An Innovative Practice Model Aimed at Enhancing the Care of Patients with Severe Chronic Kidney Disease

Kidney Palliative Care Clinic

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Disclosures:

Heather Boykin, DNP, ANP-BC has no financial relationships with commercial interests to disclose.

Learning Objectives

- Discuss the unique needs of those with chronic kidney disease
- Review various concepts and attributes of palliative care, and explore the intersection of palliative and nephrology care
- Share details of the strategic planning process, lessons learned, as well as demographics and early outcomes data

What IS Palliative Care?

What is Palliative Care

Support for patients & families throughout the course of serious illness – from diagnosis to end of life.

Focus on quality of life

Physical | Emotional | Spiritual

Assistance with goals of care & decisions

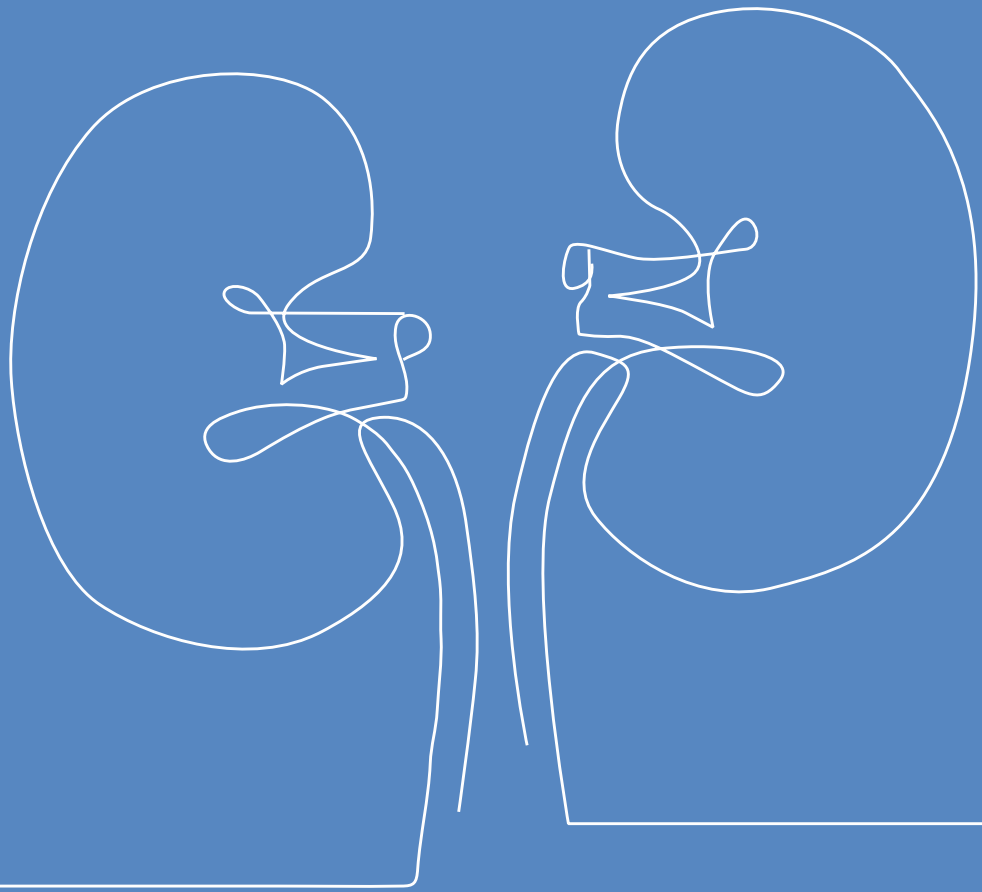
- Advance care planning
- Code status
- Difficult treatment decisions
- Transitions

Interdisciplinary team of nurses, physicians, social workers, psychologists, chaplains and/or pharmacists

Palliative Care is NOT Hospice

Palliative Care Continuum

Chronic Kidney Disease



Big Picture:
Prevalence and Impacts of Renal Disease in the US

- 37 million Americans with CKD[1]
- Higher risk for those with diabetes and hypertension
  - 1 in 3 with DM
  - 1 in 5 with HTN
- Medicare spending for CKD exceeded $70 billion in 2018[1]
- 786,000 living with ESRD[2]
  - ~70% on dialysis
  - ~30% transplanted
- Medicare spending for ESRD exceeded $49 billion in 2018[2]
- CKD/ESRD population is high utilizer of intensive care services especially near the end of life
- A vast majority of people die in the hospital

A Closer Look:

Unique needs and special considerations

- People with CKD may live with symptom burden that is comparable to advanced cancer.
- Symptom distress spans multiple domains
- People with kidney disease face limited survival when compared to the general population.
- Clinical care is increasingly challenging: large population of advanced age individuals with a greater number of complex comorbid conditions.
- Inherent risks related to dialysis in the older population
- Difficult decision-making about whether to pursue or forego renal replacement therapy and other forms of life-sustaining treatments.
- Emotional, physical and spiritual toll
- Gaps in the frequency and quality of goals of care discussions in current practice result in significant occurrence of goal discordant care, especially at the end of life.

The Facts

- Surveys show us that patient's do not often identify themselves as having a progressive, life limiting illness
  - Education needs unmet
- Literature tells us that patient ARE indeed comfortable having discussions about EOL issues
  - Communication needs unmet
- Patients want to have these conversations but many barriers
  - Addressing workflow barriers, educating colleagues in serious illness conversation, collaboration to meet these needs & devoting the TIME to do so

The Facts

- Treatment options discussion usually focuses quite narrowly on HD, PD or transplant
- RRT – may appear to have a survivorship advantage until comorbidities are accounted for – then survivorship advantage dramatically diminishes
- Older or more seriously ill patients may not benefit from these treatments or may not want them
- Poor performance status and accelerated decline in first year of RRT in individuals 70+
- Symptom burden can be very high especially as disease progresses
- Caregiver concerns & distress may be overlooked, not adequately addressed

Predictors of Poor Prognosis in ESRD

Age

- Advanced age, 75 years or older

Functional Ability Performance

- KPS versus PPS (<40, <40% respectively)

Nutritional Status

- Severe chronic malnutrition, albumin <= 2.5g/dL
- Phosphorus, low Vitamin D

Comorbidities

- Charlson Comorbidity Index
- Score of 8 or greater
- Hypotension
- CVC access

Advanced Age Specific Concerns

- Dialysis ≠ Survival
- Limited Life Extension ≠ Quality of Life
- Potential For Significant Functional Decline in First Year
- Access Surgery & Complications
- Adverse Physical Symptoms
- Significant Life Changes

The Intersection of Palliative Care and Nephrology

Mind the Gaps

- Patients with advanced stage CKD have tremendous need that is not often met by nephrology care alone.
- Barriers to palliative care involvement:
  - Nephrologist lack of comfort with collaborative model
  - Lack of understanding of palliative care
  - Lack of time to assess needs
  - Access to care challenges

THE KIDNEY PALLIATIVE CARE CLINIC

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MD

Uncertainty **Concerns**

Previous Trauma or Experiences

DISTRUST Family Pressure

Swelling **QUESTIONS**

Nausea Itching Frightened

STRESS **Unprepared**

Lack of Communication Worry

SYMPTOMS CONFUSION

- Assess and treat symptoms
- Improve comfort and preserve/ protect quality of life
- Goal setting
- Identifying preferences and values
- Plan for future
- Asses and address information needs
- Psychosocial and spiritual support
- Facilitate communication with family and providers

KPCC: Goals

Preserving Quality of Life

Minimize Hospitalizations

Assist with Treatment Options Decision Making

KPCC: Goals

- Once weekly clinic initially, now expanded
- Option for in person or virtual care based on patient's preference, ability to travel
- Patient and surrogate decision maker visit together ideally
- Alternating visits with nephrologist and KPCC or more frequently as needed
- 1 hour initial visit, 30 minute follow ups
- Hopeful for continuity of care from KPCC to inpatient, KPCC to dialysis, KPCC to hospice

KPCC: Demographics

47% African American

43% Caucasian

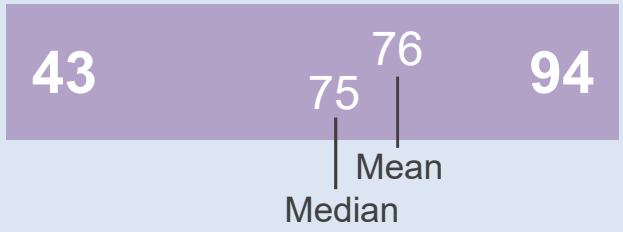
6% Hispanic

4% Non-Hispanic

58% Female

42% Male

Age Range



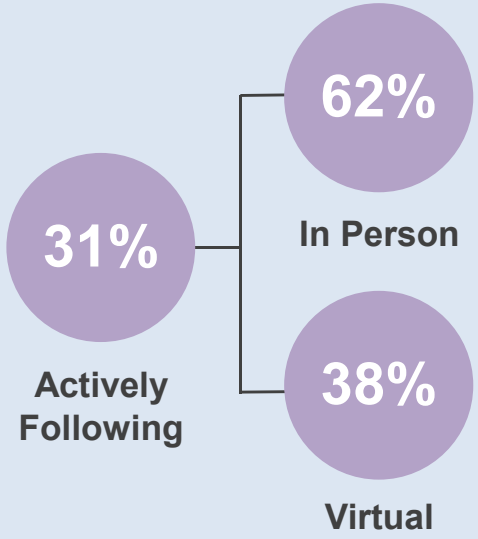
Comorbidities

- Heart failure, HTN, DM, Obesity, Cancer, ACD, Dementia, Liver Disease

KPCC: Data

First patient August 2020

Over 60 referrals to date



56%

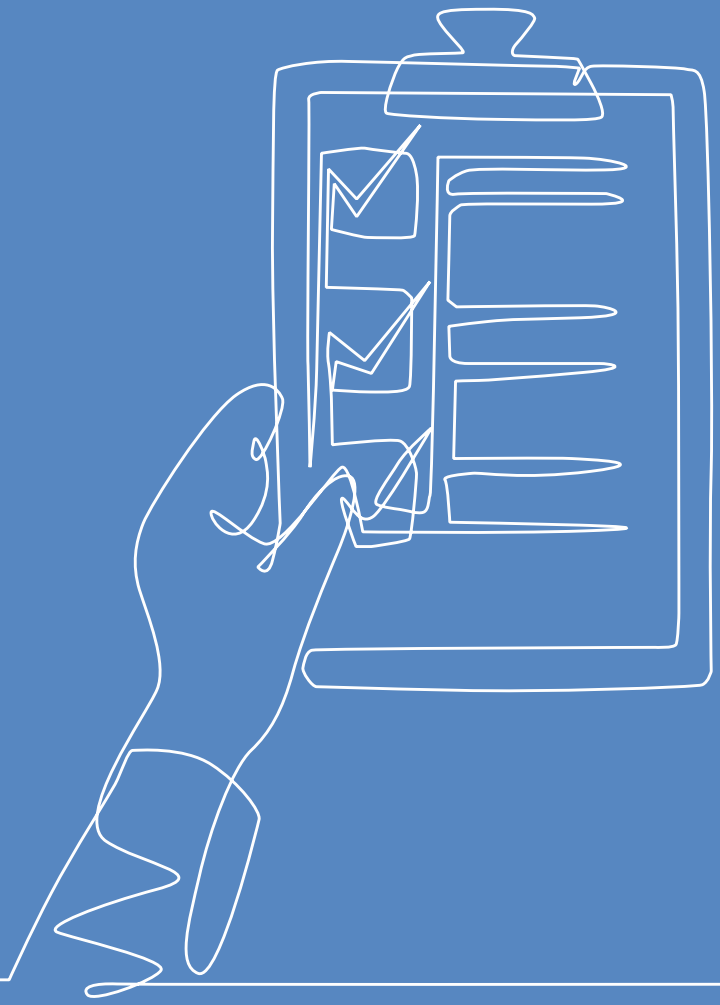
Not Actively Following

Decision for dialysis and/or initiated treatment after visit, hospice, other/inpatient visit after clinic referral, lost to follow up, referral did not progress to visit

13%

Deceased

Who is Eligible?



KPCC: Triggers for Referral

Advanced CKD at risk of progression to end-stage disease

- eGFR<20
- KFRE 2-year risk >10% (Tangri)

Increasing uremic symptoms

- Itching, nausea, loss of appetite, GI symptoms, fatigue
- Inadequate symptom control

Goal Concordant Care

- Goals of care, desire to consider options other than transplant or dialysis such as conservative care
- Advance care planning

Frequent hospital admissions

Surprise question

Poor or declining functional/cognitive status

KPCC: Palliative Care Services

Provide palliative care services in general

- Preserve QOL, symptom management, surrogate decision maker identification, ACP, avoidance of hospitalization if possible

Palliative Care specifically geared toward the specialized needs of patients with chronic kidney disease

- Address symptoms specifically related to kidney disease
- Assist in advanced treatment options discussion and decision-making
- Provide nephrology specific guidance/support for caregivers

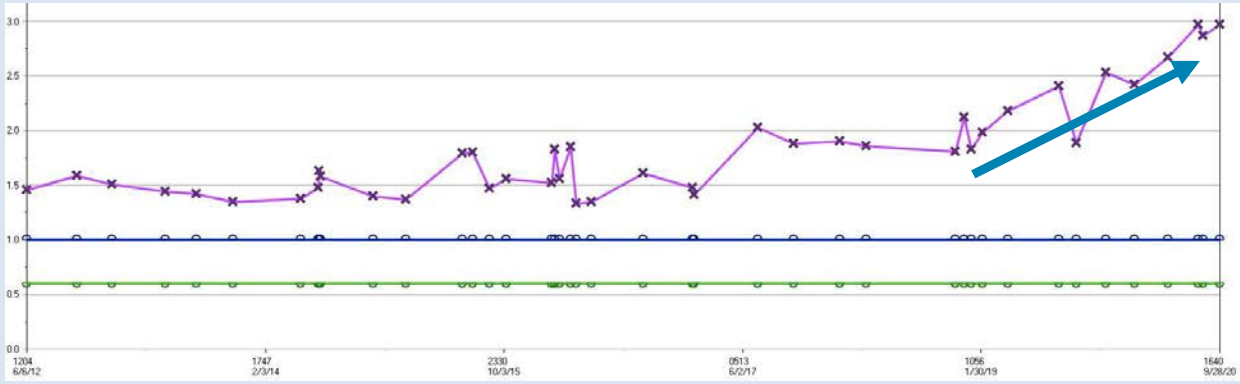
Individualized follow-up based on patient's needs

KPCC: Case 1

- **78 year old woman**
  - Rheumatoid Arthritis
  - Bilateral staghorn calculi 30 years prior
  - Perforated diverticulitis ~25 years prior requiring colostomy bag
  - Recurrent diarrhea
  - Difficulty staying hydrated
- **Has been following with nephrology >10 years**
- **Memory declining**
  - Used to come alone to visits, now with daughter
- **Uncertain about pursuing dialysis**

KPCC: Case 2

- 82 year old woman
- Some cognitive impairment
- No overt uremic symptoms
- Has previously stated she would not want dialysis
- KPCC referral made by primary nephrologist
- CR leading up to referral



- eGFR ~15 mL/min, KFRE 15% 2-year risk

KPCC: Case 3

- **81 year old female**
  - CKD 4 with steady progression to CKD 5
  - Frequent hospitalizations for anemia, GIB, volume overload
  - Progressive functional decline
  - Uremic symptoms
- **Seen by palliative care during hospitalization**
- **Patient and daughter reluctant to discuss reality of disease, goals of care**
  - Patient did not want dialysis but otherwise goals remained aggressive
  - Referred to KPCC at discharge

KPCC: Case 3

- **Significant effort to establish rapport**
  - Patient largely deferred to daughter for discussion
  - Daughter's history of undesirable encounters with healthcare providers. Also traumatic death of husband and poor experience with hospice
- **Months of cautious but steady discussion of goals, realities of disease, advance care planning and goal setting**
- **Slowly paced de-escalation of care**
- **Ultimate transition to home hospice**
  - Daughter required extensive support. Weekly to twice weekly virtual visits
  - Aggressive symptom management
  - Complicated grief, challenges of preparing for loss of mother
- **Patient passed away at home in May with daughter at bedside**

KPCC: Collaboration for Success

- Goal to contribute to and enhance care
- Devote much needed time and attention to whole person care and recognizing the role of family, ACP, symptom management and treatment options decision making
- Define areas of overlap with renal, geriatric, and other referring providers

KPCC: Next Steps for Expansion

- **Targets and next steps for expansion within 12-18 months**
  - Additional half day per week
  - Dialysis population
  - High risk transplant / frailty clinic
- **Learning opportunities for learners/fellows**
- **Basic palliative care education for nursing & ancillary staff**
- **Grand rounds presentations**
- **Advertise and offer services to outlying clinics**

KPCC: Gather and Grow

- **QI initiatives underway**
  - Patient related outcomes
  - HRQOL
  - Advance care planning
  - Greater satisfaction with goal concordant care
- **Publication**
- **Share best practices across multiple entities and venues of care**

Resources:

Center to Advance Palliative Care
www.capc.org/fast-facts
Practical, peer-reviewed palliative care topics

End-of-Life Nursing Education Consortium (ELNEC)
www.aacn.nche.edu/elnec

Hospice & Palliative Nurses Association
www.hpna.org

National Hospice & Palliative Care Organization
www.nhpco.org

UNC Kidney Palliative Care
https://www.med.unc.edu/medicine/medicine-introduces-kidney-palliative-care-clinic/

Thank you!