



Patient and Caregiver Experiences Informing an Early Palliative Care Pathway

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Background

- Palliative care is patient and family centred care that improves the quality of life of patients and their families facing challenges associated with life-threatening illness¹
 - Symptom relief
- In Alberta, the delivery of palliative care is inconsistent with many late palliative care referrals associated with 'aggressive end of life' care^{2,3}

Background

- Early Palliative Care is recommended by national and international organizations^{4,5}
 - Benefits: improved quality of life, symptom management, reduced family distress, reduced healthcare costs⁶
- In Alberta, the PaCES⁷ team developed an early palliative care pathway for advanced colorectal cancer patients

Aim

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

Methods



- Qualitative and patient-oriented study design
- Participants were recruited with the support of research team and specialist palliative care nurse in person and over the phone and followed up by a researcher after consent to contact was given

Methods



- Semi-structured telephone interviews with patients living with advanced colorectal cancer and family caregivers were conducted before and after implementation of the early palliative care pathway
- Interviews were transcribed, and the data thematically analyzed supported by the qualitative analysis software, Nvivo, using a person-centred care framework to guide analysis of the findings

Stage 1 - Findings

Prior to
implementing the
early palliative
approach to care

(May-November
2018)

- 15 patients, 7 family caregivers (all spouses)

9 were from Calgary, 13 from Edmonton

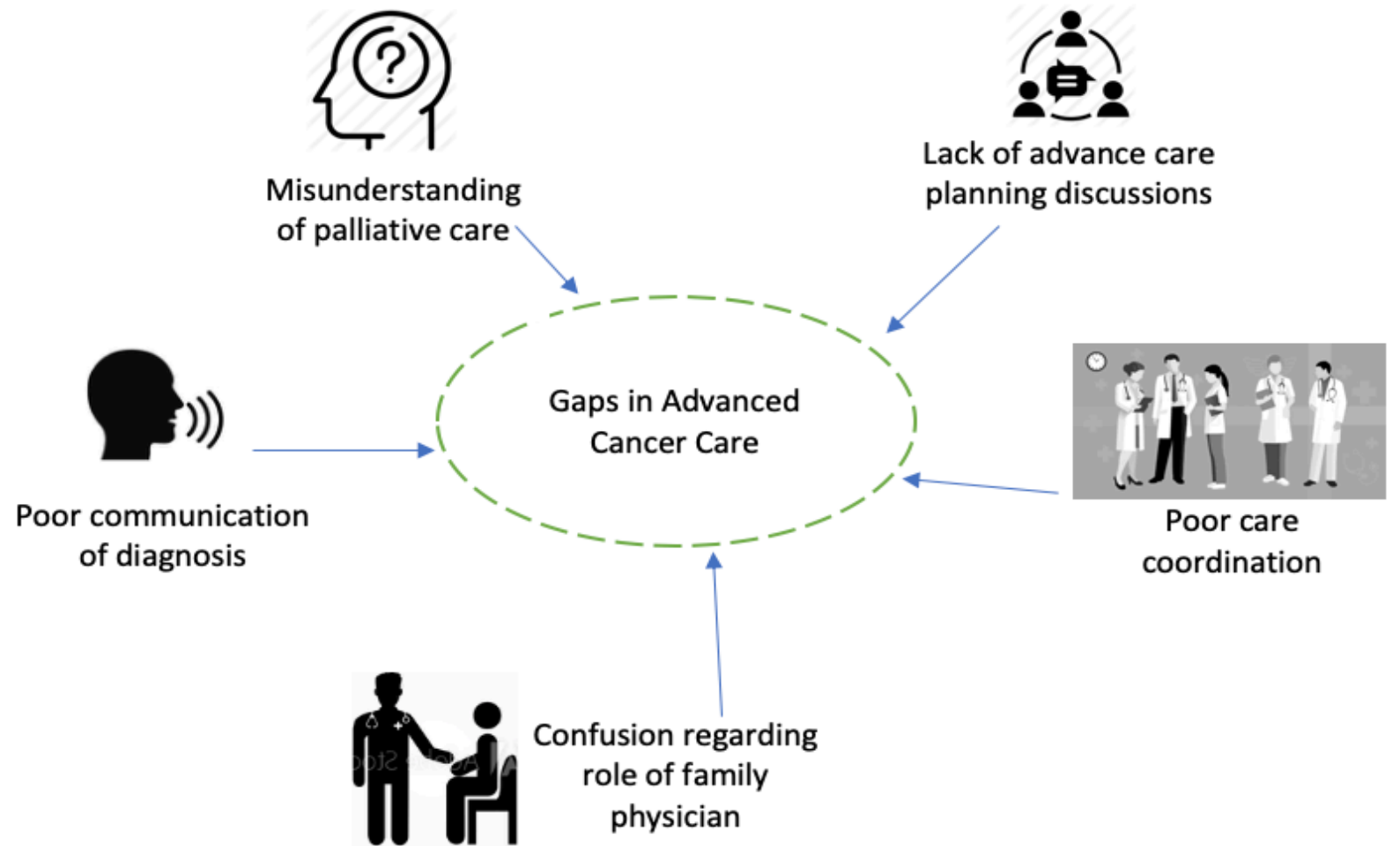
3 dyad interviews

men and women participants (13 women, nine men) whose ages ranged from 43-72

All patients were living at home at the time of the interview, and none of them had been referred to a palliative care specialist or palliative homecare

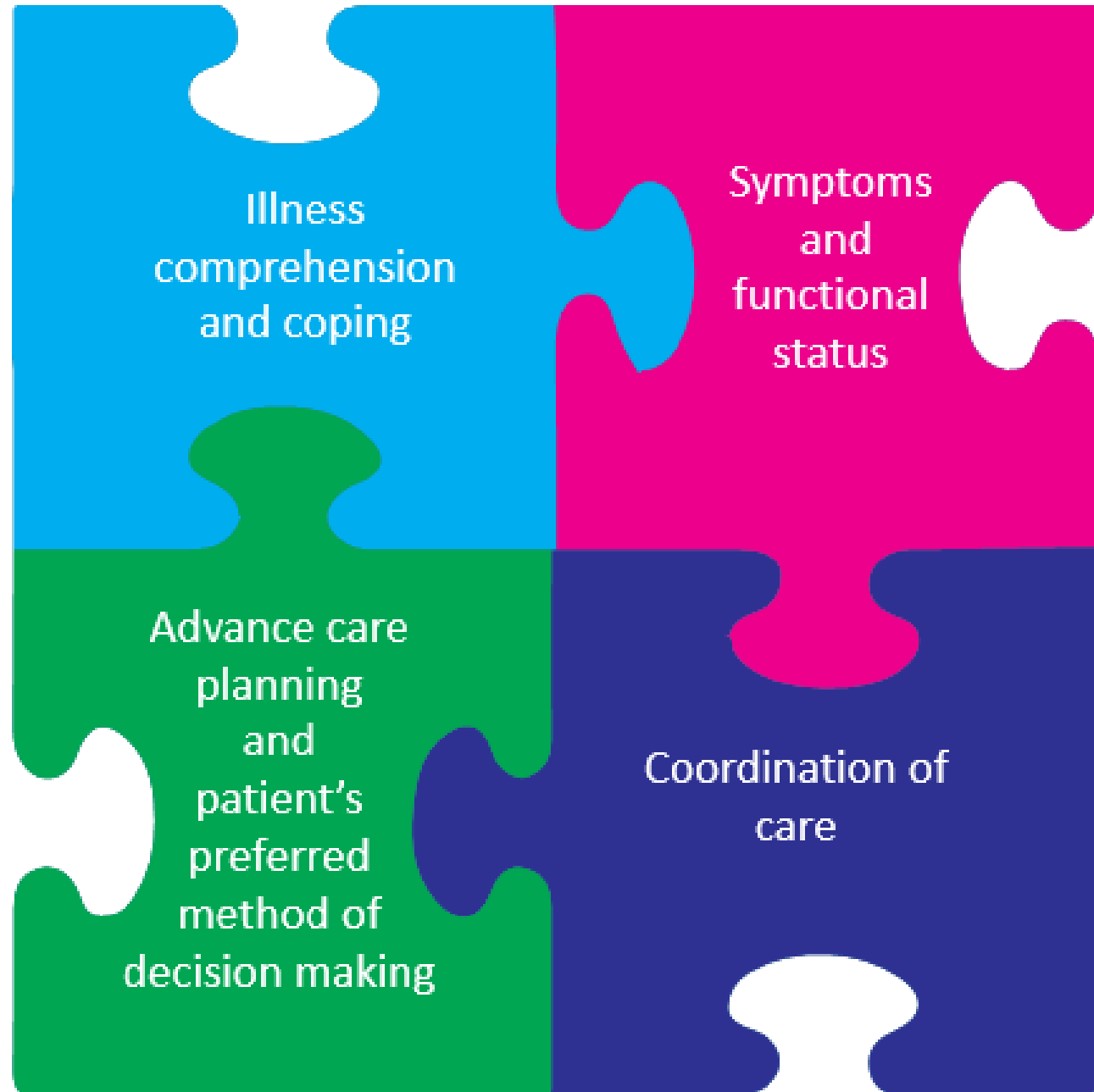
Stage 1 - Findings

Prior to implementing the early palliative approach to care



Gaps identified by patients and family caregivers in advanced cancer care

Four Essential Components to an Early Palliative Approach to Care



Stage 2 -Findings

After
implementing the
early palliative
approach to care

(September 2019
to February 2020)

- 7 patients and 5 family caregivers from Calgary
 - 2 dyad interviews
 - 8 women, 4 men whose ages ranged from 36-86
 - All patients were living at home at the time of the interview
 - At the time of the interview, patients reported having received palliative care support from one month to 12 months

Care Coordination

| Subtheme | Quotations |
|---|--|
| Communication between healthcare providers (PC Nurse, Oncology team, and FP) | “everybody is involved and everyone seems to know what’s going on- like all three branches- the RN who visits her at home or calls her, or the Tom Baker Centre, or the GP. So that seems to be working well” (Caregiver 2) |
| | “I think later on when we spoke with the palliative homecare team they would get in touch with the doctor- for instance to make something happen. That they knew medical oncologist would have the best chance at making it happen. They were able to intervene in the system and make something happen which we could never do. We were very grateful, so I guess it worked there for them to talk to one another.” (Caregiver 3) |
| | Suggestion for improvement: “Some way to represent how the services plug into each other and where the boundaries are of the services - cause that’s probably one thing that’s a little bit confusing. We would be offered a service from one part of the organization and it would be referred to another part ...full time caregiving at times is stressful, and these folks are busy so playing the telephone tag and messaging, it gets - it adds a little bit of stress to the home environment.” (Caregiver 5) |

Care Coordination

| Subtheme | Quotations |
|--|---|
| Role of Family Physician | “_____ was happy to have the GP in her team because the GP was able to provide a far more general, holistic, common sense sort of perspective in the landscape as opposed to a specialist....GP that we had- excellent in that regard, great emotional support and a great help in providing comfort and advice on how to proceed and how to make a decision.” (Caregiver 3) |
| Relationship with Palliative Care Nurse | <p>she just really wants to see how I’m doing and make sure that I’m right on track with what they’re offering me and it’s been working out really really well. She’s also a really great conduit to all the other people because you know if I have to go call the clinic, If I have to dial into clinic and get answers and help, It can always get into a giant game of telephone you know what I mean?” (Patient 6)</p> <p>“she’s very experienced in what she does, you know quite organized...she came very well prepared, considering what the situation was and what we’re dealing with. And then just listened and asked some really probing questions about where we are at physically and psychologically, our home design, are we set up, and she had a bit of a checklist and pamphlet that gave us more information that we could follow- it wasn’t a one time sales pitch, it was delivered with kindness and empathy and well thought out conversation” (Caregiver 5)</p> |

Perception of Palliative Care and Advance Care Planning

| Subtheme | Quotations |
|--|---|
| Timing of Palliative Care | "i think the earlier the better. Even though there's some stigma associated with it....For myself and my wife , the sooner we understood what was happening and what services were available, it gave us a piece of mind and it didn't diminish the hope for best quality of life and what's ahead. It did give us a chance to be a bit more prepared in our minds of what to expect" (Caregiver 5) |
| | "I'm very grateful that there are people to help if you need the help, but I also feel that I don't want to waste anyone's time by... you know, feeling that they have to do anything for me when I don't need it." (Patient 4) |
| Meaning of Palliative Care | "Mostly just supporting with symptoms so that the life you're living is a good life...I did initially think end of life when I was referred to them, but they've since explained that it's during life not just ending of life." (Patient 2) |
| Advance Care Planning Discussions | "She's very good at being- she's frank but kind, and has no problem with having these kind of conversations whatsoever, she seems very good at it which is a huge comfort ...we'd rather have it on the table and be aware of what is available to us and what else we might need." (Patient 6) |

Coping with Advanced Cancer

| Subtheme | Quotations |
|---|--|
| Support from healthcare system/care team | <p>“when I was on the pills, I found quite reassuring that the pharmacist would call and see how you’re doing on the medication and give you some, you know, things weren’t working quite right? They would give me some ideas, and that’s very reassuring. In spite of having kids and friends and that, it’s a lone journey.” (Patient 5)</p> <p>“I met with her at the beginning just to make sure that my...financially I was able to handle this. And she supported with some of the paperwork required for my disability and had the doctor fill it out on my behalf and submitted it. It just took a little bit of the coordination away from me, which was helpful.” (Patient 2)</p> |
| Value in Independence | <p>“I don’t feel I need anything...I just love cutting my own grass. Cooking, my wife and I do the cooking, the washing up, everything, I don’t feel that I am at that stage yet that I need any homecare, I do not need any. My wife and I do everything that needs to be done, without a struggle, or that it’s difficult for us to do- we just do it as we always have.” (Patient 4)</p> |

Patient and Family Engagement

| Subtheme | Quotations |
|---|---|
| Taking initiative and being informed | “We had to make decisions and decide for ourselves whether things that were recommended to us were right or not and then if we felt that the option wasn’t right we always investigated further or figured out what to do ourselves. So it was important to us to have that advice and support” (Caregiver 3) |
| Patient Advocacy | “You know if there was one thing that could be added on is the you know for somebody who doesn’t have that kind of support- some kind of patient advocate being assigned to somebody who doesn’t have that kind of support. I think it’s really important for them not to go to the appointment by themselves” (Caregiver 2) |
| Use of PPF checklist to communicate with care team | Suggestion: “it’s easier for us- because we can translate for our mom but maybe with other families it would be difficult- because it’s all in English, so offering it in other languages that might be easier. To me, I don’t think if people understand or have a translator, they’re less likely to complete things” (Caregiver 4) |

Stage 2 -Findings

After
implementing the
early palliative
approach to care

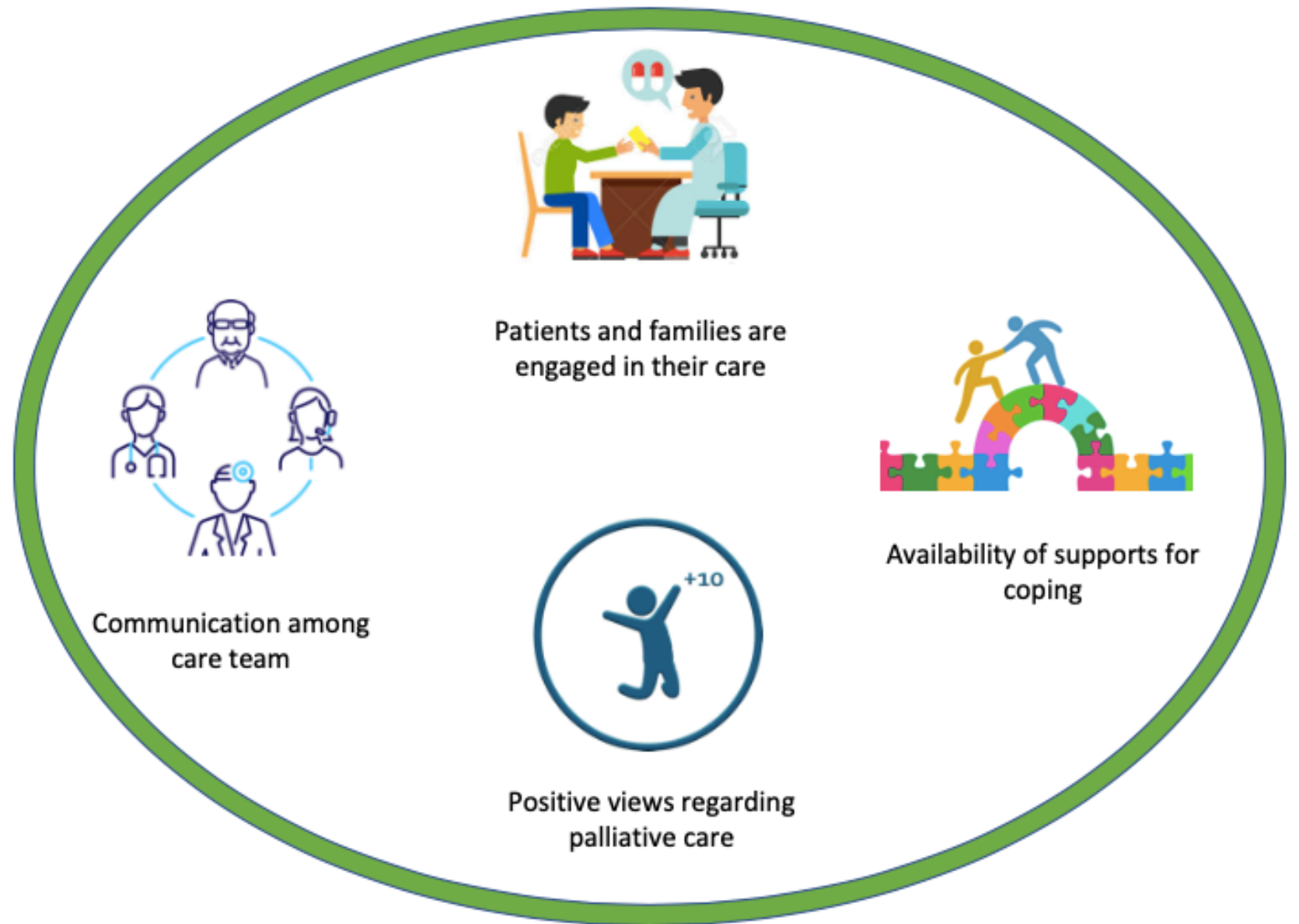


Figure 1. Patient and Family Caregiver experiences after receiving early palliative care

Comparing Findings from Stage 2 to Stage 1

- Improved understanding of Palliative Care
- Improvement of Care Coordination
 - Patient-centred relationship with early PC nurse
- Increased Involvement of the Family Physician
- Advance Care Planning Discussions

Discussion

- Early palliative care helped to provide cancer care that is patient-centred
 - Good care coordination (communication, and involvement of family physician)
 - Trusting relationship with the palliative care nurse
- Palliative care support should be provided early in the cancer journey
 - Most participants found early palliative care to be beneficial and supportive during this time. Most participants viewed the term palliative care to mean a broad, holistic care that improves quality of life
- Areas of improvement: public perception of palliative care , supporting patient preferences at end of life (care coordination during patient's last day)

Conclusions

- First study in Alberta exploring the experiences of an early palliative care pathway from the perspectives of patients and families
- Study findings are being used to inform the pathway, and further implementation in the rest of Alberta, as well as expansion into other cancers

Acknowledgements

Supervisor: Dr. Maria Santana

Committee members: Drs. Aynharan Sinnarajah and Gwen McGhan

PaCES team: Dr. Patricia Biondo, Dr. Jessica Simon, Janet Vandale, Shireen Kassam, Crystal Beaumont

Patient and Family Advisors: Alice Campbell, Karen Leaman, Janet Bennett, & Nicole McKenzie

Person Centred Care Team: Farwa Naqvi, Sandra Zelinsky, Dr. Paul Fairie, Kimberly Manalili, Kyle Kemp

PCC Framework

