

# Palliative Care in Alberta

*How Might We Help Those Whose Burden of Care is More Than They Can Manage?*

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## WHAT IS PALLIATIVE CARE?

It is the method of providing **pain and symptom management**, as well as **emotional and spiritual support** to those living with a progressive, life-altering illness.

Providers, patients, and supports work together to prevent and relieve symptoms of the illness and its associated stress, and create treatment plans which suit the unique identity of the patient and their loved ones.

## CONTINUITY OF CARE

### RELATIONSHIP INFORMATION

Also known as longitudinal or personal continuity - is the trust that a patient has with their healthcare provider(s). It is seen as the most important aspect in receiving care for many patients.

The accessibility of medical information as well as an accumulated collection of knowledge about the patient's identity and preferences. It is highly important to patients as well as providers.

### MANAGEMENT

The effectiveness of patient-related information that is communicated among providers involved, as well as with the patient. It is the combination of relationship and information continuity.

Stable

Unstable

Deteriorating

Terminal

Bereavement

### Patients

Care is created with the individual patients' needs and preferences including age, type and stage of illness and personal identity.

**Gaps Identified:** Relationship with a primary care provider, accessing care, and stigmas regarding palliative care.

### Supports

Support can come from loved ones and the community; loved ones can be involved in decisions and sometimes take on the role of a caregiver.

**Gaps Identified:** Caregiver burnout, stigmas about palliative care, and receiving support.

### Providers

Primary care providers such as family physicians and nurses work with palliative care specialists in Primary Care Networks to provide unique treatment and support for patients in Alberta.

**Gaps Identified:** Education on palliative care, resources available, and mental health supports.

# The Burdens of Care

## HOW ALBERTANS ARE ACCESSING PALLIATIVE CARE



Those in need are unaware of the available resources or when they can access palliative care

Patients rely on their providers to help them access treatment, which can be seen as gatekeeping services



## EDUCATION FOR PROVIDERS

only **36%** of Canadian family physicians felt prepared to discuss palliative care with their patients, yet **94%** found themselves having those discussions on a routinely or occasional basis

## MISCONCEPTIONS ABOUT PALLIATIVE CARE

- Palliative care is associated with death
- Palliative care is the same as hospice care
- To accept palliative care you must stop other treatments
- Palliative care means "giving up"

## FEELINGS ABOUT DEATH

Albertans may avoid accessing palliative care services in an attempt to maintain a sense of control over their life

HEALTHCARE WORKERS FACING JOB LOSS AND WAGE CUTS IN ALBERTA, REDUCING PALLIATIVE CARE RESOURCES

RUSHED APPOINTMENTS RESULT IN PATIENTS AND LOVED ONES FEELING FRUSTRATED AND CONFUSED

CARE PROVIDERS INCLUDING LOVED ONES EXPERIENCING BURNOUT

## RECOMMENDATIONS

INCREASE AWARENESS ON WHAT PALLIATIVE CARE IS, AND WHAT RESOURCES ARE AVAILABLE

EDUCATION AND SUPPORT FOR PRIMARY CARE PROVIDERS ON THE TOPIC OF PALLIATIVE CARE



COLLABORATIVE CONVERSATIONS WITH PERSPECTIVES OF PROVIDERS, PATIENTS, AND LOVED ONES

<https://storymaps.arcgis.com/stories/1ba430411ee241da9a7c2dcc019a24d>



# ALBERTA'S PALLIATIVE CARE SYSTEM

HOW MIGHT WE HELP THOSE  
WHOSE BURDEN OF CARE IS  
MORE THAN THEY CAN  
MANAGE?

REPORT BY SYDNEY HARDER

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"ALONE WE  
CAN DO SO  
LITTLE;  
TOGETHER WE  
CAN DO SO  
MUCH."  
HELEN KELLER

**Mount Royal University is located in the traditional territories of the Niitsitapi (Blackfoot) and the people of the Treaty 7 region in Southern Alberta, which includes the Siksika, the Piikani, the Kainai, the Tsuut'ina, and the Iyârhe Nakoda. The City of Calgary is also home to the Métis Nation of Alberta, Region 3.**

**SYDNEY HARDER**  
CATALYST RESEARCH FELLOW

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## INTRODUCTION

I have dedicated the past year to working with the Mount Royal University Institute for Community Prosperity and Alberta Health Services, in order to understand the system of palliative care within Alberta and to identify the crucial role that members of the palliative care community take within the system. Through research, I explored and addressed the following question: How might we help those whose burden of care is more than they can manage?

The goal of this Catalyst Fellowship is to inspire change within the community, and to understand the complexity of the systems that surround us. Fellows are encouraged to engage with the community and host events where the populations involved or affected by palliative care can gather and collaborate on future innovation within that system. Additionally, this fellowship is a cohort-based learning opportunity which has allowed us to collectively empower each other as changemakers.

My inspiration for this research was drawn from a personal experience going through the stages of palliative care with a loved one. Through that journey, I often found that this was a process where I felt ill-prepared as well as a fear of the unknown. I felt that resources were not available at an early stage, and that it was unclear

on how to access palliative care and plan for the future. Why is it that we were not given resources earlier? I believe that my experience resonates with that of many Albertans. It was a scary and confusing process to navigate despite the support we did receive during the experience. Based on my personal experience and my discoveries throughout this research fellowship, I feel strongly that it is essential to have collaborative conversations with community members (i.e., providers, patients, and support systems) in order to build empathy, increase understanding, and make positive changes to care strategies in Alberta's Primary Care Networks. In doing so, we may be able to better assist those whose burden of care is more than they can manage.

## METHODOLOGY

The methodology consisted of an initial literature review of academic sources from Alberta and other Canadian provinces to compare palliative care within the nation, and international studies to provide a diverse range of backgrounds in this topic. Inspiration from personal conversations and my story, as well as research on the topic of palliative care provides an overview of this system and supports the belief that collaborative conversation paves the road for future innovation.

# WHAT IS PALLIATIVE CARE?



# WHAT IS PALLIATIVE CARE?

The Canadian Cancer Society defines palliative care as the method of providing pain and symptom management, and emotional and spiritual support to those living with a “progressive, life-altering illness” (2020). Areas of care include the prevention and relief of symptoms of the illness and its associated stress, and providers working with patients and supports to create treatment plans which suit the unique identity of the patient and their loved ones (Canadian Cancer Society, 2020). Palliative care is tailored not only to the wishes of the patient, but to the phase of their condition, which includes stable, unstable, deteriorating, terminal and bereavement (Masso et al., 2015).

## PATIENTS

Palliative care is not exclusive to any age population and different age groups can be identified as needing tailored treatment methods and support. Pediatric palliative care provides unique medical support depending on the child’s physical or mental capacity, gestational age, or size (Alberta Health Services, 2019). In these cases, family values and beliefs are prominent in decision making and contribute to the treatment methods and support, particularly with young children. Most adult patients can make decisions independently and receive similar support based upon the personal values of that individual, though the presence of a support system is encouraged for those who require palliative care.

### The Phases of Condition

Stable

Unstable

Deteriorating

Terminal

Bereavement

(MASSO ET AL., 2015)



## SUPPORT SYSTEMS

Support systems can vary for any person facing a life-threatening illness; therefore the language that is used to recognize those involved cannot always be described within the traditional family or friend titles. “Those Who Identify as Family” or “Natural Supports” can be described as any loved one within a support system for a person that is going through the palliative care process (Project 10, 2020). In some cases, a loved one will take on the role of a caregiver in which they would provide assistance to the individual going through the palliative care process (MacMillan, 2014). As a caregiver, individuals provide physical as well as medical assistance which can allow the patient needing care to live at home in some cases (MacMillan, 2014). In addition to those interpersonal relationships, support can come from the community in the form of volunteers, organizations and religious communities (Project 10, 2020).

# PROVIDERS

## Primary Care Networks

Primary Care Networks (PCN's) improve communication amongst providers and coordinate care for the needs of patients among local communities. Family physicians, nurses, nurse practitioners, dietitians, pharmacists, social workers and mental health professionals work together through an agreement with Alberta Health Services to create programs and care for patients within each PCN area in order to provide physical and social care that is tailored to the unique needs of their community (Peaks to Prairies Primary Care Network, 2016).

## Primary Care Providers

Primary care is encompassed by a team of providers with backgrounds ranging from family physicians, nurse practitioners, physician assistants, nurse midwives, and pharmacotherapy specialists (Singleton & Amendola, 2015).

## Specialists

Palliative care is commonly associated with a team of interdisciplinary specialists which can include nurses, social workers, counselors, nutritionists, and palliative care doctors. They are found in hospitals, clinics, rehabilitation facilities, nursing homes, hospices and private practices (Global Pre-Meds, 2019). Specialists and primary care providers can sometimes work together in the PCN depending on the needs of members of that PCN community (Peaks to Prairies Primary Care Network, 2016).

# CONTINUITY OF CARE

The Health Quality Council of Alberta (HQCA) has established continuity of care as a method of measuring “the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient’s healthcare needs and personal context” (2016). Under continuity of care, there are three categories: information, relationship, and management continuity (Health Quality Council of Alberta, 2016). I found it extremely helpful to do an analysis on palliative care using continuity of care as a metric, because it laid out Alberta’s health care system in a way that paid tribute to the complexity of the relationships between the parts of the system of palliative care, particularly for the relationship between patients and providers. Studies have found that continuity of care was crucial to providing trust and comfort to patients and loved ones so that they could make informed decisions regarding treatment (Silveira & Forman, 2012).

## Information Continuity

Information continuity refers to the accessibility of medical information as well as an accumulated collection of knowledge about the patient’s identity and preferences (Health Quality Council of Alberta, 2016). Information continuity is important to primary care providers because it provides efficient access to

information on their patients, particularly when treatment plans or medications are undergoing changes initiated by other providers (Health Quality Council of Alberta, 2016). Additionally, the HQCA has found that patients value information continuity because it provides access to their information, helping them maintain a sense of control and understanding of the care that they receive, and it also means that patients do not have to repeat information to new providers (2016). Among the palliative care community, there are often medical specialists that work with family doctors in PCN’s to create a plan for those seeking treatment; therefore a strong network of information is highly important to the primary care provider and the patient.

## Relationship Continuity

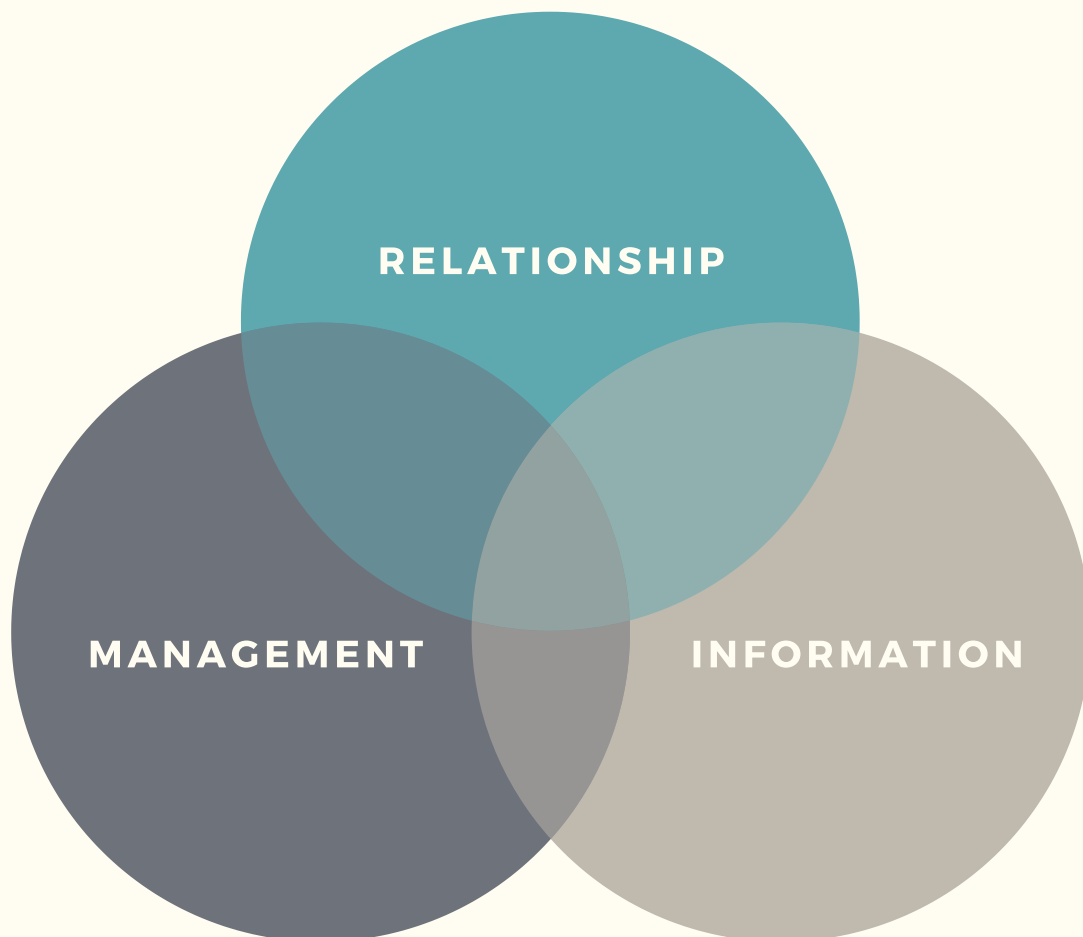
Relationship Continuity - also known as longitudinal or personal continuity - is the trust that a patient has with their healthcare provider(s) (Health Quality Council of Alberta, 2016). Long-term or complex healthcare settings may make it difficult to establish connections between patients and the diverse team of providers that work with them over time. Patients value relationship continuity, as this can create the framework for accessing information continuity, as well as management continuity which will be addressed in the next section.

## Management Continuity

Management continuity examines the effectiveness of patient-related information that is communicated among providers involved, as well as with the patient. It is a combination of information and relationship continuity - because it involves not only a distribution of information to patients and their providers, but it also involves a trusting relationship among care providers themselves,

and with their patients. A 2016 study found that when management continuity is effective, it can make up for a poor relationship between a patient and their primary care provider or family doctor (Health Quality Council of Alberta, 2016). In the context of palliative care, effective management continuity can be measured by a PCN's ability to provide care tailored to each patient and their loved ones (Silveira & Forman, 2012).

## Continuity of Care



(HEALTH QUALITY COUNCIL OF ALBERTA, 2016).

# BURDENS OF CARE

Patients, loved ones, providers, and primary care networks experience burdens of palliative care in unique ways. This section outlines the burdens of care that I have uncovered in my research and in personal communications.

“Palliative care has been shown to be particularly effective when delivered early, before the last stages of life.”

(Canadian Cancer Society, 2020)

## Patients Entering Palliative Care

One of the gaps identified by the Canadian Cancer Society in palliative care in 2016 is the matter of when and how people are initially accessing care. Lack of information on what palliative care is and who can access it prevents Albertans from benefiting from palliative care in the earlier stages.

Alberta Health Services provides criteria for those who qualify for palliative care: life-limiting, life-threatening, progressive conditions, or if the burden of disease or treatment outweighs the benefits as perceived by the health care team including the family (Alberta Health Services, 2019). The ambiguity of these criteria can leave room for missed care among Albertans who would otherwise benefit from palliative care services because they were not able to access the information which would inform a decision to access palliative care. As a result, these Albertans may find themselves in worsened physical conditions by the time they begin receiving palliative support (Davison et al., 2015).

## The Gatekeeping of Care

Providers hold a great deal of responsibility in identifying a need for palliative care in their patients, and as such this can sometimes result in cases being prolonged or missed when palliative treatment would be ideal to assist the individual with pain and symptoms management. I have identified gaps in Alberta's healthcare system where providers may be responsible for withholding or gatekeeping services in the early stages of the patient's condition. Personal communications throughout the course of this research have indicated that patients and loved ones feel that they are not advocated for in certain circumstances, such as creating a care plan and understanding their available resources. The underutilization of palliative care services may also be the result of "standardized symptom assessments," meaning that providers are assessing patients and gatekeeping palliative care services as a result of an unfair evaluation (Alcalde-Castro et al., 2020)..

Gatekeeping can also occur when providers rely heavily on patients "Green sleeves," which is a patient's physical record of advanced care planning which they keep on their person at all times (Alberta Health Services, 2018). These documents are a way to identify the needs of the patient, but the reason that Green Sleeves are potentially harmful to patients is that they may not permit access to certain care if it is not reflected in their Green Sleeves.

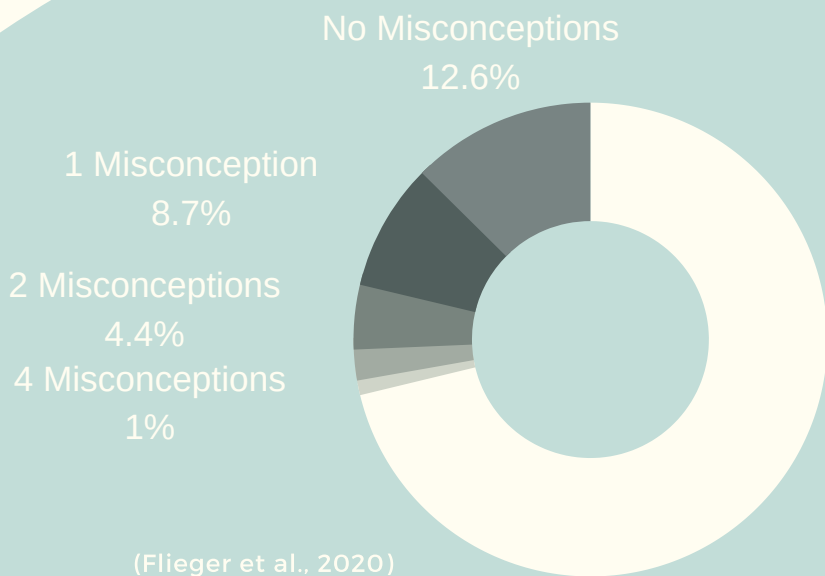
In light of the 2020 CoronaVirus outbreak, Alberta Health Services has implemented that visitors are not permitted in acute care, long-term care, supportive living, congregate living, hospice care and licensed group home settings in Alberta (Alberta Health Services, 2020, April 14). The exceptions to this rule include end-of-life patients, but it is declared that, "the attending physician, in consultation with unit manager/charge nurse, determines if the patient condition is considered end-of-life" (Alberta Health Services, 2020, April 14). This is a form of gatekeeping, as the accessibility of a patient to their loved ones during long-term treatment presently is governed by the team of providers that work with them, potentially increasing distress for both the patient and the caregivers if not handled correctly.



# Misconceptions About Palliative Care

There exists a great deal of misunderstanding around what palliative care encompasses, particularly a misconception that palliative care is exclusively end-of-life care. Since establishing itself under Canadian framework as primarily cancer care in the 1970s, palliative care has since expanded to encompass any life-limiting illness (Government of Canada, 2019). A potential cause for the misconception is that people may understand the initial framework yet lack information on how the definitions involving palliative care have shifted. A study conducted in the United States reported that 15.9% of participants believed that pursuing palliative care was “giving up” (Flieger et al., 2020). I have observed through community engagement that this mentality is also present in Alberta. The danger of this widely spread misunderstanding of the topic is that many will not pursue any palliative care treatment because it can be extremely difficult to think about themselves or their loved ones accessing end-of-life care, when the reality is that the main goal of palliative care is to continue to allow patients to have a fulfilling quality of life that suits their needs (Get Palliative Care, 2012).

## U.S. Adults and Palliative Care Knowledge



### Common Misconceptions

- Palliative care is associated with death
- Palliative care is the same as hospice care
- To accept palliative care you must stop other treatments
- Palliative care means "giving up"

(Flieger et al., 2020)

## A Fear of Death

The Canadian framework for palliative care includes death, dying, grief, and bereavement as one of the elements of their ten guiding principles (Government of Canada, 2019). As the realm of care in Alberta transitions into a more holistic approach that encompasses psychosocial and spiritual factors (Government of Canada, 2019), we can see a gap that inhibits many Albertans' accessibility to palliative care: a fear or avoidance of death (Barnett, 2020). Fear of death involves a person's negative feelings about death and dying, while avoidance of death happens when a person actively tries to avoid thoughts of death (Barnett, 2020). A study conducted in Switzerland observed that fear and pain among dying patients were largely influenced by spiritual experiences and beliefs about the afterlife (Renz et al., 2018). Attitudes on death are closely tied to the identity of each person and affect the way that a person creates their attitudes about palliative care and their self-efficacy (Barnett, 2020). This ties closely with the finding that many people believe pursuing palliative care is "giving up" (Flieger et al., 2020), and many Albertans may avoid palliative care in an attempt to maintain a sense of control over their life.

## Caregiver Burnout

The role of caregiving can be overwhelming and may lead to burnout, and it is recommended that those who take on this task establish a network made up of informal and formal support (MacMillan, 2014). Family, friends, religious or spiritual advisors, and members of the community can offer informal help with everyday tasks and emotional support. Formal assistance can come from a primary care network, specialized care providers, and community agencies which can help to relieve the burden of care (MacMillan, 2014).

As a result of the CoronaVirus Pandemic, Alberta has implemented that only one visitor may be permitted in circumstances such as end-of-life patients (Alberta Health Services, 2020). I believe this will have a major impact on caregivers, because those who are taking care of a loved one will be socially isolated. Loneliness and feelings of burnout are highly likely among primary caregivers in Canada, and it is currently undetermined how long the social isolation will last (Alberta Health Services, 2020).

## Budget Limitations

Many Albertans are worried about the recent decision to lower the budget for healthcare services in 2019 following the federal election because it will directly impact the amount of resources and providers that are available to those who are in need of palliative care (Leask, 2019, November 29). Alberta's palliative care budget for 2020 was stated to be 20 million, but it has been warned that many healthcare workers could face job loss and wage cuts in the coming future (Leask, 2019, November 29). A statement from Alberta Finance Minister Travis Toews says, "The Government of Alberta has been abundantly clear that spending restraint, change, and innovation is necessary to ensure the long-term sustainability of the high-quality services Albertans rely on" (2019). Palliative care services may suffer as a result of budgetary concerns, resulting in poor continuity of care and an increased burden of care on those involved with palliative care.

"Innovation is necessary to ensure the long-term sustainability of the high-quality services Albertans rely on."

(Toews, 2019)

## Rushed Appointments

A family doctor shared that providers often feel they need to create the appearance that they have all day to talk to a patient, when in reality they only have ten minutes. It is in these short periods of time that a provider must get themselves up to date on their patients' records as well as discuss concerns and treatment with the patient. The transition from primary to palliative care may create more work for a provider on which to brief themselves and discuss care with their patients, leading to a further burden of care for both patients anxiety about rushed appointments, and the providers burden of staying up-to-date with their patients in a timely manner. The Physician Foundation's 2017 Patient Survey reported findings that 11% of patients and 14% of primary care physicians felt they did not have enough time in their appointments, yet 9 in 10 patients indicated that relationship continuity is "the most important factor in a quality healthcare system" (Healthcare Dive, 2019). These statistics indicate that the gap may not stem from a lack of provider's concern, but that we may be asking too much of our primary care providers. My personal experiences have led me to observe a lack of empathy toward doctors who had rushed through appointments, leaving their patients and loved ones feeling like they had not been given enough time to discuss their concerns and options for treatment.

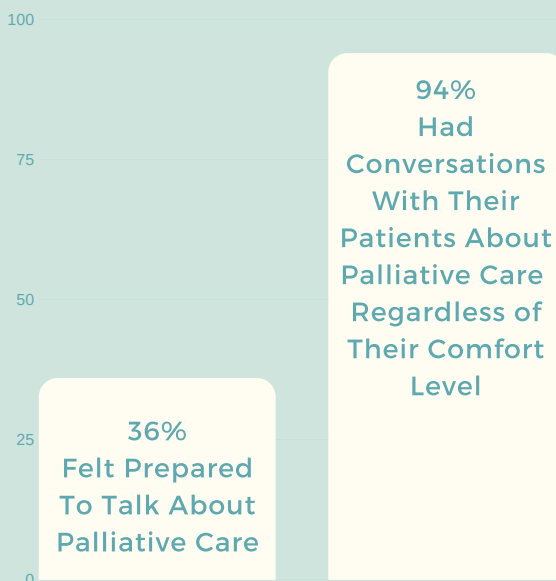


## Relationship with a Primary Care Provider

Patients who participated in the HQCA's 2016 study stated that a "trusting, patient-centred, and respectful relationship with a family doctor is central to this (healthcare)." These patients also reflected that strong relationship continuity can offset poor management continuity because they are still satisfied with the care they receive, and can discuss their healthcare concerns and plans with a trusted provider (Health Quality Council of Alberta, 2016). A study published in *The Indian Journal of Palliative Care* reported that among cancer patients, an emotional bond is the most important aspect of palliative care, and that training programs that teach care providers strategies to establish an emotional bond is recommended for delivering care effectively (Aghaei et al., 2020).

Throughout the course of my research, I found myself beginning to unravel some of my assumptions about primary care providers. It was particularly difficult to learn that many family physicians feel unprepared to discuss palliative care with their patients. In Canada, primary care providers are not required to perform palliative care rotations, and it has been observed that 8.5% of primary care physicians have a practice focus in palliative care across the country (Canadian Institute for Health Organization, 2020, January). A lack of training in this field is theorized to contribute to the statistic that only 36% of Canadian family physicians felt prepared to discuss palliative care with their patients, yet 94% of those physicians found themselves having those discussions (Canadian Institute for Health Organization, 2020, January). This evidence suggests a gap in the transition between primary care to palliative care, and it could contribute to a lack of communication amongst providers and in primary care networks. A needs assessment conducted in Canada found that the majority of healthcare providers working with cancer patients felt they lacked the communication skills that are important in supporting patients through difficult conversations (Papadakos et al., 2020).

### Primary Care Physicians' Experience with Palliative Care



## CoronaVirus Pandemic Implications

As the world enters unprecedented times palliative care will face new challenges. Palliative care specialists are already burdened with their duties to patients and the need for care for life-limiting illness will likely increase as Canadians are diagnosed with CoronaVirus. As a reaction to this, frontline providers will likely be challenged to deliver palliative care duties which may be unfamiliar to them (Ontario Palliative Care Network, 2020). Canadian providers will be asked to have difficult conversations and make difficult decisions in the event of an exceeding demand for the medical services available (Ontario Palliative Care Network, 2020). It is my belief that this pandemic will shine a powerful light on the existing burdens of care for patients, loved ones, and providers. It is recommended that across the globe, hospice and palliative care services should, “respond rapidly and flexibly; produce protocols; shift resources to the community; redeploy volunteers; facilitate staff camaraderie; communicate with patients/carers via technology; standardise data collection” (Etkind et al., 2020).

# INNOVATIVE SOLUTIONS

In this section, I have gathered Canadian sources of hope for building a future of palliative care that is supportive of patients, loved ones, providers, and primary care networks.



## Collaborative Mentoring Networks In Ontario

The province of Ontario has been focussed on building a sustainable network of providers and communities of care for family physicians through the use of Collaborative Mentoring Networks (CMNs). This innovation began in 2001 as a means to provide mental health support to physicians, and has since scaled out to encompass a broad range of complex care including palliative care. CMNs' increased the capacity and support among family physicians in treating patients with complex conditions which resulted in a decreased number of specialist referrals and increased retention among patients. Physicians involved with the CMN's have reported that they provide more informative care as well as mental health support to patients with complicated care needs (Radhakrishnan et al., 2019).

## The Canadian Society for Palliative Care Physicians

The Canadian Society for Palliative Care Physicians (CSPCP) was founded in 1993 with the vision to “advance the quality of life of the dying and their families, ensure the provision of the interdisciplinary Palliative Care and competent care of the dying by primary care physicians, supported by palliative care experts” (2019). The CSPCP provides support to palliative care physicians through the design of study modules to help future physicians in their education stages, and further advocates for the rights of patients and physicians in the context of medical assistance in dying (2019). The organization has publications in world-renowned journals such as the Oxford University Press which address interdisciplinary palliative care research (CSPCP, 2019). The efforts of this organization seek to address the identified gap regarding primary care providers who do not feel prepared to handle palliative care, and I see opportunity for the CSPCP to continue the empowerment of providers who resonate with this burden.

## Community Based Participatory Research

Community-based participatory research is needed to fill information gaps in the field of palliative care research (Riffin et al., 2016).

Patient-centered feedback is crucial to consider as the palliative care scope shifts holistic care because it is no longer centered around pain management (Government of Canada, 2019). In addressing the concerns of burdens of care amongst the palliative care community, it is logical to engage with the community to create lasting impact. A publication seeking to explore collaborative research in palliative care stated,

Especially critical is the need to align research efforts with the priorities of key stakeholder groups; namely patients, their family members, and interdisciplinary teams of healthcare providers who deliver palliative care. Systematic engagement of these groups can lead to tailored and appropriate care for underserved and vulnerable patient populations and their families as well as culturally-sensitive interventions (Riffin et al., 2016).

## Collaborative Pandemic Planning

A “Guide to Pandemic Planning for Paediatric Palliative Care” was designed in 2015 by Canadian organizations, bereaved parents and health care providers who shared their expertise on the topic as a reaction to the SARS outbreak, with the recognition that, “maintaining excellent family centered palliative care within a pandemic outbreak requires thoughtful planning” (Beaune et al., 2015). The goals of this guide are to, “support health care settings in providing palliative and bereavement care services when specialist services and resources are scarce, when children require palliative and end-of-life care and when the hospital is overwhelmed with numbers of children requiring symptom management and end-of-life and bereavement care” (Beaune et al., 2015).

## Support for Supports

Individuals providing support are fundamental to the process of palliative care, and should continue to be included in changemaking discussions in Alberta's healthcare community (Canadian Cancer Society, 2020). An example of innovation in the inclusion of supports is found in tailored assistance to those individuals who are facing the burden of loss of a loved one, which is documented as a part of the deceased patient's clinical documents (Masso et al., 2015).

Additionally, there exists an increasing amount of support for those who identify as family during other stages of the palliative care process, such as The Caregiver's Handbook which outlines resources for physical and psychosocial support as well as information for caregivers (MacMillan, 2014).

## Design Sprint

Alberta Health Services and Calgary Primary Care Networks recognized that transitions between palliative care and primary care needed to be addressed, improved and collaborated by using sprint methodology as a means to bring multiple key players together with an interest in palliative care (Singh, S., personal communication, April 5, 2020). In teams, participants were asked to address the transitions between palliative and primary care, ultimately placing undue burden on providing palliative care in Alberta. The prototype ideas were formulated and await testing and piloting once conditions become favorable and appropriate to do so given the Alberta Government's current legislative changes (Singh, S., personal communication, April 5, 2020).

As an attendee, I observed that providers were able to share their perspectives and learn from each other for the purpose of moving forward. There was a great passion for addressing the burdens of care and transitions between palliative care and primary care amongst attendees, Calgary Primary Care Networks and Alberta Health Services.

## Conversations About Death

As previously examined, fear and avoidance of death have contributed to the burdens and accessibility of palliative care amongst Albertans (Barnett, 2020). It was explored that dying patients experienced lower rates of anxiety and fear when they were open-minded about death (Renz et al., 2018). Structured conversations on the topic of death and dying have emerged on the premise to “increase awareness of death with a view to helping people make the most of their (finite) lives” (Death Cafe, n.d.). In having these open discussions, many Albertans may feel their burden of care slightly lightened in entering the terminal and bereavement stages of palliative care themselves or with loved ones. Providers may also be able to process the death of their patients and be able to tackle burnout through developing their personal understanding of death and dying. Additionally, the emergence and increasing popularity of death doulas have provided terminal palliative care patients with a support that can “educate, advocate for, and empower” them by “starting a conversation about death and embracing the dying process early” (End of Life Doula Association, 2020).

## The Catalyst Fellowship Community Conversation

One of the deliverables of the Catalyst Fellowship was to host a community conversation that would engage members of the community in the fellows' topic. It was this conversation, as well as attending the conversations of other fellows, that inspired the notion that in order to tackle complex issues such as the burden of care for those involved with palliative care, we must listen to one another and pay attention to the perspectives of those whose stories are different from ours. I was committed to designing an event that invited diverse perspectives and was open to any member of the community who had an interest in the topic. The event was advertised on social media and through Alberta Health Service networks. Among the attendees were providers from various backgrounds and those who had navigated the palliative care process. They shared stories and openly discussed their thoughts on palliative care with respect toward each other. I knew that the event was meaningful to participants because they expressed their interest in convening and shared contact information with each other to discuss further opportunities for change in their communities.

# CONCLUSION

In the process of researching and immersing myself in exploring palliative care in Alberta, I sought to understand and answer the question: How might we help those whose burden of care is more than they can manage? My project examined the system of palliative care among Alberta Health Services, primary care networks, providers, patients, and loved ones using the continuity of care as a tool for measuring the quality of care in Alberta. Through the use of this context, I identified gaps in the system where Albertans were experiencing a burden of care. Patients suffer because they are not accessing services due to a lack of information, gatekeeping of services from providers, and poor relationships with their primary care providers. Those who identify as family to patients experience burdens of care in the form of burnout and lack of resources. Providers experience a burden of care in their training, resources, and amount of time that they can spend with patients. I identified that an understanding of what palliative care is, as well as a fear of death greatly impacts the ways in which the community interacts with palliative care. Further investigation brought me to find that innovation is present in the community in the forms of support and education for providers, support for patients and family, and efforts to destigmatize death and dying in the greater community which provides benefit to those involved in palliative care.

The Catalyst Fellowship brought me to the conclusion that collaborative, open conversation is not just beneficial, but necessary when tackling a complex topic such as palliative care. It was through the generosity of community members to share their stories and in allowing myself to be humbled in learning that I do not know everything, that I was able to build empathy for those involved in palliative care. I had a genuine interest in the topic of creating empathy among the palliative care community, and I even found myself checking some of my assumptions as a result of research and the community conversation. The power of this experience led me to believe that an important step in lessening the burden of care for those involved with palliative care is to listen to one another's stories, because in the practice of deep listening and understanding, we can build empathy for one another. This is what can improve the relationship continuity among providers, patients and those who identify as family, and continue to help those whose burden of care is more than they can manage.

# Palliative Care in Alberta

*How Might We Help Those Whose Burden of Care is More Than They Can Manage?*

Sydney Harder  
Catalyst Research Fellow

## WHAT IS PALLIATIVE CARE?

It is the method of providing **pain and symptom management**, as well as **emotional and spiritual support** to those living with a progressive, life-altering illness.

Providers, patients, and supports work together to prevent and relieve symptoms of the illness and its associated stress, and create treatment plans which suit the unique identity of the patient and their loved ones.

## CONTINUITY OF CARE

### RELATIONSHIP INFORMATION

Also known as longitudinal or personal continuity - is the trust that a patient has with their healthcare provider(s). It is seen as the most important aspect in receiving care for many patients.

The accessibility of medical information as well as an accumulated collection of knowledge about the patient's identity and preferences. It is highly important to patients as well as providers.

### MANAGEMENT

The effectiveness of patient-related information that is communicated among providers involved, as well as with the patient. It is the combination of relationship and information continuity.

Stable

Unstable

Deteriorating

Terminal

Bereavement

### Patients

Care is created with the individual patients' needs and preferences including age, type and stage of illness and personal identity.

**Gaps Identified:** Relationship with a primary care provider, accessing care, and stigmas regarding palliative care.

### Supports

Support can come from loved ones and the community; loved ones can be involved in decisions and sometimes take on the role of a caregiver.

**Gaps Identified:** Caregiver burnout, stigmas about palliative care, and receiving support.

### Providers

Primary care providers such as family physicians and nurses work with palliative care specialists in Primary Care Networks to provide unique treatment and support for patients in Alberta.

**Gaps Identified:** Education on palliative care, resources available, and mental health supports.

# The Burdens of Care

## HOW ALBERTANS ARE ACCESSING PALLIATIVE CARE



Those in need are unaware of the available resources or when they can access palliative care

Patients rely on their providers to help them access treatment, which can be seen as gatekeeping services



## EDUCATION FOR PROVIDERS

only **36%** of Canadian family physicians felt prepared to discuss palliative care with their patients, yet **94%** found themselves having those discussions on a routinely or occasional basis

## MISCONCEPTIONS ABOUT PALLIATIVE CARE

- Palliative care is associated with death
- Palliative care is the same as hospice care
- To accept palliative care you must stop other treatments
- Palliative care means "giving up"

## FEELINGS ABOUT DEATH

Albertans may avoid accessing palliative care services in an attempt to maintain a sense of control over their life

HEALTHCARE WORKERS FACING JOB LOSS AND WAGE CUTS IN ALBERTA, REDUCING PALLIATIVE CARE RESOURCES

RUSHED APPOINTMENTS RESULT IN PATIENTS AND LOVED ONES FEELING FRUSTRATED AND CONFUSED

CARE PROVIDERS INCLUDING LOVED ONES EXPERIENCING BURNOUT

## RECOMMENDATIONS

 INCREASE AWARENESS ON WHAT PALLIATIVE CARE IS, AND WHAT RESOURCES ARE AVAILABLE

EDUCATION AND SUPPORT FOR PRIMARY CARE PROVIDERS ON THE TOPIC OF PALLIATIVE CARE



COLLABORATIVE CONVERSATIONS WITH PERSPECTIVES OF PROVIDERS, PATIENTS, AND LOVED ONES



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