Primary Care: the coal face for end of life care and advance care planning

APCC
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Disclosure

• Participate as collaborators on AIHS ACP-CRIO grant
• 0.2 FTE Contractor to AHS for ACP/GCD initiative (EW)
• Director PEOLC, AHS (MJ)
• Not on Speakers Bureau
• No Consulting Fees to industry
Objective

• To describe how these two initiatives in Alberta can help accelerate primary care’s influence, in the interests of our patients.
• To leave you with some access points to learn more about these initiatives as you encounter patients.
• To better understand your concerns and needs regarding these initiatives.
Acronyms

- ACP = Advance Care Planning
- GCD = Goals of Care Designations
- PEOLC = palliative and end of life care
Mr. S

- Mr. S is a 78 year old patient in your community practice, who you know well. He lives alone.
- You have had conversations with him about care goals and his wishes in case he can no longer speak for himself.
- On a Saturday evening he lands in emerg having suffered a stroke and not being able to speak. He is medically unstable.
- What should be done?
4 Key messages – ACP/GCD

• Growing literature and research supports primary care’s central place in advance care planning and end of life care.

• Widespread areas of adoption already, but the ACP/GCD initiative will be successful only if well-entrenched in primary care.

• The ACP/GCD initiative will be successful only if citizens are fully involved.

• There are many tools to assist, but much more organizational work to be done.
4 Key messages – PEOLC strategy

• Disciplined, evidence-informed strategy based on goals
• Mixed primary, secondary and tertiary care strategy
• Primary care as a fundamental pillar
• Accelerate success - by creating capacity, fostering skills, developing access portals
The Advance Care Planning/Goals of Care Designation (ACP/GCD) project aims to establish and implement standardized provincial processes for advance care planning and the determination of goals of care designations with patients in all sectors of care.
What we already know:

• We can expect to die with 2 or more chronic diseases after a few years in a state of “vulnerable frailty”
• Only 20% will die with a recognizable “palliative” phase
• ~70% of Canadians die in hospital, 20% in ICU
• At time of death:
  – 42.5% require decision-making
  – 70.3% lack capacity
(Silveira et al. NEJM 2010; 362:1211)
ACP in Canada

- Only 14% of Canadians had heard of ACP
- Half have communicated preferences to family members
- Only 9% have talked with a health care provider
- 19% have written an Advance Care Plan
- 46% had formally designated a decision maker
- Some regional differences
  
  Western provinces > East and Atlantic Canada

Source: Ipsos Reid Canadian public opinion poll
March 2012: 1,021 respondents
Key Motivators

- We need best available information to support good decision-making: unfamiliar care teams
- A modernized platform for categorizing and communicating care focus is essential
- Better transmission of information during patient transitions is required
- Patients are partners in decision-making
Patient barriers to conversations

- Unclear diagnosis and prognosis
- Doctors are too busy
- Emergency room is too stressful for these conversations
## Barriers to ACP Discussions

<table>
<thead>
<tr>
<th>Domains</th>
<th>Questions</th>
<th>Patients (n=91)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient Factors</strong></td>
<td>My diagnosis and prognosis unclear or uncertain</td>
<td>28.6% (21.6, 0.0, 100)</td>
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<tr>
<td></td>
<td>I am too sick to talk about this</td>
<td>2.2% (0.0, 0.0, 18.2)</td>
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<td></td>
<td>Issue not relevant to me at this time</td>
<td>7.7% (0.0, 0.0, 45.5)</td>
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<tr>
<td><strong>Doctors Factors</strong></td>
<td>I don’t know my doctor and he/she does not know me</td>
<td>16.5% (10.8, 0.0, 61.5)</td>
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<tr>
<td></td>
<td>Doctors have no time or are unavailable to talk</td>
<td>35.2% (30.3, 0.0, 75.0)</td>
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<tr>
<td></td>
<td>I don’t trust my doctor</td>
<td>2.2% (0.0, 0.0, 12.5)</td>
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<td></td>
<td>I don’t feel comfortable talking to the doctor about this topic</td>
<td>9.9% (2.5, 0.0, 50.0)</td>
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<tr>
<td></td>
<td>The doctor does not seem comfortable talking to me about this topic</td>
<td>1.1% (0.0, 0.0, 9.1)</td>
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<tr>
<td></td>
<td>Doctors don’t ask me about my wishes related to this matter</td>
<td>15.4% (7.1, 0.0, 100)</td>
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<tr>
<td></td>
<td>Doctor doesn’t care about me, not compassionate</td>
<td>2.2% (0.0, 0.0, 33.3)</td>
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<td></td>
<td>Hearing, and or speech, and or language problems make it difficult to communicate with MDs</td>
<td>1.1% (0.0, 0.0, 25.0)</td>
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<tr>
<td><strong>Process Factors</strong></td>
<td>I am worried that I won’t be able to change my mind on a decision</td>
<td>4.4% (0.0, 0.0, 50.0)</td>
</tr>
<tr>
<td></td>
<td>Emergency room is too busy and stressful to talk about this</td>
<td>24.2% (18.2, 0.0, 55.0)</td>
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<td></td>
<td>No opportunity to discuss this with family present</td>
<td>6.6% (5.0, 0.0, 25.0)</td>
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<tr>
<td></td>
<td>Difficult to find information and forms related to ACP</td>
<td>2.2% (0.0, 0.0, 25.0)</td>
</tr>
</tbody>
</table>


**Failure to engage hospitalized elderly patients and their families in advance care planning.** [Heyland DK]¹, [Barwich D], [Pichora D], [Dodek P], [Lamontagne F], [You JJ], [Tayler C], [Porterfield P], [Sinuff T], [Simon J]
Facilitators for conversations

• Patients tell us:
  • Doctor should initiate the conversation
  • Include family members in the conversations
## Facilitators for ACP Discussions

<table>
<thead>
<tr>
<th>Domains</th>
<th>Questions</th>
<th>Patients (n=151)</th>
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</thead>
<tbody>
<tr>
<td>Family Factors</td>
<td>Include family of patients in conversations related to ACP</td>
<td>33.8% (36.4, 16.7, 100)</td>
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<tr>
<td></td>
<td>Doctor initiates conversation</td>
<td>70.2% (75.0, 33.3, 100)</td>
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<td></td>
<td>Doctors has good communication skills</td>
<td>14.6% (18.4, 0.0, 33.3)</td>
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<tr>
<td></td>
<td>Doctor is honest about prognosis</td>
<td>5.3% (0.0, 0.0, 12.5)</td>
</tr>
<tr>
<td>Doctors Factors</td>
<td>More available info</td>
<td>19.2% (25.0, 0.0, 100)</td>
</tr>
<tr>
<td></td>
<td>Easier access to info</td>
<td>0.7% (0.0, 0.0, 3.7)</td>
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<tr>
<td></td>
<td>Have this conversation when patients are stabilized and not in crisis</td>
<td>6.6% (0.0, 0.0, 17.4)</td>
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<td></td>
<td>Encourage patients who wish to discuss this and convey their wishes</td>
<td>9.3% (0.0, 0.0, 58.3)</td>
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<td></td>
<td>Other team members (i.e., Nurses) would be easier to talk to about this</td>
<td>2.6% (0.0, 0.0, 33.3)</td>
</tr>
<tr>
<td></td>
<td>Schedule family meeting to discuss this issue</td>
<td>4.6% (0.0, 0.0, 16.7)</td>
</tr>
</tbody>
</table>


Failure to engage hospitalized elderly patients and their families in advance care planning. **Heyland DK**¹, Barwich D, Pichora D, Dodek P, Lamontagne F, You JJ, Tayler C, Porterfield P, Sinuff T, Simon J
Focus

• It is about the conversation
• Joint decision-making
  – Patient/family expertise
  – Clinician expertise
• In the case of dispute, a mechanism for resolution

Comfort Care
Focuses on providing comfort for people with life-limiting illness when medical treatment is no longer an option

Resuscitative Care
Focuses on prolonging or preserving life using medical or surgical interventions, including, if needed, resuscitation and intensive care

Medical Care
Focuses on medical tests and interventions to cure or manage a person’s illness, but does not use resuscitative or life support measures
GCD categories

- R, M, C
- Within these three general categories are 7 sub-categories
- Experience and clinician reports indicate these have been useful and more clinically relevant than “DNR” and former “levels of care”
April 1, 2014
Province Wide Adoption

- Promote best practice conversations
- Develop Provincial tools/resources
- Enhance clinical practice through education
- Ensuring that all appropriate Albertans receive a Green Sleeve and are made aware of ACP and GCD
What can we do?

“JUST ASK!”
Impact on patients / families

- 37% of patients with advanced cancer reported an EOL discussion at baseline
- Patients followed until death (median 4.4 months)
- EOL discussions associated with:
  - Decreased ICU use; decreased chemotherapy
  - Greater use of Hospice
  - Caregivers: Perception of increased quality of life (pt) with less intensification of care & better long term outcomes (less anxiety, depression or regret) and felt more prepared

US: Wright JAMA 2008;300:1665
## Goals of Care Designations

<table>
<thead>
<tr>
<th></th>
<th>R</th>
<th>Resuscitative Care</th>
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<th>2</th>
<th>3</th>
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<tr>
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<td>✓</td>
<td>✓</td>
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<td></td>
<td></td>
<td>✓</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>Medical Care</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td></td>
<td></td>
<td></td>
<td>✓</td>
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<td>✓</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>C</td>
<td>Comfort Care</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>✓</td>
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<tr>
<th></th>
<th>ICU Admit - Adult</th>
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<tr>
<td></td>
<td>Surgery</td>
</tr>
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<td></td>
<td>Site Transfer</td>
</tr>
</tbody>
</table>

- **R**: Resuscitative Care
- **M**: Medical Care
- **C**: Comfort Care

**GCD Quick Reference Card**

- Green Sleeve Tracking Record
- GCD Order Form

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ACA / GCD Resources

Understanding Goals of Care - Healthcare Decisions

Advance care planning conversations and documents help guide healthcare decisions.

www.albertahealthservices.ca
Easy to access
Education Modules

E-Learning Modules:
via *insite* MyLearningLink or www.conversationsmatter.ca
PCN links

- Clinician and patient education
- Central resource pool – materials, people
- Think about group learning sessions for patients
- Resource staff for conversations
Improving Advance Care Planning in General Practice

• Research project intended to increase the participation of patients and families in ACP in primary care.

• i-GAP will:
  – Identify barriers and facilitators to implementing ACP into primary care.
  – Identify and create tools to improve ACP engagement into primary care.
  – Evaluate/measure the impact of these tools and approaches.
Our Research Activities

Our research activities are grouped under **four main objectives**. Activities within each of these objectives contribute to a Knowledge Translation program that is designed to support adoption and impact of ACP/GCD across Alberta.

**Objective 1:** Prospectively assess the barriers and facilitators to uptake of ACP/GCD in Alberta and characterize the readiness to participate in ACP/GCD from the perspectives of two groups: (a) Public (i.e. people, patients and family) and (b) Health Care Providers (HCP) (micro level).

**Objective 2:** Assess the most effective tools for education and engagement of stakeholder groups in ACP/GCD, and based on the identified barriers and facilitators in Alberta (Activity 1), evaluate how the tools can be most effectively adapted to the local environment (micro and meso levels).

**Objective 3:** Determine the most informative indicators to monitor successful uptake of ACP/GCD across the health care system, and study how they can be used to guide continuous improvement of the ACP implementation strategy (macro/system level).

**Objective 4:** Determine the economic consequences of ACP implementation (macro/system level).

Please click on the links to the left to learn more about the research activities associated with each of our Objectives.
Advancing the agenda

- A well-crafted public awareness campaign, and partnering with legal, financial planning, banking and insurance industries
- Improved efforts at training clinicians and students, and providing accessible tools
- Adoption as a standard of care
- Incorporation into Netcare (linked to your EMRs?)
- Development of a specific time-based billing code
I'm afraid I have some bad news.

If it's about the playoffs, don't tell me! I'm taping it!
The Conceptual Framework development was built on evidence informed best practice with the goal of one harmonized Palliative and End of Life Provincial Program that is equally accessible and equitable for all Albertans.
• Inclusive of all fundamental stakeholders
• To strengthen, formalize and implement initiatives
• Designate appropriate representation on Working Groups
Current State

• **Illness Trajectory Model**
  Palliative and End of Life Care:
  is a continuum of care from the time of diagnosis of a life-limiting illness through to the time of death and into Bereavement. It demonstrates that a palliative approach to care can occur simultaneously with a curative approach or during treatment.

• **Current State Analysis**
  Involved 3 main components:
  • Systematic Literature Review
  • Data Mining for Quantitative Information
  • Qualitative Questionnaires and Primary Care Network Surveys

(Adapted by the Canadian Hospice Palliative Care Association model, Pereira (2008).)
36 Initiatives have been recommended

• Focus areas that are all foundational to the program
  1. Practice and Standards
  2. Education and Awareness
  3. Program Development
  4. Partnerships and Innovation
  5. Communication
Overall Strategy

- Primary care providers are ideally situated to help support people to plan for end of life.
- Accessing services and resources to support people to die at home.
- Helping people, not just patients, navigate the system.
Choosing Wisely and CSPCP

• Two of the “5 things”:
  – “Don’t delay palliative care for a patient with serious illness who has physical, psychological, social or spiritual distress while they are pursuing disease-directed treatment.”
  – “Don’t delay advance care planning conversations.”
Soapbox time…

• Accessible palliative/end of life care in a community requires:
  – Appropriate services in all locations of care
  – Available expertise residing within specialty services
  – Fundamental primary care focus
Arising from this...

- Programs in each sector (including EMS)
- Better community capacity for hospice
- Education in skills
- Real–time expert support (services and consultation)
- Public and provider awareness plus easy to access portals
• Provided successfully at the primary health care level if physicians, patients and families are supported well when complexities and emergencies arise.

• Framework initiatives aimed towards improving and increasing supports for Primary Care Physicians.

• 36 Framework initiatives have consolidated into 10 groups.
Consolidated Framework Initiatives

Pathways and Guidelines

- Identify and implement best practice PEOLC Standards.
- Define and standardize eligibility criteria and service standards across all care settings (Home Care, pharmacy services, hospice settings, etc.).
- Identify and agree on a set of provincially standardized common screening and assessment tools, and guides to practice.
- Enhance and provincially standardize the referral and the transition communication processes.
- Create an expert panel that works with the clinical policy team and addresses the clinical supports that are applicable to primary and secondary providers.
- Develop specific care delivery concepts for complex, high needs patients integrating various healthcare services and care providers.
- Identify and implement PEOLC care models specific to supporting those within Long Term care and Supportive Living.
- Create synergies amongst existing organizations/services within Alberta to be supported with education and practice guidelines that are evidence-based and standardized.

Education

- Inventory existing resources and partner with national and academic organizations to develop a plan to establish education standards for those directly working in PEOLC.
- Build on existing educational resources and standardize methods under a provincial focus to make educational tools more accessible to care providers.
- Formally integrate the Pain and Symptom Clinics into the palliative system resources available for primary PEOLC providers across Alberta.
- Identify specific educational and resource gaps in rural and remote communities, pilot solutions, and roll out proven methods to spread resources across all geographies.
- Develop provincial education avenues such as PEOLC rounds, sessions, and seminars for clinicians, health care aides, volunteers.
- Work with academic institutions to identify and introduce standards and strategies to support palliative care providers.
- Develop a funding mechanism that allows care providers to apply educational resources such as advanced education and seminars including grief and bereavement services.

Constructing and Strengthening Local and National Networks

- Establish a provincial PEOLC Practice and Innovations Council (PIC) that that is focused on addressing the key aspects of process of implementing community based PEOLC.
- Identify and develop connections to other patient centered initiatives in the province.
- Identify and link with a health promotion framework (e.g. the Ottawa Charter; framework for integrated care [CHPCA, QEOLCC]) to palliative service development and programs.
- Develop direct links with those who can support provision of PEOLC in local communities.
Consolidated Framework Initiatives

Research and Development

- Explore developing a provincial PEOLC volunteer network that coordinates and expands existing volunteer programs.
- Enhance connections between Cancer Nurse Navigators and 24/7 Palliative Care Consult Teams to enhance integration of services for PEOLC patients and their families.
- Identify key worker/coordinator or Nurse Navigator roles and raise awareness of existing roles to improve patient and family navigation through the continuum of Care.
- Integrate Zone PEOLC strategy and operations across all Zones as part of a provincial program for both pediatrics and adults.
- Further study if adequate funding is in place for short term and specialized equipment and supply needs and if gaps are identified develop a strategy to resolve them.

Evaluation Measures and Outcomes

- Develop provincial standards for collection of specific PEOLC data for adult and pediatric patients and publish provincial performance reports annually.
- Support education and knowledge translation regarding information that is available in current electronic health records, and within physician offices.
- Develop infrastructure, including funding and data analysis to support the use of patient/family reported outcomes model, and rolled up provincially based on best practice.

Gateway/Portal for Patients, Families and Care Providers

- Create interactive standardized PEOLC webpage’s for clinicians, patients and families that are user-friendly, maintained/updated regularly including Zone specific information and details. A central repository that is updated regularly for sharing family resources.
- Develop a one stop information portal that includes information on equipment, medication, program access, as well as online grief and bereavement resources.
- A central repository that is updated regularly for sharing family resources.
Enhancing Services

• Standardize access points and spread 24/7 on call PEOLC consult services for adults and pediatrics province wide.
• Review current structure and develop a consistent system of incentives to support physicians to establish linkages to support community based care.

Grief and Bereavement

• Identify a provincial model and develop provincial and local grief and bereavement programs within each Zone and geography.

EMS Treat in Place/EMS Assess, Treat and Refer

• Formalize and expand the EMS program across Alberta.

Building Capacity

• Develop a detailed hospice capacity plan until 2034.
2014 / 2015 Initiatives

- **Dashboard**: Development of a dashboard to measure performance indicators.
- **PEOLC EMS - Assess, Treat and Refer**: "Treat in place" spread across the province.
- **Business Cases**: Casing 2015 / 2016
- **Alberta PEOLC Website**: One stop information gateway for health care providers, patients and families.
- **ACP Evaluation**: 1 year policy review
- **Provincial 24 / 7 On Call**: Palliative Physician Support
- **Clinical Pathways / Guidelines**: In collaboration with SCNs
- **Capacity Planning**: Palliative and Hospice spaces in both urban and rural settings across the province

**2014 – 2015 Fiscal Year**
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Questions & Discussion

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• Eric.wasylenko@albertahealthservices.ca