

# Patient and Caregiver Experiences Living with Advanced Colorectal Cancer in Alberta: A Qualitative Study



**PaCES**  
PALLIATIVE CARE EARLY AND SYSTEMATIC

S. Ahmed, F. Naqvi, A. Sinnarajah, G. McGhan, MJ. Santana



University of Calgary

**INTRODUCTION**

Patients living with advanced cancer and their families often face increased psychological distress, with difficulties adjusting to their illness and coping with treatment and/or symptoms.<sup>1</sup>

Palliative care is an approach to care that improves the quality of life of patients and families through the treatment of pain and attending to physical, psychosocial, and spiritual needs.<sup>2</sup> National guidelines recommend the integration of early palliative care in cancer care to provide supportive care to patients and families.<sup>2</sup>

However, across Canada, delivery of palliative care is inconsistent due to lack of standardized care.<sup>3</sup>

**OBJECTIVE**

This study aims to incorporate the experiences of patients living with advanced colorectal cancer and family caregivers, to inform the refinement of the early palliative care pathway for advanced cancer care.

**METHOD**

Qualitative study using semi-structured telephone interviews with 15 patients and 7 caregivers from Calgary and Edmonton.

Interview guide was developed in collaboration with patient and family research partners.

Thematic content analysis, supported by Nvivo software, with deductive and inductive coding strategies.

The Patient Centred Care Framework was utilized to guide the analysis & identify whether care delivered to participants was patient centred.<sup>4</sup>

## Patients and Caregivers identified gaps in current advanced cancer care: poor communication of diagnosis, confusion regarding palliative care, and variation in level of trust in Family Physicians

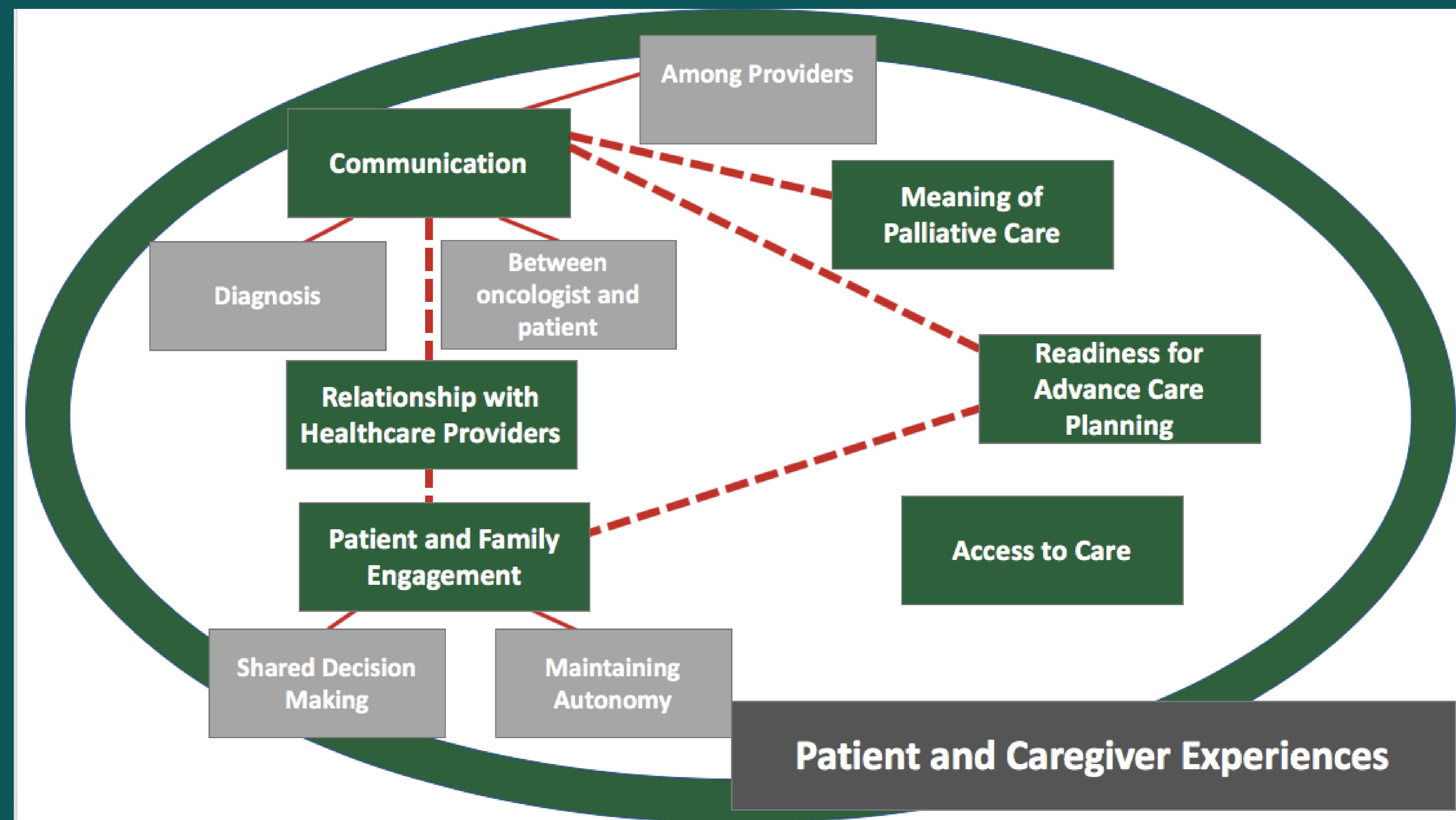


Figure 1. Main themes identified shaping Patient and Caregiver Experiences

References:  
 1. Kotronoulas G, Papadopoulou C, Burns-Cunningham K, Simpson M, Maguire R. A systematic review of the supportive care needs of people living with and beyond cancer of the colon and/or rectum. *European Journal of Oncology Nursing*. 2017;29:60-70.  
 2. Ferrell BR, Temel JS, Temin S, Smith TJ. Integration of Palliative Care Into Standard Oncology Care: ASCO Clinical Practice Guideline Update Summary. *Journal of oncology practice*. 2017;13(2):119.  
 3. Carstairs S. Raising the bar: A roadmap for the future of palliative care in Canada. Senate of Canada; 2010.  
 4. Santana MJ, Manalili K, Jolley RJ, Zelinsky S, Quan H, Lu M. How to practice person-centred care: A conceptual framework. *Health Expectations*. 2018;21(2):429-40.

**FINDINGS**

**Communication of Diagnosis:**

*"I was very very flabbergasted, I had a colonoscopy. There were 5 of us at the hospital ... in a circle sitting on our beds. And he pointed to each of us and say 'you have cancer... you don't have cancer... That's how we were told.'"* (Patient L)

**Confusion regarding Palliative Care:**

*"I think the oncologist even used the term 'palliative' in one of the initial meetings that we had with him which I found very confusing because I didn't think we were talking about end of life"* (Caregiver A)

**Patient Engagement in Care**

*"I just write down questions, related questions that don't take up a lot of their time ... because it makes me feel like a participant in my care so it feels like I have some kind of control"* (Patient C)

*"I think there just needs to be more attention paid to you know when patients are telling them things too in terms of pain ... that seems to be something that would need attention and yet it doesn't seem to."* (Caregiver B)

**DISCUSSION**

Improvement in the delivery of information to patients and families should be considered: especially in communication of diagnosis, delivery of palliative care and advance care planning information.

Improved engagement of family doctor in cancer care can enable better communication with patients, families, and cancer team.

Aspects of patient-centred care identified by patients and caregivers will inform the refinement of an early palliative care pathway for advanced cancer care.