Bridging Palliative Care and Chronic Disease in Ontario: A Respirology and Nephrology Perspective

St. Joseph’s Healthcare Hamilton
Palliative Care Team

Quality Hospice Palliative Care Coalition of Ontario
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Our Conversation Today

Who are our patients?
How do our patients die?
Approach
  • Partner
  • Care
  • Teach
Guidelines & Teaching Aids
What’s different?
Who are our patients?
• 86 years old from Nursing Home
• With urosepsis and creatinine of 632
• On background of HTN, CRF, CAD, diabetes, osteoporotic fractures
30 years old, developmental delay, renal failure, transplant, immunosuppressives
Face pain – sudden airway obstruction – emergency trach, intubation, PEG, CVL - neck cancer
4-point restraints, scared
72 years old, from Eastern Europe, minimal English, no family, closest friend is landlord, ESRD \(2^{\circ}\) to HTN, dialysis dependent. Hip fracture – healed. Foul vaginal discharge, intermittent delirium. Withdraw/Not withdraw/Withdraw/Not withdraw
• 60 years old, CRF 2\textsuperscript{nd} polycystic kidney disease, on bkd PUD – gastric resection, COPD, bilateral DVT, CAD, hypothyroid
• Admitted with herpes zoster, dehydration
• RFR: Intractable nausea, severe pain
55 years old with ESRF 2nd to lupus, rheumatoid arthritis, epilepsy. On dialysis. Presented with leg weakness. Found to have small and non-small cell cancer of the lung with spinal metastases
28 year-old mother of a 5 year-old child DM, renal failure – daily hemodialysis, severe pain = calciphylaxis covering entire torso including perineum. 

Full code – “want to live as long as possible for my son”
32 years old, ESRF 2\textsuperscript{nd} to DM, on dialysis, pancreatitis, pseudo-obstruction, gastropathy with gut pacemaker, bilateral BKA, ischemic hands, sepsis.

A “fighter”

Nephrologist away - family will wait to make decisions when he returns because “we are in this together”
• 84 years old, dementia, general frailty
• Admitted with aspiration pneumonia
76 years old with CRF, pneumonia. Developed CHF ------ diuresis ------ Worsening renal failure --------- fluids ----- CHF ------- worsening heart failure
68 years old with HTN, ASHD, OA; Progressive dyspnea with ADLs x 1 month
Suspected H1N1 – confirmed
Day 4: extubated, reintubated at pt request,
Day 8: pt requested extubation,
• 51 years old, COPD/emphysema, OSA, HTN, recurrent pancreatitis
• acute respiratory tract illness – intubated, extubated, BIPAP
• Alcohol – 6-13 beer/day
• Chronic pain from workplace accidents – Oxycontin, Methadone, Venlaxafine, Gabapentin, Baclofen
• 67 years old, COPD now endstage, followed by respirologist for > 20 years
• Admitted with acute on chronic respiratory failure
• Respirologist asked for help from colleague because decision making “too hard”
62 years old with IPF, diagnosed 6 months ago, functioning well until recently. Home O₂ x 1 month, now severe dyspnea, hospitalized, BiPap dependent
Our Conversation Today

How do our patients die?
ESRD as a palliative illness: Prognosis

- Life expectancy of dialysis patients is only 16-37% of people of same age/sex without renal disease.
- Only 33% of new dialysis patients survive 5 years.
- Survival comparable or worse than patients with many types of cancer.
Prognosis

- Younger patients with no comorbidities may survive 30 years.
- Rising median age of dialysis populations with almost 50 over 65 years old. 75-84 year olds have the greatest increase in dialysis use over past 5 years.
Theoretical Trajectories of Dying

**Sudden Death**
- High Function
- Low Time

**Terminal Illness**
- High Function
- Low Time

**Organ Failure**
- High Function
- Low Time

**Frailty**
- High Function
- Low Time
How do our patients die?

Trajectories for our patients

+ Frailty

+ Terminal Illness
Our Conversation Today

Approach
• Partner
• Care
• Teach
Approach - Partner

Complexity of patient needs means we have to work as partners

- Team
- Colleagues / other teams
- Hospital
- Community
Partners: Team

• Palliative Care Team has changed over the years – to meet needs of patients and hospital
• Original team included MD, RN, SW, Spiritual care
• Now MDs (all with specialty training, 1 works 1/2 time internal medicine & 1/2 time palliative care), CNSs (Masters’ prepared, psychologist, volunteer
Partners: MD & Allied Health Colleagues

- Colleagues want to look after own patients
- May have known them for years
- Partnering allows us all to learn most
- Join specialist colleagues in clinic –
- Resp clinic invited us to share their clinic space so that PC would be visible
- Developed guidelines to help problem solve basic pc issues if we can’t be there
Partner: Hospital

• No PC unit – Units /specialties want to look after their own patients
• But units have started creating own dedicated palliative care beds
• Team reported for years to VP Clinical administratively – now via admin director
• Team under General Internal Medicine clinically, MDs cross-appointed;
• Team members all active on hospital committees
Partner: Community

- Needed to ensure good care & ease of transitions for patients
- Close links – 3 team members worked in community palliative care
- Close links – team members active on community & family medicine committees
- Close links - work on joint projects, e.g.
Partners

• We are in this together
• We value relationship
• We communicate directly with the person responsible or able to make the change
• We talk about what matters - Courageous conversations
• We vision & plan together
Approach - Care
Approach – Patient Care

- Assess, assess, assess
- Acknowledge feelings and suffering
- Educate: anticipate and answer questions
- Identify & remove underlying causes /provocative factors
- Treat symptoms – non pharm and pharmacologic
- Negotiate a trial
- Evaluate
Approach - Patient Care Assessment

• Reason for Referral
• Chart review
  – Services involved
  – Past Medical History
  – Recent History and Reason for Admission
  – Diagnoses and Management this admission
  – Medications / Allergies
  – Social history
  – Relevant family history
  – Investigations to date
Approach - Patient Care Assessment

Palliative Care Issues

• Diagnoses and disease modifying management
• Symptom management
  – **ESAS** screen
  – Describe: OPQRST and 7 A’s
    • Aggravating, Alleviating, Associated, ADLS, Analgesia
    • Alcohol/addictions, Alternative therapies
  – **DIMES** (Description, Impact, Meaning, Expectations, Supports)
• Optimization of Function (**PPS, CAM**)
Approach - Patient Care Assessment

• Attention to Quality of Life
• Care Planning
  – Decision-maker: Who? Has POA been assigned?
  – Understanding of illness
  – Values and preferences
  – Goals of care
  – Management approach and decisions to date
  – Limits to care articulated
  – Place of care

• Support needed (practical, financial, emotional, spiritual)
• End-of-Life needs
**Approach - Patient Care Assessment**

- **Physical Exam:** Relevant focused exam and teeth to toes
- **Impressions & Questions**
- **Recommendations**
- **Follow-up**
- **Communication with healthcare providers and/or family**
Approach - Teach
Every person on our team teaches
Commitment to capacity building
  – On wards – e.g. Nephrology
  – Within disciplines – e.g. joint Social Work Palliative Care Journal Club
Team Model changes to meet needs
  – Consultation → Shared Care → Dedicated Care
Guidelines & Teaching Aids

- Palliative Care Assessment Sheet
- Algorithm for Assessing and Accessing Palliative Care Resources in Clinic
- Withdrawal from Dialysis:
  - Decision making guide
  - Guidelines for order sheet
- Discharge Planning Checklist
- Complexity Tool

*plus* …
What is Different?

Patient care

• Multiple moving parts
• Same medications but timing and dosing dependent on understanding & planning for trajectory
  – ARF, CRF, Dying on dialysis, withdrawal preserving a precious kidney while dying
  – COPD, ILD/IPF, acute vs chronic respiratory failure, withdrawal from BIPAP / ventilator
What is Different?

Partnering & Capacity Building

• Goal
• Messy
• Occasionally brilliant
What is Different?

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• Residents identified, assessed, and managed 13 different possible causes of nauses

• 100% better