condition</i></td></tr>
<tr><th>Time</th><th>Question</th><th>Comment/ Observations</th></tr>
<tr><td>00:00
(10 minutes)</td><td><u>Welcome</u>
▪ Introductions
▪ Consent forms
▪ Discuss goals of interview
▪ Briefly outline the plan for the next 1 hour</td><td></td></tr>
<tr><td colspan="3">IMPACT ON CARE EXPERIENCE
<i>To gain an understanding of how the CKM pathway is impacting the care experiences of patients and their families</i>
1) <i>Patient making informed decision</i>
2) <i>Who is involved in care</i></td></tr>
<tr><td>00:10
(7 mins)</td><td>Q1: We would like to start with… Comparing conservative kidney care and dialysis, how do your experiences/understanding of each compare?
i. Benefits/drawbacks – What about CKM/dialysis that caught your attention/sold you?
ii. Perceived differences – What aspects will increase your Quality of Life?</td><td></td></tr>
<tr><td>00:17
(6 mins)</td><td>Q2: Ideally, what role would you like your family physician to play in your care?
i. Why is this important to you?
ii. What has been your family physician’s role? (Concerns)</td><td></td></tr>
<tr><td>00:23
(7 minutes)</td><td>Q3: Who provides the most support with your care? How have they provided support? (Family, GPs, RIC staff…)</td><td></td></tr>
<tr><td colspan="3">PATIENT EDUCATION MATERIALS
<i>Explore how components of the CKM pathway (patient education materials) has affected CKM care</i></td></tr>
<tr><td>00:30
(6 mins)</td><td>Q4: Could you tell us about what (CKM patient) education materials you were provided with by the clinic staff?
i. How have you learned about your kidney disease?
Has anyone read education materials for you?</td><td></td></tr>
</table>

<table>
<tr><td>00:36
(7 mins)</td><td>Q5: Of the educational materials that you have identified, could you tell us about which ones you are <u>using</u> and <u>not using</u>? (or find helpful/not helpful) Why?
i. What might be helpful in learning about your disease; how can we get this to you?
ii. Control, visuals, completeness</td><td></td></tr>
<tr><td>00:43
(5 mins)</td><td>Q6: Next we would like to focus on talking about how you manage your symptoms… Let’s start with hearing about what helps you manage your symptoms…
i. Handouts/ website
ii. Calling a care-giver
iii. Other (my partner, friend)

Why are these modes preferred? (Is the mode related to the nature of the symptom)</td><td></td></tr>
<tr><td>00:48
(3 min)</td><td>Q7: What symptoms have you been least able to address? Most? (Why)
What is it about symptom that makes it troublesome?</td><td></td></tr>
<tr><td colspan="3">VALUE AND USE/USER FRIENDLINESS OF WEBSITE
<i>Explore how the of CKM pathway can further improve patient experience with CKM care</i>
<i>1) What’s working well (facilitators)</i>
<i>2) What’s not working well (barriers)</i>
<i>3) What could be improved</i></td></tr>
<tr><td>00:51
(8 mins)</td><td>Q8: Lastly, we would like to talk about the Website and your experiences with it…
How has the (CKM) website helped you in your kidney care?
If YES…
i. In what ways? (Decisions, symptom management, care planning…)
ii. Website related (Visuals, presentation)
iii. Relevance of content
iv. Easy use (navigation)

If NO, just a tool…
i. Has anyone in your care team used the website (awareness, lack of support)?
ii. Lack of awareness or knowledge of website
iii. Access</td><td></td></tr>
</table>

	iv. Computer literacy v. Patient condition related (severity)	
	CLOSING	
00:59 (5 mins)	Q9: Is there something else that you think we need to know about your care management, staff or anything else: i. More support ii. More education iii. Home care/GP involvement	
01:04 (5 mins)	Wrap Up & Thank you ▪ Reflect on Experience (follow up on brackets) ▪ Next Steps ▪ Reimbursements	

C) Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Pages 15-16
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Pages 15
3. Occupation	What was their occupation at the time of the study?	Page 16
4. Gender	Was the researcher male or female?	Page 16
5. Experience and training	What experience or training did the researcher have?	Page 15-17
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Page 17 .
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Page 17
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Page 15-17

Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Page 14-15
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Pages 14, 17-18
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Pages 17-19
12. Sample size	How many participants were in the study?	Page 28, 44
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Page 18
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Pages 17-19
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Pages 17-19
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Page 28, 44
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Additional file and page 20
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 18-19
20. Field notes	Were field notes made during and/or after the interview or focus group?	Page 18
21. Duration	What was the duration of the interviews or focus group?	Page18-19
22. Data saturation	Was data saturation discussed?	Page 23
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Page 22, 23

Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Page 15-16
25. Description of the coding tree	Did authors provide a description of the coding tree?	No
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 28, 44
27. Software	What software, if applicable, was used to manage the data?	Page 23
28. Participant checking	Did participants provide feedback on the findings?	Page 23-24
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Pages 28-64
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes, there was. Pages 28-64
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes. they were. Pages 28-64
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Discussion of major and minor themes Pages 28-64

D) Chapter 3 Patient Themes

Theme	3.1 Supported facilitated decision-making	3.2 Provided effective CKM patient resources	3.3 Promoted patient-centered CKM
Sub-themes	3.1.1 Enabled early treatment discussions 3.1.2 Helped patients realize they had a choice 3.1.3 Empowered patients to explore their options 3.1.4 Provided patients with useful prognostic information 3.1.5 Helped patients reflect on their values 3.1.6 Eliminated decisional conflict	3.2.1 Resources were accessible, patient-friendly and useful as a reference 3.2.2 Helped patients explain their choice to others 3.2.3 Served as clinic aids and reminders 3.2.4 Supported disease and symptom management 3.2.5 Helped with knowing what to expect	3.3.1 Engaged family physicians as desired by patients 3.3.2 Facilitated coordinated, timely, community-based care 3.3.3 Improved working relationships between healthcare providers

E) Chapter 4 Healthcare Provider Themes

Theme	4.1 Improved kidney clinic processes and patient care	4.2 Addressed a gap in CKM resources	4.3 Facilitated shared care with community providers
Sub-themes	4.1.1 Increased collaboration and trust between clinic staff 4.1.2 Facilitated staff professional development 4.1.3 Provided an effective CKM-specific PDA to facilitate decision-making 4.1.4 Enhanced personalized symptom management	4.2.1 Provided useful patient resources 4.2.2 Provided guidelines that standardized best-evidence practice 4.2.3 Provided effective patient materials	4.3.1 Increased communication and awareness 4.3.2 Building clinical expertise in family physicians

F) Challenges/Suggestions for Improvement

Theme	**Suggestion**
3.2 Provided effective patient resources	- One family member requested adding more clarity to the Crisis management plan -Another request was color-coding the CKM Booklet to facilitate easier referencing for patients
4.1 Improved kidney clinic processes and patient care	-Staff reported spending more time for CKM using the CKM Pathway which improved quality of care but presented a challenge with time constraints -Staff felt continued use of the pathway will build more familiarity, improve their efficiency and ameliorate the time constraints
4.2 Addressed a gap in CKM patient education	-Staff requested more translations of patient materials, and suggested adding a quick-facts sheet