



Patient and Caregiver Experiences of Living with Advanced Colorectal Cancer in Alberta

A qualitative Study

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Team Acknowledgements



PaCES team that supported funding, recruitment and feedback on study design: Kate Hardegger, Shireen Kassam, Patricia Biondo, Jessica Simon, Aynharan Sinnarajah, Crystal Beaumont

And Patient and Family Partners: Sandra Zelinsky, Alice Campbell, Karen Leaman, and Nicole McKenzie.



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Disclosures

No conflicts of interest to disclose

Funding:

- Alberta SPOR 2018 Graduate Studentship (jointly funded by Alberta Innovates and Canadian Institute of Health Research)
- Cumming School of Medicine, University of Calgary

BACKGROUND

Palliative care is an approach that improves the quality of life of patients and their families facing challenges associated with life-threatening illness, such as treatment of pain and attending to physical, psychosocial, and spiritual needs¹



Most people in Alberta who received palliative care, received it late (within the last three months of life)²

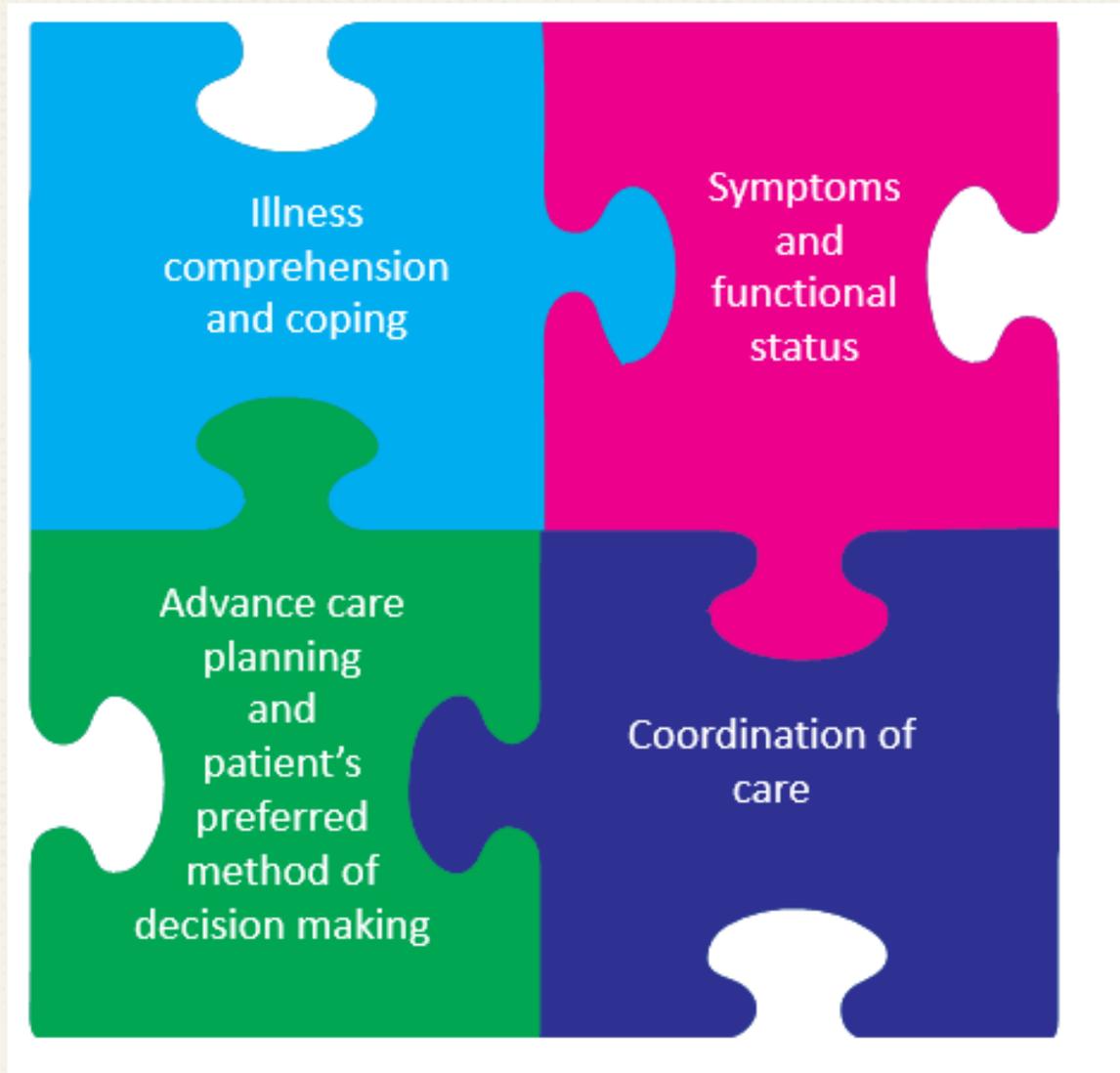
Overall Aim

This study aims to understand patient and caregiver experiences of living with advanced colorectal cancer care to inform the refinement of an early palliative care pathway for patients with advanced colorectal cancer.

Research Questions

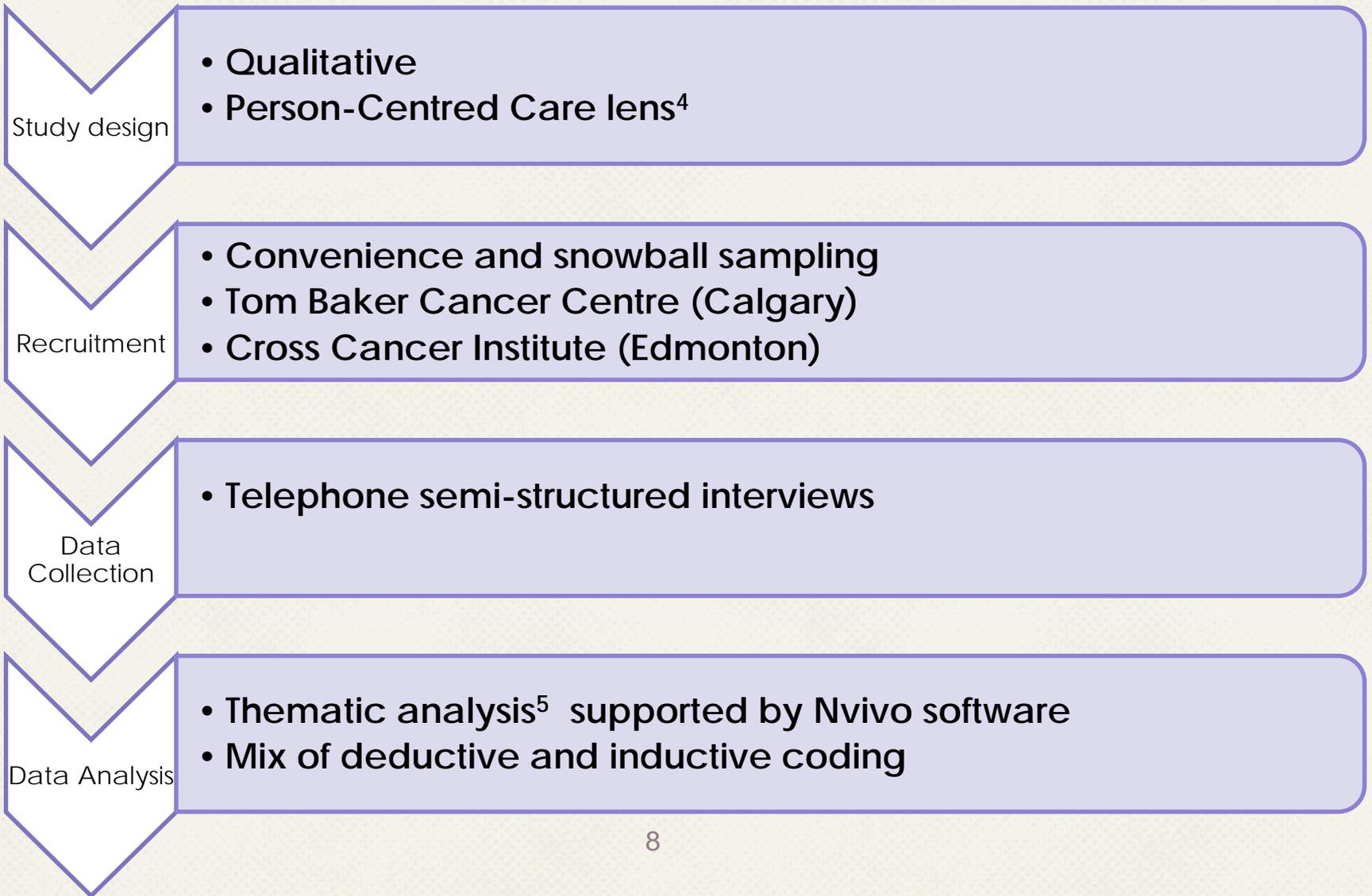
1. What are the experiences of patients living with advanced colorectal cancer and family caregivers while receiving cancer care?
2. What are the perceptions of patients and family caregivers regarding palliative care and advanced care planning?
3. How do the experiences and perceptions of participants during current standard care compare to the experiences and perceptions of participants experiencing the care pathway?

PaCES pathway



Four Essential Components to an Early Palliative Approach to Care³

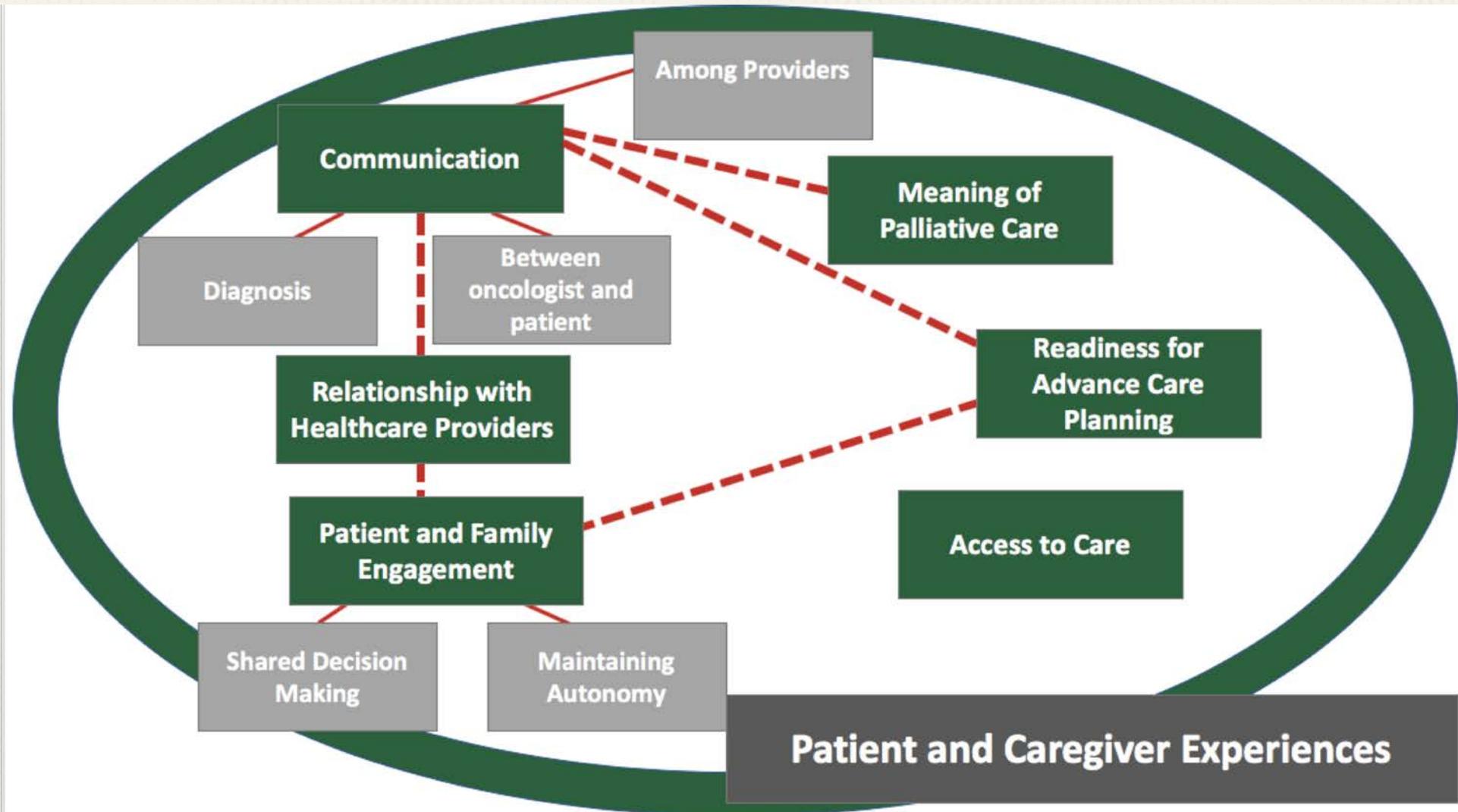
Methods



Demographic Characteristics

- 15 patients with advanced colorectal cancer & 7 family caregivers (9 from Calgary, 13 from Edmonton)
 - 13 women, 9 men (age range 43-72)
 - Three dyads
 - All patients living at home
 - None of the patients had been referred to a palliative care specialist

Findings: Themes



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)

Findings: Themes

Theme 2: Meaning of Palliative Care

- **Views on the term Palliative Care**

 - association with end of life, death

 - view as ongoing care (n=2)

 - unsure what palliative care is (n=3)

- **Information about Palliative Care**

 - palliative care mentioned at initial meeting with oncologist (n=5)

 - Most participants did not consider themselves to be receiving palliative care services

- **Time for Palliative Care Discussions**

 - need for discussions to be personalized to the individuals

Communication regarding Diagnosis



I was very very flabbergasted, I had a colonoscopy. There were 5 of us at the hospital and we all seemed to come awake at the same time. And there was a ... I don't know if he was a doctor or what he was, but we were kind of in a circle sitting on our beds. And he pointed to each of us and say 'you have cancer... you don't have cancer... you have cancer ... you don't have cancer'. That's how we were told. (Patient L)

Findings: Themes

Theme 3: Communication

- **Communication of Diagnosis**
poorly communicated (n=8)
- **Communication between patient and oncologist**
improvement over time
source of information
- **Communication amongst providers**
lack of coordination of care (poor communication between departments) (n=5)

Relationship with Oncologist



I think we work together really well. I think that he, I mean it's obviously his knowledge and I go with , I have faith in him so I go with his recommendations and but he makes me fully understand what those recommendations are. So, you know I feel as much in control of my future as I can.

(Patient G)

Role of the Family doctor



it's sort of a specialized care and once he knows for sure that we're in the right hands there's really not much that he can do that a specialist couldn't do sort of thing so you know he'd be the one to sort of adjust medications or add or take away depending on you know what's happening with general health but as far as cancer treatments well the person who sits in the driver's seat is the oncologist (Caregiver E)

Findings: Themes

Theme 4: Relationship with Healthcare Provider

- **Relationship with oncologist**
 - Trust in Physician (for treatment planning, answering questions)
 - preference for a small care team
- **Relationship with Family doctor**
 - Mixed responses (poor level of trust due to late diagnosis)
 - Mixed responses on preference for involvement in cancer care
- **Relationship with other Healthcare Professionals**
 - Provision of emotional and physical support (naturopath, therapist, nurses)

Patient Engagement in Care



I use different sources I talk to doctors I am always asking questions, I am taking the time to go to different websites to try and find different clinical studies and I have done a lot of different types of research (Patient 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...I remember when they first offered me chemo ...and it seemed irregular as to why they were offering it to me ...and I said I think I will say no because I don't want it because I was gonna lose my hair and hands and I didn't want to lose my hands because I would lose my independence and my life would change drastically. So I turned it down but felt power that I turned it down and had made a big decision (Patient C)

Findings: Themes

Theme 5: Patient and Family Engagement in Care

- **Importance of maintaining autonomy**
- **Shared Decision Making**
 - Some participants felt part of the care team & felt the care team valued their suggestions and questions
 - Some participants felt not being taken seriously at different points of their care

Discussions about Advance Care Planning



“I just know that with my husband. He doesn't want to talk about it with me I think it needs to be talked about and it's very hard for me to have a conversation with him about it ...I'm a planner and he's not and it's a very hard subject to approach him on. He knows, he knows that he is gonna die at some time but then we all are it's just a matter of when”(Caregiver D)

Findings: Themes

Theme 6: Readiness for Advance Care Planning

ACP discussions necessary

ACP should be discussed with patient when they are ready, patient should be the one making the decisions (need for discussions to be personalized to the individuals)

Varying preferences for when ACP discussions should take place

Discussion

- Improvement needed in the delivery of palliative care information
- Improvement in how diagnosis is communicated
- Involvement of the family doctor (enable better communication with patients and oncologists)
- Continued engagement of patient and families in their care
 - Need for personalized care

Future Directions

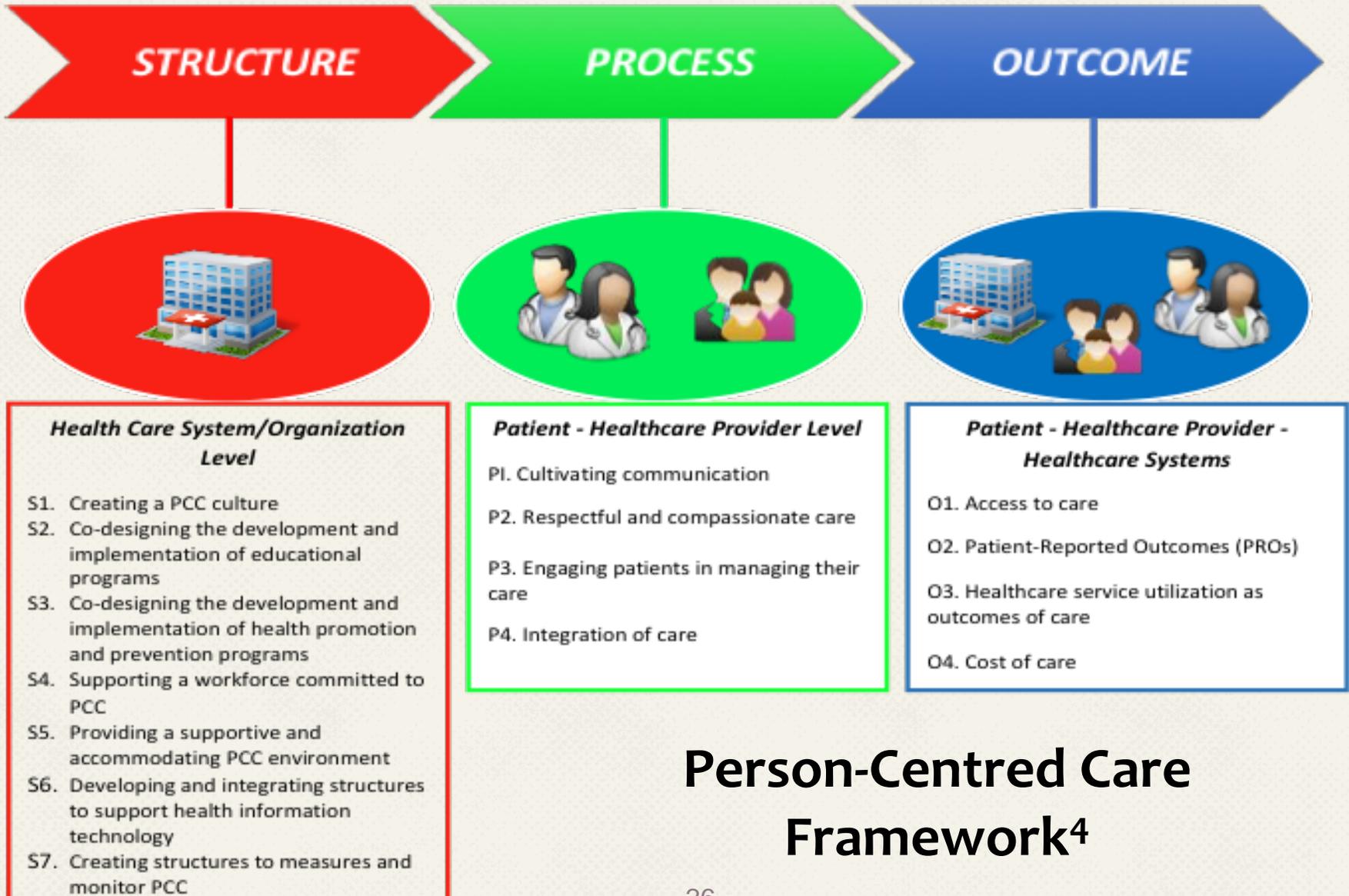
PaCES Implementation of Early Palliative Care Pathway (Jan 2019)

- Interviewing patients and family caregivers experiencing the early palliative care pathway

References

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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.
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Conceptual Framework



Person-Centred Care Framework⁴

Findings: Themes

Theme 1: Access to Care

- **Cost of care**
 - patient and family time off work
 - supplements and alternative treatments
- **Proximity to care**
 - Preference for different services to be spatially close (lab services, Cancer Centre, and other supports (therapist) all in different places)
- **After hours care**
 - Most participants know who to call after hours
 - Most participants relied on accessing emergency care after hours

Patient Engagement in Care



I think there just needs to be more attention paid to you know when patients are telling them things to in terms of pain that's a 9/10 or a 10/10 like that seems to be something that would need attention and yet it doesn't seem to. (Caregiver B)