PALLIATIVE CARE EARLY AND SYSTEMATIC (PaCES)

Integrating an Early Palliative Approach into Advanced Colorectal Cancer Care

30th Annual Palliative Education and Research Day
Oct 21, 2019
Faculty/Presenter Disclosure

Faculty: Sharon Watanabe

Relationships with financial interests:

- Grants/Research Support: CIHR, Alberta Health, MSI Foundation
- Speakers Bureau/Honoraria: Pallium
- Consulting Fees: None
- Patents: None
- Other: University of Alberta, Alberta Health Services
Faculty/Presenter Disclosure

Faculty: Aynharan Sinnarajah

Relationships with financial interests:

Grants/Research Support: CIHR, Alberta Health, Canadian Frailty Network, MSI Foundation, University of Calgary

Speakers Bureau/Honoraria: None

Consulting Fees: None

Patents: None

Other: University of Calgary, Alberta Health Services
Disclosure of Financial Support

This program has not received financial support from commercial entities.

This program has received in-kind support from the Provincial Palliative and End-of-Life Care portfolio and the Chief Medical Information office.

Potential for conflict(s) of interest:
• Presenting on behalf of Palliative & End of Life Care programs (Edmonton and Calgary Zones), Alberta Health Services; University of Calgary; University of Alberta
• No potential conflict(s) of interest
Mitigating Potential Bias

• Not applicable
• Discuss with your neighbour (2 minutes each):
  – Briefly describe a situation where a patient first received palliative care late in the course of illness. What were the consequences, if any, of the late referral?
• Share selected observations (2 minutes total)
Objectives

1. Describe the details of the first ever Alberta early palliative care pathway developed for patients with advanced colorectal cancer.

2. List key steps taken to develop the pathway including stakeholder engagement and alignment with existing AHS initiatives.

3. Summarize early findings of implementation of the early palliative care pathway in Calgary, as well as existing resources at the Cross Cancer Institute.
Agenda

• Background
  – PaCES
  – Change Management
  – Local Context

• Identifying Problems

• **Solutions**

• Implementation Process

• Experience So Far

• Lessons Learned and Conclusion
In the beginning......
<40% of patients with advanced cancer had PC consultation at CCI

2831 CCI patients died April 2013-March 2014

578 excluded
575 did not have advanced cancer
3 had incomplete records

2253 included in analysis

1443 (64%) had no CCI PC consultation
810 (36%) had CCI PC consultation
>75% had PC consultation when other sites were included

2831 CCI patients died April 2013-March 2014

578 excluded
575 did not have advanced cancer
3 had incomplete records

2253 included in analysis

1443 (64%) had no PC consultation at CCI
810 (36%) had PC consultation at CCI

1413 CCI patients lived in EZ

318 (22.5%) had no PC consultation in EZ
1095 (77.5%) had PC consultation in EZ

510 had first PC consultation at CCI
585 had first PC consultation elsewhere in EZ
PC consultation occurred relatively late

<table>
<thead>
<tr>
<th>Setting</th>
<th>Median (IQR) interval, months</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Advanced cancer diagnosis to death</td>
<td>Advanced cancer diagnosis to first PC consultation</td>
<td>First PC consultation to death</td>
</tr>
<tr>
<td>CCI</td>
<td>10 (4 – 21)</td>
<td>4.5 (1 – 15)</td>
<td>2 (1 – 5)</td>
</tr>
<tr>
<td>EZPCP</td>
<td>9 (3.8 – 21)</td>
<td>4.4 (1.1 – 15)</td>
<td>2.1 (0.9 – 4.6)</td>
</tr>
</tbody>
</table>
• Early palliative care pathway (processes and resources) for Albertans with *advanced colorectal cancer* (initially, as proof of principal)

**MISSION**

"To provide **early** and ongoing access to coordinated, comprehensive and compassionate palliative care to improve quality of life for Albertans with advanced cancer."
Vision: Improving quality of life for Albertans with advanced cancer
PaCES: Starting the Journey

The hardest part is starting. Once you get that out of the way, you’ll find the rest of the journey much easier.

Simon Sinek
• 60% patients with advanced GI cancers have late PC <3 months from death or no PC referral

• Late or no PC is associated with lower patient quality of life and higher caregiver distress

• Late or no PC associated with death in hospital for 50% of patients vs. 25% receiving earlier PC

*Temel NEJM 2010; Zimmerman Lancet 2014; Cheung Cancer 2015
Who: Colorectal cancer patients
What: Timing of palliative care (PC) access
Where: All AHS Zones
When: Deceased Jan 2011- Dec 2015
Why: Examine association with aggressive EOL care

On average, patients in this cohort are first accessing palliative care services 51 days before death → varies by zone

Table: Median duration (days) from first specialist PC access to death.

<table>
<thead>
<tr>
<th>Region of residence at death (AHS Zone)</th>
<th>Median PC duration (days)</th>
<th>Range (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Zones</td>
<td>51.0</td>
<td>0-3220</td>
</tr>
<tr>
<td>Calgary</td>
<td>56.0</td>
<td>0-2346</td>
</tr>
<tr>
<td>Edmonton</td>
<td>46.5</td>
<td>0-1782</td>
</tr>
<tr>
<td>North</td>
<td>40.5</td>
<td>0-1285</td>
</tr>
<tr>
<td>Central</td>
<td>29.5</td>
<td>0-1239</td>
</tr>
<tr>
<td>South</td>
<td>42.0</td>
<td>1-2155</td>
</tr>
</tbody>
</table>
• Most patients in Calgary (88%) and Edmonton (76%) Zone accessed PC
• Few patients in Central (12%), North (18%), South (14%) accessed PC
• Availability of PC services differ by zone
Select factors related to having aggressive end-of-life indicators (N=3337)

<table>
<thead>
<tr>
<th>Factor</th>
<th>≥1 EOL indicator</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timing of palliative care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>2.15 (1.66-2.77)</td>
<td>***</td>
</tr>
<tr>
<td>&lt; 3 months from death</td>
<td>1.53 (1.24-1.89)</td>
<td>***</td>
</tr>
<tr>
<td>≥3 months from death</td>
<td>ref</td>
<td></td>
</tr>
<tr>
<td>Region of residence at death</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Calgary (Z2)</td>
<td>ref</td>
<td></td>
</tr>
<tr>
<td>Edmonton (Z4)</td>
<td>1.35 (1.11-1.65)</td>
<td>**</td>
</tr>
<tr>
<td>South (Z1)</td>
<td>0.48 (0.31-0.73)</td>
<td>***</td>
</tr>
<tr>
<td>Central (Z3)</td>
<td>0.93 (0.61-1.43)</td>
<td></td>
</tr>
<tr>
<td>North (Z5)</td>
<td>1.92 (1.20-3.08)</td>
<td>**</td>
</tr>
<tr>
<td>Urban</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>ref</td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>2.25 (1.57-3.23)</td>
<td>***</td>
</tr>
<tr>
<td>Duration of disease (any CRC)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-6 mo</td>
<td>2.26 (1.63-3.13)</td>
<td>***</td>
</tr>
<tr>
<td>6-12 mo</td>
<td>1.97 (1.40-2.77)</td>
<td>***</td>
</tr>
<tr>
<td>12-24 mo</td>
<td>1.33 (0.98-1.82)</td>
<td></td>
</tr>
<tr>
<td>24-60 mo</td>
<td>1.08 (0.81-1.45)</td>
<td></td>
</tr>
<tr>
<td>&gt; 60 mo</td>
<td>ref</td>
<td></td>
</tr>
<tr>
<td>Age at death (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;60</td>
<td>3.25 (2.52-4.19)</td>
<td>***</td>
</tr>
<tr>
<td>61-70</td>
<td>1.85 (1.47-2.34)</td>
<td>***</td>
</tr>
<tr>
<td>71-80</td>
<td>1.43 (1.16-1.78)</td>
<td>**</td>
</tr>
<tr>
<td>&gt;80</td>
<td>ref</td>
<td></td>
</tr>
</tbody>
</table>

Patients who received no palliative care are 2.15 times more likely to experience aggressive EOL care.

Zone is an important predictor of whether a patient experiences aggressive end of life care (even after adjusting for other variables in the model).
What do we mean by *early*?

A palliative approach to care that occurs concurrently with cancer treatment.

- Early Stage Colon Cancer
- Early Stage Rectal Cancer
- Diagnosis of advanced colorectal cancer

Integrating an Early Palliative Approach into Advanced Colorectal Cancer Care

- Metastatic Colorectal Cancer
- No Remission and End of Life
- or
- Prolonged Remission

PaCES
Palliative Care Early and Systematic
Easy to say, harder to do in practice

After implementation:
Accessing PC will typically occur one year before end-of-life

Better patient outcomes & healthcare system efficiency

Current State:
PC access typically occurs two months before end-of-life

Diagnosis of metastatic CRC

Patients journey (typically 1-2 years)

Gap/Challenge 1
Identifying patients with advanced cancer via systematic screening

Gap/Challenge 2
Normalizing communication about PC as an added layer of support

Gap/Challenge 3
Ensuring key elements of early PC are systematically provided

Gap/Challenge 4
Ensuring timely access to community-based care and ongoing liaison with family physicians
Why is early PC hard to achieve?
Barriers faced by oncology clinicians in referring patients to PC, working with PC and addressing PC needs in cancer clinics.
Identifying the Problems
Processes mapped across the continuum

101 “pain points” or gaps identified
7 Problem statements

- Transitions
- Shared Definition
- Role Clarity
- Visible Patient Journey
- Goals of Care Practice
- Varied PC Skills
- Fragmented Communication
Plenty of solutions

37 pages of proposed solutions or 700 individual comments
Solutions
Integrating an Early Palliative Approach into Advanced Colorectal Cancer Care

Effective Date: January, 2019
Essential Components of an Early Palliative Approach to Care

- Illness comprehension and coping
- Symptoms and functional status
- Advance care planning and patient’s preferred method of decision making
- Coordination of care
www.ahs.ca/GURU

Information located under “Gastrointestinal” and “Palliative & Supportive Care”
What’s there? 1. Interactive care pathway

**Step 1:** Screen using Patient reported outcome Dashboard

**Step 2:** Identify Patient Needs

**Step 3:** Primary Provider Management of Unmet Needs

**Step 4:** Exploring End of Life Topics
Step 1: Screen using PRO Dashboard

<table>
<thead>
<tr>
<th>Comments</th>
<th>Qtr Entry Date</th>
<th>Previous PPF Symptom Complexity</th>
<th>Home Care (PPF)</th>
<th>Palliative Home Care (db)</th>
<th>Request for Goals of Care (PPF)</th>
<th>GCD Order (ARIA)</th>
<th>Goals of Care Date (ARIA)</th>
<th>Weight Change(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 weeks f/u as per appt slip...pt aware...ss</td>
<td>2018-Dec-31</td>
<td>L</td>
<td>N</td>
<td>N</td>
<td>M</td>
<td>M1</td>
<td>03/10/2016</td>
<td>0.18%</td>
</tr>
<tr>
<td>f/u as per appt slip...pt aware...zg</td>
<td>2019-Jan-14</td>
<td>L</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-9.17%</td>
</tr>
<tr>
<td>f/u as per appt slip.mailed...zg</td>
<td>2019-Jan-14</td>
<td>M</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>M1</td>
<td>16/02/2016</td>
<td>-2.04%</td>
</tr>
<tr>
<td>f/u as per appt slip...pt aware...zg</td>
<td>2019-Jan-15</td>
<td>L</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7.83%</td>
</tr>
</tbody>
</table>
## Step 2: Identify needs

<table>
<thead>
<tr>
<th>Component</th>
<th>Assessment Tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness comprehension and coping</td>
<td>Canadian Problem Checklist (CPC)</td>
</tr>
<tr>
<td></td>
<td>Edmonton Symptom Assessment System- Revised: anxiety and depression scales (ESAS-r)</td>
</tr>
<tr>
<td></td>
<td>Serious Illness Care Program (SICP)</td>
</tr>
<tr>
<td>Symptoms and functional status</td>
<td>ESAS-r</td>
</tr>
<tr>
<td></td>
<td>CPC</td>
</tr>
<tr>
<td></td>
<td>Eastern Cooperative Oncology Group (ECOG)</td>
</tr>
<tr>
<td></td>
<td>Palliative Performance Scale (PPS)</td>
</tr>
<tr>
<td>Advance care planning and patient’s preferred method of decision making</td>
<td>ACP GCD Tracking Record</td>
</tr>
<tr>
<td></td>
<td>CPC</td>
</tr>
<tr>
<td></td>
<td>SICP</td>
</tr>
<tr>
<td>Coordination of care</td>
<td>PPF</td>
</tr>
</tbody>
</table>
## Putting Patients First

### APPENDIX 1: PUTTING PATIENTS FIRST PAGE 1 (ESAS-R)

**Talking About What Matters To You**

**Putting Patients First**

Your answers will help us understand how you have felt since your last visit, and how you feel today. Knowing this will help us care for you. If you cannot or do not wish to fill out this form for any reason please let us know.

**Note:** Please make sure to fill out both sides of the form.

A member of your healthcare team will go over the form with you and talk to you about what concerns you the most today. If we are not able to talk about all of your concerns today, we will decide the next steps together.

### Date (yyyy-Mon-dd) Completed by:
- Patient
- Family
- Assisted by family/health professional

Please answer the yes/no questions:

1. Have you been to Emergency and/or been admitted to hospital since your last visit?  
   - Yes
   - No

2. Have your medications changed since your last visit? (e.g., stopped, started, dose change)  
   - Yes
   - No

3. Have you had a fall since your last visit?  
   - Yes
   - No

4. Would you like information on Goals of Care or advance care planning (green sleeve)?  
   - Yes
   - No

5. Are you receiving home care services?  
   - Yes
   - No

6. Have you used tobacco in the past year?  
   - Yes
   - No

Below circle the number that best describes how you feel NOW.

0 means you do not have that symptom. 10 means it is at its worst.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Score 0</th>
<th>Score 1</th>
<th>Score 2</th>
<th>Score 3</th>
<th>Score 4</th>
<th>Score 5</th>
<th>Score 6</th>
<th>Score 7</th>
<th>Score 8</th>
<th>Score 9</th>
<th>Score 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>No pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No tiredness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No drowsiness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No nausea</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No lack of appetite</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No shortness of breath</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No depression</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Best well-being (overall)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Other problem (e.g., constipation)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### APPENDIX 1: PUTTING PATIENTS FIRST PAGE 2 (CPC)

**What concerns have you had since your last visit? Check any boxes that have concerned you.**

<table>
<thead>
<tr>
<th>Emotional</th>
<th>Physical</th>
<th>Nutrition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fears/Worries</td>
<td>Fever/Chills</td>
<td>Weight gain</td>
</tr>
<tr>
<td>Sadness</td>
<td>Seeding/Brising</td>
<td>(amount)</td>
</tr>
<tr>
<td>Frustration/Anger</td>
<td>Cough</td>
<td>Special diet</td>
</tr>
<tr>
<td>Changes in appearance</td>
<td>Headaches</td>
<td>Difficulty swallowing</td>
</tr>
<tr>
<td>Intimacy/Sexuality</td>
<td>Changes to skin/hair</td>
<td>Mouth sores</td>
</tr>
<tr>
<td>Thoughts of ending my life</td>
<td>Vision or hearing changes</td>
<td>Taste changes</td>
</tr>
<tr>
<td>Social/Family/Spiritual</td>
<td>Numberness/Irking</td>
<td>Heartburn/digestion</td>
</tr>
<tr>
<td>Feeling alone</td>
<td>Sensitivity to cold</td>
<td>Vomiting</td>
</tr>
<tr>
<td>Feeling like a burden to others</td>
<td>Bladder problems</td>
<td>Diarrhea</td>
</tr>
<tr>
<td>Worry about friends/family</td>
<td>Range of motion</td>
<td>Constipation</td>
</tr>
<tr>
<td>Support with children/other</td>
<td>Bladder problems</td>
<td>Dizziness</td>
</tr>
<tr>
<td>Meaning/Purpose of life</td>
<td>Sleep</td>
<td>Mobility</td>
</tr>
<tr>
<td>Faith</td>
<td></td>
<td>Drug costs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Health insurance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other concerns</td>
</tr>
</tbody>
</table>

**Thank you for filling out the form. The rest of the form will be completed by your healthcare professional.**

---

**To be filled out by a healthcare professional only - Screening Intervention Documentation**

**Review of Form:**

- Patient declined to fill out form
- Language barrier
- Other

- Form reviewed through conversation with patient
- Review form for reasons why Patient declined discussion
- Other

**Is patient at risk?**

- Yes
- No

**Patient Priority Concern Identified:**

- Patient indicated no concern

**Specify ONE priority concern (either ESAS or CPC):**

- ESAS: Pain, Breathlessness, Nausea, Diarrhea, Appetite, Depression, Anxiety
- CPC: Emotion, Social, Spiritual, Practice, Mobility, Nutrition, Physical, Informational, Other

**Specific area indicated under the CPC domain:**

**Actions taken:**

- Provided information/education
- Offered Tobacco Cessation Advice
- Prescription provided
- Provided emotional support
- Referral suggested but patient declined
- No further action required

**Referrals:**

- Social Work
- Palliative Care
- Fatigue
- Tobacco Clinic
- Dyspnea/Respiratory
- Psychology
- Nutrition
- Home Care
- OT/Physio/Speech
- CO Navigation

**Further details on action taken:**

- See progress notes/nursing documentation for further information

**Reviewed By: (Name of Health Care Professionals)**  
**Signature of Health Care Professionals**  
**Date (yyyy-Mon-dd)**
PRO dashboard: Trending data
Step 3: Managing Unmet Needs

**Palliative & Supportive Care**

- **Metastatic Colorectal Cancer: Early Palliative Approach**
  - Interactive Care Pathway
  - Referral Based Services for Advanced Cancer Care
  - Local Tips for Providers
  - Advanced Cancer Shared Care Letters
    - Sample Physician Letter
    - Sample Patient Letter
  - Introducing Palliative Care: Tips for Health Care Professionals

**Symptom Management Summaries**

- Anxiety
- Depression
- Oral Care
- Tenesmus
- Sleep Disturbance

**Additional Resources**

- ASCO Anxiety and Depression Guideline
- ASCO Fatigue Guideline
- CAPO Pan-Canadian Sleep Disturbances Guideline
### Step 3: Local Tips – Calgary Zone

<table>
<thead>
<tr>
<th>Contents</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>AADL- Alberta Aids to Daily Living</td>
<td>3</td>
</tr>
<tr>
<td>Blood Transfusions</td>
<td>6</td>
</tr>
<tr>
<td>CAMPP</td>
<td>8</td>
</tr>
<tr>
<td>Financial Concerns</td>
<td>9</td>
</tr>
<tr>
<td>Food/Meals</td>
<td>10</td>
</tr>
<tr>
<td>Calgary Community Services – Directories</td>
<td>10</td>
</tr>
<tr>
<td>Hospice</td>
<td>12</td>
</tr>
<tr>
<td>Legal and Financial Issues</td>
<td>14</td>
</tr>
<tr>
<td>Mobile Lab</td>
<td>16</td>
</tr>
<tr>
<td>Palliative Coverage Program</td>
<td>19</td>
</tr>
<tr>
<td>Drug Benefits and Access</td>
<td>21</td>
</tr>
<tr>
<td>Palliative Oxygen</td>
<td>24</td>
</tr>
<tr>
<td>Patient Transportation</td>
<td>26</td>
</tr>
<tr>
<td>Personal Directives (PD) and Advance Care Planning</td>
<td>28</td>
</tr>
<tr>
<td>Psychosocial and Grief Support</td>
<td>29</td>
</tr>
<tr>
<td>For Care Givers</td>
<td>31</td>
</tr>
<tr>
<td>Rehabilitation Resources</td>
<td>33</td>
</tr>
<tr>
<td>Respite Care</td>
<td>34</td>
</tr>
<tr>
<td>Service Descriptions</td>
<td>37</td>
</tr>
<tr>
<td>Thoracentesis or Paracentesis</td>
<td>43</td>
</tr>
<tr>
<td>Dyspnea clinic at TBCC</td>
<td>44</td>
</tr>
</tbody>
</table>
## Step 3: Referrals Service Descriptions

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 Palliative Home Care</td>
<td>Provides in-home care, support, and comfort to people coming to the end of their lives and their families with a focus on managing symptom issues, providing emotional and psychological support. Works with clients with a progressive, life limiting illness. Provides 24 / 7 support to the patient and the family.</td>
<td><strong>ROUTINE REFERRAL:</strong></td>
</tr>
<tr>
<td></td>
<td><em>Note: Rural areas do NOT have a separate Palliative Home Care program; they have Integrated Home Care with mixed caseloads and Palliative Care Consult support</em></td>
<td>Alberta Referral Directory - Search by Edmonton OR Calgary</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Accessible in these cities through Community Care Access (for clinicians or patient self-referral):</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Edmonton:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>☎: 780-496-1300</td>
</tr>
<tr>
<td></td>
<td></td>
<td>📞: 780-496-8438</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Calgary:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>☎: 403-943-1920 OR 1-888-943-1920</td>
</tr>
<tr>
<td></td>
<td></td>
<td>📞: 403-943-1602</td>
</tr>
</tbody>
</table>
Step 3: Introducing Palliative Care

Contents

Moments to introduce palliative care: ................................................................. 2

Introducing Palliative Treatments (Chemotherapy, Radiation Therapy, and primary palliative care) 2

Shared Care Letter .................................................................................................. 2

Referring to Specialist Palliative Care .................................................................. 3

Reframing and hope ............................................................................................... 6

Family and Caregiver Support ............................................................................... 6

What it means to have a serious illness .................................................................. 7

Advance Care Planning / Goals of Care ............................................................... 7

Serious Illness Care Program (SICP) .................................................................... 7
Step 3: Coordination of Care

Shared Care Letter

Re: Advanced Cancer Shared Care

Dear Dr. [Name],

Your patient [Name] is in treatment at our Cancer Centre for an advanced, incurable, colorectal cancer. This requires a collaborative effort and a palliative approach to care. We will work closely with you to coordinate care, improve quality of life and symptom management. We appreciate your ongoing management of non-cancer related problems, while the Cancer Centre will focus on issues related to cancer and its treatment. This document outlines relevant information for you as their primary care provider related to:

- Potential signs and symptoms of cancer related emergencies
- Other palliative supportive measures
- Contact information for the Oncology Team

Please refer to the latest consultation note for conditions specific to your patient (will be sent separately). If no progress is noted or if you have further questions, please contact us. All Cancer Centre contact and progress notes, imaging, and lab work are available in Sharecare. Any time you have any concerns or any need for more information, please contact the Medical Oncologist.

We have asked the patient to make a follow up appointment with you and your team. Maintaining a close relationship is important for the patient’s well-being. Advanced care planning and follow-up of non-cancer related health issues. If there is a change in the patient’s clinical condition, please provide us with the updated information.

**CARE COMPONENTS**

- Chemotherapy and chemotherapy-related concerns
- Organizing investigations related to cancer treatment
- Symptoms (e.g., pain, anxiety, depression, sleep disturbance, constipation, nausea)
- Advance Care Planning
- Patient and family concerns
- Legal/professional services (e.g., VQA)
- Accessing community resources
- Non-cancer related medications

Please note patients with pre-existing:

- Diabetes may require changes to their medications due to changes in diet, weight loss, and assessment of insulin medications.
- Hypertension: may require adjustments, especially if they have diabetes.

It is advised to avoid becoming pregnant or fathering a child while receiving chemotherapy. An adequate method of contraception should be used for both men and women. The combination of a barrier method and the contraceptive pill would give the best protection.

**MONITORING FOR COMPLICATIONS**

Chemotherapy side effects will have been reviewed in previous letters prior to initiation of treatment:

- Fever (temperature over 38°C for one hour or 38.5°C or more), while on chemotherapy, may indicate life threatening bacterial pneumonia. Direct patient to Emergency Room.
Step 3: Shared Care Patient Handout

Advice to see Family physician

Shared Care for Advanced Cancer

To help you live well with advanced cancer, we would like to offer information and support for you and your family members. This can be a challenging time, and as your health care team, we are here for you. We encourage “shared care” that combines support from your oncology doctor (cancer team) and your family doctor (community team) to help you live your best. Together, we can get you the support you need.

Who is sharing my care?

Your family doctor and your oncology team will share your care with you. We ask that you make an appointment with your family doctor within the next month, even if you feel well. It is important to plan and put supports in place. Please take this letter with you. If needed, your family doctor can ask your oncologist (cancer doctor) for more information. Your family doctor will also receive updates from the Cancer Centre.

It is really important to have a family doctor. If you do not have one, here is how to find a list of doctors accepting patients in your area:

- Call Health Link Alberta (811)
- Visit https://www.ahs.ca and search for “find a doctor”. This website will give you choices to help you find the family doctor who is right for you. If you need help navigating the site, have a friend or family member help you.

If you have a new doctor, be sure to tell them about your cancer diagnosis and treatment. Your new doctor can request access to your treatment summary and other records. If you cannot find a family doctor, please discuss this with your oncology team.

What is “advanced cancer”?

When cancer is advanced, we focus on helping you live as well and as long as possible. Different doctors may use different words to describe when a cancer is advanced. Depending on your condition, you may hear words such as secondary, metastatic, progressive, incurable, non-curative or end-stage. When cancer is not likely to be cured, we will continue to give you medical care that will help you to live with hope and support your goals.

Who will help me manage my symptoms?

<table>
<thead>
<tr>
<th>Your Oncologist</th>
<th>Your Family Doctor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Both teams can help manage symptoms from your cancer or treatment, (such as pain, stress, constipation, or sleep problems). Make sure to ask how you can best manage each issue you have.</td>
<td>Manages your cancer treatment plan and cancer-related concerns.</td>
</tr>
<tr>
<td>Manages non-cancer related concerns. For example: refills of your medications not related to cancer treatment</td>
<td></td>
</tr>
</tbody>
</table>

PaCES
Palliative Care Early and Systematic

Alberta Health Services
Routine referral to PC nurse specialist

- Oncology Team
- Patient and Family
- GI CNS
- Family Doctor
- Palliative Home Care
Clients do not have to have personal care needs to be eligible for home care services.

Early referrals can:

1. Establish a relationship
2. Access to home care professional services e.g. OT
3. Help clients and families navigate community care services
4. Assist with advance care planning conversations
5. Support clients and families in contemplating & sharing end of life planning.
Implementation in Calgary

We are all human...change is hard.

It's okay to struggle.

[[Image of a person hugging a heart with the text "IT'S OKAY TO STRUGGLE." by Adriana.]]
Implementation Process

Pre Planning
- Learning from similar projects
- Input from front line staff and operations

Pilot
- Pilot in two oncology clinics
- Test and implement proposed changes

Refine
- Learn from pilot
- Refine process

Scale and Spread
- Implement refined process in remaining 6 GI clinics
- Phased change
How’s it going so far?
Advanced Cancer Shared Care Letter Orders

Number of MO active

Number of Letters Ordered

Camille stopped clinic visits

Jan started clinic visits

Total letters ordered = 76
Total fax backs = 39
Successes

• Correcting family physician
• GCD sent in by community providers
• Supports available through PCN
• Opportunity to ask MO questions e.g. prognosis
• Desire to engage in shared care of patient
Challenges

• Highlighting incorrect providers
  – Getting provider information updated

• Remember to sign for scanning and address questions asked on returned coversheet

• Screening and Ordering
  – Busy clinics, other opportunities?
Palliative Care Referrals

Number of MO active

Number of Referrals Ordered

January

February

March

April

May

June

Week

1

2

3

4

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

24

25

26

Number
Patients have been overwhelmingly grateful for PC support:

- “I wish you [PC] had been introduced to us at the very beginning.”

- “No one has asked me about time and the quality of my life before.”

- “I was afraid to ask about what was coming, but it helps to have it out in the open. I feel like I don’t have to push those thoughts away all the time.”
“The take home message for me is that it is important to start palliative care early and to educate patients and family that palliative care does not mean end of life care.”

“More willing to contact/collaborate with oncologists” (FP Strengthening Linkages Workshop)

“I appreciated discussing what W went through in hospital before his dying. It meant that his family could come here for help without having to repeat all of the details.”
What else?
Evaluation:
Living with Colorectal Cancer Study

• Observational study
• Interrupted time series with control
  – Palliative care referral
  – Patient reported outcomes (ESAS, EQ5D)
  – Caregiver preparedness
  – Advance care planning conversations
  – Financial impact
  – Health service resource utilization
Living With Colorectal Cancer Study

<table>
<thead>
<tr>
<th></th>
<th>Calgary</th>
<th>Edmonton</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>56</td>
<td>118</td>
</tr>
<tr>
<td>Caregivers</td>
<td>28</td>
<td>44</td>
</tr>
</tbody>
</table>

as of Aug 31, 2019

Interim Results: Workshop by Shireen Kassam

Enrollment ONGOING at CCI
Wrapping up
PaCES Project  www.pacesproject.ca

About PaCES

Our Team

Our Stakeholders

Learn more about PaCES activities

- Measuring current healthcare use
- Engaging oncology clinicians
- Understanding the rural patient experience
- Developing our early palliative care pathway
- Evaluating our early palliative care pathway

"I will be forever grateful for the many acts of kindness, both big and small — that reassured both of us that we weren't alone, that others cared, and that her life was honoured and respected to its end."

(PaCES Patient/Family Advisor, on her mother's journey with cancer)

Vision:

Improving quality of life for Albertans with advanced cancer

Mission:

To provide early and ongoing access to coordinated, comprehensive and compassionate palliative care to improve quality of life for Albertans with advanced cancer

What is PaCES?

The Palliative Care Early and Systematic (PaCES) Project is a province-wide team of researchers and knowledge end-users working together to develop and deliver an early and systematic palliative care pathway for advanced, metastatic cancer...
Palliative Care Services at CCI

• **Pain and Symptom Control**
  – For patients under the care of the CCI with inadequately controlled symptoms
  – Outpatient, multidisciplinary, inpatient, telehealth

• **Community Liaison**
  – For advanced cancer patients being discharged from care at the CCI

• **Referral from any MD or NP**
Integrate palliative care earlier

Palliative Care is an added layer of support (not just for dying!)

Supports you can use: www.ahs.ca/GURU

Attend to 4 Elements

- Illness comprehension and coping
- Symptoms and functional status
- Advance care planning and patient’s preferred method of decision making
- Coordination of care

Enhance Shared Care
Continuing the journey.....
Next steps

- Palliative Education Day
  - Options for dyad training
- Non tumour-specific Advanced Cancer Shared Care letter (patient, provider)
- Local Tips – Other Zones (Provincial Pall Care Tumor group – S Watanabe: WG members)
- Keep recruiting for Living with CRC
- Application to expand to all GI & Lung cancers; Active intervention in Red Deer & Calgary
Let us know what you’re thinking

Sharon.Watanabe2@ahs.ca
Ayn.Sinnarajah@ahs.ca

Thank you!
Knowledge Translation Framework

1. Identify the Problem
   • How to effectively increase the # of patients receiving early PC, systematically integrated across cancer, community and primary care sectors?
   • Review & Select knowledge
   • Evidence-base determined.

2. Adapt Knowledge to Local Context
   • Clinic time and physical space were identified as constraints.
   • Five elements of PC are best addressed by a palliative homecare nurse specialist.

3. Assess Barriers to Knowledge Use
   • Oncologists/nurses were surveyed.
   • Patient advisor focus groups completed.
   • Four gaps between knowledge and practice were identified:
     1. Routine screening
     2. Communicating care preferences
     3. Ensuring five elements of PC addressed
     4. Access to family physicians and home care

4. Select, Tailor and Implement Interventions
   • Develop interventions using patient and professional stakeholders feedback.
   • Implement interventions and closing four gaps to yield a continuous and integrated PC pathway.

5. Monitor Knowledge Use
   • Gap 1. # patients referred to PC per month.
   • Gap 2. # of patients with ACP Tracking Records completed per oncologist per month.
   • Gap 3. # of elements of PC addressed per patient per month.
   • Gap 4A. Proportion of prompt sheet elements contained in cancer clinic letters.
   • Gap 4B. # of patients referred to virtual home care.

6. Evaluate Outcomes
   • Primary Outcome: # of patients receiving early PC, defined ≥1 of: specialist PC visit, PC homecare service, or hospice admission, ≥3 months before death.
   • Secondary Outcomes:
     • Patient focused
     • System focused
     • Health care professional experience.

7. Sustain Knowledge Use
   • Refine interventions and PC pathway.
   • Collate/disseminate a tested implementation package to knowledge users/stakeholders in Alberta and across Canada.

Completed Research

Proposed Research

*Our tested implementation package (how to effectively implement, monitor and sustain the pathway) will be new knowledge created.
Stakeholder Groups

Clinical areas:
- Oncology (Medical, Radiation etc), Palliative Care, Home Care, Family Physicians

Roles:
- Patient / Family advisors
- Front line clinicians
- Health System leaders / managers: Provincial, Regional, Local
- Researchers
- Knowledge Translation / Implementation experts
- Data Analytics
- Quality and Safety
- Education (Patient, Health Care provider)
Pain Points- A Sampling

- Pt cannot find a Family Physician to work with Homecare/PC Consult team
- Duplicative referrals put in to prevent gap
- ER visits unnecessary but may be only place to go
- Family Physician with no capacity for home visits
- Not resourced for virtual remote care (e.g. rural)
- All Physician notes not avail (variety of systems involved, multiple services)
- Cross coverage of providers, who to go to for what?
- Role clarity
- Definition of Palliative care- different between providers and between providers and patients
- PC Consultants feel that there is an overall lateness to the referrals received (often when patient is in crisis)
- Barriers to giving and getting information (system issues)
Fishbone Analysis – Why?
**Problem Statements**

**Transitions**: No formal transition process for patients with advanced cancer to be discharged that are “No Further Recall” (NFR) to community service providers and Family Physicians creates a care gap for the patient.

**Role**: It is not clear among health care providers (HCP), patients and their caregivers who is responsible for each aspect of patient care.

**Definition**: There is no shared definition of palliative care in the eyes of HCPs and patients and no common knowledge of the palliative care services available.
**Problem Statements**

**Communication**: There is fragmented communication between healthcare providers and their teams particularly across sectors.

**Patient journey**: There is a lack of visibility of the patient’s schedule and resources being used by that patient to various healthcare providers.
Problem Statements

**Standard Goals of Care**: While a standard policy/procedure exists for the use of Goals of Care designation, the practice is varied and there are gaps in its application.

**Skill Gap**: Healthcare providers have varied skills in relation to providing a palliative care approach which leads to gaps in the patient experience and late referrals to palliative care services.
### Solutions

<table>
<thead>
<tr>
<th>TBCC change projects</th>
<th>Palliative care change projects</th>
<th>Knowledge/resources change projects</th>
</tr>
</thead>
</table>
| “Healthcare provider education”  
• Healthcare provider local training and education (grand rounds, simulation, courses, CME)  
• Communication technique- how to introduce pall care | “Healthcare provider education”  
• Healthcare provider local training and education (grand rounds, simulation, courses, CME) | “Healthcare provider resources”  
• Standard access to materials/ educational content (sharepoint, G-Drive, Websites)  
• Local Tips for providers  
• Symptom Summary tip sheets |
| “Referral process”  
• Create Standard Practice to consult pall care (business rules)  
• Palliative cluster elements of Patient Reported Outcomes (PRO) dashboard  
• “Concurrent” Chemo/Palliative treatment when on 2nd line chemo (like RT/Chemo concurrent tx) | “Referral process”  
• Change criteria to allow "well patient" access to home care services **Urban/rural Calgary zone  
• Palliative cluster elements of PRO dashboard | “Patient resources”  
• Definition of pall care- changing patient facing material **Provincial AND **Local  
• Normalizing pall care in CancerControl Alberta education material |
| “Transitions”  
• Dictation business rules (For MO), information sent to FP  
• Transition services- assessing process and addressing gaps  
• Transition package for non-curative (*shared care letters) | “Communication”  
• Home Care to fax/cc notes to Cancer Centre  
• Creation of business rules/guidelines for communication (Pall Care) |  |
| Leadership surveillance and f/u with metrics/audits (Local, cancer centre) | Leadership surveillance and f/u with metrics/audits (Local, cancer centre) |  |
Resources to Support Implementation
Available at:
- www.ahs.ca/GURU
- SharePoint under “Advanced Cancer” tab
- G Drive under “Palliative Care (Colorectal) Resources PACES”

Provider Resources
- Local Tips
- Symptom summaries
- Referral based service descriptions

Patient Resources
- Definition of palliative care in “Living Your Best”
- Using existing Advanced Cancer materials with transitions of care

Provider Skill Development
- Palliative Care introduction scripts

Oncology Team
Family Doctor

Patient and Family

PaCES
PALLIATIVE CARE EARLY AND SYSTEMATIC
Symptom Management Tip Sheets

Palliative & Supportive Care

Symptom Management Summaries

- Anxiety
- Depression
- Oral Care
- Tenesmus
- Sleep Disturbance

Additional Resources

- ASCO Anxiety and Depression Guideline
- ASCO Fatigue Guideline
- CAPO Pan-Canadian Sleep Disturbances Guideline
Care Coordination Letters

Dear [Patient's Name],

Your [Patient's Name] has been referred to the Care Coordination Team. As a result, care plans will be developed to ensure your comprehensive care needs are met. If you need to contact the team to discuss your care, please call [Contact Information].

[Care Coordination Team Contact Information]

Thank you for choosing [Healthcare Provider].

[Healthcare Provider's Name]
[Healthcare Provider's Title]
CCA Advanced Cancer Shared Care Letter (Patient):
• Pre print (DATA group) stocked in cabinets in OPD
  o Also available on SharePoint and G Drive

• Ordered by MO. Consider entering ordering when:
  o Prepping for clinic
  o When reviewing PaCES Dashboard data
  o In clinic

• Usual process will be to give patient letter on next OPD visit. Can give day of while in clinic per clinician discretion (e.g. patient needs to obtain Family MD).

• When GI clerk preps chart, letter is placed on top of blue flag for clinician to give to patient.
Information on how to get a family physician.

If your patient does not have one, you should give this letter the day of in clinic.
Templated Shared Care Letter for Family Physician:

- Templated letter in ARIA

- Clerk processes order
  - Combines letter with MO Signature Block (defines how you preferred to be contacted). Block can be changed by contacting ARIA.

- Clerk to send letter via internal ARIA fax
  - MO can add additional information and send themselves via correspondence window

- Family MD faxes back the cover sheet
  - MO acts on as needed
  - **Signs/initials** and sends for scanning into chart (HIM)
PaCES Sub-projects

- PaCES Rural
- PaCES Family Physician / SUPPORT-FM
- PaCES Oncology Provider
- PaCES Health Resource Study
- PaCES Living with Cancer Study
- PaCES Pathway
- PaCES Implementation
- PaCES Serious Illness Conversation Program

..........