

THE CONSERVATIVE CARE PATHWAY

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Conference

Learning Objectives

- Describe and discuss what defines conservative care.
- Identify key components of a conservative care program.
- Discuss how a renal program can effectively deliver optimal conservative care.
- Review literature/studies to date that indicate what patients report about decision-making and their chronic illness experience.

Meet 'Emiko'

■ Initial consult 2003

- 65 y/o Japanese woman with Type 2 DM, HTN, Dyslipidemia, CKD with CrCl 15 ml/min, proteinuria
 - Referred to KCC for modality education; predicted time to require RRT is 1-2 yrs
 - Following education, **decides she does not want dialysis**
 - She is cognitively intact, highly functional, enjoys good quality of life, mild language barrier
- Physician response (mine) – try to encourage her to change her mind

'Emiko'

■ August 2015 – F/U in KCC

- 76 y/o now, maintains decision re: 'no dialysis'
 - eGFR 15-17 ml/min, no uremic symptoms
 - Worst problem is OA – related joint pain
 - Husband died few yrs ago (hepatocellular cancer); she feels this was a 'bad death' because he 'suffered too long'
 - She maintains independent living, feels she still enjoys good quality of life
 - Requests decrease/discontinuation of 'unnecessary' meds
 - However, wants to know her lab results, is very self-disciplined re: dietary restrictions, glycemic control, etc.

WHAT IS CONSERVATIVE CARE?

- Conservative care does **NOT** mean 'do nothing'
- Organized palliative care
- Living well without dialysis
- **Patient - centered**

COMPREHENSIVE CONSERVATIVE CARE (KDIGO consensus conference 2013)

- **“Planned holistic patient – centered care for patients with stage 5 CKD which includes:”**
 - Interventions to delay progression and minimize risk of adverse events and complications
 - Shared decision-making
 - Active symptom management
 - Detailed communication, including Advance Care Planning (ACP)
 - Psychological support
 - Social and family support
 - Cultural and spiritual domains of care

..... **but does not include dialysis**

WHAT ARE THE COMPONENTS OF CONSERVATIVE CARE?

- Information sharing with patient and family
 - Impact of decision; understanding what to expect; planning ahead and preparation with family
- Aggressive control and anticipation of symptoms
- Management of complications of ESRD (EPO for anemia)
- Measures to delay progression
- Psychosocial and spiritual support
- Advance care planning
- Recognizing and planning for death
- Bereavement support

HOW CAN WE DELIVER CONSERVATIVE CARE?

- Refer to Kidney Care Clinic for personalized education describing this as a valid option
 - **CONSERVATIVE CARE = STRIVING TO OPTIMIZE QUALITY OF LIFE**
 - Maintain continuity (consistent F/U through the KCC)
 - Ensure access to various disciplines
 - **Dietician** – K, PO4 restriction; management of nausea
 - **Social Work** – ACP counseling; financial aid; palliative care benefits program; completion of forms/documents
 - **Nurse** – HCC referral/Hospice registration; ongoing education/support
 - **Nephrologist** – prognostication; symptom management
- Collaborate with Family Physician***

LESSONS LEARNED: THE CALGARY TEAM

- Dedicated nurse clinician from CKD Clinic with interest in palliative care (1.0 FTE)
- ACP nurse clinician (0.6 FTE)
- Usual nephrologist continues to direct care
- Nephrologist with interest in palliative care serves as a resource
- Multi-disciplinary professionals (SW, spiritual care, dietician)

LESSONS LEARNED: THE CALGARY TEAM

■ **Contact Checklist:**

- Review patient goals
- Explore patient choices
- Resuscitation status (Goals of Care designation)
- Symptom assessment and control
- Medication/investigation rationalization
- Spiritual needs assessment
- Death preparation
- Family/caregiver information and education
- Crisis planning
- Bereavement

LESSONS LEARNED: THE CALGARY TEAM

■ 77 PREVALENT PATIENTS

<u>GFR</u>	<u>Number</u>
<10	18
10-14	24
15-19	18
20-30	17

- Average age is 84.2 (range 50-95)
- 86% have goals of care designation documented
- 4 patients started dialysis (= 'failure'?)

LESSONS LEARNED: THE CALGARY TEAM

- Patient's preferred place of death known in 82%:
 - HOME 58%
 - HOSPICE 35%
 - HOSPITAL 7%

- Actual place of death:
 - HOME/LTC **17%**
 - HOSPICE **11%**
 - HOSPITAL **72%**

LESSONS LEARNED: THE CALGARY TEAM

- **Conclusions so far:**
 - The determined very elderly choose conservative care
 - GFR < 10 ml/min does NOT equal death
 - Late referrals are problematic
 - Support for staff very important

REVIEW OF THE LITERATURE

(Murtagh CJASN 2011)

- Prospective observational study across 3 sites in UK
- **73 patients with stage 5 CKD who chose conservative care** followed over 2 yrs; median F/U 8 months
- Mean age 81 y/o
- 66% died during F/U
- More than 1 in 3 pts reported severe fatigue, pruritus, dyspnea, pain , poor appetite, restless legs, insomnia
- Mean number of symptoms was 11.58, with 2.77 added 'renal symptoms'
- 'renal symptoms' – itching, muscle cramps, restless legs, hiccups

REVIEW OF THE LITERATURE

(Murtagh, CJASN 2011)

■ Illness Trajectory:

- Symptom burden and distress accelerated in last 3 months of life
- Functional status (measured by KPS) declined precipitously in last month of life
- Palliative needs increased exponentially in last 3 months of life

THE EXPERIENCE OF ILLNESS IN CONSERVATIVE CARE

■ EMERGING THEMES:

- CKD is a 'hidden illness'
 - "My friends and family say I don't look that sick"
 - "It's not like you have cancer...."
- Difficulties with attribution of symptoms
- Awareness of approaching death
- Fluctuant trajectories result in greater psychological and family strain
 - An unpredictable course can make planning/preparing for death difficult/stressful
- The impact of illness varies between individuals

WHAT PATIENTS SAY ABOUT CONSERVATIVE MANAGEMENT

- Reasons why they choose this option:
 - Feel they are too old for dialysis
 - Dialysis is 'too strenuous', may result in feeling worse
 - Feel well/functioning well without dialysis
 - Do not want to be a burden on their family
 - Would find travel to/from hemodialysis unit difficult
 - Have known other patients who had a bad experience on dialysis (or transplant)

WHAT MATTERS MOST TO PATIENTS?

(Singer JAMA 1999, Heyland CMAJ 2006, Belanger Pall Med 2011)

1. Good pain and symptom control
2. Family support and reduction in burden on family
3. Having priorities and preferences listened to and accorded with as much as possible
4. Achieving a sense of resolution and peace
5. Having coordinated and well-integrated care with continuity of provision

'EMIKO' (to be continued....)

- Her reasons for choosing conservative care:
 - Felt she was too old for dialysis (even at 65 y/o)
 - Did not wish to be a burden on her husband (especially when he became ill)
 - Feels well without dialysis
- In retrospect, realizes that a low GFR does NOT mean death is imminent
- **MOST NOTEWORTHY: THE NEPHROLOGIST'S (MY) INITIAL PROGNOSIS WAS WRONG!!**

TAKE HOME MESSAGES

- The conservative care pathway is a valid option for any patient with Stage 5 CKD
- Such patients benefit from consistent, multi-disciplinary care with continuity of provision
- Such care is optimally delivered in collaboration with the following:
 - Hospice/Palliative care team
 - Family physician
 - Home and community care
- Patients CAN live well without dialysis; however, intensive resources are required for support in the last 3 months of life

A Final Quote...

*"In life, there are many paths you can take and many people who share the journey.....
But it's the special people who help you along the way, who care enough to give of themselves unconditionally. Thank you for being one of those special people."*

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