

### BACKGROUND

- Early palliative care (PC) addresses **understanding** of illness, **symptom management**, **care planning/decision making** and **care coordination**
- Early access to PC leads to **fewer potentially inappropriate, aggressive (and costly) interventions** at end-of-life (EOL) and **improves outcomes**<sup>1</sup>
- Rural patients face unique challenges in transition from disease-modifying treatments to those focused on palliation<sup>2,3</sup>
- Rural PC is associated with poorer symptom control, later referrals, and limited access to specialized care

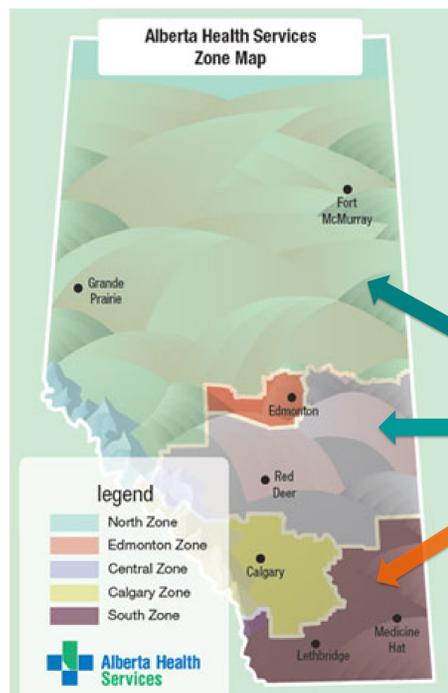
### PURPOSE

- To learn from rural Alberta patients and their families who are living with advanced cancer:
- how they perceive **early referral to PC**
  - how to improve **PC alongside cancer treatments**
  - how to make an appropriate **transition** from disease control- or cure-focused treatment to palliative-focused care

### METHODS

- Qualitative
- One-on-one interviews
- **Interpretive description** methodology<sup>4</sup> - systematic study and analysis of a phenomenon (integration of early PC), situated within a clinical context while considering the social, political, ideological complexities
- Thematic analysis - **Charmazian Grounded Theory** method of constant comparative analysis<sup>5</sup>

### Interviews



### THEMES, SUBTHEMES AND FINDINGS

#### Meaning of PC

- Misperceptions of PC
- Realisation that current care is palliative care

Much **uncertainty** about PC as a treatment option. Often perceived as EOL care.

*"...when I hear 'palliative,' I just think of someone laying in a bed and dying. And, because I'm not there, I – I just assume I don't need palliative care."*

#### Benefits of PC

- Benefits, e.g., peace of mind

PC contributed to **peace of mind**, knowing that care would be available when it was needed.

*"...it was really nice to know that she would see me at any time...and that the services are available to us and that we were aware of them."*

#### Introducing PC

- How?
- Who?
- When?
- Where to get additional information?

Want PC to be introduced **'at the beginning,'** after first assessing patient **readiness**. Want information delivered in a straightforward manner.

*"...the sooner, the better."  
"Right away, as soon as the person has been told."*

#### Health care system characteristics

- Interdisciplinary team
- Role clarity
- Home care
- Critical services needed

Communication between clinicians and **role clarity** is important.

**Home care, nurse/patient navigators and satellite cancer clinics** were identified as critical services. **Support groups** for patients and caregivers are crucial but lacking.

#### Patient/caregiver characteristics

- Advocating for health care
- Challenges with advanced cancer
- Challenges living in rural Alberta

Rural patients experience increased cost and stress of travelling distances for care.

*"I'd probably have to move closer to the clinic. Or the hospital. And uh, money wise it would cost lots more because living in town is a lot more than it is here."*

### RECOMMENDATIONS

- Health care providers should be **upfront**, providing patients/families with a clear explanation of PC, what services are available, and why PC is the most appropriate care.
  - Oncologists are key facilitators of PC introduction
  - **Distinction between PC and EOL care** should be made clear
  - Early referral to PC is viewed as advantageous
- More study is needed to identify the travel distance challenges for each community and Zone
- **Streamlining** treatment strategies, telehealth and moving care to the patient may provide system efficiencies
- **Financial resources** should be made available to patients/families living with advanced cancer in rural Alberta
- Main and satellite Community Cancer Centers should provide **support groups** for patients/families
- Expanding the **nurse navigator role** to cover all rural and urban areas should be considered
- Increasing **home care resources** in rural Alberta is critical in supporting the PC needs of patients and caregivers in their communities

### ACKNOWLEDGEMENTS

- The patients and caregivers who willingly gave their time to participate in this study
- The Community Cancer Center clinicians and home care nurses who assisted with recruitment

### REFERENCES

- <sup>1</sup>Sinnarajah A, Murray A, Wu J. Palliative care & resource use at end of life in cancer patients. Unpublished work 2015.
- <sup>2</sup>Duggleby WD, Penz K, Leipert BD, et al. 'I am part of the community but...' The changing context of rural living for persons with advanced cancer and their families. Rural Remote Health 2011;11:1733.
- <sup>3</sup>Kirby S, Barlow V, Saurman E, et al. Are rural and remote patients, families and caregivers needs in life-limiting illness different from those of urban dwellers? A narrative synthesis of the evidence. Aust J Rural Health 2016;24:289-299.
- <sup>4</sup>Thorne SE. (2008). *Interpretive Description*. California: Left Coast Press.
- <sup>5</sup>Charmaz K. (2014). *Constructing Grounded Theory* (2<sup>nd</sup> ed.). Thousand Oaks, California: Sage.