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Conservative kidney management and kidney supportive care: core components of integrated care for people with kidney failure

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Abstract

Integrated kidney care requires synergistic linkage between preventative care for people at risk for chronic kidney disease and health services providing care for people with kidney disease, ensuring holistic and coordinated care as people transition between acute and chronic kidney disease and the 3 modalities of kidney failure management: conservative kidney management, transplantation, and dialysis. People with kidney failure have many supportive care needs throughout their illness, regardless of treatment modality. Kidney supportive care is therefore a vital part of this integrated framework, but is nonexistent, poorly developed, and/or poorly integrated with kidney care in many settings, especially in low- and middle-income countries. To address this, the International Society of Nephrology has (i) coordinated the development of consensus definitions of conservative kidney management and kidney supportive care to promote international understanding and awareness of these active treatments; and (ii) identified key considerations for the development and expansion of conservative kidney management and kidney

supportive care programs, especially in low resource settings, where access to kidney replacement therapy is restricted or not available. This article presents the definitions for conservative kidney management and kidney supportive care; describes their core components with some illustrative examples to highlight key points; and describes some of the additional considerations for delivering conservative kidney management and kidney supportive care in low resource settings.

Keywords

conservative kidney management; health care policy; integrated kidney care; kidney failure; kidney supportive care

As part of its focus on integrated care of people with kidney failure, the International Society of Nephrology (ISN) brought together patients with kidney failure, health care professionals, researchers, academic and health care institutions, and policy makers to formulate a 5- to 10-year strategy to improve global access to safe, sustainable, and equitable integrated care for people with kidney failure. “Integrated kidney care” requires synergistic linkage between preventative care for people at risk for chronic kidney disease and health services providing care for people with kidney disease, ensuring holistic and coordinated care as people transition between acute and chronic kidney disease and the 3 modalities of kidney failure management: conservative kidney management (CKM), transplantation, and dialysis.¹ People with kidney failure have many supportive care needs throughout their illness; kidney supportive care (KSC) is therefore a vital part of this integrated framework to address these needs regardless of treatment modality. Action plans were categorized into 5 themes and workgroups: *monitor*, *dialysis*, *resources*, *transplantation*, and *conservative kidney management and kidney supportive care*.² The aim of the CKM/KSC Workgroup is to define key considerations for the development and expansion of CKM and KSC as core components of integrated kidney care. This will involve identification of countries with no or limited services and training programs and development of materials and pathways for implementation of sustainable CKM and KSC programs. Through a series of consensus meetings, the workgroup will perform its activities within 4 projects that have been revised since the initial publication of the strategic plan, outlined in Box 1.^{2,3} Progress with these initial projects will define the direction of future activities.

This article is the first deliverable for project 1, aimed at improving and standardizing descriptions of CKM and KSC; improving communication by stakeholders; promoting acceptance of CKM as a treatment for kidney failure; and promoting KSC as a core component of nephrology. Although we considered global issues across low- or middle-income countries (LMICs) and high-income countries, we prioritized LMICs and vulnerable populations in all countries. The specific goals of this article are to (i) define acceptable terminology to promote international understanding and awareness of CKM and KSC; (ii) describe key components of CKM and KSC; and (iii) discuss some key considerations for the development and expansion of CKM and KSC as core components of integrated care for people with kidney failure.⁴⁻⁷ This will facilitate the development of materials necessary to promote training for all nephrology trainees in this field with the same insistence as exists

for dialysis and transplant training and will foster the implementation of sustainable CKM and KSC services globally.

Terminology and definitions

We followed the guiding principles and consensus for developing terminology and descriptions of kidney disease and its treatment from the recent Kidney Disease: Improving Global Outcomes (KDIGO) Consensus Conference. These guiding principles included patient centeredness and precision.⁸ To promote patient centeredness, the terms used should be understandable to patients and the public, with acknowledgement of variation in health literacy and that current recommendations are based predominantly on qualitative data from English-speaking participants. This includes consensus on using “kidney” rather than “renal” and using “kidney failure” rather than “end-stage kidney disease” to describe glomerular filtration rate <15 ml/min per 1.73 m² for >3 months.⁸ The term “supportive” is used instead of “palliative” as it is generally preferred by patients and health care professionals.^{7,9,10} Despite the evolution of palliative care over recent decades to extend the range of services beyond terminal care for patients dying with cancer, the belief that palliative refers to care only of the dying remains prevalent among patients, family, and health care providers.^{11,12}

Precision requires careful use of the terms “treated” versus “untreated” and avoiding the term “untreated” when explicitly discussing CKM and KSC as these are both active treatments. The term “nondialysis” is also avoided when referring to CKM as it may be confused with earlier stages of kidney disease and predialysis care or withdrawal of dialysis. Terms such as “comprehensive” and “quality” should apply equally across all treatment options.

Careful consideration should also be given to context; although some patients choose CKM rather than kidney replacement therapy (KRT), many do not have the choice because of a lack of access to medical care. The lack of awareness of kidney disease, resources, and clinical infra-structure in LMICs severely restricts the capacity to prevent, detect, and treat kidney disease.^{13,14} Most people present late, at the point of kidney failure. A large proportion of these individuals may not have access to KRT, because of a lack of government-supported KRT, insufficient financial resources or affordable private health insurance, insufficient caregiver support, or logistical barriers to accessing kidney care because of distance, conflict, or safety. For these individuals, the lack of access to KRT removes any element of choice, and we refer to CKM offered to this population as “choice restricted” (Figure 1). We emphasize that the delivery of CKM in this context does not in any way excuse governments from their obligations to improve the access to integrated kidney care, including dialysis and transplantation, for their population. Unfortunately, palliative care is often unavailable too, and for this reason the workgroup has chosen to draw a clear distinction between choice-restricted CKM, where individuals have no access to KRT, but receive KSC; and untreated/undiagnosed kidney failure, where both KRT and KSC are unavailable.

Definitions, preferred terminology, and key considerations for which there was general agreement are outlined in Table 1.

Kidney supportive care

KSC is an approach to care that aims to improve the quality of life for people for whom kidney disease, either directly or indirectly, substantially impacts their well-being, treatment options, or access to care (Table 1). The definition for KSC is anchored in the World Health Organization definition of palliative care¹⁵ and was endorsed by the KDIGO Controversies Conference on KSC in 2013,⁷ the ISN-sponsored symposium on integrated kidney care in 2018,¹ and this ISN CKM international working group. KSC is a core component of integrated kidney care that helps people cope with living with kidney disease, as well as dying with kidney disease. KSC should be available according to needs for people whom kidney disease, either directly or indirectly, substantially impacts their well-being, treatment options, or access to care. This includes both those receiving KRT and those not receiving KRT (Figure 1). The core elements of KSC consist of shared decision-making, symptom management, crisis planning, advance care planning, spiritual care, care of the dying patient, and bereavement, and they require integration with community services (outlined in Table 2^{16–22}). Culturally competent shared decision-making is the foundation of KSC to ensure the components of medical care deemed most important to the patient are prioritized. Advance care planning is a form of preparation for shared care decision-making if a person can no longer speak for himself/herself. A consensus definition of advance care planning is, “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.”²³ Supporting patients’ self-management, including crisis management planning (usually around symptom crises), and appropriate linkages with community services have been deemed by patients as critical components of this care.²⁴

Many countries are emphasizing the provision of supportive and end-of-life care by “generalist” and community providers as a component of usual care. This is particularly important for LMICs, where the delivery of supportive care relies heavily on primary care, and specialty-trained palliative care clinicians are sparse. In addition, people with kidney disease have unique needs. Rather than assuming that the specialty of palliative care would attend to all supportive care issues, KSC is increasingly and appropriately being recognised as a core clinical competency for multidisciplinary clinicians caring for people with kidney disease, in both community and hospital settings.²⁵ KSC can be best provided by a multidisciplinary team that includes kidney and supportive care expertise from physicians, nurses, and allied health staff, such as dietitians and social workers, underpinned by education, research, and quality assurance. Box 2 describes the core skillset required by kidney care teams to be able to provide quality KSC and highlights the value of comanagement with specialist palliative care in more difficult or intractable cases.²⁵ However, we recognize that globally, specialists and trainees in nephrology, palliative medicine, geriatrics, and family medicine are not necessarily resourced with multidisciplinary care to adequately manage this area of medical practice. Even where available, it is not optimally accessible or of the highest quality.²⁶ Barriers are multiple

and include, but are not limited to, inadequate resources and/or finances, lack of awareness and/or priority setting, and inadequate training.

Conservative kidney management

CKM is care for people with kidney failure that focuses predominantly on providing KSC to promote quality of life but does not include KRT (defined and described in detail in Table 1). The definition of CKM is pivotal on KSC—with the intention of describing a viable, quality treatment option for people with kidney failure, incorporating the individual's preferences for survival and quality of life. Kidney failure untreated by either KRT or KSC is defined as “untreated.” Where kidney failure is untreated because it has not been diagnosed, it is defined as “undiagnosed.” Ideally, except in choice-restricted environments, CKM is chosen through shared decision-making (see Figure 1). Although the focus of CKM is providing KSC to optimize quality of life, preventative measures to slow the progression to kidney failure and manage complications remain important in so far as they align with the patient's preferences and goals for care. This requires a shift from disease-focused treatment, which often takes years to accrue benefits, to shorter-term symptom- and patient-specific goal-focused interventions in which medications are used primarily with the intention of improving symptoms and protecting kidney function. Key elements of CKM are outlined in Table 2.

Identifying people who might benefit from CKM

Where available, receiving KRT is a choice that requires the careful balance of risks and benefits. It is reasonable for people with kidney failure for whom the burdens of KRT are anticipated to outweigh the benefits to consider CKM as an alternative. This means being able to identify indicators that the benefits may be reduced, or the burdens increased, with initiation of KRT. It is important to recognize that the benefits, burdens, and their balance are preference sensitive to that individual and his/her family and will likely involve both quality of life and survival considerations and trade-offs.

There is no consensus agreement on how to measure frailty in the care of patients with kidney disease; and as a result, frailty is not routinely measured across health systems as part of kidney disease care. However, general clinical tools, such as the 1-page Supportive and Palliative Care Indicators Tool, can be used by health care professionals to help identify people with deteriorating health due to 1 advanced, life-threatening condition, and who would benefit from supportive care independent of prognosis.^{27,28} The Supportive and Palliative Care Indicators Tool has been adapted to help physicians identify patients in low-income settings who might benefit from supportive care—the Supportive and Palliative Care Indicators Tool for a Low-Income Setting.²⁹ Both versions combine general indicators and disease-specific indicators of life-limiting illnesses to provide a practical, reproducible, and structured approach to identifying people who might benefit from supportive care, and it has been used successfully in both primary³⁰ and acute care.³¹ When used by kidney care nurses, the Supportive and Palliative Care Indicators Tool resulted in a significant improvement of recognition of people with kidney failure approaching their end of life by kidney care teams.³² Factors specific to people with kidney failure that should encourage

clinicians to consider CKM and to ensure that the benefits of KRT are not consciously or subconsciously exaggerated are outlined in Box 3.

Building a platform for integrated CKM in low resource settings

Currently, KSC is nonexistent, poorly developed, and/or poorly integrated with kidney care in many countries, especially LMICs. This means that by the definitions proposed in this article, many individuals previously categorized as receiving choice-restricted CKM are untreated for kidney failure. The results of the 2018 Global Kidney Health Atlas survey illustrated that although some elements of CKM were reported to be available in 80% of the 160 countries surveyed, almost half of these countries stated that easy access to CKM was not available. Perhaps even more worrisome, only about one-third of countries reported incorporation of core elements of CKM, and only a quarter provided some level of training related to CKM and KSC to health care providers.²⁶

Integrated kidney care implicitly considers resource use and is required for the delivery of sufficient and sustainable kidney care. There is variable provision of the 4 components of integrated kidney care (prevention, CKM, transplantation, and dialysis) among LMICs, and few are adopting a coordinated approach.³³ A framework for integrated kidney care that LMIC governments can use to establish and/or scale up programs for reducing the burden of kidney failure has been suggested.³⁴ Within this framework, interventions associated with larger absolute health gains would have higher priority for investment compared with interventions with smaller absolute health gains (Figure 2³⁴).

Treatments that prevent or delay progression of chronic kidney disease require less specialized expertise and are relatively inexpensive, with large absolute gains in reducing the burden of kidney failure, and would therefore have the highest priority for funding. Publicly funded KRT would only be considered once most citizens had access to publicly funded preventative care in LMICs. Similarly, because not all people with kidney failure will benefit from or have access to KRT, providing publicly funded CKM through the provision of relatively inexpensive KSC should take priority over implementing KRT programs in LMICs, without diminishing the obligation on governments to progressively realize access to dialysis and transplantation under the international right to health. Furthermore, the need for access to KSC for all people with more advanced stages of kidney disease, even if they have access to KRT, further increases the imperative to establish, scale, and spread KSC resources and expertise. KSC and CKM programs and treatments aimed at managing symptoms among those with kidney failure should ideally be established in parallel with robust preventative care programs, as preventative care and slowing progression of disease are imperative components of CKM, especially for patients in LMICs who would have otherwise chosen KRT if access had been available.³⁴

Considerations regarding choice-restricted CKM.

There are unique considerations and ethical challenges in LMICs that need to be explicitly recognized and addressed before initiating either a CKM or KRT pathway. The balance of benefits, burdens, and individual preferences around KRT and CKM differs greatly in

the context of limited resources. The due diligence applicable to the process is depicted in Figure 3.

Among patients who start dialysis in LMICs, mortality remains high because of late presentation, suboptimal monitoring and quality of KRT, and frequent dialysis discontinuation. In a systematic review in sub-Saharan Africa, only $\approx 10\%$ of adults and 35% of children with incident kidney failure remained on dialysis for >3 months.³⁵ In settings where KRT may be available, but unaffordable, the financial harm to a person and his/her family may be greater than the short-term benefit of providing dialysis if it needs to be stopped once funds run out. Yet, families may raise funds for the treatment, even if there is limited anticipated benefit and treatment can only be sustained for a short period. Hence, there must be consideration of the impact of treatment on family and community—and a likely role for psychosocial supportive care. These issues of suitability for KRT can lead to moral distress for health care providers and call into question what information should be provided to patients and their families, once the patient is evaluated to be a good candidate for KRT.

A key step in promoting appropriate CKM and KRT provision, while recognizing the unique challenges and ethical issues, is the development of transparent guidelines that identify people who would most benefit from KRT, and by default, CKM, given resource constraints. People with kidney failure in low resource settings would continue to benefit from high-quality KSC and CKM while efforts are pursued to develop appropriate KRT programs. These guidelines designed to assist at all levels of care must be transparent and developed in consultation with stake holders, including nephrologists, social workers, patient advocates, community leaders, and ethicists. They must emphasize the involvement of a team in decision-making and an approach that includes continuity of care through CKM if KRT is not possible. They should also include conversation guides to help the clinical team support the participation of patients in shared decision-making wherever possible, informing them of their available options for care, even if limited, while always respecting their values and culture. Guidelines would need to be supported and endorsed by local and national governments. The ISN has proposed an ethical framework to guide policy decision-making and education and training of professionals to support ethical practice in the delivery of KRT and CKM.³⁶ The overarching ethical principle of utilitarianism informs the backbone of this process. Although this framework articulates core ethical principles and values to guide policy and practice shared by the international community, regional input and consensus statements are imperative to resolve unique local challenges.³⁴

Processes required to establish conservative kidney management programs.

The development, implementation, and long-term sustainability of a CKM program requires a coordinated, whole health systems approach, leveraging international and national advocacy programs. The core processes, consistent with the public health model for palliative care development, required to establish CKM and integrate at micro, meso, and macro levels are described in Table 3.^{37,38} This will require policies, education, essential medicines, research, and community support. Although all these areas are related, policy is the fundamental component; without it, other changes cannot be systematically introduced.

Policies that support the provision of CKM should align with and leverage national and regional palliative care initiatives to ensure essential treatment availability and promote accessibility and sustainability. In 2019, only 50% of countries globally reported having palliative care within their national noncommunicable diseases policy that is operational, yet 69% of all those with palliative care need are people with noncommunicable diseases.³⁷ Most adults in need of palliative care (76%) live in LMICs. Furthermore, 83% of the world's countries have low to nonexistent access to opioids; LMICs consume only \approx 10% of global opioids.^{37,39} The World Health Organization, through its decision-making body, the World Health Assembly, has committed to integrating palliative care into all relevant global disease control and health system plans, especially in resource-limited countries; and building evidence of models of palliative care that are effective in LMIC settings, including the development of indicators for evaluating palliative care services.⁴⁰

Most health professionals worldwide have little or no knowledge of the principles and practices of palliative care, which is the underpinning for KSC and CKM. Addressing this training gap for those delivering care is a matter of high importance. CKM and KSC use a multidisciplinary team approach to address the needs of patients and their families, and most CKM in LMICs will likely be delivered in the community by nonkidney specialists. KSC and CKM education, therefore, should be integrated into the undergraduate and postgraduate curricula, and in the teaching and practice of all health care professionals in nephrology, palliative care, primary care, nursing, social work, and community health care workers and will need to occur across all levels of care. It needs to be driven by the regulatory bodies responsible for these training programs.

We have proposed a hub-and-spoke model as an example of how to support competency-based capacity for CKM at institution, community, and national levels (see Figure 4). CKM hubs would likely be based within tertiary care and would serve as community focal points for CKM and KSC training, involving multidisciplinary care providers. These hubs would maintain competency in and delivery of all core components of CKM and ideally would foster CKM policy, advocacy, evaluation, research opportunities, and maintaining CKM registries to document uptake and outcomes. These CKM hubs would also help promote capacity building by training additional CKM hubs while ensuring CKM integration within home-based care and community-based primary and secondary care within their own communities.

Conclusion

Effective CKM and KSC programs are lacking across high and low resource settings. The adoption of these consensus definitions using standardized terminology should promote shared understanding and acceptance of CKM and KSC as core components of integrated kidney care. Articulation of the unique needs and challenges in high-income countries and LMICs is essential for the development and expansion of accessible, equitable, and sustainable CKM. Furthermore, clear understanding of the core components of CKM and KSC will facilitate the development of appropriate curricula to build global capacity for the skills and knowledge needed to implement sustainable programs and for the development of

additional tools, such as practical guides and technical packages, on how to deliver this care across varied resource settings.

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Box 1 |**Activities of the ISN Conservative Kidney Management/Kidney Supportive Care Workgroup within the 5- to 10-year strategic plan for integrated care of people with kidney failure²**

Project 1: Define and identify the core components of conservative kidney management and kidney supportive care to promote international understanding, awareness, and development.

Project 2: Undertake an updated environmental scan of existing conservative kidney management programs (as part of the Global Kidney Health Atlas initiative)³ that incorporates fully the considerations and elements in project 1.

Project 3: Disseminate prognostic tools and information for patients and health care providers about the range of clinical outcomes of importance to people considering conservative kidney management.

Project 4: Develop a global ISN (core) curriculum for conservative kidney management and kidney supportive care to promote training in these fields.

Project 5: Support the development of conservative kidney management programs in places where they do not currently exist, particularly for low- and low middle-income countries.

ISN, International Society of Nephrology.

Box 2 |

KSC skill sets for nephrology and specialty palliative care teams

Nephrology

- Basic assessment and management of pain and other physical symptoms
- Basic assessment and management of depression and anxiety
- Communication skills to discuss:
 - i. Prognosis
 - ii. Shared decision-making regarding kidney failure treatment options
 - iii. Goals of care and advance care planning, including wishes for resuscitation
 - iv. Conflict resolution regarding goals of care or treatment options
 - v. Relief of suffering: physical, psychosocial, and spiritual domains

Specialty palliative care

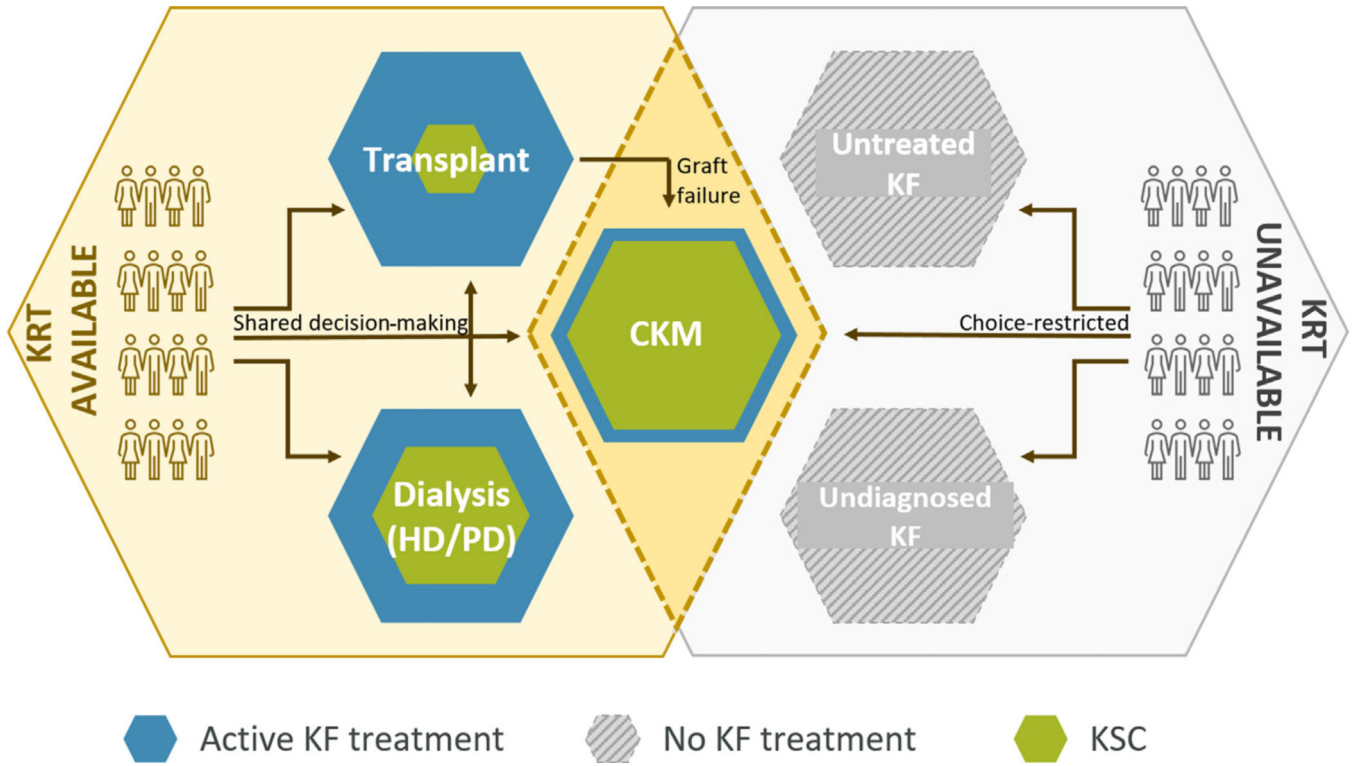
- Comanagement of refractory pain and other physical symptoms
- Comanagement of complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals of care, treatment options, or advance care planning
 - i. Within families
 - ii. Between staff and families
 - iii. Among multidisciplinary care teams

KSC, kidney supportive care. Modified from Quill TE, Abernethy AP. Generalist plus specialist palliative care – creating a more sustainable model. *New Eng J Med.* 2013;368:1173–1175.²⁵

Box 3 |**Indicators to help identify people with kidney failure who might benefit from CKM**

- Poor quality of life, including irremediable physical or psychosocial suffering, where dialysis may extend life, but prolong suffering
- Frailty: cognitive and physical domains with poor functional status
- High comorbidity, especially if severe heart failure and/or advanced age (>80 years)
- Severe malnutrition
- Clinician's response of "No, I would not be surprised" to the question ("Would I be surprised if this patient died in the next year?")
- Those whose medical condition precludes the technical process of dialysis because the patient is
 - Unable to cooperate (e.g., advanced dementia)
 - Unstable medically (e.g., profound hypotension)
 - Experiencing another life-limiting illness (e.g., advanced stage cancer)

CKM, conservative kidney management.



Active KF treatment
 No KF treatment
 KSC

Figure 1 |. Treatments and the role of kidney supportive care (KSC) for people with kidney failure (KF).
 The increasing size of the green hexagon (representing KSC) from transplant to dialysis to conservative kidney management (CKM) conceptualizes the increasing role that KSC plays with each active KF treatment. Where kidney replacement therapy (KRT) is available, people should select a KF treatment option through shared decision-making. Where KRT is not available, choices are restricted, and people typically do not receive the care they would have chosen through shared decision-making if the appropriate resources had been available. HD, hemodialysis; PD, peritoneal dialysis.

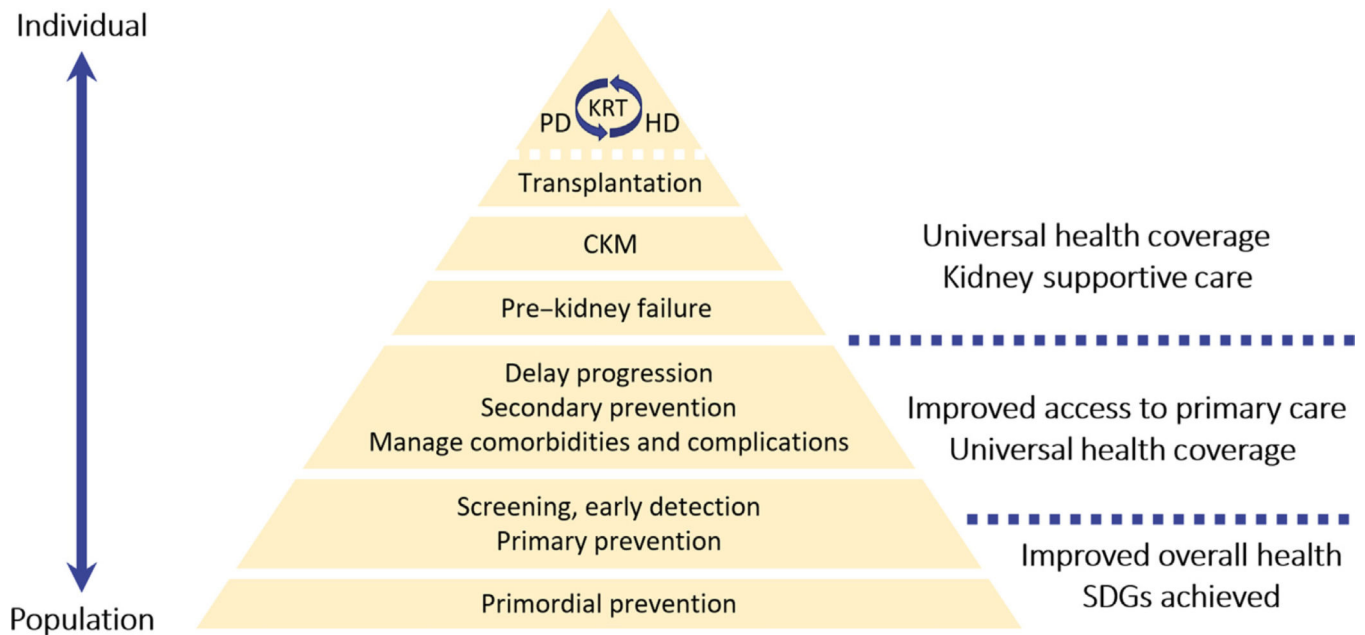


Figure 2 |. Conservative kidney management (CKM) within a framework for establishing integrated kidney care programs in low- or middle-income countries.
 Adapted from Tonelli *et al.*³⁴ HD, hemodialysis; KRT, kidney replacement therapy; PD, peritoneal dialysis; SDG, sustainable development goal.

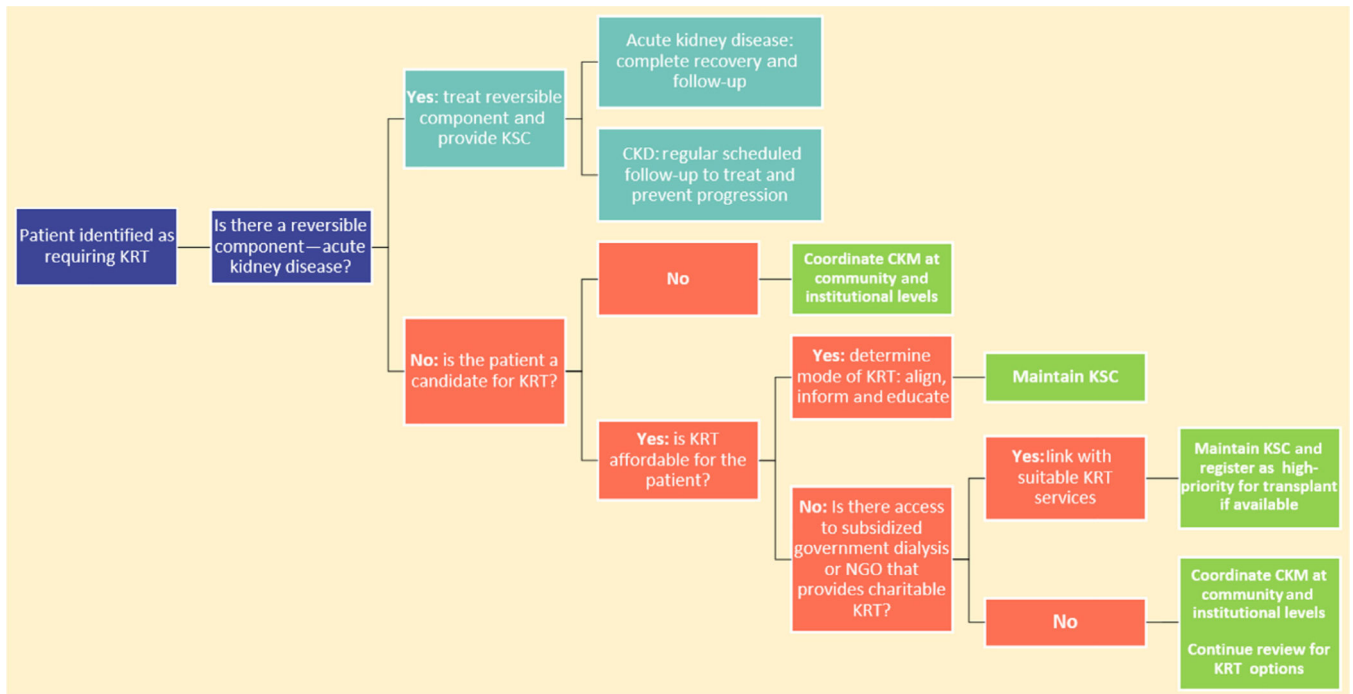


Figure 3 |. Considerations before receiving conservative kidney management (CKM) through a choice-restricted pathway.

CKD, chronic kidney disease; KRT, kidney replacement therapy; KSC, kidney supportive care; NGO, nongovernmental organization.

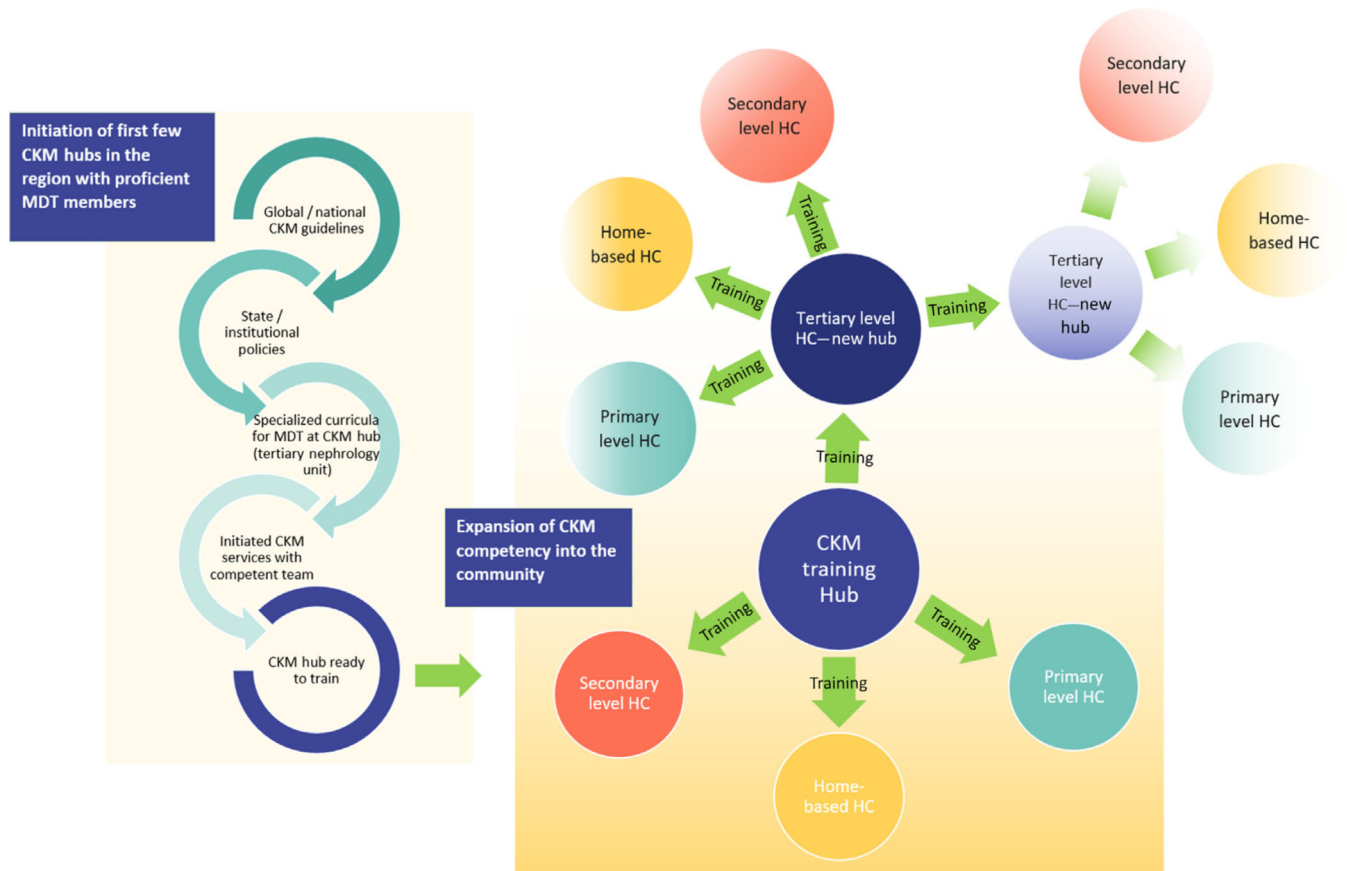


Figure 4 |. Potential hub-and-spoke model to support competency-based capacity from conservative kidney management (CKM) at institution, community, and national levels. HC, health care; MDT, multidisciplinary team.

Table 1 |

Definitions, suggested terms, and key considerations to describe treatments and situations that do not involve KRT for people with KF

Preferred term and suggested abbreviation	Definition	Key considerations
KSC	An approach that aims to improve the quality of life for people for whom kidney disease, either directly or indirectly, substantially impacts their well-being, treatment options, or access to care, and their families, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.	<ul style="list-style-type: none"> • KSC is a core component of integrated kidney care that helps individuals cope with living, as well as dying, and should be available for all people with advanced CKD according to their supportive care needs. • KSC can be provided alongside therapies intended to prolong life, including KRT, and should not be reserved for people who have chosen CKM, who have withdrawn from dialysis, or who are actively dying. • KSC prioritizes the components of health-related care most important to the individual and ensures these guide clinical decisions. • KSC integrates culturally sensitive shared decision-making, even when treatment options are limited. This requires that clinicians and those they treat jointly consider treatment options in light of the best clinical evidence and the individual's specific health characteristics, preferences, and values. This decision-making should be done within the framework of the cultural beliefs of the individual and his/her family. • KSC recognizes that individuals have physical, psychosocial, and spiritual needs.
CKM	Care for people with kidney failure that focuses predominantly on providing KSC to promote quality of life but does not include KRT.	<ul style="list-style-type: none"> • The guiding principle in CKM is that all active treatment is aligned with the individual's preferences, goals, and prognosis and is usually aimed at optimizing quality of life. Optimal CKM requires the full integration of KSC. • Interventions aimed at slowing the progression of kidney disease and managing the complications of disease—including premature death—remain important in so far as they align with the individual's preferences and goals. • Choosing CKM does not mean imminent death; most people will live for several months and some for several years with kidney failure while receiving CKM. Maximizing quality of life earlier in the disease trajectory typically requires careful balancing of symptom management and disease complications with optimizing overall function, whereas nearer the end of life, care will become almost exclusively focused on minimizing symptoms and preparing for end of life. • People receiving CKM require highly individualized, nuanced care, often for years; CKM is therefore not about "giving up" or "doing nothing." • The continuing involvement of a multidisciplinary kidney care team is important for people receiving CKM to manage physical, psychosocial, and spiritual needs, to preserve kidney function, to employ preventative health care measures consistent with the person's goals of care, and to actively support families in their caregiver roles. • CKM is distinct from CKD G5 predialysis care where the choice for KRT has been made but has not yet been started; the goals of care for these people generally focus on optimizing longer-term patient outcomes. • CKM is distinct from withdrawal of KRT in which maintenance therapy is stopped. These people typically live days to weeks and require terminal/end-of-life care, which is only 1 aspect of CKM.
Untreated KF	KF that is diagnosed, but the patient is not receiving either KRT or CKM.	<ul style="list-style-type: none"> • Untreated KF is distinct from CKM. • Health systems should aim to eliminate untreated KF entirely.
Undiagnosed KF	KF is present but has not been diagnosed; therefore, neither KRT nor CKM is provided.	<ul style="list-style-type: none"> • Undiagnosed KF is distinct from CKM. • Health systems should aim to eliminate undiagnosed KF entirely.

CKD, chronic kidney disease; CKM, conservative kidney management; G, glomerular filtration rate category; KF, kidney failure; KRT, kidney replacement therapy; KSC, kidney supportive care.

Table 2 |

Core components of KSC and CKM

Component of care	Example treatment strategies
KSC	
Shared decision-making	Ask about what is important to the patient and His/her loved ones. Ways this can be conveyed include: "As we talk about how best to care for you, what you are hoping for? What concerns you most?" Actively inquire about ways to support the patient and his/her family; "What kinds of support would be helpful to you and your family?" ¹⁶
Symptom management	Incorporate routine screening for the common symptoms of KF (such as pruritus, restless legs, fatigue, pain, nausea, insomnia, anxiety, and depression), preferably using a validated tool, such as the ESAS:Renal ^{17,18} or the IPOS:Renal. ¹⁹ Ensure access to symptom treatment algorithms, considering local resources and access to medications.
Crisis planning	Ensure patients are familiar with the common symptoms and have plans in place of how to treat them; this may include who to call for help and anticipatory prescribing.
Advance care planning	Start conversations early. Discuss how the person wants to be cared for in his/her final days of life, including location of care. Identify an appropriate substitute decision-maker and ensure this individual has the appropriate knowledge of the patient's wishes, is willing to take on the role, can honor the patient's wishes, and is able to make decisions under stressful circumstances. ^{20,21}
Spiritual care	Ask a screening question, such as "Are there spiritual concerns you would like to have addressed or discuss with a member of the health care team?" This may work well as a gateway to larger discussions and a more in-depth spiritual assessment for those who indicate distress.
Integration with community services	As a patient's condition deteriorates, self-care will become less realistic. Ensure that appropriate support is in place to assist with activities of daily living and that nursing care is available as needed.
End-of-life care considerations (care of the dying patient) and bereavement	Symptoms should be anticipated with the appropriate prescriptions in place to address symptoms as they appear, including an alternative route to oral as swallowing becomes compromised.
CKM	
Kidney supportive care	This includes meticulous and timely attention to all the core elements of KSC above.
Management of disease progression in so far as doing so aligns with the individual's priorities	Continue to avoid nephrotoxins, such as nonsteroidal anti-inflammatory drugs, to preserve residual kidney function. Consider using oral alkali therapy to prevent severe metabolic acidosis (generally 16 mmol/l). ²²
Management of medical complications in so far as doing so aligns with the individual's priorities	There are no clear benefits to normalizing serum phosphate levels with respect to bone abnormalities or vascular calcification in people receiving CKM in the last few years of life. However, there is a possibility of harm in promoting lower protein intake through a phosphate-restricted diet in people already at high risk for protein malnutrition. Hyperphosphatemia can also contribute to restless legs syndrome, and calcium and phosphorous depositions can lead to myalgias, arthralgias, and pseudogout. Treatment of hyperphosphatemia should be aimed at promoting quality of life through liberalizing diet and maintaining adequate nutrition; dietary restrictions should only be considered to minimize associated symptoms.
Does not include KRT	The exception to this would be a person with a failed kidney transplant who is unable to or has chosen not to transition to dialysis or receive another kidney transplant.

CKM, conservative kidney management; ESAS, Edmonton Symptom Assessment System; IPOS, Integrated Palliative Care Outcome Scale; KRT, kidney replacement therapy; KSC, kidney supportive care.

Table 3 |

Processes required to establish and sustain CKM programs

<p>Policy needs</p> <ul style="list-style-type: none"> • Establishment of palliative care as part of the national health care system at all levels with accompanying accountability mechanisms • Establishment of CKM as a core component of integrated kidney care that aligns with national/regional palliative care initiatives • National standards defining CKM and quality improvement outcome measures with a strategy for implementation • Clinical guidelines for the delivery of CKM services • Transparent clinical guidelines for people who might most benefit from KRT and CKM 	<p>Considerations</p> <ul style="list-style-type: none"> • These policies should be national in scope so that development of services is in line with national priorities and that the most vulnerable and marginalized in societies are reached. • Policies should promote standardization by integrating consistent terminology, definitions, core elements, and quality measures as per international standards. • They should also leverage international policy and advocacy, such as the WHO's strategic plan for national action, to strengthen palliative care as a component of integrated treatment within the continuum of care³⁷ to ensure essential treatment availability. • The monitoring of access to KSC and CKM should be undertaken at all levels of care to ensure that all those who need it receive it. Universal quality indicators should be culturally sensitive, while keeping in mind the limited resources available. This will also require accessible reporting at the local, national, and global level. Regular scrutiny and publication of the data output are essential.
<p>Education needs to support CKM competencies</p> <ul style="list-style-type: none"> • Curriculum development to train multidisciplinary team members at all levels of care, including conversation guides to facilitate shared decision-making • Basic primary palliative care training for all health professionals and paraprofessionals, including physicians, nurses, mental health professionals, clergy, volunteers, and therapists • Intermediate KSC and CKM training for all health professionals and paraprofessionals routinely working with people with CKD and kidney failure (see Box 3) • Specialist palliative care training for people with more complex symptom management needs and for those who will teach palliative care and do research (see Box 2) • Media, public advocacy, community education, and awareness campaigns 	<p>Considerations</p> <ul style="list-style-type: none"> • Leverage international expertise to build the knowledge and skills of health care professionals and volunteers • For example, the <i>Worldwide Hospice Palliative Care Alliance's Palliative Care Toolkit: Improving Care in Resource-Limited Settings</i> is geared toward empowering health workers in resource-poor settings to integrate basic palliative care into the work they are doing and is available in many languages.³⁸ • Promote and leverage ISN guidelines and initiatives for the delivery of KSC and CKM as the ISN • Patients and families also need training on how to provide care, including personal care, body mechanics, symptoms to expect, and how to manage these symptoms. This can be facilitated by community education and awareness campaigns about KSC and CKM
<p>Essential medication availability</p> <ul style="list-style-type: none"> • Palliative care medications as outlined in the WHO essential palliative care medications list should be available to all those who need them. 	<p>Considerations</p> <ul style="list-style-type: none"> • This is particularly important for opioids, which are crucial for treating pain and severe respiratory distress. • Countries can work with the INCB, UNODC, WHO, and civil society partners to address regulatory barriers and improve medication supply and management systems
<p>Academics and research</p> <ul style="list-style-type: none"> • Continuing to establish a robust evidence base for KSC and CKM is a crucial component to building commitment to greater access for those who need it. • The research agenda should be funded and should examine the access, outcomes, and cost-effectiveness of CKM and KSC. 	<p>Considerations</p> <ul style="list-style-type: none"> • Robust evidence will help support best practice around delivery of CKM, models of care, symptom management, and prognostication to support shared decision-making. • Recognizing limited funding opportunities, LMICs should partner with and leverage international KSC and palliative care research initiatives.
<p>Implementation requirements</p> <ul style="list-style-type: none"> • Opinion leaders • Build trust: collaborative planning at all service delivery levels • Trained personnel • Access to medications • Strategies and funding for all processes • Standards, guidelines, quality, and effectiveness measures, audit • Government: NGO collaboration 	<p>Considerations</p> <ul style="list-style-type: none"> • KSC and CKM will require integration across the health care system, including primary care and home care. Although some inpatient care may be needed, most KSC and CKM can be delivered to people at home. • Active involvement of the community through community leaders, health centers, volunteers, and other local stakeholders providing service in the community will promote acceptability and sustainability. • Support through public private partnerships, academic grants, and philanthropy will be needed by NGOs.

CKM, conservative kidney management; INCB, International Narcotics Control Board; ISN, International Society of Nephrology; KRT, kidney replacement therapy; KSC, kidney supportive care, LMIC, low- and middle-income country; NGO, nongovernmental organization; UNODC, United Nations Office on Drugs and Crime; WHO, World Health Organization.