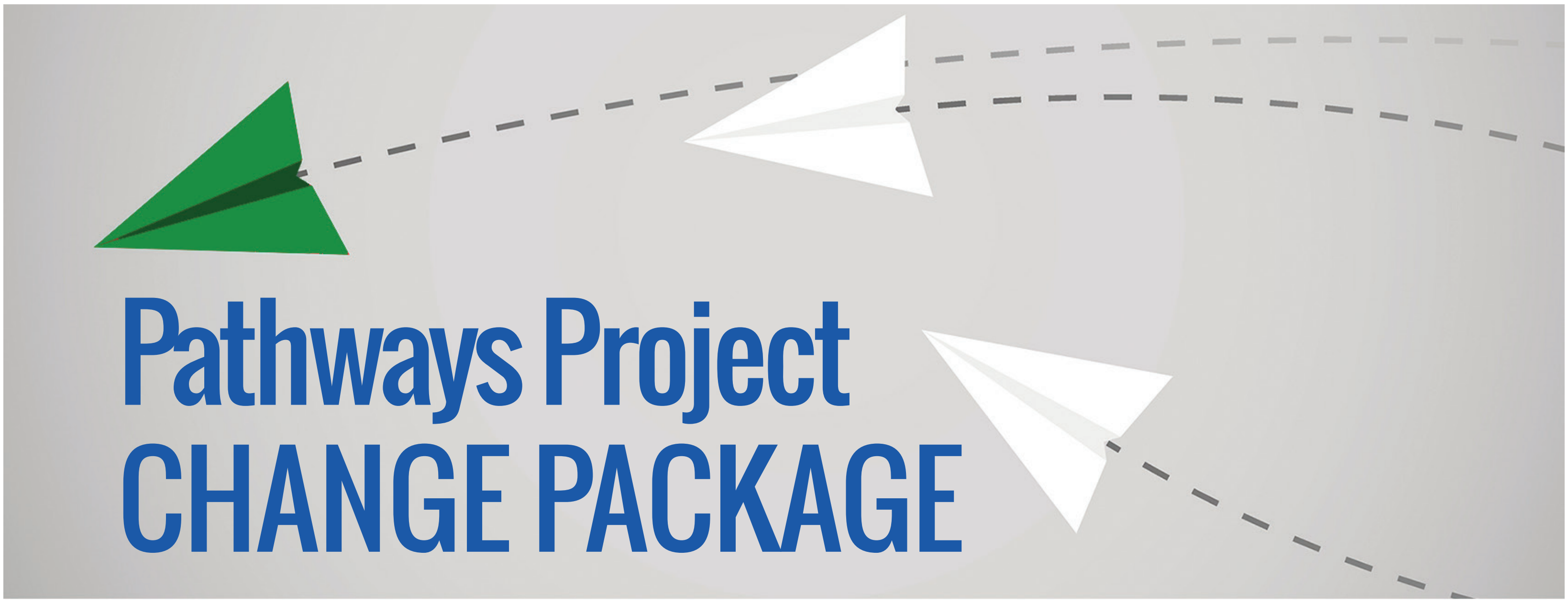


Pathways Project
CHANGE PACKAGE

Evidence-based recommendations designed to bring about improvements in the supportive care delivery for patients with kidney disease.

Supportive Care Capacity
Create the System

1. Assemble an interdisciplinary team for your setting with a day-to-day leader and champion(s)
2. Assess unmet supportive care needs in patient population
3. Provide education to staff on the principles and practices of primary supportive care, including communication skills
4. Collaborate with palliative care/hospice specialists

Values Guide Care
Elicit & Respect Patient Values and Preferences

5. Implement shared decision-making for current and advance care planning for future care options **
6. Welcome, support and involve family (defined by patient) in the care process to the extent desired by patient
7. Create structures (EMR, registries) to make proxies, advance directives and portable medical orders available and actionable across care settings

Just Right Care
The Right Care to the Right Person at the Right Time

8. Prioritize seriously ill patients with CKD and ESRD for primary and specialty supportive care interventions **
9. Provide medical management without dialysis to patients avoiding or delaying dialysis
10. Screen and manage pain and symptoms
11. Assess psychological and spiritual needs and address needs
12. Proactively identify and manage patients at high-risk for frequent hospital readmission

Throughout the Continuum
Enhanced Support at the End of Life

13. Coordinate care and care transitions with specialty palliative care and hospice
14. Offer palliative dialysis and systematic dialysis withdrawal process for appropriate patients**

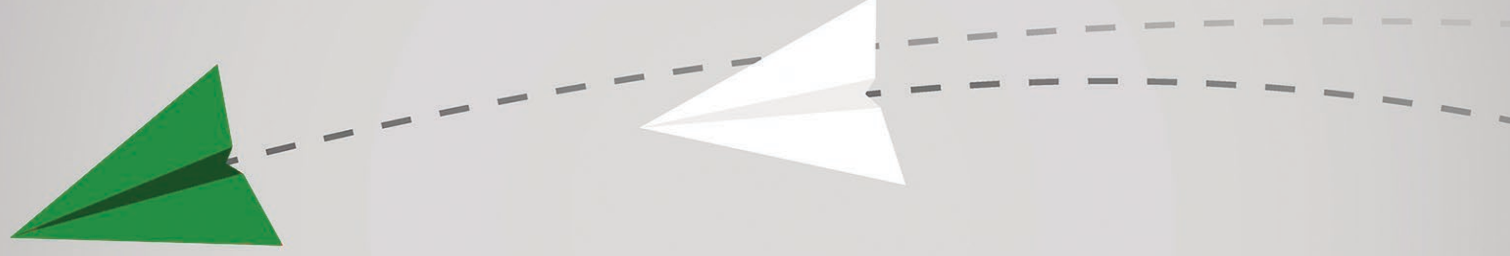
***Indicates a mandatory practice that project participants are required to test and implement*

Quality Insights

PATHWAYS Project

Coalition for Supportive Care of Kidney Patients

Publication number ESRD5-103117



Supportive Care Capacity

Create the System

Best Practice #1: Assemble the interdisciplinary team(s) needed to lead and implement supportive care

Purpose

The purpose of this best practice recommendation is to create sustained change in the dialysis and nephrology practice setting by establishing an interdisciplinary team(s) to lead change and carry out new processes. The team should include a day-to-day clinical leader and champion(s) who bring a mix of skills. Organizational leadership needs to commit to making it possible for the participating team to dedicate sufficient time, resources, and energy for the testing and implementation of new practices and processes.

There are two distinct areas that teams need to address: 1) leading and evaluating change and 2) delivery of supportive care services. Some organizations will prefer to designate distinct teams for each of these areas, while other organizations will have a single team engage in both.

Evidence

Leading Change – The Implementation Team

A key step in starting an improvement initiative is assembling an interdisciplinary team to lead the process. Successful change campaigns in areas such as reducing hospital-acquired pressure ulcers have found that interdisciplinary change teams are the most successful. This aligns well with the emphasis on interdisciplinary care in delivering palliative and supportive care. Effective implementation teams include members representing three different kinds of expertise within the organization: system leadership, technical expertise, and day-to-day leadership. The first task of the interdisciplinary team is to develop an aim statement and project plan in concert with organizational leadership.

Delivering Services – The Clinical Team

Kidney supportive care services are best delivered by an interdisciplinary team. Depending on how your service is organized, you may use a single team working across settings (CKD practice, dialysis centers, home-based end-of-life care) or different teams in each setting that coordinate closely to smooth transitions. Ideally, the team will include staff with strong supportive care expertise and will also have sufficient time from psychosocial providers such as social workers and chaplains.

In an organization that chooses to combine the two tracks of delivering care and leading the improvement effort, the overall team will consist of a supportive care interdisciplinary team, supplemented by additional members with skills and authority to manage change in areas such as information technology (IT) and medical records, finance, quality improvement, and staff education.

How to begin the improvement process:

1. Select the interdisciplinary team. Use worksheet to fill suggested roles.
2. Establish an aim statement based on your team(s) organization's strategic mission and vision. Develop a plan aligned with the established aim to guide improvement effort.

Innovation	Action	Outcome
Appoint interdisciplinary team.	Team develops an aim statement and project plan to guide change. (See Pathways Project Collaborative Charter for sample aim statements) Team meets at regular times sufficient to conduct work—test and implement recommended best practices. Some teams may meet weekly, especially at beginning of the Collaborative. Monthly meetings likely the minimum to be effective. Team provides services designed to test and implement evidence-based best practice recommendations.	Implement at least 3 evidence-based best practice recommendations (#5, #8, #14) in the Pathways Project change package.

Challenges and Strategies to Surmount Them

Challenge	Strategy
Interdisciplinary team doesn't have adequate time to plan and monitor Pathways Project.	Organizational leadership makes case for how Pathways Project advances organizational goals and priorities. Organizational leadership signs off on aim statement and project plan and advocates for resources needed for success.
Don't have access to specialty supportive care physician or nurse to serve on interdisciplinary team.	Use Pathways Project Collaborative team as opportunity to nurture relationship with supportive care service. Discuss with supportive care leaders the mutual opportunities and benefits.
Don't have ideal interdisciplinary team available for clinical team (especially social worker, chaplain, and dietitian).	Use planning for Pathways Project Collaborative implementation to determine how to access full interdisciplinary team. May start by "borrowing" hours from interested staff serving other services. Or can explore a contractual arrangement with supportive care service or other community agency.

Resources and Tools

- Worksheet to select team members
- Sample roles and job descriptions for a nurse-led model of renal supportive care (from Australia)
- Sample project charter

Key References

1. Davison, SN, Levin A, Moss AH, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Care in Chronic Kidney Disease: Developing a roadmap to improving quality care. *International Society of Nephrology*. 2015; 88 (3): 447-459.
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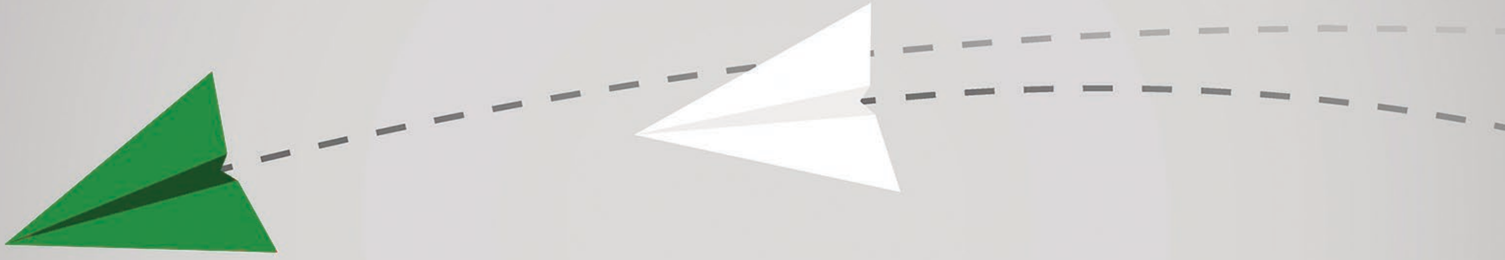
3. How Will We Manage Change? Agency for Healthcare Research & Quality. https://www.ahrq.gov/professionals/systems/hospital/pressureulcertoolkit/putool2.html.
4. Institute for Healthcare Improvement: Science of Improvement: Forming the Team. http://www.ihi.org/resources/Pages/HowtoImprove/ScienceofImprovementFormingtheTeam.aspx.



Supportive Care Capacity

Create the System

Best Practice #2: Assess unmet supportive care needs in patient population

Purpose

The purpose of this best practice recommendation is to give an overview of the need for and gaps in providing supportive care for patients with chronic kidney disease (CKD) and end stage renal disease (ESRD). Identifying these gaps is the first step in developing a plan to better address the needs of patients with kidney disease. A brief tool to assess the current level of supportive care implementation in a specific kidney care practice or organization is included.

Evidence

Supportive care aims to improve the health-related quality of life (HRQL) for patients with established CKD, at any age, and their families. Kidney supportive care can be provided together with therapies intended to prolong life, such as dialysis. Supportive care is provided by the kidney care team to help patients cope with living with serious kidney disease, regardless of life expectancy.

Use of supportive care and hospice care changes as disease progresses. Supportive care is offered by the kidney care team throughout the course of care for kidney disease. When more complex or refractory problems arise, the kidney care team partners with specialist palliative care providers to address these issues. As the disease progresses and the patient begins to value comfort more highly and wishes to minimize hospitalization, hospice care brings coordinated services focused on end-of-life needs. Hospice supports comfort and makes it possible for patients to stay at home (or in the setting of their choice).

Figure 1: Comparison of Supportive Care, Palliative Care and Hospice Care

	Supportive Care	Specialist Palliative Care	Hospice Care
Provider	Members of kidney care team who have additional training in supportive care principles and practices	Interdisciplinary team with specialty level training and certification	Interdisciplinary hospice team employed by Licensed & Certified Hospice Agency
When appropriate	Throughout the course of treatment for serious illness	At any stage of illness, whenever quality of life or goals of care are problematic	Last months of life, usually as goals of care begin to emphasize comfort
Representative skill set	Management of pain and symptoms	Management of refractory pain or other symptoms	Support for comfort and quality of life. Management of pain and symptoms in context of advancing and terminal disease progression. Management of active dying process. Support for comfortable end of life at home.
	Management of depression and anxiety	Management of more complex depression, anxiety, grief, and existential distress	Comprehensive psycho-social-spiritual support to patient and family in context of end-of-life, and continuing into bereavement period
	Discussions about -prognosis -goals of treatment -suffering -code status	Assistance with conflict resolution regarding goals or methods of treatment - Within families - Between staff and families - Among treatment teams	Delivery of comprehensive, coordinated services to allow patient to die in setting of their choice (usually at home) and minimize unwanted hospitalizations and ER visits. Includes, medical, nursing, drugs, equipment, counseling, spiritual care, volunteers.
		Assistance in addressing cases of near futility	Provision of 24/7 on call services. Bereavement follow-up of family.

Governing principles, guidelines or regulations	Davison SN, Levin A, Moss AH, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. *Kidney Int*. 2015;88(3):446-459. doi:10.1038/ki.2015.110	National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care, 3rd Edition*; 2013.	Medicare Hospice Conditions for Participation Final Rule, June 5, 2008 https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/Hospice/Hospice-Regulations-and-Notices-Items/CMS1215096.html?DLPage=1&DLEntries=10&DLFilter=condi&DLSort=3&DLSortDir=descending

The scope and evidence for supportive care in the United States has been well articulated in the National Consensus Project Guidelines, a series of Institute of Medicine reports and National Institutes of Health (NIH) and Agency for Healthcare Research & Quality (AHRQ) evidence reviews. For kidney care, the field has been guided by recommendations from an influential ESRD workgroup convened by the Robert Wood Johnson Foundation in 2002, guidelines from the Renal Physicians Association, and a recommendation from the Choosing Wisely Campaign. Internationally, Kidney Disease Improving Global Outcomes (KDIGO) held a controversies conference on supportive care in 2013 which built on prior reports. These works all concur that supportive care is needed for patients with kidney disease. Compared with many chronic disease populations, patients with kidney disease are among the sickest, with high comorbid disease burden, high symptom burden, and poor quality end-of-life care.

Despite the need, supportive care is not yet integrated into kidney care. Less than 5% of dialysis centers report that they provide high-quality supportive care to their patients. Dialysis centers identified bereavement support, spiritual support, and end-of-life care discussions as the top three unmet supportive care unmet of their patients. Goals of care discussions and shared decision-making are not routine, despite professional guidelines urging the practice. Symptom management is suboptimal, especially regarding psychosocial and spiritual distress.

The 2013 KDIGO Controversies Conference on Supportive Care in CKD urged making supportive care available to patients with kidney disease based on need, not prognosis, at any stage of kidney disease. To do this, KDIGO recommended actions to enhance:

- Symptom management
- Provision of prognostic information
- Shared decision-making and advance care planning
- Withdrawal from dialysis
- Provision of medical management without dialysis[1]

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[1] The Pathways Project prefers the term “medical management without dialysis” instead of other terms by which it has been referred, because in medical management without dialysis the patient receives full treatment but toward different patient-centered goals, comfort and quality of life.

Care Recommendations from the 2013 KDIGO Controversies Conference on Supportive Care in CKD

Symptom Assessment and Management

- Symptom assessment and management is an integral component of quality care for patients with advanced CKD. Regular global symptom screening using validated tools such as the ESAS-Renal and POS-Renal should be incorporated into routine clinical practice.
- Symptom management requires a stepwise approach. First-line treatment includes nonpharmacological interventions and then advances to more complex therapies. Second-line treatment is pharmacologic therapy. Consideration should be given to low-dose pharmacological therapy that may have efficacy across several symptoms.
- Current evidence is sufficient to support the development of clinical guidelines to aid in the stepwise approach to uremic pruritus, sleep disturbances, restless legs syndrome, pain, and depression in CKD.

Estimating Prognosis

- Estimate and communicate prognosis to patients and families, balancing biomedical facts with relevant emotional, social, cultural, and spiritual issues. Such communication should be viewed as an integral component of shared decision-making in order to align treatment goals with patient preferences. It will aid in the timely identification of patients who are most likely to benefit from supportive care and is essential for quality care.

Shared Decision-Making and Advance Care Planning

- Shared decision-making is recommended to align treatment with patient and family goals, values, and preferences. Because patients' health status, preferences, and treatment options may change over time, shared decision-making requires a flexible approach of reevaluation and redirection to ensure that the goals of care and treatment plans remain aligned with patients' values and preferences.
- The treatment care team should engage in advance care planning. These discussions should start early in the illness trajectory and should include discussions about health states in which patients would want to withhold or withdraw dialysis.

Withdrawal from Dialysis

- Withdrawal from dialysis is ethically and clinically acceptable after a process of shared decision-making. It is incumbent upon all providers caring for a patient contemplating stopping dialysis to address potentially remedial factors contributing to the decision such as depression or other symptoms such as pain as well as potentially reversible social factors.
- Situations in which it is appropriate to withdraw dialysis include the following:
    - Patients with decision-making capacity who, being fully informed and making voluntary choices, refuse dialysis or request that dialysis be discontinued.
    - Patients who no longer possess decision-making capacity who have previously indicated refusal of dialysis through appropriate advance care planning.

  - Patients who no longer possess decision-making capacity and whose properly appointed legal agents/surrogates refuse dialysis or request that it be discontinued.
  - Patients with irreversible, profound neurological impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment.
- Ensuring access to appropriate supportive and/or hospice care is an integral part of the care following a decision to withdraw from dialysis.

Comprehensive Medical Management without Dialysis

- "Comprehensive medical management without dialysis" is planned holistic patient-centered care for patients with G5 CKD that includes the following:
  - Interventions to delay progression of kidney disease and minimize risk of adverse events or complications
  - Shared decision-making
  - Active symptom management
  - Detailed communication including advance care planning
  - Psychological support
  - Social and family support
  - Cultural and spiritual domains of care

Improvement Process

The Pathways Project change package, which is an aggregate of 14 evidence-based best practices, is designed to help dialysis centers and nephrology practices that care for patients with CKD implement supportive care throughout the continuum of care. The first section of the change package, "Supportive Care Capacity: Create the System," provides guidance for establishing the resources and structure for delivering supportive care. The first step is to perform a needs assessment to determine strengths and weaknesses in the practice to help prioritize next steps in improving supportive care. The Kidney Supportive Care Implementation Quotient (KSC-IQ) assessment is available online to start this process.

Innovation	Action	Outcome
Use the online Supportive Nephrology Care Implementation Quotient (SNC-IQ) Assessment to assess staff perception of organizational strengths and weaknesses in supportive care.	As part of planning for change, broadly survey staff using the SNC-IQ. Use the findings to establish an aim statement and priorities for testing and implementing best practices. Repeat SNC-IQ staff survey yearly to monitor for improvement or changes in priorities.	Priorities specific to your practice setting for improving supportive nephrology care.

Resources and Tools

- Kidney Supportive Care Implementation Quotient (KSC-IQ) Assessment.
- Description of palliative care: https://getpalliativecare.org/whatis/
- International consensus on key priorities in implementing supportive kidney care. Davison SN, Levin A, Moss AH, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. *Kidney Int*. 2015;88(3):446-459. doi:10.1038/ki.2015.110.
- Practice guidelines: Renal Physicians Association. *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis: Clinical Practice Guideline*. 2nd ed. Rockville, MD: Renal Physicians Association; 2010. https://www.renalmd.org/store/ViewProduct.aspx?id=7014408

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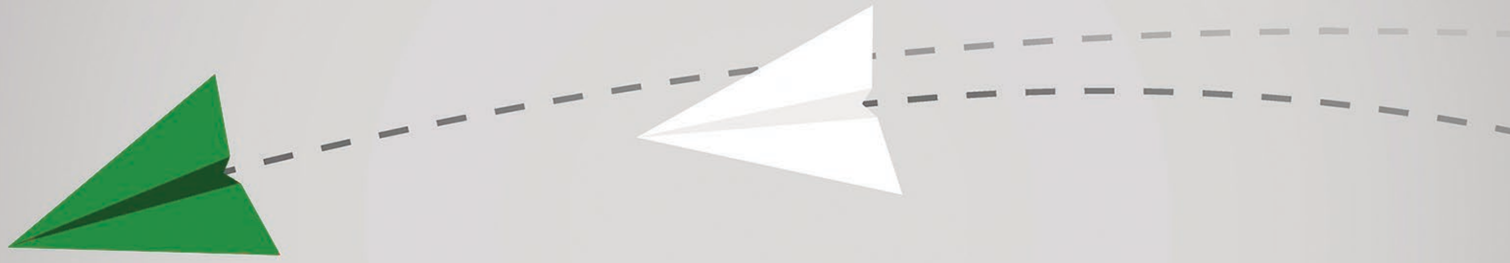

Supportive Care Capacity

Create the System

Best Practice #3: Provide education to staff on the principles and practices of primary supportive care

Purpose

The purpose of this best practice recommendation is to identify the knowledge and skills needed for chronic kidney disease (CKD) practice and dialysis center staff to provide supportive care to their patients. The goal is to increase their preparedness and confidence in providing this care.

Supportive care refers to basic management, which is provided by the kidney care team, of pain and symptoms, including anxiety and depression, and basic discussions about prognosis, goals of treatment, code status, quality of life, and suffering.

Evidence

Supportive care is especially appropriate for patients with CKD because, compared with many other chronic disease populations, patients with CKD are arguably among the sickest. In a 3-year cross-sectional retrospective study of over 50,000 deceased Veterans Affairs patients, those with end stage renal disease (ESRD) had the greatest comorbid disease burden, and their families rated the quality of their end-of-life care significantly worse than that for patients with cancer or dementia.

Patients with CKD and ESRD are characterized by multiple comorbidities, a high symptom burden, increased age, and a shortened life expectancy. Patients frequently have hypertension, diabetes mellitus, hyperlipidemia, and cardiovascular disease in addition to kidney disease. Patients older than 75 years are the fastest growing population on dialysis, and dialysis patients live on average less than one-third as long as age-matched patients without kidney failure. Patients with ESRD and advanced CKD experience a similar overall burden of physical and emotional symptoms including depression and comparably low quality of life.

There is a need for supportive care education for dialysis personnel; fewer than 5% of dialysis centers report they provide high-quality supportive care to their patients. They identified bereavement support, spiritual support, and end-of-life care discussions as the top three unmet supportive care needs of their patients.

Goals of care discussions and shared decision-making are poorly integrated into advanced CKD and dialysis patient care. In a large Veterans Affairs study of advanced CKD patients, the majority of patients over the age of 85 with the highest comorbid disease burden were started on dialysis even though they can be predicted to do poorly on it. The percentage of patients with advanced CKD choosing medical management without dialysis in the U.S. is significantly lower than in Canada, Australia, and the United Kingdom.

Most nephrologists have not received training in their fellowship on supportive care, and nephrologists and dialysis mid-level providers are largely unaware of the presence and severity of symptoms among their hemodialysis patients.

Improvement Process

Innovation	Action	Outcome
Designate a "champion" in the CKD practice or dialysis center to lead the education. Design and develop a program of supportive care education including the following topics: a. Seriously ill CKD and ESRD patient identification b. Pain and symptom management and assessment c. Shared decision-making and advance care planning d. Psychological and spiritual support e. Communication skills Implement supportive care education for all advanced CKD practice and dialysis center personnel.	Educate the champion in supportive care and network him/her with the Pathways team and local palliative care/hospice specialists for backup and support. Assemble a curriculum with the assistance of the Pathways Project Collaborative and local palliative care/hospice specialists. Develop an education strategy for CKD practice and dialysis center (in-person, online, handouts, etc.) to effectively and efficiently provide education. Explain what supportive care is, why it is relevant to the care of patients with kidney disease, how to assess pain and common symptoms using numerical rating scales, PAINAD, ESAS-Renal, IPOS-Renal, and PHQ-4. Identify patients at high-risk of death in next 12 months using	The champion becomes the "go to" person in the CKD practice or dialysis center for supportive care, owns the responsibility (which can be delegated) for pain and symptom management and advance care planning, and consults specialist supportive care for more complex cases. Supportive care curriculum is ready to implement. Team knows what supportive care is, which patients it might benefit and how, and how to assess and refer patients to champion for primary supportive care interventions. Patients' symptoms are assessed and managed. Patients with a predicted high-risk of mortality in 1 year are referred to champion, serious illness conversations are conducted, and outcomes are

Innovation	Action	Outcome
	“surprise” question and online CKD and ESRD calculators and know to refer high-risk patients from above for conversations. Team knows how to assess and refer patients with psychological and spiritual concerns. Team knows how to use Ask-Tell-Ask approach to identify patients and families who would benefit from discussion and refer them.	documented. Psychological and spiritual concerns are addressed. Conversations are conducted.

Challenges and Strategies to Surmount Them

Challenge	Strategy
Few or no personnel in CKD practice or dialysis center with supportive care knowledge and skills.	Solicit interest, recruit a champion, and provide training for champion/leadership role.
Champion/leadership may have interest but has no established skills or experience in supportive care education.	Network for mentoring with Pathways Project team and local supportive care/hospice personnel with knowledge, skills, and experience.
No time for education in already busy practice and dialysis center schedule.	Garner institutional buy-in for the time commitment and identify learner-centered preferences for supportive care education and use multiple formats as appropriate.

Resources and Tools

- Description of palliative care: https://getpalliativecare.org/whatis/
- BC Renal Symptom Assessment and Management: http://www.bcrenalagency.ca/health-professionals/clinical-resources/symptom-assessment-and-management. Accessed on November 20, 2017.
- Edmonton Symptom Assessment-Renal: http://www.palliative.org/NewPC/_pdfs/tools/ESASr%20Renal.pdf
- Integrated Palliative Care Outcome Scale-Renal (IPOS-Renal): https://pos-pal.org/maix/ipos-renal-in-english.php
- Patient Health Questionnaire-4 to screen for anxiety and depression: http://www.midss.org/content/patient-health-questionnaire-4-phq-4

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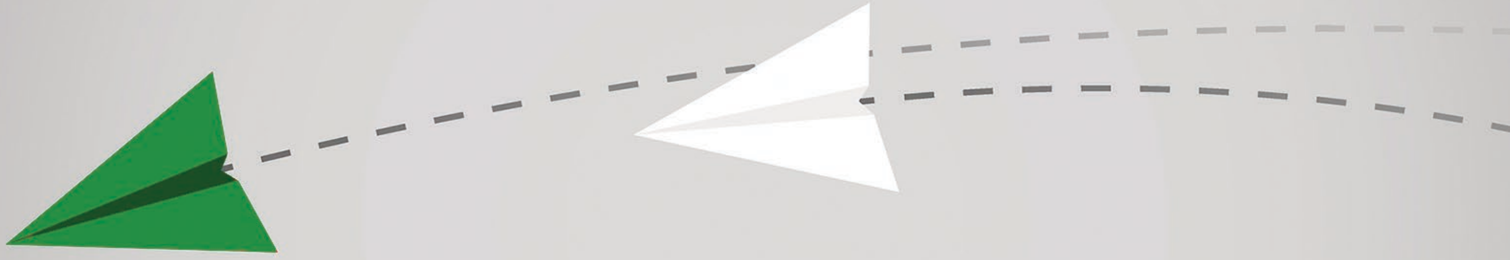
Quality Insights PATHWAYS Project Coalition for Supportive Care of Kidney Patients

Publication number: ESRD5-122117c



Supportive Care Capacity

Create the System

Best Practice #4: Collaborate with palliative care/hospice specialists

Purpose

The purpose of this best practice recommendation is to establish a close working relationship with local community-based palliative care and hospice programs, which is essential to developing supportive kidney care.

Benefits of close collaboration between nephrology and palliative care include:

- For patients: improved quality of life for patients through reduced symptom burden (physical and psychosocial).
- For patients: more consistent and earlier access to the “safety net” services (e.g., home visits, 24/7 call service) that can reduce ED visits and hospitalizations if symptoms escalate.
- For kidney care team: knowledge exchange improves supportive care skills, especially confidence in managing symptoms, addressing psychosocial issues, and holding goals of care conversation.
- For specialist palliative care team: knowledge exchange improves understanding of kidney-specific palliative care challenges.

Evidence

Dialysis center staff in the U.S. rank specialty palliative care consultation as the second most important change needed to improve supportive nephrology care. The 2015 Kidney Disease Improving Global Outcomes (KDIGO) conference on renal supportive care issued a strong call for improving supportive kidney care through better delivery of both primary and specialty palliative care to renal patients. However, there is little evidence comparing implementation options within renal populations. While the evidence for the impact of supportive/palliative care has been mounting for other patient populations (mostly patients with cancer and patients in the ICU), the evidence for renal patients remains scarce. Implementation questions, such as whether it is better to embed palliative care specialists into the renal team or refer patients to palliative care consultations, have not been empirically tested.

Qualitative evidence collected by the Pathways Project strongly suggests that effective collaboration between renal teams and palliative care teams is a critical success factor in implementing renal supportive care. All renal supportive care programs interviewed developed a collaborative process that went far beyond a typical “consult when needed” approach. One respondent called the relationship “symbiotic:”

> “I think the success of our program is because of our relationship with this palliative hospice team out in the community. They know us. We invite them to our education sessions. There's a real back and forth. They've learned a lot from us. We've learned a lot from them. It's a really symbiotic relationship.”

Improvement Process

Without evidence to suggest which approaches are most effective, the choice should be based on local opportunities and needs. Approaches to consider include:

- Provide care jointly: Outpatient kidney supportive care clinic run jointly by nephrologist and palliative care physician or palliative care advanced practice nurse, possibly also able to call on other members of palliative care team such as social worker and chaplain.
- Embed palliative care specialist into renal team: Palliative care physician or advanced practice nurse is added to renal practice.
- “Skill up” the kidney care team: At least one nephrologist or nephrology nurse takes additional training in palliative care.
- Intentionally network to build relationships and understanding: Joint educational workshops to support shared learning for nephrology and palliative/hospice staff to learn from each other.
- Consult triggers: Use consult triggers to generate consultation referrals to the palliative care team.

Innovation	Action	Outcome
Decide what collaborative approach(es) fits your program best and develop the contractual arrangements and procedures to implement. Whichever approach is selected, specialty palliative care consultation should be readily available.	Use a formal consult trigger to screen and refer patients for palliative care consultation. Track the proportion of seriously ill patients seen by palliative care specialists or in supportive care clinic. Conduct QI review to see impact of renal/palliative care collaboration.	Improved patient symptom scores and patient reported quality of life. Increased number of patients receiving specialty palliative care consultation. Increased number of patients referred to hospice. Increased number of patients who receive concurrent dialysis/hospice care (or concurrent dialysis/palliative

Innovation	Action	Outcome
		care). Improved kidney team's comfort with supportive care needs such as advance care planning and basic symptom management.

Challenges and Strategies to Surmount Them

Challenge	Strategy
Financial constraint: Cost of palliative care staff and services not usually fully covered by Medicare reimbursement.	Within ESCO structure, ESCO savings from avoided hospitalizations can cover the difference between cost of palliative care and billed revenue for palliative care services.
Financial constraint: Concurrent hospice care and dialysis not covered by Medicare for patients whose terminal diagnosis is ESRD.	1) ESCO covers cost of hospice home care (approximately $150/day) while patient transitions from dialysis treatment to hospice care, or 2) ESCO and hospice share risks for period of concurrent care, or 3) Hospice covers a defined number of dialysis treatments during transition period.
Capacity shortage: Local palliative care service does not have sufficient capacity to meet kidney care needs (usually applies only to non-hospice palliative care).	Joint planning between ESCO and palliative care service to develop shared capacity.

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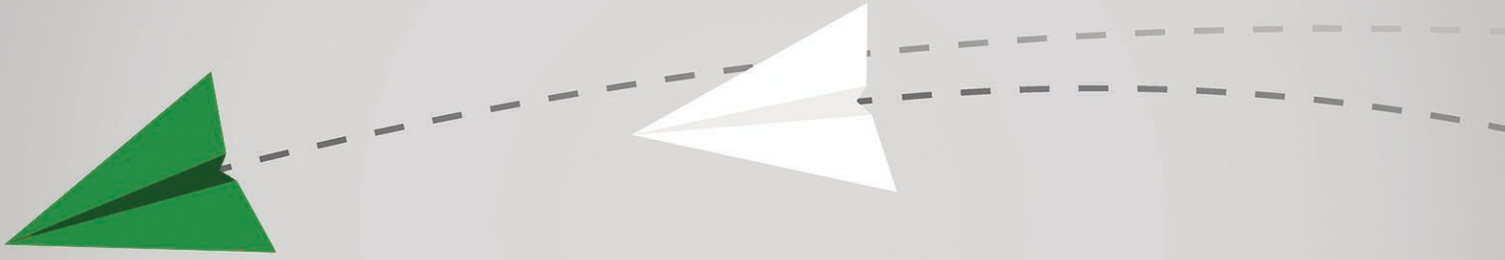

Values Guide Care

Elicit & Respect Patient Values and Preferences

Best Practice #5A: Advance Care Planning

Purpose

The purpose of this best practice recommendation is to inform clinicians of the importance and key elements of advance care planning and to provide them with an approach to implement advance care planning with patients with advanced chronic kidney disease (CKD) and patients on dialysis. The goal is for clinicians to engage seriously ill CKD and patients with end stage renal disease (ESRD) in advance care planning so that the patients' wishes for end-of-life care can be known and respected.

Evidence

Advance care planning is a process of communication 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. The goal of advance care planning is to help ensure that people experiencing serious and chronic illness receive medical care that is consistent with their values, goals, and preferences even when they become unable to make decisions for themselves.

Advance care planning involves 1) designating a healthcare surrogate who will be empowered to make decisions on the patient's behalf if the patient becomes unable to; 2) engaging in a goals of care conversation eliciting preferences and values that the patient wants to guide his or her future care; 3) discussing those preferences with family, the healthcare surrogate, and the medical care team; and 4) documenting in appropriate formats so the patient's wishes are actionable and legally enforceable.

The benefits of the advance care planning process and goals of care conversation include 1) that patients get more of the care they want (such as time at home) and less of what they don't want (such as ICU days at the end of life); 2) that clinicians know with whom to make decisions if patients lack decision-making capacity; and 3) that families experience less anxiety and guilt over decisions they make on their loved one's behalf.

Through two decades of research and systematic reviews of the literature, we have learned:

- Advance care planning is an ongoing process involving two-way communication that incorporates patient values and preferences.
- Multimodal interventions that build on communication are usually more effective than a narrow focus on forms to be completed.
- Family members often do not know what patients prefer, even when they are the designated decision-makers.
- Patients and family members prefer earlier communication and feel empowered by an advance care planning process.
- Advance care planning does not have a detrimental effect on distress, anxiety, or hope.
- Some interventions improve concordance between patient preferences and care received.
- Some interventions may reduce costs, although true cost-effectiveness has not been studied.

Improvement Process

Innovation	Action	Outcome
Designate a team member(s) to lead team in advance care planning process and goals of care conversation with patients.	Routinely invite all patients to engage in advance care planning and goals of care conversation.	Increased number of patients with healthcare proxy and contact information in medical record.
Provide patient information booklets and websites with resources.	Provide information and education about advance care planning to patients and families.	Increased number of patients with advance directives/medical orders (POLST/MOLST) in medical record.
Have a place in the electronic medical record (EMR) and/or registry where advance directives/medical orders are stored and retrieved.	Integrate advance care planning and goals of care conversation into work flow. Include steps for providing information and education, eliciting patient choices, helping patient discuss with family.	Increased referrals to supportive/palliative care and hospice services.
	Routinely document advance care planning and goals of care conversations in medical record using standard template, including proxy decision-maker.	Patients' treatment wishes respected at the end of life.
	Routinely store up-to-date advance directives/medical orders in EMR and/or registry	

Innovation	Action	Outcome
	accessible to personnel. Revisit advance care planning and goals of care annually or when condition changes. For sicker patients (“surprise” question – “no” response, recent hospitalizations, worsening function), nephrologist completes POLST/MOLST and submits to EMR/registry.	

Challenges and Strategies to Surmount Them

Challenge	Strategy
Concern that talking about end of life may be upsetting.	Normalize advance care planning and goals of care discussion. “Advance care planning is something I talk about with all of my patients. Most people find it helpful to have a plan B – just in case.”
Racial, ethnic and cultural differences in approaches to advance care planning and end-of-life preferences not well integrated into conversations, tools.	A consistently patient-centered approach considers knowledge gaps and poor health literacy and tailors communication to an appropriate literacy level and makes room for patients and families to bring their own values and preferences into the conversation. Look for tools and guides that have been tested with a wide variety of patients.
No time (especially for nephrologist).	Designate a team member (with appropriate training) such as nurse or social worker. Nephrologist introduces importance of advance care planning and then turns over to staff to carry on with details of goals of care discussion. Bill for discussions to receive reimbursement (Medicare 99497 and 99498).

Resources and Tools

- Make Your Wishes About You (MY WAY) patient guide: “Planning Today for Tomorrow’s Healthcare: A Guide for People with Chronic Kidney Disease”: https://kidneysupportivecare.org/Files/ACPforCKDbrochure4302018Web.aspx

- MY WAY coaching curriculum: “Curriculum Guide for Advance Care Planning”: https://kidneysupportivecare.org/Files/CurriculumGuideAdvanceCarePlan4302018bWeb.aspx
- Serious Illness Conversation Guide—7 questions to ask and suggested format for discussion: https://www.researchgate.net/publication/259316398_Serious_Illness_Communications_Checklist
- The Conversation Project: http://theconversationproject.org/ and http://www.ihi.org/resources/Pages/IHIWhitePapers/ConversationReadyEndofLifeCare.aspx
- Prepare for Your Care: https://www.prepareforyourcare.org/page
- State-specific legal forms in all states: www.caringinfo.org/i4a/pages/
- Choosing a healthcare proxy and power of attorney: How to Choose a Health Care Proxy & How to Be a Health Care Proxy Workbook and Giving Someone a Power of Attorney For Your Health Care
- Frequently Asked Questions about Billing the Physician Fee Schedule for Advance Care Planning Services: https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeeSched/Downloads/FAQ-Advance-Care-Planning.pdf
- Quality Advance Care Planning Chart Audit and Review Form

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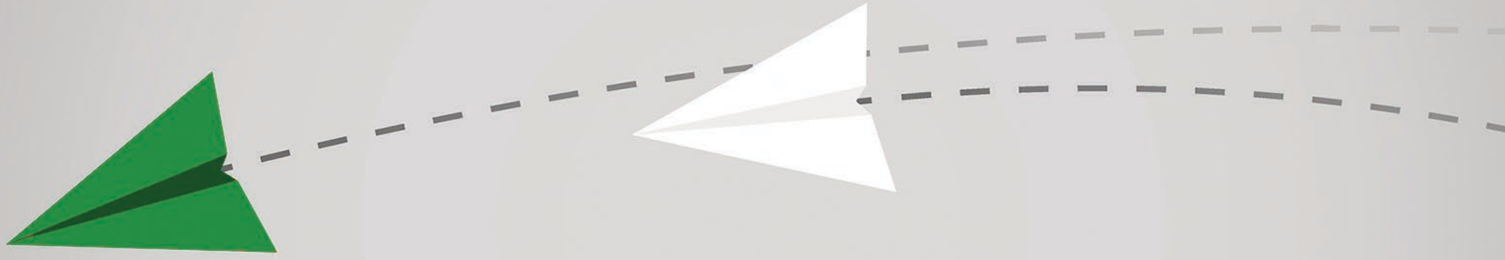

Values Guide Care

Elicit & Respect Patient Values and Preferences

Best Practice #5B: Shared Decision-Making

Purpose

The purpose of this best practice recommendation is to describe why shared decision-making is key to implementing patient-centered supportive care and to provide a framework for delivering supportive care. The goal is for nephrology clinicians to incorporate shared decision-making into all aspects of medical treatment decisions for patients with advanced chronic kidney disease (CKD) and end stage renal disease (ESRD).

Evidence

Shared decision-making is the recognized preferred model for medical decision-making because it addresses the ethical need to fully inform patients about the risks and benefits of treatments, as well as the need to ensure that patients' values and preferences play a prominent role. It has been described as the *pinnacle* of patient-centered care. Because of the number and complexity of decisions involved in treating kidney failure, a shared decision-making relationship is particularly important for patients with acute kidney injury—stage 4 and 5 CKD—and those requiring dialysis for ESRD. Participants in shared decision-making should involve at a minimum the patient and the physician. In addition, patients should identify and include a person who could serve as their decision-maker in the event they lose decision-making capacity. If a patient lacks decision-making capacity, decisions should involve the person legally authorized to make healthcare decisions on behalf of the incapacitated patient.

The American Society of Nephrology (ASN), the Renal Physicians Association (RPA), and Kidney Disease: Improving Global Outcomes (KDIGO) all recommend shared decision-making to assist patients and families in making decisions about whether to start, continue, or stop dialysis.

Shared decision-making involves:

- Establishing a relationship between physician and patient
- Fully informing patients about diagnosis, prognosis, and all treatment options (including medical management without dialysis)

- Providing an estimate of prognosis specific to the patient, as well as information about the impact on quality of life of various options
- Making a joint decision about treatment

Although shared decision-making and decision aids have sometimes been conflated, decision aids are only one tool for encouraging shared decision-making, which is, at its heart, a collaborative relationship between the patient and the medical team. A review of over 100 trials of decision aids found that after exposure to the tools, patients' knowledge increased, patients made more accurate assessments of risk, they reported more involvement in decision-making, they did not become more anxious, and they reported being more satisfied and more confident in their decisions.

Sadly, shared decision-making is poorly integrated into the care of patients with kidney disease. Most patients requiring dialysis are unable to recall a discussion of the risks and burdens of dialysis, and less than 10% recall being told of an option for medical management without dialysis. Research has found that patients with CKD and ESRD wish to have prognostic and quality of life information, while the majority of nephrologists report reluctance to discuss prognosis, even when prompted. Patients report that they have a sense of no real choice—"there was no decision—it just happened"—and nephrologists feel compelled to offer dialysis to every patient, regardless of predicted benefit.

For older, frail patients with CKD for whom the benefits of dialysis may be uncertain, a shared decision-making process that takes account of specific patient concerns and capacities is especially important. An Australian study found that patients choosing between dialysis and medical management without dialysis were willing to forgo, on average, seven months of life expectancy to reduce the number of required visits to the hospital and 15 months of life expectancy to increase their ability to travel.

Improvement Process

Innovation	Action	Outcome
Have available high quality decision aids and patient education material, including web resources. Have available an evidence-based tool for estimating patient-specific prognosis.	Provide education and training to the team to increase skill and comfort in conducting shared decision-making conversations. Ensure shared decision-making conversations are conducted with patients with the worst prognoses incorporating patient-specific estimates of prognosis to the extent desired by the patient. Use decision aids and education material that include information about medical	Increased patient and family comfort with treatment decision process. (Consider measuring with CollaboRATE tool) Increased number of seriously ill patients with CKD who are informed of medical management without dialysis as an option. Decreased number of patients regretting that they started dialysis.

Innovation	Action	Outcome
	management without dialysis. Use best case/worse case decision aid for seriously ill patients with advanced CKD considering dialysis. Provide patients with relevant information about likely impact of decisions on quality of life, including time spent in medical treatment.	

Challenges and Strategies to Surmount Them

Challenge	Strategy
Concern that these conversations are too time-consuming.	Train team members such as nurse educator and/or social worker to conduct conversations. Use decision aids (such as booklets and websites with videos) that patient/family can explore before and after discussions.
Conversation is held by one provider, but never conveyed to others, nor updated.	Designate a structured way to share advance care planning information among team members, including nephrologist and other physician specialists. The electronic medical record (EMR) may be helpful, but also require workflow adaptations.
With respect for a variety of cultural backgrounds and customs, concern that some patients will not want to have these discussions.	Use an “Ask-Tell-Ask” approach to offering a culturally respectful process.
Existing patient education material subtly biased against medical management without dialysis.	Use decision aids/ patient education materials that give balanced discussion of medical management without dialysis as an appropriate option for some people.
Discomfort felt by team or family members who consider withholding dialysis as unethical.	Educate team members about uncertain value of dialysis for frail older patients with comorbidities.
Uncertainty in prognosticating.	Acknowledge uncertainty and help patients to understand how to think about it.

Resources and Tools

Evidence-based decision aids that include medical management without dialysis

- Best Case/Worst Case Decision Aid

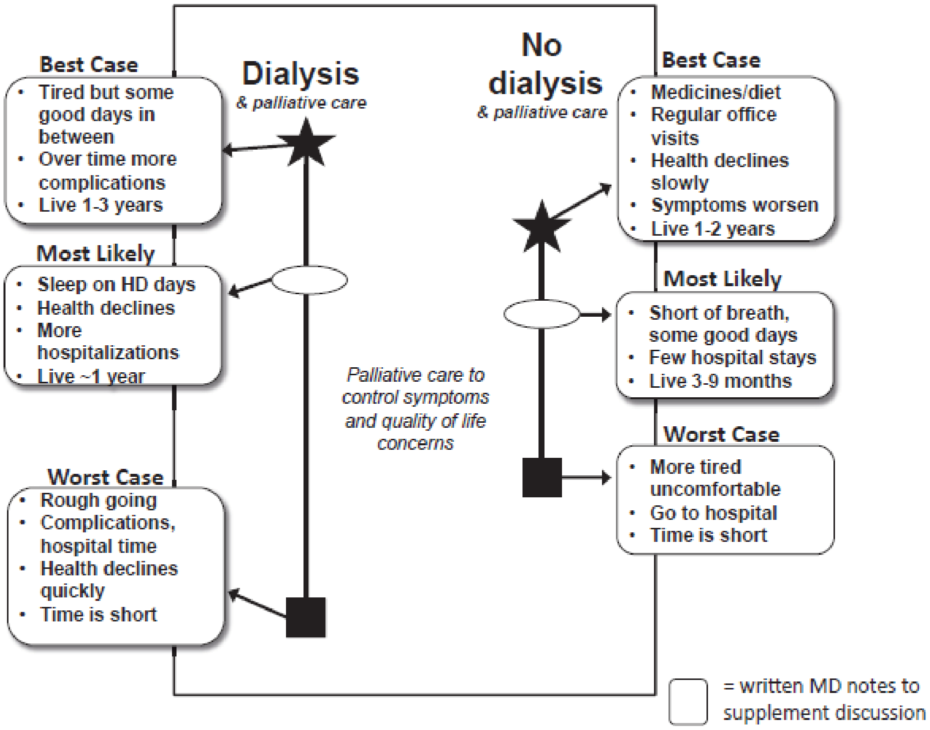

Figure 1. "Best Case/Worst Case" tool involves the drawing of a pen-and-paper diagram by the physician. Each treatment option is depicted by a vertical bar; the length of the bar represents the range of possible outcomes. The "best case" is represented by a star; the "worst case," by a box; and the "most likely" outcome, by an oval. The physician describes each "case" using narrative derived from clinical experience and relevant evidence and writes key points on the diagram. Abbreviation: HD, hemodialysis. Adapted from Kruser et al[11] with permission of John Wiley and Sons.

Grubbs V. Time to recast our approach for older patients with ESRD: The best, the worst, and the most likely. Am J Kidney Dis. 2018;71(5):605–607. Adapted from Kruser et al with permission of John Wiley and Sons.

- YODDA - Yorkshire Dialysis Decision Aid, University of Leeds: http://www.yodda.leeds.ac.uk/Survey/Outcomes?page=8
- My Kidneys, My Choice: https://www.cann-net.ca/images/Patient_decsion_aid_for_treatment_of_kidney_disease_Canada-_Feb_6_2014.pdf
- Health professionals' guide to My Kidneys, My Choice decision aid: http://kidney.org.au/cms_uploads/docs/my-kidney_my-choice_health-professionals.pdf
- Australian website: http://kidney.org.au/cms_uploads/docs/mykidneymychoice-for-patients.pdf

Additional websites with tools and information useful in shared decision-making discussions

- Kidney supportive care resources: https://stgrenal.org.au/renal-supportive-care#Hub
- Online prognosis calculators for ESRD patients (hemodialysis patients): http://www.touchcalc.com/calculators/sq

- Online prognosis calculator for CKD patients: https://qxmd.com/calculate/calculator_446/predicting-6-and-12-month-mortality-in-ckd-patients
- U.S. Department of Veterans Affairs Goals of Care Conversations Training: https://www.ethics.va.gov/goalsofcaretraining/Practitioner.asp
- Communication skills pathfinder: https://communication-skills-pathfinder.org/about/

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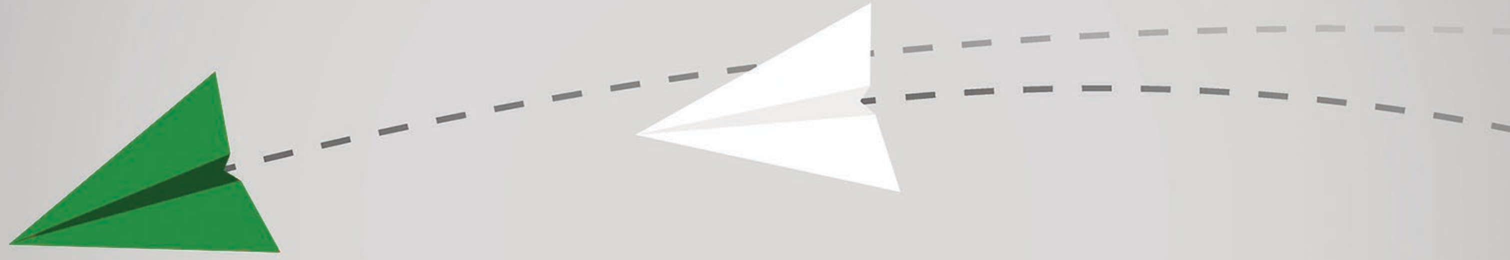

Values Guide Care

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Best Practice #6: Welcome, support, and involve family (as defined by patient) in the care process, to the extent desired by patient

Purpose

“No man is an island, entire of itself.” John Donne, 1572-1631

The purpose of this best practice recommendation is to inform clinicians of the importance of family caregiver involvement and the roles they can play in increasing the overall quality of life of patients with advanced chronic kidney disease (CKD) and end stage renal disease (ESRD). The goal is to prepare clinicians to engage family caregivers in all aspects of the patient’s care (as allowed by the patient) and to decrease caregiver burden and stress by learning about their needs and referring them to community resources to support the patient and family.

Family, friends, and community are key to supporting health and providing care during illness, but actively welcoming family (as defined by the patient) into healthcare processes can be daunting. The U.S. healthcare system, with its ethical emphasis on individual autonomy, legal protections for privacy, and reimbursement system rooted in individual coverage, puts up many barriers to meaningful family involvement. This Best Practice suggests initial steps kidney care providers can take to foster family involvement. Evidence for these practices is still scarce in the kidney care area, so these recommendations are offered to stimulate innovation by kidney care teams.

Evidence

At least 17.7 million individuals in the U.S. are family caregivers of someone age 65 and older who has a significant impairment. Caregiving creates substantial health and economic burdens, with caregivers having higher rates of depressive symptoms, anxiety, stress, and emotional difficulties, elevated levels of stress hormones, higher rates of chronic disease, and impaired health behaviors. Caregivers also experience economic harm, in part because of the many hours of care and supervision and the costs of hiring help. For some, caregiving can bring positive impacts along with the stress. Numerous surveys suggest that, for some people, caregiving instills confidence, provides lessons on dealing with difficult situations, brings them closer to the care recipient, and assures them that the care recipient is well cared for.

In the kidney care context, most caregiving studies have looked at caregivers of dialysis patients, where significant burdens and quality of life decrements have been documented. If caregivers burn out or suffer ill health themselves, this can have a deleterious impact on the patient's care. On the other hand, engaging and supporting caregivers can positively impact the patient. Patients who have caregivers engaged in physician visits are more likely to verbalize an understanding of dialysis options, more likely to receive care that is congruent with their own unique values, and less likely to have depression. Including family members in medical visits can help caregivers become better prepared for the challenges of caregiving. Even though the initiation of dialysis often comes at a time when patients are very ill and having thoughtful discussions with families and physicians is difficult, talking about options including supportive care has been shown to ease caregivers' anxiety about the future.

The Institute of Medicine suggests that physicians can play a crucial role in connecting caregivers to necessary resources. Caregivers who believed physicians listened during visits experienced less depression, and extensive family counseling has been shown to reduce length of stay in the intensive care unit (ICU) by one day. A randomized control trial found that caregivers of patients with dementia were four to five times more likely to use support groups or supportive counseling when referred by their physician. Interventions such as the Enhanced Discharge Planning Program, which engage caregivers by addressing caregiver needs and developing strategies to support caregivers, have been shown to decrease caregiver burden and stress.

The understanding that healthcare impacts families and that families in turn impact healthcare is gaining broader acceptance, but the evidence to determine how best to support families is still developing. The Institute for Patient- and Family-Centered Care offers a comprehensive array of training, technical assistance, and resources to involve families in hospital, ICU, and primary care, but has not yet offered specific resources for kidney care. Suggestions for intervention range from provider-level actions to system-level change. Relatively simple actions that could be implemented in a kidney care setting involve:

- Screening family members to identify mental health needs and caregiver burden needs
- Including family members' names in medical record
- Including family members in decision-making
- Training family members in care tasks

Improvement Process

Successful family engagement can be initiated by introducing open-ended questions about family views, offering empathetic responses, and making referrals to community resources to help family members and caregivers. Referrals to community resources should extend beyond providing phone numbers to include a warm handoff and ongoing engagement with community resources.

Innovation	Action	Outcome
Nephrologist to engage caregivers in discussions about caregiver expectations and needs. Nephrologist (or supportive care team) to engage patient and caregivers in discussions about shared decision-making prior to hemodialysis initiation. Designate a team member to conduct yearly assessment of caregivers. Develop list of local resources to support caregivers, including caregiver support groups, respite care, counseling, and funding resources for caregivers (e.g., transportation). Designate adequate space where family members can be comfortably engaged while patient is receiving care. Establish a bi-monthly “CKD/ESRD Resources Workshop” for patients and caregivers. Provide educational materials tailored to family members (e.g., brochures or information that discusses the role of caregiver as CKD and ESRD progresses, guide to local resources).	Conduct assessment of caregivers at least annually. Ask caregivers: “How is caregiving going for you?” “How is the family doing?” Add empathetic responses such as “It must be a very difficult time for you.” Nephrologist uses Serious Illness Guide to engage families in discussions about shared decision-making. Make list of local resources available to caregivers in brochure, on bulletin board, and on website. Refer caregivers who score high on assessment to local support and education groups and community resources. Make information available in waiting room via brochure, commercial, or bulletin board. Invite family members to attend dialysis, attend team meetings, or hold private meetings. Hold meetings for caregivers and patients every 2-3 months and invite all new patients’ caregivers to attend. Invite guest speakers, such as nephrologist, elder care attorneys, and respite care agencies. Consider surveying	Decreased caregiver burden and stress. Increased family understanding of patient’s values and wishes; decreased conflict at points of crisis. Identification of high risk caregivers – caregivers at increased risk of decline in well-being and/or ability to provide care (e.g., prevalence of physical symptoms, increased mortality, higher rates of depression, etc.). Increased access to supportive resources for caregivers and decreased caregiver stress. Increased collaboration and communication with caregivers. Increased access and understanding of community resources for patients and families. Increased staff understanding of unique needs of patients and caregivers.

Innovation	Action	Outcome
Provide programming for family members, such as engagement and education groups.	caregivers and patients about unmet needs and establish programming to address those needs.	
Provide bereavement support or identify local hospice bereavement group to refer caregivers to at time of death.	At time of patient death send bereavement card and list of local bereavement resources.	

Challenges and Strategies to Surmount Them

Challenge	Strategy
Culture of U.S. healthcare system, nephrology especially, is focused on organs and parts of a person. It is unfamiliar with expanding focus to whole individual, let alone family system.	Involve team members such as social workers and chaplains who have been trained in a system view that incorporates family and community.
Privacy and autonomy concerns about sharing health information.	Recognize that while some people do have privacy concerns, others feel equally strongly about having family members informed and helping to make decisions. Obtain explicit permission and direction from patients as to whom they would like to have involved in visits, education sessions, decision-making.
Clinicians are unfamiliar with tools for assessing caregiver and family functioning.	See assessment tools in a comprehensive inventory of caregiver assessment measures compiled by the Family Caregiver Alliance: https://www.caregiver.org/selected-caregiver-assessment-measures-resource-inventory-practitioners-2012 See webinar from Family Caregiver Alliance: https://www.caregiver.org/webinar-caregiver-assessment-i-why-and-what-should-we-assess Consider using caregiver risk screening tool: http://www.msvu.ca/site/media/msvu/CRS%20%20English%20WATERMARK.pdf
Little or no reimbursement for assessing or caring for someone who is not the identified patient.	Palliative care consults often include family. Social work services, if covered, can include family.
Clinicians have no time for or are uncomfortable with complexity of involving multiple family	Palliative care consult can address complex family issues.

Challenge	Strategy
members, especially when there is family conflict.	Designate staff member to take responsibility of reaching out to caregivers. Consider exploring billing at higher level or using advance care planning code, when appropriate.
Caregivers are at high risk for burnout.	Invite caregivers to office visit or dialysis. Yearly assess caregivers using caregiver risk screening tool.
Clinicians unfamiliar with community resources.	Develop resource list for caregivers and families and include in brochure, bulletin board, or commercial. Consider scheduled, regular “resource programming” to connect patients and caregivers to known resources.
No strategy to engage bereaved caregivers.	Send bereavement card and include list of local bereavement resources.

Resources and Tools

- Caregiver Risk Screening Tool: http://www.msvu.ca/site/media/msvu/CRS%20%20English%20WATERMARK.pdf
- Institute for Patient- and Family-Centered Care: http://www.ipfcc.org/
- Family Caregiver Alliance. National Center on Caregiving: https://www.caregiver.org/
- How to Run a Family Meeting: http://www.clinicaladvisor.com/critical-care-medicine/how-to-run-a-family-meeting/article/584832/
- *Warm Handoffs: A Guide for Clinicians*: https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/patient-family-engagement/pfeprimarycare/warm-handoff-guide-for-clinicians.pdf and https://www.ahrq.gov/professionals/quality-patient-safety/patient-family-engagement/pfeprimarycare/interventions/warmhandoff.html

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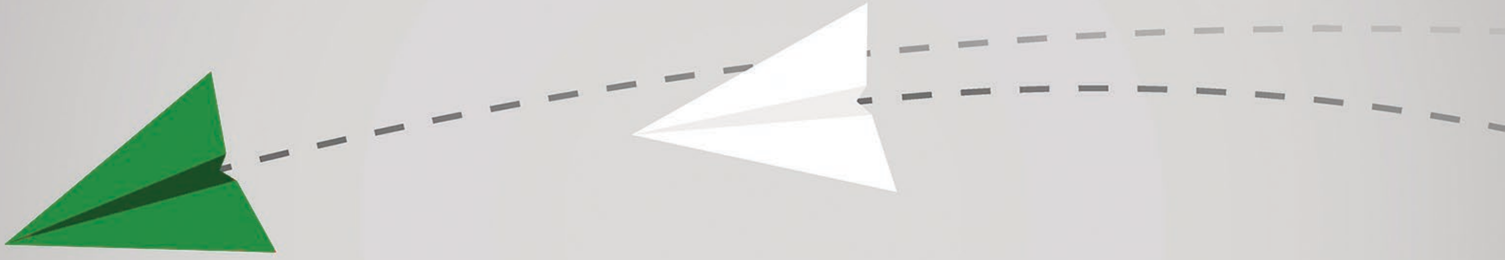

Values Guide Care

Elicit & Respect Patient Values and Preferences

Best Practice #7: Create structures (EMR, registries) to make proxies, advance directives, and portable medical orders available and actionable across care settings

Purpose

To be actionable, patient preferences as expressed in advance directives, documented in goals of care conversations, and recorded in medical orders (POLST/MOLST) must be readily available across all settings in which the patient is cared for.

The Institute for Healthcare Improvement (IHI) Conversation Ready project says:

> Knowing, confirming, and documenting patients' end-of-life care wishes is as important as knowing, confirming, and documenting their allergies. Just like allergy information, information about end-of-life care wishes should be readily accessible in patients' health records. Many healthcare systems have existing processes to prompt providers to ask patients if they have a proxy and/or advance directive, but often there is no means to document additional information beyond a "Yes/No" response — and no place within the health record to reliably record additional information...

There are three general approaches for making advance directives available across the care continuum:

1. Low-tech approaches relying on patient/family to bring copies with them to emergency department, hospital, nursing home, etc.
2. Standardized formats or templates within an electronic medical record (EMR) that are accessible by multiple providers.
3. Registries of advance directives or of POLST forms that any provider can check. Usually providers cannot access these directly from the EMR but must log in to registry separately.

Benefits of establishing a systematic approach to accessing advance directives:

- **For patients:** Increased confidence their wishes will guide treatment if they are unable to speak for themselves.
- **For providers:** Saves time in finding content of advance directives, medical orders, proxy decision-makers, and results from earlier goals of care discussions.
- **For healthcare systems:** Systematizes and supports advance care planning, which is associated with more patient-centered care and lower end-of-life costs.

Evidence

Using EMRs to support advance care planning

This is a rapidly evolving area, as EMR capacity is changing quickly. A 2017 review identified 16 observational and experimental studies of using the EMR to improve advance care planning. Nine of these studies reported comparisons of the studied EMR intervention, and all of the studies reported efficacy in improving one or more advance care planning outcomes. However, only one of these was a randomized control trial, and none looked specifically at nephrology settings or patients with kidney disease. The types of EMR changes covered included:

- **Documentation templates:** Three studies used templates with structured elements, limiting documentation to a coded schema, while five other studies used templates to indicate components that should be documented, but did not specify how data were to be entered. Template content included fields for documentation of a surrogate and sections for documentation of the patient’s goals or values. None of the identified templates reported specific fields for prognosis or expected outcomes of treatments, which the authors identified as an opportunity for improvement.

- **Electronic order sets:** Order sets were an early approach to advance care plan documentation. All of the described order sets included code status orders. Inclusion of other orders, such as treatment limitations, limiting hospital transfer from a nursing home, antibiotics, and nutrition and hydration, varied.

- **Automated prompts:** Eight studies used the EMR to prompt advance care planning discussions. Triggers included patient age, diagnoses associated with limited life expectancy, nursing home admission, placement of do-not-resuscitate (DNR) orders, or code status orders that were discrepant from prior orders. Most prompts appeared as alert boxes in the EMR screen, although one was emailed and one prompt printed to a paper encounter document, while another appeared on the electronic problem list utilized in an ambulatory clinic.

Using registries to support advance care planning

Registries can be designed to support two functions: electronic completion of forms online or repositories for forms. Registries may also combine these functions.

- **Electronic form completion systems:** These are software or web-based modules allowing electronic documentation of POLST orders or other advance care planning documents, resulting in printable POLST forms or other forms or documentation. These systems allow hard-coded programming to reduce error and prevent combinations of orders that are not actionable. They can require that certain information be captured, reducing data errors or incomplete data. They can also be programmed to walk users through form completion, prompting with information or education. Guides for the conversation between healthcare professionals and patients, including potential scripts, can be built in. These systems may be stand-alone, integrated into an EMR, or accessible through a health information portal or exchange.

- **Form repositories:** Repositories are databases, either stand-alone or web-based, designed to store forms, generate content, or both, and to make that information available when needed. This model primarily supports document storage. Data may be entered manually or captured from EMRs. Individuals can submit their own documents via mail, fax, or in-person while healthcare professionals may submit directly through their hospitals, health systems, clinics, or other care environments.

- **Hybrid electronic form systems with repository functionality:** A hybrid system combines the two systems described, allowing electronic form completion with form storage functionality or, alternatively, with automated submission to a related repository.

There are several types of registries currently in use. The most well-known registries are the POLST/MOLST registries which are codified in state law in seven states. Since POLST forms are completed by providers, not patients, POLST registries are accessed only by providers. On the other hand, another type of state registry accepts and holds forms directly from consumers. These registries currently operate in 13 states. Finally, at least seven national registries are also in operation. While use of the POLST form itself has been well-characterized and impact of POLST registries in a few states has been assessed, there is as yet no published overview of efficacy of all types of advance directive registries.

Improvement Process

1. Determine whether you will use a low-tech approach (such as a folder with paper copies of forms), your existing EMR, or a state or national registry, or some combination of these.
    a. Assess registry options available in your state. There may be an existing program you can follow to encourage patients to enter their information and providers to check for it. Review the national registry options to see if any could meet your local needs.
    b. Assess the capacity of your EMR to record and display advance care planning information and to hold advance directives and medical orders. EMR companies are constantly adding capacity. There may be an available module to support advance care planning that you can deploy. You may even be surprised to find that your current EMR already has adequate capacity and it is more a matter of creating processes so that providers can use that capacity consistently and effectively.

    c. Consider using the low-tech approach to supplement EMR and registry approaches, especially in the interim while EMR and registry projects are being ramped up. As an example, see the "Green Sleeve" used in Alberta, Canada, which can be found in the Resources and Tools section of this document.
2. Carefully consider workflow.
    a. Conduct a careful evaluation of the actual work flow for eliciting and recording advance care planning information. Note who is responsible, whether it is performed consistently, and the barriers that may exist.
3. Establish or clarify process for entering advance care plan information in EMR or registry.
    a. Who is responsible for entering advance care plan information? For uploading forms received from patient?
    b. How often is advance care plan information reviewed/verified? By whom?
    c. How is advance care plan information transmitted to other providers, especially during transitions of care?
    d. Especially for dialysis centers, make sure that advance care plan information is routinely included along with other clinical data— such as dialysis prescriptions, medication lists, run sheets, or monthly laboratory values— that is transmitted at transitions in care, especially to the acute care setting where inpatient or subsequent dialysis will be provided.
    e. How are copies provided to patient for sharing with family and other providers?

Innovation	Action	Outcome
Establish a system that makes advance care planning information available across settings. This might be electronic – such as a registry accessed by all providers, an EMR template or section for advance care plan, or a paper-based system such as the Alberta "Green Sleeve" program.	Encourage patients to have their advance care plans up to date in whichever system is being used. Educate providers (nephrology team and any associated emergency and inpatient providers) how to enter and access patient's current advance care plan information.	Increased proportion of patients with recent advance care plan in EMR or registry. Increased proportion of patients whose wishes are conveyed accurately during transitions. For patients who have elected medical management without dialysis, reduce pressure to start dialysis on emergency basis.

Challenges and Strategies to Surmount Them

Challenge	Strategy
EMR constraints: Changing an EMR can take a very long time, both in programming changes and in getting staff to understand and adopt EMR capacity.	Try small changes and tips, such as Epic SmartPhrases (also known as "dot phrase"), to make better use of existing EMR capacity. For instance, many EMRs already have an advance care planning note section, but it is not consistently

	used or checked. Decide how to use the existing record, and then encourage, audit, and reward its use.
If not already available in your state, establishing a registry from scratch may be too big for a nephrology team to tackle.	Start small and simple. Implement something like the Alberta "Green Sleeve" – a folder that patients keep with them if they go to the hospital and that EMS knows to check if in a patient's home.

Resources and Tools

- Alberta "Green Sleeve" Program: http://www.albertahealthservices.ca/assets/Infofor/hp/if-hp-acp-fast-fact-green-sleeve.pdf and https://myhealth.alberta.ca/Alberta/Pages/advance-care-planning-green-sleeve.aspx

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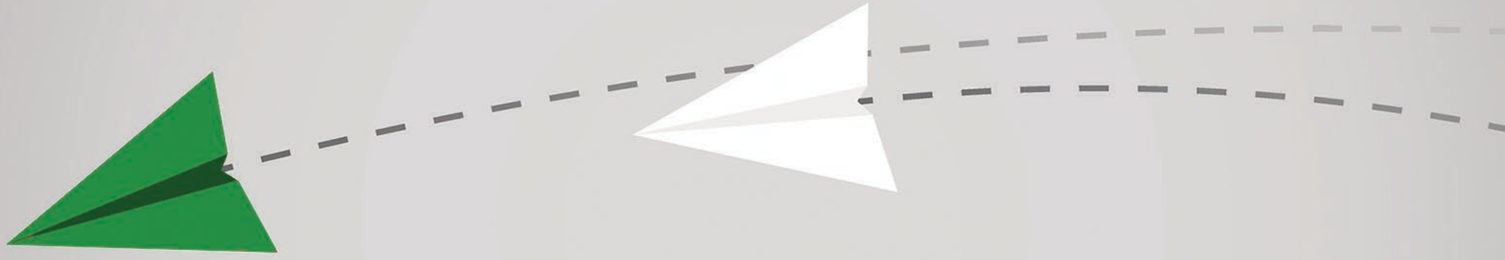

Just Right Care

The Right Care to the Right Person at the Right Time

Best Practice #8: Identify seriously ill patients with CKD and ESRD appropriate for supportive care interventions

Purpose

The purpose of this best practice recommendation is to identify and prioritize for supportive care interventions those patients with advanced chronic kidney disease (CKD) and end stage renal disease (ESRD) who are at highest risk for death in the next year. The goal is to promote their comfort and quality of life according to their values and avoid unwanted prolonged suffering.

Patients who are likely to be most appropriate for supportive care interventions are seriously ill older patients with CKD and multiple comorbid conditions who may prefer medical management without dialysis if given the choice, and patients with ESRD failing to thrive on dialysis who might want to consider stopping.

Evidence

Serious illness is a condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress.

Statistically significant objective independent markers of a poor prognosis for patients with CKD and ESRD are older age, especially if greater than 75 years, comorbidities, poor functional status, and poor nutritional status. For patients with advanced CKD who have two or more of these independent markers, dialysis may not confer a survival advantage.

With a “No” response to the “surprise” question—Would I be surprised if this patient died in the next 6-12 months?—nephrologists and nephrology nurse practitioners have been able to identify patients with CKD and ESRD who are greater than three times more likely to die in the next year and who are appropriate for advance care planning and other supportive care interventions.

Based on current research of applying the “surprise” question to patients with kidney disease, of those patients with stage 4 or 5 CKD, 5-10% of those with a “Yes” response and 24-37% of those with a “No” response were dead at one year; of patients receiving dialysis, 11-17% of those with a “Yes” response and 29-54% of those with a “No” response were dead at one year.
In multiple studies of patients with CKD and those receiving dialysis, the “surprise” question has been the strongest predictor (compared to comorbidities, functional status, nutritional status, or age) in multivariate logistic regression analysis of a high-risk of death in one year.

Use of objective variables (age, comorbidities, functional status, and nutritional status) in addition to the subjective intuitive “surprise” question in an integrated prognostic model for patients with advanced CKD and ESRD creates a more accurate model with a C-statistic of ≥.78.

Improvement Process

Innovation	Action	Outcome
Ask clinic or dialysis center rounding clinicians (nephrologist, nurse practitioner, or PA) once a month to answer the “surprise” question on all patients. Designate a team member in the clinic or dialysis center to calculate online integrated prognosis.	Prioritize patients with a “surprise” question response of “No, I would not be surprised” for a serious illness/ advance care planning discussion in the next month.	Increased number of patients who have participated in a serious illness conversation. Completed medical orders (DNR or POLST) for patients who wish treatment limitations. Increased number of patients with advance directives and medical orders (POLST) in the electronic medical record and registry (if available). Increased number of referrals for seriously ill patients to consult with palliative or hospice specialists, as appropriate.

Challenges and Strategies to Surmount Them

Challenge	Strategy
Clinicians need a prompt or trigger to answer the "surprise" question once a month on patients on dialysis or each clinic visit for patients with advanced CKD.	Routinize asking of the "surprise" question on the same week of the month when the clinician is rounding or on each clinic visit for stage 4 and 5 CKD patients and record the answer in a designated location in the electronic record.
"Surprise" question response may not trigger an action.	Create system in which the advance care planning facilitator is notified of "surprise" question "No" response patients
Need a trained advance care planning facilitator (nurse or social worker usually) who is comfortable having serious illness conversations with identified patients.	Use Serious Illness Conversation Guide, VitalTalk format, or Veterans Affairs Goals of Care Conversations training materials. All provide communication skills for a serious illness conversation in which a patient's goals of care are elicited. For training materials for physicians, advance practice nurses, and physician assistants see: https://www.ethics.va.gov/goalsofcaretraining/Practitioner.asp For training materials for nurses, social workers, psychologists, and chaplains see: https://www.ethics.va.gov/goalsofcaretraining/team.asp
No time (especially for nephrologist).	Designate a staff member (with appropriate training and dedicated time) such as nurse or social worker to conduct the conversation.

Resources and Tools

There are online calculators that include the "surprise" question and estimate prognosis of CKD and ESRD patients. For CKD patients, the link to the calculator is https://qxmd.com/calculate/calculator_446/predicting-6-and-12-month-mortality-in-ckd-patients, and for hemodialysis patients the link is http://www.touchcalc.com/calculators/sq or https://qxmd.com/calculate/calculator_135/6-month-mortality-on-hd.

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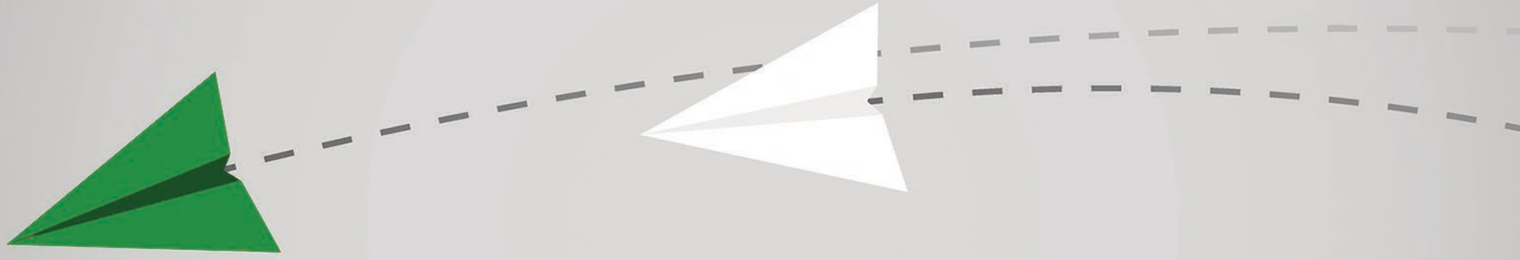

Just Right Care

The Right Care to the Right Person at the Right Time

Best Practice #9: Provide medical management without dialysis to patients avoiding or delaying dialysis

Purpose

The purpose of this best practice recommendation is to describe why some patients with advanced chronic kidney disease (CKD) may prefer medical management without dialysis as a treatment option and to explain what this option entails. The goal is to support the development of this option in advanced CKD practices in the United States.

For some patients with advanced CKD, dialysis might not confer a survival advantage and/or might involve more medical treatment, pain, and suffering than patients want to undergo. Patients who are likely to be most appropriate for medical management without dialysis are seriously ill older patients with CKD (literature documents over the age of 75 years) and multiple comorbid conditions, frailty, limited functional status, and poor nutritional status.

Evidence

Researchers have used a range of terms to refer to non-dialysis care in end stage renal disease (ESRD) but without clear definition. Such terms include “conservative care,” “maximal conservative management,” “kidney supportive care,” “palliative care,” or “supportive care.” The Pathways Project prefers the term “medical management without dialysis” because the patient receives full treatment but toward a different patient-centered goal—comfort and quality of life—as opposed to the disease-oriented goal of maximal life prolongation.

The Kidney Disease Improving Global Outcomes (KDIGO) Kidney Supportive Care conferees defined “medical management without dialysis” as holistic, patient-centered care for patients with stage 5 CKD that includes the following:

- Interventions to delay progression of kidney disease and minimize risk of adverse events or complications that include strict blood pressure control with renal-protective antihypertensive medications and management of anemia, bone-mineral metabolism, acid-base, electrolytes, and fluid balance

- Shared decision-making
- Active symptom management
- Detailed communication, including advance care planning
- Psychological support
- Social and family support
- Cultural and spiritual domains of care

In the United Kingdom and Australia, up to 20% of patients with stage 5 CKD who are referred to a nephrologist and informed of their treatment options choose medical management without dialysis. In most studies in the U.S. the percentage choosing medical management without dialysis is less than five percent.

When given the choice, some patients with advanced CKD chose medical management without dialysis and were willing to forgo seven months of life expectancy to avoid required visits for dialysis and 15 months of life expectancy to increase their ability to travel.

The available evidence suggests that for seriously ill patients, quality of life and symptom control are achieved about equally for patients who start dialysis and those who opt for medical management without dialysis. One study noted that life satisfaction declined in a population of patients after starting dialysis where it did not in those choosing medical management without dialysis.

More so than comparably aged patients on dialysis, patients on medical management without dialysis are more often referred to hospice and more often die at home.

Improvement Process

Innovation	Action	Outcome
Establish a systematic approach to delivering medical management without dialysis that identifies the patients receiving medical management without dialysis and the staff delivering it. Establish 24/7 coverage for patients in the medical management without dialysis pathway. It may include coverage provided by hospice for those in hospice.	Offer the option of medical management without dialysis to patients with advanced CKD as part of informed consent for options for treatment as CKD deteriorates. Develop protocols for usual care during “maintenance” phase of medical management without dialysis and during periods of “intensive” care. For instance, establish norms for maintenance care such as bi-monthly in-office visit with	Patients who choose medical management without dialysis are managed in a medical management without dialysis pathway. Terminally ill patients are referred to hospice. Few patients on medical management without dialysis are admitted to the hospital in the final 30 days of life.

Innovation	Action	Outcome
Determine whether special team will manage all medical management without dialysis patients or whether each nephrologist manages them according to protocols.	semi-monthly check-in call by coordinator and a crisis action plan so that in an emergency a member of the support team is called first, not 911. Include instructions for EMS if 911 is called.	

Challenges and Strategies to Surmount Them

Challenge	Strategy
In the U.S. there are just a few advanced CKD practices that offer a medical management without dialysis pathway.	Pathways Project encourages establishment of medical management without dialysis pathways and provides backup support, resources, and collaborations with local hospice and palliative care programs.
Need a team to provide medical management without dialysis.	Advanced CKD practice forms team from personnel in office and clinic and local palliative care /hospice.
Lack of knowledge of supportive care approach for patients who choose medical management without dialysis.	Pathways Project shares protocols, and CKD practices collaborate with local palliative care/hospice.
Perception that reimbursement is lacking for the medical management without dialysis pathway.	Optimize billing for outpatient supportive care that includes advance care planning codes and time-based billing.

Resources and Tools

- Essentials of Medical Management without Dialysis from Pathways Project
- Alberta Health Services Canada Chronic Kidney Management: http://www.ckmcare.com/Pathway/AtAGlance
- New South Wales Australia Renal Supportive Care: http://eih.health.nsw.gov.au/bvh/streams/renal-supportive-care
- BCRenal, an agency of the Provincial (British Columbia) Health Services Authority-Conservative Care Pathway http://www.bcrenalagency.ca/resource-gallery/Documents/BCPRA%20Conservative%20Care%20Pathway%20Guideline.pdf

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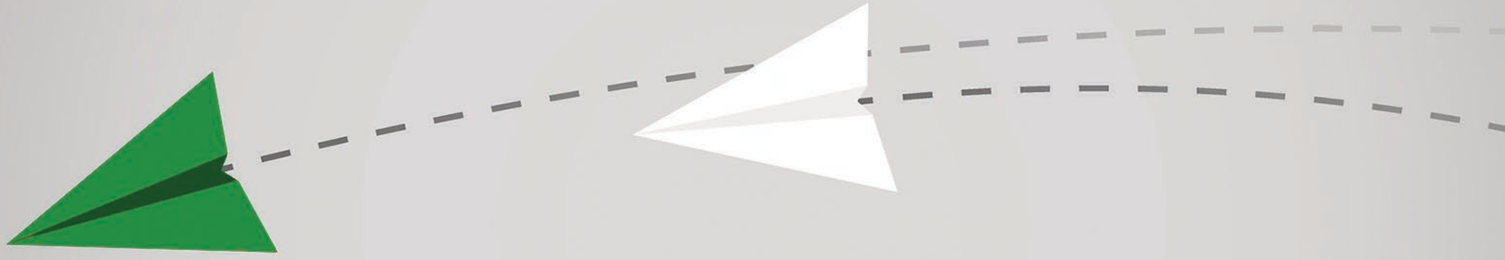
Quality Insights

PATHWAYS Project

Coalition for Supportive Care of Kidney Patients

Publication number: ESRD5-122117j



Just Right Care

The Right Care to the Right Person at the Right Time

Best Practice #10: Screen and manage pain and symptoms

Purpose

The purpose of this best practice recommendation is to inform clinicians of the frequency and severity of advanced chronic kidney disease (CKD) and end stage renal disease (ESRD) patients' pain and other symptoms and to provide them with validated methods to assess and manage symptoms. The goal is to improve the treatment of patients' symptoms and thereby enhance the quality of their lives.

Evidence

Patients with advanced CKD and ESRD have a median of nine symptoms, and their symptom burden is comparable to patients with cancer. Validated symptom assessment tools for these patients include the Edmonton Symptom Assessment Scale-renal (ESAS-r), which includes 11 symptoms, the IPOS-Renal, which includes 17, and the Dialysis Symptom Index, which includes 30. Particularly severe and troubling symptoms include uremic pruritus (itching), sleep disturbances, restless legs syndrome, pain, and depression. Dry skin, fatigue, itching, anorexia, and bone/joint pain each have been reported by >50% of patients.

Regular symptom assessment using validated tools helps redirect treatment toward a patient-centered care model. Patient-centered care emphasizes treatment that matters most to patients and aligns treatment to patients' values, preferences, and goals. Patients with advanced CKD have identified symptom assessment and management as a top priority.

Researchers have noted an inverse relationship between the number and severity of troublesome symptoms and patients' reported quality of life. For example, moderate or severe pain has been associated with higher rates of depression, irritability, insomnia, decreased perception of social support, decreased life satisfaction, and consideration of dialysis withdrawal. Changes in biochemical parameters have not been associated with an improvement in quality of life, but treatment of symptoms has been.

Pain, one of the most commonly encountered symptoms in patients with CKD and ESRD, affects more than 50% of patients, of whom almost half rate it as moderate to severe in intensity. The most common causes of pain in dialysis patients include musculoskeletal and neuropathic pain and pain related to the dialysis procedure, including arteriovenous access pain and cannulation. A review of analgesic use in patients with CKD found that despite a high prevalence of pain, use of pharmacologic analgesics is low and less safe medications, such as nonsteroidal anti-inflammatory drugs (NSAIDs), are given.

Attention to pain in CKD and ESRD patient care is patient-centered and is an essential skill for clinicians. Starting in payment year 2018, pain management and assessment of clinical depression are reporting measures for the ESRD Quality Incentive Program (QIP) administered by the Centers for Medicare & Medicaid Services. The ESRD QIP will reduce payments to ESRD facilities that do not meet or exceed certain performance standards.

Studies show that nephrologists, nurse practitioners, physician assistants, and nurses are largely unaware of the presence and severity of symptoms in patients who are on maintenance hemodialysis. Investigators have found that the symptoms of patients with CKD and ESRD are under-recognized, their severity is underestimated, and treatment is largely lacking.

Improvement Process

Innovation	Action	Outcome
Designate a team member who will “own” responsibility for ensuring that patients are regularly screened and treated for symptoms with validated standardized tools. Designated team member will have access to evidence-based literature reviews on management of common and troublesome symptoms. Patients whose symptoms scores do not improve will be reported to the designated person “owning” pain and symptom management.	Patients will be assessed at least monthly or each clinic visit for pain and other symptoms using validated tools such as ESAS-Renal or IPOS-Renal, and assessments of scores ≥ 5 will be reported to the appropriate team member. Designated team member will treat patients according to guidelines and evidence for symptom management in CKD and ESRD. Designated team member will refer patients with complex pain and symptoms to specialist palliative care clinicians.	Patients with troublesome pain or other symptoms will be identified and their scores recorded in the electronic medical record in a palliative care tab under symptom assessment in which the ESAS-Renal or IPOS-Renal scores are kept. Patients’ symptom scores will decrease while patient safety is maintained and opioid abuse is avoided. Patients with complex pain and other symptoms will be treated by palliative care, mental health, and substance abuse specialists as appropriate.

Challenges and Strategies to Surmount Them

Challenge	Strategy
Clinicians need a system to routinely screen patients for pain and other symptoms.	Routinize use of the ESAS-Renal or IPOS-Renal once a month in dialysis center or on each visit to CKD clinic and record the answer in a designated location in the electronic medical record.
Many clinicians do not know how to treat pain or symptoms in patients with CKD and ESRD.	Champion will have training in supportive care and access to specialists and resources to advise regarding more complex cases
An appreciable number of patients with CKD and ESRD will have a substance use disorder.	Provide training on safe prescribing of opioids to supportive care staff and consult with specialist supportive care as needed
No time (especially for nephrologist).	Designate a staff member (with appropriate training and dedicated time) such as nurse practitioner or nurse to conduct screenings and provide treatment and follow-up.

Resources and Tools

- BC Renal Symptom Assessment and Management: http://www.bcrenalagency.ca/health-professionals/clinical-resources/symptom-assessment-and-management. Includes guidelines for management of common symptoms as well as patient education material for specific symptoms.
- Edmonton Symptom Assessment-Renal (ESAS-r): http://www.palliative.org/NewPC/_pdfs/tools/ESASr%20Renal.pdf
- Integrated Palliative care Outcome Scale-Renal (IPOS-Renal): https://pos-pal.org/maix/ipos-renal-in-english.php
- Patient Health Questionnaire-4 to screen for anxiety and depression: http://www.midss.org/content/patient-health-questionnaire-4-phq-4

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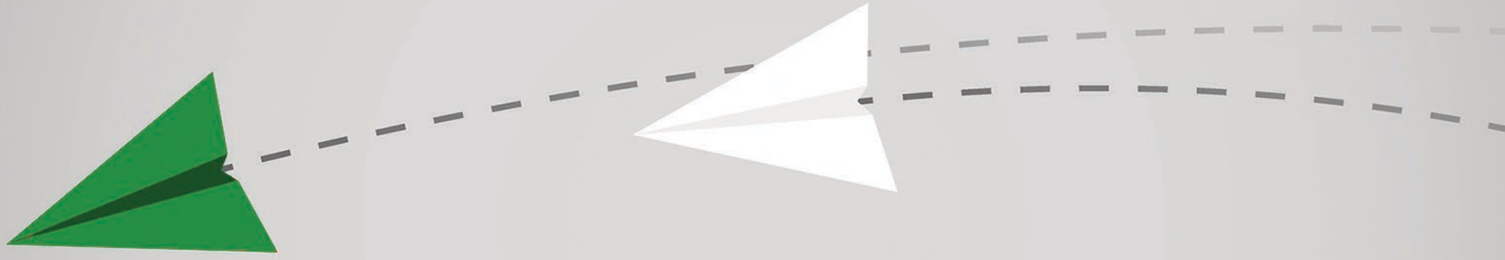
Publication number: ESRD5-122117k



Just Right Care

The Right Care to the Right Person at the Right Time

Best Practice #11: Assess and address psychological and spiritual needs

Purpose

The purpose of this best practice recommendation is to inform clinicians of the frequency and severity of advanced chronic kidney disease (CKD) and end stage renal disease (ESRD) patients' psychological and spiritual needs and to provide them with validated methods to assess and manage them. The goal is to improve the treatment of patients' symptoms and spiritual needs and thereby enhance the quality of their lives.

Evidence

Patients with CKD and ESRD have multiple comorbidities, significant impairments in quality of life, and high rates of hospitalization and death. These patients undergo a complex treatment regimen including numerous medications, dietary restrictions, and high pill burdens, and most ESRD patients undergo 3–4 hours of hemodialysis three times per week. Such factors contribute to their significant decrements in psychological and spiritual well-being. For individuals who live with kidney disease, and for those on dialysis, being dependent on dialysis treatment for survival precipitates a search for meaning and hope in their lives. Their psychosocial and spiritual needs often center on the uncertainty of their life, their vulnerability, a sense of hopelessness, fear, depression, anger, loss of roles and self-identity, and a fear of dying.

Patients with kidney disease rate psychological and social needs among the top 10 priorities of topics to be researched to improve their quality of life. They are concerned with the psychological and social impact of kidney failure on themselves and their families and what can be done to reduce it. Patients with kidney disease also rate in their top 10 priorities of topics to be researched identifying the causes of depression in patients with kidney disease and effective treatments to address the identified causes. As one nephrologist, Suzanne Watnick, commented, when patients walk into a dialysis unit they are not concerned with how they are doing with the disease-oriented quality measures in the ESRD Quality Incentive Program (QIP), but how they will feel and how their treatment will impact their life.

Depression is the most common psychiatric disorder in hemodialysis patients, affecting about 25%, a rate that is over four-fold higher than in the general population. It is associated with worse patient-centered outcomes, such as lower quality of life, greater burden of somatic symptoms, sexual dysfunction, cardiac events, hospitalizations, mortality, and withdrawal from dialysis. Depression is also associated with non-adherence to the dialysis prescription and a higher likelihood of shortening the length of and/or skipping dialysis treatments, excessive fluid intake, and lower medication adherence. It is not clear whether depression has a causal role in poor outcomes associated with ESRD or if depression is secondary to increased disease comorbidity and illness severity.

Anxiety is thought to be present in over 20% of patients treated with dialysis and is considered to be linked with depression, lower perceived quality of life, and perhaps most importantly, poorer behavioral adherence. Anxiety is characterized by disruptive feelings of uncertainty, dread, and fearfulness and may be manifested by palpitations, tremors, indigestion, numbness/tingling, nervousness, shortness of breath, diaphoresis, and fear. Many of the seemingly irrational behaviors of patients and behaviors which place them in conflict with staff and physicians may be the expression of an underlying anxiety disorder. Examples of such behaviors include aggressive demands to sign off dialysis instantly or to be treated by a particular technician or use a certain machine.

Like other symptoms for dialysis patients, depression and anxiety are underdiagnosed and undertreated. Regular symptom assessment using validated tools helps redirect treatment toward a patient-centered care model. Patient-centered care emphasizes treatment that matters most to patients and aligns treatment to patients’ values, preferences, and goals.

Spirituality is an important contributor to quality of life, and research has identified that CKD patients have substantial unmet spiritual needs. There is also a growing body of evidence that demonstrates spirituality may promote psychosocial adjustment to illness.

Improvement Process

Innovation	Action	Outcome
Designate a team member who will “own” responsibility for ensuring that patients are regularly screened and treated for anxiety and depression, and that spiritual needs are assessed with validated standardized tools. Designate a team member who will have access to evidence-based literature reviews on management of anxiety and depression and therapist for cognitive behavioral therapy	Patients will be assessed at least quarterly for anxiety and depression using PHQ-4 and spiritual needs using FACIT-Sp. Assessments of ≥ 3 on anxiety and/or depression on the PHQ-4 and ≤ 33 on the FACIT-Sp will be reported to the champion. Designated team member will treat or refer patients according to guidelines and evidence for anxiety and depression management in CKD and ESRD. Patients with unmet spiritual	Patients with anxiety and/or depression or unmet spiritual needs will be identified and their scores recorded in the electronic medical record (EMR) in a palliative care tab under symptom and spiritual assessment in which the PHQ-4 and FACIT-Sp scores are kept. Patients’ symptom scores will decrease and spiritual needs will be met. Patients with complex pain and

Innovation	Action	Outcome
(CBT) will evaluate and treat if available. Patients whose symptom scores do not improve will be reported to the designated person "owning" anxiety and depression management.	needs will be referred for pastoral care. Designated team member will refer patients with major anxiety or depression to specialist palliative care or psychiatry clinicians.	other symptoms will be treated by palliative care, psychiatric, and substance abuse specialists as appropriate.

Challenges and Strategies to Surmount Them

Challenge	Strategy
Clinicians need a system to routinely screen patients for anxiety and depression.	Routinize use of the PHQ-4 once a month in dialysis center or on each visit to CKD clinic.
Many clinicians do not know how to treat anxiety and depression in CKD and ESRD patients.	"Champion" will have training in primary supportive care and access to specialists and resources for treatment of anxiety and depression and unmet spiritual needs.
Clinicians uncomfortable with addressing spiritual needs.	Consult palliative care to assist with addressing patient/family spiritual needs.
No time (especially for nephrologist).	Designate a team member (with appropriate training and dedicated time) such as nurse practitioner or nurse to conduct screenings, make referrals, and follow-up.

Resources and Tools

- BC Renal Symptom Assessment and Management: http://www.bcrenalagency.ca/health-professionals/clinical-resources/symptom-assessment-and-management.
- Edmonton Symptom Assessment-Renal: http://www.palliative.org/NewPC/_pdfs/tools/ESASr%20Renal.pdf
- Integrated Palliative Care Outcome Scale-Renal (IPOS-Renal): https://pos-pal.org/maix/ipos-renal-in-english.php
- Patient Health Questionnaire-4 to screen for anxiety and depression: http://www.midss.org/content/patient-health-questionnaire-4-phq-4
- Functional Assessment of Chronic Illness Therapy-Spiritual Well-being: http://www.facit.org/facitorg/questionnaires

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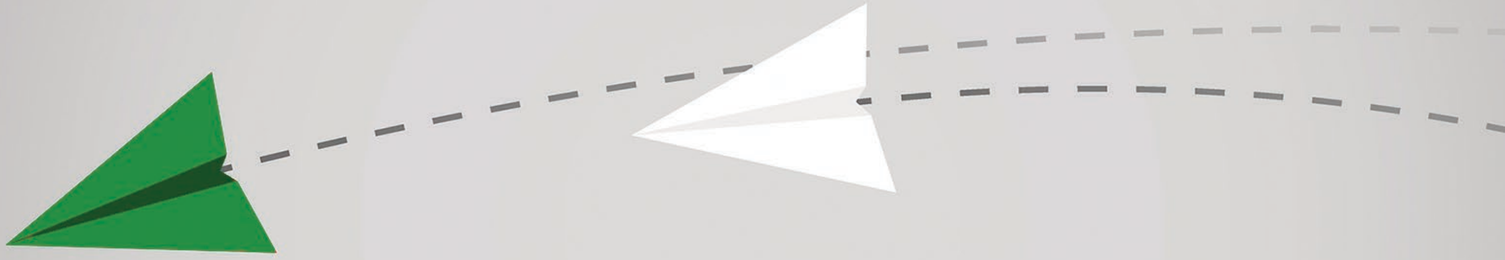

Just Right Care

The Right Care to the Right Person at the Right Time

Best Practice #12: Proactively identify and manage patients at high-risk for frequent hospital readmission

Purpose

The purpose of this best practice recommendation is to 1) inform clinicians of the factors for dialysis patients associated with a high-risk of hospital readmission within 30 days after discharge; and 2) provide them with an approach to decrease their readmission rate. The goal is to improve the procedures in dialysis centers for the treatment of such patients to ensure timely care coordination and thereby enhance the quality of their lives by reducing the discontinuity in their care that can result in disruptive hospital readmission. Decreasing readmission rates will not only avert the adverse health consequences for individual patients but also decrease the cost of their care. The Pathways Project recognizes that decreasing the number of patients who are hospitalized will decrease the number of patients who are potentially readmitted within 30 days. While this best practice does not focus on decreasing the hospitalization rate, it acknowledges that doing so is an extremely important patient-centered goal worth attaining.

Evidence

Patients treated with dialysis have among the highest readmission rates of all Medicare beneficiaries, and hospitalization accounts for 40% of all Medicare expenditures for their care. Hospitalization has significant adverse consequences for them. It is associated with significant decreases in albumin, hemoglobin, phosphorus, and weight which become worse with increasing length of stay. The transition from being a hospital inpatient back to the dialysis facility is a critical one in which many patients need to recover from an acute decline in their baseline health status. Unfortunately, a discontinuity between inpatient and outpatient care is common, which can hinder the recovery process and result in a preventable medication error, adverse event, and re-hospitalization. Regrettably, dialysis patients returning to their outpatient facility may have their standing orders prior to admission reinstated (“resume previous orders”) with no adjustments for new diagnoses or treatment changes made in the hospital.

Studies suggest that the appropriate and timely reassessment (within seven days of discharge) of a post-hospitalized dialysis patient may be an effective strategy to interrupt the downward spiral of repeated hospitalizations and the subsequent deteriorating course. Good communication between the hospital care providers and the dialysis clinicians is needed so that the latter know the reasons for hospitalization and changes made during admission in order to facilitate care continuity from hospital to dialysis center. Among those things that have been noted to be important within a week after discharge are dry weight adjustment, medication reconciliation, reassessment of anemia management, scheduling of needed medical follow-up from hospitalization, and monitoring for recovery from acute illness. Patients post-discharge who need particularly close attention are those who have powerful predictors of higher risk for 30-day readmission: low serum albumin, catheter vascular access, and intradialytic hypotension.

Patients, especially those over the age of 75 with frailty and/or significant comorbidities such as ischemic heart disease, dementia, or peripheral vascular disease, who are experiencing frequent re-hospitalizations may be failing to thrive on dialysis and at high risk of death over the coming months. Such patients and their families are likely to welcome an advance care planning discussion that gives them the opportunity to consider and express their values and preferences for end-of-life care. For patients who wish to die outside the hospital and especially those who do not want to return to the hospital, research has shown that they are more than three times more likely to have their wishes respected if they complete Physician Orders for Life-Sustaining Treatment (POLST). In one study after an advance care planning discussion with POLST completion, all dialysis patients died outside the hospital, and the vast majority died with hospice. For patients who are frequently re-hospitalized, the “surprise” question—Would I be surprised if this patient died in the next six months?—which is incorporated into an online integrated prognostic model for hemodialysis patients (http://touchcalc.com/calculators/sq) can be used to identify those with a limited prognosis.

Improvement Process

Innovation	Action	Outcome
Designate a person who will “own” responsibility for coordinating care of recently discharged patients and ensure that discharged patients are evaluated on their first dialysis visit after discharge. Designated person will have immediate access to discharge summary and medications.	At the time of hospital discharge, designated person will receive from inpatient team nurse clinician reasons for hospitalization and changes made during admission. Designated person will use a checklist to ensure that all needed post-hospital follow-up occurs and adjustments in patient care post-hospitalization are made. Patients will be assessed on their first dialysis visit after discharge for dry weight adjustment, medication	Clinicians treating patients on their first dialysis visit after discharge will know reasons for hospitalization and changes made during admission so care continuity from hospital to dialysis center will occur. Clinicians treating patients in an outpatient dialysis center will adjust treatment to promote patient health and decrease risk of readmission.

Innovation	Action	Outcome
	reconciliation, needed medical follow-up from hospitalization, and recovery from acute illness.	

Challenges and Strategies to Surmount Them

Challenge	Strategy
Clinicians need a system in place to support a routine and thorough "hand-off" of patients who are returning to the dialysis center after hospitalization.	Routinize a process of communication on the day of discharge from the hospital provider to the care coordinator at the dialysis center.
Important changes in medications or clinical status may fail to be communicated.	Institute a care process in which the hospital provider and dialysis center care coordinator use a checklist to ensure accurate and complete communication of pertinent information about the patient's follow-up outpatient treatment.
No time.	Prioritize the process of communication and assign it to a dedicated staff person in both the hospital and the dialysis center.
Care of patients who are frequently re-hospitalized and failing to thrive on dialysis may not include a frank discussion with the patient and the family about their values, preferences, and goals for end-of-life care.	Use the "surprise" question once a month on dialysis rounds to identify patients appropriate for an advance care planning discussion including their preferences with regard to returning to the hospital and their preferred site of death.

Resources and Tools

- HD Mortality Predictor: http://touchcalc.com/calculators/sq
- CKD Mortality Predictor: https://qxmd.com/calculate/calculator_446/predicting-6-and-12-month-mortality-in-ckd-patients

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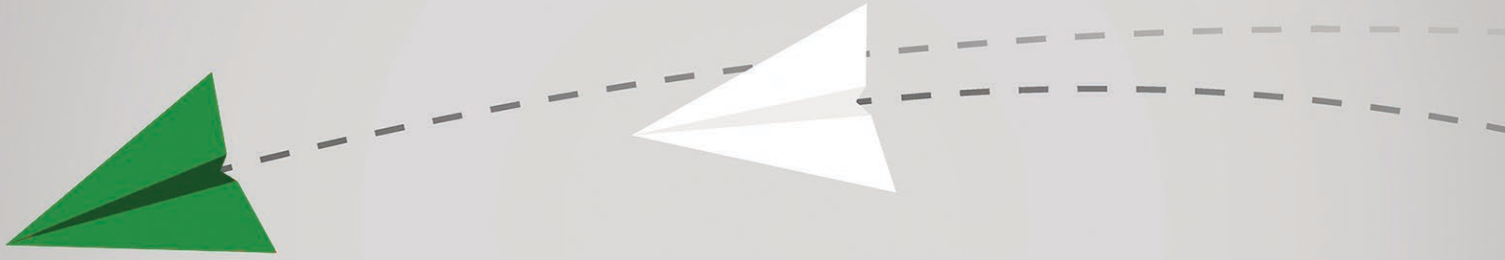
Quality Insights
PATHWAYS Project
Coalition for Supportive Care of Kidney Patients

Publication number: ESRD5-122117m



Throughout the Continuum

Enhanced Support at the End of Life

Best Practice #13: Coordinate care and care transitions with specialty palliative care and hospice

Purpose

The purpose of this best practice recommendation is to proactively involve supportive care early in care to help with symptom management, avoidance of hospitalizations, and preparation for the end-of-life period and to ease transition to hospice care at the end of life.

Evidence

Supportive care, also called “generalist palliative care,” refers to skills that all clinicians should have: basic management of pain and symptoms, including anxiety and depression, and basic discussions about prognosis, goals of treatment, code status, quality of life, and suffering. Supportive care is delivered to patients with kidney disease by both primary care providers and by the kidney care team, who are usually in frequent contact with patients. Ideally, palliative care specialists should be available to help with managing more complex and difficult cases.

The early introduction of supportive care along with usual disease-modifying treatment has been shown to be beneficial for cancer patients and heart failure patients. However, robust supportive care is largely unavailable to U.S. patients with kidney disease. In a 2013 survey of dialysis center staff, only 4.5% of 487 respondents believed they were presently providing high-quality supportive and end-of-life care. These respondents felt that offering specialty palliative care consultation was the second most important change needed to improve care, with guidelines to help with decision-making for terminally ill patients named as the first most important change.

The trajectory of end stage renal disease (ESRD) is usually characterized by a sharp escalation in symptoms and decline in functional status two to three months before death. If this escalation is not anticipated and planned for, it leads to missed opportunities to control symptoms, support patients and families, and avoid unwanted hospitalizations. In 2016, 27% of Medicare patients with ESRD had a hospital admission or discharge within three days of death, almost unchanged from the 26.4% in

2000. The same percentage (27%) of patients with ESRD were using hospice at the time of their death in 2013, although the rate was much higher for those who discontinued dialysis (53.2 % vs. 9.1% for those who did not discontinue), most likely reflecting both the intertwined nature of these two treatment decisions and financial and regulatory barriers to concurrent receipt of dialysis and hospice services for many patients with ESRD. Rates of both end-of-life hospitalization and hospice use vary widely by state, suggesting that it is not just patient preference, but possibly also system capacity that is driving utilization patterns.

Early involvement of specialty palliative care is a key aspect of innovative, supportive nephrology programs worldwide. It is important not only for supporting patients during end-of-life, but also in improving symptom control and psychosocial support during the chronic disease management phase. The Pathways Project interviewed leaders of supportive care nephrology programs and found several recommendations for building in strong access to palliative care and hospice for patients with kidney disease. When planning for end of life, these leaders recommended early referral to community palliative care or hospice, prior to when end-of-life needs arose. This referral was sometimes accomplished as a joint visit of the nephrology nurse and palliative care or hospice nurse to introduce services. The focus was on planning for smooth transition, knowing what would need to be in place, and having plans ready to deploy as soon as symptoms escalated. Careful joint planning between the kidney program and the local palliative care or hospice service touched on where the patient wanted to be at the end of life (home or inpatient) and other aspects of patient-centered goals. The kidney programs relied on palliative care or hospice to arrange logistics, especially when a patient wanted to stay at home. Preemptive planning, rather than waiting for when the patient was “ready” or needed end-of-life care, was important. The kidney programs reported that they often needed to educate the palliative or hospice programs on how to approach this preemptive planning period:

> “So I would refer these patients to the hospice or the palliative care in the community, and they'd go and see them, and they'd come and say, ‘Well there's nothing for us to do, they don't have any palliative care needs.’ And, then what would happen is they wouldn't be under a palliative care team, and that tip would happen, and they'd die very quickly without access to palliative care. So we learned early on that we needed to explain to palliative care teams, ‘Actually, they may be relatively asymptomatic, but this group of patients deteriorates very rapidly, and you need to meet them much earlier on in order to anticipate that tip. And, you need to have a responsive and sort of flexible service for this group of patients.’"

Finally, the supportive nephrology leaders reported that joint education, workshops, and networking between kidney services and local palliative care/hospice staff members were helpful in building understanding and relationships among staff members.

> “We actually ran conferences or workshops where we got the nephrology and palliative care people to sit together in locality areas by table and talk to each other. And, it was fascinating because it was the first time some of them had met, and do you know they ended up having conversations like, ‘Oh, can I come and see your hospice? Can I come and see your inpatient palliative unit? Can I come and see your dialysis unit?’ And, so there was this flow back and forth that went on organically, where people suddenly

started to go to a dialysis unit and learn what it was people had to go through and what were the concerns that the dialysis staff were looking out for. And similarly, what was a hospice like, and why could they manage dialysis there or whatever. And it's just been fascinating because it has meant there's sort of demystification of what the other side is doing."

Improvement Process

Innovation	Action	Outcome
Establish relationship and process with local palliative care and hospice programs. (See Best Practice #3) Provide joint networking and education opportunities to build relationships between kidney and palliative care staff.	Refer early to palliative care/hospice program that will manage end-of-life care prior to when patient "needs" end-of-life care. Conduct joint kidney/palliative care or hospice home visit early to introduce service – before intensive end-of-life needs arise. Use structured planning process to prepare for patient-centered end-of-life period. (See example checklist) Use pre-arranged process for quickly "turning on" hospice services when need arises, especially after hours.	Less crisis when patient rapidly tips into end-of-life period, resulting in: • Fewer emergency hospitalizations • Higher attainment of patient preference for end-of-life care, especially staying at home • Improved bereavement outcomes for family Increased number of patients referred to hospice. Increased number of patients who receive concurrent dialysis/hospice care or concurrent dialysis/palliative care.

Challenges and Strategies to Surmount Them

Challenge	Strategy
Patient reluctance: Patients don't see themselves as ready for end-of-life services or are frightened by prospect of meeting with hospice staff.	Tailor message about early referral to patient/family concerns: • Elicit goals from patients such as "I don't want to be in pain, go to the hospital, or have dialysis." • Respond with: ○ "Do you know anyone who has been through that before?" and listen for language that might be about hospice.

Challenge	Strategy
	If patient doesn't reply, "Did you know that hospice is something that can help you with those things?" ○ "You are in charge here. Sometimes someone will come do a home visit just to give you information." ○ "Did you know that hospice often provides a home health aide and pays for all medications related to pain?" ○ "We find it is very helpful to have a plan B in place 'just in case.'" ○ "Meeting palliative care or hospice 'just in case' can take a load of stress off of family caregivers. It gives them a back-up plan so they know who to call if something happens." ○ "Palliative care or hospice is the best way I know to help you stay at home (or whatever other goal patient has expressed)." ○ "Hospice isn't just about dying; it's about helping you have the best quality of life possible."
Financial constraint: Concurrent hospice care and dialysis not covered by Medicare for patients whose terminal diagnosis is ESRD.	Work out contractual arrangement with palliative care or hospice service ahead of time to provide concurrent dialysis and hospice care.

Resources and Tools

Planning checklist for medical management without dialysis patients from Southern Alberta Kidney Program – consider using this checklist to help kidney and palliative care services jointly plan for transition and end-of-life care: https://myhealth.alberta.ca/health/pages/conditions.aspx?hwid=tu6095&%20#av2405

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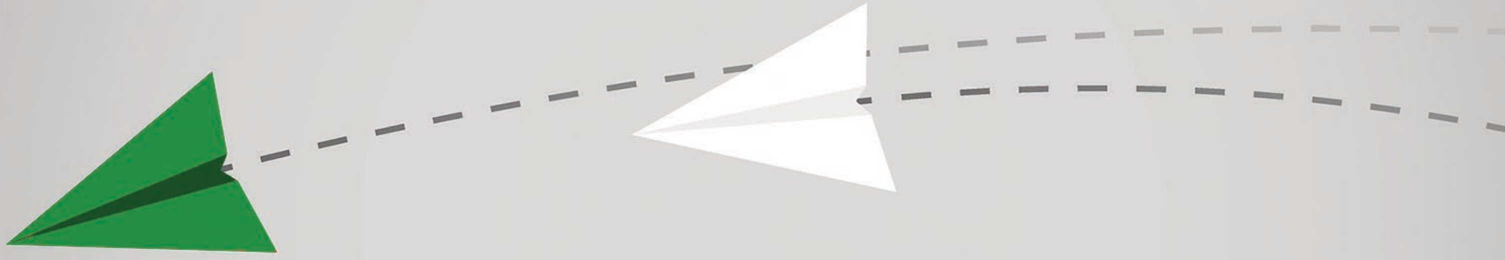
Publication number: ESRD5-122117n



Throughout the Continuum

Enhanced Support at the End of Life

Best Practice #14: Offer palliative dialysis and systematic dialysis withdrawal process for appropriate patients

Purpose

The purpose of this best practice recommendation is to identify the values and preferences of individual patients with end stage renal disease (ESRD) in regard to what is most important to them—quality of life versus quantity of life. The goal is to 1) offer dialysis patients who are failing to thrive on dialysis and who prioritize quality of life over quantity of life the options of palliative dialysis and dialysis withdrawal and to 2) provide to dialysis centers an approach to implementing these options that is sound clinically, ethically, and legally.

Evidence

Like most Americans, patients treated with dialysis often value quality of life over quantity of life. In multiple studies, dialysis patients have indicated that they prefer to avoid pain and suffering even if they live for a shorter period of time. The high dialysis discontinuation rate is a reflection of their value preference. Approximately 25% of dialysis patient deaths are due to dialysis discontinuation, and the most common reason for discontinuation is an unacceptable quality of life secondary to failing to thrive on dialysis. Patients with kidney disease have also reported that they would be willing to make trade-offs in which they live a shorter period of time and forgo dialysis to have more independence and not be restricted to a three-times-per-week dialysis schedule.

Since the 1980s, ethicists and legal scholars have agreed that it is ethically permissible to withhold and withdraw life-sustaining treatment including, under certain circumstances, dialysis. In 2000, the American Society of Nephrology and the Renal Physicians Association published a clinical practice guideline, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*, in which they defined four circumstances in which it is appropriate to withhold or withdraw dialysis:

1. Patients with decision-making capacity, who being fully informed and making voluntary choices, refuse dialysis or request that dialysis be discontinued;

2. Patients who no longer possess decision-making capacity who have previously indicated refusal of dialysis in an oral or written advance directive;
3. Patients who no longer possess decision-making capacity and whose properly appointed legal agents/surrogates refuse dialysis or request that it be discontinued; and
4. Patients with irreversible, profound neurological impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment.

In the updated 2010 guideline, the Renal Physicians Association endorsed the same recommendation with regard to these treatment decisions.

Nephrologists have identified potential triggers for consideration of dialysis withdrawal:

- Poor prognosis based on patient-specific estimate
- Accelerating comorbid illness constituting a non-renal terminal illness
- Increased frequency of hospitalizations
- Physical or cognitive functional decline, including nursing home admission or worsening dementia
- Overall decline in health such that patient is exhausted and the burdens outweigh the benefits for the life sustained by dialysis

Palliative dialysis is a consideration for patients who are thought to have less than one year to live. Palliative dialysis represents a transition from a conventional disease-oriented focus of dialysis as rehabilitative treatment to an approach prioritizing comfort and alignment with patient preferences and goals of care to improve quality of life and reduce symptom burden.

With a supportive care approach to dialysis, clinicians and social workers assume responsibility for initiating discussion of prognosis and the patient's values and goals for care. Patients predicted to be in their last year of life whose goals are to have their symptoms ameliorated, their suffering minimized, and medical interventions limited are likely good candidates for palliative dialysis.

With a palliative dialysis approach, a dialysis index > 1.2 does not necessarily need to be met if that goal is inconsistent with the patient's preferences. Additionally, dietary restrictions are reduced, management of hyperphosphatemia and hyperparathyroidism is more permissive, laboratory monitoring is decreased to the bare minimum, dyslipidemia is not treated, hypertension may not be as tightly controlled, and a catheter as dialysis access is acceptable. On the other hand, advance care planning needs to be comprehensive to identify the patient's preferred decision maker in the event of incapacity and for completion of a Physician Orders for Life-Sustaining Treatment (POLST) form so that desired treatments are ordered and treatment limitations are in place to spare the patient an unwanted intensive care unit or general hospital admission.

Improvement Process

Innovation	Action	Outcome
Dialysis center appoints a "champion" to identify patients	The designated champion in the dialysis center has a goals of	Increased number of patients who have participated in a goals

Innovation	Action	Outcome
who have a poor prognosis and/or are failing to thrive on dialysis. The champion calculates patient-specific estimates of prognosis for these patients.	care discussion with identified patients.	of care conversation. Increased number of completed medical orders (DNR or POLST) for patients who wish treatment limitations. Increased number of patients on palliative dialysis. Assist patients who wish to stop dialysis with developing a comprehensive plan to ensure respect for their wishes and symptom control. Increased referral of patients to palliative care specialists or hospice as appropriate.

Challenges and Strategies to Surmount Them

Challenge	Strategy
No time (especially for nephrologist).	Designate a staff member (with appropriate training and dedicated time) such as nurse or social worker to facilitate the conversation.
Patients utilizing the palliative dialysis approach may not meet ESRD Quality Incentive Program (QIP) measures.	Continue to educate CMS that “one size does not fit all” and that there need to be separate measures for patients on palliative dialysis.
Dialysis center may not be familiar with a systematic and comprehensive approach to patients choosing to withdraw from dialysis.	Use checklist in Table 4 of reference #6, Schmidt et al, to implement systematic dialysis withdrawal process.

Resources and Tools

There are online calculators that include the “surprise” question and estimate prognosis of ESRD patients. For hemodialysis patients the link is http://www.touchcalc.com/calculators/sq or https://qxmd.com/calculate/calculator_135/6-month-mortality-on-hd. For CKD patients, the link to the calculator is https://qxmd.com/calculate/calculator_446/predicting-6-and-12-month-mortality-in-ckd-patients.

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Publication number: ESRD5-122117o