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Patient and Caregiver Experiences Living with Advanced Colorectal Cancer & Receiving Early Palliative Care in Alberta

Ahmed, Sadia

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Patient and Caregiver Experiences Living with Advanced Colorectal Cancer & Receiving
Early Palliative Care in Alberta

by

Sadia Ahmed

A THESIS
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Thesis Abstract

Background: Palliative care is patient centred care that improves the quality of life of patients and families facing challenges associated with life-threatening illness. In Alberta, most people who received palliative care received it late, impacting their quality of life. An early palliative care pathway that incorporates patient and caregiver experiences is needed to ensure that priorities of patients living with advanced cancer care are at the forefront of quality care.

Overall aim: This study aims to understand patient and caregiver experiences of advanced colorectal cancer care and receiving early palliative care to inform development and refinement of an early palliative care pathway for patients with advanced colorectal cancer.

Methods: This is a qualitative study that is embedded within a larger program of research on the implementation of the Palliative Care Early and Systematic (PaCES- a province-wide project aimed at developing and delivering an early and systematic palliative care pathway for advanced colorectal cancer patients and their caregivers in Alberta) intervention. We conducted telephone interviews with patients living with advanced colorectal cancer and family caregivers to understand their experiences before implementing the early palliative care pathway (standard cancer care) and after the implementation of the palliative care pathway. Patients and caregivers were recruited with the help of clinician-research team members in Calgary and Edmonton. Data was thematically analyzed using deductive, inductive, and iterative coding strategies.

Findings: Gaps in standard oncology care included poor care coordination, misunderstanding of palliative care, confusion regarding role of family physician, and lack of advance care planning discussions. Four main themes shaped participants' experience of early palliative care: care coordination, perception of palliative care, coping with advanced cancer, and patient and family engagement. Main differences before and after implementation of the care pathway were in care coordination and communication with and among healthcare providers, understanding of palliative care, involvement of the family physician, and advance care planning discussions.

Conclusions: Early palliative care delivered by a specialist palliative care nurse can improve advanced cancer care. The early palliative care pathway seeks to implement a standardized pathway that can be implemented across Alberta (including urban and rural settings), to guide routine advanced cancer care.

Keywords: early palliative care, patient centred care, patient-oriented research, advanced cancer care

Preface

This is a paper-based thesis including a chapter on the introduction to the thesis, and literature review (Chapter 1). Chapter 2 describes the methods and approaches, chapters 3 and 4 are manuscripts prepared for submission (see below). Chapter 5 is a discussion of the thesis and conclusions. The following two manuscripts have been prepared for submission:

Chapter 3 (paper one)

Ahmed S, Naqvi F, Sinnarajah A, McGhan G, Simon J, Santana MJ. Understanding Patient and Caregiver Experiences of Advanced Cancer Care in Alberta: A Qualitative Study. *In progress*

Chapter 4 (paper two)

Ahmed S, Naqvi F, Sinnarajah A, McGhan G, Simon J, Santana MJ. Patient and Caregiver Experiences Informing an Early Palliative Care Pathway. *In progress*

Author Contributions

AS, JS, and MS conceived and designed study, with input from SA. SA conducted all the interviews and worked with SFN on the analysis and interpretation of findings, with feedback from AS, JS, GM, and MS. SA wrote both articles, and all authors (SFN, AS, GM, JS, and MS) provided critical feedback and approved the version to be published.

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CHAPTER 1: INTRODUCTION

1.1 Overview of Thesis

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.(1) Following an advanced cancer diagnosis of a loved one, family members are also affected, and they often experience symptoms of anxiety, sadness, and depression.(2, 3) As a model, patient centred care emphasizes the needs, preferences, and values of patients to provide care.(4, 5) Palliative care has been defined as patient and family centred care that improves quality of life and addresses physical, emotional, social, and spiritual needs of patients.(6) Palliative care is patient and family centred care, and aims to facilitate patient autonomy, access to information and choice.(7, 8) However in Alberta, most people who received palliative care, received it late (within last 3 months of life).(9) A palliative approach to care is recommended to provide optimal symptom relief.(7, 10-12) An early palliative approach to care is recommended for patients, implemented at the time of, or shortly after diagnosis.(13) Late palliative care has been associated with negative patient and caregiver experiences, greater emotional distress, and decreased quality of life.(14) Whereas, early palliative care has been associated with improved quality of life of patients, improved advance care planning, patient and family satisfaction, as well as lower healthcare utilization.(13, 15, 16) Moreover, family caregivers have also been found to benefit from early palliative care, with a decrease in depressive symptoms,(17-19) stress burden,(19) and improvement in social functioning.(18)

Across Canada and within Alberta, delivery of palliative care is inconsistent due to lack of standardized care.(20, 21) The implementation of an early care pathway in palliative care can improve patient and caregiver quality of life, improve symptom burdens, attend to needs of patients and families, and reduce healthcare costs. Additionally, incorporating patient perspectives in the implementation of

care pathways can ensure the priorities of patients and families are at the forefront of care. There is a need for early palliative care pathways to be part of routine advanced cancer care, to ensure patients and families are receiving adequate support to meet their needs.

The Palliative Care Early and Systematic (PaCES) team in Alberta developed an early palliative care pathway for advanced cancer care.⁽¹⁰⁾ This study aims to understand patient and caregiver experiences of advanced colorectal cancer care and receiving early palliative care to inform the development and refinement of an early palliative care pathway for patients with advanced colorectal cancer. The specific research questions were:

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 early palliative care and advance care planning?
3. How do the experiences and perceptions of participants during current standard cancer care compare to the experiences and perceptions of participants experiencing the early palliative care pathway?

The objectives are to capture patient and family caregiver experiences with advanced colorectal cancer care and receiving early palliative care. These objectives were addressed through two stages: the first qualitative study (chapter 3) informs the development of the early palliative care pathway by identifying gaps in current cancer care. The second qualitative study (chapter 4) informs the refinement of the care pathway by identifying elements of early palliative care that mattered most to patients and family caregivers. Additionally, patient and family caregiver experiences before implementation of the early palliative care pathway were compared to participant experiences after implementation of the early palliative care pathway to inform elements of the early palliative care pathway that mattered most to patients and families.

Incorporating patient and family caregiver perspectives in the implementation of the early palliative care pathway will allow for the delivery of patient centred care. This study is patient and family caregiver informed, not only by incorporating patients and families as participants, but also including them as advisors in the study design and dissemination of the project.

1.2 Literature Review

A systematized review of the literature was conducted, due to time constraints. This type of review is typically conducted by graduate students, as we did not have two reviewers available.(22) Google Scholar was searched using terms such as advanced cancer care, colorectal cancer, and early palliative care. Only articles in English were selected from 2000 to date.

1.2.1 Burden of Advanced Cancer

Cancer is considered the leading cause of death in Canada.(23) In Alberta, 1 in 2 Albertans will develop cancer.(24) Colorectal cancer is the second most common type of cancer and 49% of colorectal cancers were diagnosed at an advanced stage in most provinces and territories.(23) In Alberta, there were 2,089 new cases of colorectal cancer, and 709 deaths due to the disease in 2016.(24) Patients with an advanced cancer diagnosis are those who have distant metastases, late stage cancer that is life-limiting and/or with a prognosis of 6 to 24 months.(7) Patients with advanced cancers often experience emotional distress, and have trouble coping with physical symptoms.(1, 25) Patients experience symptoms such as fatigue, pain, weakness, loss of appetite and lack of energy.(25) Patients with advanced cancers often undergo aggressive end of life care such as repeated hospitalizations, emergency department visits, and admission to the intensive care unit within last month of life.(26) Aggressive end of life care has been associated with lower quality of life for both patients and families in a number of studies.(27-29) Most advanced cancer patients prefer palliative treatments than life-extending care.(27)

1.2.2 Patient Centred Palliative Care

The Institute of Medicine in the 2001 Quality Chasm report highlight six aims for quality improvement, naming patient centred care as one of the priorities for quality care.(30) Patient centred care is defined as the provision of respectful and responsive care to patients, and also attending to individual patient preferences, needs and values.(30) Previous studies have found late referrals to palliative care services were inadequate for the provision of patient centred care.(31-33) For instance, in the study by Morita et al.,(31) family caregivers who reported late referrals to palliative care found they were not sufficiently prepared for managing care for their loved ones, especially as their loved one's condition changed. Family caregivers also reported insufficient communication about end of life care with physicians.(31) Additionally late referrals to palliative care affects patient preferences to die at home, as they are more likely to stay in hospital and die in hospital once admitted.(32, 33) Integrating patient centred care in healthcare systems has been noted to be a priority in many countries, to encourage responding to the needs of patients. Kvale & Bondevik(29) found patient centred concepts such as empowerment (being respected, listened to, given honest information, and being valued), shared decision making about disease treatment, and partnership in nursing care were priorities for patients with cancer. Palliative care that is patient centred was found to be the most beneficial for patients and families.(29, 34, 35) In one study interviewing family caregivers, participants reported experiencing patient centred care in community based palliative care, noting that care was accessible and largely responsive to patient needs.(34) Family caregivers mentioned that service providers were also responsive to their wishes and desires.(34) However in their study, participants responded that shared decision-making about treatment and ongoing management of care was lacking between patients and healthcare providers.(34)

1.2.3 Models of Palliative Care and Oncology

The four models when integrating oncology with palliative care are: time-based, provider-based, issue-based, and system-based, identified by Hui & Bruera.(36) The time-based model focuses on the

early timing of palliative care, with increasing involvement of palliative care teams as disease progresses.(36) From the time-based model, palliative care is integrated after cancer screening and diagnosis, and alongside active cancer treatment into hospice care.(36) This model is in accordance with current recommendations for the early integration of palliative care.(7) The provider-based model is based on the needs and complexity of the patient. Primary palliative care is provided by the oncology team until the patient needs become more complex, after which they can be referred to the palliative care team.(36) The application of the provider-based model can vary across different settings. For instance, in the Palliative and End of Life Alberta Provincial Framework, it is recommended that primary palliative care be delivered by interdisciplinary primary care providers including oncology, family practice, and home care teams.(37) Primary palliative care is defined as clinical management, care coordination, and referrals.(37) Another model identified by Hui & Bruera(36) is the issue-based model, which considers multiple medical concerns of patients, and is based on an integrated model of care including specialist providers to meet patient needs. The system-based model provides a pre-defined criterion to aid oncologists in referring patients to specialist palliative care services.(36) For instance, in Alberta, the Edmonton System Assessment Scale (ESAS) is completed by patients with cancer, at routine outpatient cancer clinic visits, to rate their symptoms on a scale of 0 (symptom not present) to 10 (worst possible severity).(38) Symptoms greater than 6 on the scale may provide an indication to the oncologist that specialist palliative care services are needed for management of those symptoms.(38) Models of palliative care can also be categorized into the following three categories: solo practice models, coordinated care/congress model, and integrated care model.(13) The solo practice model places responsibility on the oncologist to provide palliative care.(13) The coordinated/congress care model describes collaboration between the oncologist, nurses, and specialists for supportive/palliative care.(13) In the coordinated/congress model, the oncologist refers the patient to various specialists to provide aspects of palliative care.(36) For example, a patient having concerns with pain symptoms could be referred to the cancer pain clinic. A patient experiencing depression would be referred to a psychiatrist

or therapist, and if they had spiritual concerns, then the oncologist would refer the patient to the chaplain. The third category-the integrated care model refers to the routine referral of patients to early palliative care services provided by specialist palliative care teams.(13) Under this model, the oncologist may provide as much or as little palliative care, as a specialist palliative care team will be able to provide quality palliative care. Hui & Bruera(36) recommend the integrated care model as it ensures standard access to early palliative care concurrent with cancer care. Different cancer centres need to consider various factors when implementing a model including the size of the facility, availability of staff and resources, and patient needs.(38)

1.2.4 Defining Early Palliative Care

Early palliative care is defined as the integration of an early palliative approach into standard oncology care at the time of, or shortly after diagnosis.(13) Integrating a palliative approach to care means combining a palliative approach to care with disease-specific management.(39) Palliative care is an added layer of support throughout the disease trajectory.(39) Associations such as Choosing Wisely Canada(11) and the American Society of Clinical Oncology(7) recommend the integration of early palliative care services for advanced cancer care. Specifically, it is recommended that palliative care services should be delivered through interdisciplinary palliative care teams, and be delivered within eight weeks of diagnosis for advanced cancer patients.(7) In December 2018, Health Canada released a national framework for palliative care in consultation with stakeholders from all provinces and territories to guide a collective vision for palliative care in Canada.(40) In the report, early palliative care is also recommended, as well as research and the collection of data on palliative care.(40)

Within the literature, analyses of trials integrating an early palliative approach to standard oncology care have identified key elements of early palliative care.(7) For instance, the American Society of Clinical Oncology (ASCO) brought together an expert panel to update clinical guidelines based on a systematic review of the medical literature.(7) The ASCO recommendations outline the

following as essential components of palliative care: rapport and relationship building with patient and family caregivers, management of symptoms, distress, and functional status, understanding and education about illness and prognosis, clarifying treatment goals, assessing and supporting patients and families with coping needs, assisting with medical decision making, coordination with other care providers, and provision of referrals to other care providers as needed.(7) Temel et al.(41) utilized and adapted the ASCO guidelines in their palliative care trial for the ambulatory setting. In their trial, they along with the ASCO recommendations, included the following additional components for palliative care clinicians to follow: identifying care plans for future appointments, and noting new medications prescribed. Boucher et al.(42) utilize the term ‘best supportive care’, defined as treatments oriented towards palliation rather than cure, and are provider dependent. In their clinical checklist, the following domains are included: symptom management, assistance with decision making, illness comprehension, and care plan.(42) Within symptom management, addressing financial or legal concerns, and spiritual concerns is included.(42) The World Health Organization guidelines for comprehensive palliative care includes the following services: management of complications of treatment and the disease, management of pain and other symptoms, psychosocial care for patients and caregivers, spiritual understanding and approaches for patients and caregivers, care of the dying, and bereavement care.(43) In Alberta, the Palliative Care Early and Systematic (PaCES) team synthesized the literature to develop an early palliative care guideline into the following four components: illness comprehension and coping, symptoms and functional status, advance care planning and patient’s preferred method of decision making, and coordination of care.(39)

1.2.5 Early Palliative Care interventions

A 2016 systematic review of 43 randomized control trials implementing palliative care found palliative care was associated with improved quality of life of patients, reduced symptom burden, improved advance care planning, patient and family satisfaction, as well as lower healthcare

utilization.(16) More recently, a 2017 systematic review of seven randomised and cluster-randomised controlled trials compared effects of early palliative care interventions versus treatment as usual/standard cancer care on the following outcomes: health-related quality of life, depression, symptom intensity, and survival among adults with a diagnosis of advanced cancer.(13) Early palliative care is still a relatively new, emerging field, and therefore conclusions about its benefits can be made once more studies have been conducted. From the studies included, patients receiving early palliative care had significantly higher quality of life than those receiving usual cancer care.(13) Additionally, patients receiving early palliative care had significantly lower symptom intensity than those patients receiving usual cancer care.(13) However, effects on depression and mortality were uncertain.(13) Levels of depressive symptoms for those receiving early palliative care did not differ significantly from those patients receiving usual cancer care.(13) The authors of this systematic review did not identify any interventions based on a solo practice model. However, they identified three studies following a coordinated care model and four studies following the integrated care model (summarized below).(13)

1.2.5.1 Early Palliative Care interventions based on coordinated care model

Studies identified as coordinated care models included collaboration of different healthcare providers to deliver the early palliative care intervention. In the following three studies, an advanced practice nurse (clinician with training in palliative care) coordinated and linked care from different specialist disciplines. In the ENABLE II randomised controlled trial, the early palliative care intervention was led by two advanced practice nurses with palliative care speciality training and consisted of both telephone-based education and care management for people with advanced cancer and caregivers.(44) The educational component focused on patient-activation, self-management, and empowerment.(44) When concerns were identified, participants were encouraged to contact the palliative care clinical team or the advanced practice nurse would contact specific specialist teams or refer the patients to community resources.(44) Participants were also invited to attend a monthly group

shared medical appointment led by a certified palliative care physician and nurse practitioner to ask questions about medical problems or related issues.(44) From their study, they found patients experienced higher quality of life and mood with the nurse-led palliative care intervention.(44) However, they didn't find improvements in symptom intensity scores or decrease in hospital stays or ICU or emergency care visits.(44) The ENABLE III trial utilized a telehealth model, with an initial in-person palliative care consultation with a palliative care clinician, followed by telephone coaching sessions.(45) The sessions focused on problem solving, symptom management, self-care, identification and coordination of local resources, communication, decision-making and advance care planning (also a component of the ENABLE II trial).(45) The ENABLE III trial added new sessions called a life-review approach, encouraging participants to examine their challenges associated with their illness as personal growth opportunities.(45) From this trial, the authors found a 15% improvement in 1-year survival in patients with advanced cancers.(45)

McCorkle et al(46) carried out a 10-week palliative care intervention for advanced gynecologic and lung cancer patients, who were diagnosed within 100 days. The study was led by an advanced practice nurse who coordinated with oncology multidisciplinary clinics to deliver the intervention via phone and in-person.(46) Clinic teams included advanced practice nurses, nurse coordinators, physician assistants, medical social workers, medical oncologists, surgeons, and radiation oncologists.(45) The components of the intervention included monitoring patients' status, providing symptom management, executing complex care procedures, teaching patients and family caregivers, clarifying illness experience, coordinating care, responding to concerns, collaborating with other providers, and discussing goals of care.(46) Patient physical and emotional symptoms remained stable or significantly improved from baseline (also found in the control group who received enhanced usual care).(46) Additionally there were significant improvements in functional competence (self-management in daily activities).(46)

1.2.5.2 Early Palliative Care interventions based on integrated care model

In the studies implementing an integrated care model, oncologists referred patients to specialist palliative care teams based on symptom burden and patient needs. In the integrated model, the oncologist provides ongoing cancer care, while palliative care needs are primarily delivered by specialist palliative care teams. Maltoni et al.(47) compared outcomes for patients with advanced pancreatic cancer receiving early palliative care from the beginning of chemotherapy (systematic early palliative care), and patients receiving on-demand early palliative care. Patients receiving on-demand palliative care were referred to a palliative care consultation when the oncologist or patient requested the consultation based on symptoms reported by patients.(47) Patients in the interventional arm had an appointment scheduled with a palliative care specialist who discussed a number of health-related areas in accordance with general palliative care guidelines by the US National Consensus project, and based on a pre-determined checklist.(47) The checklist is the same as the one used by Temel et al.(41) The palliative care specialist was able to prescribe medications and request interventions for patients' physical, psychological, and spiritual needs. The palliative care specialist worked with the oncologist to make recommendations on decision making processes with patients. The authors reported patient outcomes, and use of health services in two different papers. In their paper assessing patient outcomes, patient quality of life and symptom burden significantly improved with systematic palliative care.(48) In their paper assessing use of health services, the authors found significantly higher use of hospice services for patients systematically referred to early palliative care.(47) Additionally, participants receiving the intervention died at home or in hospice more often than those receiving on-demand palliative care.(47) Frequency of hospitalizations and emergency department visits was not significantly different between those who received systematic or on-demand palliative care.(47)

Tattersall et al.(49) provided early contact with a palliative care nurse consultant for patients with advanced cancer with ongoing oncologist care. The palliative care nurse consultant outlined available palliative care services such as advice about symptom control, and review by a palliative care physician.(49) The nurse offered to follow up with patients monthly by telephone to check on their well-

being, or provide contact details of palliative care service.(49) In this trial, participants preferred to contact the palliative care nurse themselves when they needed assistance, and the authors reported that many participants made contact with the palliative care nurse during clinic attendance.(49) Only 8/60 patients in the early palliative care group received greater than two phone calls from the palliative care nurse.(49) The authors found a trend towards decreased quality of life and severe pain and appetite (classified as score greater than five on the McGill Quality of Life questions within the three months prior to death) in the early palliative care intervention group, however this finding was not statistically significant.(49) The authors note this trend may be due to chance imbalances between the treatment groups.(49) The authors suggested that patients in the early palliative care intervention group may have been more comfortable reporting their symptoms since they had contact with the palliative care nurse.(49) The findings from this study differ from the other studies in the 2017 review, however this may due to the ‘dose’ of the intervention, as contact with the palliative care was less compared to the other studies.

Temel et al.(41) in their 2010 article, implemented a care model for early palliative care within eight weeks of diagnosis for patients with advanced lung cancer. A member of the palliative care team (palliative care physician or advanced practice nurses) met with patients to assess physical and psychosocial symptoms, discuss and establish goals of care, assist with decision-making regarding treatment, and coordinating care on basis of individual patient needs.(41) Temel et al.(41) found associations between early integration of palliative care with survival prolonged by approximately two months, improvements in quality of life and mood. Patients receiving early palliative care services were more likely to have discussed advance care planning (such as discussion of resuscitation preferences), experienced less chemotherapy, and longer hospice care.(41)

The study by Zimmermann et al.(50) examined care in both outpatient clinics and inpatient and hospice care. Their intervention was carried out by a palliative care physician and nurse who would meet with patients at outpatient clinic for an assessment of symptoms, psychological distress, social support,

and home services.(50) The palliative care physician and nurse also discussed goals of care with the patient and family, assessed needs of patients and families, and supported with coping and psychological distress and discussion of advance care planning according to patient and family readiness.(50) Palliative care nurses provided routine follow-up phone calls with patients after each visit.(50) For inpatient care, patients would have direct access to the palliative care unit for symptom management.(50) The study authors did not find any significant differences in quality of life between those who received early palliative care services and those who did not as well as quality of life of caregivers.(50) However, the authors observed improved caregiver satisfaction among those who received the early palliative care intervention.(50)

1.2.5.3 Conclusions on Early Palliative Care Intervention trials

The 2017 systematic review on the benefits and efficacy of early palliative care interventions found evidence of low certainty.(13) From the meta-analysis of seven studies, the authors found small effects for improvements in quality of life and decrease in symptom intensity.(13) In additional meta-analyses, they did not find any significant differences between groups for survival or decreased depression.(13) However, they found evidence of low certainty for effect estimates for survival and depression.(13) The authors did not identify any notable differences in patient outcomes between coordinated and integrated delivery models for early palliative care.(13) In the coordinated care delivery model, palliative care needs of patients were delivered by a multidisciplinary team of providers. In the integrated care models, palliative care specialist teams led the interventions and delivered early palliative care. The authors also note the evidence base for early palliative care is growing, and they identified 20 ongoing studies, and 10 studies awaiting assessment that were not included in their review.(13) For instance, the trial by Vanbutsele et al.(51) (published in 2018) demonstrate benefits in quality of life from early and systematic integration of palliative care for advanced cancer patients.

1.2.6 Experiences with Early Palliative Care: Patient and Family Perspectives

Few studies have reported on the experiences of receiving early palliative care from the perspectives of patients and family caregivers as well as the perceptions regarding palliative care and its name.(52-57) Studies have utilized semi-structured interviews to understand the experiences of patients and families.(52-56) Within the early palliative literature, dyad interviews are included (patients and their family caregivers), however they were interviewed separately.(52-54, 56, 58) Differences in perception of care experience from patients and their family caregivers were not identified for most of the studies that included both patients and family caregivers.(19, 52-54, 58) All of the qualitative studies summarized below report positive patient and family caregiver experiences with early palliative care. Some of the findings include improved communication, care coordination, patient engagement, advance care planning discussions, and support for patients and families. However, stigma with the term 'palliative care' was reported to be a concern in one of the studies.

Zimmermann et al.(52) interviewed patients with advanced cancer and their family caregivers on their perceptions of palliative care after conducting a cluster randomized trial of early palliative care versus standard care.(50) In their study, they found patients and caregivers initially misperceived palliative care to be synonymous with death. After receiving early palliative care, most participants were more comfortable with palliative care and had a broader understanding of the support from palliative care. However, some patients receiving early palliative care continued to be uncomfortable with the term palliative care, due to stigma surrounding the term, especially when discussing palliative care with others.(52)

Hannon et al.(53, 56) note benefits to an integrated model for palliative care. Hannon et al.(53) interviewed patients and family caregivers from the intervention arm of a cluster-randomized trial (by Zimmermann et al.)(50) for early palliative care on their experiences of receiving early palliative care. The authors described specific elements of palliative care valued by patients and family caregivers such as prompt, personalized pain and symptom management, holistic support of patients and caregivers, guidance in decision making and preparation for future decisions.(53) Participants in their study

described the role of the palliative care team as guiding patients and family caregivers in navigating the cancer care system, helping to understand medical information provided by other healthcare providers to guide decision making, and acting as a safety net for future support. In another paper, they described early palliative care facilitated coordinated, timely and efficient care.(56) Participants also described the role of their oncologist and palliative care physician as being discrete, important, and complementary for the provision of advanced cancer care.(56) The primary role of the oncologist was described by participants as directing anti-cancer treatment through a tailored approach.(56) Participants described the oncologist as a ‘scientist’, providing information to patients and families about the cancer and treatment. Participants described the palliative care physician’s role as managing symptoms, and providing holistic care by being supportive emotionally as well as physically, and providing support to family members as well.(56) From the perspectives of family caregivers, the oncologist was not responsible for paying attention to any particular needs of the caregivers, as they noted the palliative care team was able to provide support to the family.(56)

Dionne-Odom et al.(54) interviewed rural advanced cancer patients and family caregivers to elicit feedback and identify modifications to an outline of an early palliative care intervention for family caregivers. They proposed a telephone-intervention outline that was based on published evidence-based interventions.(19, 59, 60) Their telephone-based intervention was well-received by participants, and feedback received suggested inclusion of faith and spirituality by having a chaplain or other religious professional available for referral.(54) Participants thought a mostly telehealth approach was acceptable, but preferred there to be initial face-to-face contact with the palliative care team to establish trust and rapport.(54) Participants also mentioned the need for the intervention to be adaptive to specific needs of caregivers as these needs change over time. (54)

ENABLE, an evidence-based early palliative care intervention was adapted for heart failure.(58) Akyar et al.(58) interviewed patients and their family caregivers with advanced heart disease following the ENABLE early palliative care intervention. Patients and caregivers found the intervention to be

useful in improving patient engagement, improving communication, and advance care planning.(58) Participants found early palliative care supported them emotionally by allowing them to talk about their challenges, allowed them to reflect on their experiences, supported planning, and helped them gain illness management and decision making skills.(58) Participants emphasized early palliative care needed to be introduced closer to diagnosis, and to continue using a mostly phone-based approach. (58)

Maloney et al.(57) interviewed advanced cancer patients who participated in the early palliative trial (ENABLE II).(44) In their study, advanced cancer patients expressed the intervention helped them gain problem-solving skills, helped them to cope with uncertainty and concerns about the future, and made them feel empowered in taking an active role in their care.(57) Contact with the nurses also made participants feel supported, reassured, and hopeful.(57) Some patients who were asymptomatic found less benefit from the intervention, as well as patients who were relatively well and didn't want to meet often with healthcare providers.(57)

Flidner et al.(55) interviewed advanced cancer patients regarding their perceptions and experiences of a structured early palliative care conversational intervention (SENS-Trial) in Germany. The SENS-trial was a single conversational intervention facilitated by a palliative care physician and nurse in the outpatient clinic.(55) Flidner et al.(55) found their early palliative care intervention was well received by patients with advanced cancer diagnoses. Patients described the intervention as supportive and helped them to prioritize their future care.(55) Patients found the conversations to be based on trust and attentiveness, and facilitated conversations with family.(55) Patients also reflected realistically on sensitive topics and plan for their future.(55) The authors noted patients expressing a change in how they understood palliative care and being more open to advance care planning.(55)

1.3 Palliative Care Early and Systematic (PaCES) Project

In Alberta, delivery of palliative care is inconsistent with many late palliative care referrals associated with 'aggressive end of life' care.(61) This master's thesis is supporting the PaCES project on

the implementation of an early palliative care approach in routine advanced cancer care in Alberta. The PaCES (Palliative Care Early and Systematic) project is a province-wide initiative, engaging multiple stakeholders such as researchers and knowledge end users to develop and deliver an early and systematic palliative care pathway for advanced colorectal cancer patients and families in Alberta.(10) The PaCES stakeholder network is extensive and includes Alberta Health Services' strategic clinical networks (SCN) (Cancer SCN, Seniors SCN, Primary Healthcare Integration Network), healthcare providers such as oncologists, palliative care, primary and homecare senior research mentors, leaders, and administrative knowledge users, and patient and family advisors. The PaCES pathway follows an integrated model of care, through early referral of advanced cancer patients to specialist palliative care nurse consultative visits and palliative homecare supports more than three months before death. The specific components of the early palliative care pathway are adapted from Temel et al.'s(41) elements of an early palliative approach to care: 1) illness comprehension and coping; 2) Advance care planning and patient's preferred method of decision making; 3) Symptoms and functional Status; 4) Coordination of Care.(39) The key steps in the implementation of the care pathway are: 1) Screening to identify patients who would benefit from an early palliative approach to care; 2) Identifying patients' needs using assessment tools such as the "Putting Patients First", Canadian Problem Checklist (CPC) and Edmonton Symptom Assessment System-Revised; 3) Primary Provider management of unmet needs; 4) Exploring End of Life topics such as end of life planning, estate and funeral planning, hospice access, medical assistance in dying (MAID), and grief and bereavement.(10) To facilitate care coordination and communication, a shared care letter was distributed to family physicians and to patients. Additionally, patients were referred to a specialist palliative care nurse to provide advice and care to address any complex needs of patients. The clinical practice guideline for an early palliative approach to advanced colorectal cancer care was published in January 2019 by the Guideline Resource Unit (GURU) of Alberta Health Services.(39) The concurrent early palliative care referral intervention was first implemented in Calgary with Edmonton as the control site to allow for testing and refinement of the

pathway before dissemination in Edmonton and across Alberta. The PaCES project is funded by the Canadian Institute of Health Research and Alberta Health grants, with in-kind support from Alberta Health Services. This thesis supports the refinement of the early palliative care pathway, by capturing patient and family caregiver experiences with advanced cancer care and receiving early palliative care.

As a Master's trainee under the supervision of Dr.Santana and the PaCES research team, my role was collaborating with the team to design the qualitative studies, putting together the interview guide, ethics application, study proposal, conducting the study, data analysis, and writing up the studies for publication. The PaCES team supported the recruitment of the qualitative studies, provided feedback on study findings, and supported the dissemination of the work at various conferences and stakeholder meetings.

CHAPTER 2: Methods

2.1 Conceptual Framework

The delivery of palliative care is patient and family centred care. Palliative care aims to deliver patient centred care by incorporating patient and caregiver wishes, preferences, values, and engaging them in their care.(62) Additionally, it aims to reduce burden and suffering of patients and caregivers.(62) The Person-Centred Care (PCC) Framework was used to guide the analysis of the findings from the interviews with patients and family caregivers.(5) The PCC framework provides a guideline for healthcare organizations on the delivery of quality person centred care to patients and families. The framework consists of specific domains categorized under structure, process, and outcome following the Donabedian model of care.(63) Structure domains refer to the foundation of PCC- the necessary materials, healthcare resources, and organizational characteristics.(5) Examples of structure domains include creating a PCC culture, and co-designing the development and implementation of educational programs. Process domains refer to the interaction between patients and healthcare providers.(5) Examples include cultivating communication, respectful and compassionate care, and engaging patients in managing their care.(5) Outcome domains refer to the outcomes of care- the results of implementing the structures and processes of care. Examples of outcome domains are access to care, patient-reported outcomes, and cost of care.(5) According to the framework, the structures of care need to be successfully integrated in healthcare systems to guide the processes and outcomes of care.(5) This framework informed some of the questions for the interview guide, specifically questions related to the processes and outcomes of care. For instance, interview questions based on the processes of care were included pertaining to communication between patient and healthcare providers, as well as communication among healthcare providers. Interview questions based on the outcomes of care were included pertaining to access to care and patient reported outcome measures. The conceptual PCC framework was used to guide understanding of patients and family caregiver experiences with cancer

care in Alberta. Specific domains from the PCC framework informed codes in the analysis of the findings. The PCC framework was applicable in the context of this study as it applies to all diseases/conditions and at different stages of care. The experiences of patients living with advanced colorectal cancer and their family caregivers gave us an understanding of the application of patient centred care domains in their cancer care, and whether the care received was patient centred. The conceptual framework is included in Appendix A.

2.2 Study Design

This qualitative study is embedded within a larger program of research on the implementation of an early and systematic palliative care pathway for advanced colorectal cancer patients in Alberta. A qualitative study design was chosen to gain in-depth understanding of the experiences of patients living with advanced colorectal cancer and family caregivers. A qualitative study design was appropriate for this project as our objectives were exploratory, rather than explanatory. Additionally, the paradigm used in this research was interpretivist, as priority is given to the participants' subjective experiences and understanding of the world, and knowledge being developed both experientially and socially.(64) Within this paradigm, we are interested in participants' interpretations of their world, and in this study context, their interpretations of the cancer care received.

This is a patient-oriented research project, involving three patient and family advisors from the PaCES research team. Two of those advisors were family caregivers of advanced cancer patients, and one advisor was both a patient herself and also a family caregiver for her mom. This project addressed the following key elements of patient-oriented research: engagement of patient partners, focus on patient-identified priorities in order to improve patient outcomes, partnership with stakeholders, and aiming to apply the knowledge generated to improve healthcare systems and practices.(65) The patient advisors involved in this research project have expertise in patient-oriented research projects, and have been engaged in health research for a number of years, including the development of the PaCES early

palliative care pathway. We engaged these patient and family advisors in our research project from the beginning of the study by reaching out to them and co-developing the interview guide for patient and caregiver interviews. Working with patient and family advisors helped to identify topics/questions that would guide the PaCES pathway. Additionally, patient and family advisors helped to reframe questions to ensure they were appropriate to ask patients and family caregivers. Patient and family advisors were engaged throughout the project, through presentation of findings at different stages and incorporating feedback received on data analysis. Patient and family advisors were invited to attend and provide feedback on study findings with the rest of the PaCES research team. Additionally, presentations were given to stakeholders, including patient and family advisors at stakeholder meetings with the large PaCES network.

2.3 Recruitment

For participants who received standard oncology care

Patients and their caregivers were recruited with the help of the PaCES research team at the Tom Baker Cancer Centre, Calgary, and Cross Cancer Institute, Edmonton, Alberta through purposive, convenience and snowball sampling. The inclusion criteria for this study were patients with advanced colorectal cancer, older than 18 years of age with any of the following: failed first-line chemotherapy (disease progression on imaging), high symptom need (any score on the Edmonton Symptom-Assessment System Revised (ESAS-r) greater than or equal to 7), and if they are unable to receive first-line chemotherapy.(10) The exclusion criteria for this study were participants who were deemed inappropriate by clinic staff to be approached for an outcomes study for any reason (for example, in crisis).

Sampling was purposive and convenient because potential participants were approached at clinics and given information on the study by a PaCES researcher. If participants were interested in taking part, they were asked to complete a consent-to-contact form for follow up. Snowball sampling was employed as

potential family caregiver participants could be identified by patients who we interviewed. Family caregivers were also contacted directly by the study team for an interview. Dyad participants (patient and their family caregiver) and non-dyad participants were recruited and interviewed separately. Dyad participants were recruited to explore similarities and differences in perceptions of patients and their family caregivers of advanced cancer care. Linked interviews are recommended by researchers, as it can provide a deeper understanding of needs and experiences than individual accounts.⁽⁶⁶⁾ A family caregiver was defined as a relative or friend of the patient (over the age of 18), whom the patient described as their primary caregiver (someone who provided unpaid assistance and support to the patient). Potential participants who gave consent to be contacted were followed up with a phone call with more information and to schedule a time to be interviewed. Additionally, potential participants were emailed information about the study, and were given our email address for further information if interested. Participants were offered a \$20 gift card as a thank you for their participation.

For participants who received early palliative care supports

Patients and their caregivers were recruited with the help of the PaCES palliative care nurse specialist at the Tom Baker Cancer Centre, Calgary and by telephone, through purposive, convenience and snowball sampling. The inclusion criteria for study participants was those who received early palliative care supports and the same criteria as listed above. Sampling was purposive and convenient as potential study participants were approached by the palliative care nurse at appointments or by phone and given a description of the study. If participants were interested in taking part, they were asked to complete a consent-to-contact form for follow up. Snowball sampling was employed for recruitment of family caregivers (patient participants could refer their family caregiver to participate in the study as well). Other details on recruitment listed above were the same.

2.4 Interview Guide Development

We developed an interview guide with our patient and family advisors and other research team members (oncologists and health service researchers). Specifically, they provided input on improving the questions asked to patients, and insights into what further questions could be asked through three rounds of feedback over email. The conceptual Person-Centred Care framework also informed some of the questions for the guide, specifically those relating to the processes and outcomes of care. The interview guide consisted of open-ended questions as well as probing questions on the following topics: perceptions regarding the term palliative care, communication of diagnosis, experiences with healthcare providers (specifically the oncologist and family physician) throughout cancer care, experiences with resources received, and perceptions of advance care planning. For interviews conducted after the implementation of the care pathway, the interview guide was modified to include additional questions specific to the care pathway. Topics relevant to the care pathway that were included in the second interview guide were: experience of early palliative care supports received, introduction and timing of palliative care, any changes participants would make, coping with cancer, discussions about advance care planning and end of life planning. Demographic characteristics from participants were also collected at the time of interview such as age, sex, marital status along with other baseline questions on the patient's care team, location living in last month and information on palliative care services received. The interview guides developed in collaboration with patient and family partners can be found in Appendix B.

2.5 Data Collection

Prior to implementation of the early palliative care pathway, we conducted semi-structured telephone interviews with 15 patients with advanced colorectal cancer and 7 family caregivers from Calgary and Edmonton receiving standard cancer care. After the implementation of the early palliative

care pathway in January 2019 in Calgary, we interviewed a different set of patients with advanced colorectal cancer and family caregivers from Calgary (7 patients and 5 family caregivers).

Telephone interviews were recorded using a digital audio recorder. Notes were taken during the interviews. Debriefing followed each interview to address any questions the participants had and to summarize the purpose and future directions of the project. Telephone interviews were chosen as the mode of interviewing, because participants were located both in Calgary and Edmonton. A previous study conducted by the PaCES team in rural Alberta found that patients preferred to be interviewed over the phone rather than driving into the cancer centre for an in-person interview, and they were comfortable sharing their experiences with advanced cancer care and perceptions of palliative care over the phone.⁽⁶⁷⁾ For certain sensitive topics such as discussion of advance care planning, participants may be more comfortable sharing their views over the phone without someone present. The mode of interviewing was kept consistent for both groups of participants.

2.6 Data Analysis

Interviews were transcribed, and the data thematically analyzed supported by the qualitative analysis software, NVivo. We chose to conduct a thematic analysis to allow for the identification of themes and patterns. We employed the six-phase thematic analysis process described by Braun & Clarke.⁽⁶⁸⁾ The first phase was to become immersed in the data, through reading and re-reading the transcripts, and jotting down initial impressions.⁽⁶⁸⁾ This first phase allowed for remembering the conversations with each participant as well as to visualize specific codes for analysis. The second step was to generate initial codes and organizing data in a meaningful and systematic way.⁽⁶⁸⁾ Coding was performed by two members of the research team, using a mix of deductive, inductive, and iterative coding strategies. Through the deductive coding process, some of the codes were pre-defined from both the interview guide and conceptual framework. We were able to identify some codes and organize them in a coding book, as a reference for the two researchers who coded the transcripts (myself and a research

assistant). Codes identified from paper one guided the codes for the transcripts for paper two. However, coding was also inductive as new codes were identified from the data that were not already included in the coding book. Some strategies within the inductive process of coding were looking for repetition of topics that came up frequently, and looking for codes/categories used by participants themselves to describe their experiences. The coding process was iterative because when a new theme emerged, the transcripts were read once again to ensure codes and themes were not missed. Transcripts were read multiple times to generate codes and differences in coding were resolved through discussions between the two researchers who coded the data. The third step was to identify themes by organizing the initial codes and grouping them together into broader themes.(68) The software, Nvivo was utilized to visually organize the codes in a coding tree. We grouped codes together to form themes. In step 4, we reviewed the themes to ensure the themes represented the coded data, were coherent and distinct from another.(68) Through this step, we discussed and received feedback from PaCES research team, including our patient and family advisors. In step 5, we defined the themes by capturing the “essence” of what each theme was about.(68) From this step we aimed to understand the relationship between themes and subthemes. The final step was the writing up of the report for broad dissemination.(68) Through this step, we prepared two manuscripts for publication. The manuscripts are reported in accordance to the consolidated criteria for reporting qualitative research (COREQ) (Appendix C).(69)

2.7 Ethical Considerations

The Health Research Ethics Board of Alberta Cancer Committee gave ethics approval for the study (HREBA.CC-18-0013_REN1). We sought informed consent from the participant, and participation in this study was completely voluntary. Participants had the choice of not answering any questions they felt uncomfortable with, and the choice to withdraw from the study at any time in addition to the data that was collected. However, in our interviews all participants chose to answer all the questions asked, and no one withdrew from the study. The results of the project were coded in such a

way the identity of the participant was not physically attached to the final data such as transcripts that we produced. The statements only identified the participant as 'patient x' or 'caregiver x'. Electronic versions of recordings and transcripts were stored on password protected computers of the principal investigator and the student. Electronic recordings were deleted after being transcribed. Study transcripts will be kept for a minimum of 5 years after the manuscripts have been published. Only the researchers had access to the list of participant names. Participants were identified as patient x or caregiver x in research output.

2.8 Trustworthiness Measures

In order to enhance trustworthiness within this study, we employed strategies to increase credibility and dependability.(70) We used member checking to increase credibility. This included asking participants to clarify responses during the interview, to ensure we did not misinterpret what they had said. Peer debriefing between my supervisor and I, and other PaCES research team members was employed to increase credibility. Routine discussions with my supervisor and PaCES research team members took place to talk about recruitment and thematic saturation. This peer debriefing process also allowed for discussions with my supervisor about codes and themes, to ensure they accurately represented the data. We kept an audit trail of the research in order to be transparent and increase our dependability. Complete records of the start of the research project to the end were kept, which included transcripts and notes. Qualitative data will be kept for a minimum of 5 years after the manuscripts have been published.

Chapters 3 and 4 present the interviews conducted before and after implementation of the early palliative care pathway. Appendix F presents an overview of the demographics of the participants interviewed.

CHAPTER 3

Patient and Caregiver Experiences with Advanced Cancer Care: A Qualitative Study Informing the Development of an Early Palliative Care Pathway

Sadia Ahmed¹, Syeda Farwa Naqvi¹, Aynharan Sinnarajah^{1,2,3}, Gwen McGhan⁴, Jessica Simon^{1,2}, Maria J Santana^{1,5}

3.1 Abstract

Background: Palliative care is an approach that improves the quality of life of patients and families facing challenges associated with life-threatening illness. In Alberta, most people who received palliative care received it late. Late palliative care negatively impacts patient and family caregiver experiences and decreases quality of life. In order to effectively deliver palliative care, patient and caregiver priorities need to be incorporated in advanced cancer care.

Aim: This study aims to understand patient and family caregiver experiences of advanced colorectal cancer care to inform development of an early palliative care pathway for patients with advanced colorectal cancer.

Design: qualitative and patient-oriented study

Settings/participants: Semi-structured telephone interviews with patients living with advanced colorectal cancer and family caregivers were conducted to explore their experiences with cancer care services received prior to pathway implementation. Interviews were transcribed, and the data thematically analyzed supported by the qualitative analysis software, NVivo.

Results: 15 patients and 7 caregivers from Edmonton and Calgary were interviewed over the phone. A total of 6 main themes were identified: 1. Communication with and among Care Team (including

communication of diagnosis); 2. Relationship with Healthcare Providers; 3. Meaning of Palliative Care; 4. Patient and Family Engagement; 5. Readiness for Advance Care Planning; 6. Access to Care.

Conclusions: Early palliative approaches to care may be improved by delivering routinely consistent palliative care information; involving collaborations among different disciplines such as oncology, primary care, and palliative care; and including patients and their caregivers in the development of care pathways.

3.2 Introduction

Cancer is considered the leading cause of death in Canada.(23) Colorectal cancer is the second most common type of cancer and 49% of colorectal cancers were diagnosed at an advanced stage in most provinces and territories.(23) Patients living with advanced cancers often experience emotional distress, and have trouble coping with physical symptoms, including fatigue, pain, weakness, loss of appetite, and lack of energy.(1, 25) Following an advanced cancer diagnosis of a loved one, family members are also affected, and they often experience symptoms of anxiety, sadness, and depression.(2, 3) It has been found that patients with advanced cancers often undergo potentially inappropriate “aggressive end of life care” such as repeated hospitalizations, emergency department visits, and admission to the intensive care unit within last month of life.(26, 27) These types of interventions have been associated with lower quality of life for both patients and families in a number of studies.(27, 28, 41) As a result, most advanced cancer patients prefer palliative treatments than life- extending care, and prefer to die at home.(27)

Palliative care is patient and family centred care that improves quality of life and addresses physical, emotional, social, and spiritual needs of patients.(6) In Canada efforts have been made to improve palliative care. Specifically, associations such as Choosing Wisely Canada(11) and the American Society of Clinical Oncology(7) recommend the integration of early palliative care services for advanced cancer care, eight weeks into diagnosis. Health Canada also released a national framework for palliative care in consultation with stakeholders from all provinces and territories recommending the integration of early palliative care in current health systems.(40)

Organization and delivery of palliative care across jurisdictions is inconsistent, impacting quality of care received.(12) The delivery of palliative care needs to be patient centred and patient informed to meet the needs of patients and families. In order to inform an early palliative care pathway for cancer, we first need to understand the current experiences of advanced cancer patients and their family

caregivers. The primary objective of the study is to describe the patient and caregiver experiences with advanced colorectal cancer care. The secondary objective is to describe patient and family caregiver perceptions with palliative care and advance care planning to inform delivery of early palliative care.

3.3 Methods

The Health Research Ethics Board of Alberta Cancer Committee gave ethics approval for the proposed study (ID: HREBA.CC-18-0013) in February 2018.

Conceptual Framework

The delivery of palliative care is patient and family centred. The Person-Centred Care framework provides a guideline for healthcare organizations on the delivery of quality of care to patients and families. This framework consists of specific domains categorized under structure, process, and outcome, outlined by Donabedian's framework.⁽⁶³⁾ Structure domains refer to the foundation of PCC and are described as the necessary materials, healthcare resources, and organizational characteristics for PCC.⁽⁵⁾ Process domains refer to the interaction between patients and healthcare providers.⁽⁵⁾ Examples include cultivating communication, respectful and compassionate care, and engaging patients in managing their care.⁽⁵⁾ Outcome domains refer to the outcomes of care - the results of implementing the structures and processes of care. Examples of outcome domains include patient-reported outcomes.⁽⁵⁾ The Person-Centred Care (PCC) Framework was used to guide the analysis of the findings from the interviews with patients and family caregivers.⁽⁵⁾ The conceptual framework is included in Appendix A.

Study Design

A qualitative patient-oriented study design was chosen to gain in-depth understanding of the experiences of patients living with advanced colorectal cancer and family caregivers. This study is embedded within a larger program of research (PaCES described below) on the development and

implementation of an early and systematic palliative care pathway for advanced colorectal cancer patients in Alberta.

Palliative Care Early and Systematic (PaCES) Project

In Alberta, delivery of palliative care is inconsistent with many late palliative care referrals associated with ‘aggressive end of life’ care.(61) The PaCES (Palliative Care Early and Systematic) project is a province-wide initiative, engaging multiple stakeholders such as researchers and knowledge end users to develop and deliver an early and systematic palliative care pathway for advanced colorectal cancer patients and families in Alberta.(10) The PaCES team have defined early palliative care as patients received at least one of: consultative visit for a specialist palliative care provider, palliative homecare service or hospice admission greater than or equal to 3 months before death.(39) The specific components of the early palliative care pathway are adapted from Temel et al.’s(41) elements of an early palliative approach to care: 1. Illness comprehension and coping; 2. Advance Care planning and patient’s preferred method of decision making; 3. Symptoms and functional Status; 4. Coordination of Care.(39) Details of the clinical guideline can be found on the provincial health authority website.(10, 39)

Recruitment

Patients and their caregivers were approached at clinics by research team members to give consent to be contacted (at the two metropolitan, tertiary cancer centres in a Canadian province serving a population of about 4.3 million). Sampling was purposive, convenience and snowball sampling. The inclusion criteria for this study were patients with advanced colorectal cancer, greater than 18 years old with any of the following: 1. Failed first-line chemotherapy (disease progression on imaging); 2. High symptom need (any score on the Edmonton Symptom-Assessment System Revised (ESAS-r)(71, 72) greater than or equal to 7); 3. Unable to receive first-line chemotherapy.(10) The exclusion criteria for

this study were participants who are deemed inappropriate by clinic staff to be approached for any reason (for example, in crisis). Potential participants were followed up by a researcher (SA) to take part in the phone interview. The potential participants were told about the goals of the study, and of the researcher's role within the project. Dyad participants (patient and their family caregiver) and non-dyad participants were recruited and interviewed separately, in order to analyze individual accounts. A family caregiver was defined as a relative or friend of the patient (over the age of 18), whom the patient describes as their primary caregiver (someone providing unpaid assistance and support to the patient), and they did not need to live in the same residence. Participants were offered a \$20 gift card as a thank you for their participation.

Data Collection

The interview guide was developed using the PCC framework with feedback from clinician-researchers specializing in palliative care (AS, JS), a health service researcher (MS), and three patient and family advisors on the team (Appendix B interview guide). We conducted telephone interviews with patients and family caregivers from May-November 2018 (SA). All interviews were audio-recorded and notes taken by a qualitative researcher (SA). Debriefing followed each interview to address any questions the participants might have. Interviews ranged from 20-90 mins.

Data Analysis

Interviews were transcribed, and the data thematically analyzed with the support of the qualitative analysis software, NVivo. We employed the six-phase thematic analysis process described by Braun & Clarke.(68) Coding was performed by two members of the research team (SA & SFN), using a mix of deductive, inductive, and iterative coding strategies. Thematic saturation was achieved with the interviews, defined as no additional codes or themes were identified during data analysis.(73)

In order to enhance trustworthiness within this study, we employed strategies to increase credibility and dependability.⁽⁷⁰⁾ We used member checking to increase credibility. This included asking participants to clarify responses during the interview and afterwards over the phone. Peer debriefing between team members was also employed to increase credibility. This process allowed for discussions on codes, themes, and thematic saturation with team members. Complete records of the start of the research project to the end were kept, which includes audio recordings, transcripts, and notes. This audit trail is important in being transparent within the research process and therefore increasing dependability. The manuscript and results of this study are reported in accordance to the consolidated criteria for reporting qualitative research (COREQ) (Appendix C).

3.4 Findings

A total of 15 patients with advanced colorectal cancer and seven family caregivers (all spouses) were interviewed. Of those patients and caregivers, nine were from one centre and 13 were from the other. We had men and women participants (13 women, nine men) whose ages ranged from 43-72. Three of those seven family caregivers were spouses of three patients interviewed (three dyad participants, but interviewed separately). 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. Six main themes were identified in the analysis: 1. Communication with and among Care team (including communication of diagnosis); 2. Relationship with Healthcare Providers; 3. Meaning of Palliative Care; 4. Patient and Family Engagement; 5. Readiness for Advance Care Planning; 6. Access to Care. Mention of participants will include both patient and caregiver, unless otherwise stated. Supportive quotes for each theme can be found in Table 1. Figure 1 summarizes the gaps identified in current advanced cancer care.

1.Communication with and among care team

Most participants specified nurses, oncologist, family physicians, family members and friends as key members of their care team. One participant also mentioned other key members including their social worker and therapist. Another mentioned seeking a naturopath for management of pain.

Communication with the care team and among care team members was important to patients and family caregivers. Participants mentioned a need for care integration (improved coordination of care) between their care providers, and some found it currently lacking in their cancer care. Participants preferred there to be evident teamwork between different healthcare providers. One caregiver says: *“We found that there’s a real challenge in communication in terms of some departments in [health organization]. And so, if we have the oncology team and palliative team both involved in care... they need to be in sync.”*

(Caregiver B)

Most patients knew who to call after hours, for instance some called the cancer clinic, triage line, or emergency. However, some participants found calling someone after hours to be challenging due to lack of response, or delayed response.

1.1 Communication of diagnosis

Hearing the diagnosis of advanced cancer was shocking for all participants, and many mentioned poor communication of the initial diagnosis. Some participants spoke about hearing about their diagnosis in uncomfortable situations and not feeling informed about what to expect. For instance, one participant mentioned hearing they had cancer over the phone: *“actually, it was communicated to me through the phone initially. When they told me I had colon cancer, the doctor who had actually performed the colonoscopy called me.”* (Patient H).

Another patient mentioned being told after their surgery, *“Well one guy [resident] comes up to me while I’m laying in bed and says - he was talking to somebody else. That’s how I heard. So, everything was a screw up. All my information was just casually overheard or by accident or something.”* (Patient I)

Participants emphasized the need for clinicians to understand the patient perspective when delivering an advanced cancer diagnosis.

2.Relationship with oncologist and cancer team

The oncologist is a key member for a patient with advanced cancer, and most patients mentioned seeing their oncologist/cancer team on a consistent basis (every 2-3 weeks). Most participants spoke of the importance of communicating with their oncologist and cancer team, and some participants mentioned they perceived improvement in the relationship with their oncologist over time. Patients and caregivers relied on their oncologist and cancer team (such as the nurses at the cancer centre) for information regarding their cancer diagnosis, treatment, medications. Participants also preferred to speak and see their cancer team for concerns about their care.

One participant spoke about how their oncologist made them feel in control: *“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...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)

2.1 Role of the family physician

There were mixed responses from participants on how they felt about their family physician. Some participants expressed lacking trust in their family physician for their care, due to previous circumstances where they felt their care was lacking. For instance, a late diagnosis, and not taking concerns of patients and families seriously. Other participants mentioned they found their family physician useful in ensuring they had all the information they needed, facilitating tests, and going through goals of care. However, some participants found the role of the family physician during cancer care to be unclear, and sought the cancer team for most of their care. Some participants also found their specialist teams to be sufficient in providing their care, and didn’t find a need to seek their family physician. One family caregiver mentioned their family doctor should be made aware, but not play a

huge role in cancer care *“he should be made aware and you know be on top of it but 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”* (Caregiver E)

3. Meaning of palliative care

Patients and family caregivers were asked what the term palliative care meant to them. For some participants, they associated palliative care with end of life and death. Additionally, almost all participants did not consider themselves to be receiving palliative care or identify their care as including an early palliative approach to care. Participants mentioned palliative care having a negative connotation, impacting how patients and families view palliative care. For instance, one participant describes palliative care as, *“somebody who is dying on their last legs, cannot do anything for themselves and end up in the hospice.”* (Patient G).

There were other participants who viewed palliative care as more encompassing, and ongoing care. One participant described palliative care as ‘comfort care’, *“I’d think of it as comfort care. You know probably less medical... more sort of helping patients deal with the day to day”* (Caregiver B) Another patient described how communicating with different care providers, and receiving cancer care for a long time changed her perception of palliative care. There were also some participants who were unsure what palliative care meant. Most participants noted palliative care was not extensively or adequately discussed with their healthcare team, and some mentioned hearing the term in an initial meeting by their healthcare providers, but never explained. Participants emphasized that care teams need to take time to explain palliative care to their patients, as people have different perceptions of what it means.

4. Patient and family engagement in care

Patients and family caregivers emphasized importance of being engaged in their care. Participants wanted to not only be informed about their diagnosis, treatment, and care plan but also be an

equal member of the care team, and engaged in shared-decision making. One participant notes how they conducted their own research beyond clinical appointments, *“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).

Being their own individual and having the capacity to make their own decisions was mentioned by most participants. Some family caregivers recalled instances where they felt their spouse (the patient) was not taken seriously, which resulted in delayed treatment. For instance, pain management was one aspect of care that two family caregivers found to be poor in current care.

Patient-reported outcome measures are one way to engage patients in their care. Patients were asked about the patient-reported outcome measure they filled at their appointments at the cancer clinic, specifically the *“Putting Patients First”* checklist, which allows patients to rate their symptoms and other concerns. Most participants found the checklist simple, straightforward, and quick. Some patients found rating their symptoms allowed for reflection and opened the discussion with their healthcare providers. Most family caregivers helped their loved ones complete the checklist at the appointment. One caregiver mentioned there should be a checklist given to caregivers, as they are affected by their loved one’s illness too. Caregivers also noted that clinicians need to follow up with patients after they fill out the checklist, even if patients rate their symptoms positively. For instance, one caregiver mentioned patients tend to underplay their symptoms, *“when it’s a little pain, she’ll (patient) underplay just how bad the pain is and that actually had some consequences with it so I just want to recommend ... nurses and doctors really need to quiz the patient a little bit”* (Caregiver B)

5. Readiness for advance care planning

Participants were asked about their views on advance care planning after the following definition was read to them: “advance care planning is a way to help you think about, talk about and document wishes for health care in the event that you become incapable of consenting to or refusing treatment or

other care.”(74, 75) Most participants had not discussed advance care planning with their care providers. However, all participants noted the importance of planning for the future, and the importance of having these discussions with their care teams. Patients had mixed responses on the timing of discussions, as some preferred to have these discussions early on in their care, while others preferred to have advance care planning discussions near the end of life. Some participants perceived advance care planning as planning for end of life. One family caregiver spoke about the difficulties discussing future planning with their spouse (the patient), *“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). However, all participants emphasized advance care planning discussions should be individualized to meet patient preferences and comfort level.

6.Access to care

Some participants discussed the distance to cancer care services as being a barrier. For instance, some participants spoke about appointments that would have been better as a phone call. Additionally, most participants noted seeing more than one healthcare professional for their care (such as a therapist), however most services were physically further apart from each other, *“like the therapist. I have to really go across town to see her. I think when you're diagnosed with something like that, having the support right there where you know you can just go to the next room”* (Patient H).

3.5 Discussion

This study highlights current gaps in advanced cancer care to inform the delivery of cancer care and early palliative care in Alberta. Patients and family caregivers highlighted the importance of communication in their experiences of cancer care. Communication between provider-patient (a process

domain in the PCC conceptual framework) has found to be key to the delivery of person centred care.(5) Communication between patients and healthcare provider is also important in building good interpersonal relationships between healthcare providers and patients/families.(76) Most participants communicated with their cancer team consistently, and were able to develop a trusting relationship with their cancer team. Those patients who had a negative experience regarding their diagnosis (such as a delay), or did not communicate often with their family physician, were reluctant in seeing their family physician and involving them in their care. Aabom et al,(77) also found that patients with advanced cancer often lose touch with their family physician, due to receiving treatment and developing relationships with their cancer team. In our study, some participants relied on their family physician for emotional and informational support. Similarly, Hall et al.(78) found patients valued emotional, informational, and instrumental support from primary care during cancer care(for example medical information, reassurance about their experiences, practical and emotional support). Psychosocial needs such as managing daily life, emotions, and social identity are often unmet in cancer treatment.(77) Family physicians can deliver psychosocial support to patients and their families, and also play a key coordinator role in the delivery of palliative care. Family physicians need to be included in collaboration with specialist teams to deliver effective palliative care. When communicating and involving different healthcare teams (family physicians, specialist teams), clear roles should be defined to mitigate confusion for both patients and families, and their care teams.

Early Palliative Care Approach

An early palliative approach that is patient centred is necessary to support patients and families in their illness, as outlined by Temel et al,(41) and the PaCES early palliative care pathway.(39) Elements of early palliative care include relationship and rapport building, helping patients cope with their illness, and helping them to understand their illness.(13) Early palliative care is also focused on patient engagement, information sharing, and discussing preferences with regards to advance care

planning, key concepts of patient centred care.(13) This study highlights a misunderstanding of palliative care. Most participants considered palliative care to be synonymous with end of life or death and not as an added layer of support for people living with serious illness. From the patient's perspective, palliative care was not extensively discussed with them at their appointments. Zimmermann et al.(52) also found patients and caregivers misperceived palliative care to be synonymous with death in their study. Previous studies have found late referrals to palliative care services were inadequate for the provision of patient centred care.(31-33) Temel et al.(41) in their 2010 article, implemented a care model for early palliative which led to improved quality of life for patients with advanced cancer. Patients receiving early palliative care services were more likely to have discussed advance care planning (such as discussion of resuscitation preferences), experienced less chemotherapy, and longer hospice care.(41) Palliative specialist teams should work in collaboration with cancer teams and family physicians on presenting palliative care as an early support that can be implemented at all stages of an illness. The delivery of palliative care information should be consistent and routine, to mitigate stigma with the term. Currently, strategies to promote improved understanding of palliative care have been implemented in Alberta with the revision of patient education materials and digital resources. Additionally, a 'shared care letter' has been implemented in Calgary, highlighting the role of different care providers, including the family physician and oncologist in helping to manage care of patients.(39) The shared care letter aims to enhance communication between patients/families, family physicians, and specialists to provide an effective early palliative approach to care.(39)

This study also finds that from a patient perspective they have not been well supported or engaged in the key elements of an early palliative care approach such as care coordination and advance care planning. Most participants in our study had not discussed advance care planning with their care team, and therefore participant readiness for advance care planning discussions were mixed. Limited knowledge may impact timing of advance care planning discussions, a finding also captured by Shaw et al.(79) Advance care planning discussions need to be individualized to the patient, a finding also

emphasized by Simon et al.(80) An early palliative approach to care needs to embody patient and family engagement. Both patients and family caregivers from our study valued being involved in their care, and seen as an equal member of their care team. Thus, patient and family caregivers are being involved in the development of early palliative care pathways for advanced cancer in our province. The patient perspective can allow for a greater understanding on what will work well and what won't work in the delivery of early palliative care. The implementation of an early care pathway in palliative care can improve patient and caregiver quality of life, improve symptom burdens, and attend to needs of patients and families.

Strengths and Limitations

A methodological strength of this study lies in its qualitative design. Through in-depth interviews, we were able to understand the experiences of patients living with advanced colorectal cancer and family caregivers as they navigate cancer care in Alberta. Probing interview questions allowed for clarification and improved understanding of participants' responses. Another study strength is the patient-oriented design, engaging patient and family advisors. The involvement of patient and family advisors allow for patient priorities to guide health research. For instance, in our project the questions that formed the interview guide were developed in collaboration with our patient and family advisors. As a result, the findings of the study have been readily incorporated into pathway design. A limitation of this study may be the mode of interviewing chosen- telephone interviews. As the interviews that were conducted are one-time interviews, rapport-building with all participants was not possible. However, all participants interviewed were comfortable sharing their views over the phone, and this did not limit what they shared with the interviewer. Additionally, studies that have compared telephone and face to face interviewing, have found both modes to be comparable in quality.(81) As we were interviewing advanced cancer patients living in two different cities, telephone interviewing was most convenient.

3.6 Conclusion

This study highlighted patient and caregiver experiences of advanced colorectal cancer care to inform a pathway to enhance early palliative approach to care. Early palliative approaches to care may be improved by consistent and routine delivery of palliative care information, involve collaborations among different disciplines such as oncology, primary care, and palliative care, and include patients and family caregivers in the development of care pathways. Future studies will examine the experiences of patients and family caregivers following the implementation of a pathway to support early palliative care approaches integrated with cancer-modifying therapies.

Declarations

Competing Interests: The authors declare that they have no competing interests.

Author's Contributions: AS, JS, and MS conceived and designed study. SA and SFN worked on the analysis and interpretation of findings, with feedback from AS, JS, GM, and MS. SA drafted the article, and all authors (SFN, AS, GM, JS, and MS) provided critical feedback and approved the version to be published.

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Data management and sharing: This study analyzes qualitative data and the participants did not consent to have their full transcripts made publicly available. No additional data.

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Author Details:

1. Department of Community Health Sciences, University of Calgary, Calgary, Alberta, CANADA
2. Department of Oncology, Cumming School of Medicine, University of Calgary, Calgary, Alberta, CANADA
3. Department of Family Medicine, Cumming School of Medicine, University of Calgary, Calgary, Alberta, CANADA
4. Faculty of Nursing, University of Calgary, Calgary, Alberta, CANADA
5. O'Brien Institute for Public Health, Cumming School of Medicine, University of Calgary, Calgary, Alberta, CANADA

Table 1. Supportive Quotes for themes identified

Theme	Description	Quote
Communication with and among care team	Frustration with triage line (after hours care)	“it's very frustrating because I cannot call the oncologist or even, you know, even her nurse... most of the time I am trying to ask her nurse because I know that she can ask the oncologist, but it's very difficult to get to her, so every time they say that “if you have any questions just call” I go “oh no.” Very frustrating. And sometimes you don't get a call back at all” (Patient B).
	Confusion regarding which care provider to see	“I had problems with my stoma- every time they change it, there's blood-- I don't know if I should go to my family doctor or the guy who did the stoma. Like you know who do you go see?” (Patient D)
	Preference for communication with care team about patient's wishes	“Many times, my husband would go with me to the oncologist which is normal. But I was never asked if I wanted him in the room...there were many times where I wanted to discuss things by myself without him there and I was never asked” (Patient I)
Relationship with Oncologist and cancer team	Improvement in relationship with oncologist	“The oncologist has since made good about telling us about other things that are out there and responding to some other things that we brought to his attention ... immunotherapy and clinical trials and genetic testing for markers and tumors and those sorts of things. So between our efforts and his efforts, which have been really good in the last couple of years..., that's how we've obtained further information” (Caregiver A).
Role of the Family Physician	Differences between the role of the FP and oncologist	“it's sort of a specialized care and once he [family physician] 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 ...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)
Meaning of Palliative care	Care teams need to explain palliative care to patients	“I'm just going to say when people say palliative care... when it's a doctors and nurse you know, in some cases, maybe have to take the time to describe what that actually means. Because I think there is a maybe a scary connotation to the term for some people” (Caregiver B)
		“no one has explained it to me other than saying you know once you stop treatment, you'll go to palliative care. That's as far as they have said.” (Patient I)
Patient and Family Engagement in Care	Patient identifies ways they have maintained their autonomy and engaged in their 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).
	Caregivers as advocates	“even though we were communicating that this pain is pretty bad and I'd go with her to every appointment, so even when she downplayed it, I would make sure that the nurse and doctor understood it's bad, bad enough that she can't get out of the bed most days. We waited until like literally a month ago to have a meeting with the pain team at the hospital and I'm really confused as to why that would happen” (Caregiver B).

	Patient found checklist useful	“I’ve filled it out many times... I did get a call back from the hospital once or maybe twice, which was very reassuring because I knew that somebody was actually looking at it” (patient C).
	Checklist isn’t enough to capture patient symptoms	“I think it’s more quantitative than qualitative... To me it doesn’t really say a whole lot. You can’t explain what’s going on.”
Readiness for Advance Care Planning	Need to feel ready for ACP conversations	“probably not until it's actually necessary. I know that sounds terrible, but I don’t know if I could deal with it right away... I think it's one of those things that information can be provided and when I’m ready, or you know at least provided to my family.” (patient H)
Access to Care	Preference for phone appointments	“chemo treatment is not really fun so she’s sick a lot of the time. It would be a heck of a lot easier for her if she didn’t have to you know get in the car and drive across town to the hospital and sit in the waiting room for you know for half an hour, 45 minutes. I guess I’m curious why is it not feasible to do little things over the phone.” (Caregiver B)

Figure 1. Gaps identified by patients and family caregivers in advanced cancer care

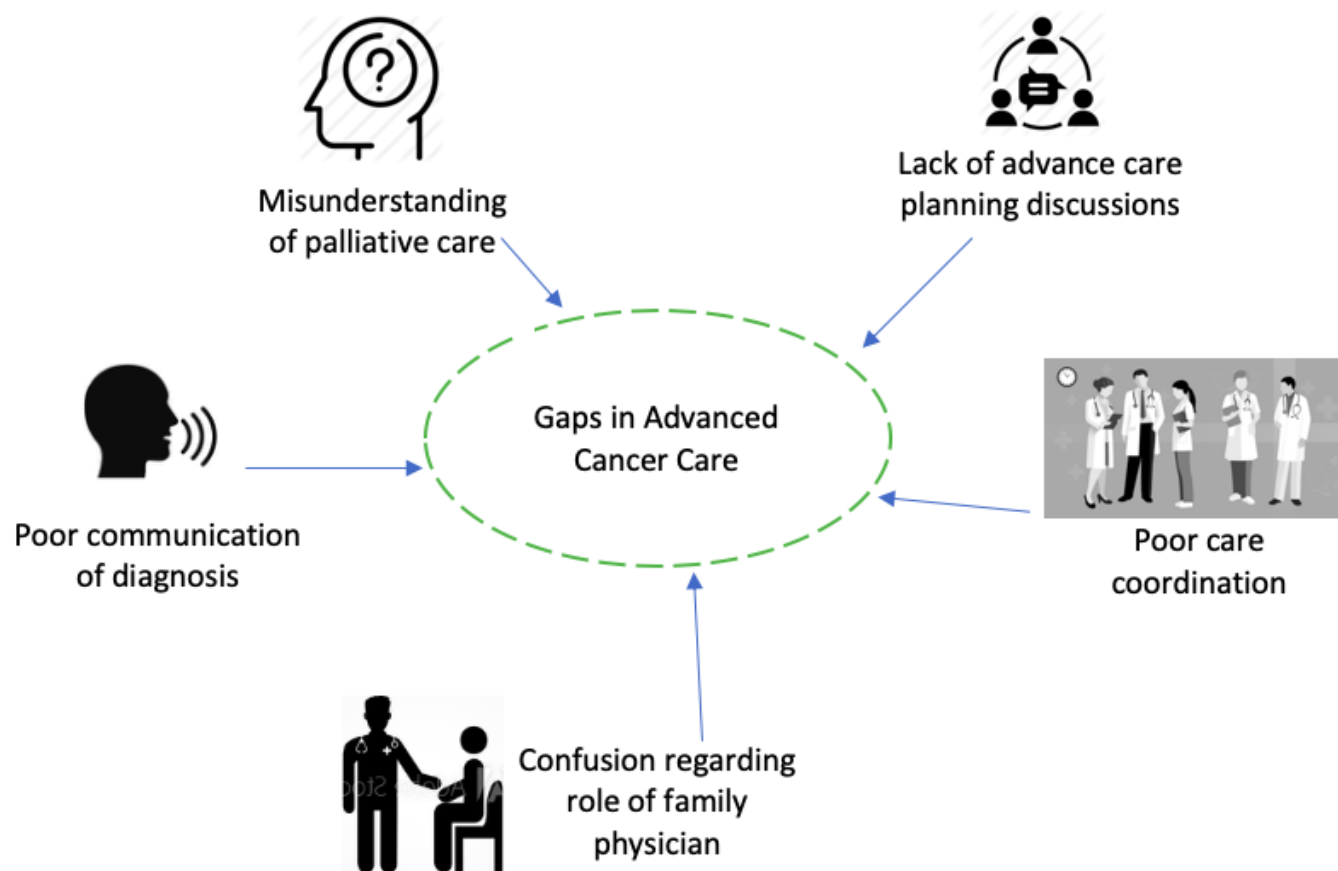
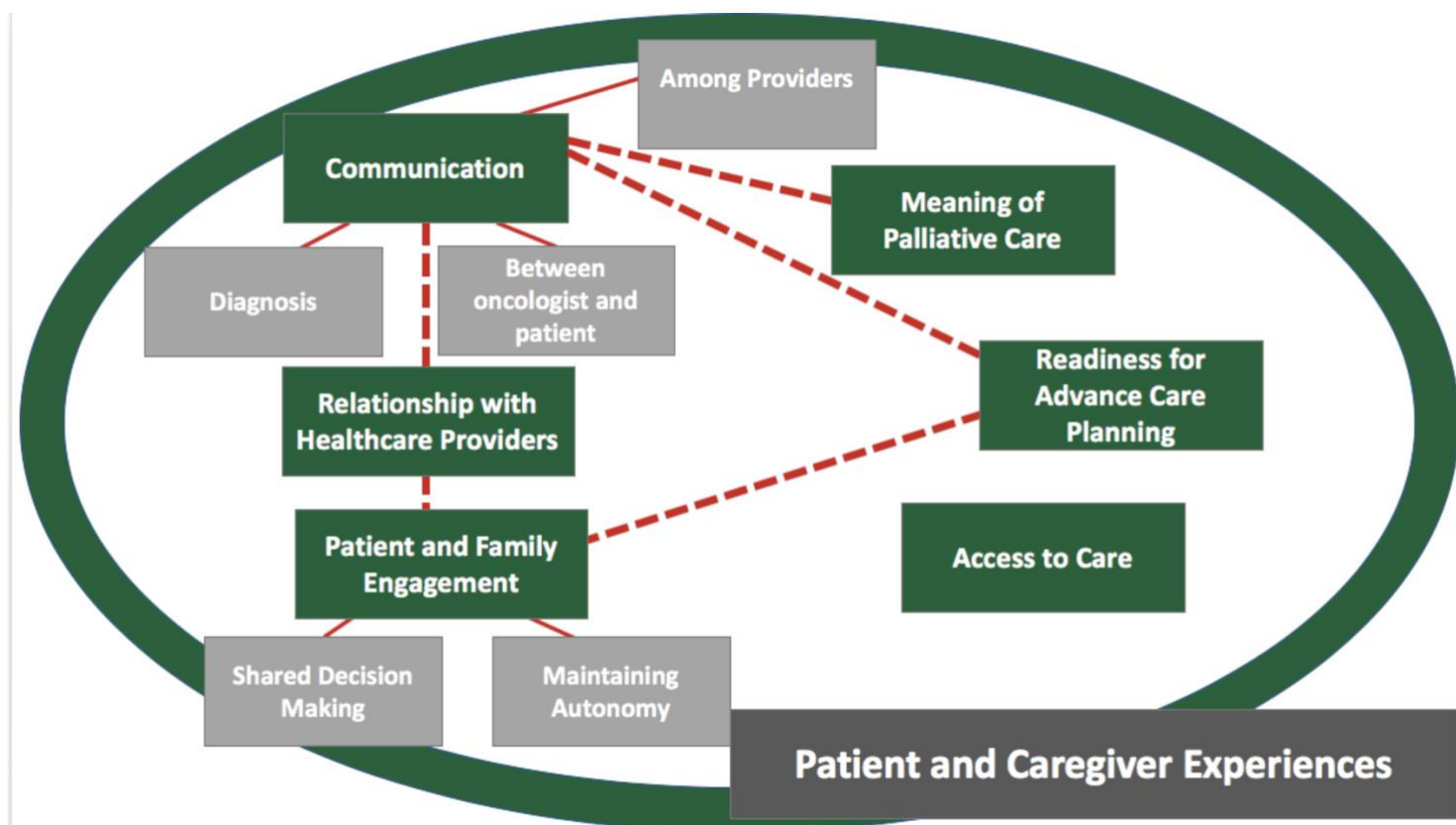


Figure 2. Coding Tree (Patient and Family Caregiver Experiences with Advanced Cancer Care)



CHAPTER 4

Patient and Caregiver Experiences Informing an Early Palliative Care Pathway

Sadia Ahmed, Syeda Farwa Naqvi, Aynharan Sinnarajah, Gwen McGhan, Jessica Simon, Maria J Santana

4.1 Abstract

Background and Aim

The Palliative Care Early and Systematic (PaCES) program in Alberta, Canada implemented an early palliative care pathway for advanced colorectal cancer patients in January 2019, aiming to provide specialist palliative care nurse consultative visits and palliative homecare support more than three months before death. This study aims to understand the experience of patients and family caregivers receiving early palliative care supports and compare those experiences with participants experiencing standard oncology care.

Methods

This is a qualitative and patient-oriented study. The interview was co-developed with patient and family advisors and oncologists on the team. Participants in Calgary were recruited from the specialist palliative care nurse over the phone, and followed up by a researcher after consent to contact was given. Semi-structured telephone interviews with patients living with advanced colorectal cancer and family caregivers were conducted to explore their experiences with an early palliative approach to care. Interviews were audio-recorded. Interviews were transcribed, and the data thematically analyzed supported by the qualitative analysis software, NVivo.

Findings

A total of 12 participants (7 patients, 5 family caregivers) were interviewed over the phone after implementation of the care pathway. Participants expressed that visits from their early palliative care

nurse was helpful, improved their understanding of palliative care, and improved their care. Four main themes shaped their experience of early palliative care: care coordination, perception of palliative care, coping with advanced cancer, and patient and family engagement. Main differences before and after implementation of the care pathway were in care coordination and communication with and among healthcare providers, understanding of palliative care, involvement of the family physician, and advance care planning discussions.

Conclusions

Early palliative care delivered by a specialist nurse can improve advanced cancer care, including an improved understanding and acceptance of early palliative care. This work was conducted in the context of colorectal cancer but may have relevance for the care of other advanced cancers.

4.2 Background

As a model, patient centred care emphasizes the needs, preferences, and values of patients to provide care.(4, 5) Palliative care has been defined as patient and family centred care that improves quality of life and addresses physical, emotional, social, and spiritual needs of patients.(6) Patients with advanced cancers often experience high symptom burden, and can have trouble coping with their illness. A palliative approach to care is recommended to provide optimal symptom relief.(7, 10-12) However, delivery of palliative care is inconsistent, with variations within jurisdictions impacting access to palliative care.(12) Among those with advanced cancers, there are some patients who were referred late to palliative care or not at all.(10, 82)

Organizations in North America such as Choosing Wisely(11) and American Society of Clinical Oncology (ASCO)(7) recommend the integration of early palliative care alongside usual oncology care, eight weeks into diagnosis for patients with advanced cancer. Additionally, delivery of early palliative care through an interdisciplinary palliative care team is recommended.(7) Multiple benefits to integrating early palliative care have been identified for both patients and healthcare systems such as reduced hospitalizations, and receiving care outside the ICU in the community where patients prefer. (83) Other studies have identified benefits to patient outcomes from early integration of palliative care(41, 84), such as improvements in quality of life, and patient and family caregiver satisfaction.(16)

Family caregivers have also been found to benefit from early palliative care, with a decrease in depressive symptoms,(17-19) stress burden,(19) and improvement in social functioning.(18)

Few qualitative studies have explored the impact of early palliative care on patients and families, especially from the patient and family perspective.(53, 55, 57) A greater understanding is needed on what matters most to patients and families to inform the delivery of early palliative care. An early palliative care pathway was implemented in Calgary, Alberta, Canada for advanced colorectal cancer, addressing the following components: understanding of illness and coping with advanced cancer, advance care planning and shared decision making, attending to symptoms and functional status, and

coordination of care.(41) A previous study was conducted on current cancer experiences of advanced colorectal cancer patients and family caregivers to inform development of the early palliative care pathway (chapter 3). This study aims to report patient and caregiver experiences after implementation of an early palliative care pathway, and compare their experiences to those who previously received standard oncology care.

4.3 Methods

The Health Research Ethics Board of Alberta Cancer Committee gave ethics approval for the proposed study (ID: HREBA.CC-18-0013) on February 2018.

Study Design

We conducted a qualitative patient-oriented study, embedded within an implementation of an early palliative care pathway for advanced colorectal cancer in Alberta, Canada (described below). A qualitative study design was chosen to gain in-depth understanding of the experiences of patients and family caregivers with an early palliative care pathway for advanced colorectal cancer. We employed semi-structured telephone interviews. The interview guide was developed in collaboration with clinician-researchers specializing in palliative care, and three patient and family advisors on the team.

Palliative Care Early and Systematic (PaCES) Care Pathway

All patients interviewed had received care after the implementation of the PaCES, an integrated early palliative care pathway for advanced colorectal cancer in the colorectal cancer clinics in Calgary, AB. This pathway includes guidelines for screening and referral of patients to early palliative care, identifying patient needs, primary palliative care management of unmet patient needs (by family physicians, oncologists, and nurses with training), and clinicians supporting advance care planning discussions, and specialist palliative care services to provide advice or care for complex patient

needs.(10) To facilitate care coordination and communication, a shared care letter was distributed to family physicians and to patients. Additionally, patients were referred to a specialist palliative care nurse to provide advice and care to address any complex needs of patients. Details of the clinical guideline can be found on the provincial health authority website.(10, 39)

Recruitment and Data Collection

The eligibility criteria for participants were patients with advanced colorectal cancer, older than 18 years of age who had at least one visit with a specialist palliative care nurse and with any of the following conditions: 1. Failed first-line chemotherapy (disease progression on imaging); 2. High symptom need (any score on the Edmonton Symptom-Assessment System Revised (ESAS-r)(18, 19) greater than or equal to 7); 3. Unable to receive first-line chemotherapy. Family caregivers of patients were also eligible to participate. A family caregiver was defined as a relative or friend of the patient (over the age of 18), whom the patient described as their primary caregiver (someone providing unpaid assistance and support to the patient). The family caregiver did not need to live in the same residence as the patient. Participants were phoned by a palliative care nurse specialist or told in person about the study. Participants completed a ‘consent to contact’ form if interested in being interviewed, and then were followed up by the first author for more information about the study, the role of the researcher and to schedule an interview time. Dyad participants (patient and their family caregiver), and non-dyad participants were recruited. Dyad participants were interviewed separately. Participants were offered a \$20 gift card as a thank you for their participation. We conducted interviews with patients and family caregivers from September 2019 to February 2020. All interviews were conducted by a qualitative researcher (first author), and were audio recorded. Notes were taken during the interview, and debriefing followed afterwards to address any questions the participants may have. Interviews ranged from 20 to 70 minutes. Interviews conducted prior to pathway implementation are summarized in a previous paper (chapter 3).

Conceptual Framework

The delivery of palliative care is patient centred, as it aims to consider patient preferences, values, and needs.(4) Therefore the Person-Centred Care (PCC) framework(5) was utilized to inform the interview guide and guide the analysis of the findings. The Person-Centred Care framework provides a roadmap for organizations to implement a person-centred care healthcare system. The framework consists of specific domains categorized under structure, process, and outcome following the Donabedian model of care.(63) Structure domains refer to the foundation of PCC- the necessary materials, healthcare resources, and organizational characteristics.(5) Examples of structure domains include creating a PCC culture, and co-designing the development and implementation of educational programs. Process domains refer to the interaction between patients and healthcare providers.(5) Examples include cultivating communication, respectful and compassionate care, and engaging patients in managing their care.(5) Outcome domains refer to the outcomes of care- the results of implementing the structures and processes of care. Examples of outcome domains are access to care, patient-reported outcomes (PROs), and cost of care.(5)

Data Analysis

Interviews were transcribed by two researchers, and the first author checked and corrected all transcriptions to ensure nothing was missed. We utilized the qualitative software, NVIVO to aid in data analysis. We conducted a thematic analysis of the transcripts to allow for the identification of themes and patterns, using the six-step thematic analysis process described by Braun and Clark(68). Coding was performed by two members of the research team, using a mix of deductive, inductive, and iterative coding strategies. Coding was deductive using some of the pre-determined codes from interviews conducted prior to implementation of the care pathway and using the Person-Centred Care framework as a guide for a coding book. As outlined in the Person-Centred Care framework,(5) the processes of care, referring to the interactions between healthcare providers and patients are most relevant to the findings

from this study, and were used to guide deductive coding for qualitative analysis. However, coding was also inductive as new codes were identified from the data that were not already included in the coding book. The coding process was also iterative as when a new code emerged, the transcripts were read again to ensure codes were not missed. After organizing codes into themes, they were presented to the research team, including patient and family advisors for feedback. The manuscript and results of this study are reported in accordance to the consolidated criteria for reporting qualitative research (COREQ) (Appendix C).(69)

We employed strategies to increase credibility, such as peer debriefing between team members including patient and family advisors to discuss themes identified. Complete records of the start of the research project to the end were kept, which transcripts and notes. This audit trail process is important in being transparent within the research process and therefore increasing dependability.

4.4 Findings

A total of 12 participants (7 patients, 5 family caregivers) were interviewed over the phone after pathway implementation. Participant age ranged from 36 to 86 years. Date of referral to a specialist palliative care nurse ranged from January 2019 to November 2019. Interviews were conducted eight months after implementation of early palliative care. At the time of the interview, patients reported having received palliative care support from one month to 12 months.

Patient and family caregiver experiences with early palliative care supports can be summarized into the following main themes: Care Coordination, Perception of Palliative Care, Coping with Advanced Cancer, and Patient and Family Engagement. Within care coordination, the following subthemes were identified: communication between healthcare providers, role of family physician, relationship with palliative care nurse. Within perception of palliative care, the subthemes: timing of palliative care, and meaning of palliative care were identified. Within coping with advanced cancer, the following subthemes were identified: support from family and friends, support from healthcare system,

strength in faith, value in independence, and advance care planning discussions. Within the theme patient and family engagement, the following subthemes were identified: taking initiative and being informed, patient advocacy, and use of Putting Patients First checklist to communicate with care team. Associated sub-themes are summarized in Table 1 to 3 with supportive quotes. Themes identified prior to implementation of the care pathway are summarized in Table 4. Figure 1 presents a visual summary of the findings. Study findings from interviews conducted with patients and families who received standard oncology care are reported in another article.

1.Care Coordination

Participants talked about their healthcare providers working together to provide care for the patient. Participants mentioned instances where they perceived teamwork and communication between the care team, especially between the oncologist, palliative care nurse, and family physician. Most participants talked positively about their care being coordinated by their care team. Participants referred to the palliative care nurse as aiding communication and helping to coordinate their care. One caregiver mentioned how they thought the communication between their palliative care nurse and oncologist was present and necessary to design treatment that provided the patient with the best quality of life: *“we don’t always see the direct interaction but we do get the feedback that the care staff (palliative care team) has been in touch with the doctor (oncologist). When we meet with the doctor (oncologist), the doctor will mention - she reviewed the palliative care report and understands the circumstance, a little bit more thorough. I think that’s good right now, your primary doctor understands the specialty treatment, the treatment is for the physical too, but if your doctor also has the understanding of the mental- how your patient’s doing...better prepared to design the treatment that’s going to provide the best quality of life.”* (Caregiver 5)

The family physician is another healthcare provider that most participants mentioned as an important member of their care team. Most participants saw their family physician and wanted their

family physician to be informed about their cancer care. The role of the family physician was identified as providing emotional support, managing pain, providing a holistic view of care, ordering prescriptions, going over reports during appointments received from other healthcare providers (bloodwork, CAT scans, etc), and managing other healthcare conditions. One patient mentions her preference for involvement of her family physician:

“yes he’s involved and informed, and I make sure that when they ask me about CT scans or MRIs - if I want any other doctor to look at them- I send them to him- because he phones me a lot to see how I’m doing.” (Patient 7)

Patients and family caregivers also developed a bond with their palliative care nurse and communicated with her about their care. Participants mentioned the palliative nurse was a liaison to other services and helped to coordinate their care. Participants described the interactions with their palliative care nurse to be patient centred. One family caregiver described the care provided by the palliative care nurse as genuine and thorough: *“she seems to have a genuine care for her- takes notes and asks a lot of questions - she touches my mom, basically to see how she’s doing- her hands , with the numbness and cracks in her fingers, and in her last visit my mom told her she had trouble with bowel movements so and she’ll kind of check on my mom and rub her stomach and refer some meds she should take- she’ll talk to the doctor about having some new meds.”* (Caregiver 4)

However, there were some areas for improvement in care coordination identified by two family caregivers. One family caregiver brought up a recommendation for the care team to outline the specific responsibilities of each service that is introduced. Sometimes, knowing which service to reach out to can be confusing for patients and families, and therefore communication about how the services work with each other is needed. Another family caregiver described the care as being coordinated, until the last day of the patient who passed away without having access to the early palliative care nurse, which resulted in the patient dying in hospital.

2.Perception of Palliative Care

Most participants found the timing and introduction of early palliative care to be appropriate, and participants emphasized earlier integration of palliative care to be most beneficial for patients and families. Most participants viewed the term palliative care to mean a broad, holistic care that improves quality of life. For some participants, their view of palliative care changed after speaking to the palliative care nurse. One patient notes the change in perception: *“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) However, there were still some participants that found the term held stigma and associated it with end of life.

3.Coping with Advanced Cancer

Participants described different sources to help cope with their cancer and care. Participants spoke about receiving support from family, friends, different healthcare providers in managing their care, and some participants talked about their faith bringing them strength. Some participants also mentioned how their palliative care nurse specialist facilitated access to different resources such as a therapist. Participants appreciated both the informal and formal supports they had received throughout their care. One patient described respectful and personalized care from two healthcare providers, the pharmacist and dietician in helping her with the symptoms of her chemotherapy: *“I wasn’t able to eat very well when I was on chemo...I contacted the dietitian and she was super helpful...She sent me recipes, she talked to me over the phone and the pharmacy- after the chemotherapy which was really powerful, I had neuropathy in my feet...So I was just sitting at home crying and they finally got me onto this medication which didn’t really do much but they also found me a dedicated pharmacist- ...she would call every week to see how I was doing with the neuropathy, what was changing. She was absolutely fantastic.”* (patient 7)

Some participants also talked about valuing their independence and being able to do things on their own. For one patient, this meant he did not feel he needed the support from the palliative care nurse and homecare, due to being able to work on his own and having the support of his wife.

For most participants, the palliative care nurse facilitated advance care planning discussions. Most participants had discussed their goals of care, wishes and preferences, values, and end of life planning with their care team (including with family members). Some participants described these discussions took place even before meeting with their palliative care nurse. Participants described discussions with their palliative care nurse to be helpful and did not feel pressured during the process. One caregiver describes the process of revisiting their goals of care: *“recently we changed those goals of care with the help and advice of the palliative care nurse we found that very helpful. Again they had a holistic landscape of the situation to help you make that decision. And the implications of those various choices”* (Caregiver 3) However, for two patients, they did not feel they needed to have advance care planning discussions early. For these two patients, they did not have any discussions about advance care planning yet, therefore lack of information may have impacted their readiness for these discussions. One patient associated advance care planning with end of life planning and did not feel like they could plan that. This patient also associated palliative care with end of life care, which may have impacted his readiness for advance care planning, *“It’s difficult for me to say where I would end my life. How or where I would like to be or go and so on but none of that, I don’t have any interest in that...To end in a hospital that’s okay for me I told that, if it’s at home that’s okay. I just cannot plan that. It’s something I don’t believe I have any control over- planning”* (Patient 4)

4.Patient and Family Engagement in Care

Most participants described being well informed about their cancer care, and services offered to them, even before seeing the palliative care nurse. Having information available to them and being well informed helped participants to make decisions about their care. Some participants talked about their

care team engaging them in their care and supporting them in making decisions. For instance, one patient spoke about their palliative care nurse supporting her in decision making process: *“he’s (husband) here pretty much every visit that she comes for so he can be part of the discussion very good at sharing all kinds of information, very good at giving us space to make decisions. There’s never been any question on who’s making that decision. We’re given time, we’re given space, and we can ask questions. I’ve stumbled into a team with really good folks”* (Patient 6)

Some participants also mentioned the importance of advocating for your care, as sometimes patients can be pressured into decisions on treatments. Some family caregivers brought up the need for a patient advocate/navigator in the healthcare system, especially if patients didn’t have a support system early on in the cancer journey: *“when I’m dictator, there will actually be a patient navigator who actually acts like that who can navigate the system, and has a holistic view of the landscape and can say this - now that we know who you are and what your wishes are”* (Caregiver 3)

These family caregivers noted either a poor experience with a patient navigator or not having that support early in to the patient’s diagnosis of advanced cancer care.

Participants were asked to fill out a patient-reported outcome measure at their appointments (Putting Patients First checklist), which outlines symptoms and concerns patients may have. Most participants found this checklist useful in guiding the focus of appointments and being able to communicate more openly with their oncologist. One caregiver mentions how it can be difficult for patients to talk about their concerns, so having the checklist opened up communication: *“you know what? It is my mom, it’s very difficult to talk about herself and her symptoms. So usually kind of the week before we’re going there, we sort of talk about it. So then when we’re filling out the form before she sees a physician, it’s easy”* (Caregiver 1)

Comparison with patient experiences prior to palliative care pathway (Appendix G)

Care coordination and communication with healthcare providers was identified as important to patients and families. Compared to interviews conducted before implementation of the care pathway, **care coordination was identified as an improvement.** Involving the oncologist, family physician, and palliative care nurse specialist made participants feel they were well supported. Participants mentioned the palliative care nurse as a liaison to allow for greater access to care and ensuring they received timely care. Participants interviewed prior to the palliative care pathway expressed frustrations with their care providers not communicating with each other. However, in these interviews, while participants did not observe direct communication, they received feedback and assurance that their providers were in contact and coordinating their care.

There were also differences in how participants perceived palliative care between the two sets of interviews. Most participants interviewed prior to pathway implementation were either unsure what palliative care meant or associated it with end of life or death. In the interviews conducted post-implementation, most participants described palliative care as more holistic and encompassing quality of life. However, there were still a couple of patients that were concerned the term held stigma, especially when discussing their care with others.

Involvement of the family physician was another improvement after implementation of the early palliative care pathway. Interviews pre-implementation revealed mixed views on involvement of the family physician in cancer care. Some participants in the pre-implementation interviews found the role of the family physician in cancer care to be unclear, and some participants did not see their family physician on a routine basis. However, interviews conducted post-implementation revealed most participants involving their family physician in their care and finding that their family physician was well informed about their care. Participants also identified clear roles for their family physician including providing emotional support, managing physical symptoms, and informational support (going

over their reports with them). Most participants in our study found the involvement of their family physician to be helpful and appreciated the support.

Another component to the early palliative care pathway is **discussions about advance care planning** which include discussing preferences, values, and wishes of patients and families. Most participants interviewed pre-implementation did not have advance care planning discussions with their care team and had mixed views on the timing of these discussions. However, interviews conducted with participants post-implementation of early palliative care revealed most participants having discussed advance care planning with their care team and having their wishes documented. Participants valued being engaged in the process and feeling in control of their decisions. Participants identified the palliative care nurse as someone they spoke to about advance care planning, who helped to facilitate this process.

4.5 Discussion

Both patients and family caregivers highlighted important aspects of palliative care shaping their care experience that were patient centred. From our interviews, participants described experiencing respectful and coordinated care while receiving cancer care.

Care coordination and communication are essential in the delivery of patient centred care.(5) In the Person Centred Care framework, sharing of patient information between healthcare providers is necessary, as well as providing access to information and resources to patients and families.(5) In our study, care coordination was found to improve after implementation of the early palliative care pathway. Early palliative care integrated with oncology care can facilitate coordinated care, a finding also identified by Hannon et al.(56) Participants in our study described a positive patient centred relationship with the palliative care nurse, describing the interactions as genuine. Similarly, in the Hannon et al.(56) study, participants described the relationship with their palliative care physician as comfortable and personal. The palliative care nurse may also fulfill the role of a patient navigator, as

some family caregivers emphasized the importance of that support early on in the patient's cancer trajectory. Improved communication between patients and healthcare providers was also found in other studies integrating palliative care.(58, 85) In our study, only one family caregiver was interviewed whose spouse had passed away, therefore the family caregiver brought up an important recommendation of ensuring patient preferences are attended to on their last day.

In our study, most participants had an improved understanding of palliative care after discussions with the palliative care nurse, similar to the study by Fliedner et al.(55) However, there were still a couple of participants who noted the term palliative care can be stigmatizing in our study. Perception of palliative care can be a barrier to referral to palliative care. The study by Hannon et al(53) also found some participants perceived palliative care negatively, impacting how comfortable they were with palliative care supports. In the study by Zimmermann et al(52), most participants found the term palliative care stigmatizing, and didn't think the supports they were receiving should be named palliative care.

Involvement of the family physician was important for participants interviewed after the early palliative care pathway, and most described their family physicians involved in their care. This finding is similar to a survey conducted with patients in Germany about their view of care provided by their family physician.(86) 85.5% of patients in that study wanted their family physician to be informed about their cancer therapy on a regular basis, and were supported by their family physician in cancer care.(86) In Zimmerman et al.(50) early palliative care trial, where routine communication with family physician was a component of the intervention, patient satisfaction with care significantly improved as well. Shared care model for cancer care is recommended, with some programs in Canada involving family physicians in integrating palliative care in their practice.(87)

Advance care planning discussions are an important component to the early palliative care pathway, and most participants interviewed after pathway implementation positively described their experiences with advance care planning discussions. Similarly, other studies delivering early palliative

care also found advanced cancer patients were able to manage discussions about advance care planning and found them beneficial.(53, 55)

Strengths and Limitations

While quantitative studies can provide information on effectiveness of early palliative care, a strength of this qualitative study is that it provides more in-depth understanding to the care experienced by patients and family caregivers. This study identified aspects of the PaCES early palliative care pathway that were beneficial for patients and family caregivers, and aspects of care that they valued. Another strength of this study is the comparison of care experiences before and after implementation of the care pathway, to inform improvements in early palliative care. A limitation of this study may be that different participants were interviewed before implementation of the care pathway and after, so we did not observe differences among the same participants. We were not able to understand whether attitudes/perceptions of palliative care and care experiences have changed over time from current cancer care to the implementation of early palliative care. However, our participants have an advanced cancer diagnosis (with a prognosis of 6 to 24 months), therefore it was not possible to have participants participate in two interviews due to the time frame of the study. Additionally, the interviewer from study one could be seen as influencing perceptions of palliative care, therefore it was important to interview a different set of participants after implementation of the care pathway to mitigate interviewer influence on participant views. Rather than understanding whether care experiences have changed, we focused on the differences and similarities in the care experiences and perceptions in the two qualitative studies. Additionally, all patients were similar in their health condition (advanced colorectal cancer).

4.6 Conclusions

Early palliative care delivered by a specialist palliative care nurse can improve advanced cancer care, including an improved understanding and acceptance of early palliative care. Incorporating patient

perspectives in the implementation of care pathways can ensure the priorities of patients and families are at the forefront of care. This study used a patient-oriented approach in the design and in identifying what matters to patients and family caregivers in early palliative care. This study is the first in Alberta to compare experiences of patients and family caregivers before and after implementation of an early palliative care for advanced cancer. The PaCES program is currently implemented in Calgary for advanced colorectal cancer however it can likely be expanded to other centres and other cancers as none of the findings appeared specific to colorectal cancer. Future studies could examine whether this care pathway can be implemented in other non-cancer diseases and compare the experiences of patients across different conditions.

Declarations

Competing Interests: The authors declare that they have no competing interests.

Author's Contributions: AS, JS, and MS conceived and designed study. SA and SFN worked on the analysis and interpretation of findings, with feedback from AS, JS, GM, and MS. SA drafted the article, and all authors (SFN, AS, GM, JS, and MS) provided critical feedback and approved the version to be published.

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Consent for Publication: Not applicable

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Data management and sharing: This study analyzes qualitative data and the participants did not consent to have their full transcripts made publicly available. No additional data.

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Author Details:

6. Department of Community Health Sciences, University of Calgary, Calgary, Alberta, CANADA
7. Department of Oncology, Cumming School of Medicine, University of Calgary, Calgary, Alberta, CANADA
8. Department of Family Medicine, Cumming School of Medicine, University of Calgary, Calgary, Alberta, CANADA
9. Faculty of Nursing, University of Calgary, Calgary, Alberta, CANADA
10. O'Brien Institute for Public Health, Cumming School of Medicine, University of Calgary, Calgary, Alberta, CANADA

Table 1. Care Coordination

Subtheme	Quotations
Communication between healthcare providers (PC Nurse, Oncology team, and FP)	<p>“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)</p>
	<p>“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)</p>
	<p>“The oncologist asked me, that they have a nurse who deals with palliative care, and if she could visit me. And I agreed to that, and she told me when I last spoke to her, that she checks up about me with the oncologist, so they’re in contact.” (patient 4)</p>
	<p>“I’m glad that my doctor- oncologist talked to my doctor and asked if he would be willing to look after some of the cancer- stuff and he said yes- he’d be more than happy to do it. So everybody really has been so good.” (Patient 5)</p>
	<p>Suggestion: “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. There’s only so much you can remember as you get older.” (Caregiver 5)</p>
Role of Family Physician	<p>“he’s been mum’s physician for a long, long time. So just having him support anything that’s going on is, you know... my mom’s very comfortable with him. And so, it just and it helps support the treatment he manages. You know, does the reorders for her steroids and that kind of stuff.” (Caregiver 1)</p>
	<p>“_____ 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. You know we were grateful for the specialist but it was almost like a man with a hammer- who sees everything with a nail...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)</p>
	<p>“yes he is he’s a longtime family doctor and has become a personal friend over the years and is very concerned about my case so yes he’s involved and</p>

	<p>informed, and I make sure that when they ask me about CT scans or MRIs - if I want any other doctor to look at them- I send them to him- because he phones me a lot to see how I'm doing... I know he thinks he let me down because we didn't find it sooner, but it's not his fault. That's to say he's very involved and concerned." (Patient 7)</p> <p>"he (FP) talks to me haha... and then he always goes over the results of any tests and that- and I mean the oncologist always goes over the tests from the scans and then he follows through and wants to know how I'm doing with this and that and the others, so he's following. If I have any problems and ...if he doesn't know the answer, he'll get in touch with the oncologist." (Patient 5)</p>
Relationship with Palliative Care Nurse	<p>"I think my concerns- she takes note of it and she has told me personally that she would pass on the information to the oncologist. And it's been helpful too, when I had a fever and she came in to check on me, she directly called my doctors office....It puts my mind to rest I think, having that extra support because I've had to call the triage and so that takes hours for them to call back, and you know they're busy so for a nurse to call back and that nurse that may be calling me back from the office, may have never seen me before. So I like the idea that I can call the palliative care nurse, and you know I can get a hold of them right away or they'll call me back shortly there after." (Patient 1)</p> <p>"____(PC nurse) is somebody that I've been so impressed with, and I really enjoy her, quite lovely, but also what she recommends and anytime she does make a recommendation it's actually quite solid and down-to-earth and practical I really like that. And you know 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>

Table 2. Perception of Palliative Care

Timing of Palliative Care	“then more recently when we were put with the palliative homecare team, then again made sense the timing was correct- xxx (patient) was starting to weaken and when it was suggested during a regular appt with the medical oncologist, everybody was in agreement that this was the right time to get back in touch with those folks to maybe look into some things to help us out. So I would say the timing is appropriate.” (Caregiver 3)
	“I feel like it’s pretty good, i think the earlier the better. Even though there’s some stigma associated with it, if you’re talking to someone about palliative care that means you’re down the path along that end of life journey. For us, and I can’t speak for anyone else. 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 and to know there’s services out there” (Caregiver 5)
	“I think earlier on is better. Yeah, so that was right after the diagnosis that I had that it had spread right to my liver. It wasn’t stage 3 anymore, it was stage 4. So, at that point, and it was early on so that’s better so you kind of get accustomed to it. And earlier on I think is better than later.” (Patient 1)
	“I don’t know how she could provide a key that I don’t need right? I could do everything myself right now, and I would not want to waste anyone’s time if they just come to check up on me. If I felt the need for a person, you know and 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	“we had lots of discussions about this because mom was quite upset about being followed by palliative care. So, we certainly had the discussion that this is not end of life care, but this is more about controlling your symptoms. But palliative care claim to fame is to make people comfortable and more ethical with what we’re trying to do” (Caregiver 1)
	“quality of life, there’s no remission- palliative, well you’re terminal not immediately necessary, you’re not at the end stage. It’s quality of life as disease progresses. So it’s dynamic and not linear thing” (Caregiver 2)
	“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)
	“palliative care is someone that comes in and helps you adjust to what you do living day to day and I know it can mean that you may have to go into

	palliative care somewhere. But I think its just the first step in looking after the treatment as it goes along.” (Patient 5)
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Table 3. Coping with advanced cancer

Subtheme	Quotations
Support from family and friends	“my parents have a lot of friends, they have a huge social - it definitely made it easier for us, because they’ll come by and take my mom and dad out for like coffee. My mom loves ping pong and there’s a club where they all have their friends, so that’s where she’ll meet , and go and play some ping pong. If it was just the family, it would be really hard. So it’s nice to have friends who step up to the plate and make it easier” (Caregiver 4)
	“a really good home caregiver is also a really good gate keeper. If you got somebody who can manage, and it could be a friend doing it too, it could be your spouse, but the gate keeper who says ‘she’s not having company today, she’s too tired’” (Patient 6)
Support from healthcare system	“But for myself I could use a bit of support and it’s nothing to do with the cancer, but more so my relationship with my mom, so I don’t what they do there- I can find out by going, I’m sure I can find a counsellor” (Caregiver 2)
	“She (<i>oncologist</i>) was accepting of the fact that xxx(patient) was talking to the herbalist-- and was okay with that- as well as the naturopath who was giving her vitamin c- umm the herbalist xxx had been seeing for years and the naturopath xxx sought out and started to see. None of these were referrals from the conventional medicine world. What she did wind up with is someone from the conventional medicine world who was tolerant and sympathetic.” (Caregiver 3)
	“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)
	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)
Strength in faith	“I’ll also wish to mention here that I’m a bible believing Christian. I live my entire life by faith. F A I T H not F A T E. I don’t live my daily life by hope, I live my life by faith in the lord Jesus Christ. And it has been that way not since

	I've had cancer but from the very beginning of my life, I grew up in a Christian family and still do it that way." (Patient 4)
	"I just take it as it comes that way and I have a pretty strong faith...I go to church too that supports me as well." (Patient 1)
Value in Independence	"I don't feel I need anything. Because if I ask somebody come cut my grass, 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)
	"xxx (patient) always took responsibility for all the decisions that were made uhh we both felt that because it's her body and her life so it's really her decision but i believe she was always grateful to have me present and attended any sessions of any significance" (Caregiver 5)
Advance Care Planning Discussions	"recently we changed those goals of care with the help and advice of the palliative care nurse we found that very helpful. Again they had a holistic landscape of the situation to help you make that decision. And the implications of those various choices. And they helped us to change the goals of care at the foothills hospital" (Caregiver 3)
	"At first I just looked at it, didn't wanna do it. it took me time to accept as your mind kind of relaxes, and you think yea maybe we should plan for it. It's going to happen so it's good to be prepared. So yea I said I was going to take care of it, and gave my mom and dad the official sign, and put it in place" (Caregiver 4)
	"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 to have somebody been assigned to help you dance around the issue all the time and poking at it for both of us 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)
	"it was tough, emotionally difficult, but was handled well and was handled in a way -- she said you don't have to focus too too hard on it right now, but something to think about. There wasn't too much pressure or anything."(Patient 2)

Table 4. Patient and Family Engagement

Subtheme	Quotations
Taking initiative and being informed	<p>“I probably ask way too much, I get copies of the blood work...It’s almost like if you’re interested and take an interest in understanding the disease and symptoms and treatment management, then the doctors are really helpful. They know that you want to learn and understand and how you can be of help to them and the patient... I am, and also how available. I also think I’m very fortunate because I am retired and can spend that. I’m not sure what i would do if I was still working. We would have to have made some serious changes, and serious decisions.” (Caregiver 5)</p>
	<p>“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)</p>
Patient Advocacy	<p>“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)</p>
	<p>“The patient is the quarterback. And whether we like it or not, we have to get educated on what’s going on because decisions will be made that we don’t understand or might not like.” (Caregiver 3)</p>
	<p>“but the medical side, they were fighting me so that was tough it was very tough to stand up to that medical team when you know this is a very personal decision do you know what you do here in the circumstances and I said I know what I need to do and I’m doing it, but they really had a hard time with it really really had a hard time with it.” (on choosing to stop chemo) (patient 6)</p>
Use of PPF checklist to communicate with care team	<p>“they refer back, they address anything that has changed, and if anything is particularly high, they’ll delve into that deeply and uh yea that is an invaluable tool” (Caregiver 2)</p>
	<p>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)</p>

	<p>“That sheet we fill it out religiously, I think it’s helpful, we get copies of reports that come back and we always look at them and see okay this is where we are at” (Caregiver 5)</p>
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Figure 3. Patient and Family Caregiver experiences after receiving early palliative care

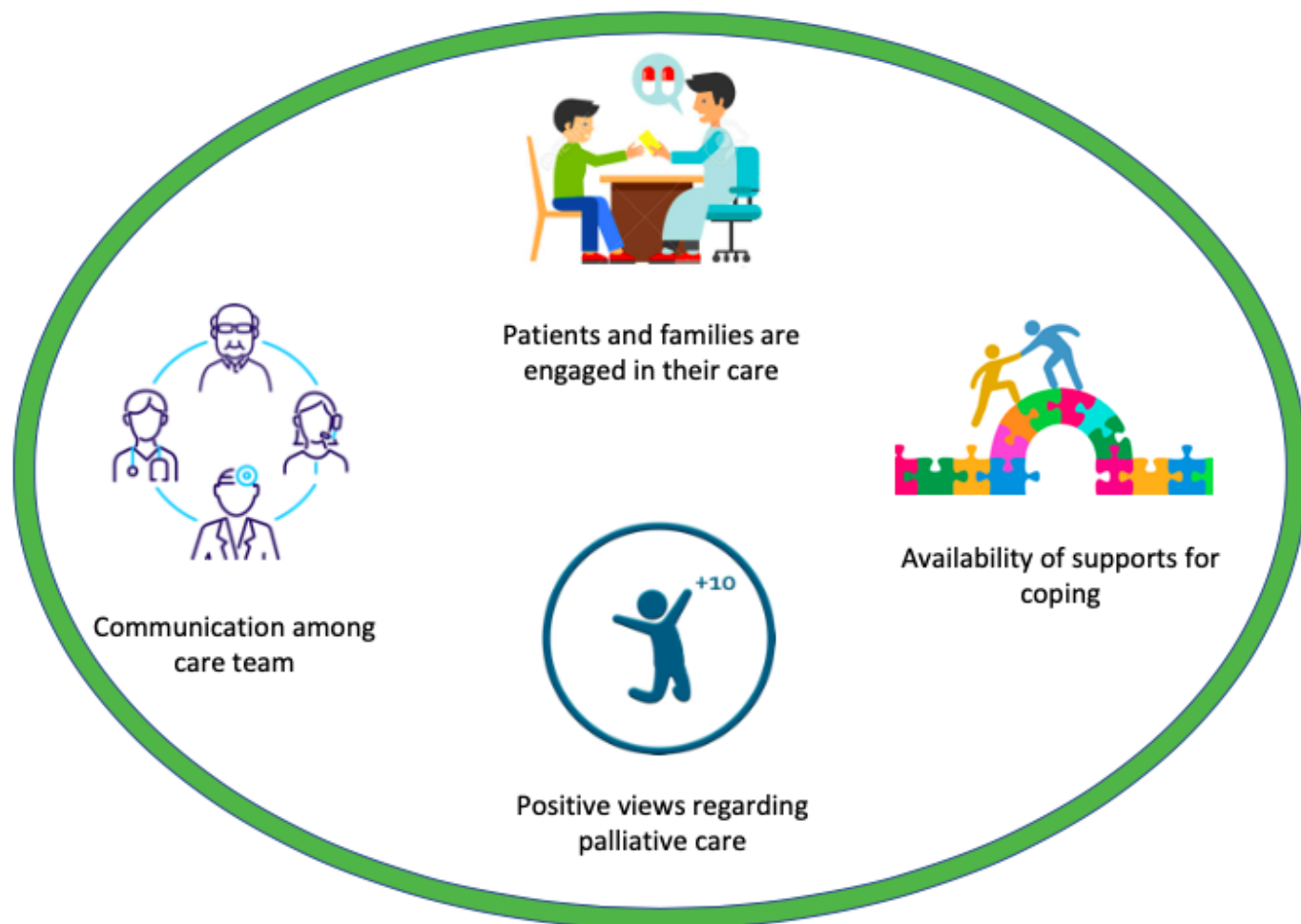
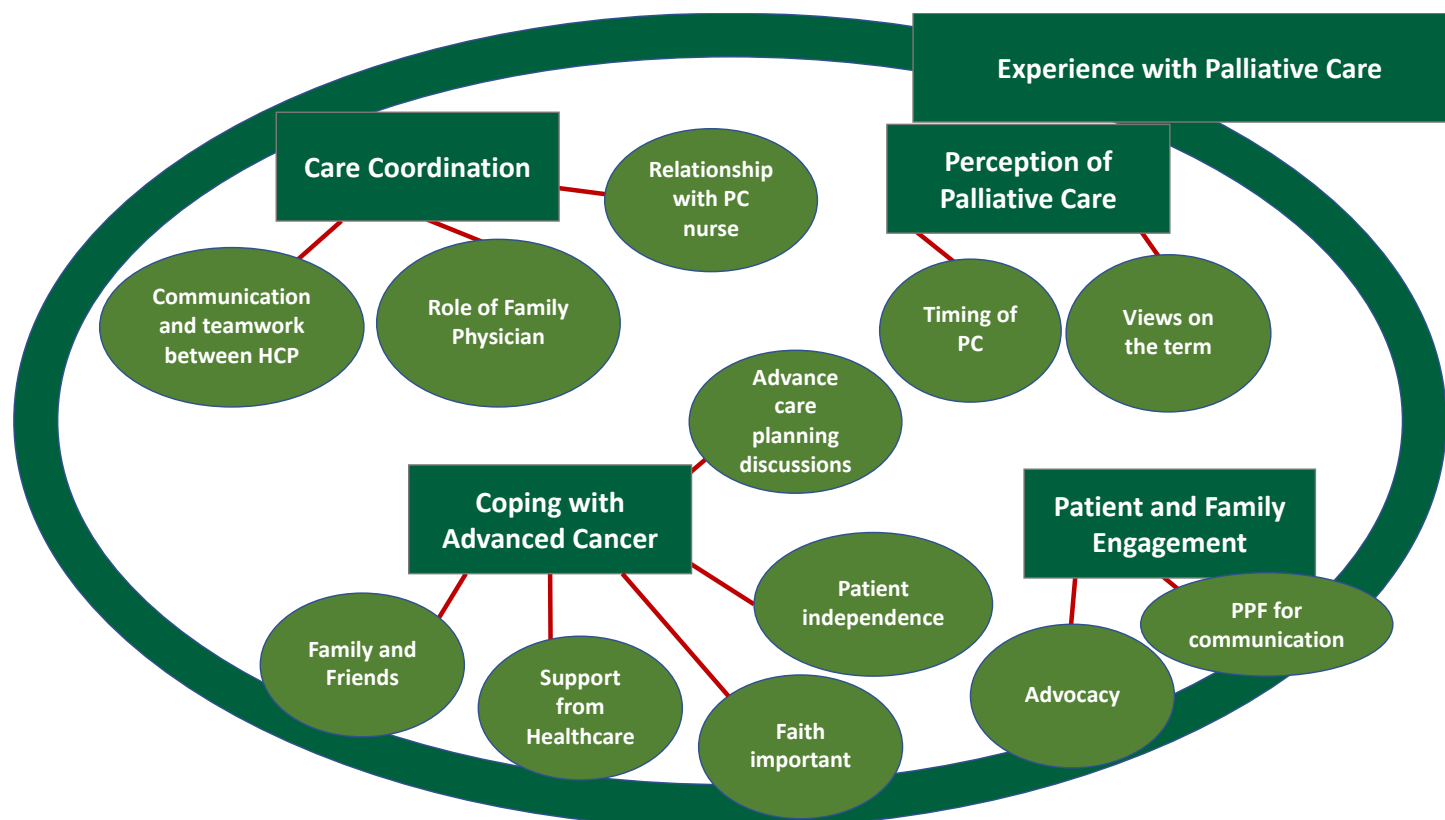


Figure 1. Patient and Family Caregiver experiences after receiving early palliative care

Figure 4. Coding Tree (Patient and Caregiver Experiences with Early Palliative Care)



CHAPTER 5- Discussion

5.1 Summary of early palliative care literature

Early palliative care is an emerging field, therefore there are an increasing number of studies examining the benefits of early palliative care, and the evidence base identified for outcomes such as quality of life, physical symptoms, and mortality is growing. The few trials that have been identified show promising findings for benefits to patients and caregivers. There is a need for further investigation in early palliative interventions among different populations and settings. Additionally, few studies have been identified examining the impact of early palliative care from the patient and caregiver perspective. Our study fills this gap in the literature by comparing the experiences of patients and family caregivers prior to an early palliative care pathway implementation and post-pathway implementation.

5.2 Summary of Main Findings

Prior to early palliative care pathway implementation

The interviews conducted prior to the implementation of the care pathway were necessary to understand current views of palliative care and gaps in oncology care in Alberta. In paper one, we interviewed patients with advanced colorectal cancer and family caregivers from Calgary and Edmonton, Alberta. Participants in these interviews received standard oncology care. From those interviews, we were able to identify aspects of oncology care needing improvement, that could be incorporated in an early palliative care pathway. Main themes identified from paper one were: 1. Communication with and among Care team (including communication of diagnosis); 2. Relationship with Healthcare Providers; 3. Meaning of Palliative Care; 4. Patient and Family Engagement; 5. Readiness for Advance Care Planning; 6. Access to Care. Participants identified the importance of communication among healthcare providers to provide coordinated care. Some participants expressed frustrations with the lack of care coordination, impacting timely patient centred care. Participants also valued the relationship with their oncologist, and they mentioned having trust in their oncologist for

their care. In contrast, the relationship with their family physician was mixed, as some participants expressed not seeing their family physician often and not finding a need for the family physician. The role of the family physician during cancer care was also unclear for some participants.

Most participants misunderstood palliative care to mean end of life and preparation for death, or were unclear about what it meant. Readiness for advance care planning discussions was mixed, as most participants did not have advance care planning discussions with their care team. These findings present some opportunities for improvement through integration of an early palliative care approach.

After implementation of the early palliative care pathway

In paper two, implementation of an early palliative care approach included the introduction of an early palliative care nurse specialist. We interviewed patients with advanced colorectal cancer and family caregivers in Calgary, AB on their experiences with early palliative care supports, and views on palliative care and advance care planning. Main themes identified in these interviews were care coordination, perception of palliative care, coping with advanced cancer, and patient and family engagement. Participants expressed that visits from their early palliative care nurse were helpful, improved their understanding of palliative care, and improved care coordination. Most participants also wanted their family physicians to be involved in their care, and found their family physician to be a support during cancer care. Participants found there to be improved communication and timely care after receiving early palliative care support. Most participants perceived palliative care positively as supporting them day to day, and aiming to improve their quality of life. As a result of the early palliative care pathway, participants were able to become better informed about their care, and felt they were engaged in their care. Receiving support from the palliative care nurse and other members of the care team helped participants cope with their cancer care.

5.3 Comparison of Findings and Alignment with Literature

Themes identified in our interviews from paper 2 align with the early palliative care approach to care. These include care coordination, patient and family engagement, coping with advanced cancer, and patient understanding of the meaning of palliative care. These themes also encompass domains of patient centred care. Comparison of participant experiences before and after early palliative care pathway implementation will be expanded within these broad themes.

5.3.1 Care Coordination

Care coordination is defined using these five key elements: 1) involvement of numerous health care providers, 2) providers dependant on each other to carry out separate activities in a patient's care, 3) provider knowledge about their role and role of others and other resources, 4) providers relying on each other for exchange of information, and 5) integration of care activities having the goals of facilitating appropriate delivery of healthcare services.(88) The aim of care coordination is to provide patients with the right care, at the right time, in the right setting.(88) Care coordination is described as an essential component of an early palliative approach to care, and was identified as important to patients and family caregivers in our study. Additionally, care coordination and communication are essential in the delivery of patient centred care.(5) In the Person-Centred Care framework, sharing of patient information between healthcare providers is necessary, as well as providing access to information and resources to patients and families.(5) In paper one, participants mentioned lack of communication among healthcare providers as well as lack of involvement of the family physician. In the PaCES early palliative care pathway, a palliative care nurse specialist was introduced in the care team to meet and follow up with patients and families. In paper two, care coordination was identified as a main theme and following subthemes: communication between healthcare providers, role of family physician, and relationship with palliative care nurse. Participants thought their care was coordinated, as most participants indirectly saw communication among care providers through sharing of reports and follow up with care providers.

Additionally, they felt they received timely care, through the support of the palliative care nurse specialist.

In paper one, participants had mixed views on the role of the family physician in advanced cancer care. Some participants had poor communication and relationships with their family physicians which may have impacted their desire for involvement of the family physician. Some participants in our study also found the communication and appointments with their cancer team was sufficient for their care. Aabom et al,(77) also found patients with advanced cancer often lose touch with their family physician, due to receiving treatment and developing relationships with their cancer team. In paper two, we notice a shift in the perception of patients and family caregivers, as most participants saw their family physician, and appreciated involvement of their family physician in their care. Other studies have also found patients want continued involvement of the family physician in advanced cancer care, for instance in emotional support, information transmission, and symptom relief.(89) In Zimmerman et al.(50) early palliative care trial, where routine communication with family physician was a component of the intervention, patient satisfaction with care significantly improved as well. Communication between the oncologist, family physician, and patient via a shared care letter is a component of the PaCES intervention. Our two qualitative studies conducted pre and post early palliative care pathway implementation suggest an improvement in family physician involvement due to the use of shared care letters. However, other early palliative care interventions do not report any differences in family physician involvement. Other studies examining early palliative care trials and patient experiences with early palliative care do not report the role of the family physician in coordination of care. Therefore, the improvement in family physician involvement following an early palliative care pathway may be a novel finding from our study. Shared care model for cancer care is recommended, with some programs in Canada involving family physicians in integrating palliative care in their practice.(87)

The addition of the palliative care nurse specialist in the care team was most beneficial for participants in facilitating communication and access to different care providers and resources. Early

palliative care integrated with oncology care can facilitate coordinated care, a finding also identified by Hannon et al.(56) In their study, concurrent palliative care alongside oncology care made the experiences of patients and caregivers more satisfactory and holistic, and also helped to provide timely and efficient care.(56) Participants in our study described a positive patient centred relationship with the palliative care nurse, describing the interactions as genuine. Similarly, in the Hannon et al.(56) study, participants described the relationship with their palliative care physician as comfortable and more personal. Improved communication between patients and healthcare providers was also found in other studies integrating palliative care.(58, 85)

5.3.2 Patient and Family Engagement

Engaging patients and families in their care and in shared decision making is necessary for the delivery of patient centred care.(5) In the Person-Centred Care framework, providing necessary information to patients, discussing and engaging patients and families in care plans is described as necessary to build communication and engage patients in managing their care.(5) In both papers one and two, participants wanted to be involved in their care and be an equal member of the care team. In both papers, most participants described wanting to know more about their cancer, and some participants talked about being well informed through their care team. In paper two, with involvement of both the early palliative care nurse specialist and family physician, participants mentioned being engaged in shared decision making. Participants talked about their care providers giving them enough information to feel comfortable in the decisions they made. Patients in our study also mentioned how their family caregiver was involved at every step and was present at key appointments. Maintaining autonomy is also something participants in both papers mentioned, and valuing their independence. In the early palliative care trial by Yoong et al.,(90) involving and engaging family members was prominent in all palliative care clinic visits. Similar to our study, Yoong et al.(90) found palliative care clinicians engaged patients and families in decision making about treatments and the effects it would have on them. Akyar et al.(58)

also described patients and caregivers in their early palliative care trial were engaged in asking questions and were encouraged to talk to their healthcare providers about various treatment decisions.

In our study, a Putting Patient's First checklist was used to keep track of symptoms patients may have which facilitated communication with caregivers as well with the oncology team. Similarly, Akyar et al.(58) also noted caregivers finding their symptom tracking sheet to be very useful in being able to talk to their loved ones' about their symptoms.

5.3.3 Coping with Advanced Cancer

Illness comprehension and coping is one of four essential components of an early palliative approach to care.(10) Studies have found that addressing how patients cope, and how their families and others close to them cope is associated with improved patient outcomes.(91) Participants' ability to understand their illness and cope with both their illness and the care received was facilitated by the support systems in their lives. The participants in our study identified social support, support from healthcare staff (including palliative care team, and family physician), strength in faith, and support from self as key resources in coping with their advanced cancer. Fliedner et al.(55) also found participants in their study found support from participating in the early palliative care intervention. In their study, some participants started involving their social network such as their families in advance care planning discussions, after taking part in the intervention.(55) However, in our study we found most participants had already involved their families from the very beginning, especially in advance care planning discussions. In our second paper, the palliative care nurse specialist facilitated access to different resources such as therapist. This finding is also supported by the Hannon et al.(53) study integrating an early palliative care intervention.

Advance care planning is a process supporting patients in understanding and sharing their personal values, life goals, and preferences regarding future medical preferences.(10) In paper one, we found mixed responses for patient readiness for advance care planning discussions as most participants

were not familiar with it. However, most participants in our study had agreed that these discussions would need to be individualized for each patient, which is also recognized by Simon et al.(80) in their study. In paper two, we identified an improvement in advance care planning discussions. In our study, the palliative care nurse specialist and oncologist facilitated advance care planning discussions, helping patients and families talk about emotional but necessary topics. In the Bagcivan et al.(91) study, addressing psychosocial needs, spirituality, coping, and advance care planning discussions were key components of the early palliative care consultations. Other studies have also found improvements in advance care planning because of early palliative care.(41, 90) Ongoing advance care planning discussions are recommended for the provision of quality care.(91) There is evidence for positive impacts of advance care planning discussions on preference concordant care (care provided being consistent with expressed preferences), concordance between patient and family preferences, and documentation of wishes.(92) In our study, participants expressed positive experiences with advance care planning discussions.

5.3.4 Meaning of Palliative Care

Most participants interviewed prior to pathway implementation were either unsure what palliative care meant or associated it with end of life or death. In the interviews conducted post-implementation, most participants described palliative care as more holistic and encompassing quality of life. The term ‘palliative care’ still holds stigma, and some patients were still uncomfortable with it, especially when discussing palliative care with other people in their lives. Reframing palliative care as ‘supportive care’ may be an option to consider. In a randomized trial that examined patient perception with ‘supportive care’ and ‘palliative care’, patients with advanced cancer viewed the term supportive care more favorably and had better understanding of it.(93) Some centres have rebranded their palliative care programs to ‘supportive care services’. In Canada, BC Cancer includes pain and symptom management/palliative care under supportive care services.(94) One cancer centre in the USA observed

higher outpatient referrals after changing their program from palliative care to supportive care.(95) A follow up qualitative study with oncologists at that centre found most oncologists mentioning the name change had no impact on their referral patterns.(96) However, most oncologists at that centre supported the name change as they perceived their patients preferred the term supportive care.(96) Other services encourage education regarding palliative care rather than a name change.(97, 98) Hannon et al.(97) call their clinic the Oncology Palliative Care Clinic and promote early referrals to palliative care. Milne et al.(98) encourage improved communication with patients, caregivers, and physicians to correct misconceptions about palliative care. Whether or not a name change is implemented, it is important to integrate palliative care early in the cancer trajectory, shortly after diagnosis to better support patients and families. In the PaCES pathway, patient education materials such as pamphlets have been designed with feedback from patient and family advisors on what palliative care means. However, education about early palliative care through videos may be another strategy to communicate with patients, families, physicians, and the public. Digital storytelling is a strategy adopted by Alberta Health Services to promote patient stories and inform clinical practice. Additionally, working with patients and families to develop digital stories would potentially have more impact in dispelling misconceptions about early palliative care. Digital stories have been utilized for communicating health information.(99) In one study, rural community members reported digital stories were helpful to begin difficult conversations about cancer.(99) Digital storytelling can also be utilized as a participatory research practice, by collaborating with communities in developing their stories from their perspectives.(100) In this study context, digital storytelling can be utilized for patient-oriented research by collaborating with patients and families in developing an educational video about early palliative care.

5.4 Strengths and Limitations

A methodological strength of this study was in its qualitative design. Through in-depth interviews, we were able to understand the experiences of patients living with advanced colorectal

cancer and family caregivers as they navigated cancer care in Alberta. Probing interview questions allowed for clarification and improved understanding of participants' responses. Another study strength was the patient-oriented design, engaging patient and family advisors in the research. The involvement of patient and family advisors allowed for patient priorities to guide health research. For instance, in our project the questions that formed the interview guide were developed in collaboration with our patient and family advisors. A barrier to participation in research is often travel which was mitigated as we conducted telephone interviews. Another strength of this study was comparison of experiences before and after implementation of a care pathway for early palliative care in order to identify improvements in care. Participants before and after implementation of the care pathway were also all patients with advanced colorectal cancer or family caregivers.

A limitation of this study may be the mode of interviewing chosen- telephone interviews. As the interviews that were conducted were one-time interviews, it may have been harder to build rapport and participants may have found it difficult to discuss sensitive topics or discuss their care in detail. However, some participants may have been more comfortable sharing their views over the phone than in person. Additionally, studies that have compared telephone and face to face interviewing, have found both modes to be comparable in quality.(81) As we were interviewing advanced cancer patients living in two different cities for paper one, telephone interviewing was most convenient for participants and the study.

Another limitation of this study may have been potential self-selection bias, as participants who had more positive experiences in their cancer care may have chosen to participate than participants who have had a negative experience. Additionally, participants in health research are often those who are more educated, and of higher socioeconomic backgrounds. Strategies to ensure diversity of participants were emphasized at recruitment that responses of participants were not shared with any physicians, as well as emphasis that this research was being carried out through the University of Calgary, and not through their specific health care provider. Additionally, participants were offered a gift card as a thank

you for their participation. Another limitation of this study may have also been the comparison of two different sets of interview participants (in the current cancer care group, and those experiencing the care pathway). We were not able to understand whether attitudes/perceptions of palliative care and care experiences had changed over time from current cancer care to the implementation of early palliative care. However, our participants had an advanced cancer diagnosis (with a prognosis of 6 to 24 months), therefore it wasn't possible to have participants participate in two interviews due to the time frame of the study. Additionally, the interviewer from study one could be seen as influencing perceptions of palliative care, therefore it was important to interview a different set of participants after implementation of the care pathway to mitigate interviewer influence on participant views. Rather than understanding whether care experiences changed, we focused on the differences and similarities in the care experiences and perceptions in the two different interviews.

5.5 Outcomes/Significance

This thesis is the first study in Alberta exploring the experiences of an early palliative care pathway from the perspectives of patients and families. The study findings will be used to inform refinement of the pathway, and further implementation in the rest of Alberta, as well as expansion into other cancers. The interviews conducted prior to implementation of the care pathway with patients experiencing current cancer care informed stakeholders of the current gaps in advanced cancer care, including attitudes towards palliative care and advance care planning. Findings were first shared with committee members and the PaCES core research team to discuss themes, and receive feedback on the themes. Afterwards findings were shared with stakeholders including oncologists, researchers, family physicians, and nurses. Interviews conducted with participants in Calgary experiencing the early care pathway will inform understanding of patient and caregiver perceptions towards palliative care and advance care planning, and inform the refinement of the care pathway. With the implementation of an early care pathway in Alberta, the PaCES project aims to increase number of patients receiving early

palliative care and improve patient and caregiver experiences of advanced cancer care. Outcomes of the PaCES project include improved patient symptom control, improved readiness for caregiving, and increase in community based palliative care. The outcomes of this qualitative project were understanding the care experiences of patients and families. The incorporation of patient and family experiences and perspectives will allow for the delivery of patient centred care. The identification of key elements of palliative care valued by patients and families can inform early palliative care pathways in other provinces and territories.

The knowledge dissemination plan of this thesis is to inform an early palliative care pathway through various avenues, and increase awareness of early palliative care. Study findings from paper one were presented at seven conferences in 2019: The CanPros conference, 30th Palliative Education & Research Day, The Multinational Association of Supportive Care in Cancer (MASCC)/International Society of Oral Oncology (ISOO) Annual Meeting, Canadian Association for Health Services and Policy Research (CAHSPR) Scientific Conference, Applied Research in Cancer Control (ARCC) Conference, Strategy for Patient-Oriented Research (SPOR) Summer Institute, and Spirituality Conference: Inspiring Person-Centredness. Additionally, a podcast episode was recorded with the Strategy for Patient Oriented Research (SPOR) Patient Engagement platform about early palliative care and this thesis. The target audience for this podcast episode was the general public, patient and family research partners, or anyone interested in patient-oriented research. Study findings from paper one will be shared with the PaCES collaborative which includes stakeholders at all levels such as patients, families, physicians, strategic clinical networks, academic partners, community partners, and Alberta Health Services. I will work with the PaCES team including patient and family advisors and my committee members to discuss how best to present the findings, and ideas for dissemination. Study findings will be shared at stakeholder meetings, as well as in conferences attended by healthcare professionals, researchers, quality improvement experts, and patients and families (for example Canadian Association for Health Services and Policy Research (CAHSPR), Strategy for Patient-oriented

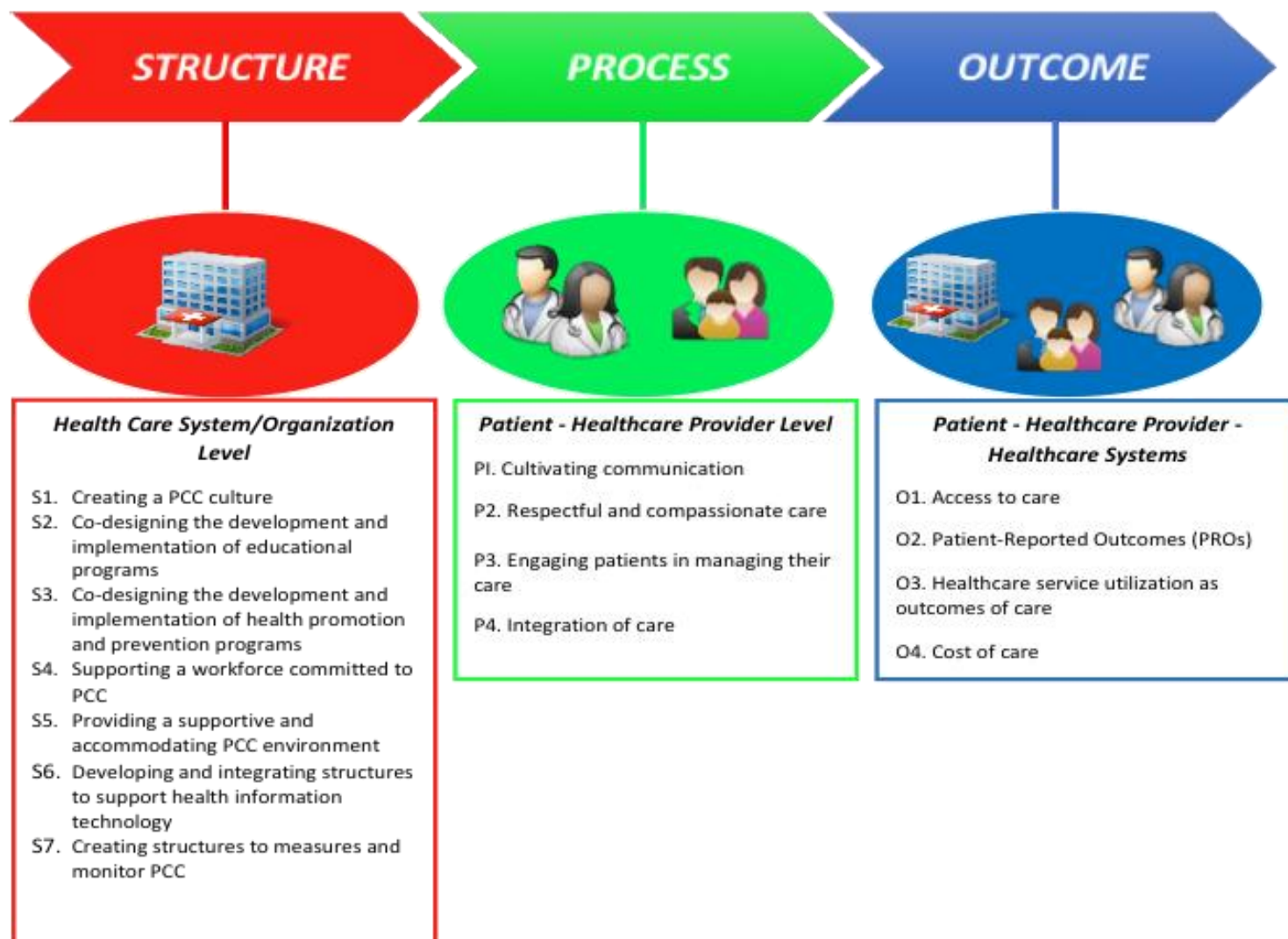
research (SPOR) Summer Institute, and Multinational Association of Supportive Care in Cancer (MASCC)). Two manuscripts have been prepared for submission in an Oncology/Palliative Care journal for wide dissemination. Other ways of presenting this information and the audience for this information will be discussed with our core research team. Some ideas that have been presented include a webinar presentation targeted at clinician-researchers and patients, as well as clinical rounds aimed at oncologists and nurses. Some of the study participants have also expressed interest in hearing about the study findings, therefore a poster will be shared with them to show appreciation for their contributions to this work.

5.6 Directions for Future Research

Overall this thesis adds to the early palliative care literature by first identifying gaps in oncology care and what matters to patients and families to inform a care pathway for early palliative care. This thesis also identifies improvements in cancer care by capturing the experiences of patients and families experiencing an early palliative care pathway. This thesis presents initial experiences with an early palliative care pathway from the perspectives of patients with advanced colorectal cancer and family caregivers. Our study did not ask in-depth questions on the experience of caregiving. It would be interesting to further explore the experiences of caring for a family member with advanced cancer from the perspective of family caregivers. In our study, involvement of family physician was an important component of the early palliative care pathway. Future studies should explore impact of ‘shared care’ in early palliative care, especially with involvement of family physicians in early palliative care. Additionally, it would be interesting to explore the impact of further refinements to the early palliative care pathway on the care experiences of patients (with other advanced cancers) and family caregivers. As Calgary is the first site for implementation of the care pathway, future research could explore and compare the care experiences in Calgary with other areas in Alberta (such as Edmonton). We are currently in the midst of a global pandemic, which may impact patient access to palliative care, care

coordination, and in carrying out the care pathway. Future research should explore the impact of COVID-19 on implementation of the early palliative care pathway, and patient and caregiver experiences as a result of the pandemic.

APPENDIX A: CONCEPTUAL FRAMEWORK



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.

APPENDIX B: INTERVIEW GUIDE

Patient Interview Guide

For caregiver interviews: rephrase all questions mentioning “you” to “your loved one’s”

At the cancer clinic, patients are routinely asked to complete a screening tool for issues that are commonly important to patients called PPF (Putting Patients First – ESAS-r with Canadian Problem Checklist).

How useful has the PPF (Putting Patients First – ESAS-r with Canadian Problem Checklist) been for you? How did your clinicians review your answers with you at your visit/s? How did your care or treatment plan change because of the answers? Are there any changes you would make to the tool itself? Are there changes you would make to the way it is collected?

Palliative Care and what it means

1. What does palliative care mean to you?
2. Palliative care is an added layer of support for patients and their families or loved ones, who are living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment. Some elements of palliative care are provided by your family doctor and cancer doctors and nurses, while other elements are provided by specially trained doctors and nurses who work with your existing team to provide that extra layer of support, for example in your own home as “palliative home care services”.

How much does this description fit with what you thought about palliative care? What are your thoughts on the term ‘palliative care’? Is there a term that you would prefer to use?

Are you currently receiving palliative care services?

If not...

- a. When should palliative care services be added to your cancer care? When should information about palliative care first be provided to you? How should this information be presented to you (written, website, in person)? Who should be present for these discussions?

If yes

- a. When would you say palliative care was added to your cancer care?
How was it presented to you?

3. What has your experience of palliative care been like so far? Would you change something?

Communication regarding your diagnosis and care

4. How/when/by whom was your diagnosis/diagnoses communicated to you? What went well? What could have gone better?
 - a. Specifically, how was your diagnosis of advanced cancer communicated to you? What went well? What could have gone better?
5. How would you have liked information about your diagnosis to be communicated to you? (website, brochure, youtube video, one-on-one, e-mail, face-to-face discussion?)

In order to have better prepared yourself for your initial visits to the cancer centre, is there any information that should've been provided to you that would've helped you during those visits?

6. Which sources do you currently use for information?
7. Which resources have you received from the TBCC?
8. What is your opinion on the resources you receive during your TBCC (Tom Baker Cancer Centre) visit(s)?' examples are:

<https://myhealth.alberta.ca/Alberta/AlbertaDocuments/Living-Your-Best-During-Systemic-Treatment.pdf>

<http://www.cancercare.ns.ca/site-cc/media/cancercare/support%20knowledge%20hope.pdf>

9. Reflecting on your experiences, what information is lacking?
10. Do you know who to call when you have a question? How about on weekends and weeknights?
11. Have you reached out to anyone before when you had a question or concern? If so, who and approximately how many times?
12. Would you like your care team to contact and check-in on you regularly to see how you're doing or would you prefer to contact the care team when you need to?
13. Who are the current members of your care team? Who would you like to be a part of your care team to discuss your treatments and care?(e.g. Your medical oncologist, Family doctor, family member)
14. From your perspective, ideally how should the palliative nurses and doctors work with your oncologist (cancer doctor)?
 - a. How should your family doctor be involved?
15. Is there anything specific you think could be or should be provided within your community's family doctor's clinic to help you more?
16. When should discussions about homecare supports take place?
17. What supports are most needed for caregivers and what is the best way to provide that support?

Advance Care Planning

Advance Care Planning (ACP) is a process of reflection on and communication of a person's future healthcare preferences. ACP encourages ongoing dialogue between a patient, his or her family, and the health care team that can guide medical decision-making including when a person becomes incapable of consenting to or refusing healthcare.

ACP is Advance Care Planning is a process that helps you to: 1) Think and talk about your goals for healthcare. 2) Create plans that reflect your goals and 3) Document your future healthcare plans.

Should you be ill or injured and unable to speak for yourself, Advance Care Planning ensures that you have someone else to speak for you so your healthcare wishes are heard and respected.

18. When would you like discussions about advance care planning to take place? e.g. Initial consultation (first time the diagnosis of metastatic cancer is discussed) The first follow up visit after the initial consultation, whenever the patient brings it up etc

19. When discussing advance care planning, who should be in the room to support you and/or take part in the discussion?

Cost of Care

20. What additional costs have you incurred due to cancer? (that you had to pay yourself and not covered by insurance)

Before we wrap up, is there anything else that you would like to add or do you have any questions for me?

Modified Interview Guide (Paper two)

Patient Interview Guide

For caregiver interviews: rephrase all questions mentioning “you” to “your loved one’s”

Views on PPF Tool

At the cancer clinic, patients are routinely asked to complete a screening tool for issues that are commonly important to patients called PPF (Putting Patients First – ESAS-r with Canadian Problem Checklist).

How useful has the PPF (Putting Patients First – ESAS-r with Canadian Problem Checklist) been for you? How did your clinicians review your answers with you at your visit/s? How did your care or treatment plan change because of the answers? Are there any changes you would make to the tool itself? Are there changes you would make to the way concerns you might be having are collected?

Palliative Care and what it means

1. What does palliative care mean to you? What are your thoughts on the term ‘palliative care’?
2. Palliative care is an added layer of support for patients and their families or loved ones, who are living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment. Some elements of palliative care are provided by your family doctor and cancer doctors and nurses, while other elements are provided by specially trained doctors and nurses who work with your existing team to provide that extra layer of support, for example in your own home as “palliative home care services”.

What are your thoughts on this description for palliative care?

- a. Probes: Are there any terms that you prefer to use instead of palliative care?

Probes: Who would you say have been providing you with palliative care supports? Have you met a specialist palliative care provider? E.g. Jan Vandale? Like a palliative care nurse or doctor? Are you receiving home care? (has this been presented to you as palliative home care?)

When would you say palliative care was added to your cancer care?

How was it presented to you?

What do you think of the timing of palliative care supports in relation to your experience of cancer?

3. What has your experience of palliative care been like so far? Would you change something? Has Jan's visit had some impact on you or others around you? (has something changed?)

Coping

4. What supports have you used or are hoping to use to help with your coping?
 - a. How have your oncology team or Palliative care team or home care team or family physician team helped you and/or your caregiver around coping with the advanced cancer?
 - b. What are your other sources of support for coping? What informal supports do you have available to you?

Resources and Information about Care

5. Which resources have you received from the TBCC (Tom Baker Cancer Centre)?
6. Have you received a pamphlet/information sheet on "Shared Care for Advanced Cancer" from your visits? How useful do you find this?
<https://www.albertahealthservices.ca/assets/info/hp/cancer/if-hp-cancer-guide-metastatic-colorectal-letter-patient.pdf>
7. What is your opinion on the resources you receive during your TBCC (Tom Baker Cancer Centre) visit(s)?' examples are:
<https://www.albertahealthservices.ca/assets/info/cca/if-cca-systemic-treatment.pdf>
How would you like to receive booklets/information/websites like that?
8. Reflecting on your experiences, what information is lacking?
9. Do you know who to call when you have a question? How about on weekends and weeknights?
 - a. Have you reached out to anyone before when you had a question or concern? If so, who and approximately how many times?
 - b. Would you like your care team to contact and check-in on you regularly to see how you're doing or would you prefer to contact the care team when you need to?
10. From your perspective, ideally how should the palliative nurses and doctors work with your oncologist (cancer doctor)?
 - a. What is your perception about how your care team is communicating with each other?
 - b. Do you or your caregivers have to step in to pass on health information to different parts of your care team?
11. When did you see/how often do you see your family doctor?
 - a. How is your family doctor be involved? How would you like them to be involved?
 - b. Is there anything specific you think could be or should be provided within your community's family doctor's clinic to help you more?
12. Are there any supports that are still lacking?
13. What supports are most needed for caregivers and what is the best way to provide that support?

Advance Care Planning

Advance Care Planning (ACP) is a process of thinking ahead and talking to your family and your healthcare team about what is important to you, in case a time comes when you no longer have the

ability to speak about or choose the kind of medical treatments you want. Some people also document their wishes and legally name someone who will help make their medical decisions for them in a “personal directive”

14. When and how often would you like discussions about advance care planning to take place? e.g. Initial consultation (first time the diagnosis of metastatic cancer is discussed) The first follow up visit after the initial consultation, whenever the patient brings it up etc
15. When discussing advance care planning, who should be in the room to support you and/or take part in the discussion?
16. Have you had a discussion around this already? If yes, who initiated it? Which clinician was involved? Was your caregiver involved?
 - a. Do you have any feedback on how this was done? What went well? What could have gone better?
 - b. Was it repeated over time?
 - c. Do you have a personal directive?

End of Life

17. Has anyone brought up end of life planning with you so far? If yes, how was it done?
 - a. Was it done too early? Or just at the right moment? Or too late?

Cost of Care

18. What additional costs have you incurred due to cancer? (that you had to pay yourself and not covered by insurance)

Before we wrap up, is there anything else that you would like to add or do you have any questions for me?

APPENDIX C: COREQ Checklist- COREQ (Consolidated criteria for Reporting Qualitative research) Checklist for Chapter 3

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	page 31
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	page 31
Occupation	3	What was their occupation at the time of the study?	page 31
Gender	4	Was the researcher male or female?	page 31
Experience and training	5	What experience or training did the researcher have?	page 31
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	page 31
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	page 31
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	page 31
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	page 29
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Page 30-31
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	Page 30-31
Sample size	12	How many participants were in the study?	Page 32
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	Page 30-31
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	N/A
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	Page 32
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 31
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A

Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	Page 31-32
Field notes	20	Were field notes made during and/or after the interview or focus group?	Page 31-32
Duration	21	What was the duration of the inter views or focus group?	Page 32
Data saturation	22	Was data saturation discussed?	Page 31
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	Page 31-32
Description of the coding tree	25	Did authors provide a description of the coding tree?	Page 31-32
Derivation of themes	26	Were themes identified in advance or derived from the data?	Page 31-32
Software	27	What software, if applicable, was used to manage the data?	Page 31-32
Participant checking	28	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Page 32-37
Data and findings consistent	30	Was there consistency between the data presented and the findings	Page 32-37
Clarity of major themes	31	Were major themes clearly presented in the findings?	Page 32-37
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Page 32-37

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

APPENDIX C: COREQ Checklist

COREQ (Consolidated criteria for Reporting Qualitative research) Checklist for Chapter 4

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	page 51
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	page 51
Occupation	3	What was their occupation at the time of the study?	page 51
Gender	4	Was the researcher male or female?	page 51
Experience and training	5	What experience or training did the researcher have?	page 51
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	page 51
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	page 51
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	page 51
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	page 52
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Page 51
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	Page 51-52
Sample size	12	How many participants were in the study?	Page
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	Page 51
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	N/A
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	Page 53
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 51-52
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	Page 51-52
Field notes	20	Were field notes made during and/or after the interview or focus group?	Page 51-52
Duration	21	What was the duration of the inter views or focus group?	Page 53

Data saturation	22	Was data saturation discussed?	Page 52
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	Page 52-53
Description of the coding tree	25	Did authors provide a description of the coding tree?	Page 52-53
Derivation of themes	26	Were themes identified in advance or derived from the data?	Page 52-53
Software	27	What software, if applicable, was used to manage the data?	Page 52-53
Participant checking	28	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Page 53-58
Data and findings consistent	30	Was there consistency between the data presented and the findings	Page 53-58
Clarity of major themes	31	Were major themes clearly presented in the findings?	Page 53-58
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Page 53-58

checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

APPENDIX D: Patient Consent Form

Informed Consent Form for Participation in a Research Study (Patient Consent Form)

Living with Colorectal Cancer: Patient and Caregiver Experiences and Perceptions of Palliative Care

Supervisor: Dr. Maria Santana
Department of Pediatrics, Cumming School of Medicine
University of Calgary
403-955-2783

Non-Emergency contact numbers are noted at the end of this document under the section heading **"WHO DO I CONTACT FOR QUESTIONS?"**

For assistance with terminology within this consent form, please refer to the Canadian Cancer Society Glossary of Terms at <http://info.cancer.ca/e/glossary/glossary.html>.

You are being invited to participate in a research study because you are a person living with advanced colorectal cancer in Alberta. This consent form provides detailed information about the study to assist you with making an informed decision. Please read this document carefully and ask any questions you may have. All questions should be answered to your satisfaction before you decide whether to participate.

The study staff will tell you about timelines for making your decision. You may find it helpful to discuss the study with family and friends so that you can make the best possible decision within the given timelines.

Taking part in this study is voluntary. You may choose not to take part or, if you choose to participate, you may leave the study at any time without giving a reason. Deciding not to take

part or deciding to leave the study will not result in any penalty or any loss of medical or health-related benefits to which you are entitled.

The study staff will discuss this study with you and will answer any questions you may have. If you do consent to participate in this study, you will need to sign and date this consent form. You will receive a copy of the signed form.

WHAT IS THE BACKGROUND INFORMATION FOR THIS STUDY?

The delivery of palliative care services varies in different places, proving difficult for standardization of quality care. Patients and their caregivers' experiences with advanced care have been documented in the literature. We define early access to palliative care as comprising at least one of the following: a consultative visit by a specialist palliative care provider, and/or palliative homecare service ≥ 3 months before death. For cancer patients, palliative care may be used concurrently with cancer-focused treatments like chemotherapy, soon after the diagnosis of advanced cancer. Late or no palliative care is associated with lower quality of life, higher caregiver distress and costly end of life care. A patient-centred care model ensures patients and caregivers are actively involved in the planning, delivery, and assessment of their care. Lack of timely, palliative care impacts patients' experience with their condition and care.

WHY IS THIS STUDY BEING DONE?

We need to understand the experiences of individuals living with advanced colorectal cancer and their caregivers. This will help to monitor the quality of current cancer care and guide future improvements in Alberta.

WHAT ARE OTHER OPTIONS IF I DECIDE NOT TO PARTICIPATE IN THIS STUDY?

You do not have to take part in this study in order to receive continued medical care. Your participation is entirely voluntary. If you choose not to participate, you will continue to be offered the best care available.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

Around 20 participants will take part in the study from Edmonton and Calgary.

WHAT WILL HAPPEN DURING THIS STUDY?

You will be asked a series of questions regarding your views of palliative care and advance care planning. You will also be asked about your experiences receiving health care services. The interview will take around 20-40 mins over the phone.

WHAT ARE THE RISKS ASSOCIATED WITH PARTICIPATING IN THIS STUDY?

Talking about experiences during cancer care may bring up some uncomfortable emotions. You are free to end the interview at any time, and you do not have to answer any question that you feel uncomfortable with. If you have any concerns or distress you may discuss this with your healthcare provider.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

Participation in this study may or may not be of personal benefit to you. However, some participants in this kind of research have found their involvement to be beneficial because they were encouraged to talk about their health care experiences and concerns.

Based on the results of this study, it is hoped that in the long-term, patient care can be improved.

DO I HAVE TO PARTICIPATE?

Your participation in this study is entirely voluntary and you are free to refuse to answer any question and are free to end the interview at any time.

HOW WILL MY PERSONAL INFORMATION BE KEPT CONFIDENTIAL?

The results of the interview project will be coded in such a way that your identity will not be physically attached to the final data such as transcripts that we produce. Your statements will only identify you as 'person x'. Results of this research may be published or reported to government agencies, funding agencies, or scientific groups, but your name will not be associated in any way with any published results.

Interview recordings, printed transcripts and notes will be stored in a locked cabinet in the Supervisor's office. Records assigning pseudonyms will be stored separate from data in a locked cabinet of the Supervisor's office. Electronic versions of recordings and transcripts will be stored on password protected computers of the principal investigator and the research assistant. Only the researchers will have access to the list of participant names. For the purpose of tracking accounts by individual participants, pseudonyms will be assigned to each participant.

Study participant pseudonyms will be used in research output. Select quotes from Participants may be used in research output in conjunction with participant background data. As the respondents come from a big pool of possible respondents it is unlikely that people will be able to

identify the person from quotes. Participants will be debriefed immediately following the interview to address new questions that may have arisen about the rationale for, or potential use of, specific information gathered. Participants will be invited to contact the investigator by phone, email or in person at any time following data collection should further questions or concerns arise.

WILL MY HEALTHCARE PROVIDER(S) BE INFORMED OF MY PARTICIPATION IN THIS STUDY?

Your family doctor and health care provider(s) will not be informed by the study team that you are taking part in the study. You can choose to let your family doctor/health care provider know, if you like. If you are undecided, the study doctor can discuss this with you.

WILL THERE BE ANY COSTS INVOLVED WITH PARTICIPATING IN THIS STUDY?

Participation in this study will not involve any additional costs to you or your private health care insurance. Participation may cause some inconvenience to you (e.g. finding time to participate in the interview).

WILL I BE COMPENSATED FOR PARTICIPATING IN THIS STUDY?

You will be offered a \$20 gift card to Tim Hortons, as a thank you for your participation.

WHO DO I CONTACT FOR QUESTIONS?

If you have questions about taking part in this study, please contact:

Dr. Maria Santana
403-955-2783

If you have questions about your rights as a participant or about ethical issues related to this study and you would like to talk to someone who is not involved in the conduct of the study, please contact the Office of the Health Research Ethics Board of Alberta – Cancer Committee at:

Telephone: 780-423-5727

Toll Free: 1-877-423-5727

APPENDIX E: Demographic/Baseline Questionnaire

Patient or caregiver? ___ Patient ___ Caregiver

Gender: _____

Age range (v) one:

___ <40

___ 41-50

___ 51-65

___ 66-75

___ 76-85

___ 86 +

Diagnosis (patients only): _____

Current Marital Status (patient only): (v) one

- ☐ Married or living as married
- ☐ Widowed
- ☐ Never married
- ☐ Divorced or separated; not remarried

Last location of living in last month: (v) one (If in hospital, then month prior to hospitalization)

- ☐ Home
- ☐ Retirement Residence
- ☐ Long-Term Care or Nursing Home
- ☐ Supportive Living or Lodge
- ☐ Ward in another hospital
- ☐ Other (specify): _____

Education – highest level achieved: (v) one

- ☐ Elementary School or less
- ☐ Some High School
- ☐ High school graduate
- ☐ Some college (including CEGEP)/ trade school
- ☐ College diploma (including DEC)/trade school
- ☐ Some university
- ☐ University degree
- ☐ Post Graduate degree

Who are the current members of your care team?

Have you received palliative care services so far?

___ Yes

___ No

(Ask if answered yes to previous question) Who provided palliative care services so far to you (or your loved one)? (v) one

___ Home Care

___ Palliative Care Consult Team

___ Family Physician

- ☐ Oncology team
- ☐ Other

(Ask if answered yes to previous question) If you (or your loved one) were referred to Home Care or Palliative Care Team, who made the referral: (v) one

- ☐ Family physician
- ☐ Oncology team
- ☐ Other

(Ask if answered yes to previous question) If you (or your loved one) were referred to Home Care or Palliative Care Team, how long ago (or if your loved one has died, how long before death), did this occur: (v) one

- ☐ < 1 month
- ☐ 1-3 months
- ☐ 3-6 months
- ☐ > 6 months

APPENDIX F: Demographic Characteristics of Participants

	Paper 1	Paper 2
Patients interviewed	15	7
Caregivers interviewed	7	5
Age range	43-72	36-86
Gender	13 women, 9 men	8 women, 4 men
Living at home	yes	yes
Referral to palliative care	no	yes

APPENDIX G: Comparison of Experiences Before and After Implementation of the Palliative Care Pathway

	Before Pathway Implementation (May-November 2018)	After Pathway Implementation (September 2019- February 2020)
Perception of palliative care	Confusion and association with end of life/death	Holistic, encompassing quality of life
Care coordination and communication with healthcare providers	Some participants mentioned lack of communication and team work between healthcare providers	Palliative care nurse specialist acted as a liaison to other care providers, and helped coordinate care among care providers
Involvement of family physician	Mixed responses regarding relationship with family physician, lack of clarity of family physician role	Most participants found their family physician was well informed and involved in their care
Discussions about advance care planning	Most participants did not have advance care planning discussions, mixed views on timing regarding these discussions	Most participants discussed advance care planning with their care team, including close family

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