Strengthening Linkages: Integrating an Early Palliative Approach with Advanced Cancer Care

Dr. Jessica Simon on behalf of the PaCES Project
www.pacesproject.ca
Faculty/Presenter Disclosure

• Faculty: Jessica Simon

• Relationships with financial interests:
  – Grants/Research Support: CIHR, Canadian Frailty Network, Alberta Innovates
  – Speakers Bureau/Honoraria: None
  – Consulting Fees: None
  – Patents: None
  – Other:
    • Associate Professor, Department of Oncology, University of Calgary
    • Palliative Care Consultant Physician, AHS Calgary Zone
    • Physician Consultant Advance Care Planning and Goals of Care, AHS Calgary Zone

PaCES project Funding:
Objectives

1. Define four key elements of early palliative approach to care
2. Describe "shared care letters” to improve collaboration
3. Utilize on-line resources to identify and meet early palliative care needs
Vision: Improving quality of life for Albertans with advanced cancer
• 60% patients with metastatic 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;
What do we mean by early?

A palliative approach to care that occurs concurrently with cancer treatment

Integrating an Early Palliative Approach into Advanced Colorectal Cancer Care

Early Stage Colon Cancer

Early Stage Rectal Cancer

Metastatic Colorectal Cancer

Diagnosis of advanced colorectal cancer

No Remission and End of Life

or

Prolonged Remission

PaCES
Palliative Care Early and Systematic
Kaplan–Meier Estimates of Survival According to Study Group

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
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

Patients journey (typically 1-2 years)

1. Identifying patients with advanced cancer via systematic screening
2. Normalizing communication about PC as an added layer of support
3. Ensuring key elements of early PC are systematically provided
4. Ensuring timely access to community-based care and ongoing liaison with family physicians

Diagnosis of metastatic CRC
concurrent palliative care

End-of-life
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.
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
To improve the quality of life for people affected by advanced colorectal cancer by integrating an early palliative care approach into advanced cancer care.
Information located under “Gastrointestinal” and “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
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>Qsr 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>
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### Step 2: Identify needs

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<thead>
<tr>
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<tbody>
<tr>
<td>Illness comprehension and coping</td>
<td>Canadian Problem Checklist (CPC)</td>
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<tr>
<td></td>
<td>Edmonton Symptom Assessment System- Revised: anxiety and depression scales (ESAS-r)</td>
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<td>Serious Illness Care Program (SICP)</td>
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<td>Symptoms and functional status</td>
<td>ESAS-r</td>
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<td></td>
<td>CPC</td>
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<tr>
<td></td>
<td>Eastern Cooperative Oncology Group (ECOG)</td>
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<tr>
<td></td>
<td>Palliative Performance Scale (PPS)</td>
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<tr>
<td>Advance care planning and patient’s preferred method of decision making</td>
<td>ACP GCD Tracking Record</td>
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<tr>
<td></td>
<td>CPC</td>
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<tr>
<td></td>
<td>SICP</td>
</tr>
<tr>
<td>Coordination of care</td>
<td>PPF</td>
</tr>
</tbody>
</table>
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 admitted to hospital since your last visit?  ☐ Yes ☐ No
2. Have your medications changed since your last visit? (eg. 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  In the past 30 days?  ☐ Yes ☐ No

Please 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

No pain 0 1 2 3 4 5 6 7 8 9 10 Worst possible pain
No tiredness (Tiredness/lack of energy) 0 1 2 3 4 5 6 7 8 9 10 Worst possible tiredness
No drowsiness (Drowsiness/feeling sleepy) 0 1 2 3 4 5 6 7 8 9 10 Worst possible drowsiness
No nausea 0 1 2 3 4 5 6 7 8 9 10 Worst possible nausea
No lack of appetite 0 1 2 3 4 5 6 7 8 9 10 Worst possible lack of appetite
No shortness of breath 0 1 2 3 4 5 6 7 8 9 10 Worst possible shortness of breath
No depression (Depression/feeling sad) 0 1 2 3 4 5 6 7 8 9 10 Worst possible depression
No anxiety (Anxiety/feeling nervous) 0 1 2 3 4 5 6 7 8 9 10 Worst possible anxiety
Best well-being (How your feel overall) 0 1 2 3 4 5 6 7 8 9 10 Worst possible well-being
No Other problem (eg. constipation) 0 1 2 3 4 5 6 7 8 9 10 Worst possible

Continue on back side →

APPENDIX 1: PUTTING PATIENTS FIRST PAGE 2 (CPC)

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

Emotional
☐ Fears/Worries  ☐ Sadness  ☐ Frustration/Anger  ☐ Changes in appearance
☐ Intimacy/Sexuality  ☐ Thoughts of ending my life

Social/Family/Spiritual
☐ Feeling alone  ☐ Feeling like a burden to others  ☐ Worry about friends/family
☐ Support with children/partner  ☐ Meaning/Purpose of life  ☐ Faith

Practical
☐ Work/School  ☐ Finances  ☐ Getting to and from appointments
☐ Home Care  ☐ Accommodation  ☐ Quitting tobacco
☐ Drug costs  ☐ Health insurance  ☐ How much alcohol you drink

Mobility
☐ Dizziness  ☐ Walking/Mobility  ☐ Trouble with daily activities (e.g. bathing, dressing)

Other Concerns:
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 health care professional only - Screening Intervention Documentation

Review of Form:
☐ Patient declined to fill out form  ☐ Language barrier  ☐ Other
☐ Form reviewed through conversation with patient
If form not reviewed why:  ☐ Patient declined discussion  ☐ Other:
Is patient at falls risk?  ☐ Yes ☐ No
Patient Priority Concern Identified  ☐ Patient indicated no concerns
Specify ONE priority concern (either ESAS or CPC):
ESAS:  ☐ Pain  ☐ Drowsiness  ☐ Appetite  ☐ Depression  ☐ Well-being
☐ Tiredness  ☐ Nausea  ☐ Shortness of breath  ☐ Anxiety  ☐ Other
CPC:  ☐ Emotional  ☐ Practical  ☐ Mobility  ☐ Social/Family/Spiritual
☐ Nutrition  ☐ Physical  ☐ Informational  ☐ Other
Specific area identified 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/Physical/Speech  ☐ O2/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

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- 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

### Provincial Content

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<td>Blood Transfusions</td>
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<td>CAMPP</td>
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<td>Financial Concerns</td>
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<td>Hospice</td>
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<td>Legal and Financial Issues</td>
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<td>Palliative Coverage Program</td>
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<td>Palliative Oxygen</td>
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<td>Service Descriptions</td>
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<td>Thoracentesis or Paracentesis</td>
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<tr>
<td>Dyspnea clinic at TBCC</td>
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Step 3: Referrals service descriptions

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<tr>
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<th>Description</th>
<th>Contact Information</th>
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<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></td>
</tr>
<tr>
<td></td>
<td>*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</td>
<td>ROUTINE REFERRAL:</td>
</tr>
<tr>
<td></td>
<td></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>
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<td></td>
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<tr>
<td></td>
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<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>
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Step 3: Introducing palliative care

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PaCES
PALLIATIVE CARE EARLY AND SYSTEMATIC
Step 3: Coordination of Care

Shared Care Letter

Re: Advanced Cancer Shared Care

Dear Dr. [Insert Name],

Your patient [Insert 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 and ensure the best possible outcomes for your patient. We appreciate your ongoing management of non-cancer related issues. The Cancer Centre will focus on access to cancer related and supportive care.

The following information will be sent to you:
- Potential signs and symptoms of cancer related emergencies
- Other palliative supportive measures
- Contact information for the GI oncology team

Please refer to the latest consultation note for progress specific to your patient (will be sent separately). If no progress is noted or you have further questions, please contact us. All Cancer Centre consults and progress notes, will be sent to you by email. In the meantime, if you have any concerns or are in need of more information, please contact the medical oncologist.

Coordinating Care

We have asked the patient to make a follow-up appointment with you and your team. Monitoring of disease, referrals, and treatment is important for personal support. Advance care planning and treatment of non-cancer related health issues. Studies suggest that active involvement with the patient, physicians, oncologists, and healthcare providers and outcomes within the community improve patient and quality of life. We ask that non-cancer related decisions and issues are discussed by the team. Symptom control can be co-ordinated together. To optimize shared care, please communicate to us any significant changes or updates.

Care Concerns

- Cancer Care Team
- Family Medicine Team

Symptoms and chemotherapy-related complications

- Organizing investigations related to cancer treatment
- Nephrology (i.e., renal, urology, nephrology, sleep, diabetes, metabolic, psychological)

Advance Care Planning

- Patient and Family concerns

- Legal/Financial concerns (e.g., ROA)

- Accessing community resources

- Non-cancer complications

Please note patients with pre-existing:
- Diabetes may require changes to their medications due to changes in urine intake, weight loss, and concurrent antidiabetic medications.
- Anti-hyperglycemics may require adjustments, especially if they lose weight.

It is advised to advise becoming pregnant or breastfeeding 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 visits prior to initiation of treatment:
- Fever (temperature over 38.0°C for one hour or 38.3°C for two hours) while on chemotherapy, may indicate life threatening febrile neutropenia. Direct patient to Emergency Room.

Attention Reception Staff: Please ensure this is given to the family physician. After it is reviewed and completed, please fax back to Tom Baker Cancer Centre @ 403-283-1651

Shared Care Information Exchange

We are sharing the care of this advanced colorectal patient. To foster collaborative care, we would like to provide you the opportunity to ask any questions and individualize this patient’s care plan.

Please confirm your clinic is the patient’s current medical home:

- [ ] Yes
- [ ] No
- [ ] (If no, no further comments are required)

Please confirm you are managing non-cancer related concerns and medication refill:

Comments

Please provide clinic contact information stamp, if the medical oncologist needs to contact you:

Do you feel comfortable participating in the palliative approach to care for our patient?

Approach to Care

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comments</td>
<td></td>
</tr>
</tbody>
</table>

Surgery Management (if applicable if required)

Psychosocial: if a family distressed - SW access and other supports available?

Palliative Care: do you have a Goals of Care Form (Green Sheet) on file? Please fax copy if yes.

Non-urgent questions you would like answered:

Please fax this letter to: 403-283-1651.

Non-urgent messages for the oncologist can be left at:

[Ave Sig Block]
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](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>Manages your cancer treatment plan</td>
<td>Manages non-cancer related concerns. For example:</td>
</tr>
<tr>
<td>and cancer-related concerns.</td>
<td>- refills of your medications not related to cancer treatment</td>
</tr>
</tbody>
</table>

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.
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.”
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.
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
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

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 cancer patients.

“\textit{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)
Wrapping up
Take home points

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

Enhance Shared Care

[Diagram showing the 4 elements of care]

PaC CES
Palliative Care Early and Systematic
Acknowledgements

Dr. Ayn Sinnarajah
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Dr. Amy Tan
Dr. Marc Kerba
Dr. Sharon Watanabe

And all of the PaCES Collaborative members
Let us know what you’re thinking

Jessica.simon@ahs.ca

Thank you!