Palliative Care in Non-malignant Conditions
Opportunities for quality improvement from an internal medicine perspective

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Objectives
- Learn that acute illnesses in patients with chronic diseases often are missed opportunities re-evaluate goals of care
- Understand the barriers to palliative care in non-malignant conditions
- Learn the basic approach to designing a quality improvement project

Case 1
- Illness trajectory

Case 1
- Barriers to palliative care
  - Lack of formal diagnosis of dementia
  - Language barrier
  - Challenges in ascertaining prognosis
  - Family fears about withholding fluids and treatment for infection
  - Need for repeat discussions
  - Reflexive treatments offered at time of deterioration

Disclosures
- None

Introduction

Left image: CDC

Case 1
- Illness trajectory

FUNCTION

TIME

Memory loss
3 month decline
Cognition & function
Pneumonia
Aspirations
Death
Case 1

• Lessons learned
  – Some families may respond to a strong recommendation from medical team
  – Reviewing natural history of disease can help
  – Persistence necessary
  – Reassurance may be required
  – These things take time and energy

Case 2

• Illness trajectory

Case 2

• Barriers to palliative care
  – Pre-morbid functioning was stable for years prior to acute illness
  – Patient’s wishes had never been clarified before
  – Therapies to treat pneumonia and hypernatremia are simple and cheap and can be initiated reflexively in the emergency department
  – The I.V. falling out was a chance event
  – Family felt burdened with responsibility of end-of-life decision-making

Case 2

• Lessons learned
  – Pneumonia and hypernatremia are often part of a natural death
  – These events can represent an opportunity to clarify goals of care and philosophy of care
  – Ask: should we do anything? (Rather than, Can we do anything?)

Common chronic diseases on GIM

• Dementia
• Stroke
• Congestive heart failure
• Chronic obstructive pulmonary disease
• Decompensated cirrhosis
• Chronic kidney disease

Common acute illnesses on GIM

• Pneumonia
• Stroke
• Myocardial infarction
• Acute kidney injury
• Sepsis
• Delirium
• Exacerbation of chronic disease (e.g. CHF, COPD)
The problem

• Non-cancer conditions are less likely to receive palliative care
• Non-cancer conditions have significant symptoms
• Non-cancer conditions are increasing in prevalence

Auditor General’s Report

• Cancer patients
  – 30% of deaths in Canada
  – 80% of CCAC end-of-life clients
  – 85% of hospice beds

COPD vs. lung cancer

• (Graph: COPD patients had worse symptom scores than patients with non-small cell lung cancer)

Symptoms in CHF

• Last 3 days of life
  – 41% of patient surrogates reported severe pain
  – 63% reported severe dyspnea

Barriers to palliative care in non-malignant disease

• Disease-related issues
• Provider-related issues
• Patient/carer issues
• Systems issues

Barriers to palliative care in non-malignant disease

• Disease-related issues
  – Difficulty prognosticating
    • Variable disease trajectory
    • Multiple tools
    • Low predictive ability of tools
  – Wide variety of diseases
    • May have unique symptoms/management needs
Variable disease trajectory
27 CHF patients
• (Chart showing variable disease trajectory)

COPD prognostication
• (COPD BODE calculator)

CHF prognostication tools
• Reduced ejection fraction:
  – EHMGR (Emergency Heart Failure Mortality Risk Grade)
  – HFSS (Heart Failure Survival Score)
  – Seattle Heart Failure Model
• Preserved ejection fraction:
  – ?

Dementia prognosis – ADEPT score
• (Table of ADEPT score sensitivity and specificity)

Breathlessness by condition
• (Graph of breathlessness by medical condition compared with cancer)
Final common pathway?

- 50% prevalence in a systematic review
  - Pain
  - Fatigue
  - Anorexia
  - Dyspnea
  - Anxiety
- Similar between cancer and non-cancer conditions

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Provider-related issues

- Lack of knowledge or training
- Confusion/conflict about roles
- Skepticism about value of palliative care
- Missed opportunities to discuss goals of care
- Discussions are difficult and time-consuming

UK focus group on CHF and palliative care

- “The most severe criticism was reserved for the cardiologists, who were charged by all groups with failing to recognise palliative care needs or practise holistically”
- “Implicit in the discussions was that care for people dying with heart failure had not been planned. This was most clearly expressed by the cardiologists, who acknowledged the need to develop those formal and informal connections between specialties that are essential to coherent care”

Implantable cardioverter-defibrillator

- 100 next of kin surveyed
  - 27 reported discussion about deactivating ICD before death
    - Most of these discussions occurred during last hours/minutes of death
  - 27 received shocks in last month of life
    - 8 within last minutes of life

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<td>• Survey of 220 cardiology trainees in UK</td>
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<td>• 45% report receiving no training in palliation of advanced heart failure symptoms</td>
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### End-of life communication by physicians with COPD patients

- Survey of 115 patients
- Severe COPD
- Oxygen-dependent

### Community-based palliative care for dementia

- Retrospective cohort study in Australia of patients in last year of life
- 6% of dementia cohort had community-based palliative care (compared with 26% in comparison cohort of other diseases)
- Patients not receiving community palliative care visited ED twice as often

### Weight loss in nursing home

- 69 year old man in long-term care
- Prior to admission to long-term care
  - End-stage heart failure
  - Multiple admissions to hospital
  - Declining functional status
- Unrecognized 33 kg weight loss in 2 months
- Patient died
  - Cause of death: dehydration due to CHF and CAD, in a man with cirrhosis

### Weight loss case findings

- No indication that the physician had an overall plan of care
- Not clear that the physician understood the prognosis for the patient or was aware of the weight loss
- Not clear if the physician was aware of the large doses of diuretics and possibility of dehydration
- No evidence that physician had communicated with long-term care team about the diagnosis, prognosis and care plan for the patient
- Little evidence of communication with the patient himself or his family

### Dementia end-of-life

- 19.5% of nursing-home residents dying of advanced dementia were hospitalized within last month of life (4.6% to ICU)
- 37% of hospitalizations were at the request of relatives, most frequently for curative or life-prolonging treatment
Dementia end-of-life

- “Worryingly, none of the decisions to hospitalize involved the in-house palliative care consultants of the nursing homes although a large majority of residents were receiving palliative care; no hospitalizations took place because the resident needed palliative treatment”
- Information about wishes and preferences for future care transferred with patient in 19%

Code status documentation on GIM

- 20% had complete and consistent code status documented
- “Older patients and patients receiving comfort measures were more likely to have a clinically relevant inconsistency in code status documentation

Patient/caregiver related issues

- Some patients do not wish to discuss prognosis; may be focused on cure
- Fear of palliative care
- Negative association with cancer

Systems issues

- Funding
- Training
- Structure of palliative care services
- Support for discussions about end-of-life care

Opportunities for improvement

- Integration with medical subspecialists
  - Education
  - Physical integration with clinics
- Goals of care discussions
  - Inpatient
  - Outpatient
- Long-term care

Increasing access for patients with non-malignant disease

- Background/setting
  - United Kingdom, hospital (inpatient/outpatient)
- Intervention
  - Hired palliative care physician specifically to increase access for patients with non-malignant disease
  - Letters sent to GP’s
  - Educational events for GP’s, nurses
  - Meetings with specialty societies and physicians
  - Postgraduate education event
  - Education and listening events for hospice staff
- Results
  - Referrals increased from 5.7% to 18.2% in 15 months
  - Majority for respiratory disease (69%), neurologic disease (22%)

Hayle et al., BMJ Supportive & Palliative Care 2014;13(Suppl 1):A1–A110

Houttekier et al., Palliative medicine 2014
### Barriers to discussion of goals of care in hospitalized patients

- Family members’ difficulty accepting loved one’s poor prognosis
- Family members’ difficulty understanding limitations/complications of life-sustaining therapies
- Lack of agreement amongst family members about goals of care

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### Anatomy of a QI project

- Identify a problem
- Form a team
- Identify and engage stakeholders
- Develop an aim
- Find root causes
- Choose methodology
- Select measures
- Select interventions
- Collect baseline data
- Implement interventions
- Collect data
- Analyze data
- Sustain and spread change
- Communicate successes/failures

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### Other considerations

- Ethical conduct of study
- Ongoing stakeholder engagement
- Cost

Ethical screening tool for QI projects:
http://www.aihealthsolutions.ca/arecci-a-project-ethics-community-consensus-initiative/

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### Identify a problem

- Draw from your clinical experience
- Frustrations/irritations
- Adverse/critical events
- Staff/patient feedback
- Collect data

*E.g.: Code status documentation for patients with severe dementia on Internal medicine is poor (0/6 patients this month, and 1/6 last month)*

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### Form a team

- Point-of-care staff  *E.g.: Nurses, residents*
- QI expertise
- Executive sponsors  *E.g.: Nurse manager, department chief*
- Project charter

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### Develop an aim

- How much, by when?
- Specific
- Measurable
- Actionable
- Realistic
- Timely

*E.g.: Code status discussion for 100% of GIM patients with severe dementia within 2 days of admission by July 2016*
Identify and engage stakeholders

- University Health Network
- Women’s College Hospital
- Diabetes Transition Clinic
- Internal medicine wards
- Nurse managers
- Ward clerks
- Administrative assistant
- Diabetes nurse educators
- Department of endocrinology
- Department of medicine
- Administration
- Medical staff
- Residents and medical students
- Medical staff of clinic
- Chief medical residents
- Chief of medicine
- Site chair(s)
- Department of endocrinology
- Chief of endocrinology
- Internists who are also endocrinologists
- Chief of endocrinology
- Diabetes nurse practitioner
- Tech support
- Blackberry support
- Intranet support
- Centre for innovation in complex care
- RAPID post-discharge clinic
- Administrative assistant
- Patients and families
- External
- Canadian Diabetes Association
- Ontario Health Links
- Media

Find root causes

- (Fishbone diagram with example root causes)

Choose methodology

- PDSA (Plan – Do – Study – Act)
- LEAN
- Six Sigma

Select measures

- Outcome measures
  - e.g., % of patients with discussion about goals of care within 2 days of admission
- Process measures
  - e.g., % of patients with code status documented in chart within 2 days of admission
- Balancing measures
  - e.g., family/patient satisfaction

Select interventions

- Intervention should be linked to desired change through theory/evidence
- May be single intervention or a bundle
- Choose interventions that create less work for people (i.e. have an inherent advantage)
- Local context is critical
  - e.g., education session for residents at beginning of each month
  - e.g., reminders for clinicians initiated by ward clerk
  - e.g., automatic palliative care consult

Collect baseline data

- Must know what your baseline rates are to know if your change works
Implement interventions

- Start small-scale rather than implementing system-wide
- Get feedback from users as you go

e.g., test out code status reminder system with a few volunteers, then one medical team, then multiple teams, multiple hospitals, etc.

Collect and analyze data

- Collect the least amount of data possible
- Harness existing data sources
- Collect data frequently (every 2-4 weeks)
- Use statistical process control, not traditional research statistics
- Avoid before-and-after designs
- Monitor fidelity of implementation of your interventions

e.g., % of clinicians who actually read the reminders

Run chart

Sustain and spread change

- One of the most challenging parts
- Focus on “hardwiring” change

e.g., automate reminder system, or standardize workflows

Communicate successes and failures

- Rounds
- Conferences
- Journals
  - BMJ Quality Improvement Reports

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Questions?

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