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Identification of core components and implementation strategies for a Conservative Kidney Management Pathway across a complex, multisector healthcare system in Canada using World Cafés and the Theoretical Domains Framework

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ABSTRACT

Objective Develop a Conservative Kidney Management (CKM) Pathway for patients unlikely to benefit from dialysis. We sought to determine (1) core components of care and (2) implementation strategies across a multisector healthcare system.

Design We used the Knowledge to Action Cycle and the Theoretical Domains Framework to identify barriers and facilitators to CKM. Activities included a current state assessment, World Cafés, interviews, focus groups and readiness for change assessments.

Setting A provincial initiative in Alberta, Canada.

Participants 282 participants were purposively selected to reflect those involved in the care of patients receiving CKM. This included policy-makers, multidisciplinary healthcare professionals, patients and their family.

Main outcome measures Theoretical domains linked to pathway content and implementation strategies.

Results Environmental context and resources, social/professional role and identity, knowledge and social influences were the most influential behaviour change domains identified. The most effective strategies for facilitating behaviour change were identified to be education, training, environmental restructuring and modelling. Core components of care were determined to be guidelines for treating symptoms and disease complications consistent with the philosophy of CKM, timely communication of the choice for CKM, coordination with community services, crisis planning, advance care planning and tools to enhance patients' capacity for self-management and shared decision-making. This resulted in development of Alberta's CKM Pathway, an interactive, digital, decision-support tool consisting of: (1) a patient decision aid; (2) a patient/family portal; and (3) a healthcare professional portal, where all resources can be freely accessed.

Conclusions The pathway was codesigned by patients and healthcare professionals and involves tailor-made combinations of tools to address unique patient needs and system-community circumstances. Most of the strategies are adaptable to local context and are likely translatable to the implementation of sustainable CKM in other national and international jurisdictions.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This work was built around behaviour change theory and targeting implementation strategies to address identified barriers.
⇒ The project and subsequent Conservative Kidney Management (CKM) Pathway were codesigned with extensive input from and attention to the needs of a diverse group of end users across a large healthcare system.
⇒ This work integrated a rigorous theory-based knowledge translation approach to identify facilitators and barriers to CKM. This will help to understand the mechanisms of change, including how and in which contexts interventions are effective and will inform further scale and spread of CKM nationally and internationally.
⇒ Participation of patients living with frailty was challenging and at times family members were required to speak from the patient perspective when patients were unable to attend engagement sessions.
⇒ The methods used in this work were specific for identifying opportunities for improvement in CKM within Alberta, Canada; however, many of the identified strategies are adaptable to local context and are likely translatable to the development and implementation of sustainable, quality CKM in other national and international jurisdictions.

INTRODUCTION

Dialysis is a form of life support aimed at extending life and/or restoring health and quality of life for people with end-stage kidney disease (ESKD). However, starting dialysis

confers neither a survival nor a quality-of-life advantage for some, especially patients older than 75 years with multimorbidity and/or frailty. These patients often experience accelerated functional and cognitive decline after starting dialysis without receiving a survival advantage or an improvement in symptom burden.[1–5] Moreover, they are subjected to substantial treatment burden and their care is associated with high rates of hospitalisation and aggressive procedures, which are often poorly aligned with their preferences or goals of care.[6]

Conservative (non-dialysis) kidney management (CKM) is a treatment option for patients with ESKD who are unlikely to benefit from dialysis and/or who choose to not start dialysis.[7] Based on the principles of patient-centred care and shared decision-making, CKM focuses on optimising quality of life, symptom management and advance care planning, while continuing appropriate interventions to delay the progression and complications of the disease.[7] When managed conservatively, older patients with multimorbidity and/or frailty can live as long as patients who choose to start dialysis, but with better preservation of function, decreased symptom burden, fewer hospitalisations and better quality of life without the substantial burdens and complications associated with dialysis.[1–4]

The international nephrology community recommends that for patients unlikely to benefit from dialysis, dialysis should not be the default therapy and advocates strongly for the provision of quality CKM.[7] However, despite the growing recognition of the potential harms of dialysis in an increasing proportion of older patients with multimorbidity and/or frailty, it remains uncommon for these patients to forgo dialysis. In a recent study involving predialysis patients identified as high risk for death within the next year, physicians voiced a preference for CKM for only 13%.[3 7] These decisions tended to be limited to patients with an extremely poor prognosis such as those with advanced cancer or dementia. Even for those aged≥85 years, dialysis continues to be the default therapy.[8 9] Only 14.5% of patients with ESKD receiving care within the US Department of Veteran Affairs had a documented decision against dialysis, although this number likely over-represents the percentage of patients who ultimately forgo dialysis.[8] Patients receiving USA Medicare appear even less likely to forgo dialysis, favouring higher intensity care despite poor prognoses.[9]

These findings are consistent with reports that most older patients on dialysis feel they are not fully informed of their treatment options, rarely recall being given the option for CKM, have little input into the decision to start dialysis and that dialysis as a treatment choice is often poorly aligned with their preferences.[10 11] Even in countries such as Canada and Australia where rates of 'untreated' older patients with ESKD, defined as an outpatient estimated glomerular filtration rate of 15 mL/min/1.73 m or less and who do not receive renal replacement therapy (dialysis or kidney transplant), are reported as much lower, these data do not represent patients who ultimately do not receive dialysis.[12 13] The reality is that patients over the age of 75 years are the most rapidly growing group of patients starting maintenance dialysis, despite the increasing prevalence of multimorbidity and frailty with advancing age.

The 2018 Global Kidney Health Atlas survey showed a wide variation in capacity and structures for CKM worldwide, with low accessibility and suboptimal quality, particularly in low-income countries.[14 15] CKM is one of the five themes in the International Society of Nephrology's recently developed Strategic Plan for Integrated Care of Patients with Kidney Failure to facilitate the global uptake and integration of CKM.[16] Recent work has highlighted that clinicians lack an understanding of the core components and benefits of CKM and/or how to provide this care, with varied and often limited knowledge and skills to navigate the complex path from the decision to forgo dialysis through to the end of life.[17]

To address this critical gap in care, a 4-year project was initiated in 2015 to develop, implement and evaluate a CKM Pathway across Alberta, Canada.[18] The goal was to (1) ensure that dialysis and conservative treatment decisions reflect the priorities and preferences of individual patients and are grounded in realistic expectations about prognosis and the benefits and harms of treatment and (2) provide sustainable, high-quality, evidence-based care for those patients who choose CKM in a coordinated, standardised and equitable manner across Alberta, Canada.

This manuscript describes the first phase of this work that involved the rigorous, multifaceted development of a unique and innovative provincial CKM Pathway that identifies both the components and processes of CKM and the strategies required for implementation across a complex multisector healthcare system and targeted towards addressing barriers.

METHODS

Participants and setting

Healthcare in Alberta, Canada, is provided to its 4.4 million residents through one healthcare system, Alberta Health Services. Specialist kidney care in Alberta is provided under the umbrella of a provincial programme, Alberta Kidney Care (AKC), that is divided operationally into AKC North and AKC South. The care of patients with advanced chronic kidney disease (CKD) within the province is coordinated by eight multidisciplinary CKD clinics staffed by nephrologists, registered nurses, clinical nurse educators, social workers, pharmacists, managers and administrators.

We undertook a multidisciplinary stakeholder assessment to (1) ensure participants reflected the full spectrum of end users for the CKM Pathway; (2) establish strong engagement and support across the provincial healthcare system for the initiative; and (3) develop a provincial steering committee to govern the project. Participants were therefore purposively selected to maximise variation and reflect the diverse mix of stakeholders involved in

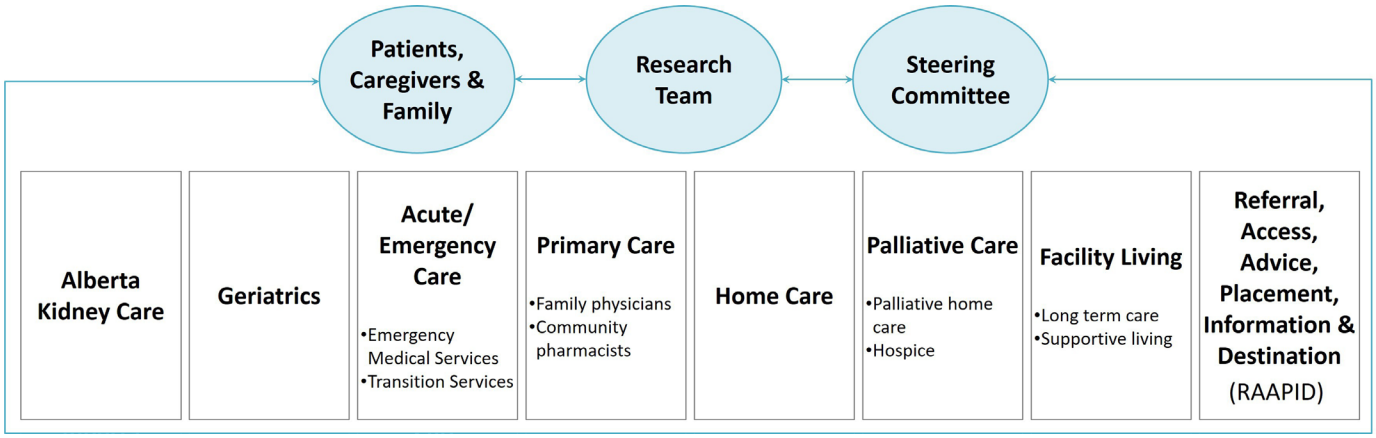

Figure 1 Stakeholder engagement. RAAPID is a provincial call center that serves as a single point of contact for care providers which facilitates urgent healthcare advice and when necessary, coordinates admission and repatriation of patients.

the care of patients receiving CKM. This included interdisciplinary CKD clinic staff from all eight CKD clinics along with patients, family members, policy-makers and interdisciplinary healthcare professionals across the continuum of care including local opinion leaders within primary, geriatric, palliative and emergency medicine (see figure 1). The steering committee was made up of two members from each representative stakeholder group (figure 1) to ensure all research activities remained aligned with patient and healthcare provider needs.

Study design

Implementing CKM required changes in individual and collective behaviour. This required an understanding of the influences on behaviours in the context in which they occur. We therefore used an integrated knowledge translation (KT) approach that followed the Quality Enhancement Research Initiative Framework and the Knowledge to Action Cycle (KTA) to assure adequate development, refinement and evaluation for successful large-scale implementation.[19–21] Using these frameworks, we merged the KTA[21 22] with the Theoretical Domains Framework (TDF)[23–26] to assess, map and influence provider behaviour in the context of individual, organisational and systems level factors. Figure 2 illustrates the research methods and activities used, aligned with each component of the KTA cycle. These methods included stakeholder assessment, literature review and environmental scan, World Cafés, interviews, focus groups and readiness for change assessments as described below.

Data collection

A review of the literature and an environmental scan were conducted to identify gaps in knowledge and skills, assess variations in CKM practice and identify existing resources for CKM across the provincial healthcare system. This involved interviewing CKD clinic staff and managers regarding staffing mix, CKM resources available for staff and patients, processes to identify and assess patients appropriate for CKM and access to community resources.

Stakeholders, including patients and family members, from across the province were invited to participate in one of the two World Cafés to (1) determine the core components of CKM that would require integration into a CKM Pathway; (2) identify local and system-specific barriers and facilitators to provide quality CKM; and (3) explore meaningful strategies that would achieve changes in behaviour required for the provision of CKM. A World Café is a valuable participatory method that enables participants to interact and build relationships, gather and share experiences, explore issues, create shared visions and translate them into action steps.[27] Participants moved between four tables every 30 min in groups of six to eight to discuss each of four questions (see box 1). Groups were rearranged every round (instead of travelling as a

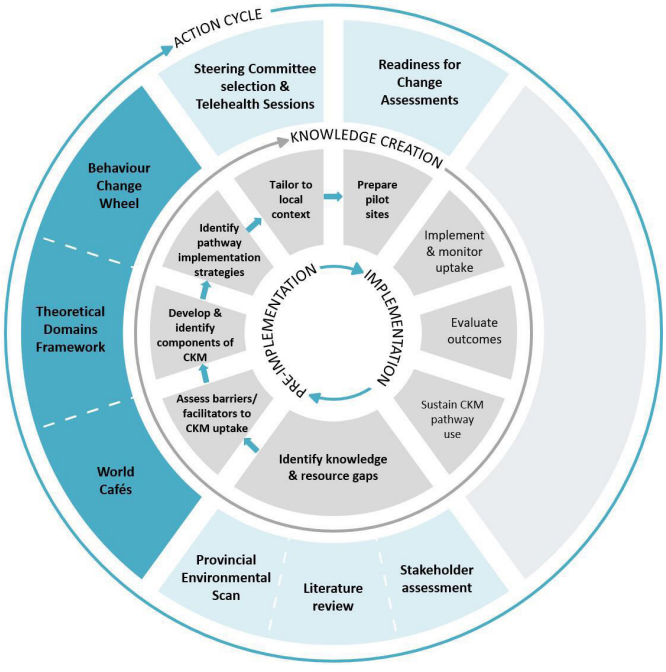

Figure 2 Knowledge to Action Cycle and research methods used for the development of the Conservative Kidney Management (CKM) Pathway.[19–21]

Box 1 World Café questions

⇒ Taking the perspective of a healthcare provider or caregiver, what makes providing conservative kidney management (CKM) a challenge?
⇒ Taking the perspective of a patient receiving CKM (or family member), what challenges do you experience in making that decision, managing your care, and interacting with your care providers?
⇒ What is working well in terms of CKM?
⇒ What opportunities or ideas could be implemented to improve CKM?

cohort). A stationary host facilitated the conversation at each table and summarised the previous discussion, while an additional facilitator documented and displayed all ideas on flipcharts as they were generated during discussion. The goal was to change the dynamic of each table at every round to spark new thoughts, build on the prior conversation and maximise the breadth and depth of idea generation. At the end of the four rounds when all participants had answered all four questions, key insights and themes were shared with the entire group.

Relevant domains were further explored in 3 follow-up interdisciplinary focus groups and 10 semi-structured patient/family interviews. Interviews and focus groups were audio recorded, transcribed verbatim and field notes were taken. Patient/family interviews were conducted either in their homes, in a healthcare clinic or over the phone.

Analysis

We used the TDF and the behaviour change wheel (BCW) to categorise the barriers and facilitators to the provision of CKM identified through the World Cafés, focus groups and interviews.[23–26] The TDF is a synthesis of 33 theories of behaviour and behaviour change clustered into 14 domains aimed to answer the question: 'What conditions internal to individuals and in their social and physical environment need to be in place for the required changes in behaviour?', in this case, the provision of CKM. At the centre of the BCW are three components: capability, opportunity and motivation that interact with each other to drive behaviour (COM-B)[25] (see figure 3). Imbedded in the COM-B core components are the 14 TDF domains, which facilitate a comprehensive analysis of the possible influences on behaviour. The BCW was used to identify implementation strategies (or intervention functions) most likely to address the identified barriers, thus promoting uptake and optimal use of the CKM pathway.

Two researchers independently analysed the World Café and interview data deductively, using content analysis. Transcripts were coded line by line, considering all responses in relation to the definitions of the 14 TDF domains and/or the constructs within the domains and then attributed to one or more of the domains.[28] Disagreements were resolved by consensus-based discussion between the coders. When consensus could not be reached, discussions were held with the larger research team. Using an iterative approach to data collection and analysis, participants were provided numerous opportunities to provide feedback on evolving themes as they were being identified and for interviewers to refine the interview questions.

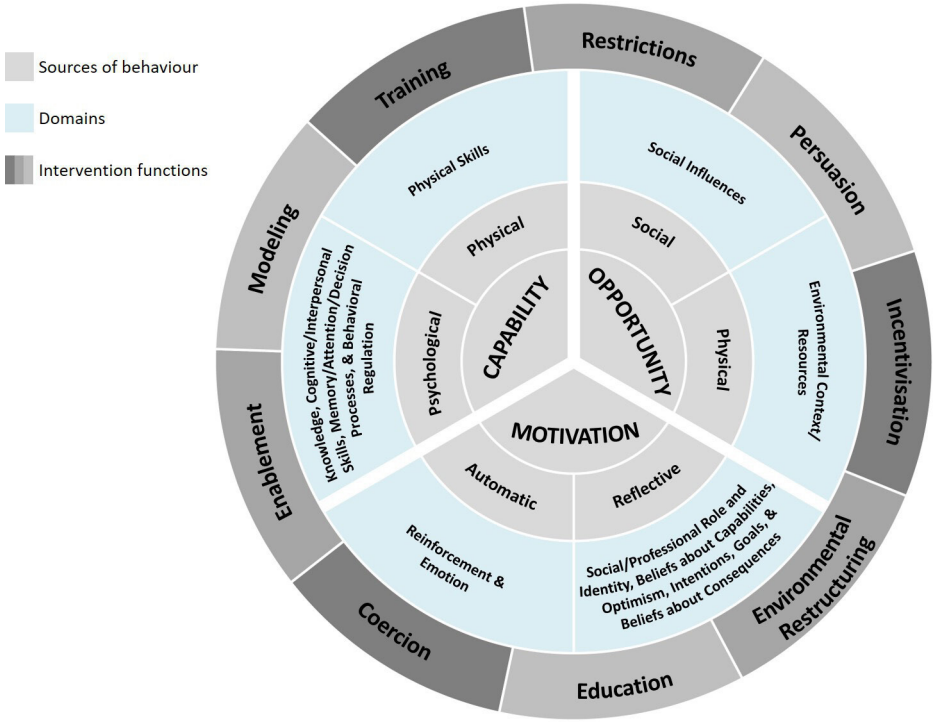

Figure 3 The behaviour change wheel and Theoretical Domains Framework.[25]

The frequency of TDF domain coded phrases was calculated to determine those most reported. Two reviewers independently mapped the results onto the COM-B and related intervention functions of the BCW, to generate the proposed strategies for the implementation of a CKM Pathway across Alberta.

The content components within the CKM pathway were generated using the results of the literature review and environmental scan and incorporating a codesign approach that involved end users. Once the proposed CKM Pathway content components and implementation strategies were identified, a readiness for change assessment was conducted to prepare sites for CKM pathway implementation and to tailor the implementation strategies to meet local context.[29] The managers at each of the implementation sites completed a screen tool with the lead nephrologist (SD) to determine the most appropriate, validated readiness assessment survey tool to administer to all CKD staff. Based on the screening results, the Organizational Readiness for Change Social Agency Staff survey[30] was completed as an online survey by all CKD clinic staff and nephrologists in AKC North. This tool focuses on motivations for change in terms of programme and training needs, resources, personality attributes of programme leaders and staff and organisational climate to understand the most relevant factors involved in implementing changes to a programme.[31]

Simultaneously, brainstorming within the research team and local stakeholder working groups was used in combination with the TDF results to refine and develop strategic applications at the local level. This involved video/teleconferences to ensure input from patients and other stakeholders in rural areas, especially those who were unable to participate in the World Cafés. For example, the implementation strategy of 'Educational meetings' was refined to identify specific educational objectives for target audiences based on the knowledge and skill gaps identified through the readiness for change surveys, provincial environmental scan, World Cafés and literature review.

The final proposed CKM Pathway components and implementation strategies were shared and agreed on in a provincial telehealth session with participants from the World Cafés and the broad stakeholder groups located across Alberta. The candidate pathway components and implementation strategies were then presented to and approved by the project steering committee as being most likely to enhance CKM provincially and to support behaviour change in the local context.

Patient and family involvement

Patients and family members were extensively involved throughout this work; they were involved in the qualitative components of the project and the iterative process of defining the content components and implementation strategies required for the digital CKM pathway. The kidney clinic nurses identified patients and family member participants from their practice, considering factors such as the patient's physical, emotional and cognitive health. Those patients identified as suitable were introduced to the project by their clinic nurse during a routine appointment. Those who expressed an interest in participating were then contacted by a member of the research team.

RESULTS

Findings from the literature review confirmed that specific models of care and interventions for CKM had yet to be determined.[4 5 32 33] Furthermore, there were no established patient decision aids specifically designed to facilitate discussions between healthcare providers and patients regarding the choice between dialysis and CKM.[34]

The racial make-up of the total participants is reflective of the general Alberta population, with the largest group (78.4%) being white (table 1).[35] Women made up 80% of participants, reflective of the gender makeup of healthcare providers.

Figure 4 illustrates the results of the World Cafés mapped to the TDF. Opportunity involves all the factors that lie outside the individual who makes the target behaviours possible and includes social influences, that is, those interpersonal processes that can cause individuals to change their thoughts, feelings or behaviours and the physical environment.[28] Both physical and social opportunity for CKM were limited as reflected by barriers within environmental context and resources such as a lack of coordinated community supportive care services, a reliance on acute care to deal with symptom crises, a perceived lack of timely access to specialist palliative care advice and the perceived need for social influences to better support decision-making for older patients with frailty in culturally diverse communities, especially around end-of-life care issues. There was an identified lack of capability, predominantly in the psychological domains such as a lack of CKM-specific knowledge and conflicting views and attitudes around more conservative/palliative approaches to care among and between the interdisciplinary teams caring for these patients. However, there was acknowledgement of the need for enhanced physical capacity that pertained to skills, predominantly around advance care planning conversations and decision-making for CKM. Motivation is what energises and directs behaviour and includes automatic processes such as habits and emotional responding, as well as reflective processes such as analytical decision-making. Reflective motivation was working against the provision of CKM, predominantly in the domain of social and professional role and identity; the lack of clarity regarding responsibilities of kidney clinic staff versus primary care and palliative care staff was perceived as particularly problematic.

The most effective strategies for facilitating behaviour change were identified to be education (to impart knowledge and develop understanding), environmental restructuring (to change the physical and social context), training (to develop key skills) and modelling (to provide an example for people to imitate and aspire to) (see

Table 1 Participant demographics

Demographics	Steering committee	World Cafés	Follow-up interviews and feedback sessions	Total unique participants
N				
Participants	26	76	218	282
Gender				
Women	20	64	170	227
Men	6	12	48	55
Race				
Aboriginal	1	1	4	6
Arab	0	0	2	2
Black	0	0	5	5
Chinese	2	6	10	17
Filipino	0	0	4	4
Japanese	0	2	2	4
Korean	0	0	1	1
Latin American	0	2	3	4
South Asian	1	2	11	13
Southeast Asian	0	0	2	2
West Asian	0	0	2	2
White	22	62	172	221
Not disclosed	0	1	0	1
Discipline				
Administrative	1	1	19	21
Allied health	0	12	36	44
Emergency medical services	0	1	2	3
Dietician	0	4	13	16
Occupational therapist/physical therapist	0	0	4	4
Pharmacist	0	1	3	3
Social worker	0	4	12	14
Spiritual care provider	0	2	1	3
Psychologist	0	0	1	1
Nurse	4	16	54	68
Clinical nurse specialist/nurse practitioner	4	6	11	19
Registered nurse	0	10	43	49
Patient/family	1	4	29	34
Family caregiver	1	4	11	16
Patient	0	0	18	18
Physician	4	15	25	37
Primary care	2	7	14	19
Specialist	2	8	11	18
Policy-maker	13	24	45	68
Director/department head	8	9	19	26
Programme/operations manager	2	4	8	12
Patient care/unit manager	1	7	10	17
Senior consultant/executive lead	2	4	8	13
Project team	3	4	10	10

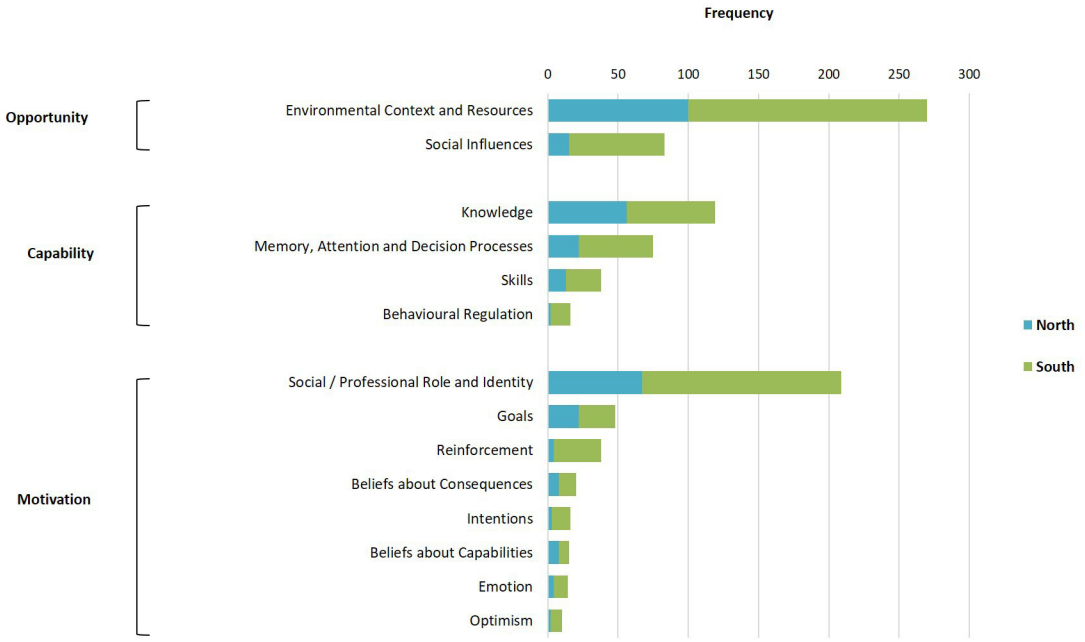

Figure 4 Conservative Kidney Management (CKM) World Cafés results mapped onto the Theoretical Domains Framework.

figure 5). These strategies each applied to all or most of the most common TDF domains and were used to help develop the CKM content and create a detailed map to support the implementation of the CKM Pathway. The only domain not targeted was coercion.

Table 2 summarises the core components of CKM, the current barriers associated with these components and the tools and processes that were identified to address these barriers and facilitate the uptake and provision of CKM through the CKM Pathway. Stakeholders described the need for a holistic and integrated approach that highlighted CKM as a patient choice, involving individualised care centred around shared decision-making and a systematic approach to identify patients most appropriate for CKM. Aspects of palliative care were identified as core components such as symptom management, advance care planning and psychological, social, cultural, spiritual and bereavement support. However, the need for CKM-specific guidelines around interventions to delay the progression of ESKD and minimise complications were also deemed important, in so far as they aligned with an individual patient's goals for care. Supporting

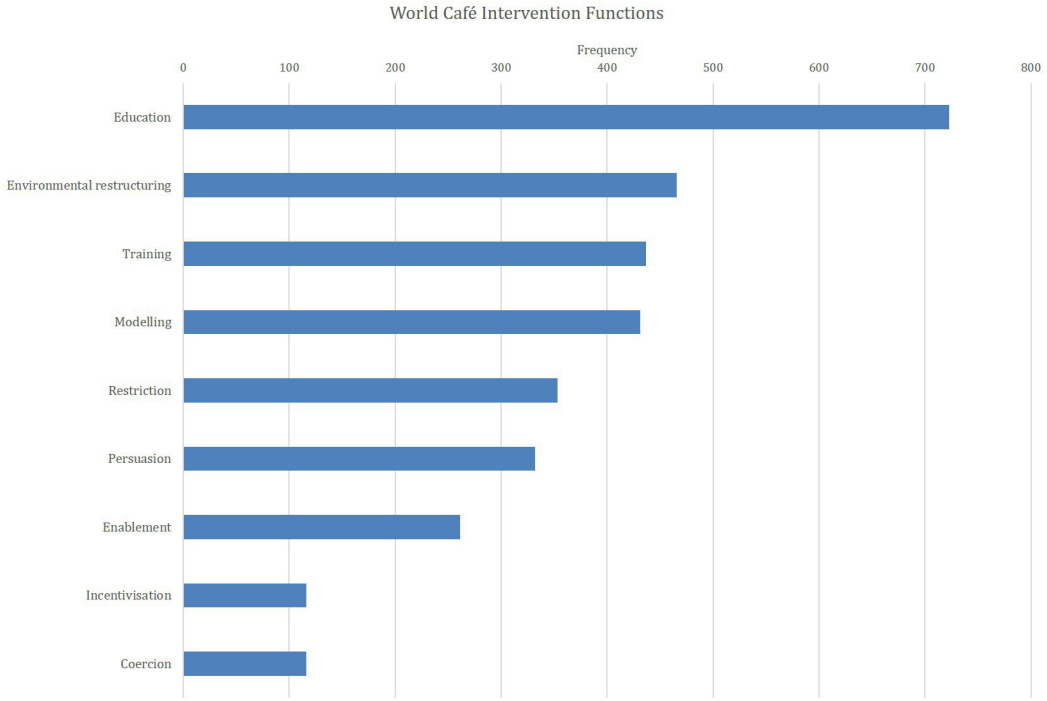

Figure 5 CKM World Cafés results mapped to Conservative Kidney Management (CKM) strategies.

Table 2 Core components of CKM in relation to associated barriers and the CKM pathway tools and processes identified to facilitate the provision of CKM

Core components of CKM	Barriers to CKM	CKM pathway tools and processes (Facilitators of CKM)
Acceptance of CKM as a treatment modality/choice	i. CKM inconsistently discussed as a viable treatment option	i. Formal recognition of CKM as a treatment modality and systematic incorporation of CKM into patient education and patient care plans
Identify patients appropriate for CKM through shared decision-making	i. Poor understanding and knowledge of appropriate patients for CKM ii. Inconsistent discussions of patient's values and incorporation into decision-making processes	i. Systematic approach to determine harms and benefits of CKM and dialysis for individual patients based on frailty, comorbidities, values and prognosis ii. A mobile, interactive, digital patient decision aid for dialysis versus CKM to facilitate conversations
Standardised, evidence-based CKM interventions: a. symptom management b. CKD complications/CKD progression c. end-of-life care	i. Lack of guidelines or clinical standards for CKM ii. CKM often perceived as no/minimal active care iii. Limited understanding of how care should change depending on where the patient is in their illness trajectory iv. Highly variable CKM clinical practices v. Highly variable comfort with providing palliative care	i. Systematic approach to patient assessments ii. CKM guidelines for symptom management iii. End-of-life (terminal) symptom guidelines iv. CKM clinical guidelines to manage the complications of advanced CKD and CKD progression v. CKM Care Plan: what to do and when; can be shared across care providers as a communication tool
Self-management support	i. Limited patient education materials for any aspect of CKM ii. Poor patient knowledge about disease progression or self-management strategies iii. Limited and inconsistent linkages with supportive programmes (especially home care, palliative care, emotional and spiritual care, exercise/PT/OT)	i. Standardised CKM patient education materials to promote informed decision-making ii. Patient 'My Pathway at a Glance' that outlines key components of CKM across the illness trajectory iii. Symptom management handouts: what patients can do at home to help with their symptoms iv. Advance care planning resources v. End-of-life planning resources vi. Linkage to community care resources (ie, home care, palliative care and other community resources)
Timely and appropriate communication of choice for CKM and overall goals of care	i. No provincial standard to identify that a patient has chosen CKM ii. Inconsistent communication between primary and kidney care around CKM iii. Uncoordinated process for physician-to-physician support calls about CKM iv. Ad hoc incorporation of advance care planning into patient care, including inconsistent Goals of Care conversations and completed designations*	i. Formalised documentation of choice for CKM on the provincial Green Sleeve† ii. Standardised letter to notify primary care physician and home care when patient is on the CKM pathway with the link to the online pathway. iii. 24×7 physician-to-physician support through RAAPID‡ iv. Formal incorporation of advance care planning into the CKM Care Plan v. Formal incorporation of Goals of Care Designation* into the CKM Care Plan

Continued

Table 2 Continued

Core components of CKM	Barriers to CKM	CKM pathway tools and processes (Facilitators of CKM)
Coordinated 'shared' care and crisis planning	i. No clarity on the roles of primary care and specialist care for CKM provision ii. Individual care plans are shared inconsistently among interdisciplinary team members iii. Lack of formal relationships or consistent processes for accessing community resources and addressing psychological, social, cultural or spiritual concerns iv. Ad hoc crisis planning	i. Standardised letter to primary care that negotiates a plan for shared care. ii. Standardised CKM Care Plan that is uploaded into the electronic medical record iii. Scripts to Health Link (provincial patient phone line) iv. Triage protocol for provincial physician-to-physician consult line (RAAPID‡) v. Streamlined processes to identify individual patient's need and referral processes to community care vi. Formal crisis planning developed in partnership with the provincial emergency medical services (EMSs): A. Patient Crisis Plan 'My Crisis Plan' B. Healthcare provider crisis plan C. Integration of EMS programme to treat patients in their home when possible§
Bereavement Support	i. Poor linkage to bereavement supports	i. Linkages to provincial bereavement supports
Access to CKM Pathway/Information	i. Delivery system not in place to ensure access to all components of CKM in a user-friendly, intuitive, and efficient platform	i. Public, online access to CKM Clinical Pathway through a web-based portal ii. Mobile responsive iii. Interactive—able to access the relevant information at a clinical encounter—'2 min' rule iv. Healthcare provider portal v. Patient, family and caregiver portal

*Goals of Care Designation: Alberta's medical order used to describe and communicate the general aim or focus of care including the use or non-use of life-sustaining treatments and the preferred location of that care.
†Green Sleeve: a green plastic pocket 'owned' by patients who hold important advance care planning documents and other forms that outline a patient's goals for healthcare and their choice of CKM to emergency responders.
‡Referral, Access, Advice, Placement, Information & Destination (RAAPID): This is a provincial call centre that serves as a single point of contact for care providers which facilitates urgent healthcare advice and when necessary, coordinates admission and repatriation of patients.
§EMS Assess, Treat and Refer Programme: EMS designed to provide urgent care and support to people and their families who have chosen to remain at home for palliative and end-of-life care.
CKD, chronic kidney disease; CKM, Conservative Kidney Management; OT, occupational therapy; PT, physiotherapy.

self-management, ensuring appropriate communication of choice for CKM, crisis management planning and appropriate linkages with community services were also deemed critical to ensure optimal patient outcomes.

Access to CKM resources was a major concern and stakeholders advocated for a freely accessible pathway through a healthcare provider portal (appropriate for use by all members of the interdisciplinary team) and a patient portal, allowing patients and families to access and navigate the CKM Pathway and resources in a meaningful and contextual way. The final digital CKM Pathway therefore consists of: (1) a patient decision aid to support shared decision-making around dialysis versus CKM; (2) a patient/family portal; and (3) a healthcare professional portal. This is freely accessible online at https://www.CKMcare.com.18. The Pathway features guidelines for symptom management and for managing the complications of ESKD in a manner that is consistent with the philosophy of CKM and the patient's goals of care.[36] The Pathway also provides educational tools for patients and families to enhance their capacity for self-management and shared decision-making.

Stakeholders recognised that the CKM illness trajectory can be highly variable. A patient may remain functional and stable for years, while others may deteriorate more rapidly over a few months. Comprehensive CKM recommendations, while focusing predominantly on the patient's goals of care and preferences, also need to consider the patient's general condition and prognosis. Earlier in the disease trajectory, maximising quality of life likely requires a careful balance between preserving function and addressing symptom burden, while control of symptoms and comfort generally takes precedence in the last weeks and days of life. The care needed by a patient in these two instances may differ. End users clearly voiced the need to be able to access this complex patient-specific information, at the time of clinical contact, in a timely manner of approximately 2 min. To accomplish this, the CKM Pathway is interactive and uses tree-and-branch logic to allow patients and healthcare providers to use it in a manner that is responsive to an individual patient's clinical condition and needs. Given the poor general awareness of the full range of activities required for comprehensive CKM, the Pathway operationalises practice guidelines into 'how to' steps for care delivery. The 'Pathway at a Glance' is an interactive screen that allows patients and healthcare providers to navigate the CKM Pathway in a stepwise fashion, ensuring all aspects of CKM can be addressed in a timely manner (see figure 6). The Pathway coordinates care through strong linkages with relevant primary and palliative care services and encourages the completion of advance care planning and detailed crisis management plans to avoid unnecessary admissions to the emergency department or hospital.

DISCUSSION

A systematic and comprehensive approach to CKM and an infrastructure to support individuals who choose CKM, as recommended by international guidelines, is required for all CKD patients unlikely to benefit from dialysis.[7] Prior to developing the CKM Pathway, care providers across Alberta were delivering some elements of CKM but in a fragmented and variable fashion. As a result, most Albertans with advanced CKD, especially in rural communities, were without access to coordinated and comprehensive CKM. The goal of a CKM pathway was to provide sustainable, high-quality, evidence-based care for patients unlikely to benefit from dialysis in a coordinated, standardised and equitable manner that addressed key barriers to the provision of CKM.

This initiative allowed for the systematic identification of key barriers and their subsequent mapping to behaviour change techniques. The most influential domains were identified as environmental context and resources, social/professional role and identity, knowledge and social influences. The most effective strategies for facilitating behaviour change were found to be education, environmental restructuring, training and modelling. These informed both the content and implementation

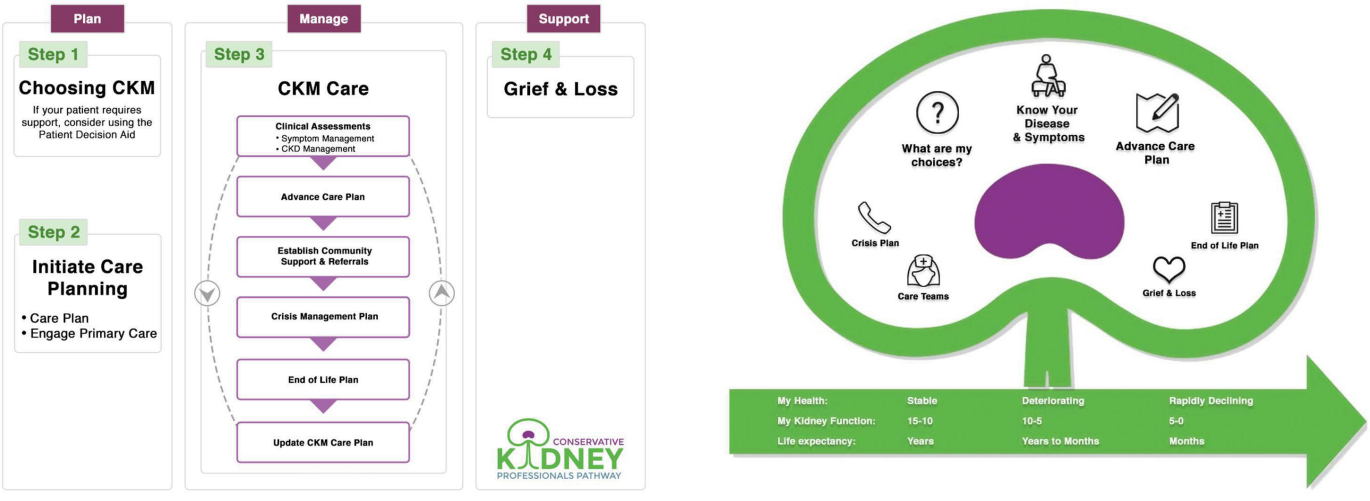

Figure 6 Snapshots of the interactive 'Pathway at a Glance'.[18]

strategies within the CKM pathway developed for use across a complex healthcare system.

The CKM patient decision aid, included in the CKM pathway, is the first of its kind internationally. Based on the patient's unique situation and health status, it focuses the conversation on anticipated outcomes with CKM versus dialysis. This includes a focus on outcomes that are important to patients such as quality of life, symptoms and functional status. It then balances their prognosis with their values and preferences around other life issues of importance such as their wish to travel, have control over their time or avoid surgery or hospitalisations. Supporting these conversations with tools such as this decision aid is critical, given recent work has identified that decisions about maintenance dialysis do not appear to reflect patients' preferences and values or their prognosis.

Our findings highlighted that while CKM-specific clinical guidelines are important, they addressed only one of the eight core components of CKM identified by our end-user participants (see table 1) and in isolation would be unlikely to change behaviour and improve patient outcomes. Other critical contributors, such as environmental context and resources, are needed to inform a comprehensive CKM pathway. In fact, the degree of environmental restructuring required was substantial, a concept that is less discussed in the literature.

Developing a crisis plan for patients and providers touched on every identified TDF domain and became a key component of the CKM Pathway. A crisis plan can help make transitions smoother, improve communication, educate patients and families and support implementation of practical, evidence-based guidelines. The organisation of the pathway into distinct steps to operationalise all key components of CKM care was also targeted. This type of organisation has been shown to be an effective strategy for increasing uptake of evidence-based practice and optimising patient outcomes.[22 37]

Successful integration of CKM will depend on changing multiple behaviours of multiple types of people (eg, multidisciplinary healthcare professionals, managers, administrators and family members) at the provider, site and system levels as well as supporting self-care behaviours of patients. This requires an understanding of the influences on behaviour in the context in which they occur.[28] Our rigorous integrated theory-based KT approach to identify the influences on behaviour (facilitators and barriers) to codesign CKM content and processes will help us understand the mechanisms of change, including how and in which contexts interventions are effective to inform further scale and spread of CKM nationally and internationally. The multifaceted, evidence-informed current state assessment used together with qualitative data was critical to identify innovations that could be adapted for provincial use and understanding where to focus resources. Furthermore, data triangulation using multiple methods of data collection increased the likelihood of valid findings.

The CKM Pathway was developed with extensive attention to the needs of a diverse group of end users across a large healthcare system. Our approach enabled a highly successful collaboration between patients, their families and interdisciplinary healthcare staff throughout the codevelopment process. This approach has been shown to result in care pathways that are more likely to meet the specific needs of patients, are adaptable to local context, are more likely to be implemented into clinical practice and provide more sustainable improvements in care.[38–41] However, there are very few cases where complex care pathways, especially those that involve palliative and end-of-life care services, have simultaneously involved the patients, families and healthcare professionals in their design and implementation.[42] Using two-way communication, such as validating the proposed interventions with a broad stakeholder group, was a core strategy used to maintain stakeholder engagement throughout the project, which subsequently continued throughout the implementation and evaluation phases.

There were challenges to patient participation due to the frailty of this population; family members were encouraged to speak from the patient's perspective when patients were unable to attend engagement sessions. The methods used in this work were specific for identifying opportunities for improvement in CKM within Alberta, Canada; however, many of the identified intervention strategies are adaptable to local context and are likely translatable to the development and implementation of sustainable, quality CKM in other national and international jurisdictions. Resources within the CKM Pathway will need to be continuously updated to ensure the provision of current evidence-based care as knowledge in this area advances.

CONCLUSION

Despite research clearly indicating the benefits of patient-centred care through CKM, it was unknown how best to conceptualise and implement CKM into clinical practice. The result of this study is a publicly accessible, online, interactive CKM Pathway that was codeveloped by patients and healthcare professionals. It involves tailor-made combinations of structures, processes and techniques to address unique patient needs and unique system-community circumstances. The goal of this CKM pathway is to provide sustainable, high-quality, evidence-based care for patients unlikely to benefit from dialysis in a coordinated, standardised and equitable manner that addresses key barriers to CKM.

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