Assessing Patient and Caregiver Preferences for Early Palliative Care Delivery in Rural Alberta

An Interpretive Descriptive Study in an Advanced Cancer Context

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BACKGROUND

• Early palliative care (PC) addresses end-of-life (EOL) and improves outcomes1
• Early access to PC leads to how to make an appropriate planning/decision making and care coordination
• Rural patients face unique challenges in transition from disease-modifying treatments to those focused on palliation2,3
• Rural PC is associated with poorer symptom control, later referrals, and limited access to specialized care

OBJECTIVE

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METHODS

• Qualitative
• One-on-one interviews
• Interciseptive methodology4 - 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 analysis5

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

• Interviews with patients and caregivers

RESULTS

• Misperceptions of PC • Realisation that current care is palliative care
• Benefits, e.g., peace of mind
• How? • Who? • When? • Where to get additional information?

Themes, Subthemes and Findings

Meaning of PC

Benefits of PC

Introducing PC

Health care system characteristics

Patient/caregiver characteristics

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.

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

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REFERENCES