



Good Palliative Care

Comprehensive Conservative Renal Care at Scarborough Health Network

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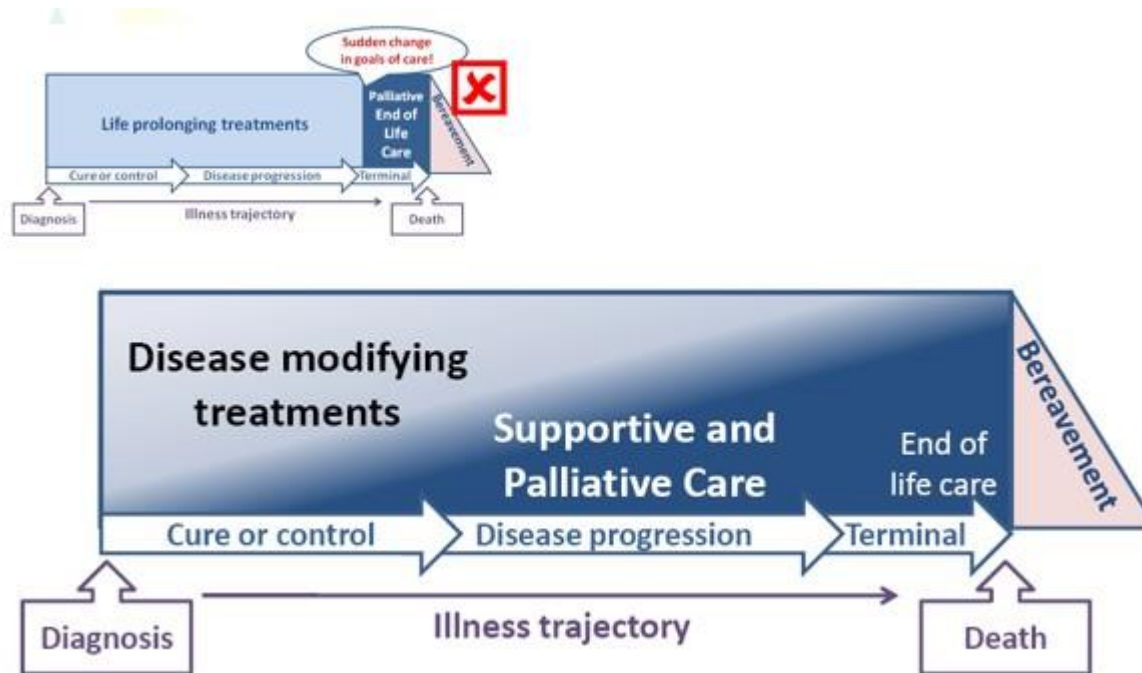
AGENDA

1. What is the Palliative Care Approach?
2. What does Assessment Look Like?
3. Planning: Advance Care Planning & Goals of Care Discussions
4. Management Strategies
5. Initial Outcomes
6. Next Steps

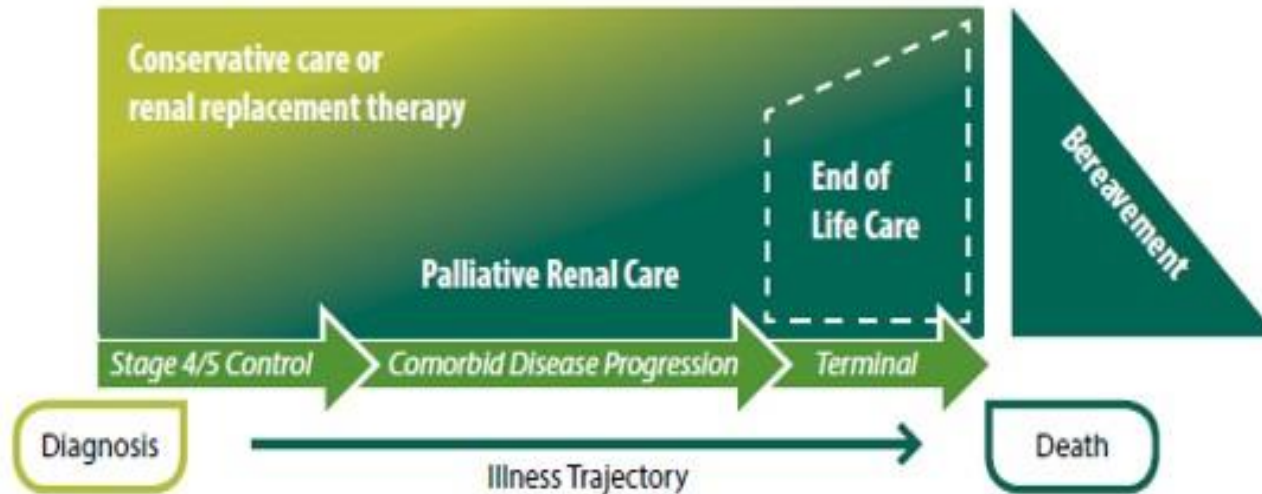
“Palliative” “Palliative Care”

Defining Palliative Care

Traditional v.s. current



Early palliative care in chronic kidney disease



Key Features of Palliative Care

- Not limited to end-of-life (EOL)
- For individuals with life-limiting illnesses
- Can be done alongside treatments to control the disease
- Aims to improve or maintain quality of life
- Holistic care: physical, psychological, spiritual, social
- For all ages
- For cancer and non-cancer diagnosis
- Best provided by interprofessional team
- Is active care

**What is the
palliative care
approach?**

The Palliative Care Approach

Generalist Level

Identify

- Identify patients early who may benefit from palliative care

Assess

- Their understanding of the illness & information needs
- Symptoms
- Psychosocial & spiritual needs
- Quality of life
- Values, wishes, preferences

Plan

- Advance care planning
- Goals of care and care plans,
- Treatment plans
- Link to resources and other care providers
- Prepare for emergencies

Manage

- Symptoms
- Psychosocial & spiritual needs
- Essential discussions
- Refer for assistance as needed

**What does
assessment look
like?**

The Surprise Question

**Would I be surprised if
this patient were to die
in the next year?**

- Joanne Lynn. RAND Lecturer USA and senior advisor on end-of-life care
- Gold Standards framework, UK
- You JJ, et al. CMAJ 2014
- Moss AH, et al. Clin J Am Soc Nephrology 2008

<https://www.ckmcare.com/CKMPathway/PathwayIntroduction>

Patient Decision Aid

As your kidney function declines, one of your biggest choices is whether to get **Dialysis** or **Conservative Kidney Management (CKM)**.

Dialysis is not for everyone. Dialysis can't cure kidney failure, but it may help you live longer and feel better. The older and sicker you are, the less likely it is that dialysis will help you. Some people will live as long and feel better with CKM, which does not include dialysis.

It's your choice whether to have CKM or dialysis. This tool is to help you decide if CKM or dialysis is right for you. You can use it to talk with your healthcare team and loved ones about your decision. It should take 15 to 25 minutes to complete. You can come back to it, or share it with someone you trust by using the email button or printing your responses. How you respond is anonymous and confidential.

It's your choice whether to have **Conservative Kidney Management (CKM)** or **dialysis**, this tool will help you determine how CKM or dialysis may benefit you personally.

" The Patient Decision Aid helped make sure that he knew the **decision** he was making, why he was making it, and using the right sort of **values** for what he was **choosing** "

- Family Member

[Continue to review treatment options](#)

**COMPREHENSIVE CONSERVATIVE RENAL CARE SOCIAL
WORKER CONSULTATION**

Tel. no. (416) 438-2911 ext. 6697 Fax no. (416) 431-8255

Open discussion with patient and family about patient's wishes for treatment

❖ Tell me about your decision to not start dialysis

❖ Tell me what happens when you do not start dialysis

❑ Is there a need to review other modality options?

- ❑ "Conservative management: Making a choice to live well without dialysis" handout given
- ❑ Initiate discussion on Goals of Care
- ❑ Initiate discussion of Advanced Care Planning
 - ❑ "TSH Advance Care Planning Workbook" given
- ❑ Patient and family must agree with referral to CCRC Pathway
- ❑ Primary nephrologist **& GP (SEND PHYSICIAN LETTER)** notified of referral to CCRC Pathway.
- ❑ **Complete ACP section of CKD KARDEX**



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 choose 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 Workbook for Patients with Chronic Kidney Disease

*Making Healthcare Decisions
for Yourself*

Nephrology Program

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Scarborough, ON, M1P
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Assess Symptoms

Uremia:

These are some of the signs and symptoms that your kidneys are getting worse and usually means you may need dialysis soon.



vomiting and weight loss

嘔吐
體重下降



nausea and poor appetite

噁心
沒有胃口



itchy skin

痕癢



cramps

抽筋



skin colour changes

皮膚變色



weakness and fatigue

虛弱
疲勞



swelling

腫脹



shortness of breath

呼吸短促、困難

IPOS-Renal Patient Version



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 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Shortness of breath	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Weakness or lack of energy	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Nausea (feeling like you are going to be sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Vomiting (being sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Poor appetite	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Constipation	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Sore or dry mouth	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Drowsiness	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Poor mobility	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Itching	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Difficulty Sleeping	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Restless legs or difficulty keeping legs still	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Changes in skin	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Diarrhoea	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

Please list any other symptoms not mentioned above, and tick the box to show how they have affected you over the past week?

1. 0 1 2 3 4
2. 0 1 2 3 4
3. 0 1 2 3 4

Advance Care Planning & Goals of Care Discussions

Planning

Getting Started: Writing your Advance Care Plan

Here are some questions you can ask yourself to help you think about your health care wishes.

What is most important to me about my physical or mental well-being?

Examples

- ❖ It is important for me to be able to communicate in some way, even if I cannot speak.
- ❖ It is important that my family be comforted.

What makes each day meaningful to me?

Examples

- ❖ Life has meaning when I communicate with my friends and loved ones.
- ❖ When I can practice my faith.

What beliefs or values do I think will help my family, friends or health care providers know what is important to me?

Examples

- ❖ I would like to stay home as long as it is not too hard on my family or caregivers.
- ❖ Do everything possible to keep me alive until I can say goodbye to family who are coming to see me.

What are my wishes for organ and tissue donation when I die?

Examples

- ❖ I have signed a donor card which is in my wallet.
- ❖ I do not wish to donate organ and/or tissue when I die.

When I think about death, what do I worry about?

Examples

- ❖ I worry that I will be in pain.
- ❖ I worry that my family will not know what to do.

When I am nearing death, are there things I would wish for (or would not wish for)?

Examples

- ❖ I would like music, prayer, religious or spiritual rituals/readings in my own language.
- ❖ I do not want music or flowers in my room.

When I am nearing death and cannot speak or be understood, are there things I would like my friends and family to know?

Examples

- ❖ I love you.
- ❖ I forgive you.

Write down how you feel about the different types of Healthcare Treatments (refer to page 6), such as CPR and being on a ventilator:



Goals of Care

Once you have your Advance Care Plan, your health care team will approach you to talk about your **Goals of Care**. This discussion also often occurs when your condition changes, such as when you are admitted to the hospital. Your team will talk to you about your health, your current condition, the care that would and would not help you and what you can expect from that care and treatment. Doing so helps your team to formulate a treatment plan that respects your wishes.

When having these discussions with your healthcare team, you need to provide a copy of your **health care wishes**. Be sure to ask questions and take time to think about your choices. You may need to have several discussions before coming to a decision.

There are **three levels of goals of care**:

1. Medical Care with Cardiopulmonary Resuscitation (“Full Code”)

This level is the most aggressive level of care. This treatment plan includes any appropriate investigations and interventions to diagnose and treat your condition **including CPR and ICU/CCU admission** if you become very ill.

2. Medical Care with No Cardiopulmonary Resuscitation (“No CPR”)

This level of treatment includes any appropriate investigations and interventions to diagnose and treat your condition **excluding CPR**.

3. Comfort Care

The goal in this treatment level is to optimize your comfort. Investigations and interventions that help maintain **quality of life** would be given. This treatment plan does not include CPR, ICU/CCU admission, or treatments like dialysis.

Other examples of goals of care include:

- I want to live as long as I can (so I am prepared to accept aggressive treatments)
- I want to continue working at any cost
- I have suffered a lot and want to avoid further pain
- I do not want any more surgeries or painful interventions

- I do not want to spend any more time in hospital
- It is very important for me to pass away in my own home
- I do not want to go to a nursing home
- I do not want to be a burden to my family and friends
- I want to go to my son’s wedding next year

In discussing your goals of care with your doctor, you may also discuss any wishes or thoughts that you may have, such as when to stop dialysis.

Just like your health care wishes, your goals of care can change any time. Ask your health care team if you want to have further discussions. Your health care team will also review your goals of care whenever your condition significantly changes.

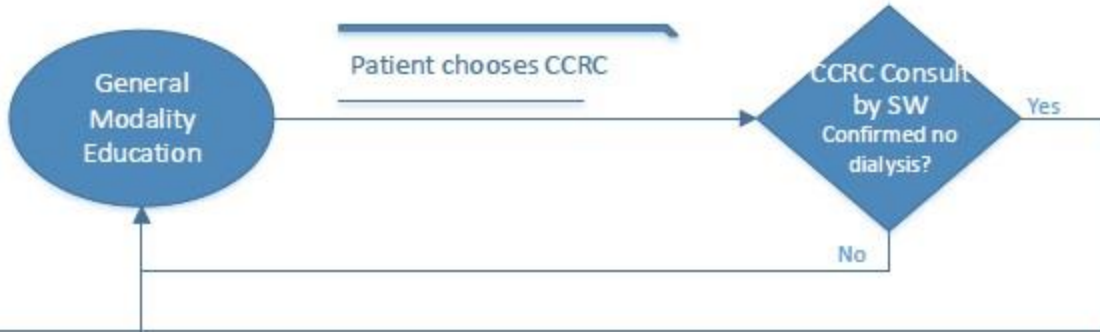
It is important to know that the choices you make now may not be ideal if you become very ill. Your healthcare team will consider your wishes, but will not offer you treatment that is of no benefit.

Management Strategies

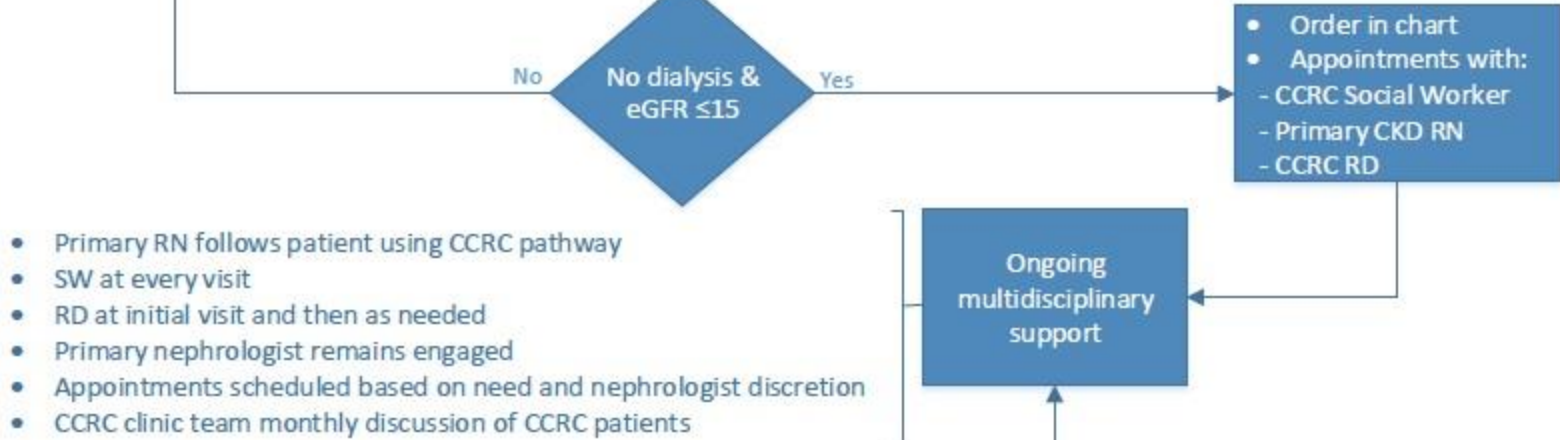
Comprehensive Conservative Renal Care (CCRC) Flow

Scarborough and Rouge Hospital

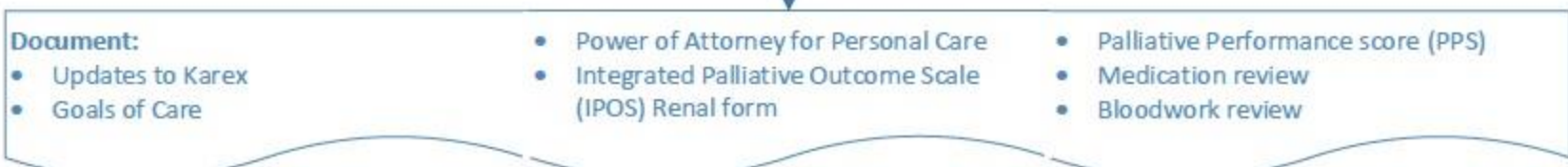
MCKC



CCRC



Tracking



CCRC Session Guides

Comprehensive Conservative Renal Care (CCRC) Social Worker Sessions

Session 1

- ❖ Open discussion with patient and family or guardian about patient's wishes for treatment.

- Is the patient still happy with the decision to forgo dialysis?
- Is there a need for home care/support services?
 - Review CM pathway process **[provide CCRC Pathway Intro Letter]**
- What is the preferred place of care as the illness progresses?

[provide Renal Palliative Information Sheet]

- ❖ Initiate discussion around ACP:

- provide workbook** and go through it
- Discussion around Power of Attorney **[provide POA kit as needed]**
- Discussions around Goal of Care initiated and advised to review with RN/NP/PA/Nephrologist
- code status **[provide DNR Confirmation Form + CPR Decision Aid info]**
- Review **CCRC Medical Letter** to be included in CCRC Package

Session 2

- Is the patient still happy with the decision to forgo dialysis?
- Is there a need for home care/support?
 - Review the preferred place of care as the illness progresses
 - Referral to SRH PCC? CCAC PCCT? SCHC PCCT?
- Review ACP workbook incl. ACD & Goals of Care
- Obtain copy of DNR Form to include in chart and CCRC package
- Obtain copy of POA to include in chart and CCRC package
- Discuss:
 - Has the pt been asked about sharing information with family?
 - Has family discussion taken place where appropriate?
 - Crises Planning:
 - Have plans for crises situations been discussed and understood by th carer/family? i.e. Are medications available?

- Have the carer/family been provided with contact information for the relevant services and persons? i.e. CKD RN, GP, Nephrologist; Palliative MD on call **[provide Contact List and Crises Plan sheet]**

Sessions 3

- Is the patient still happy with the decision to forgo dialysis?
- Follow-up outstanding ACD sections of ACP booklet
- Follow-up completion of **"Contact List and Crises Plan"** Sheet for CCRC package
- Discuss/review family's crises plan:
- Is there a need for home care/support?
 - Has the pt decided on a preferred place of care?
 - Review palliative care options
 - Is there a need for out-patient palliative care referral?
- Death preparation
 - Does the patient have a will? **[provide: Making a Will + Information for Executors and Others]**
 - Have funeral arrangements been discussed? **[provide list of funeral homes + Be a Donor brochure]**

Session 4

- Is the patient still happy with the decision to forgo dialysis?
- Is there a need for home care/support?
- confirm preferred place of care wish
 - Has the patient/family toured hospice?
 - Review palliative care process
- Discuss/review family's crises plan:
- **Provide "SRH Palliative Care" Booklet**
- **Provide Bereavement support services info i.e. SCHC HPC *NEW, Scarborough ONLY**

Initial Outcomes

CCRC Pathway

Goals

- Supporting patient and family's goals of care and treatment decisions
- Supporting patient's wishes towards a "good death" as evidenced by Quality of Dying AGPAR
- Supporting patient and family with their preferred place of care at end-of-life
- Hospice palliative care and support services provided at the right place, and at the right time
- Support for the caregivers as they support their loved one's journey towards end-of-life

SHN CCRC PATHWAY DATA

- **55** patients listed
- **12** patients not returning to clinic
- **43** active patients as of Jul. 9, 2019

- Of those who died at home- **79%** verbalized their wish to receive their EOL care at home
- Of those who died in the hospital- **47%** verbalized their wish to receive their EOL care at hospital

DIALYSIS QUALITY OF DYING APGAR (QODA)

Physical (symptom management) dimensions:

1. **Pain** (during the last week of life)
0= severe & distressing pain
1= the pain distressed the patient somewhat
2= no pain, or the pain did not distress the patient

2. **Non-Pain symptoms** (last week of life)
i.e.: confusion, dyspnea, spiritual distress, etc.
0= severe & distressing symptom
1= the symptom distressed the patient somewhat
2= no symptom or the symptom did not distress the patient

Psychosocial (peace) dimensions:

3. **Advance care planning**
During the last week of life, to what extent were patient's wishes followed- regarding a course of treatment that focused on extending life as much as possible even if it meant more pain and discomfort - or, on a plan of care that focused on relieving pain and discomfort as much as possible even if it meant not living as long.

- 0= formal health care proxy or living will had *not* been completed, documented, or communicated to staff who managed the terminal care.
1= intermediate
2= formal health care proxy or living will had been completed, documented, and communicated to staff who managed the terminal care.

4. **Peace/Dignity**
During the last week of life, did the patient die on his/her own terms? (Consider the following information, if available):

Was the patient lucid, coherent, able to take leave of loved-ones or have them say good-bye, complete most of the desired tasks, attend to spiritual matters, die where the patient chose, and leave the family united?

- 0= mostly not peaceful/dignified
1= mostly peaceful/dignified – intermediate
2= peaceful/dignified

5. **Duration dimension**
Time – Dying was prolonged or brief?

- 0= prolonged - in that the dying period lasted 6 months or more. If dialysis was discontinued, then death occurred 3 weeks or more after the last dialysis treatment.
1= intermediate - in that the dying period (terminal period) was less than 6 months but more than 1 month. If dialysis discontinued, death occurred between 2 and 3 weeks after the last dialysis session.
2= brief - the dying took place in sleep/suddenly/ unexpectedly, or occurred within one month of being in a terminal state. If dialysis was discontinued, then death took place 2 weeks or less from the time of the last treatment.

TOTAL DIALYSIS QODA SCORE _____
(Mark the score with an asterisk *, if some aspect was unusual and warrants a narrative)

70% of those families surveyed after the death of their family member reported 8 or more points on the QODA

Family QODA Feedback

- ❖ “happy with the great job and support to my father”
- ❖ Wife reported that her husband reserved a financial donation to the hospital upon his death
- ❖ “very helpful” and the primary nurse was “very nice”
- ❖ Daughter shared that MCKC communication is good and she was very appreciative of the care her father received
- ❖ Son shared that CCRC care was “excellent” and felt extremely satisfied
- ❖ Daughter was very glad of the help from the Nephrologist and team. Found the help by the social worker was good, and she was grateful for the social worker’s assistance
- ❖ “I’m happy with the way it ended. Very happy with the service”. Son felt that they were well cared for
- ❖ Family gave a basket of fruits to team as a thank you
- ❖ Daughter shared that she was “happy with the great job and support for my father”

Family QODA Feedback

- Initially family had challenges with transition and transfer to specialized palliative care teams. Feedback was that they had too many people to call, and the HPC teams often did not return calls. So the patient would end up in ED because they could not access physician home visits.
 - Gave feedback to HPC agencies to improve
 - Included updated crises planning at every visit as patient's condition changed, and to ensure families knew who to contact
 - Rely on families to call when health status changes to assist with navigating services i.e. nursing agency and HPC team, but sometimes families forget their crises plan and go to ED anyway
- Lower QODA scores were related to the management of the patient and their symptoms either at home by specialized team, or if they had to go to ER and get support managing by the specialized team, or ED staff

Next Steps

- Inter-program coordination/feedback loop to improve transition points within hospital visits
- Hospital-wide Patient Centered Decision Making Pathway Working Group to standardized goals of care discussions and palliative care
- Advocate for more supports to caregivers. Most caregivers have already given up their work so they can be full-time caregivers and often ask about income support
 - Access to more respite programs especially for home
 - Access to more support especially for overnight if patient's wish to remain at home for EOL
 - Hospice facilities needed in Scarborough instead of using PCU since patients, and especially caregivers have shared their preference for EOL care in supportive facility for when they cannot manage patient at home
- Provincial effort to standardize palliative care in Ontario: Ontario Renal Network, Palliative Care Ontario, Hospice Palliative Care Ontario
- National effort to standardize palliative care in Canada: Pallium Canada, National Conservative Kidney Management Working Group

- ❖ Dr. P. Tam
- ❖ E. Macatangay
- ❖ C. Gunn
- ❖ S. Chan
- ❖ J. Faigal
- ❖ A. Ecclestone
- ❖ Dr. S. Davison
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- ❖ Pallium Canada, LEAP Renal

THANK YOU!

Questions?