Care at the End

Transitioning to a palliative approach for frail elders at home
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Objectives

• Identify challenges in home-based palliation of frail elders
• Describe the “tool kit” for providing home-based palliative care
• Apply a palliative approach to common conditions at end-of-life, with cases
Outline

• Background
  – Home VIVE program
  – Vancouver context

• Tool kit
  – System supports and Day-to-day tools

• Cases
  – Challenges in prognostication and decision-making
  – Symptom management

• Discussion and summary
Home ViVE
(Home Visits to Vancouver’s Elders)

• Longitudinal primary care practice
• Exclusively home-based
• Interdisciplinary team
  – 6 part-time FP’s
  – 2 full-time NP’s
  – 3 RN’s
  – 1.5 Physio, 1 OT, 2 Rehab Assistants
  – MOA, administrator
Goals

• Maintain or improve function, independence and safety
• Manage chronic diseases, respond to acute changes
• Support patients’ and caregivers’ choices
• Avoid or delay hospitalization
• Avoid or delay residential care admissions
• Provide good palliative care at EOL
Demographic

• Age over 80
• Moderately or severely frail (Clinical Frailty Scale)
  – Medical and/or psychiatric impairment
• High MAPLe (Method of Assessing Priority Level) and CHESS (Changes in Health, End-stage disease and Signs and Symptoms) scores
  - RAI-HC
How do we measure frailty?

Clinical Frailty Scale*

1. **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2. **Well** – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g, seasonally.

3. **Managing Well** – People whose medical problems are well controlled, but are not regularly active beyond routine walking.

4. **Vulnerable** – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being "slowed up", and/or being tired during the day.

5. **Mildly Frail** – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6. **Moderately Frail** – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.

7. **Severely Frail** – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8. **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. **Terminally Ill** - Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common symptoms in mild dementia include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In moderate dementia, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In severe dementia, they cannot do personal care without help.


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Home ViVE

- High intensity / Low volume practice
  - Home visits average 20-30 minutes
  - ‘Stable’ patients seen by MD every 4-8 weeks
  - Palliative or patients with acute changes in status seen more often
  - Other team members may also be involved
  - 24/7 availability

- Deaths 20% per year
- Home deaths approximately 40%
Toolbox

• System Supports
  – Provincial programs
    • Advance Care Planning
    • BC Palliative Care Benefits
    • Expected Death at Home

• Local supports
  – Home Health
  – Home Hospice program
  – Geriatric programs
BC Palliative Care Benefits Program

• Life expectancy 6 months or less
• Expanded drug coverage
  – Medications for pain and other symptoms
  – Some OTC meds
• Medical supplies and equipment
  – Catheters, continence products, dressings, CADD pumps, needles/syringes
  – Walkers, wheelchairs, hospital bed, mechanical lift, commode
Expected/Planned Death at Home

- DNR form completed
- Notification of Expected Death at Home form
  - Done before the death
  - Allows Funeral Director to remove a body from home without pronouncement (not required by law in BC, but commonly requested by families)
Local palliative supports

- Home Health
  - Community RN’s, Home support workers
- Home Hospice Program – consultative model to support primary providers
  - Home-based patients
  - Nursing home residents
- Palliative drug box
- In-home shift care nursing in last days
Top 5 Drugs in the Palliative Box

- Hydromorphone
- Glycopyrrolate
- Methotrimeprazine
- Haloperidol
- (Lorazepam)
<table>
<thead>
<tr>
<th>Grouping</th>
<th>Description</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sudden Death</td>
<td>Accident, fall, trauma, sudden cardiac</td>
<td>2.9</td>
</tr>
<tr>
<td>Terminal Illness</td>
<td>Cancer, CRF</td>
<td>28.4</td>
</tr>
<tr>
<td>Organ Failure</td>
<td>COPD, CHF</td>
<td>33.8</td>
</tr>
<tr>
<td>Frailty</td>
<td>Dementia, MS, Parkinson’s</td>
<td>29.3</td>
</tr>
<tr>
<td>Other</td>
<td>Not in other groupings</td>
<td>5.6</td>
</tr>
</tbody>
</table>
Shifting to a Palliative Approach

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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.”

Who might benefit from a Palliative Approach?

• The Surprise Question
  – “Would you be surprised if this person died in the next 6-12 months?”

• Not sure? Use general or disease-specific prognostic indicators
  – Gold Standards Framework
  – iPal tool (ipalapp.com)
  – SPICT
General Clinical Indicators

• Decreasing activity and functional status declining
• Increasing need for support
• Progressive weight loss >10% in 6 months
• Repeated admissions (crises)
• Advanced disease, **multi-morbidity**, decreasing response to treatment
• Low serum albumin
Cancer Trajectory

Health Indicators

Time

Increasing Symptom Burden
Multiple System Involvement

Cancer therapy
Symptom Mgt
Support
Cancer Trajectory

• The most important predictive factor in cancer is performance status and functional ability
  – Patients spending more than 50% of the time in bed / lying down have a prognosis estimated to be about 3 months or less
### Palliative Performance Scale (PPSv2) version 2

<table>
<thead>
<tr>
<th>PPS Level</th>
<th>Ambulation</th>
<th>Activity &amp; Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Conscious Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>Full</td>
<td>Normal activity &amp; work, No evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>90%</td>
<td>Full</td>
<td>Normal activity &amp; work, Some evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>80%</td>
<td>Full</td>
<td>Normal activity with Effort, Some evidence of disease</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>70%</td>
<td>Reduced</td>
<td>Unable Normal Job/Work, Significant disease</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>60%</td>
<td>Reduced</td>
<td>Unable hobby/house work, Significant disease</td>
<td>Occasional assistance necessary</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>50%</td>
<td>Mainly Sit/Lie</td>
<td>Unable to do any work, Extensive disease</td>
<td>Considerable assistance required</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>40%</td>
<td>Mainly in Bed</td>
<td>Unable to do most activity, Extensive disease</td>
<td>Mainly assistance</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>30%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity, Extensive disease</td>
<td>Total Care</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>20%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity, Extensive disease</td>
<td>Total Care</td>
<td>Minimal to sips</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>10%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity, Extensive disease</td>
<td>Total Care</td>
<td>Mouth care only</td>
<td>Drowsy or Coma +/- Confusion</td>
</tr>
<tr>
<td>0%</td>
<td>Death</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
Dora

- 93 year old woman, living on her own since husband’s death 20 years ago
- Hx of orthopedic injuries in an MVA 1975
- OA knees
- ?CHF
- Decreased mobility since 2000, attending Adult Day Program and requiring increasing home support over the years
Dora

- Cognitively intact, strong-willed, “would rather die than go to a nursing home”
- Increasingly house-bound 2009, no consistent primary care, enrolled in Home VIVE program
- Early issues with leg edema, cellulitis, skin ulcers
- Interventions included OT and Physio, wound care (RNs) and medical mgt
Dora

• May 2013 she revealed that she had “an infected L nipple”, wanting topical antibiotic but refusing exam
• Eventual exam suspicious for breast cancer
• June 2013 mammogram and core biopsy – which was unfortunately non-diagnostic
• Patient refused anything more other than analgesia (Acetaminophen, Codeine, Hydromorphone)
Dora

- Over the following months the lesion progressed to fungating destruction of the nipple and increasing ulceration
- Dressing changes painful “8/10” needing Sufentanyl, background pain requiring Hydromorphone and Gabapentin for neuropathic component
- Worsening mobility
Dora

- Autumn 2013 patient refused assessment at BC Cancer Agency for possible XRT or hormonal treatment
- Wound occasionally foul, draining, bleeding, significant time required for daily dressings
- February 2014 intermittent SOBOE, exam suspicious for L pleural effusion, limited activity and spending more time in bed due to fatigue
- March 21, 2014 severely SOB, caregiver called 911
Dora

• In ER started on oxygen, otherwise she refused pleural tap or admission
• She clearly wished a palliative approach and she was aware that she was nearing the end of life
• Thoracentesis done at home (1 litre) with some symptomatic benefit
• Continued rapid deterioration, bed-bound, sleeping more, minimal intake, diminished urine output
Dora

• Daily visit from RN, frequent MD visits
• Shift care nursing initiated April 4, palliative drug box (s/c meds)
• Died comfortably April 7, 2014
Dora

• Challenges
  – Respecting autonomy, negotiating care
  – Pain management including (background and ‘incident’ pain)
    • Hydromorphone regular and prn, Sufentanyl, Gabapentin
  – Dyspnea management
    • Hydromorphone, Lorazepam and thoracentesis
  – Difficult wound care, odorous and bleeding
    • Charcoal dressing, Tranexamic acid topically
Chronic Disease Trajectory (2-5 years)

- Disease Progression
- Acute Exacerbations
- Chronic Disease Trajectory (2-5 years)
- Health Indicators
- Chronic Disease Mgt
- Surveillance
- Acute Intervention
- Hospitalization
- Symptom Mgt Support

Time
Chronic Disease Trajectory

• “There will not be a distinct terminal phase. The week we die will start out like any other and some unpredictable calamity will occur. Amongst those of us with advanced heart failure, we will have had a 50-50 chance to live for 6 months on the day before we died”
  • Lynn, J (2004) Sick to death and not going to take it anymore
Specific Clinical Indicators

• CHF
  – NYHA Stage 3 or 4, SOB at rest or minimal exertion
  – Repeated hospital admissions with CHF symptoms
  – Symptoms persist despite optimal therapy
Specific Clinical Indicators

• COPD
  – Severe disease (FEV1 <30% predicted)
  – Repeated hospital admissions (3 in past year)
  – Requires long-term oxygen therapy
  – SOB walking 100 m on the level, house-bound
  – Signs and symptoms of R heart failure
  – More than 6 weeks of steroids in past 6 months
  – Anorexia, weight loss, complicated pneumonia
Brenda

- 86 year old woman, retired clerk, war bride from England, widowed 1995
- Lives in apartment with 24/7 private caregiver support
- Unable to get out to see FP, referred to Home VIVE program January 2013
- Recent hospitalization for severe epistaxis, INR 6
Brenda

• Hx includes Pulmonary Fibrosis, prior PE, DM-2, CHF, AVR, Depression, Anxiety, OA, Falls. She is cognitively intact
• She had been on Palliative Benefits for 2 years already. Fluctuating course mostly due to the respiratory symptoms.
• Numerous hospitalizations with associated complications (C. diff, Delirium, Deconditioning)
Brenda

• O2 prn for ambulation in the apartment, uses walker
• Financial concerns about paying for private care vs moving to assisted living and also having to buy the equipment that had been provided under the Palliative Benefits program
• Hydromorphone for severe hip OA pain, very sensitive to dosage changes (confusion)
Brenda

- Debate between Cardiologist and Respirologist as to the cause of her SOB. Clinical suggestion of LV failure though Echo does not confirm this and her bioprosthetic aortic valve works well. Patient is sensitive to volume changes from diuresis. Lung disease apparently stable on CT but her **SOBOE is worse**....

- General deterioration in function
Brenda

- Hospitalized January 2014 with UTI, pneumonia and septic shock due to Group B Strept bacteremia -> Delirium
- Goals of care discussion, she does not want more hospitalizations -> resume Palliative Care Benefits Feb 2014
- Diuretics (Lasix and Zaroxolyn) titrated to patient’s weight. Hydromorphone short- and long-acting for symptom management, Ativan prn, continuous O2
Brenda

• Describes feeling awful and anxious much of the time, becoming dependent for ADL’s. More SOBOE. Diuresis makes her breathing easier but fatigues her due to volume shifts

• Family meeting March 24, 2015 to review fluctuating situation, approach to symptoms management and difficulty prognosticating

• Family and caregivers burning out
Brenda

• Fell out of bed early hours of March 26, caregiver attended and found her to have expired. She probably had a sudden cardiac event and died prior to falling
Brenda

• Challenges
  – Prognostication, Advance care planning and goals of care conversations
  – Numerous crises requiring quick response
  – Management of symptoms (opioids, benzo, diuretic) and complications (antibiotic associated diarrhea, fluid retention on steroids)
  – Longitudinal support for patient, family and caregivers
Frailty/Dementia Trajectory

Health Indicators

- Nutrition
- Socialization
- Exercise
- Assistive Devices
- Functional Support
- Symptom Mgt

Muscle Loss
Sensory Loss
Cognitive Loss
Isolation
Pain

Time
Frailty / Dementia Trajectory

• Degree of dementia corresponds to degree of frailty
• Prolonged time course of inevitable deterioration (6-10 years)
• Advanced dementia has many of the symptoms of other life-limiting illnesses
• High likelihood of eating problem, aspiration pneumonia and/or febrile illness (CASCADE study)
Specific Clinical Indicators

• Frailty
  – Deteriorating function, multi-morbidity
  – At least 3 of the following: Weakness, slow walking speed, significant weight loss, exhaustion, depression, low physical activity
Specific Clinical Indicators

• Advanced dementia – when to consider a palliative approach
  – Unable to walk without assistance
  – Incontinence
  – Unable to do ADL’s
  – Barthel score <3
  – No consistently meaningful conversation
  – Any 1 of the following: Weight loss, UTI, severe pressure sore, recurrent fever, reduced intake, aspiration pneumonia
Margaret

- 86 year old woman widowed since 1977
- Referred to Home VIVE in November 2010
- Had been living alone until recently, felt to be unsafe and incapable. Now in son’s home with 24/7 care
- Dementia (mixed Vascular and Alzheimer’s) with BPSD, symptoms present for “about a year”
Margaret

• Using ER for primary care
• Hx CVA’s, CAD, CKD, Hypothyroid, Smoker, OP with spinal compression fractures and chronic back pain
• At intake MMSE 16/27, patient on Quetiapine and Risperidone for BPSD
Margaret

- Continued ER visits July 2011 (dizziness), May 2012 (back pain), Sept 2014 (UTI)
- Admissions June 2013 UTI and back pain, Oct 2014 UTI and delirium, Dec 2014 agitation and paranoia
- PATH training subject Nov 2013, Goals of care include palliative approach, dementia has progressed to “severe”
Margaret

• Several “near misses” over the years, palliative meds initiated then stopped

• At present dementia staged as “very severe” – totally dependent, mostly non-verbal, intake reduced, episodic choking

• Palliative care benefits – hospital bed, lift, supplemental caregivers, palliative drug box again in the home
Margaret

• Challenges
  – Prolonged course to advanced dementia has made it difficult for family to see dementia as a life-limiting illness and shift from crisis care to a palliative approach
  – Patient has had very difficult behaviours at times making it challenging to provide care at home
Practice Points

• Pain is common in elderly patients
  – Chronic non-cancer pain (ex. Neuralgias, Joint Pain), Cancer-related pain

• Pain is often under-reported, under-diagnosed and under-treated
  • Auret and Schug 2005, Drugs and Aging

• Patients with dementia experience no less pain than other older adults
  • AGS 2002
Practice Points – What works

• Establishing a trusting relationship
• Identifying the ‘circle of care’ including substitute decision maker
• Assessing and communicating prognosis and options for care
• Facilitating advance care plan and goals of care conversations ‘upstream’. Review in a crisis
• Being responsive and available