

# Palliative Care Early and Systematic (PaCES): Assessing patient and caregiver preferences for early palliative care in rural Alberta

*Ayn Sinnarajah*

*Co-Lead, PaCES Project*

*Medical Director, Palliative & End of Life Care, Calgary*

*Assistant Professor, University of Calgary*

**PaCES**

PALLIATIVE CARE EARLY AND SYSTEMATIC

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## Disclosure of Financial Support

- PaCES has received financial support from **CIHR and Alberta Health** in the form of **research grants**
- PaCES has received in-kind support from **Alberta Health Services** in the form of **stakeholder input, some logistical support (e.g. QI expert, leadership support)**

### Potential conflicts of interest:

- **Dr. Sinnarajah** has received **research grant funding** from: **CIHR, Alberta Health, Canadian Frailty Network**

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# Mitigating Potential Bias

**Grants and in-kind support are for research and knowledge translation and explicitly to conduct PaCES project.**

## PaCES Core Team

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P. Tang



S. Watanabe



J. Simon



S. Kassam



M. Earp



M. Kerba



A. Tan



J. Vandale



P. Biondo

C. Bond

## PaCES: Palliative Care Early and Systematic

- 2003-2010: 54% of decedents in CZ from GI ca did not receive early palliative care (Sinnarajah et al 2015)
- 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.”*

- One goal of PaCES initiative was to understand rural perspective

## PaCES Rural: Who's responsible

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- Robin Gray
- Janet Vandale (Slides)
- Shelley Raffin Bouchal
- Patricia Biondo
- Terri Woytkiw
- Pansy Angevine
- Aynharan Sinnarajah
- Grateful acknowledgment: MacLean Thiessen, Med Onc; CCC clinicians and home care nurses; patients and caregiver participants

## Rural PC

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- <30% Canadians have ready access to PC overall, certainly lower for rural Canadians
  - Geographic isolation
  - Limited access to hospital- or community-based PC
  - Poorer symptom control
  - Later referral
  - Caregivers greater unmet needs in tangible support
- Unique palliative needs, strengths and challenges for which urban-specific programs are not designed or necessarily helpful

## Study aims

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- To understand from rural patients living with advanced cancer and their family caregivers how to deliver PC services alongside cancer treatments
- To understand participants' perceptions of PC being delivered early in the cancer trajectory



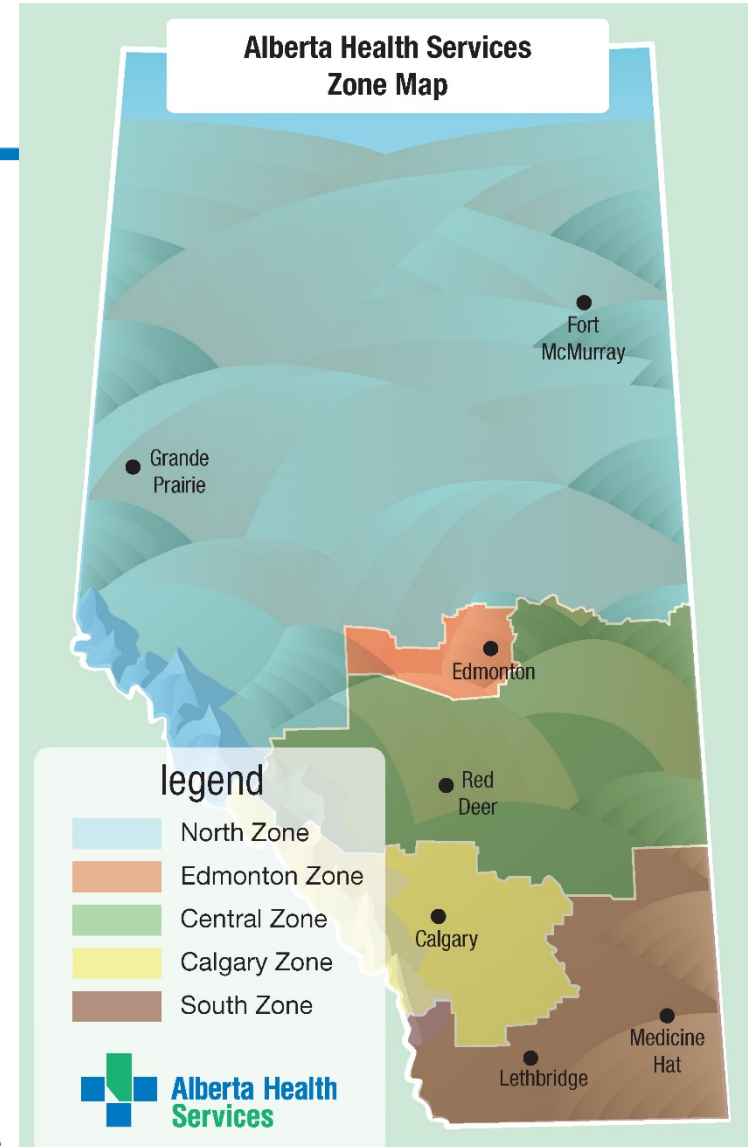
## Methodology

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- Qualitative – Interpretive Description (ID; S. Thorne, 2008)
- Generates knowledge: subjective, **experiential, tacit and patterned** aspects of human health experience, not for purpose of theorizing, but to gain **contextual understanding** of a phenomenon to guide **clinical practice**.
- Context: unique cultural, political, economic realities of rural communities
  - ethical imperative: hear, document rural pts' experiences, viewed through contextual lens
- Goal of ID inquiry: generate knowledge relevant to healthcare disciplines

## Location

- Alberta Health Services:
  - North Zone
  - Central Zone
  - South Zone
- 1/3 of provincial population
- 95% of geographic area



## Participants

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	Patients (n=13)	Caregivers (n=9)
<b>Age (years)</b>		
41-50	1	2
51-65	9	5
66-75	3	2
<b>Gender</b>		
Female	7	6
Male	6	3

- 11 referrals from oncology team, 2 from FP

## Analysis

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- **Constant comparison analysis** (Charmazian constructivist GT)
- Data clustered into 5 categories of themes:
  1. Meaning of PC – understanding/not understanding
  2. Benefits of PC – supportive holistic care
  3. Introducing PC – directly, early, carefully
  4. HC system characteristics – working from the same playbook
  5. Rural patient/characteristics – life on the outskirts

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Understanding/not understanding

## MEANING OF PALLIATIVE CARE

## Meaning of Palliative Care

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- Conflation with EOL care:

*When I hear 'palliative,' I just think of someone laying in a bed and dying and because I'm not there, I assume I don't need PC*

- Limited awareness:

*I'm not 100% sure what it is*

*...if there's actual, physical things they could be doing for me now while I'm still maintaining my life, then it should be introduced that way. 'Cause I think there's a misconception here.*

## Meaning of Palliative Care

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- ” Evolution of PC understanding:

*Life care*

*Providing QOL  
during the process  
of my illness*

- Cancer care and PC non concurrent:

*Nothing more we can do*

*...not there yet*

- Loss of hope, dignity and independence:

*I'm a very independent person and I just can't see myself asking people for help. I doesn't matter how sick I am.*

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Supportive holistic care  
**BENEFITS OF PC**



## Benefits of PC 1

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- Pain and symptom management
- Access to resources (specialists, equip't, palliative prescriptions)
- Home care – **needed 24/7**
- Navigating trajectory, an uncertain future; coping

*...at least we know a little bit  
more about what is coming*

*...peace of  
mind*

*...all encompassing  
care*

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Directly, early, but carefully  
**INTRODUCING PC**

## Introducing PC – directly, early, but carefully

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### HOW:

- Plain language, detailed conversations: “...*more honesty.*”
- Combined w/ written material
- 2 participants preferred “supportive” to “palliative”

*...it would be nice if you were approached with a definition of what PC has **become.***

### WHO:

- Knowledgeable
- Relationship, “rapport,” “trust”

*I think it should be, in the rural area, the ones that see them all the time*

## Introducing PC – When?

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- “*earlier is better,*” if PC understood to be holistic and throughout trajectory

*I think it's good if they introduce it right at the start because it's not just that it's EOL care...it's that it is life care.*

- Titrated approach

*Don't scare the hell out of them by hitting them too soon*

- Individualized
- Expected HCPs to interpret “readiness” to receive info

## ...readiness

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*“...just not there yet.”*

*“...not ready.”*

- Lack of readiness >>>>associated with perception of PC as EOL care and perception of PC as **NONconcurrent w/ onc care**
- Conversely:

*It was rather overwhelming, because right away I think...the end's nearer than we hoped or thought. But now...I think it's been fantastic to have as soon as you get that final diagnosis, to have that intervention right away makes it way less scary now because we can use that term, 'palliative' in our daily conversation just like we got used to using the word 'cancer.' ...It's far less daunting.*

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Working from the same playbook

# HEALTH CARE SYSTEM CHARACTERISTICS

## Health Care System Characteristics

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- Home Care:
  - 24/7 support at home deemed critical particularly at EOL
  - Common refrain in the rural PC literature
- Communication between HCPs, particularly difficult in rural communities
  - Many different locations of care and many HCPs
  - Complex system
- Community Cancer Centre: Hub of health care for participants
  - A godsend – allowing for treatment close to home
  - Maintained the feeling of community, otherwise missed in an urban center

## Health Care System Characteristics

*...cause when you don't know who to call and you've got 10 numbers of the list...and if you are in a panic or sudden situation where something has changed, it can be really frustrating and stressful*

- Role confusion prevalent
- ?Expand role of Cancer Centre nurse navigators to cover entire illness trajectory – would also enhance communication between Onc & PC teams
- Role of family physician: cradle to grave – longitudinal relationship
  - Communication and relationship challenges w/ onc (lack of a common record)
  - Our participants recommend regular case conferences



Life on the outskirts

# RURAL PATIENT/FAMILY CHARACTERISTICS

## Patient / Family Characteristics

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- Geographic isolation “dials up the intensity” of living w/ advanced cancer
- Travel most common hardship for our participants: “*We made 41 trips from Cardston to Lethbridge....*”
  - Time, financial burden, fatigue, toll on well-being
  - Hidden costs:
    - Rural realities force hard decisions: “*Well, if I wasn’t able to get to my treatments, I would have to get some else to drive, or just quit my treatments altogether.*”
    - Giving up work: loss of financial stability, identity
    - Bakitas et al 2015: locally accessible PC allows families to continue to be engaged and productive in their communities – cost saving

## Patient / Family Characteristics

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Psychosocial supports not accessible for rural patients and families

- Consistent suggestion of local pt and caregiver support groups to ease burden
- "Life on the outskirts" also source of strength
  - Strong sense of community
  - Resilience
  - Caring for one another

## Conclusion

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- PC not fully understood – barrier to early and integrated PC
  - Findings support education may overcome avoidance of PC
- Expectation of individualized, titrated PC intervention
- Rural specific:
  - 24/7 home care considered essential
  - Improved communication with and between HCPs: regular case conferencing
  - Support for burden of travel
  - ? Nurse navigator role expansion
  - Local support groups for patients and caregivers.

Thank you



# APPENDIX

## Elements of early PC

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- Hoerger et al 2018: how does the content of PC visits vary across the illness trajectory?

Defining the Elements of Early Palliative Care  
That Are Associated With Patient-Reported  
Outcomes and the Delivery of End-of-Life Care