End of Life Care for Persons with End Stage Renal Disease

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El Dia De Los Muertos

Never make assumptions!

Objectives

- Develop an awareness and understanding of Renal Conservative Therapy as a viable modality option

- Facilitate and “normalize” end of life conversations with peritoneal dialysis patients early in their treatment

What is Renal Conservative Care?

- Kidney care without dialysis treatments or transplant
- Preserve kidney function
- Symptom management
- Quality of life
- Maximize health/well being
- End of Life planning/crisis management
- Support for families and individuals
- Individualized care

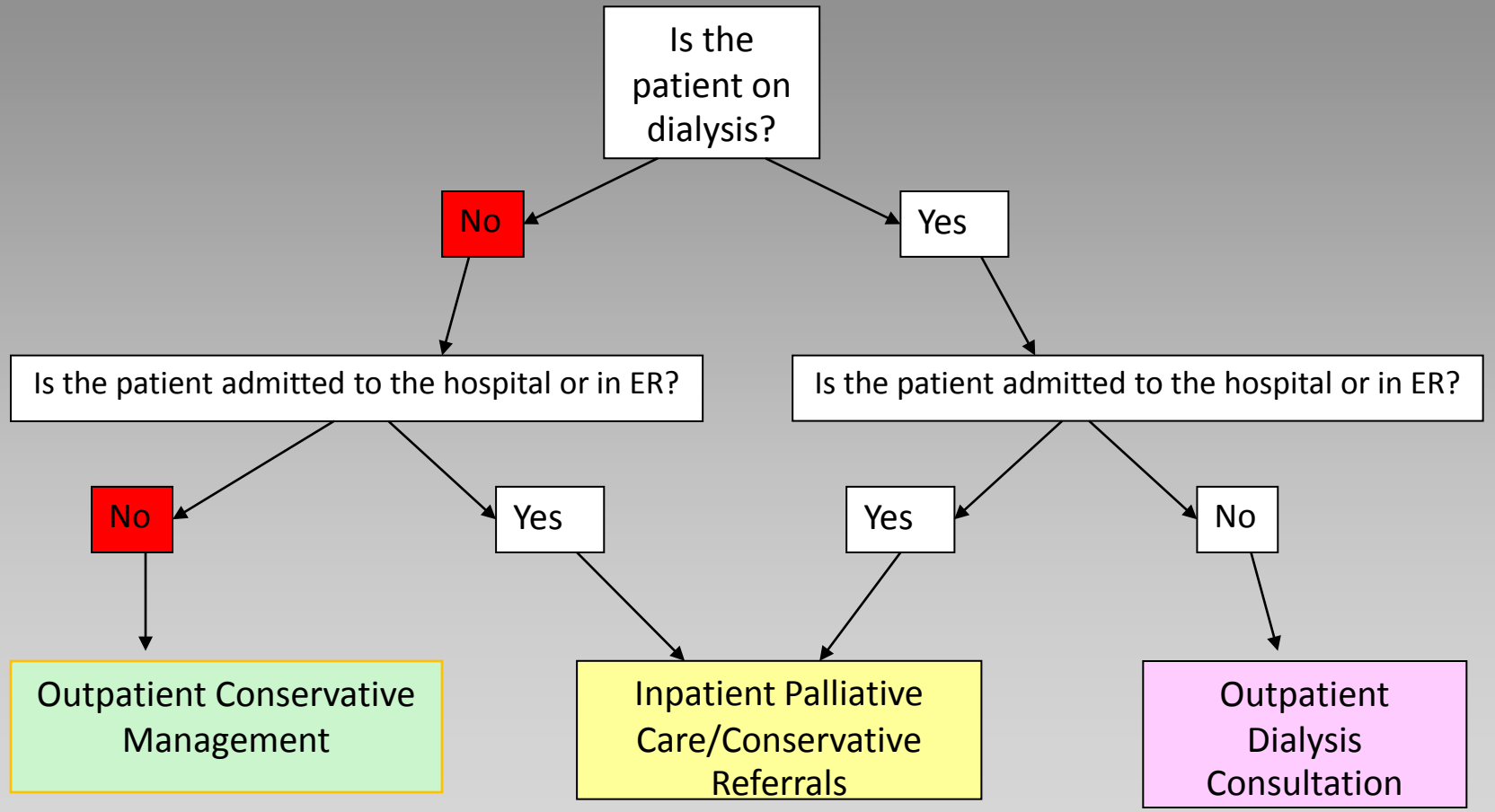
Collaboration with Others

Demographics

- Typically individuals with advanced age 80+ years young

- Younger individuals usually have secondary disease process such as cancer or multiple comorbidities

Referral Pathway



Outpatient Conservative CKD Management

Who can be referred?

Patient has declined aggressive treatment for ESKD including any form of dialysis or transplant

AND

GFR less than or equal to 15*

OR

Failed transplant who do not want dialysis.

OR

Those experiencing ambivalence about the decision to choose dialysis or conservative management and who require more info.

All of the following must take place before referral:

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

2.Initiation of Advanced Care Planning

3.Goal of Care must be determined

4.Patient and family must be notified and in agreement of referral

5.Nephrologist must be informed of referral

Who can refer?

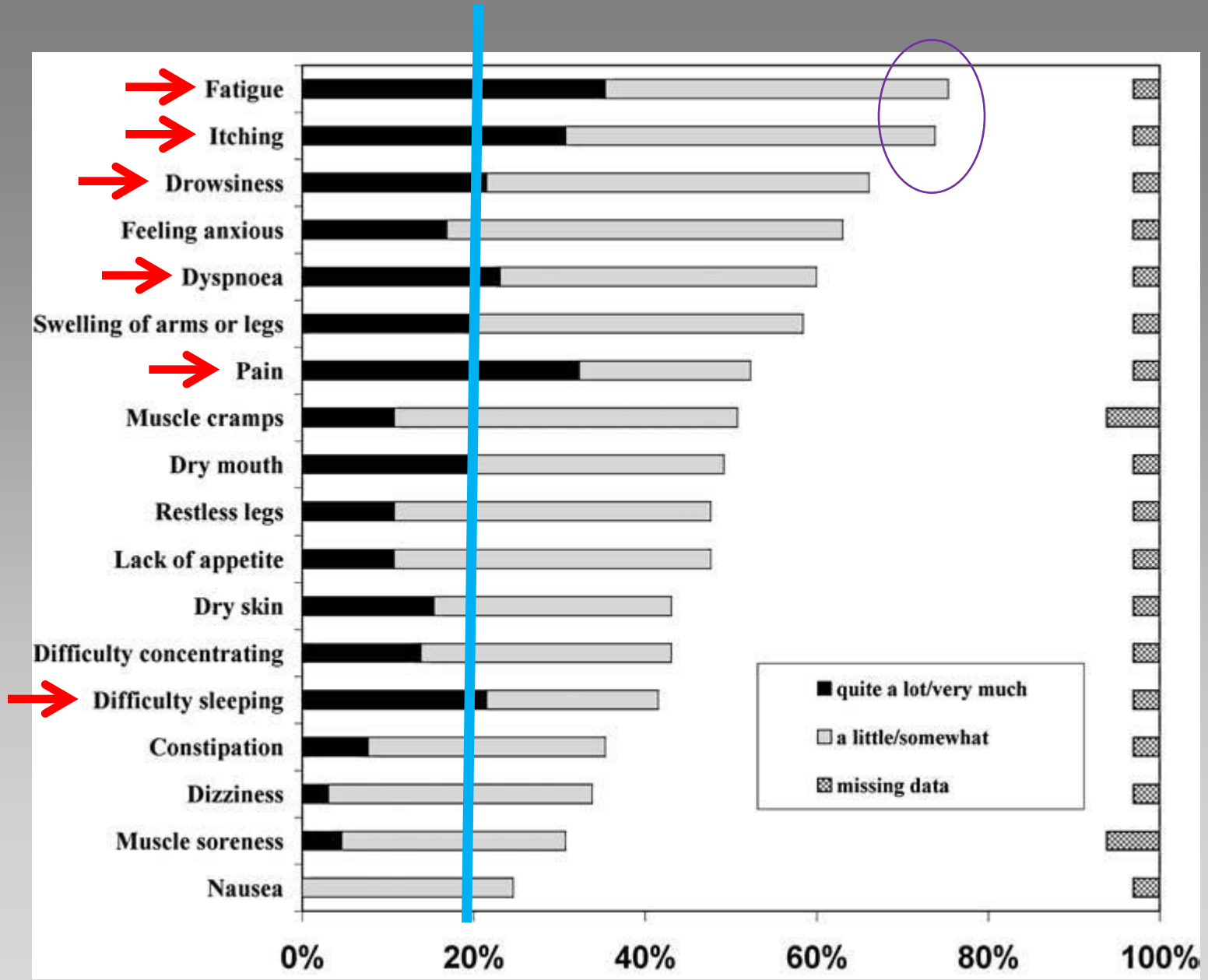
RN, NP, nephrologist, resident/fellow, or renal social worker

Contact: Lisa Blacklock/ Pat Holmes Phone: 403-955-6534 Fax: 403-955-6867

Edmonton Symptom Assessment System (revised version) Please circle the number that best describes how you feel NOW:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
No tiredness *(Tiredness=lack of energy)*	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
No drowsiness *(Drowsiness=feeling sleepy)*	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
No nausea	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
No lack of appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
No shortness	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
No depression *(Depression=feeling sad)*	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
No anxiety *(Anxiety=feeling nervous)*	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Best wellbeing *(Wellbeing=how you feel overall)*	0	1	2	3	4	5	6	7	8	9	10	Worst possible wellbeing
No _____ *Other problem (for example, constipation)*	0	1	2	3	4	5	6	7	8	9	10	Worst possible _____

Patient name: _____
Date: _____
Time: _____



Murtagh et al

Indicators that identify patients approaching end of life

- Significant weight loss (>10% in 6 months)
- Severe hypoalbuminuria (serum albumin <25 g/L)
- A “NO” response to the “surprise” question

“Would you be surprised if this patient dies in the next 6 months?”

Other Indicators - Renal EOL

- Change in living/functional situation
- Change in medical condition
- Loss of spouse/main support person
- Loss of dialysis access
- Changes to cognition, capacity, or demeanor
- New or worsening symptoms

How can I tell if a patient is ready to talk or plan about end of life?

Emotional indicators of readiness may include:

- Anger
- Anxiety / Fear
- Sadness / Despair
- Asking, “Why me?”
- Spiritual Distress
- Hopelessness

Verbal cues

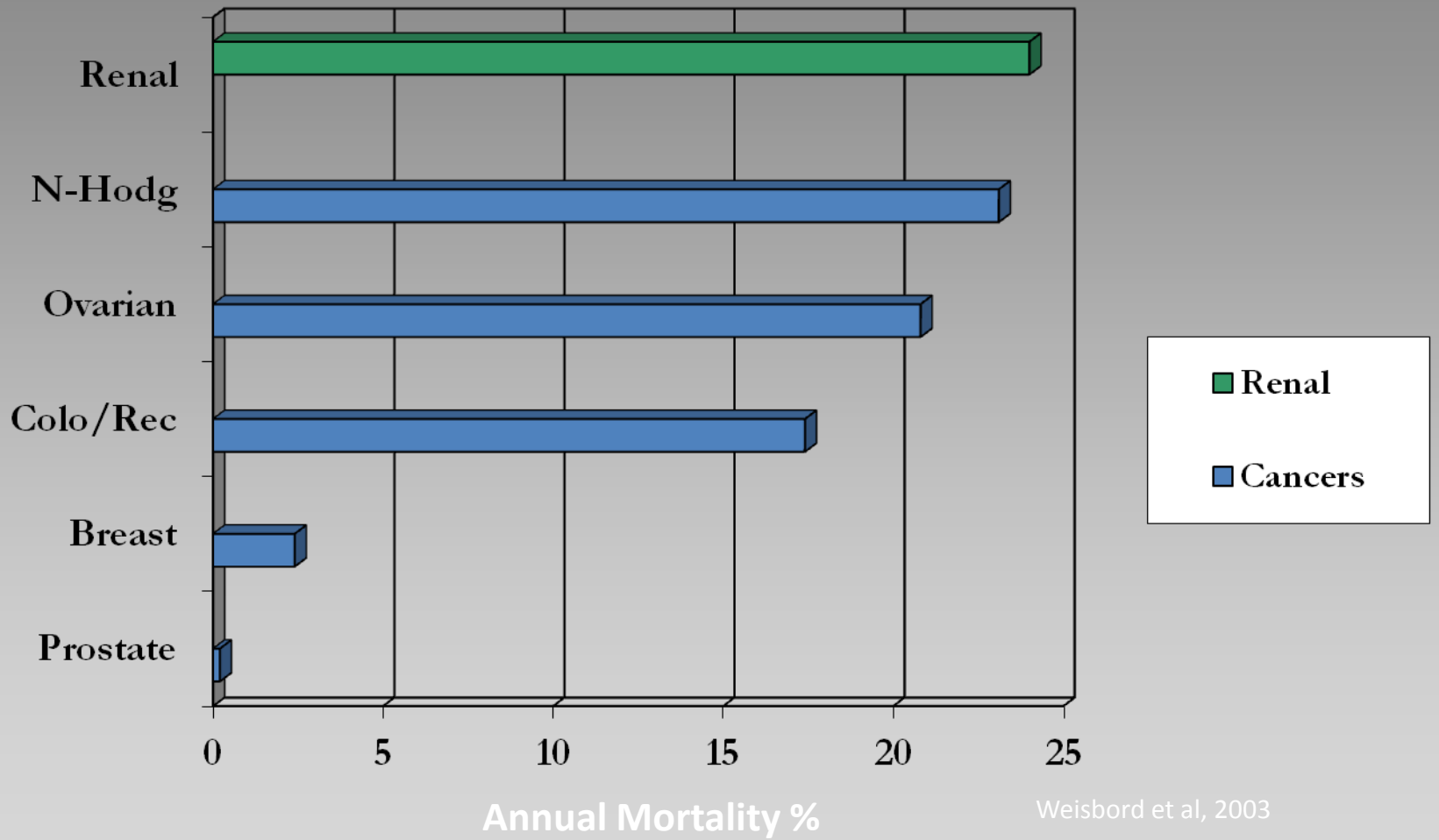
- “I am tired. I don’t want to be a burden.”
- “I don’t know if all this treatment is worth it to me anymore.”
- “I’ve simply had enough!”
- “ What happens if I stop dialysis?”

Process

- Advance Care Planning
- Goals of Care
- Emergency Planning
- End of Life Planning

Early conversations with our dialysis patients about ACP is very important

Comparison of Mortality Rates in Renal and Cancer Diagnosis



Weisbord et al, 2003

Basic Communication Skills

- What makes you uncomfortable?
- Can you really “fix” the situation?
- When is it appropriate to not say anything?
- Can you let the person express him/herself?
- Can you remember the most common basic communication skills?

Non verbal Communication

- Sit down!
- Maintain eye contact
- Keep still!
- Physical barriers
- Stay present!

What NOT to Say….

- *I understand … I know how you feel*
- *Things will work out, you'll see — everything will be all right*
- *At least you have … (your family, a good doctor)*
- *I worked with another patient with your same situation and they …*
- *Try not to worry*

ACP conversation tips

- Speak honestly
- Emphasize that changing the focus of care does not mean less care or giving up
- Explore health states when someone may need to speak for person (Stroke/ Coma/ Cognitive loss)
- If a patient responds with ambivalence ... It is ok, do not push the topic.
- Record your conversation for future reference.

Advance Care Planning in Alberta

Addressing EOL wishes

- Personal Directive

Goals of Care

- Resuscitative: R1 R2 R3
- Medical treatment: M1 M2
- Care and comfort: C1 C2

Links to Advance Care Planning : AB

- Alberta Government- www.myhealth.alberta.ca
- Alberta Health Services- www.conversationsmatter.ca
- National ACP Website- www.advancecareplanning.ca

Advance Care Planning in B.C.

Three options for addressing EOL wishes

- Advance Directive
- Representation Agreement
- Nomination of Committee

Goals of Care

- Code Status: CPR or DNR +
- MOST Designation: M1, M2, M3, C1, C2

Helpful Links to Advance Care Planning BC

Ministry of Health - http://www.health.gov.bc.ca/hcc/advance-care-planning.html

Nidus Personal Planning Resource Centre and Registry - http://www.nidus.ca

Watch the PGT website for updates to this document and other related resources - www.trustee.bc.ca

National ACP Website – www.advancecareplanning.ca

Outcomes

- QODA
- Family response post death
- home/hospice/hospital/ Nursing home
- Grief support

QODA
(Dialysis Quality of Dying Apgar)

1. Physical dimensions
    1. Pain
    2. Non-Pain Symptoms
2. Psychosocial dimensions
    1. Advance care planning
    2. Peace/dignity
    3. Duration dimension

Score/10 – the higher the score the better the death

John

John (cont.)

Appetite is gone

Vomiting

Pruritis, worse at night

Sleeping during the day

Family reports “He is just not himself”

3 kg wt loss since last clinic visit

Labs: GFR: 9, urea: 44, Hgb: 98, Ca: 2.10, P04: 2.34, CO2: 19,

alb: 26, K: 3.3

John (cont.)

John’s PD Nurse

John's PD Nurse (cont.)

- Acknowledge & clarify verbalized feelings
- Allow expression of wishes & preference of treatment
- Offer multidisciplinary expertise: ACP clinician, Pastoral Care, psychologist, Social worker, Conservative Care clinician
- Meeting with family & caregivers
- Transfer modality
- Continue ACP

Summary

- Elements of the Renal Conservative Care modality and how it provides an option to caring for our patients and families that focuses on quality of life and is patient centered

- A main feature of ACP is that it is a PROCESS of ongoing conversations with patients (and families) concerning beliefs, values, and wishes for end of life care, and can take place long before end of life

- With some basic communication skills, we don’t need to be experts. We just need to listen

Acknowledgements

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