TAKING OWNERSHIP IN PALLIATIVE CARE: FAMILY PHYSICIANS MAKE A DIFFERENCE

PRIMARY CARE ONCOLOGY DAY: PALLIATIVE CARE
WEDNESDAY FEBRUARY 20, 2019

SANDY BUCHMAN MD CCFP (PC) FCFP
Disclosure Statement

I have no actual or potential conflict of interest in relation to this presentation.

With thanks to Pallium/LEAP program and Dr. Jose Pereira in the preparation of this presentation.
### Learning Objectives

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<tr>
<td>1</td>
<td>To understand the recommended “palliative care approach/model in 2019.</td>
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<td>2</td>
<td>To appreciate the critical role of the FP/PCP in providing PC working with an inter-professional team.</td>
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<td>3</td>
<td>To describe the skill sets/competencies required in providing Primary Palliative Care.</td>
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<td>4</td>
<td>To learn about the supports that need to be in place for family physicians to provide high quality palliative care to their patients.</td>
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Mr. H. J. ‘s Story - Part 1
The Main Question:

- Should we, as family physicians, “own” palliative care/symptom management, much like we “own” diabetes or chronic disease management?
The Imperative
The number of Canadians aged 65 and older is up and is close to 6 million (2016 census)

• The 2016 Census counted 5,935,635 people aged 65 and older in Canada, an increase of more than 990,575, or 20% between 2011 and 2016.
• This rate of growth was more than double the 5.0% increase for the Canadian population as a whole.
• Chronic conditions (at least one): 44% of all adults

The Tip Of the Iceberg!

The tip: 1% of the population will die & Require EOL care

Below the surface: Progressive life limiting illness & life threatening illnesses – These patients require a palliative care approach

In a family medicine clinic, 1% of patients on roster die annually

Increased in certain populations.

Long Term Care
Heart Failure Clinics
Residential Homes
Oncology
Some Fast Facts

- Three-quarters of Canadians would turn to their family physician (73%), for more information on hospice palliative care services.
- By 2025, only 20% of Canadians will die with an illness that has a terminal phase. Two-thirds of Canadians who die will have two or more chronic diseases and will have lived for months or years in a state of fragile health or “vulnerable frailty.”
- Only 16-30% of Canadians get access to Specialist Palliative Care
- Expensive invasive procedures in the last year of life account for about 18% of Canadians’ lifetime health care costs – and these procedures often do not prolong life or benefit the patient. Sometimes they cause more suffering and hasten death

CHPCA Fact Sheet, 2014
Why do Family Doctors matter?

- Primary care is the extended family
- Single & often first point of contact
- Expert in the Doctor-Patient relationship
- Expert in continuity of care across time & location including home visiting
- Holder of the cumulative patient record
- Linked to family members
- Cost effective (Starfield)
- Special skills – anesthesia, surgical, GPO, palliative
- Links to the community
Why have family doctors and their primary care teams incorporate Palliative Care into their practices?

- To improve the patient and family experience through **early** increased symptom assessment and management by primary care providers in the community with the necessary back up and support.
To have trust and confidence in the doctors looking after you” (55.8%)

The most important elements in this survey related to trust in the treating physician, avoidance of unwanted life support, effective communication, continuity of care and life completion.

What Canadians Say:
The Way Forward Survey Report

- 87% believe that a palliative approach to care should be AVAILABLE EARLY on in the course of a disease.
- 94% believe it should INCLUDE ALL CARE PROVIDERS.

HOSPICE PALLIATIVE CARE IN CANADA
HARRIS/DECIMA THE WAY FORWARD SURVEY RESULTS*

The cancer journey
Better cancer services every step of the way

PREVENTION → SCREENING → DIAGNOSIS → TREATMENT → RECOVERY/SURVIVORSHIP → END-OF-LIFE CARE → PSYCHOSOCIAL & PALLIATIVE CARE

Ontario Cancer Care Ontario
Action Cancer Ontario
For which of the following patients would you activate “palliative care”?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
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<td>3. A patient with shortness of breath at rest due to chronic obstructive airway disease (COPD)</td>
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<td>4. A patient with ALS who has no symptoms except for moderate weakness</td>
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<td>5. A patient with ALS who is experiencing shortness of breath</td>
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<td>6. A patient with end-stage renal disease who requests discontinuation of dialysis</td>
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WHO Definition of Palliative Care

“...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.”
End of life care is an important part of palliative care, and usually refers to the care of a person during the last part of their life, from the point at which it has become clear that the person is in a progressive state of decline.

It’s not only about Terminal (End-of-Life) Care

Palliative care “phases”
- Distinct stages in a patient’s illness journey.
- Classified according to the clinical need of the patient.
- Provide an indication of the level of care required.
- Phases are not necessarily sequential. \(^{(Smith 1996)}\)
- Use these to allocate appropriate resources and care plans.
- Increased frequency of assessments are required for unstable conditions and deteriorating and terminal phases.
  [www.pco.c.org.au]
Old Model: Initiating Palliative Care “Late”

- Life prolonging treatments
  - Cure or control
  - Disease progression
  - Terminal

Illness trajectory:
- Diagnosis
- Death
- Palliative Care
- End of Life
- Bereavement

Sudden change in goals of care!
When the illness progresses and the patient enters the terminal phase (end of life), the focus of care turns more towards comfort measures.

Examples:
- Cancer: chemotherapy, radiotherapy, surgery
- CHF: Heart failure treatments
- Treat hypercalcemia, infections, delirium, fractures, GI obstruction, heart failure, etc

An Integrated Supportive & Palliative Care approach

Supportive & Palliative Care begins early in the illness trajectory, alongside treatments to control the disease.
- Symptom management
- Address psychosocial & spiritual needs
- Goals of care discussions

Do not wait for the last days or weeks to initiate a Palliative Care Approach. Integrate it earlier in the illness trajectory to avoid sudden transitions of care at end of life. Earlier Palliative Care improves quality of life, reduces psychological distress and allows patients to make better care decisions.
The Palliative Care Approach

**In patients with progressive disease, take the approach of “Hoping for the best, while also preparing for the worst”. Use the following 3-step approach.**

<table>
<thead>
<tr>
<th>1. Identify</th>
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<tbody>
<tr>
<td>Identify patients who may benefit from a palliative care approach earlier in the illness trajectory (could be alongside treatments to control the disease) by using:</td>
</tr>
<tr>
<td>- The “Surprise Question”</td>
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<tr>
<td>- General Indicators of Decline</td>
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<tr>
<td>- Disease-Specific Indicators of decline</td>
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<tr>
<th>2. Assess</th>
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<tr>
<td>- Explore patient’s understanding of illness and prognosis, information preferences and goals of care</td>
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<td>- Use the “ESAS” plus history to identify symptoms and quality of life issues</td>
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<tr>
<td>- Assess functional status with Palliative Performance Scale (PPS) or Eastern Cooperative Oncology Group Performance Status (ECOG)</td>
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<tr>
<td>- Assess resource needs</td>
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<th>3. Plan</th>
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<tr>
<td>- Develop an appropriate care plan based on the phase of the illness</td>
</tr>
<tr>
<td>- Start symptom management</td>
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<tr>
<td>- Activate appropriate resources</td>
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<tr>
<td>- Continue care and be pro-active</td>
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The Starting Point: Primary Level Palliative Care

<table>
<thead>
<tr>
<th>Care provided by non specialist clinicians in palliative care (with or without the support of specialist teams):</th>
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<tbody>
<tr>
<td>Oncologists</td>
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<tr>
<td>Internists</td>
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<tr>
<td>Geriatricians</td>
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<tr>
<td>Pediatricians</td>
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<tr>
<td>Respirologists</td>
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<tr>
<td>Cardiologists</td>
</tr>
<tr>
<td>Neurologists</td>
</tr>
<tr>
<td>Critical Care Physicians</td>
</tr>
<tr>
<td>Emergency Care Physicians</td>
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<tr>
<td>Surgeons</td>
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</tbody>
</table>

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<tr>
<th>Primary Care Palliative Care</th>
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<tbody>
<tr>
<td>Care provided by primary care clinician in clinics or the community</td>
</tr>
<tr>
<td>Family Physicians</td>
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<tr>
<td>NPs</td>
</tr>
<tr>
<td>FHTs</td>
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<tr>
<td>Community Nurses</td>
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<tr>
<td>CCAC</td>
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<tr>
<td>Emergency Care Physicians</td>
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</tbody>
</table>
### Primary Palliative Care

- Identify “palliative” patients early
- Assess & Manage Pain, Symptoms, Depression and Anxiety
- Identify social & spiritual needs
- Goals of Care discussions & Advance Care Planning
- Supportive counseling
- Prepare for emergencies
- Be available to patients, families & home care providers

### Specialty Palliative Care

- Management of complex or refractory pain or other symptoms
- Management of more complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment
  - Within families
  - Between staff and families
  - Among treatment teams
- Assistance in addressing cases of near futility
Who provides palliative care? “Approach” vs. “Specialist service”

- Most patients require only primary-level Palliative Care (Palliative Care Approach)
  - Family medicine clinic
  - Oncology team
  - Internal med clinics
  - Cardiology clinics
  - COPD clinics
- May occasionally require assistance of specialist palliative team
  - consultation or shared care support
- A small number of patients with complex needs require transfer of care to specialist palliative care services
True or False?

- Initiating palliative care early in the illness

<table>
<thead>
<tr>
<th></th>
<th>True</th>
<th>False</th>
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<tbody>
<tr>
<td>1. Increases depression</td>
<td>![False]</td>
<td>![True]</td>
</tr>
<tr>
<td>2. Increases anxiety</td>
<td>![False]</td>
<td>![True]</td>
</tr>
<tr>
<td>3. Reduces hope</td>
<td>![False]</td>
<td>![True]</td>
</tr>
<tr>
<td>4. Shortens life expectancy</td>
<td>![False]</td>
<td>![True]</td>
</tr>
</tbody>
</table>
True or False?

- Initiating palliative care early in the illness….
“Early” palliative care does not increase distress or shorten survival

- Survival is equal or better with palliative care.

  - Of 4,493 Medicare patients who died of CHF or cancer, hospice use was associated with increased survival.\(^1\)

  - Patients with lung cancer who used hospice had increased survival; chemotherapy use in last 2 weeks of life did not improve survival\(^2\)

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Several studies show:

• Inappropriate treatment and care choices
  • E.g. nth line chemotherapy with no benefit expected
  • ICU admissions
  • Inappropriate use of emergency rooms & hospitalizations
  • “Futile” CPR

• Lack of preparation for EOL by patients and families
• Unrealistic expectations & false hope
• Sudden change in goals of care distressing

What is impact of introducing palliative care “late”? 
Best Practices: Early Palliative Care

Early Specialty Palliative Care — Translating Data in Oncology into Practice

Ravi B. Parikh, A.B., Rebecca A. Kirch, J.D., Thomas J. Smith, M.D., and Jennifer S. Temel, M.D.

Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial

Camilla Zimmermann, Nailsa Swani, Monika Kryzenowska, Brefini Hanner, Natascha Leight, Amit Oza, Malcolm Moore, Anne Rydall, Gary Reddy, Ian Tannock, Allison Donner, Christopher Lo

Summary
Background Patients with advanced cancer have reduced quality of life, which tends to worsen towards the end of life. We assessed the effect of early palliative care in patients with advanced cancer on several aspects of quality of life.

Effects of a Palliative Care Intervention on Clinical Outcomes in Patients With Advanced Cancer
The Project ENABLE II Randomized Controlled Trial

Marie Bakitas, D.N.S., A.P.R.N.
Kathleen Duley Lyons, Sc.D, OTR
Mark T. Hegel, Ph.D.
Sedal Balas, M.D.
Frances C. Brokaw, M.D., MS
Janetie Senville, Ph.D.
Jay C. Hull, Ph.D.
Zhongyi Li, MS
Tat D. Tosteson, Sc.D.
Ira B. Brock, M.D.
Tim A. Alder, Ph.D.

Context There are few randomized controlled trials on the effectiveness of palliative care interventions to improve the care of patients with advanced cancer.
Objective To determine the effect of a nursing-led intervention on quality of life, symptom intensity, mood, and resource use in patients with advanced cancer.
Design, Setting, and Participants Randomized controlled trial conducted from November 2008 through May 2009 of 322 patients with advanced cancer in a rural, National Cancer Institute-designated comprehensive cancer center in New Hampshire and affiliated outreach clinics and a VA medical center in Vermont.
Interventions A multicomponent, psychosocial intervention (Project ENABLE [Educate, Nurture, Advise, Before Life Ends]) conducted by advanced practice nurses consisting of 4 weekly educational sessions and monthly follow-up sessions until death or study completion (n=161) vs usual care (n=161).

Main Outcome Measures Quality of life was measured by the Functional Assessment of Cancer Therapy-Palliative Care instrument (FACT-P; 0-100, higher score indicates better quality of life).

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer


Published Online: February 20, 2014
http://dx.doi.org/10.1056/NEJMoa1306636
NEJMzA035151585466436
“Early” vs. “Late” Palliative Care

- Randomized study\(^1\) of patients with newly diagnosed metastatic lung cancer
- **Randomized to:**
  - **“Early”** PC: PC referral at time of referral to medical and radiation oncology
  - **“Late”**: PC referral only at the end of life when all other treatments had failed (“usual care”)
- **Results**
  - Compared to late referred patients, patients with early palliative care referrals had:
    - Less depression & anxiety
    - Better quality of life
    - Lived longer (3 months)
  - Similar Results obtained in a random control trial conducted in Canada\(^2\)

**References**
2. Zimmerman et al., Lancet 2014
The proactive function of coordination of care designed to improve the quality of life of patients living with life-limiting illnesses and those of their families

• Identification includes:
  • A holistic assessment of the patient’s needs across multiple domains including physical, psychosocial-spiritual, grief and loss
  • Assessment of family members’ needs related to psychosocial-spiritual, grief and loss.

• The process can be supported by tools, triggers and/or general decline indicators to assist practitioners with assessing patient needs

What is actually meant by earlier identification?
The Benefits of Earlier & Integrated Palliative Care

- Providing palliative care (including palliative homecare) earlier increases patient satisfaction with their care.
- Leads to better control of pain and other symptoms & better supports patients and their families emotionally and psychologically.
- Reduce hospitalizations in the overuse of potentially ineffective or aggressive treatments at the end of life.
- Integrating palliative care early means providing distinct services centered on the needs and preferences of patients and the needs and preferences of their families.
Mr. H.J.’s Story – Part II
Mortality in congestive heart failure (CHF)

- What is the annual mortality rate of patients with NYHA Class II?
  - Annual mortality rate 5-15%
    - Of these, 50-80% die suddenly

- What is annual mortality rate of patients with NYHA Class IV?
  - Annual mortality rate 30-70%
    - Of these, 5-30% die suddenly

Only about 1 in 10 patients with end-stage heart failure are aware of their prognosis
Early Palliative Care: Different for People with Different Conditions?

What does early palliative care look like for people with different illness trajectories?
Illness trajectories

Only 10% of people die suddenly!
Illness trajectory: Advanced cancer

Cancer Trajectory

- More rapid decline in last months and weeks
- Last few months to weeks

Level of Functioning
- 100% Normal activity
- 50% Mostly sitting or lying down
- 30% Bed bound

Time
- Usually months to years

Diagnosis

Mississauga Halton Central West Regional Cancer Program
In partnership with Cancer Care Ontario
Illness trajectory: End-stage organ failure

End-stage Heart or Lung Failure

Gradual decline over years or months with intermittent crises or serious episodes; more frequent crises & hospitalizations in the last year

Level of Functioning

- 100% Normal activity
- 50% Mostly sitting or lying down
- 30% Bed bound

Time

- Diagnosis
- Usually years
- Last year
- Death
Illness trajectory: Dementia & frailty

Gradual decline over years to months.
Illness trajectory patients with progressive cancer

If not yet initiated, a Palliative Care approach should be activated.

Decline is generally gradual until PPS reaches about 50% to 60% (ECOG 3). Thereafter the decline is often more rapid.

Life expectancy of days to weeks (ECOG4)

PALLIATIVE ALERTS – ILLNESS TRAJECTORY IN PROGRESSIVE CANCER

- Encourage patient to see family physician regularly or find one. Explore patient’s understanding of illness, discuss prognosis and goals of care.
- Ensure ESAS and PPS/ECOG done at each visit.
- Start advance care planning. Discuss code status. Review treatment plan.
- Initiate home care
- Establish plans to deal with emergencies (e.g. pain crisis)
- DNR and advanced directives
- Discuss preferred versus optimal place of death based on needs and circumstances

Note that this data represents mean values; for some patients the decline may be more gradual while for others it may be more precipitous.

Seow H et al. JCO 2011;29(9):1151-1158

Weeks before death

Death

PPS Functional Status
1. **The surprise question:** would you be surprised if this patient were to die in the next 6 to 12 months?
   - An intuitive question that integrates comorbidity, social, and other factors.

2. **Choice/need:** the patient with advanced disease makes a choice for comfort care only, not curative treatment, or is in special need of supportive/palliative care.

3. **Clinical indicators:** specific indicators of advanced disease for each of the three main end-of-life patient groups – cancer, organ failure, elderly frail/dementia

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http://www.goldstandardsframework.org.uk/  
“Ask the question”

Would I be surprised if this patient died in the next year?

Joanne Lynn. RAND Lecturer USA and senior advisor on end of life care Gold Standards framework, UK.
**Gold Standards Framework: General and Disease specific indicators**

**INDICATORS OF APPROACHING END OF LIFE**

<table>
<thead>
<tr>
<th>General Indicators of Decline</th>
<th>Disease-specific Indicators of Decline</th>
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<tbody>
<tr>
<td>Performance status declining (PPS ≤ 50% or ECOG ≥ 3)</td>
<td>Cancer</td>
</tr>
<tr>
<td>Progressive weight loss (≥10%) over past 6 months</td>
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<tr>
<td>Two or more unplanned admissions to hospital in past 6 months because of disease-related complications</td>
<td>Nutritional disease</td>
</tr>
<tr>
<td>A new diagnosis of a progressive, life limiting illness</td>
<td>Metastatic disease</td>
</tr>
<tr>
<td>Repeated unplanned/crisis admissions to hospital</td>
<td>Significant weight loss due to primary cachexia</td>
</tr>
<tr>
<td>Sentinel event (serious fall)</td>
<td>Refer to prognostic indicator tools (PPS, PaP, PPI): can help but do not refer to them blindly</td>
</tr>
<tr>
<td>Serum albumin &lt; 25 g/l</td>
<td>Neurological disease</td>
</tr>
<tr>
<td>Two or more advanced conditions (co-morbidity)</td>
<td>Progressive deterioration in function despite optimal therapy</td>
</tr>
<tr>
<td>Renal disease</td>
<td>Symptoms which are complex and difficult to control</td>
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<tr>
<td>Stage 4 or 5 chronic kidney disease (CKD)(eGFR &lt; 30 ml/min) with at least 2 of the following indicators:</td>
<td>Dysphasia leading to recurrent aspiration pneumonia; sepsis, dyspnea, breathless or respiratory failure</td>
</tr>
<tr>
<td>“No” to Surprise question</td>
<td>Speech problems with increasing difficulty communicating and progressive dysphasia</td>
</tr>
<tr>
<td>Patient chooses “no dialysis” option, discontinuing dialysis or not opting for dialysis if transplant failed</td>
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</tr>
<tr>
<td>Difficult physical or psychological symptoms despite optimal tolerated renal replacement therapy</td>
<td>Respiratory disease (≥ 2 of following)</td>
</tr>
<tr>
<td>Symptomatic renal failure</td>
<td>Severe airway obstruction (FEV1 &lt; 30%) or restrictive deficit (VC &lt; 60%)</td>
</tr>
<tr>
<td>Neurological disease</td>
<td>Meets criteria for long term oxygen therapy (PaO2 &lt; 7.3kPa)</td>
</tr>
<tr>
<td>Persistent severe symptoms despite optimal tolerated therapy</td>
<td>Breathless at rest or on minimal exertion between exacerbations</td>
</tr>
<tr>
<td>Symptomatic right heart failure</td>
<td>Persistent severe symptoms despite optimal tolerated therapy</td>
</tr>
<tr>
<td>Loss of appetite and weight</td>
<td>Respiratory disease (≥ 2 of following)</td>
</tr>
<tr>
<td>Recurrent hospital admissions (≥ 3 in last 12 month) due to disease</td>
<td>Severe airway obstruction (FEV1 &lt; 30%) or restrictive deficit (VC &lt; 60%)</td>
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### Disease-specific Indicators of Decline

**Heart disease** (≥ 2 of following)
- NYHA Class III/IV-dyspnea at rest on minimal exertion
- Repeated hospital admission with heart failure symptoms
- Persistent symptoms despite optimal tolerated therapy
- Significant weight loss due to cachexia

**Liver disease**
- Advanced cirrhosis with one or more complications:
  - Intractable ascites
  - Hepatic encephalopathy
  - Hepatorenal syndrome
  - Bacterial peritonitis
  - Recurrent varicea bleeds
- Serum albumin < 25 g/l and PTT raised or INR prolonged > 2
- Hepatocellular carcinoma
- Not fit for liver transplant

**Dementia**
- Unable to walk without assistance
- Urinary and fecal incontinence
- Unable to communicate meaningfully
- Unable to do Activities of Daily Living (ADL)
- Plus any of the following:
  - Weight loss
  - Urinary tract infections
  - Severe pressure sores (stage 3 or 4)
  - Recurrent fever (aspiration pneumonia, urinary tract infections)
  - Reduced oral intake
Frailty – Clinical Indicators

Multiple co-morbidities with impairment:

- Deteriorating performance status
- Combination of at least three of the following symptoms:
  - weakness
  - slow walking speed
  - significant weight loss
  - exhaustion
  - low physical activity
  - depression
Although they can be late, “triggers” may be another way to identify patients requiring a palliative care approach if not identified earlier.

Does this patient have unmet palliative needs?

- High symptom burden
- Critical event
- Short prognosis
- Serious, incurable diagnosis
- Functional deterioration

Review current care and care planning (From SPICT™):
- Review current treatment and medication so the person receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals, and a care plan with the person and their family.
- Plan ahead if the person is at risk of loss of capacity.
- Record, communicate and coordinate the care plan.
Other promising tools for early identification - HOMR

Hospital One-year Mortality Risk (HOMR)
 Highly accurate (c=0.89-92)
 Derived validated in Ontario, Boston, Alberta (retrospective data)
 Uses simple administrative data

Data includes:
 Death Risk (life tables)
 Sex
 Charlson Comorbidity Index
 Admitting service
 #ED visits in previous 12 months
 Living Status (Home, LTC, etc.)
 Admission urgency (Ambulance)
 Seen in cancer clinic within last 12 months
Prognosis discussion

- Although most family members had not had a prognosis discussion, 90% of them indicated that they would like to have such a discussion.

- It is incumbent on health care professionals to foster opportunities & climate for discussions.

- When prognosis is discussed with patients & families, satisfaction with care is greater.

- Having time to adequately prepare for life’s end is important to most seriously ill Canadians & their families.

Impact of avoiding these prognostic discussions

- High burden of suffering for patients
- Inappropriate utilization of resources
- Care that is inconsistent with patients’ wishes
- Patients lose good time with their families
- Lose opportunities for reflection and preparing for their life’s end
- Spend more time in the hospital and ICU

Harrington SE, Smith TJ: The role of chemotherapy at the end of life:“When is enough, enough?” JAMA 2008; 299:2667-2678
What do patients with end-stage COPD want to discuss?

- Components of EOL care that patients with end-stage COPD would like to discuss with their physicians:
- Diagnosis & disease process
- Role of treatments in improving symptoms, QOL & duration of life
- Prognosis for survival & QOL
- What dying might be like
- Advance care planning for future medical care & exacerbations

Curtis JR, Wet al. Patients’ perspectives on physicians’ skills at end-of-life care: differences between patients with COPD, cancer, and AIDS. 

Importance of Family Physician Involvement in Home Palliative Care*

- Patients experiencing low continuity of care made 3.9 times more ED visits than those experiencing high continuity in Nova Scotia**

- In Ontario, physician house call or palliative care assessment was associated with a decreased odds ratio of ER visits, ICU admissions and Chemo in the last 2 weeks of life – these being suggested indicators of poor end-of-life care***

*Goldman, R. Capstone Project - Family Physicians and Home Palliative Care: An Assessment of Capacity and Willingness to Engage – Proposal as part of the requirement of a Masters Thesis 2009 - Personal Communication


Do Family Physicians still provide home based palliative care in Toronto?

- 67% of Family Physicians asked that the Palliative Care physician group assume primary responsibility for their patients
- 26% requested a “shared care” approach but only 1/3 would be available for urgent calls
- FP availability for after hours calls was not clear

Moran E, Goldman R, Adams D, Husain A. How family physicians see their own roles and that of palliative care specialists caring for their patients, after referral to a metropolitan home palliative care service. Eur Journal of Palliative Care 2007;10th Congress of the European Association for Palliative Care Connecting Diversity Programme and abstracts Budapest, Hungary, 7–9 June 2007 Poster abstract 458:142
Challenges to providing Palliative Care in the Office or Home Setting

- Family Physicians wish to remain active in the care of their dying patients
- Challenging to address the complex issues at the end of life in the home setting
- Family Physicians often receive insufficient training in Palliative Care and experience difficulty in accessing specialist services
Challenges to providing Palliative Care in the Office or Home Setting

- Ability to make housecalls:
  - Skill set – both in Palliative Care and in “house calls”
  - Time away from busy office
  - Geographic distances (esp. in rural settings)
  - Traffic

- Overall lack of knowledge and skills in EoL care

- Lifestyle issues: willingness to provide 24/7 coverage both individually and in team models

- Remuneration

- Lack of sufficient number of FDs to provide needed care.
Enriching Family Physician Capacity to deliver quality Palliative Care

Goal:
- To enhance family physician capacity to deliver palliative home care through collaboration with interpersonal palliative care specialists in a shared care model

Strategies:
- Improve access to palliative care through the use of screening criteria and case finding on family practice offices;
- Improving primary care physicians’ knowledge, skills and confidence through practice-based education and shared clinical care with palliative experts;
- Improving the quality of palliative home care through specialist team enhancements

Methods:
- West Lincoln Hospital Palliative Care Team in Niagara became the Enhanced Palliative Care Team (EPCT): An APN, PMP, psychosocial spiritual advisor, bereavement counselor, CCAC CM.
- 3 FHTs with 3 physician leaders
- 24/7 support to community nurses and FPs
- APN role was also that of “navigator”

Case finding and screening ensured timely access to the EPCT:

1. Would you be surprised if this patient died in the next 12 months?

2. If no, does the patient have pain, symptom issues or supportive care needs?

3. Tools: ESAS, Confusion Assessment Method, PPS and National Comprehensive Cancer network’s patient and caregiver Distress Scale
   • Family Physicians remained MRP – EPCT collaborators in care and second line support
Key Components of the shared-care model for optimal palliative care

PALLIATIVE ENHANCED INTEGRATED PRIMARY CARE TEAM

• APN Navigator; Palliative Medicine Consult; Shared 24/7 Call; Psychosocial & Bereavement Counseling; Designated CCAC Manager;
  • Enhanced Services (24 Nursing; Drugs; Equipment)

ACCESS
• Best Practice: Early Identification of Palliative/Population-Based Screening Across Sectors/Rostering

ASSESSMENT
EOL Domains
• Outcome-Based (ESAS, PPS, CAM, Patient Distress, Family Distress)

EDUCATION/DECISION SUPPORT
• Practice-Based Education to Support GP Adoption of Best Practices (Academic Detailing)
  • Decision Support: “Just in Time”

COORDINATED CONTINUOUS CARE
• Follows Patient Across Care Sectors
  • Integrated Care & Team Planning (Right Provider)
  • Explicit Resource Allocation: Respite Need Tool, Bereavement Risk

EVALUATION OF PATIENT/FAMILY EXPERIENCE
Coordinated Continuous Care & Education and Decision Support

- Communication between members of the EPCT and the FPs was a priority
- Weekly Meetings about patients
- APN link to FP offices – key person of contact amongst FPs, patients, families, other EPCT members

- Educational needs of MDs and RNs identified by APM & PMP
- Coordinated practice and evidence-based strategies (“just-in-time” case based teaching, chart reviews, academic detailing)
- 15 clinical and educational sessions to the 3 Involved family practices
- Interdisciplinary: MDs, RNs (office & Community, pharmacists, students, etc.)
Results

- 40% increase in yearly referrals
- 4 FPs became Physician Practice leaders in Palliative Care for their FHTs
- 59% home deaths vs. 28% before the project
- Mean length of Patient participation in the project was 145 days (5-445).

**Most important for FDs:**
- Having access to PC consultants 24/7
- Practice based education
- Valued personal contact with EPCT
- Felt patients benefitted from comprehensive home palliative care/seamless integration
- Program permitted maintenance of role as primary care provider

**Most important for RNs:**
- Valued improved trust and working relationships with FDs
- Felt less isolated in handling complexities of home based palliative care
- Support from APN enhanced their skill set and thus their confidence in decision-making

The INTEGRATE Project
The INTEGRATE Project: 3-Year Pilot Project

GOAL: Enable identification and management of patients to benefit from a palliative care approach early and across settings

1. Inter-Professional Palliative Care Education
   *Pallium Canada LEAP Education + Decision Aid + CCO Website*

2. Integrated Palliative Care Model

Four Cancer Centres (CCs)
Four Primary Care Practices (PCPs)
Participating Sites

- 4 Primary Care Practices
- 4 Cancer Centres
  - Lung
  - Head & Neck
  - Central Nervous System
  - Gastrointestinal

Disease-Agnostic
Integrated Palliative Model

**INTEGRATED CARE APPROACH**

**INTER-PROFESSIONAL EDUCATION**

LEAP Provider Tool
CCO Website

**Step 1: IDENTIFY**

“Would you be surprised if this patient died in the next year?”

No

Assess Symptoms & Functional Status

Discussion with Patient & Family
Advance Care Planning and/or Goals of Care discussions

Symptom Management

Triage & Referrals

**Step 2: ASSESS**

Linkages to Home and Community Care

Standardized Reporting from Oncology to Primary Care

**Step 3: PLAN/MANAGE**

Primary care/ oncology
CCAC coordinator/nurse
Palliative clinic nurse

Rounding on shared patients

Community Palliative
Oncology
Provider Education

- 142 Primary Care Providers and 157 Oncology Providers participated in education sessions.

Provider survey pre and post education show significant changes in knowledge, attitudes and skills. Participants indicated that course:

- 91% Was relevant to practice
- 90% Met learning needs
- 94% Was a productive team-building exercise
- 93% Is worth recommending to others
Primary Disease Site of Patients Identified with the Surprise Question (N=166)

63% of patients had > 3 comorbid conditions

- Cancer: 43%
- Heart disease: 17%
- Chronic Lung Disease: 7%
- Dementia: 10%
- Frailty: 7%
- Other: 11%
- Chronic Kidney Disease: 5%

* Other: Liver disease, Motor Neuron Disease, Parkinson’s, ALS, Diabetes, Stroke

This is an interim evaluation summary, and may not reflect data in the final evaluation report.
<table>
<thead>
<tr>
<th>Primary Care Team</th>
<th>Start Date</th>
<th># of Dr’s</th>
<th>Total # Patients/Dr</th>
<th># of Patients ID (% of practice Target – 1%)</th>
<th># of Reported Patient Deaths (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sunnybrook Academic Family Health Team</td>
<td>April 2015</td>
<td>10</td>
<td>9,603</td>
<td>55 (0.5%)</td>
<td>25 (45%)</td>
</tr>
<tr>
<td>Forest Hill Family Health Group</td>
<td>May 2015</td>
<td>3</td>
<td>4,666</td>
<td>9 (0.2%)</td>
<td>6 (67%)</td>
</tr>
<tr>
<td>Barrie and Community Family Health Team</td>
<td>June 2015</td>
<td>15</td>
<td>24,553</td>
<td>134 (0.5%)</td>
<td>47 (35%)</td>
</tr>
<tr>
<td>Petawawa Centennial Family Health Team</td>
<td>Nov. 2014</td>
<td>8</td>
<td>6,293</td>
<td>96 (1.5%)</td>
<td>24 (25%)</td>
</tr>
</tbody>
</table>
• 78% had an ACP discussion
  o Mean time to discussion is 28 days
• 73% had the documented ACP discussion transmitted to the Primary Care Provider
  o >75% of Primary Care Providers receiving INTEGRATE report indicated “that it will be helpful in the management of their patient.”
• 73% are receiving CCAC services following identification
  o Assessment after referral occurs within 7 days for the majority of the patients (≥78)
  o Time from assessment to service reflect appropriate prioritization (<7 days for ≥94% of referred patients)
Patient/Caregiver Experience Evaluation (N=19)

- **Positive experiences of care** (relationships with providers and service accessibility)
  - Providers **initiated ACP discussion** and did so at the right time
  - Providers **supported caregivers** in preparing for the death of their loved ones and they felt involved in decision-making about the care to the extent they wanted

- **Different levels of patient ‘readiness’** to have the ACP and GoC conversations

- **Difficulty pinpointing the palliative aspects of care;** more focused on cancer care experience as a whole and on completion of daily tasks

- **Confusion regarding different providers,** their roles and who to contact when
## Provider Awareness & Comfort

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Opportunities (o)/Weaknesses (w)</th>
</tr>
</thead>
</table>
| • LEAP provider education well attended and well received  
• Increased confidence amongst providers in doing palliative care  
  ✓ *Earlier identification of patients*  
  ✓ *Introduction of ACP*  
• Physicians doing more palliative care work | • LEAP refresher or sharing of tools available for providers and patients (o)  
  ✓ *Increased educational efforts aimed at enhancing patients understanding of palliative care as not limited to end of life* |
Provider Evaluation Takeaway Messages (N=119)

- LEAP helped develop a common language and approach for clinical collaboration
- **Significant positive change** in provider comfort and confidence in delivering palliative care
- **Model was most successful** when embedded into existing clinical work flows; partnerships pre-existed and senior managers were accountable
- Achieving **provider buy-in** and confidence
- Determining **patient readiness**, both clinically and emotionally
- Still room to improve communication and coordination between providers/sites, clarify roles and responsibilities
Symptom management decision support Apps

Evidenced Based Tools to Guide Care

Disease Pathway Management
Just in time Support for FDs/PCPs

Integrated Communication

Online Resources

Tools

Coaching

Palliative and End-of-Life Care Network
CME on the Road

- Peer reviewed Interprofessional Courseware
  - LEAP Courses:
    - Core, LEAP LTC, LEAP
    - Acute, LEAP Non-Cancer, LEAP First Nations
- Palliative Pocketbook
- E-Book
- Apps
- E-learning: Palliative Snippets
- Competency Mapping
- Partnerships i.e. Departments of Family Medicine, OCFP
RESPECT
Risk Evaluation for Support: Predictions for Elder-life in the Community Tool

WWW.PROJECTBIGLIFE.CA
What are the additional supports needed for physicians who practice palliative care as a “Special Interest” or “Focused Practice”?

- Monthly Journal Club, Complex Case Rounds, Forum to discuss shared concerns
- Collaborative Mental Health Program oriented to palliative care
- A culture of safety - M & M Rounds – critical to growth, quality of care
- Coaching & mentoring
- Strong leadership – system & academic - in one’s practice & locally, provincially , nationally
Conclusion

• That FPs are critical to improving care for patients with life-limiting illness by utilising a palliative care approach
• That FPs (and all specialists) who look after patients with life-limiting illness must introduce palliative care early in the illness trajectory to improve outcomes
• That engagement of more FPs to provide Palliative Care to Patients with life-limiting illness cannot be accomplished without simultaneously providing the supports and resources to undertake this type of work & approach
Mr. H.J. Story Part III
It's not only about End-of-Life Care…
You may not be a specialist in palliative care, but you can make a difference.
Recall The Main Question:

- Should we, as primary care providers, take “ownership” of palliative care much like we “own” diabetes care or chronic disease management?
Thank you!