THE ROLE OF SOCIAL WORKERS AS LEADERS IN PALLIATIVE CARE

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Scarborough Health Network Regional Renal Program Conservative Management of Renal Patients

OVERVIEW

- Establishing a Comprehensive Conservative Renal Care (CCRC) program
  - Education
  - Clinical team and partnership
  - Logistics
  - Statistics & Initial Outcomes via QODA
  - Future goals

RATIONALE FOR A CCRC PROGRAM

- High symptom burden that is often complex
- Patients can live for months to years
- Complex decision making regarding choosing or stopping dialysis
- Variability of illness trajectories
- It is important to develop an integrated care pathway to support these patients as well as their caregivers.
- Involvement with palliative services

Davison et al. KI 2015;doi:10.1038/ki.2015.110

AIM

To develop a clinical pathway that provides

- (1) psychosocial symptom management for patients with advanced CKD who decide on no dialysis and
- (2) support for caregivers to help them cope with their family member's illness.

OUR CCRC TEAM

- Nephrologists (1 champion)
- Social Workers (1 champion)
- CKD Registered Nurses (2 champions)
- Dieticians (1 champion)
- Pharmacists
- Spiritual & Religious Care
- Leadership Team

EDUCATION

- Conferences
  - "Renal End of Life" workshop (University of Calgary)
  - "Moving Forward with Renal Supportive Care" Conference 2015 (University of Calgary)
  - LEAP program
- Lunch and Learns
  - Spiritual & Religious Care
  - SCHC Hospice Palliative Care

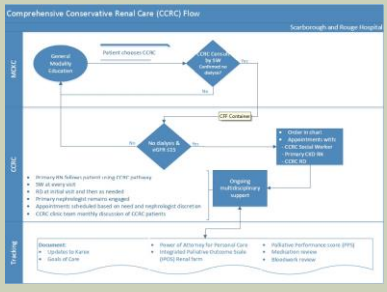
PARTNERSHIP

- Palliative care team
- Community partners
  - Scarborough Centre for Healthy Communities Hospice Palliative Care Team
  - Providence Healthcare Palliative Care Unit (PCU)
  - CE LHIN Home and Community Care

LEARNING MODULES FOR CKD CLINIC STAFF

1) Introduction to CCRC and the CCRC Pathway (Nephrologist)
2) RN experience with CCRC (RN)
3) Advance Care Planning (SW)
4) Palliative Care in CKD (Palliative MD)

REFERRAL PROCESS



RESOURCES FOR PATIENTS

- Deciding on CCRC
- Discuss with primary nephrologist

Adapted from Alberta Health Services, (2010b).

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Conservative Management: Making a Choice to Live Well Without Dialysis

As your kidney disease gets worse, you will start talking with your healthcare team about the choices you have for treatment. These choices may include dialysis or conservative management. Your team will help you make your decision by answering your questions and giving you the information you need to understand your choices. Whatever treatment you choose, the team knows that this is a very personal decision and will support whatever decision you make.

The information in this handout will help you understand what conservative management is, why you might want to choose it, and what you can expect if you do chose it.

What is conservative management?

Conservative management is for those who choose not to include dialysis as part of their treatment plan. It means that you will work closely with your kidney doctor and healthcare team to:

- Prevent and treat the symptoms and complications of kidney disease
- Protect and maintain the kidney function you have left
- Receive supportive medical and psychosocial care when needed
- Help you plan for the future

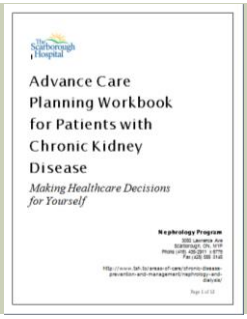
The goals of conservative management are for you to live well without dialysis, be as comfortable as possible, and have a good quality of life.

Why choose conservative management?

Dialysis is not for everyone. For example, being older or having other medical conditions may mean that dialysis will not help someone live longer or improve their quality of life.

For some patients, the side effects of dialysis may even reduce their quality of life or increase their suffering. Dialysis will not treat other medical conditions (e.g., diabetes, heart conditions, arthritis, and chronic pain).

ADVANCE CARE PLANNING



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Advance Care Planning Workbook for Patients with Chronic Kidney Disease

Making Healthcare Decisions for Yourself

Nephrology Program

CCRC PATIENTS IN MCKC CLINIC

- Primary care model
- RNs follow their own patients
- MDs follow their own patients or transfer to CCRC nephrologist
- Structure of clinic visit:
  - RN (30 min)
  - SW (60 min)
  - MD (30 min)
  - RD as needed (initial visit 30 min)

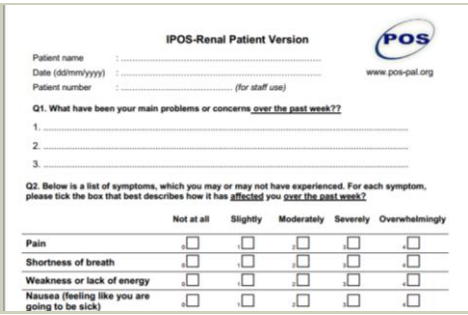
TOOLS

- CKD clinic KARDEX
- CCRC booking codes and CCRC specific intervention categories in e-charting
- CCRC Social Work Consultation Sheet
- CCRC Session guide sheet
- CCRC Pathway Intro Letter
- Referral to Palliative Care Information sheet
- Physician letters to GP and for CCRC Package
- Contact List and Crises Plan sheet

OUR CCRC PATHWAY

- Reassess goals of care (shared decision making)
- Discuss advance care planning
- Symptom assessment tool
  - Integrated palliative outcome scale – Renal version (IPOS-renal)
  - Done by RN

IPOS-RENAL



IPOS-Renal Patient Version

POS

www.pos-pal.org

Patient name : .....

Date (dd/mm/yyyy) : .....

Patient number : ..... *(for staff use)*

Q1. What have been your main problems or concerns over the past week??

1. .....
2. .....
3. .....

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past week?

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Shortness of breath	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Weakness or lack of energy	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Nausea (feeling like you are going to be sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

OUR CCRC PATHWAY

- Minimize frequency of blood draws
- Simplify medications
- Assess home support
- Evaluate caregiver burden
- Phone support to reduce frequency of clinic visits
- Refer to palliative care team when appropriate
- Make plans for a “good death”

CCRC PATIENTS AT SHN

- 68 listed
  - 51 active and attending clinic
  - 17 active at home or transferred to palliative care
- 62 deaths (since Jan 2014)
- 27 started dialysis
- Database to track GFR, date of consultation, referring MD, primary RN, date referred to palliative, residence, preferred place of death

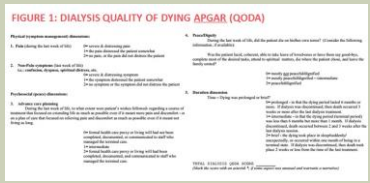


FIGURE 1: DIALYSIS QUALITY OF DYING APGAR (QODA)

(1) **Cohen LM et al**. Measuring quality of dying in end-stage renal disease. *Semin Dial 2004; 17 (5):376-9.*

QUALITY OF DYING AGPAR (QODA)

After a patient’s death, nurses asked caregivers to evaluate the quality of care using the “Quality of Dying AGPAR (QODA)” (Fig 1). QODA measures the quality of dying over 5 areas: pain, non-pain symptoms; advance care planning; peace/dignity; and duration dimension. Data was also collected on place of death and whether or not the death occurred in the patient’s preferred place of death

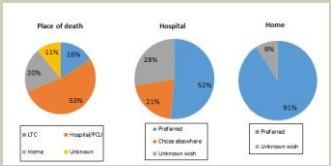
2014-2017 OUTCOMES

Using QODA, 83 % of the caregivers surveyed scored 8 or above which demonstrated a "good death".

Of the 55 patients who expired between 2014 to 2017, 16% died in long-term care (LTC); 53% died in hospital or palliative care unit (PCU); 20% died at home; and in 11% place of death was unknown.

Of those who died in hospital, 52% had chosen the hospital/PCU as their preferred place for death.

Of those who died at home, 91% had chosen home as their preferred place for death.



ACHIEVEMENTS

- Coordinate advance care planning for dialysis patients
  - ACP KARDEX CHECKLIST
- Access to Spiritual & Religious Care
- Collecting data to identify progress and ways to improve program
- Poster presentation at CNS (2018)
- CCO Human Touch Awards- Nominated (2017)

FUTURE GOALS

- Participate in more educational opportunities to improve ACP and hospice palliative care
- Memorial for nephrology patients
- Identify more resources to support patients at home or hospice and optimize the referral processes
  - Future exploration of additional resources in the community i.e. Palliative Beds in Yee Hong LTC
- Develop a care pathway for patients who wish to withdraw from dialysis
- Further engagement with SHN Palliative Care leadership team
- Liaise with psychiatry team to optimize supportive care

SUMMARY

- Developing a CCRC pathway is essential to optimizing care of CKD patients
- CCRC requires a multidisciplinary team and partnerships with palliative care and community services
- Other programs have helped greatly in establishing our CCRC pathway
- CCRC enables patients and their families to have autonomy in their end-of-life care
- Our CCRC pathway helps patients and families cope in their palliative care journey.
- Our pathway also improves quality of care since it helps to place patients in their preferred care setting at their end of life.

THANK YOU

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