Communicating to Distance Family Members during Palliative Care

Bridging the Distance

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For my dad.

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ABSTRACT

Bridging the Distance

Communication within families can be a critical concern for a person diagnosed with a life-limiting illness. As the patient is faced with decisions about their care, family members are also faced with decisions about their supporting role during this emotional time. Access to information—or lack of access to information—can be a key factor in the ability to feel connected to a loved one, as they experience decline at end-of-life.

Added to the complexity of connection and decision-making at end-of-life is an increasingly aging demographic; a changing family structure, no longer defined by traditional roles and geographic proximity; and a Canadian society that is unable, or unwilling, to discuss death and dying.

A design research approach, supported by systems thinking and future shifts, is used to better understand the communication needs of family members at a distance during palliative care. The project also explores a complex problem, rooted in what it means to be human: to live life, and to accept the death of our loved ones and ourselves

Keywords: family, communication, distance, end-of-life, palliative, service design

Acknowledgements

List of Illustrations

Contents

CHAPTER 1

Looking Back…

My parents were born in Thunder Bay, a prominent shipping and forestry town in Northwestern Ontario (named Port Arthur at the time). They grew up there, were married there, owned a family business, had three children and enjoyed their lives there. It is family lore that my favourite place to go as a child was the airport. My dad would pull the car up to the chain-link fence that separated the parking lot from the runway tarmac, so we could watch the planes take off. My mom swears she knew then that I would not spend my life in Thunder Bay, as they had.

In the spring of 2005, my dad was diagnosed with prostate cancer. He was 65. I had been living in Toronto for almost 14 years. My youngest brother lived in Winnipeg and my middle brother lived 10 minutes from my parents' house in Thunder Bay.

One of the first appointments with the oncologist was set-up in such a way that my brother in Winnipeg and I could conference-call into the hospital and join the conversation. We wanted to hear the doctor's

prognosis first-hand, and ask our own questions, even if it was not possible for us to physically be there. It didn't happen.

The hospital was unable to connect us into the call. Upon reflection, almost seven years later, I realized that this was an indication of how my connection to the healthcare journey of my dad's illness would unfold.

Sadly, my dad's story is not uncommon. He was given a prognosis of three to five years. There were many doctors and many treatments over those years, but the cancer was too advanced for early-detection treatments. In the end, chemotherapy was the only option. But while the chemo did its job and attacked the cancer, it also attacked his heart. In October of 2009, he blacked out and fell down the stairs. On the holiday Monday of Thanksgiving weekend, I was on a plane to Thunder Bay to meet with my family, doctors, nurses and social workers to decide how to proceed with my dad's treatment, as he was not lucid enough to tell us himself.

Assessing the status of my dad's health as it related to the need to travel meant communication and decision-making were tightly intertwined.

The next four months would be full of grief, pain, confusion and guilt; I was completely unprepared to navigate the landscape of death from afar. When should I be in Thunder Bay? When should I go home? Should I bring my two-year-old son with me? How much would he remember of his dying grandfather's last days? How much time could I take off work? How could I be part of the many decisions that needed to be made if I wasn't in Thunder Bay? Would I be able to speak with the doctors from Toronto? The questions were overwhelming.

Looking back now, I am able to reflect on a number of themes that emerged during that time.

Communication Challenges and Emerging Patterns

It was my dad's desire to die at home. I don't recall those exact words being spoken by him, but we all knew he wanted to be at home. When he was first diagnosed, his healthcare team consisted of two oncologists and his family doctor. After the initial meeting with the doctors, I spoke to my parents on the phone, eager to know what happened. What was said? What is the prognosis? What happens next? Did they give you a timeframe? Somehow, when I hung up the phone at the end of our conversation, I felt better, as if it weren't as bad as we thought. However, as the hours passed, I thought more and more about the information shared and what it meant. It wasn't good. When I spoke with my dad, he was optimistic and hopeful. He was that kind of person and continued to maintain that outlook until he reached the end of his life. But, he also did not want to worry me, and I often wondered if

I was getting the full story. My mom could provide more details and was very focused on supporting my dad, doing her best to remain hopeful, in spite of the gravity of a stage-4 cancer diagnosis.

A pattern of communication developed quite early in my dad's cancer journey, and in how I experienced that journey from my home in Toronto. Immediately following an appointment or family meeting, I would call my parents to hear the outcome. My brother in Winnipeg would also call independently. We would then call each other, comparing our understanding of what we heard and determining what we thought it meant. Did we both interpret the news in the same way? Was this a positive development or something to cause immediate concern? Should we go home for a visit now or wait for a time when we could be of greater value? What should we do?

This pattern formed our communication throughout the first three to four years of my dad's illness. I noticed that when my dad called with an update on an appointment or treatment, it was more-optimistic news. If my mom called, it usually meant bad news.

During the early years, the challenges were primarily related to gaining access to information about treatment progress, how the medical team assessed progress and how my dad was feeling in general. The only method for receiving information was secondhand, through my mom. She was my dad's primary support and caregiver—recording information, keeping track of appointments and medication, updating family and friends. She later took on the responsibility of medical care in the home. I often had my own questions, which I would ask, but there was no infrastructure for accessing the healthcare practitioners directly.

After the initial lost connection on the conference call, it was never attempted again.

When my dad's health became critical in October, there were added pressures to the communication patterns that our family had organically developed over time. Previously, planning travel had a certain amount of flexibility, but now timing was essential. Phone calls almost always ended in wonder: did I need to book a flight as soon as I hung up the phone? Gauging the status of my dad's health and the need to travel meant communication and decision-making were tightly intertwined.

Feelings of isolation, common during this period, were exacerbated by built-up frustration from an inability to hear information first-hand. Over time, I focused on the lack of communication—between myself and the healthcare team—as the primary cause of stress related to my

dad's illness. This primary focus framed the initial phase of research for this project, despite the existence of other stressors, which I am only now reflecting on.

Travel, Work and Financial Stress

As the cancer progressed into decline, and consequently towards end-of-life, the issue of distance became much more difficult to manage. I was lucky that the flight from Toronto to Thunder Bay was relatively short and that there were numerous flights each day by multiple airlines. However, despite accessible flight options, it was often expensive due to the need for immediacy. Flying back and forth would become a great financial strain on my own family; it also required accommodation by my employer. The expenses continued to build, draining our savings and resulting in a reliance on credit to facilitate the necessary travel.

I was working full-time in a fast-paced design studio, as an Associate Creative Director, and it was common for me to leave work on Friday, go straight to the airport, spend the weekend in Thunder Bay, then take the 6:30 a.m. flight back to Toronto on Monday morning. I would be at my office by 9:30 a.m. On these weekends, my husband would stay home with our son and juggle his own responsibilities with daycare pickups and drop-offs. I often referred to these trips as "sliding door" weekends (after the movie of the same name), as I travelled between two different worlds, each not fully acknowledging the existence of the other.

On trips where I took my son with me to Thunder Bay, I used vacation days or sick days, or negotiated to leave early or return late to work, so it was easier to manage flying with a toddler. More than once, I pushed the stroller up to the check-in counter in a panic,

needing a kind attendant to escort us to the gate in a hurry so we wouldn't miss the flight. The juggling of flight schedules, work schedules, childcare and finances—continually keeping watch for seat sales—became part of our everyday activities.

As a result, I often experienced high levels of anxiety in both locations. In Thunder Bay, I was worried about my responsibilities as a parent and wife, which included my obligations at work to ensure that I kept my job and did not put my family's financial stability in jeopardy. In Toronto, I worried that I was not spending enough time in Thunder Bay, providing support to my parents as they experienced the dramatic decline that accompanies a life-limiting cancer. At times, it was a pressure cooker and, more than once, I paid a visit to my doctor—certain that I was about to have a heart attack. The grief associated with coming to terms with losing my

> I often experienced high levels of anxiety in both locations. In Thunder Bay, I was worried about my responsibilities at home... in Toronto, I worried that I was not spending enough time with my dad.

father, coupled with the stress of maintaining employment and raising a toddler, created intense stress and anxiety. The addition of distance between my home and my parents' home intensified everything.

Lack of Support and Not Knowing to Ask

Reflecting back on that time, I never thought of seeking out local support groups in Toronto. When I visited my family doctor, she suggested that running would help alleviate the anxiety, which it did. But she didn't make a suggestion for any support groups or services that might have been available in Toronto. And I did not think to ask.

Nor were there any options in Thunder Bay. The healthcare team—which now included a nurse, a social worker, a palliative care nurse, the oncologist, a physical therapist and a nephrologist—rarely engaged with me specifically, unless there was a family meeting or family conference.

In those cases, I flew to Thunder Bay; we would gather in my dad's room at the hospital to assess his condition and determine next steps to get him home, which is where he desired to be. After one meeting, the oncologist suggested that I look into a leave from work and indicated that Unemployment Insurance offered a program that would allow me to take time off when my dad was at end-of-life. Unfortunately, at that point, I was under too much stress to take on something new. I couldn't begin to think about working through paperwork and applications to access the program. Only later did I learn about the Compassionate Care Benefit and wished I had known about it earlier.

End-of-Life at Home

In the end, my dad's choice to be at home, surrounded by family, was honoured. He returned home by Christmas, which is where he stayed until he passed away in early February. To ensure that he was

comfortable, and that his care would be manageable for my mom, many aspects of the healthcare environment came home with him, including the hospital bed that took centre stage in my parents' bedroom. In the house that my parents had purchased right after they were married—the home that their children grew up in—is where my dad spent the last few weeks of his life. Surrounded by photos of his children and grandchildren—beautiful memories of a life well-lived. My mom took on the lion's share of the caregiving responsibilities and was able to access support through the local Community Care Access Centre. A personal support worker came every couple of days and a palliative care nurse came every day, sometimes up to three times a day, during the last few weeks. She ensured that pain management was sufficient and instructed my mom on how to administer it at prescribed times during the day. She spent time alone with my dad, assessing his status, listening to him talk when he

was able, and gently guiding him through what she knew was to come. She shared much-needed information with our family, explaining what we might witness with a human body shutting down—preparing us as best she could for what death might look like.

She also provided emotional support for me personally, as I struggled to say goodbye to my dad while negotiating, how to protect my son from experiencing the grief that had enveloped the house. She guided our family through the experience with care and compassion, and I don't know what we would have done without her. I am not sure how anyone can ever prepare to witness the passing of a parent, but we were lucky enough to not have that experience in the halls of a hospital.

The Day After
After my dad passed away, the next few days were filled with planning and preparing for the funeral. These

days were busy, and filled with family and friends that came together to celebrate his life. As difficult as the funeral was, the get-together afterwards was surprisingly comforting. Many people from the community came to pay their respects, but also show support to my family and share wonderful memories. Hearing stories about my dad's spirit and joy for life was a welcomed change to the deep sorrow of waiting by a bedside, watching every breath to see if it would be the last one. These few days brought great comfort after a long journey, but then I got on a plane and flew back to Toronto.

Once I was home, I went right back to work. I had been away for weeks, used all of my vacation time and had responsibilities to catch up on. Back in Toronto, I felt like my entire world had changed overnight but no one around me knew about it. I was angry and had little concentration while at work. Over the previous four months I learned that people generally don't

want to talk about illness and dying. It's uncomfortable and they don't really know what to say. Once my dad had died, the silence was debilitating. Most people extended a sincere "sorry for your loss," and I was thankful for that. But then they wanted to move on and not dwell on the past. No one said it, but I felt their overriding belief was that I should move on.

One day, an acquaintance called to say she knew how I felt, as she lost her mother a few years earlier. We talked for a while about the things only people who have lost a parent know about. It was a relief to speak with someone who understood what I was going through and knew how isolating it was to be surrounded by people who—though sorry for my loss—couldn't really understand why I was not acting like myself.

My dad was my biggest supporter. He believed the best for me and the best of what I could be. When he died, I felt like his view of who I was, and my

Over the previous four months, I learned that people generally don't want to talk about illness and dying. It's uncomfortable and they don't really know what to say.

potential in the world, died with him. During this time, it never occurred to me to go to a support group or gain bereavement support; because he died in Thunder Bay, there was no connection to healthcare or mental-health support in Toronto. It wasn't until two years later that my family doctor suggested I talk to someone to help me process his illness and his death. It has been five years this past February since he died, and I have only been back to Thunder Bay once—for the first anniversary of his passing. It's just too hard.

We Were the Exception
My family was lucky enough to have had a full team of caring people, led by an exceptional nurse, to care for my father through the dying process. I've since come to understand that we were the exception and not the rule. Few patients receive the care that my dad did and few families receive the palliative support we did. As grateful as I am for that access, all efforts, across the trajectory of my dad's illness, depended on my

physical presence in Thunder Bay. That was the only way to be fully involved, informed and connected to his journey.

I don't believe that my experience was unique. I suspect that more and more people follow opportunity—for school or work or relationships—and move away from where they grew up.

But the choice to live at a distance should not equate to forfeiting access to information when our loved ones are diagnosed with a life-limiting illness. If technology can provide a platform for us to see what our friends had for lunch, why can we not design for the exchange of information and connection when it matters most?

This project honours my dad's fight with cancer. It is my way of finding meaning in his loss and I hope to make a difference for other families where distance complicates the already-difficult end-of-life experience.

CHAPTER 2

Palliative Care in Ontario

"Palliative care is aimed at relieving pain and suffering and improving the quality of life for people who are living with, or dying from, an advanced illness or are bereaved. Palliative care aims to meet not only physical need, but also the psychological, social, cultural, emotional and spiritual needs of each patient and his or her family" (Office of the Auditor General of Ontario, 2015). For the purposes of this research project, "palliative care," "hospice care," "hospice palliative care" and "end-of-life care" have the same meaning.

The delivery of palliative care services in Ontario has a short history, marked by inconsistency in service delivery and inequitable access (Office of the Auditor General of Ontario, 2015). As the aging demographic moves towards age 65, there will be increased pressure on the healthcare system to meet the needs and expectations of baby boomers, who often do not have adult children that live in close proximity (Arnup, 2013) and who may not be able to provide in-person care support if needed.

Figure 1

CHAPTER 2

Palliative Care in Ontario

ONTARIO'S POPULATION: A SHIFTING DEMOGRAPHIC

As the population ages, the growing number of people over age 65 will challenge the healthcare system to meet demands.

(Public Health Ontario, 2013)

10%

Approximate % of people over 65 years of age.

15.2%

In 2013, the population over 65 years of age equalled just over 15% at 2,057,899.

24%

The number of people over 65 years of age is projected to be more than 4 million— 24% of the population.

1990   **2013**   **2031**

The History of Palliative Care

The concept of palliative care in Ontario is a relatively new one. Although the term was first conceived in Montreal in 1976, the definition of palliative care was created in 1981 by the Toronto-based organization Palliative Care Foundation (later renamed the Ontario Palliative Care Association). After amalgamating with the Hospice Association of Ontario to form Hospice Palliative Care Ontario in 2011 (Williams, Kelley, Dykeman & DeMiglio, 2014), the organization continues to focus on advocating for quality hospice palliative care in Ontario (hpco.ca, 2015).

It wasn't until 1992 that the Ministry of Health allocated $4.8 million in funding to four palliative care initiatives. In 2005, the renamed Ministry of Health and Long-Term Care (MOHLTC) announced the End-of-Life Care Strategy: $115.5 million in funding to be distributed over three years, with the goal of integration, coordination and quality of care for palliative care in Ontario (Williams, Kelley, Dykeman & DeMiglio, 2014).

This initiative was an important one for the palliative care movement in Ontario, as "there had never been targeted funding for palliative end-of-life care in Ontario for actual service delivery until the October 2005 End-of-Life Care Strategy funding" (Williams, Kelley, Dykeman & DeMiglio, 2014). Although some progress was made towards the goals defined by the strategy, the End-of-Life funding ended in 2008, leaving palliative care providers and advocates with no financial support to move towards a more integrated system.

Today, palliative care services and support are housed within an Ontario healthcare system that is complex, highly bureaucratic and defined by rising costs and limited resources (Canadian Caregiver Coalition, 2013).

Healthcare spending accounts for over 40% of the province of Ontario's spending (Speer & Palacios, 2014). As the Ontario government continues to face the challenge of reducing the substantial acquired provincial debt, there is a primary focus on reforming the healthcare system to "put patients first," while acknowledging current financial limitations (Ministry of Health and Long-Term Care, 2015).
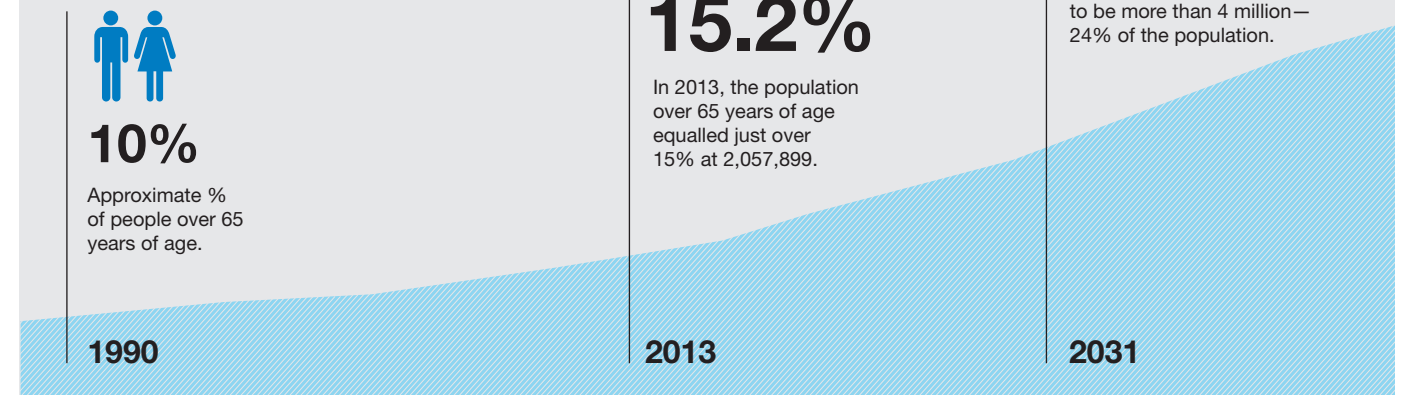
Aging Demographics

Like many Western countries, Canada is also on the cusp of experiencing a demographic shift: the number of people aged 65 and over increase dramatically over the next 20 to 30 years, as baby boomers age (Arnup, 2013). In 2011, the percentage of Canadians in retirement accounted for 14.4% of the population. By 2021, that number will increase to 18.5% and increase again to 24% in 2031. Adding further strain to the healthcare system is increasing life expectancy. On the whole, Canadians are living longer, but with more complex care needs (Arnup, 2013).

The reality is that, by the time the aging population reaches its apex, more than 425,000 people will die each year in Canada (Quality End-of-Life Care Coalition of Canada, 2010)—up from 245,000 in 2010 (Statcan.gc.ca, 2014). Almost 40% of those deaths will occur in Ontario and, considering that each death "affects the immediate well-being of approximately five other people" (Gauvin, Abelson & Lavis, 2013), the impact will be significant.

Statistically, it is clear that the aging population will create many challenges for the healthcare system in Ontario. So where does this leave palliative care? Unfortunately, the current system of palliative care in Ontario is "a patchwork of services with very little integration, a lot of overlap and significant gaps" (Gauvin, Abelson & Lavis, 2013).

Despite advocacy for increasing services and support, palliative care in Ontario is marred by inequitable access to programs that are not consistent across the province (Office of the Auditor General, 2015). As well, the need for palliative care services greatly outweighs current programs and services. Research conducted by the Canadian Institute for Health Information indicates that only 16% to 30% of Canadians are able to access palliative or end-of-life services, despite the estimation that as many as 90% (Gauvin, Abelson & Lavis, 2013) of patients would benefit from such services. Training and education in a palliative care approach is also not meeting the demand, as front-line staff often consider themselves lacking specific knowledge and skills for providing care at end-of-life (Gauvin, Abelson & Lavis, 2013).

Figure 2

Palliative care in Ontario is currently "a patchwork of services with very little integration, a lot of overlap and significant gaps" (Gauvin, Abelson & Lavis, 2013) and "the present system is ill-prepared to deal with what is to come" (qhpcco.ca, 2014).

Challenges with Delivery

In December 2014, the Office of the Auditor General of Ontario released a report assessing the state of palliative care in Ontario. Although the last decade has brought attention to the need for palliative care, both provincially and federally, Ontario still lacks a strategic-policy framework and a province-wide system for the consistent delivery of palliative services (Office of the Auditor General of Ontario, 2015). For patients at end-of-life, there are four possible ways to access palliative services: in the home, where Community Care Access Centres (CCAC) facilitate support; hospitals; hospices; and long-term care facilities. In 2005, the Ministry of Health and Long-Term Care launched a three-year initiative to provide end-of-life funding.

This initiative also included the objective to shift end-of-life care from acute care environments into the community—primarily the home and hospices (Office of the Auditor General of Ontario, 2015).

Although the three-year initiative realized some improvements, "inequities and barriers to accessing end-of-life care still existed across regions and service sectors in Ontario" (Office of the Auditor General of Ontario, 2015).

In response, a collaboration of palliative care stakeholders, including the MOHLTC, LHINs and the Quality Hospice Palliative Care Coalition of Ontario, created a vision for palliative care in Ontario in 2011, titled "Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action" (Office of the Auditor General of Ontario, 2015) with a focus on improving the delivery of palliative care in Ontario.

However, recent statistics still suggest that there is inadequate support for home care, with over 70% of Canadians dying in an acute care hospital (Gauvin, Abelson & Lavis, 2013), despite research indicating that more than half of Canadians would choose the home environment for their end-of-life care (Environics Research Group, 2013).

Where is Distance?

Despite acknowledging the increased healthcare demands that will accompany the aging demographic, and the reality that adult children often do not live in close proximity to their parents, there is a gap in current palliative care discussions that has the potential to cause additional stress to an already-strained healthcare environment. Although distance between family members is acknowledged as part of modern family life, there is little discussion on the impact of distance, either to patients and caregivers or to the healthcare system. As well, there are no proposed initiatives to support patient and family-centred care when distance is a factor. If the healthcare system in Ontario is to support the shift away from acute care facilities and into the home, greater attention should be paid to the family support that will be available to support the patient and the caregiver.

PALLIATIVE CARE IN ONTARIO: COSTS AND ACCESS

Although palliative care services are funded by the provincial government, through the Ministry of Health and Long-Term Care, many different stakeholders are involved before services reach the patient and family.

(Office of the Auditor General, 2015)

MINISTRY OF HEALTH AND LONG-TERM CARE (MOHLTC)

Establish strategic direction and policy for the province

MOHLTC funds the LHINs who plan, fund & integrate healthcare services locally

PROVINCIAL

REGIONAL

Palliative Unit Bed

ACUTE CARE HOSPITAL

funds

LHINs 14 Local Health Integration Networks

2/3 of the LHINs budget

funds

$700/day The cost of a palliative bed in a hospital setting ranges from $630 to $770 per day.

$1,100/day The cost of an acute care hospital bed in Ontario is approximately 40% more than a bed in a hospital palliative unit.

CCACs 14 Community Care Access Centres

Long-Term Care Facility

Other*

COMMUNITY

CCAC facilitates access to services & support

funds

Hospice Residential

$439/day The cost for a hospice bed. Hospices receive partial funding from the government with the balance achieved through fundraising.

HOME

$100/day When patients choose to receive end-of-life care at home, the cost of providing services is sustantially less.

Home Care

Community Support Services

Faith-based Organizations

Private Care paid by the Patient/Family

Patient & Family navigate

$26 billion is the estimated replacement costs to the healthcare system for informal (family) caregivers, which would account for 14% of the healthcare expenditures in Canada. (Canadian Hospice Palliative Care in Canada, 2014)

Patient & Caregiver

Local Family

navigates from afar

Distance Family Member

* Approximately 60 other organizations, which also received funding, are involved in the delivery of palliative care services and support in Ontario (Office of the Auditor General, 2015).

Figure 3

A Patient's Journey

Common care models visualize the patient at the centre of a circle, surrounded by healthcare practitioners and family providing support (Seow, 2015). Whether a circular model of healthcare delivery is an accurate depiction of actual experience or not, it is worth considering how a patient moves in and out of the healthcare system, as well as the proximity of both local and distance family members.

ACUTE CARE HOSPITAL

I'm afraid treatment is no longer effective

Let's determine how to support you at home…

Specialist Doctor | Patient & Caregiver | CCAC Case Worker

ACUTE CARE HOSPITAL

ER VISIT

The pain is so bad, I didn't know what to do…

Doctor | Patient | Caregiver

ACUTE CARE HOSPITAL

ICU

Do you know your wife's wishes for end-of-life?

Doctor | Caregiver | In-hospital Palliative Care Bed

Here are the treatment options…

ACUTE CARE HOSPITAL

I think we should run some tests

Specialist Doctor | Patient & Caregiver | Local Family

How is everything going?

Patient | Family Doctor

Family Doctor | Patient

REGIONAL

| 100% PPS* | >> PPS* | >> | >> | >> | >> | >> | 0% PPS* |

HOME

I have a doctor's appointment today…

Patient

I have cancer

Patient & Caregiver | Local Family

We'll go to the appointment together…

Patient & Caregiver | Distance Family Member

Tell me what the doctor said… how are you feeling?

Patient & Caregiver | Local Family

I brought over dinner, how was the day?

I will be here a couple times a week…

Patient & Caregiver | In-home PSW

Let's talk about the goals of care for your wife…

In-home Palliative Nurse | Patient | Caregiver

I really didn't know it was this bad…

Local & Distance Family

Your mother really wanted to stay at home

Caregiver, Local & Distance Family | In-home Palliative Nurse | Patient

How is your pain today?

I'm going to adjust your medication

GP or Palliative Doctor

COMMUNITY

Local Family

Local Family

Local Family

Hospice will be able to provide more comfort…

Caregiver | Residential Hospice Bed

DISTANCE

I'm going to plan a visit

Distance Family Member

I'm not sure what is happening…

Distance Family Member

I hope I get there in time…

Distance Family Member

*Palliative Performance Scale (PPS)
"An assessment tool that measures a patient's functional status and assigns a score. The lower the score, the less time the patient is estimated to have remaining to live. The scale provides a way to measure progressive decline over the course of a patient's illness" (Office of the Auditor General of Ontario, 2015). The PPS score is often a factor in determining access to a hospice or palliative unit bed, as well as the number of hours allocated to support in the home.
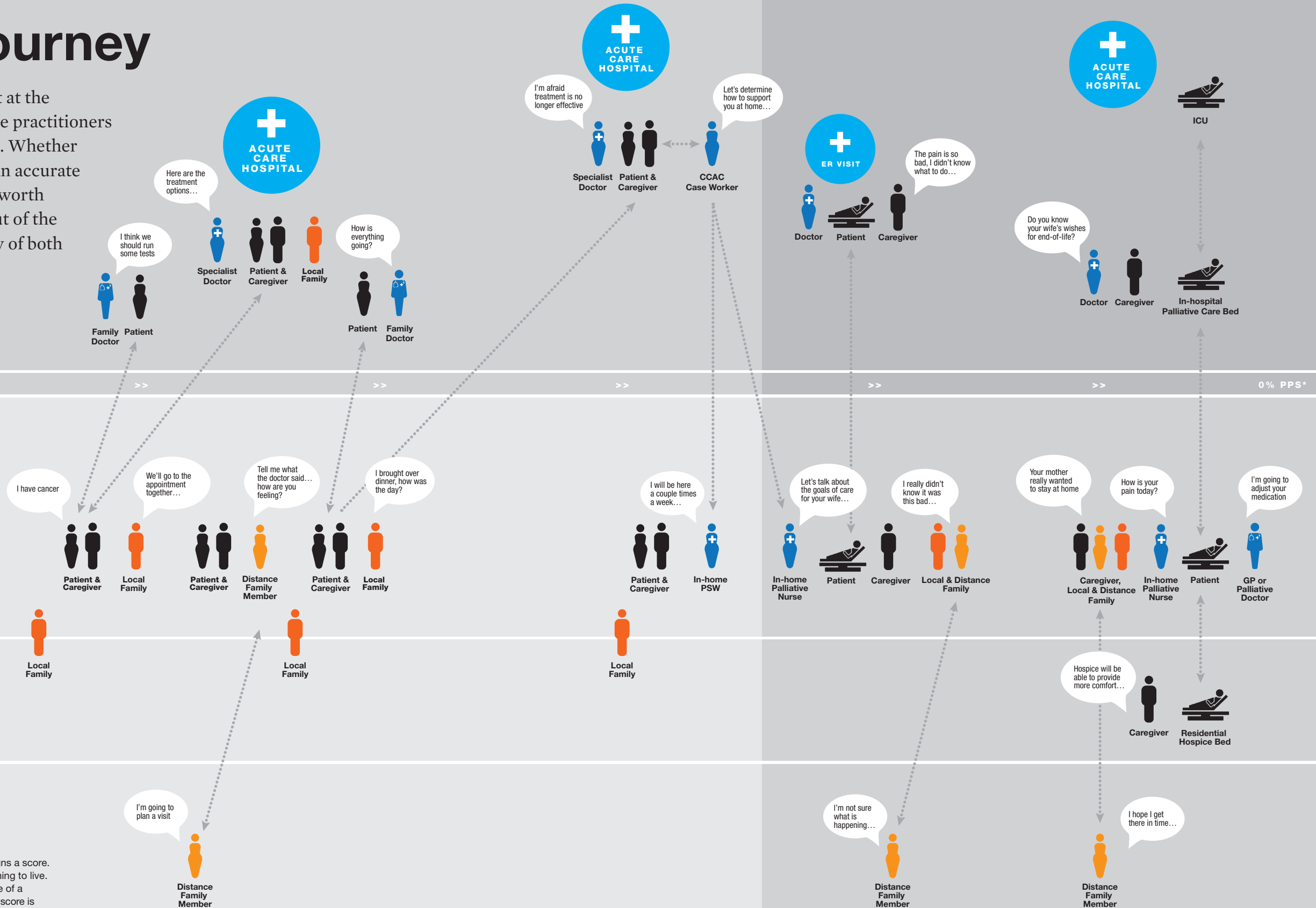
A Service Design Approach

The project approach has undoubtedly been driven by my personal experience. Using a service design methodology, the goal was to engage people with lived experiences to better understand the challenges of experiencing end-of-life at a distance. To support a holistic understanding of the environment, it was important to hear from both Distance Family Members as well as healthcare practitioners who support patients and caregivers at end-of-life.

Although still an emerging practice in Canada, service design focuses on designing for the needs of customers (SDN, 2015) and applies established design processes to the development of services (Stickdorn & Scheider, 2011). As patient and family-centred care is at the core of the palliative philosophy, a service approach was a perfect fit.

An initial literature review revealed that the distance family member was under-represented in current research and served as the foundation for framing the following project research questions:

What are the needs of family members who are at a distance from a loved one during palliative care?

How might we better meet the needs of family members who are at a distance during palliative care in Ontario?

Service Design & Healthcare

Figure 4

SERVICE DESIGN PROCESS

Hugh Dubberly proposes a methodology that is focused on an "integrated design process and people-centered research."

(Dubberly & Evenson, 2010)

Project Methodology

In collaboration with fellow Strategic Foresight and Innovation student Adam Starkman, we have developed a project methodology, and a corresponding research plan: combining a service design methodology with foresight and systems thinking, we aim to develop solutions that are human-centred, viable and sustainable.

Both of our respective projects deal with vulnerable populations within the healthcare sector. As designers, we are uniquely positioned to bring "a holistic and systemic design perspective to the complex problems of healthcare" (Jones, 2013). It is through this holistic and systemic approach that we are able to identify and define problems, generate new ideas, and converge on solutions that can be implemented and ultimately result in positive change (Basadur Applied Creativity, 2015).

Design research is an evolving field (Sanders & Stappers, 2008), especially within a healthcare system that is strongly rooted in an evidence-based approach. As we developed our project methodology, we quickly determined that, for both patient and family populations, it is imperative to engage those with lived experiences to inform the identification of needs, opportunities and challenges. Furthermore, we selected research methods and techniques that involve these individuals as co-creators in the development of the ultimate solution. This participatory approach is important because the users themselves will measure the success of any proposed innovation in the uptake of services.

Service Design

Service design is defined by five key principles (Stickdorn & Schneider, 2011):

1. User-Centred:
Services should be experienced through the customer's eyes.

2. Co-Creative:
All stakeholders should be included in the service design process.

3. Sequencing:
The service should be visualized as a sequence of interrelated actions.

4. Evidencing:
Intangible services should be visualized in terms of physical artifacts.

5. Holistic:
The entire environment of a service should be considered.

Moreover, as Hugh Dubberly illustrates (see Figure 4), our approach moves from an exploratory process intended to gain understanding of the needs and desires of the users, to a generative phase where users co-create possible innovations, and finally to an evaluative stage where solutions are socialized and implemented (Dubberly & Evenson, 2010).
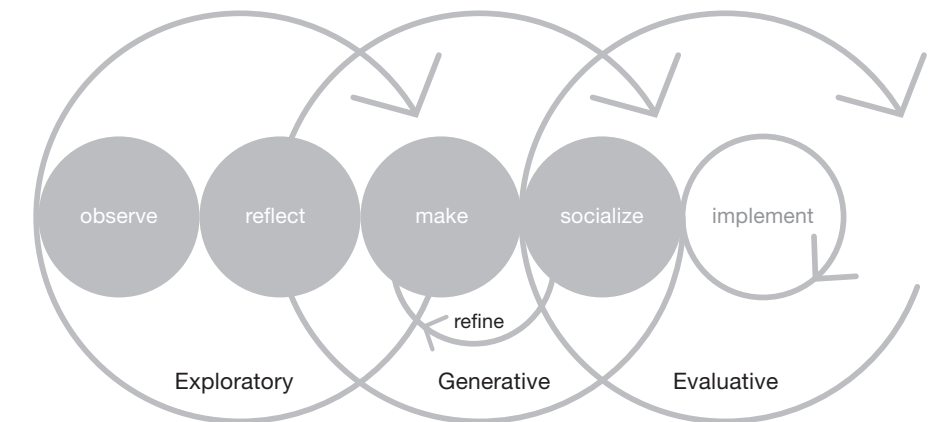
Strategic Foresight

The proposed methodology does not proclaim to incorporate a fulsome approach to futures work, but does suggest that any proposed change or intervention should take into account the current situation, while being mindful of the forces that are shaping the future (Stein & Goodman, 2007). Foresight methodologies, such as Horizon Scanning (Popper, 2008)— which provide a framework for the identification, examination and understanding of emerging shifts, based on social, technological, environmental, economic, political and values (STEEP-V) factors—have been adopted to understand potential impacts on the particular area of interest (Loveridge, 2002).

For the purposes of this project, scanning was limited to an environmental scan and the identification of key shifts that might impact the acceptance or sustainability of proposed interventions.

Systems Thinking

Once again, it would clearly be an overstatement to suggest that this project will address the systemic challenges that exist within the Province of Ontario's healthcare system. However, in order to identify meaningful opportunities for change, or targets for innovation, it is important to understand the system in which we are operating. It is our understanding of the whole that will enable us to influence specific parts of the system (Ackoff, 2004). Greg Van Alstyne, professor in the Strategic Foresight and Innovation program, has expressed how to consider the two scales simultaneously, in that "problems are systemic, but interventions are local."

Systems mapping is an effective visualization tool that communicates the complexity of the system, and through the iterative evaluation of the system map allows for more effective and meaningful strategy development (Blair, Boardman, & Sauser, 2007).

The project does not intend to change the current system, or influence the future system in a broad way. However, the project does aim to enhance the ability of distance family members to participate in the journey of their loved one during end-of-life care. In order to do that, it is important that to understand the root of the problems, to consider the factors that contribute to the challenges observed, and to actively engage individuals with lived experience in the design of meaningful solutions.

By understanding the needs of family members at a distance through human-centred research, the goal of this project is to ultimately propose interventions that address their needs and encourage connection and information exchange, while taking into consideration the context and limitations of the current healthcare system.

Overview of Methods

The following methods were used to support the project.

Literature Review
Research of secondary sources was conducted to gain knowledge on "communication to distance family during palliative care." The full literature review content is included in Appendix B on page 98.

Systems Mapping
Systems mapping was used to illustrate learnings on the current healthcare system, as it relates to palliative care in the province of Ontario, including current policy papers and the presence of advocacy organizations. Data points were gathered from available online research, including websites, policy papers, newspaper articles and other material that highlighted the existing landscape in which palliative care lives.

Horizon Scan
Building on the literature review and complementary to the Systems Mapping of the current palliative care landscape in Ontario, a horizon scan foresight methodology focused on the family structure, living situations, technology use in family communication and attitudes towards death and dying. Based on a five-year horizon, scanning for signals of change—found in blogs, journals, policy papers, popular culture, websites, magazines, etc.— was used to identify patterns indicating shifts in the current landscape (Jackson, 2013). Signals were sorted using the STEEP-V (Loveridge, 2002) framework and gathered into a focused set of shifts with particular relevance to the research questions.

Confessional Ethnography
As the topic for this major research project is based on a personal experience, I undertook a confessional ethnographic exercise (Rode, 2011) for the purpose of formally reflecting on my own experience. The purpose of the confessional ethnography was to reveal personal biases that were influencing this project before embarking on research with participants with the intention of approaching gathered data from a more self-aware and, where possible, neutral standpoint.

Distance Family Member Interviews
Semi-structured interviews (see Appendix D on page 106) were conducted to gain a focused understanding of the needs of family members who lived at a distance from a loved one in palliative care. Challenges and barriers to being connected with their loved one's journey, as well as the identification of any existing services they encountered, were of particular interest. As distance was a factor in many identified participants, email interviews were offered to participants as an alternative to in-person or telephone interviews, due to geographic barriers and/or scheduling challenges. The email interview was also useful for distance family members who were interested in participating in the research, but who needed time to reflect on the questions due to the sensitivity of the topic.

Healthcare Practitioner Interviews
It was critical to hear the perspective of healthcare professionals who interact with the patient and their family members during palliative care (see Appendix D on page 106). Recruitment was approached with an eye to capturing insight from different healthcare roles and included doctors, nurses and social workers. Specific questions were crafted to better understand their experience with family members at a distance when working with patients diagnosed with a terminal illness. Insight from these professionals was critical to understanding the barriers that might be presented, and therefore, to better supporting the needs of the Distance Family Member, as well as the impact that Distance Family Member actions may have on the patient and local caregiver.

Journey Mapping
User insights informed the creation of customer journey maps to visualize the distance family member experience. The purpose was to provide "a high-level overview of the factors influencing user experience, constructed from the user's perspective" (Stickdorn & Schneider, 2011).

Data Processing
Themes from interviews were created using an analysis and sorting technique informed by a thematic analysis approach (Fereday & Muir-Cochrane, 2008).

PARTICIPANTS & LIMITATIONS

Participants
Due to the sensitivity of the topic, Distance Family Members were recruited through the researcher's personal network and social connections. Geographic distance of participants ranged from a two-hour drive to a five-hour flight from out of country. A total of eight interviews were completed in the following formats:

3 Email Interviews
2 In-person Interviews
3 Telephone Interviews

Healthcare practitioners were recruited through professional networks of the researcher, as well as through Saint Elizabeth, secondary advisor on the project. A total of nine healthcare practitioners participated in the research:

2 Doctors
3 Nurses
4 Social Workers

All practitioners had experience working in palliative care in Ontario.

Limitations to the Project
As recruitment was conducted through known social networks, Distance Family Members interviewed are of a similar socio-economic status; cultural diversity is not represented. Participants are all female and, therefore, future research should aim to hear the male voice.

Due to constraints associated with the project timeline, a number of concepts and themes, relevant to the topic of palliative care, are not included in this document. Specifically, existing research on the caregiver is not included in the scope of work.

Finally, system mapping included in this project is restricted to a high-level viewpoint. Due to the complexity of the Ontario healthcare system, as well as the researcher's position "outside the system" nuanced illustrations of day-to-day service delivery were not possible.

CHAPTER 4

Shifts Impacting the Landscape

To promote a broader picture of the potential pressures on the delivery of palliative care services in Ontario, a horizon scan methodology was used to identify shifts in three pivotal areas significant to the project: family structure, technology use for family communication, and Canadians' relationship to the concept of death and dying. Using the STEEP-V framework (Loveridge, 2002), signals were captured to shed insight on potential shifts. A short time horizon of five years was used to ensure immediate relevance for potential interventions and acknowledged the slow-to-adapt nature of the healthcare environment in Ontario, and policy in general.

Why these three areas?
As family is at the core of the palliative care approach, it is important to understand how the family structure has evolved over recent decades; how individuals and families communicate with each other has also changed. This is particularly important when distance is a factor. Finally, society's relationship with death and dying can have an impact on whether patients and their families will be open to a palliative care philosophy for end-of-life and to potential interventions to support distance family members.

SHIFT 1

Family: Traditional to Diverse

Fading Traditions

What was once understood of the definition of the traditional Canadian nuclear family—consisting of a married man and woman, with biological children, that stay married for the duration of their lives—is long gone. The family model, once defined by the man who went to work to financially support his family and the woman who stayed home to raise their children, is now less relevant to the realities of modern life. In 1961, marriage accounted for 91.6% of families in Canada (ohrc.on.ca, n.d.) and although it is still the predominant family structure, it has declined significantly to 67% in 2012 (www12. statcan.ca, 2014). Today, there is much greater diversity in the family structure.

The Changing Face of Families

The 2014 study on "The Changing Face of the Canadian Family," published by the Ontario Human Rights Commission, acknowledged that the definition of family has broadened significantly to include many variations (ohrc.on.ca, n.d.), such as single-parent families, common law families, blended families, same-sex families and adopted families. As well as changing structures, our definition of what family means is also changing

and often includes identifying friends as family rather than those relationships defined by bloodlines. In addition to the change in family structure, families are also decreasing in size, due to the decline of the birth rate in Canada (MacDonald, 2012).

The rise in same-sex marriages and same-sex families can be attributed to policy change that occurred with the passing of Bill C-38, the Civil Marriage Act, in July of 2005, which legally allowed same-sex couples to marry in Canada. As a result, same-sex marriages tripled in the five years that followed the passing of the bill (www12.statcan.ca, 2014).

The rise in blended families can be attributed to divorce at varying stages of life, including a recent trend towards "grey divorce," which has seen an increase in people over 65 ending their marriages (Nguyen, 2012).

Multi-generational living arrangements are becoming more common as families respond to the "boomerang effect," which sees adult children of the Millennial generation returning home to live with their parents when they are not able to find sustainable employment (MacDonald, 2012). In addition, the higher divorce

rates identified in the aging population have contributed to people from different generations living together under one roof; as well, the emergence of communal living for people over 65 has been a way to reduce financial burdens and provide social support later in life (Cavendish, 2014).

Gender Roles and Caregiving

Beyond changing family structures, changing gender roles, related to care, are also a significant factor of family life in Canada. In 1961, less than 10% of women were part of the workforce, in contrast to the almost 60% of women that were part of the paid workforce in 2009 (statcan.gc.ca, 2013). As women pursue career opportunities, men are taking a more active role in raising their children. An article in *The Atlantic* recognized "The Rise of Daddy Daycare." It acknowledged that more men are choosing to be stay-at-home dads, as their wives become the primary breadwinner (White, 2014). Federal policy also allows the flexibility for either the mother or the father to access up to 35 weeks of parental leave within the first year of a child being born or adopted (servicecanada.gc.ca, 2014).

Although caregiving is still primarily seen as the role of women, small shifts in care duties are also being reflected in men taking on greater responsibility for aging parents. "In 2009, according to a National Alliance for Caregiving/ AARP study, men accounted for 34% of the nearly 65 million family caregivers in the U.S. But more recent surveys show the number of men in this traditionally female role has risen rapidly, driven by a combination of factors, including the recession, changing gender expectations and longer life expectancies" (Snelling, 2013). In Canada, The Change Foundation, recently released its 2015– 2020 Strategic Plan. Focusing on patient and family caregiving experiences, the plan acknowledges that women (53%) and men (47%) are evenly matched when it comes to caregiving responsibilities (The Change Foundation, 2015).

Regardless of whether caregiving is in the hands of men or women, both genders are feeling the pinch. As more women delay having children until they are older, multi-generational caregiving is becoming a common reality. This results in the "sandwich generation" which has the responsibility of concurrent care— that of raising children and caring for aging parents (Arnup, 2013).

DESIGN IMPLICATIONS

Variations, and diversity, seen in modern families are important to acknowledge, and gender roles and the distribution of caregiving responsibilities should not be pre-assumed to live solely with women.

Recent policy developments in Ontario and Canada identify the family as a critical piece in providing care for the aging demographic. However, the impact of the "changing face of the Canadian Family" (ohrc.on.ca, n.d.), as well as the reality that adult children do not always live in close proximity to their parents (Arnup, 2013), is not well-considered in current policy. Changing gender roles, work pressures and childcare responsibilities will have an effect on whether individuals in families will be able to fulfill caregiving roles for their aging parents, and to what degree. The shift in gender roles is particularly important, as healthcare often assumes that women will take the lead in caregiving tasks, whereas it is reasonable to expect that men may increasingly share these responsibilities in the future. Interventions designed to support the Distance Family Member need to consider the broader context of changes in family structure and ensure that inclusivity of the diverse definitions of family are addressed.

SHIFT 2

Communication: Direct to Digital

Personal Communication

Over the last 25 years, there is no question that technology has significantly impacted the way that people communicate with each. The reliance on face-to-face interaction, telephone conversation or mail delivery to keep in contact with family at a distance has been augmented or replaced by an ever-increasing number of platform options designed to bring people together through digital access. Today, eight in 10 Canadians are on the Internet (cira.ca, 2015) and three-quarters of parents use social media sites, such as Facebook and Twitter (London, 2013). Platforms that prioritize imagery are also increasingly popular, as two-thirds of parents have adopted Pinterest and Instagram as a way to keep in contact with friends and family (Sanghani, 2013).

"It seems pretty obvious to most observers that our social networks have changed in the past few decades thanks to technology. The widespread use of cell phones...the rise of the internet, and the advent of social media have changed the way we work, the way we live, and the way we make and maintain friendships" (Masket, 2014).

Where geographic distance used to be a barrier to staying in touch, technology has significantly closed that gap. Given that the widespread availability of mobile devices, such as smart phones, we have instant access to any information we need and any method for contact. And we don't put them down. We have integrated mobile devices into every part of our lives. "With 91% of people sleeping within arms reach of their mobile device, it is safe to say that we are both addicted to our mobile device and dependent on it" (Newman, 2014).

As individuals change their communication patterns, so do families. Siblings text each other during the day, grandparents use Skype to virtually visit their grandkids in another city, and parents "use WhatsApp to say dinner is ready" (Sanghani, 2013). The impact of technology on families is not just how they communicate when they don't live together, but also how they communicate when they do live together.

Research conducted by sociologist Barry Wellman suggests that "decades ago, our social networks were decidedly local; we primarily spoke with our neighbors and nearby friends and family members" (Masket, 2014). However, "more recently, we have become, in Wellman's words, "glocalized,"" simultaneously involved in both local and long-distance relationships" (Masket, 2014). For families that rely on communication over distance to maintain connections, the shift to a wider network of relationships can be highly beneficial.

As the technology behind mobile devices and tablets has advanced at a rapid pace, high-quality cameras, including video, are now standard offerings and have supported online video-conferencing applications, such as Skype and FaceTime. Adoption rates for Skype have been dramatic, with worldwide users reaching 300 million in 10 years (Steele, 2013), compared to over 100 years for telephone and 25 years for cell-phone users. The attraction of online video conferencing is hard to resist, as users share stories of Skype allowing a

> As individuals change their communication patterns, so do families. Siblings text each other during the day, grandparents use Skype to virtually visit their grandkids in another city and parents "use WhatsApp to say dinner is ready" (Sanghani, 2013).

soldier serving overseas to witness the birth of a child or a classroom of primary school children experiencing a "virtual field trip" to the bottom of the ocean (Steele, 2013).

Networking People Together

Along with a shift in person-to-person communication is the emergence of online platforms that strengthen the connection of people in an existing social circle, and around a person and/or caregiver in need of support. Although Facebook is commonly used to keep in touch with family (Jones, 2014), when there is a health crisis, the issue of privacy may drive families to seek out alternate platforms. Tyze Network and CaringBridge are two examples of specialty-technology networks designed to support caregiving.

Tyze is an online-care collaboration tool that organizes people around one person—a social network for the purpose of creating a caring network for people with an illness or disability. Private, secure, mobile and without advertising, the tool facilitates sending updates, managing appointments, organizing friends

and family who can help and creating a "private care space" to share news, stories and photos (tyze.com, 2014). CaringBridge is a similar platform that supports the sharing of updates and coordinating help, while ensuring online privacy and security (CaringBridge, 2015).

Although the healthcare environment might be considered lagging behind in a more liberal adoption of technology for the purposes of communication, Ontario is able to draw on The Ontario Telemedicine Network (OTN) as a secure network. Considered a "world leader in telemedicine, OTN helps Ontarians get more out of the health care system by bridging the distance of time and geography to bring more patients the care they need, where and when they need it" (OTNhub, 2015). Although the primary purpose of the OTN is to support care delivery within Ontario, there are examples of the service supporting communication between distance family members.

At the Thunder Bay Regional Health Sciences Centre, the OTN has been used to create a Tele-Visitation program. Providing health services for Northwestern Ontario, the population in the region has only approximately 122,000 people. However, the geographic area served is large and spread out, and within the catchment area are 70 First Nations communities, including 24 that are only accessible by air or icy winter roads (Nicholas, 2013).

Initially developed to address the needs of First Nations patients that had family in remote communities, the Tele-Visitation program "is the virtual transportation of a patient's family to the bedside, regardless of the patient's location within an acute care setting" (Nicholas, 2013). Even though the program was initiated to support more positive outcomes for patients in acute care, a new opportunity for expansion may include end-of-life visitation as a tool for the Palliative Care Team within the hospital (Nicholas, 2013).

DESIGN IMPLICATIONS

Mobile devices and inter-connectivity is on the rise. Younger generations will expect to have access to information and will not have the same expectations of privacy and confidentiality. Healthcare providers will need to respond.

Mobile devices and emerging online platforms are intrinsically changing how people communicate with each other. Younger generations, such as Millennials and Generation Y, have been born into a time where mobile connectivity and access to information is ubiquitous. In a February 2015 Report on the Networked Society, Ericsson predicts that, by 2016, smart-phone subscriptions will surpass that of basic telephones (Ericsson, 2015) and that "90% of individuals over 6 years old will have a mobile phone" (Ericsson, 2015). With the ability to connect whenever we want, with whomever we want, at our finger tips, expectations for access to information will be high. This expectation of immediately available information will impact the healthcare system and healthcare providers, as "digital natives"—those born into technology (Prensky, 2001)—demand access and test the boundaries of privacy and confidentiality.

Death: Denying to Discussing

The Medicalization of Dying

In 2013, the Vanier Institute of the Family published a report titled "Death, Dying and Canadian Families," which highlighted Canadians' uncomfortable relationship death. This was underpinned by a number of historical contexts that led to the "medicalization of death and dying," during the period between the 1950s and 2000, which moved death into hospitals and away from the home (Arnup, 2013). As advances in science and medicine progressed with the perception that anything could be cured "physicians... focused increasingly on curate measures, [and] death came to be seen as a medical failure" (Arnup, 2013).

This increased preference for medical interventions removed death from the community and created a society of Canadians that did not see death until later in life. "People were no longer present at the time of death and, as such, death itself became shrouded in mystery and fear" (Arnup, 2013).

What we are witnessing today is a general avoidance of death and a portrayal of healthy, active living well past retirement (Arnup, 2013). SunLife Financial ran a campaign in 2011 to promote their "Money for Life" retirement program; it included a TV spot showing a retired couple, in motorcycle jackets, riding into the sunset on their yellow scooter (SunLife Financial, 2012). And there is certainly no shortage of propaganda in media and advertising selling society on longevity. When Martha Stewart released her book *Living the Good Long Life: A Practical Guide to Caring for Yourself and Others* just after turning 70 in 2013, she shared her belief that there is "a new generation of aging in the modern world" and that "70 is the new 50" (Peppers, 2013)!

While this might be attainable for some, the reality can be quite different. Even though life expectancy in Canada has increased to 81 years, (statcan.gc.ca, 2012), we are not without healthcare challenges. Recent research indicates that many Canadians experience death after a long period of illness and decline (Arnup, 2013).

The proliferation of stories describing how life will be long and vibrant, plus the aspirations of a few, highly visible people—such as Google Ventures head Bill Maris, who is dedicating more than $400 million to "slow aging, reverse disease and extend life" (Brooker, 2015)—is it any wonder that people are not open to accepting death. Adding the fear and stigma that has been built up over the last few decades, it is perhaps not surprising that only 25% of Canadians over the age of 30 have completed plans for end-of-life (Environics Research Group, 2013). How can we plan for something we do not want to talk about? How do we accept something we are actively trying to delay, or stop from happening?

New Conversations in New Ways

There are some indicators that people are beginning to find ways to start the conversation about death and dying. And perhaps it is not surprising that a number of examples are arising from individuals and organizations within communities.

Death Cafe is a volunteer organization that invites people to join others to "gather to eat cake, drink tea and discuss death." Since the first event in the U.K. in 2011, there have been more than 1,700 Death Cafe's held in non-medical, community environments in 26 countries (Deathcafe.com, 2015).

Gatherings, such as The Death Cafe and Death over Dinner, prioritize a less formal, and more comfortable, environment to foster open dialogue, free from stigma and fear of asking questions. The Death Cafe—a volunteer organization that began in 2011—invites people to local cafes, where attendees can have a coffee and discuss their thoughts with others. Although the organizer is generally someone with end-of-life care experience, their role is to guide and encourage people to openly share their thoughts with those at their table and freely follow where the conversation takes them. The Death Cafe has seen events take place in more than 26 countries in less than five years (Deathcafe.com, 2015). Toronto joined the movement in December 2014.

Let's Have Dinner and Talk about Death (Death over Dinner) is similar in that it encourages people to invite their friends over for dinner and talk about "views on death to life through food and drink" (Let's Have Dinner and Talk About Death, 2015).

Founder Michael Hebb was asked to present the Death over Dinner concept at the 2013 TEDMED conference in Washington, D.C. (TEDMED, 2015).

Both The Death Cafe and Death over Dinner promote open conversations, in non-medical environments, with the ultimate goal of reducing the stigma and fear that surrounds our relationship with end-of-life.

There are also examples, such as My Gift of Grace and The Conversation Project, designed to encourage people to make Advance Care Plans (outlining wishes for end-of-life). Both projects use a friendly, approachable format to help people make the leap to thinking about what their preferences might be for end-of-life. My Gift of Grace is designed as a card game for families when everyone is home for Thanksgiving, and aims to "explore the use of design to create space for meaningful conversation about death, dying and life" (My Gift of Grace: A conversation game for living and dying well, 2015).

The Conversation Project provides a conversational toolkit that can be downloaded from a website, and that encourages people to have discussions around the kitchen table, rather than in the Intensive Care Unit when there is a crisis (theconversationproject.org, 2015).

Some municipalities are also taking initiatives to ensure, that citizens are making Advance Directives. In La Crosse, Wisconsin, almost 96% of people who die have made Advance Care Plans which is 60% more than the average across the U.S. (NPR, 2015). Driven by a local resident, and a medical ethicist in the hospital who witnessed many families suffer with decision-making for a loved one who had not expressed their wishes, initiative has nurses trained to talk to patients about planning long before a crisis occurs. Now described as "the town where everybody talks about death," La Crosse has the lowest healthcare costs associated with end-of-life in the United States (NPR, 2015). Closer to home, a recent study suggests that Canadians may be making a shift as

well. Even though only a quarter of people over 30 have made plans, the study revealed that "eight in ten Canadians are at least somewhat comfortable in discussing end-of-life care issues" (Environics Research Group, 2013), which is encouraging.

A Doctor Shares
From the perspective of the medical community, Dr. Atul Gawande's 2014 book, *Being Mortal*, suggests that doctors are also beginning to acknowledge the need to have conversations about end-of-life preferences, but, it is also the responsibility of healthcare practitioners to provide a realistic picture of outcomes associated with curative treatments offered (Gawande, 2014). The success of the book extended to television with a documentary series on PBS's *Frontline*, which shared patient and practitioner stories at end-of-life (PBS, 2015). The series encouraged viewers to think about #whatmattersmost (Twitter.com, 2015) by igniting an ongoing Twitter conversation about aging, death and making informed choices about our final days.

DESIGN IMPLICATIONS

Fear and denial are very real aspects of how Canadians relate to death and dying. Yet opportunities are emerging within the community to offer innovative, and non-medical, platforms to encourage discussion.

It is the uprising of events, such as these that prompted *The Atlantic* to declare that "Death is Having a Moment" (Hayasaki, 2013), reflecting an emerging shift in how society is coming to terms with death and dying. By no means do these signals suggest we have moved passed the fear and denial of the last 50 or 60 decades. It does, however, indicate that there is a window opening on which to build upon. As aging demographics collide with an already-overburdened healthcare system, all Canadians will be encouraged to make decisions about end-of-life preferences and accept that, despite advances in curative treatments, life does not go on forever. If we are to make decisions thoughtfully, we need to re-humanize death and minimize fear to allow for open dialogue. Design interventions need to acknowledge both the stigma attached to talking about death as well as the potential for creating space for conversations when supported by frameworks that are comfortable, human and conversational and that are designed to take place far in advance of a healthcare crisis.

CHAPTER 5

Understanding Lived Experiences

Themes and Insights from the Research

Building on the secondary research, interviews were conducted with both Distance Family Members and healthcare practitioners.

As the Distance Family Member voice is not well represented in the existing literature, eight interviews were conducted with participants who had lived experience of being at a distance from a loved one at end-of-life.

Interviews were also conducted with nine healthcare practitioners that deliver palliative care services in Ontario—including doctors, nurses and social workers—to better understand the impact that Distance Family Members have on the delivery of palliative care services.

Thematic analysis (Fereday & Muir-Cochrane, 2008) was used to establish a final set of nine themes, which reflect the experience of being at distance from the Distance Family Member, as well as the challenges that healthcare practitioners face when supporting patients and families where distance is a factor.

Figure 5

THEME 1

Personal Pressures

It is not surprising that the weight of responsibility that distance family members feel towards their home life is both a significant consideration and a barrier to visiting their loved one in person.

Distance Family Members described numerous concerns about how to maintain their lives at home, which often included coordinating schedules with a spouse or partner, childcare issues, arranging for care of pets and animals, as well as commitments at work and managing their own health and wellness.

Juggling Childcare and Elder Care

The issue of elder care competing for time and attention with raising children is a characteristic known as the "sandwich generation" defined by adults attempting to fulfill both childcare needs and the care of their aging parents (Arnup, 2013), often while maintaining full-time employment. The very tactical requirements associated with reorganizing family schedules, including drop-offs and pickups from school or daycare, are a by-product of an increasingly busy modern family life.

"I've got a seven year old and an 11 year old and my husband works a lot of hours, sometimes he'll work 50–60 hours a week. So, I'm in charge of picking the kids up and dropping them off...I'm lucky, I have my mother-in-law who lives 5 minutes away...but the problem is she has MS so she can't drop the kids off...I was able to drop the kids off [there] but my husband had to rearrange his day and then he would work late, so I would get the kids and I'd get home late...it was a real juggling act."
— Distance Family Member

"It was extremely stressful. I wanted to be with her 24/7, but I had other life pressures that I had no choice but to deal with. I constantly felt I was not spending enough time there."
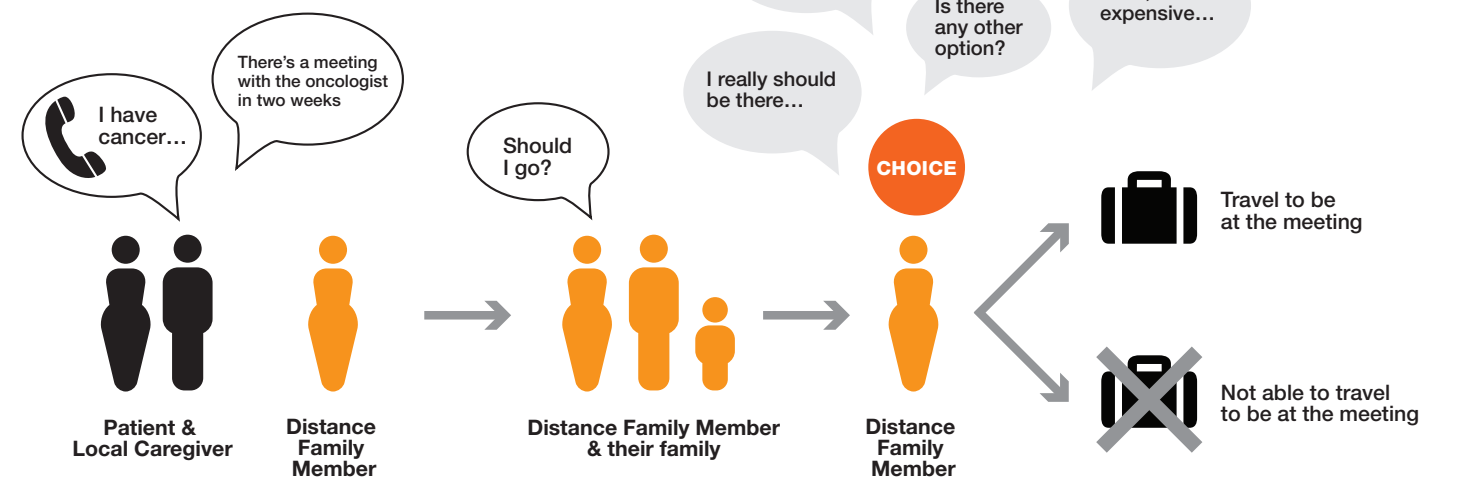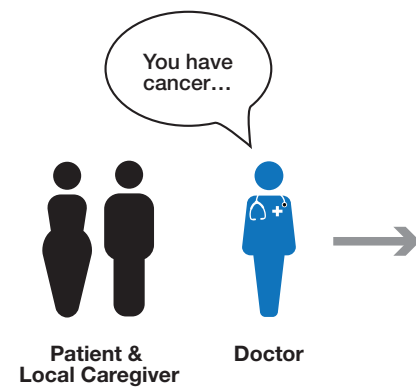*– Distance Family Member*

Emotional burdens—specifically guilt, shame and helplessness—were shared often by Distance Family Members, due to the challenge of balancing life at home and spending time with their loved one.

Work Pressures

The prominence of work, and the need to keep employment sustainable, can be aligned to the financial stresses caused by frequent travel over an extended period of time, as well as maintaining work to uphold the financial responsibilities needed to support day-to-day family life. The timeframes associated with the illness trajectories for those interviewed, ranged from two years to six-plus years. With many Distance Family Members making multiple trips over the course of a year, the expense of travel can become significant.

Despite the supportive nature of most employee/employer relationships—and for some, work was seen as a way to stay connected to their "home reality"—it presented a barrier to spending more time with loved ones. As one Distance Family Member acknowledged, despite the two hour drive, *"...I was unemployed during my mothers stay in hospital, I was there almost every day, all day. My sisters are still working and could not be there as often."*

Many Distance Family Members created routines for upkeep of work responsibilities while they were away. This helped to normalize their schedules, both at home and at work.

"It's a four hour flight with two planes, I would be there for three weeks and here for 2 weeks...they allowed me to work there...my schedule was work in the morning then have lunch with mom, spend the afternoon and then go back until 8 o'clock and from 8 o'clock until midnight I would work again."
— *Distance Family Member*

This juxtaposition of keeping up the home life and the desire to be supportive of their loved one created an ongoing weighing of outcomes, based on which needs were greater at any given moment. Regardless of the decision, Distance Family Members expressed increased stress and anxiety over the conflicting demands.

"It was extremely stressful. I wanted to be with her 24/7, but I had other life pressures that I had no choice but to deal with. I constantly felt I was not spending enough time there."
— *Distance Family Member*

Emotional Toll

Emotional burdens—specifically guilt, shame and helplessness—were shared often by Distance Family Members. The challenge of balancing life at home and spending time with their loved one often resulted in Distance Family Members wishing they were able to spend more time; many felt they weren't there enough and either lost time or missed a lot of the good days.

"There was just this feeling of hopelessness...or helplessness I should say, because I couldn't be there the way that I wanted to be there...and I guess a bit of guilt. I could see that my mom was in severe distress and I did my best to support her. But, you can only do so much when it's a four hour round trip and it's the dead of winter. It was really tough." — *Distance Family Member*

It is perhaps this later sense of helplessness—intersecting with the limitations created by distance—that resulted in feelings of guilt. A number of Distance Family Members spoke of feeling "a daughter's guilt" because they were not able to be with their loved one as often as they would have liked, or thought they should have been.

DESIGN IMPLICATIONS

Distance Family Members have multiple pressures, including family life, childcare and work, that can restrict how much time they are able to travel to visit a loved one. Emotional consequences are common and need to be acknowledged.

The responsibilities of home are a critical context for understanding the Distance Family Member. When dealing with the expected death of a loved one, feelings of stress, guilt, anxiety and helplessness are some of the costs of being at a distance—the result of having to balance two lives: their own lives at home and the responsibility they feel towards their loved one who is nearing end-of-life. It is a difficult situation, as the Distance Family Member is always trading one for the other; always sacrificing one for the other.

For practitioners, this is an important consideration, as any interaction with the Distance Family Member will likely be clouded by this context and the emotions that are attached to the conflict. It is also important for families, including the Distance Family Member, to be aware of this context, since it can affect interactions with the patient and caregiver. As such, it will be important for design interventions to provide mechanisms that ideally de-escalate the high-stress feelings that Distance Family Members can bring with them when they visit in person.

As well, identifying options to bridge the distance, other than travel, should be considered. If it is possible to support the Distance Family Member's ability to feel connected to their loved one throughout the decline of their illness, then there is the potential to mitigate stress and decrease the prominence of feelings of guilt and helplessness.

Figure 6

Communication Breakdown

FILLING IN THE BLANKS

Distance Family Members often compared their understanding of what they heard with siblings, also at a distance, to form a more complete understanding of what was happening with their loved one.

Issues with communication was one of the most common themes shared by Distance Family Members. Due to the distance, information almost entirely flowed through other family members who were local, including the caregiver and siblings. Distance Family Members expressed frustration with the delay of information, as well as disappointment that information was often edited, not correct or not frequent enough. Many Distance Family Members mentioned that they frequently "felt out of the loop" and, in cases where information was shared, it did not express any change in status, even though they suspected there were changes.

"[The hardest thing] was probably not being told things all the time. Being left out of the loop. Mom wouldn't always feel it was necessary to tell us that dad had a fall. We'd find out about it 3 weeks later. I would rather know the day it happened." — Distance Family Member

Distance Family Members expressed that asking questions of healthcare practitioners was generally not possible, which reinforced their dependence on the caregiver and other local family. It was not uncommon for siblings at a distance to support each other in formulating an understanding of the current health status, especially in situations where a pattern of delay or "status quo" updates had occurred.

"My sister would sometimes supply information to my brother and I. My brother lives away as well. Sometimes mom would tell him different things and then she'd tell me different things and she'd tell my sister different things. And then the three of us would converse to see what we were missing." — Distance Family Member

Use of various technology platforms to facilitate communication within families were adopted, such as email or text. It should be noted, however, that the experience with technology was not consistent. For example, when considering options for improved communication, one Distance Family Member thought weekly email communication would
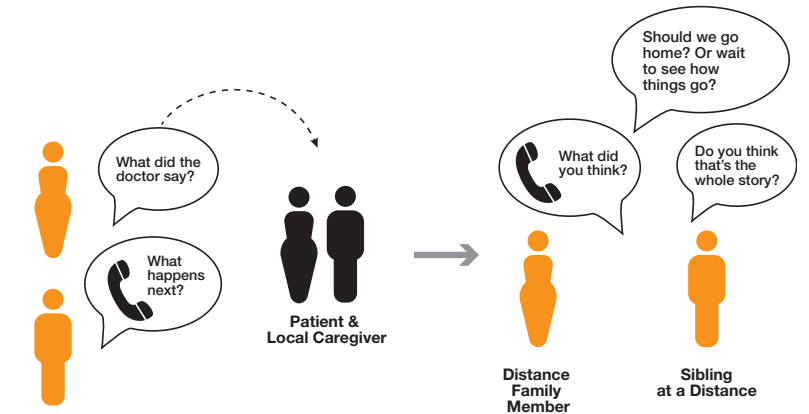
"I discovered that my family was keeping a lot of my mom's deteriorating health from me. I had just gotten married and moved away and they didn't want me to worry. It was intended out of concern for me, but it left me feeling very disconnected from my family."

be very beneficial. Conversely, another Distance Family Member considered email to be a less positive form of communication, as it fostered misunderstandings. Due to the variation in how Distance Family Members communicated, or desired to communicate, it appears that family preferences and existing family-communication patterns would dictate what technology would serve them best.

Although Distance Family Members often accepted that their local family was protecting them, or did not want them to worry, the lack of accurate information received in a timely way resulted in many emotional consequences.

"I discovered that my family was keeping a lot of my mom's deteriorating health from me. I had just gotten married and moved away and they didn't want me to worry. It was intended out of concern for me but it left me feeling very disconnected from my family." — Distance Family Member

Healthcare Practitioners Experience of Communication

Healthcare practitioners recognized the challenges associated with family communication and revealed that they often find themselves in the middle of family conflict as a result. Healthcare practitioners observed that, from their perspective, family dynamics and challenges with information sharing contributed to conflict over goals of care and often required intervention to help a family that was not communicating well. However, the Distance Family Member can be at a disadvantage, as they are not as visible as the caregiver and other local family, especially when the patient is receiving support in the home.

"...everybody thinks they know what's in mom's best interest. As a nurse you are listening to mom. And yet the children haven't listened to mom because they are thinking what they think mom should know. Even though mom has already shared with us what she wants...I think that is complicated by distance...because when the family members are in the home the nurses form relationships with the family members as well." — Nurse

"If our patients are not understanding the significance or nature of their disease...how can those patients communicate and share information to loved ones?"

One healthcare practitioner expressed frustration with the level of disruption a Distance Family Member could cause the patient and, their own ability to fulfill the patients goals of care.

"Because some family members can be quite detrimental...can be really awful, especially when they start making plans or making suggestions that are totally inappropriate. Like trying to feed a patient that can not eat anymore." — Social Worker

As the primary concern for healthcare practitioners is to care for the patient, a Distance Family Member who arrives for a visit, lagging behind their loved one's journey of decline, may not be at a point of acceptance and consequently interfere with the goals of care. This was most noticeable at key indicators of decline, particularly close to end-of-life, when feeding is no longer appropriate. Understanding the perspective shared by the Distance Family Member that communication was often challenging, it is possible that they did not receive enough information to construct an accurate

portrait of decline. Without this understanding, the Distance Family Member may do inappropriate things when they visit in person, as they have not been kept aware of the small declines along the way. Without the pattern of small declines, the larger changes—such as loss of mobility and no longer taking in food—is a significant shock.

Another issue identified by healthcare practitioners was the speed of which information was desired by Distance Family Members, suggesting that "issues arise when you're not giving enough information timely." This sentiment was consistent with communication concerns that emerged from Distance Family Member interviews.

Finally, healthcare practitioners expressed two barriers to providing consistent updates to Distance Family Members. First, current workflow practices do not provide the time or structure to communicate with Distance Family Members. As well, all healthcare practitioners identified that it was the family's responsibility to inform healthcare practitioners of Distance Family

Members. This exchange might take place in the hospital, at entry to a hospice or upon first visit to the home. Second, one doctor expressed the concern that many patients are not understanding the nature of their treatments and, therefore, it is an unrealistic expectation that they would be able to explain their prognosis to others.

"There are patients themselves that may be reluctant to involve distant family at an early time because 'well, we don't want to bother them...it's not that serious yet' and there is a lot of literature in the cancer fields, looking at how much patients actually understand about the nature of their treatment...where in fact 80% of the cancer patients were not actually sure of the nature of their treatment, meaning was it a curative treatment? Was it a palliative treatment? This is significant. If our patients are not understanding the significance or nature of their disease...then how can those patients be communicating and sharing appropriate information to loved ones if they don't get it themselves?" — Doctor

DESIGN IMPLICATIONS

Distance Family Members identify communication challenges, inadequate information distribution and lack of consistency as primary reasons for feelings of disconnection.

The Distance Family Member seeks accurate information in a consistent and timely manner, so they may appropriately weigh their responsibilities at home against the decline of their loved one. Lack of information leaves them feeling disconnected, guilty and out of sync. Any design intervention to support the Distance Family Member's need for information should address accuracy and consistency and not be filtered by a third party.

Design interventions for communication should also consider the impact of family dynamics on the distribution of information when another family member is the conduit.

Interventions should also educate families on the need for establishing positive communication patterns in advance of a crisis. Use of technology, although promising, should recognize that families will have a variety of communication preferences and will have adopted new platforms in varying degrees.

Healthcare practitioners should be encouraged to have a role in ensuring that information is distributed evenly to all family members that have been identified.

Seeking Human Updates

Types of Information

Universally, the types of information sought by Distance Family Members were about well-being and status of living, rather than specific medical details. Distance Family Members spoke of wanting to know if their parent was able to get out of bed, to eat breakfast or if they were unable to eat due to nausea. They wanted to know if they were in pain or were able to sit up in bed comfortably. Were they able to get dressed and go to the washroom?

"…[If] I could look at the end of the day and see 'oh, he had a shower today and got dressed, took his pills, had his needle, meals-on-wheels came, everything is fine.' … and you could look everyday and see 'he's getting showered twice a week…someone is coming in to dress his foot, someone is coming in to dress his incision — whatever, if you could just see it."
— Distance Family Member

Quite commonly, Distance Family Members were seeking information on the human aspects of living or the visible signs of decline. They wanted to know if it was a good day or a bad day. Did they smile today?

Although one Distance Family Member indicated that she wanted to know medical information, she clarified it was not the medical data that was of interest.

"…I think the tangible stuff—what medication is he on? How's his blood pressure? How is he fairing? And then there would be the emotional stuff—how are his spirits?… I didn't have access to that a lot of the time. I would have to drive down to physically see him to know."
— Distance Family Member

Desire for Frequency and Consistency

When asked, in the interviews, what kind of support they might be looking for, a common request from the Distance Family Member was for regular updates on how their loved one was doing. The suggested format of the updates varied—including phone calls, emails, checklists and websites—but the desire for frequency and consistency was common for most participants.

"…if they could fire out a weekly email about how that person is doing. A really general checklist—didn't have a fall, had a fall. I'm not sure what they would write but if they could fire off something every week."
— Distance Family Member

However, participants also noted that information provided should reflect the nuances of decline associated with changes at end-of-life, however subtle. Moreover, while the opportunity to ask more questions would be beneficial, there was no indication that the response had to be immediate, suggesting that the asynchronous nature of emails or websites could also fulfill this need.

When requesting updates on the condition of their loved one, Distance Family Members shared that it was common for caregivers and local family to indicate that "everything is the same," even though Distance Family Members suspected that not to be true. As Distance Family Members struggle with not having access to information—or accurate information—repeating this issue in a new format would only serve to increase current frustrations.

DESIGN IMPLICATIONS

Distance Family Members seek information that reflects the human side of decline, rather than specific medical data. Access to this information helps them form an understanding of the overarching status of their loved one.

Although the current focus in the healthcare environment is on access to personal medical data, the information that the Distance Family Member desires is quite different. The Distance Family Member seeks information about quality of living and status of decline—the day-to-day status of how their loved one is faring with aspects such as mobility, pain level, ability to sleep and dress as well as whether they are able to eat. The Distance Family Member does not seek data or information in the form of medical jargon. They seek real language to describe quality of life.

This is a noted difference from allowing access to medical records, which is the current focus of discussion within Ontario's healthcare environment. Although patients and/or alternate decision-makers would still need to give consent, information on the human side of decline would not require translation of medical data by healthcare practitioners to be understood by family members.

With consistent and frequent access to this type of information, the hypothesis is that the Distance Family Member will have the ability to formulate a pattern of decline over time and then translate this aggregated knowledge into a better understanding of the status of their loved one. If they are better able to understand the decline in consistently shared information about human status, then perhaps this will mitigate anxiety levels prior to an in-person visit and will better prepare the Distance Family Member for the change that has occurred since their last visit.

THEME 4

The Daughter from California

The "Daughter from California" is a categorization that emerged late in the secondary research, with the surfacing of two articles, "Distance Caregiving a Parent with Cancer" and "Lack of Communication and Control: Experiences of Distance Caregivers of Parents with Advanced Cancer," led by Polly Mazanec, a PhD and nursing professor in the Frances Payne Bolton School of Nursing at Case Western Reserve University.

Both articles outlined unique characteristics attributed to the "Daughter from California" or the "Daughter from New York" which included many of the characteristics revealed by the Distance Family Members that participated in this research project. Those characteristics include the demands of work and family, feelings of guilt and anxiety, concerns about communication and lack of information, and the need to feel connected to what was happening with their parent.

From the perspectives of some the healthcare providers identified as part of Mazanec's research, the distance caregiver was like a seagull, flying in, making a mess of things and then flying out again (Mazanec & Giarelli, n.d.).

History in Geriatrics

Origins of the "Daughter from California" categorization can be traced to a 1991 article published in the *Journal of American Geriatrics Society*. It described the case of a geriatric patient in her 80s being cared for by her daughter who established a care plan based on providing comfort and pain management and included a do-not-resuscitate (DNR) order. However, "when the second daughter arrived from California, it was quickly apparent that she had been unaware of her mother's recent deterioration. She was appalled by her mother's condition... [and] demanded that the mother receive whatever treatment was necessary to maintain life." The case study describes meetings with both daughters, which resulted in a change in the goals of care to satisfy the "Daughter from California," which were then reversed as soon as she returned home a few days later (Molloy, Clarnette, Braun, Eisemann & Sneiderman, 1991).

Many practitioners interviewed in this research project acknowledged a widespread understanding of the 'Daughter from California' concept.

Figure 7

TWO SIDES OF THE DAUGHTER FROM CALIFORNIA

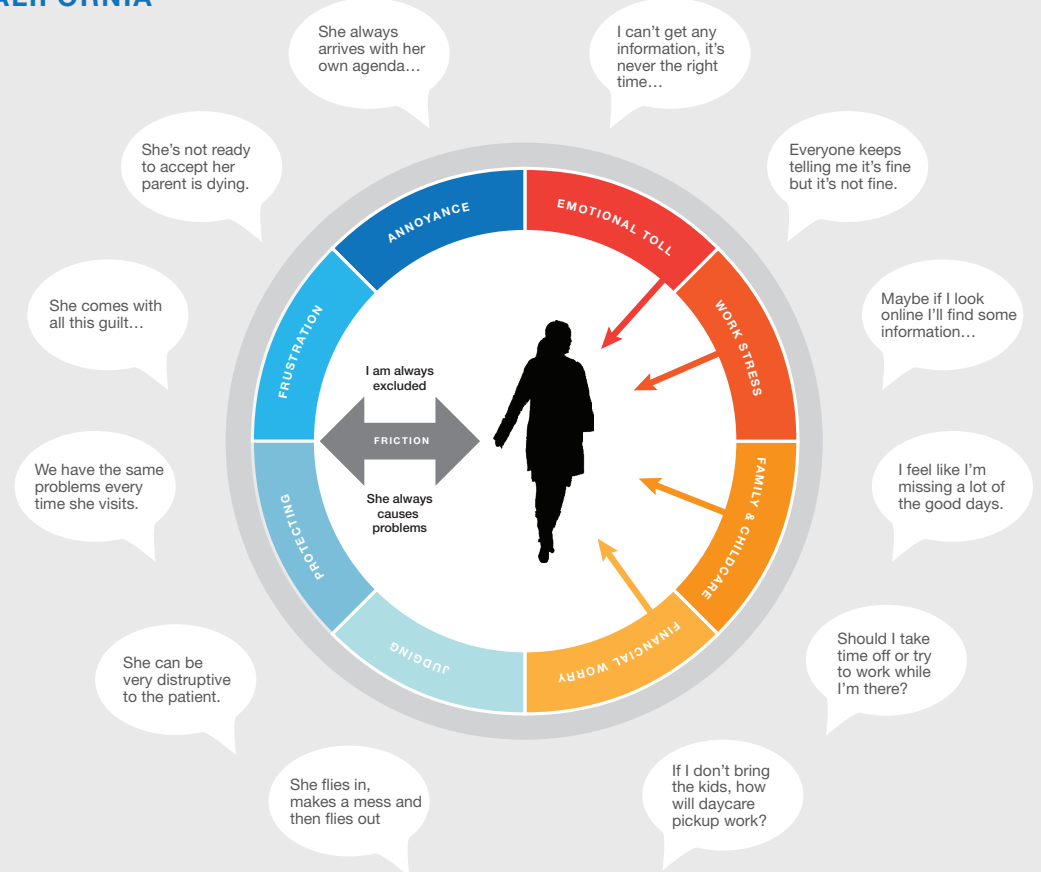"...it's a biased assumption that we have in healthcare—it's the daughter who lives in California who believes she knows it all, who comes in at the 11th hour and wants to change the plan of care. That's the assumption." — Nurse

It is important to note that part way through the practitioner interviews, it became clear that the concept of the "Daughter from California" was deeply connected to the opinion that practitioners formed about the Distance Family Member. Many of the frustrations expressed about the Distance Family Member were

similar to the "Daughter from California." Practitioners shared stories of the daughter coming for visits with her own agenda, with a lot of guilt. She often had money and was usually highly educated, and she brought *"the stresses from work, from life, not being there, feeling guilty...and not wanting to recognize that maybe their parent will no longer be there a few months down the road."* — Nurse

In addition to the assumptions mentioned above, a number of practitioners suggested that the type of person who moves away from

their parents is different than the type of person who stays. This affects how they want to engage when they do visit in person. They also suggested that it forms the guilt they bring with them.

"...the issue with guilt, we do have the families that for whatever reason the Daughter from California moved to California, the theory being you think you're going to get away from your issues if you move far away and we know that doesn't happen and there is often guilt around that." — Social Worker

Regardless of the reasons the Distance Family Member moved away, the characteristics that describe the "Daughter from California" were revealed to impact practitioners significantly. As Distance Family Members have an asynchronous relationship with their loved one's illness, they are always a few steps behind, rarely able to see the decline for themselves. As this is compounded by a perceived lack of information and feelings of "being out of the loop," there is always a need to bring the Distance Family Member up to speed when they visit in person.

"...the references to the Daughter from California Syndrome, and that is certainly well-known...it's often the most challenging for family from away because they haven't necessarily been present to monitor and see the changes which are happening to their loved one on a day-to-day, week-to-week basis. Their contact is often more fragmented, or intermittent, or they visited last six months ago and they've talked on the phone monthly but they haven't actually been able to see those significant changes which are happening with their loved one and

therefore, because they perhaps haven't also necessarily been part of the discussions around the treatment options...the family member from away really find themselves doing a lot of catching up and trying to figure out what's happening and trying to catch up with the folks who have been local. And often times, seeing is believing. There's a lot more disbelief and denial which occurs when we haven't been privy to the process in person." — Doctor

As the Distance Family Member travels back and forth, the asynchronous relationship that forms creates a pattern of not knowing that is cyclical. Each time they arrive for a visit, they are not prepared for what they will see, and each time they are shocked, and are driven to fix things before returning home. The combination often results in disruptive behaviour, which is frustrating for practitioners and requires significant effort to bring them along to an understanding of the goals of care. Practitioners, especially those who worked in the home, identified that establishing parameters to protect the patient and caregiver from outside stressors was a critical

aspect of their role. In these cases, the Distance Family Member was viewed as having the potential for a particularly negative impact.

Compounding the need for practitioners to synchronize Distance Family Members with a loved one's journey of decline is the demand for information to aid in decision-making around travel. Practitioners expressed frustration with Distance Family Members wanting specificity on the end-of-life decline, so they may plan travel and organize family and work commitments. This suggested that they were "wanting guarantees regarding prognosis which we are unable to give."

It is the combination of disruptive behaviour, demands for information and intermittent in-person visits that does not foster relationship building between Distance Family Members and practitioners. Subsequently, the "Daughter from California" syndrome is reinforced, whether the particular details are consistent with the origins or not, and regardless of whether any efforts have been made to keep the Distance Family Member up to date between visits.

DESIGN IMPLICATIONS

The Distance Family Member is often painted with the same brush as the characteristics that describe the "Daughter from California." Greater consideration should be given to the conflicting pressures felt by the Distance Family Member and the benefits of facilitating positive interactions with healthcare practitioners.

There are two sides to the "Daughter from California"— the perspective of the Distance Family Member who feels pressure to uphold the responsibilities of their home life and the needs of their loved one; and the perspective of the healthcare practitioner, who feels that the Distance Family Member comes with their own agendas, are demanding of time and come with a lot of emotional burdens. Both perspectives are true and both perspectives need to be acknowledged.

Any proposed intervention needs to be aware of the deeply embedded view of the "Daughter from California" within the healthcare community. This bias will not be easy to overcome, as it assumes that the daughter moved away from home to escape, as opposed to following education, career opportunities

or relationships. It will be important to support the Distance Family Member's ability to have a more synchronous relationship with their loved one's illness, so when they do visit in person they are not as unprepared for the level of decline. Supporting synchronization will reduce the disruption experienced by practitioners when interacting with Distance Family Members. Interventions that support positive interactions between Distance Family Members and practitioners should be prioritized, and education on how to address the specific needs of Distance Family Members should be considered for healthcare practitioners supporting patients and their families at end-of-life.

Figure 8

THEME 5

The Ability to See Decline

The decision to travel or not to travel is based on a number factors. As previously indicated, the ability to rearrange family life, and ensure that children and pets were cared for, was the most important factor. Employment responsibilities, and whether an employer was supportive or not, heavily influenced decision-making around travel. However, if there was a crisis with their loved one, that tended to take priority for the Distance Family Member.

"My decision-making was more about my own personal life. Should I take a leave of absence from my new job? How will my leaving affect my new marriage? In the end it was not necessarily a challenge at all. My mom was dying and I really had one option. Spend as much time with her as possible before she passed away." — Distance Family Member

Defining Distance

The concept of distance is defined, most often, as the geographic proximity between the patient and their distance family member. Although there is limited research on what is meant by distance, recent research on the long-distance caregiver acknowledges that the perception of distance is more important than the actual number of kilometres or hours travelled (Mazanec, 2012).

However, during the course of this research project, an alternate concept of distance emerged it suggested that geography is not the only determining factor; the ability to "see" decline in the patient first-hand also determined distance.

As Distance Family Members indicated that travel acted as a connector between home and their loved one—those who are able to travel more often are better able to "see" for themselves the condition of their loved one. They are able to see how they look, if they can eat, if they are no longer mobile or need help going to the washroom. These are critical signs that indicate a trajectory of decline and they are dependant on an in-person visit. When Distance Family Members are not able to travel as often, they must rely on other communication, which can be delayed, edited or withheld by local family with existing family dynamics. As a result, fragmented communication maintains the distance rather than closing the gap.

ABILITY TO "SEE" DECLINE: A DISTANCE FRAMEWORK

The framework proposes an alternate definition of distance, based on ability to "see" decline rather than geographic proximity.
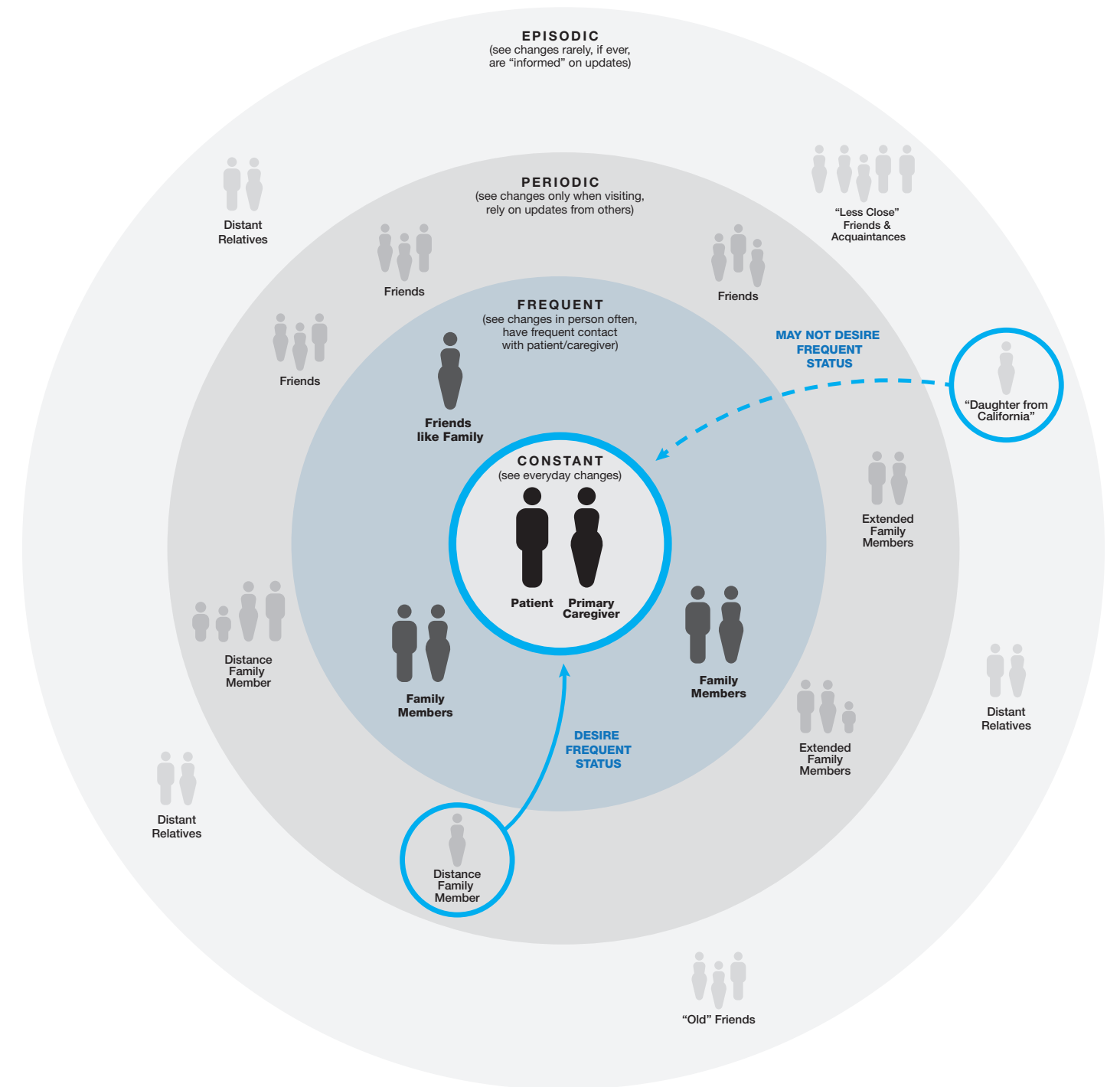
Distance Family Members indicated that travel acted as a connector between home and their loved one—for those who are able to travel more often, they are better able to "see" for themselves the condition of their loved one.

One of the practitioners shared a story about a local family member who was geographically close, but due to personal health and physical limitations, was not able to visit her loved one in person. In this situation it did not matter that the family member was local, her personal limitations resulted in distance. For all intents and purposes, she might as well have lived across the country and not down the street. In response to the situation, the healthcare practitioner established a communication plan to provide regular updates to the family member, so she was informed of the status, and decline, of her loved one.

"...we had a situation, we had a woman, a daughter, massively sick... couldn't leave her basement apartment, couldn't leave it...I would call her three set days a week, she knew what time I would call, it gave her security knowing she was able to connect with the hospital even though she wasn't able to come to visit and I called her three times a week and if I was ever not here...I would ask one of my colleagues to call... but three times a week, this is the update, this is how your father's doing, he's ok...and I

never met the woman in my life, never met her face-to-face and she was so grateful...she felt great about the care she got here without ever having stepped a foot into our facility, which is great...it's good when that can happen...so you do what you can do..." — Social Worker

As the ability to visit a loved one in-person may be limited, due to distance, financial, physical or social constraints, it is worth considering an alternate framework to describe distance based on proximity. Decline of a loved one can then be "seen" based on the following proposed categories:

Constant
The people in this category interact with the patient every day and are privy to seeing everyday changes and decline in quality of life. "Constant" status would typically be characterized by the caregiver who lives in the home with the patient and/or secondary caregivers who provide support activities daily for both the patient and the primary caregiver.

Figure 9

SYNCHRONOUS AND ASYNCHRONOUS EXPERIENCES WITH DECLINE
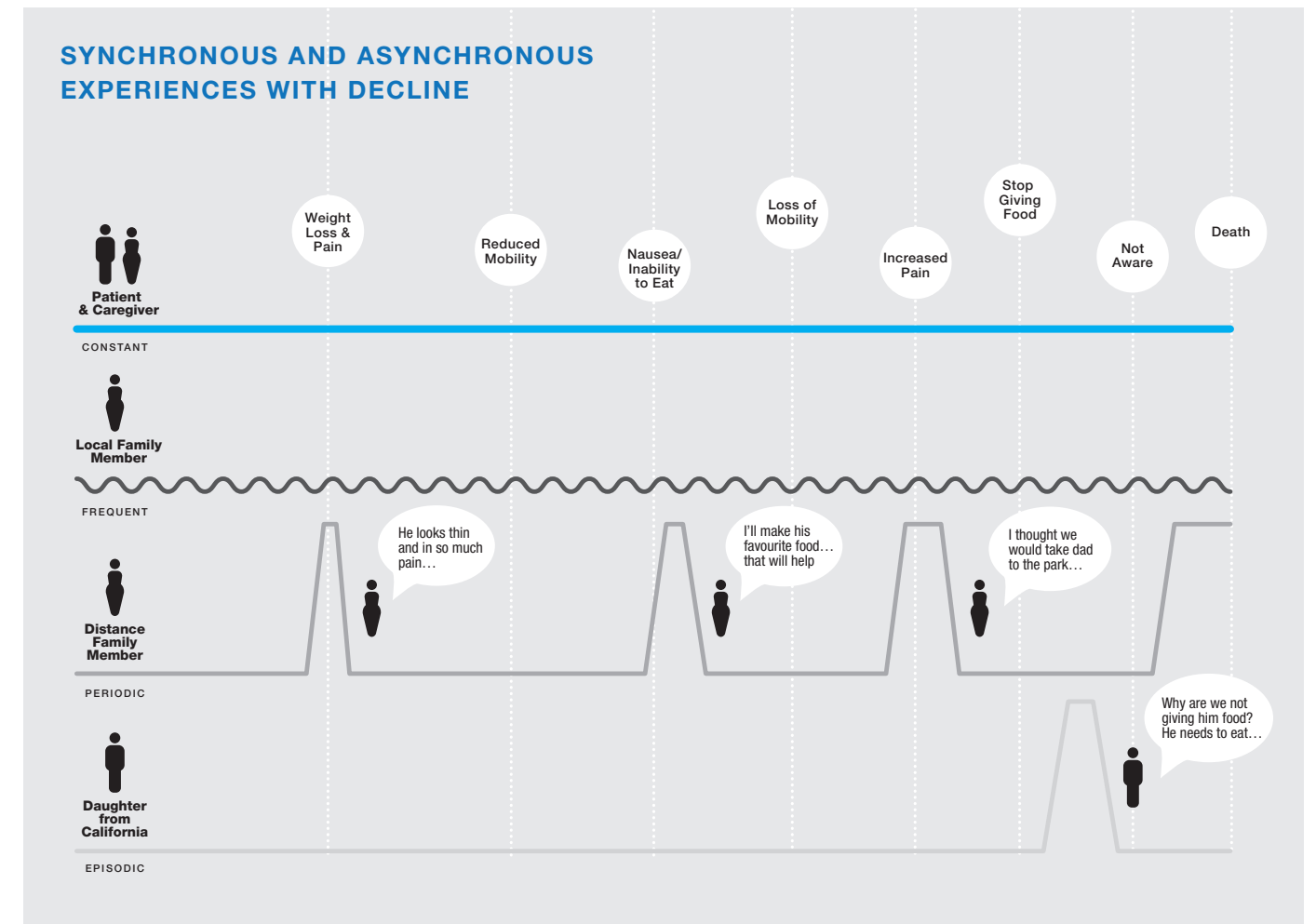
Frequent
These are family and friends in the local community who are able to witness decline in the patient—perhaps every few days or a couple times a week. They have frequent contact with the patient and caregiver, possibly providing additional support in the home or with the tasks of daily life.

Periodic
Family members who only visit occasionally and, as such, might be more surprised at the extent of decline when they do visit in person. This group might include local or extended family who do not check in regularly, friends from the patient's

or caregiver's larger social circle, and distance family who travel for in-person contact.

For the Distance Family Member, the amount of decline is often a surprise or shock, which can be attributed to the extent of communication and accuracy of information that was available to them in the time between visits.

Episodic
This last category includes the larger social network mapped as part of the initial literature review research (see Appendix B on page 98). Episodic people see changes in health status and decline in quality of life rarely, if ever. They rely on

updates from the caregiver or, more likely, from people they know in the "Frequent" or "Periodic" status groups, through a more delayed time frame. This group is not likely to seek status updates often, but wants to hear from others in the social network about how the patient is doing.

Conflict can occur any time family members have a periodic experience of decline but desire frequent status. For example, the desire to know what changes are happening, paired with limitations on the ability to travel and "see for themselves," contributes to the disconnect that Distance Family Members expressed.

The Remote Distance Family Member

It should also be noted that there is another category of Distance Family Member: those who are remote and may not desire frequent status. This person may remain in the background or may visit "out of the blue," as described by a number of practitioners. This second category of the Distance Family Member is perhaps more consistent with the characteristics expressed by the "Daughter from California Syndrome," discussed in an earlier theme (on page 48).

Although this person will bring many of the same challenges highlighted by Distance Family Members, they have not tried to actively engage with their loved one throughout their illness or journey of decline. As this group of Distance Family Members has not seen any decline themselves, and may not have sought out or received status updates, they may have the most extreme response to circumstances if they do visit in person. They have the largest learning curve toward acceptance of their loved one dying, if they are able to do so at all.

Potential for Technology to Facilitate Communication

The use of technology can facilitate connection and improve the ability of the Distance Family Member to see decline. In addition to the example above, where a healthcare practitioner established a schedule for providing updates, a number of other examples emerged from the interviews. Practitioners identified cases where video-conferencing technology had been used to connect family members who were not able to travel. These included Skype, FaceTime and Ontario Telemedicine Network. At times, video conferencing was also used to facilitate communication between the practitioner and the patient.

"I had one family where English was not their first language. But the son, who was a dentist or physician, was in England and I had to visit at certain times everyday so he would be on Skype and he was my translator."
— Nurse

There were also examples of the use of conference calls during family conferences and group emails from practitioners to keep multiple family members up to date. In general, all practitioners agreed that technology is beginning to play a more prominent role, and that even though "the healthcare system will be slow to respond" in adopting new technologies for the purposes of communication, "it's just going to happen." Younger generations with more technological expectations will drive that change.

"...we are also talking about a younger generation who has an acceptance of the data age. They accept sharing data about everything and are comfortable with that. I think about what my kids are putting on the internet—what they are comfortable with in terms of relinquishing freedom or privacy— and it's just a different attitude. I think that's going to help push change...and [we will] recognize that in exchange for giving up a little bit of privacy, there are long-term benefits to helping us communicate better and share information better. This may be a compromise that people are willing to make." — Doctor

DESIGN IMPLICATIONS

Distance is not only defined by geography. The ability to "see" the human side of decline is an important consideration for the Distance Family Member. Facilitating "seeing" the little things, across an illness trajectory, has the potential to build towards an overall sense of understanding.

By considering an alternative definition of distance—one of "seeing decline" rather than geography—we might consider alternate ways to bridge the gap. Families have already adopted technology as a way to communicate regardless of geographic proximity. Interventions that position technology platforms as a bridge to facilitate other "seeing" would serve to align the learning curve the Distance Family Member experiences with the in-person visit. Existing platforms already embedded in the healthcare system, such as the Ontario Telemedicine Network, have the potential to support Distance Family Members who want to attend family meetings and have time with their loved ones more regularly, and mitigate dependance on physical travel.

By considering this criteria for intervention, the goal is to de-escalate the build-up of stress and anxiety around "not knowing" and bring the Distance Family Member along on the journey of decline more synchronously. This will better prepare them for what they will see when they do visit. The hypothesis is, that if they are better prepared, they will question the goals of care less, be less disruptive to practitioners and local family, and require less time to get "up to speed." This also better positions the Distance Family Member to be able to contribute supportive activities to the patient and caregiver, which many Distance Family Members expressed as the desire to "do their part."

THEME 6

Systemic Challenges

Throughout the practitioner interviews, a number of systemic challenges rose to the surface, including demand and limits on time, limited resources, a lack of formal palliative training, and the mounting pressures due to the demands of aging demographics with increasingly complex care needs.

Demands on Time

While doctors and nurses agreed that keeping Distance Family Members updated would ultimately be beneficial for everyone involved—the patient, the caregiver, the distance family member and the practitioner—demands on their time is the most significant barrier to providing those updates. Many practitioners noted the challenge in allocating enough time to see everyone, acknowledging, "we do the best we can."

As well, both practitioner roles shared stories of taking the time to educate patients and families on what to expect of decline towards end-of-life. They also expressed the fact that Distance Family Members required education and re-education at each in-person visit to align them to the goals of care established by the patient and caregiver.

"...another challenge in the situation is when...maybe you have come to an agreement and everyone is on the same page and then so-and-so flies in and is there for the first time seeing their loved one at this state. And they are asking 'Why are we doing this?', 'What is this about?' and 'What about this IV therapy?' And you have to start from scratch again and really educate that person on what the goals of care are." — Doctor

For family physicians, the demands on time are increasing. The Ministry of Health and Long-Term Care looks to them to, not only initiative end-of-life conversations, but also follow their patients' care through to end-of-life. As current billing practices are based on a one-issue-per-visit model, in 15-minute increments, it is difficult for family practitioners to balance these demands against how their time is organized.

Scarce Resources

The issue of fighting for resources is felt at both the hospital level and in home care. In the day-to-day practice of delivering palliative care services and support in the home, nurses expressed frustration over getting referrals too late in the patient's illness trajectory, not having enough information on the patient's history, as well as the difficulty in making a case to provide enough support in a system with significant funding constraints.

"...if I tell a case manager that this patient is 40–50% PPS, you'd only have two hours a week of PSW (Personal Support Worker). They use that as a measuring tape as to what type of servicing they can get. You have to fight tooth and nail to say 'this is what's going on in the home, this is why I'm asking for more.'" — Nurse

Physician access in the home was also a prevalent concern, as was communication between various practitioners and the quality of care concerns that accompany inconsistencies in service delivery.

"There is a move to improving access to palliative care but it's not always even. In my lessons learned, where the gaps are in palliative care is physician access. The nurse in the home can provide the best care possible but without the physician that orders the meds to problem solve, to discuss medical treatment plans... for us that is where a huge gap in home care is. It is probably the number one reason why clients are admitted to hospital." — Nurse

However, these day-to-day challenges of delivering palliative care can also be attributed to a number of larger systemic issues, not all unique to the Ontario healthcare environment.

"...a big part of it is the recognition that the baby boomers are reaching that age group where they are going to require those types of services and this is a large population bulge that is going to challenge our healthcare system. Because, in many ways we have also already recognized that baby boomers expectations of outcomes has been shaped with their living through the largest changes in healthcare in terms of prolongation of life expectancy." — Doctor

This generational expectation puts even greater pressure on the ability of practitioners to have conversations about end-of-life. However, the training and skills required for this type of support can be viewed as currently not sufficient enough. As one practitioner expressed, the concern that "we don't have enough palliative care experts to do this work." Despite more attention to specialized palliative training, formal training programs for both doctors and nurses are not yet embedded in their education and are often part of post-education training or ongoing skills development.

It is also important to acknowledge—in addition to issues of demands on time and the need to fight for resources within the complexities of the larger, complex healthcare system—if the issue of medicalization of death and dying over the last few decades.

"...every nurse is expected to be able to provide palliative care, even though up until now there has been no formal training built into their education or it wasn't part of their curriculum in college or university. We are still in that continuing education in how to get the knowledge and skill [to provide palliative care]." — Nurse

As well, current policy on end-of-life is encouraging the shift away from acute care and into the community for end-of-life. However, there has not been enough discussion about what palliative care means for the patient. Despite the model proposed by the Canadian Hospice Palliative Care Association in 2002, practitioners shared stories of the need to help patients and families navigate the transition between acute care and palliative care, which can be perceived as abrupt and shocking. In order to make this transition smoother, the healthcare system will need to dedicate more resources to palliative care, so earlier support of patients and families is possible.

It is also important to keep in mind that the issues of demands on time, the need to fight for resources and the larger complexities of the Ontario system have been embedded in the societal issue of medicalization of death and dying over the last few decades (Arnup, 2013). This is not just in Canada, but in many developed countries around the globe.

"...we have taken death and dying out of the community and made it a healthcare issue...we've medicalized a natural process to the point where it becomes foreign to the population, to the community. What we need to do is to de-medicalize death and dying such that it's something that we can comfortably talk about, that we're not afraid of and open these dialogues and really look at it. As a community we're responsible for caring for our frail and dying and the healthcare system can provide some of that, and can support us, but it really needs to be broader than the healthcare system in order to be an effective mechanism to support patients and families." — Doctor

DESIGN IMPLICATIONS

Demands on healthcare practitioners' time, as well as limited resources within the healthcare system, will be a barrier to adoption of proposed interventions. New services to support Distance Family Members must also support practitioners in the daily work of delivering palliative services.

With the healthcare system in Ontario under pressure to both cut costs and meet the service demands of an aging demographic that is living longer with more complex care needs, demands on healthcare practitioners' time is increasingly overburdened and restricted by administration parameters. As such, any intervention to support the Distance Family Member should not depend on practitioners devoting more time than they currently have available, nor should it require a substantive amount of additional training, as general palliative care skills training is still under-supported.

Ideally, any proposed design intervention should acknowledge existing best practices and methods already in place in the healthcare system and should serve the goal of reducing the

disruption to their already-demanding workflow. Proposed interventions should also take into account the need to educate patients, caregivers and families on what decline at end-of-life looks like. Although it is not reasonable to assume that any one intervention will have the ability to remove the role of practitioners from guiding patients and their families through this journey, there is an opportunity to support this educational aspect and better prepare people for having conversations with practitioners about choices at end-of-life.

Planning Early

There is a lack of understanding around the legal boundaries associated with designating a Power of Attorney and the responsibilities required to fulfill that role. As well, the authority allocated to the Power of Attorney, and the potential impact on the family unit, are also not well understood, especially when decision-making is involved.

Power of the Power of Attorney

Many of the healthcare practitioners interviewed referred to the importance of the Power of Attorney (POA), as both the substitute decision-maker for the patient and the primary point of contact for the communication of information to other members of the family unit and the larger social circle, if they so choose. The parameters of the POA dictate that "legally it's only the POA" that receives confidential medical information and not anyone else, regardless of the relationship to the patient.

"I have to go to the POA or substitute decision-maker. So if you are asking any questions...[your mom] is my point of contact. I will give her all the information, but it's her role to decide what she wants to do with that. I would give you the same information that your mom has allowed me to give you but if you asked in particular, I would say 'you have to ask your mom about that.'" — Nurse

The privacy and confidentiality of the patient comes first and is always protected. Healthcare practitioners all acknowledged the importance of the POA and the boundaries that are attributed to the role. If there were multiple POAs within a family, then everyone would have the ability to receive information directly from the healthcare practitioners. It was also not unusual for POAs to give permission for doctors and nurses to provide updates to Distance Family Members if they asked.

"I usually speak to the person who's the designated substitute decision-maker... and then they would share it with everyone else. But, if a family member says 'can you call so-and-so directly,' then I'll do that. That happens fairly frequently, or that person will sometimes call and speak to the nursing staff and request that the doctor calls them." — Doctor

However, there was a suggestion that there is sometimes room within everyday practice for some disclosure of information, based on how well known the Distance Family Member is to the practitioner. If the attending doctor or nurse had met the Distance Family Member on numerous occasions, they would be more likely to communicate information when the Distance Family Member called. Some healthcare practitioners also suggested that POAs might not always have a clear understanding of what responsibilities are associated with the role and that families generally did not understand the implications of the POA, especially related to access of information on the patient's status.

Advance Care Planning

Closely associated with the role of the Power of Attorney is the concept of Advance Care Planning, which identifies a person's wishes for medical interventions and goals of care at end-of-life and identifies an alternate decision-maker to carry out those wishes if they are unable to. During the interviews with healthcare practitioners, the POA and alternate decision-maker roles were often used interchangeably. It is critical that healthcare practitioners are able to identify patient preferences, as they inform the many choices available throughout a life-limiting illness. It is even more important that patients express their wishes clearly, so they are not subjected to medical interventions they may not have wanted if they were able to speak for themselves. However, recent statistics suggest that only 25% of Canadians over 30 have completed Advance Care Plans (Environics Research Group, 2013).

The absence of an Advance Care Plan can be the cause of significant conflict within families. In cases when an Advance Care Plan has been completed but has not been shared equally among family members, conflicting opinions on medical options often play out in the ER or even in the home—since the goals of care are not clear. When a patient has determined that their end-of-life wishes will include a palliative approach, it is critical that all family in the patient's core circle understand what a palliative philosophy means and that everyone who needs to know—and might weigh in at a later date—is also informed of the patient's wishes.

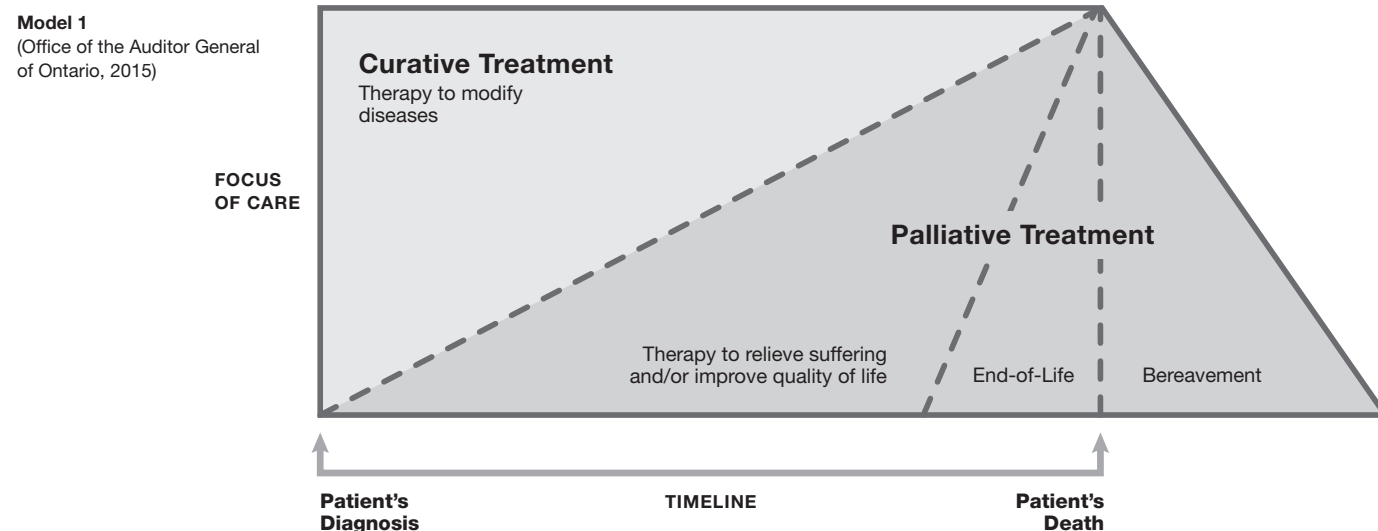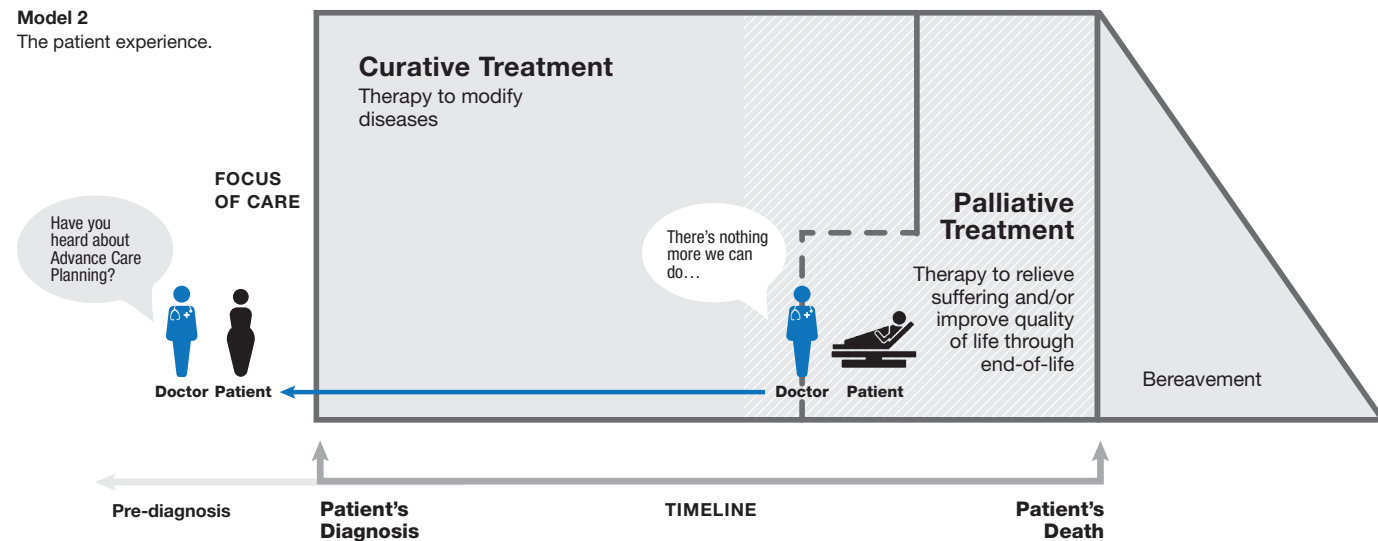*"I think a big thing that will help in palliative...is advance care plans because, no matter what, the POA is supposed to act on behalf of the patient and until you know what the patient wants from an earlier time... then all of the complications are null and void because it doesn't really matter in the end what everyone else wants if they know what the patient wants." — Social Worker*

Figure 10

CURATIVE VS. PALLIATIVE ACROSS THE TRAJECTORY OF ILLNESS

The aspiration for palliative care is to have support available to patients at the point of diagnosis (Model 1). In reality, palliative care is accessed quite late in the illness trajectory and the transition from acute to palliative treatment can be a shock. It is important to have end-of-life conversations far in advance of a crisis (Model 2).

"The acute care model is curative or trying to avoid the progression of the disease…from that point to a palliative point can be a very short time…you have to do a mind switch so very quickly and it is very hard to reconcile that." – *Social Worker*

Model 2
The patient experience.

Curative Treatment
Therapy to modify diseases

FOCUS OF CARE

Have you heard about Advance Care Planning?

There's nothing more we can do…

Palliative Treatment
Therapy to relieve suffering and/or improve quality of life through end-of-life

Bereavement

Doctor Patient

Doctor Patient

Pre-diagnosis

Patient's Diagnosis   TIMELINE   **Patient's Death**

Model 1
(Office of the Auditor General of Ontario, 2015)

Curative Treatment
Therapy to modify diseases

FOCUS OF CARE

Palliative Treatment

Therapy to relieve suffering and/or improve quality of life

End-of-Life

Bereavement

Patient's Diagnosis   TIMELINE   **Patient's Death**

It is important to note that many healthcare practitioners acknowledged the difficulty that patients and families faced when making decisions regarding end-of-life during a time of crisis. In the situation where a patient had not engaged their family in conversations about end-of-life wishes before the life-limiting illness, it was very difficult to determine those wishes while also coming to terms with the disease.

"I get involved in some really difficult cases where we walk into the home to have those discussions with clients and as much as the family members want to have those conversations, the client will say 'we're not having those conversations' because they are still trying to process that they have a life threatening illness and there is no cure." — Nurse

Healthcare practitioners reiterated that "if you have a crisis oriented gathering, it's game over" and that it is increasingly important to make decisions about end-of-life—and have those conversations—far in advance of a potential health-care crisis.

"What I see is that it's really painful to do the present when steps have not been taken to address the inevitable. So I am trying to back it up and trying to get people involved at a much earlier stage so that when you get to the palliative care stage, these steps are done, the conversations have begun, you have a plan and you're not just scrambling…it's way too late to wait until it's in palliative…it's way too late." — Social Worker

Defining what is important for goals of care and identifying the people who should be included, and the roles they will play, is a critical component of Advance Care Planning. Determining wishes earlier, rather than later, offers families the opportunity to set their path with clarity and lay claim to what is important to the individual and their family. In terms of supporting Distance Family Members as part of Advance Care Planning, one healthcare practitioner suggested that it is essential to *"reclaim some of what is important to you. So if making sure everyone is hearing the same information…if that is important to you as a family, then you have to name it early on." — Social Worker*

Patients and families struggled when making decisions about end-of-life during a time of crisis. When a patient had not engaged their family in conversations about end-of-life wishes, it was very difficult to make decisions about goals of care while also coming to terms with the disease.

From the healthcare practitioner's point of view, conversations about end-of-life have not been a consistent part of patient-doctor/nurse interactions in the past, and even though the importance of Advance Care Planning is acknowledged, it is still a new expectation.

The Who and What of Advance Care Planning?

Most healthcare practitioners agreed the responsibility for having early conversations about end-of-life was a natural fit for the family physician; one doctor shared a pilot project that inserted the conversation "in the annual physical, like a stamp." Specialists, ER doctors, palliative care doctors, nurses and social workers also have opportunities to introduce the topic at various points across the illness trajectory, as the patient moves through the healthcare system. These conversations support patients and caregivers in end-of-life decision-making, regardless of whether a formalized Advance Care Plan is the outcome.

However, even though most healthcare practitioners agreed that end-of-life conversations needed guidance from someone with expertise, they did not necessarily restrict conversations to live within a healthcare environment. Individuals and families could begin to think about these issues themselves and the conversation did not need to "be driven by healthcare, [but rather] it needs to be driven by society."

Barriers to Early Advance Care Planning

Recent statistics suggest that only 25% of Canadians over 30 are currently completing Advance Care Plans (Environics Research Group, 2013) and a number of barriers arose during this research project to support why that might be the case. Many healthcare practitioners shared stories about patients and families wanting to wait until later to discussion plans, as they were focused on treatment options or sometimes family norms did not include opening discussions about death and dying.

From the healthcare practitioner's point of view, conversations about end-of-life have not been a consistent part of patient-doctor/nurse interactions in the past, and even though the importance of Advance Care Planning is acknowledged, it is still a new expectation. As well, healthcare practitioners haven't always had the training required for guiding these conversations. When they do initiate conversations, they can be limited to the do-not-resuscitate (DNR) order rather than the broader conversation about goals

of care. Finally, the societal barriers of not wanting to talk about death and dying—and the general "stigma where if you're doing an advance care plan, you're saying 'I'm going to die soon'"—contributes greatly to a general lack of acceptance. Instead, healthcare practitioners agreed that Advance Care Planning can be "self-empowering" and will go a long way to ensuring that individuals are able to make choices for themselves about interventions and options at end-of-life.

"...when you actually can communicate all along the way and make a plan, roles that involve everyone, with an engaged healthcare system, and a conversation with the doctor at the point when treatment is no longer effective, then you all rally together. You know death is imminent and when you come together you end it well together. Whether you do that in a residential hospice or whether you do that at home...you don't do it in an ER." — Social Worker

DESIGN IMPLICATIONS

Advance Care Planning is best discussed early, ideally before a critical illness. Plans should be shared with family members and consider parameters for communication and distribution of information.

Design interventions connected to Advance Care Planning should acknowledge the advantage of encouraging conversations as early as possible, but will also need to address the underlying challenge of asking a society with a fear of death to make plans for their own final days.

As the aging population edges closer to this phase of life, it is more and more critical that Advance Care Plans are adopted more broadly, as demands on time and resources in the healthcare system will only become greater. Despite increasing demands on the healthcare system, proposed interventions should acknowledge the current belief that end-of-life conversations are best embedded in the healthcare system and that there is an important role for family facilitation by someone with expertise.

The positioning of the Power of Attorney—as the conduit for information distribution—is an important consideration in addition to the traditional decision-making requirements associated with the role. For both the Power of Attorney and Advance Care Planning, providing a framework to share individual decisions with family members should be considered and, specific to the Distance Family Member, should take into consideration communication and distribution of information needs.

THEMES

In addition to the seven themes identified earlier, two larger, overarching themes emerged.

THEME 8

Distance Exacerbates Everything

Losing a loved one is a difficult and painful experience, which is not unique to Distance Family Members. However, an overarching insight that emerged from interviews with both Distance Family Members and healthcare practitioners is that the physical barrier of distance complicates an already-stressful situation for the whole family.

Distance between the patient and family members can add more pressure on the caregiver tasked with caregiving and decision-making responsibilities, but also the distribution of information. Existing family-communication patterns are challenged by the emotional stress of accepting that a loved one is dying as well as the demands to keep everyone updated on the progression of decline.

For the Distance Family Member, emotional status is heightened by feelings of stress, anxiety, guilt and helplessness, due to the inability to support their loved one in person and see for themselves the state of decline. When Distance Family Members do travel to visit in person, they often bring these emotional conditions with them. This can impact the patient, the caregiver, local family and healthcare practitioners.

Communication delays, misinformation and the desire to feel connected to their loved one's journey continues to put stress on local family and healthcare practitioners, which is intensified even more if the patient has not expressed their wishes for end-of-life and family members struggle among themselves on the best options for care.

Unfortunately, there is little evidence of existing infrastructure or services, within the healthcare system to support the Distance Family Member gaining information.

"We teach communication in simplistic terms. Do we bring up 'how do you communicate with Distance Family Members? No, it's not there." — Nurse

As well, existing biases about the "Daughter from California" have the potential to decrease problem-solving when it comes to meeting the needs of the Distance Family Member. Family complexities at end-of-life can be considerable, and there are measurable challenges within the healthcare system to ensuring that the patient and the caregiver are able to find the resources they need, especially when it comes to supporting palliative care in the home. However, that should

not preclude the development of services to support the Distance Family Member; finding ways to keep them informed and connected to their loved one's health decline will ultimately reduce the pressure on the patient, caregiver and local family, as well as potentially reduce disruption to the goals of care and the time and effort currently dedicated to bringing the Distance Family Member up to speed each time they arrive for a visit.

THEME 9

Without hope, you have nothing

Perhaps the most poignant theme that emerged from the research is the role of hope and how it can inform our relationship with end-of-life. When someone is diagnosed with a potentially life-limiting illness, there is hope for a cure—both by the patient and their loved ones. Quite often, that hope is attached to the desire for recovery, even when decline is progressing to the point where a cure is no longer a realistic outcome.

"If I go in to meet a patient for the first time and they are sounding hopeful and they are going to go do chemo, I'm not talking about the DNR." — Nurse

Yet hope should not be so tightly bound to the notion of not giving up the desire for a cure. In reality, human beings have the capacity to allow for hope to evolve over time and adapt to changing circumstances. This can be true for both patients and loved ones, regardless of whether they are local or at a distance.

"I think some people hope that somehow a miracle will happen and they are going to get out. And maybe at the end, they hope they have found ways to remember their parents or their loved one." — Social Worker

If a certain hope is no longer attainable, it makes room for a new definition of hope. When the hope for recovery has faded, we might hope for time. When time is growing shorter, we might hope for comfort or no pain. In the end, we might hope to be at home, surrounded by the people we love, in the place that is the most familiar.

Every illness has a unique trajectory. People will hold hope for themselves and for their loved ones in equally unique ways, but also potentially common ways. When reflecting on my own experience of losing my father to cancer, I had many hopes along the way.

I hoped for a cure.
I hoped for time.
I hoped my son would remember his grandfather.
I hoped I was there enough.
I hoped he knew how much I loved him.
I hoped he knew he would be missed.

Each of these hopes unconsciously underpinned my decisions and actions throughout my father's illness. While much attention is given to the need to specify end-of-life wishes in the form of tactical decisions and medical interventions, perhaps the key is to prioritize hope, by focusing conversations about end-of-life on the sharing of hopes. If we can share what we hope for ourselves and what we hope for our families—throughout an illness as well as after death—perhaps we can build up to conversations about how those hopes can be fulfilled. Hope can provide the foundation for families to talk about end-of-life, while not abandoning the sense of giving up on hopes for the present, which is a critical part of the journey.

"Hope is everything and it's not something we ever want to take away from people." — Social Worker

Interventions for Prototyping

By better understanding the lived experiences of Distance Family Members and healthcare practitioners, nine themes emerged from the research, which have provided valuable insight into the end-of-life experience. These insights were aggregated with the secondary research on palliative care delivery in Ontario, and the three identified future shifts, to inform a set of design criteria. The purpose of the design criteria is not only to define guidelines and principles for future interventions to support the Distance Family Member, but also to transition the research into an actionable proposal.

With the set of design criteria in mind, three interventions for prototyping are proposed to better meet the needs of family members who are at a distance from a loved one during palliative care in Ontario.

INTERVENTIONS FOR PROTOTYPING

Design Principles

1.
Focus on the whole family.

"Palliative care really recognizes that patients and their families are the centre goal of our care and we would like to try to..help patients and their families...to understand the illness, understand the illness trajectory, understand the prognosis associated with it, as well as the types of plans and preparations required... if we're thinking about a palliative approach, this disease is an illness we can't cure." — Doctor

2.
Re-prioritize privacy and confidentiality.

"The healthcare system will be slow to respond...due to the nature of the bureaucracy that exists around healthcare information and the privacy act." — Doctor

3.
Earlier is better than later.

"What I see is it's really painful to do the present when steps have not been taken to address the inevitable. So I am trying to back it up to get people involved at a much earlier stage so that when you get to the palliative care stage, these steps are done, the conversations have begun, you have a plan and you're not just scrambling." — Social Worker

4.
Support frequent and regular communication.

"I would argue the stress comes when you are not giving enough information timely." — Social Worker

5.
In-person interactions should not be the only option.

"I think technology could play a better role in including distance family members. This of course can be placed directly on the family but also if hospitals or hospices had an infrastructure of Skyping or web chats, etc, I think the experience would have been easier and I would have felt more included and less stressed." — Distance Family Member

6.
Reflect the human side of decline.

"If I could see at the end of the day that he had a shower today and got dressed, took his pills, had his needle, meals-on-wheels came..." — Distance Family Member

7.
Include all variations of families.

"I'm noticing that we are seeing that diversity in families. Sometimes family isn't immediate family, sometimes it's the friend or the neighbour...and there are lots of family members." — Nurse

8.
Minimal time required of healthcare practitioners.

"How do I bill to have that time? Because I have so many patients that I need to see today. How do I allocate time to see everyone? And I only deal with you on one issue and then I have the next patient. Challenges in end-of-life care are vast." — Nurse

9.
Acknowledge and define roles for everyone.

"You've got to have everybody having a role, at least for the information end of things...you have to build it in so it's not crisis oriented." — Social Worker

10.
Support acceptance of the dying process.

"What we need to do is to de-medicalize death and dying such that it's something that we can comfortably talk about. That we are not afraid of." — Doctor

11.
Use plain language.

"...if our patients aren't understanding the significance or nature of their disease...then how can those patients be communicating and sharing appropriate information to loved ones if they don't get it themselves?" —Doctor

12.
Focus on hope.

"Hope is everything. It's not something we ever want to take away from people." — Social Worker

PROPOSED INTERVENTION 1

PATHS:
A Practitioner's Checklist

Facilitating Human-Centred Updates

The PATHS (Practitioner Assessment Tool of Human Status) checklist allows practitioners to update pre-determined family members on the current status of their loved one, based on an assessment of the tangible human signs of decline. Although the checklist could be used in a hospital palliative unit or residential hospice, it is primarily intended to assist communication and distribution of information when the patient has made the decision to be at home. As practitioners are already over-burdened, with high demands on their time, the checklist format is proposed as a model already understood in the healthcare environment.

Available as an app for mobile devices, a list of indicators can be customized based on each patient's individual circumstance. The checklist format allows practitioners to fill in an assessment in a time-efficient way, while not highlighting any personal patient health data. Rather, the checklist reflects the general status of living and decline. For example, the checklist may identify quality of sleep, level of mobility, ability to dress, level of pain, appetite,

presence of nausea, whether they sat up in bed, and overall mood. The platform also provides space for a short, but unique, comment from the practitioner.

Ideally, the checklist would be introduced during an initial home visit by a palliative nurse. When the nurse hears the patient story, who the family is and where they are located, the nurse can position the checklist as a way to ease the caregiver of day-to-day strain from managing communication with distance family members. The checklist would only be put in place with agreement from the patient or alternate decision-maker if necessary.
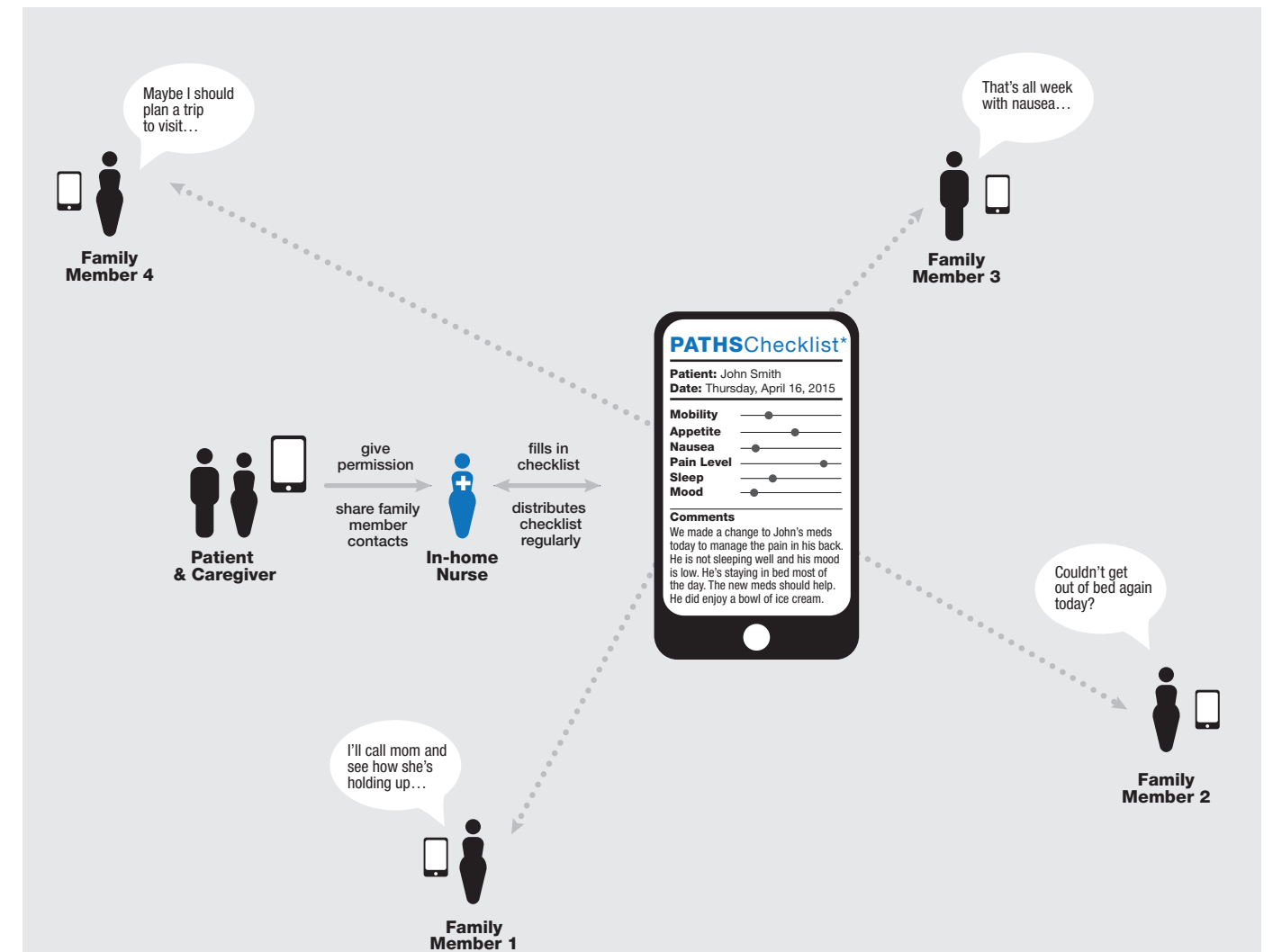
Although there will be an initial time investment to set-up the PATHS checklist for each family, the goal is to provide short, but frequent, updates to family members, so they may become better connected to the journey of their loved one and begin to see the natural patterns of decline that are visible as end-of-life approaches. In-person visits from Distance Family Members can require practitioners to dedicate time to bring them up-to-date on changes that have occurred with their loved one. This is especially true when the

decline is greater than the Distance Family Member has anticipated. The goal of the PATHS checklist is to have the time spent setting up the checklist offset by time saved later in the trajectory of a patient's decline.

Next Steps

Establishing a collaboration with a healthcare organization, such as Saint Elizabeth, to further develop the PATHS checklist would be an critical next step. By working with a partner, further research can include a co-creative workshop with practitioners, distance family members and caregivers to determine the overall service design experience as well as to define the optimal content range for use within the checklist. Although personal health data is not to be included, it will be important to ensure that privacy and confidentiality can be maintained through available IT infrastructures as well as the ability to integrate the checklist into existing practitioner workflow. It will also be important to seek out potential funding partners to facilitate the development of the platform to its fullest potential, including high fidelity prototypes for testing with practitioners and families.

Figure 11

PATHS:
A Practitioner's Checklist

*The above sketch is included to illustrate design possibility and will require several design cycles to develop properly.

Point of Intervention
The PATHS checklist is best adopted later in the trajectory, either within a residential hospice, a palliative care unit or, particularly, in the home. There is also opportunity for long-term care facilities and nursing homes to introduce the checklist as part of the intake procedure for new patients and their families.

Potential Value
The PATHS checklist would ensure Distance Family Members receive regular updates and build an understanding of their loved one's decline. Practitioners may also spend less time bringing Distance Family Members "up to speed" during visits. There is also potential to adopt PATHS to facilitate knowledge sharing amongst practitioners caring for the same patient, but with differing roles.

Potential Barriers
Even though the checklist will not include personal medical data, privacy and confidentiality may be a barrier for organizations. As well, there would be an internal learning curve and change of workflow for practitioners and IT staff within organizations. They would be required to build capacity for use, as well as ongoing management of the checklist.

Outstanding Gaps
The issue of whether the PATHS checklist should provide family members with an opportunity to ask questions is still to be resolved. The benefit of providing a platform for asking questions needs to be weighed against the time required of practitioners to answer those questions. The app should not be designed with functionality that increases time demands on practitioners.

Figure 12

PROPOSED INTERVENTION 2

The Alternate Communicator

Supporting Communication

The Alternate Communicator is a new, non-clinician role within families, identified through Advance Care Planning. The role is similar to the alternate decision maker (Power of Attorney) but with the specific responsibility of communication. It reflects current practice where all communication of information must go through the patient—if they are able—or the alternate decision-maker. As the patient experiences decline, the alternate decision-maker takes on an increasing amount of caregiving responsibilities, especially if the patient has made the decision to be at home. The added pressure of communication, often accompanied by the demand for immediacy, can be overwhelming.

By formally identifying a point person for the distribution of information, some of the pressures associated with communication could be alleviated.

Characteristics

The Alternate Communicator is a person with a natural capacity for communication and has frequent access to the patient and caregiver (see page 53). They are adept at managing the exchange of

information and they, very likely, already take on aspects of the role within the family circle.

It is important that the Alternate Communicator understands existing family-communication patterns and know how family members like to receive information and the level of detail. The Alternate Communicator will have the ability to distribute information without filtering it through personal biases and will be able to minimize emotional inter-ference. They need to be empathetic, understanding and be able to gauge the comfort level of all family members, including those at a distance.

Responsibilities

The Alternate Communicator will be a listener. They may go to appointments as support or receive frequent downloads regarding status. The Alternate Communicator "is someone that is capturing the story and sharing" and they become particularly important as decline progresses. Identifying the person who communicates is especially important in families that are large and have people at a distance.

As decline progresses, the Alternate Communicator can also take on a

gatekeeping role—distributing information, while protecting the caregiver from frequent questions and calls for updates. By mitigating some of the tasks of communication of the caregiver, the Alternate Communicator can re-frame information-seeking to inform a collective understanding of decline and, can focus conversations on support.

Next Steps

Understanding caregiver experiences with communication is an important next step and will require further research. Next steps towards prototyping should invite caregivers, patients, local and distance family, and healthcare practitioners to participate in a co-creation workshop to explore the viability of the Alternate Communicator role in practice.

As it is possible to align the Alternate Communicator with the existing legal structure in Ontario—which already provides the option to identify more than one Power of Attorney—exploring possibilities for education and awareness on the importance of communication at end-of-life is an important next step.
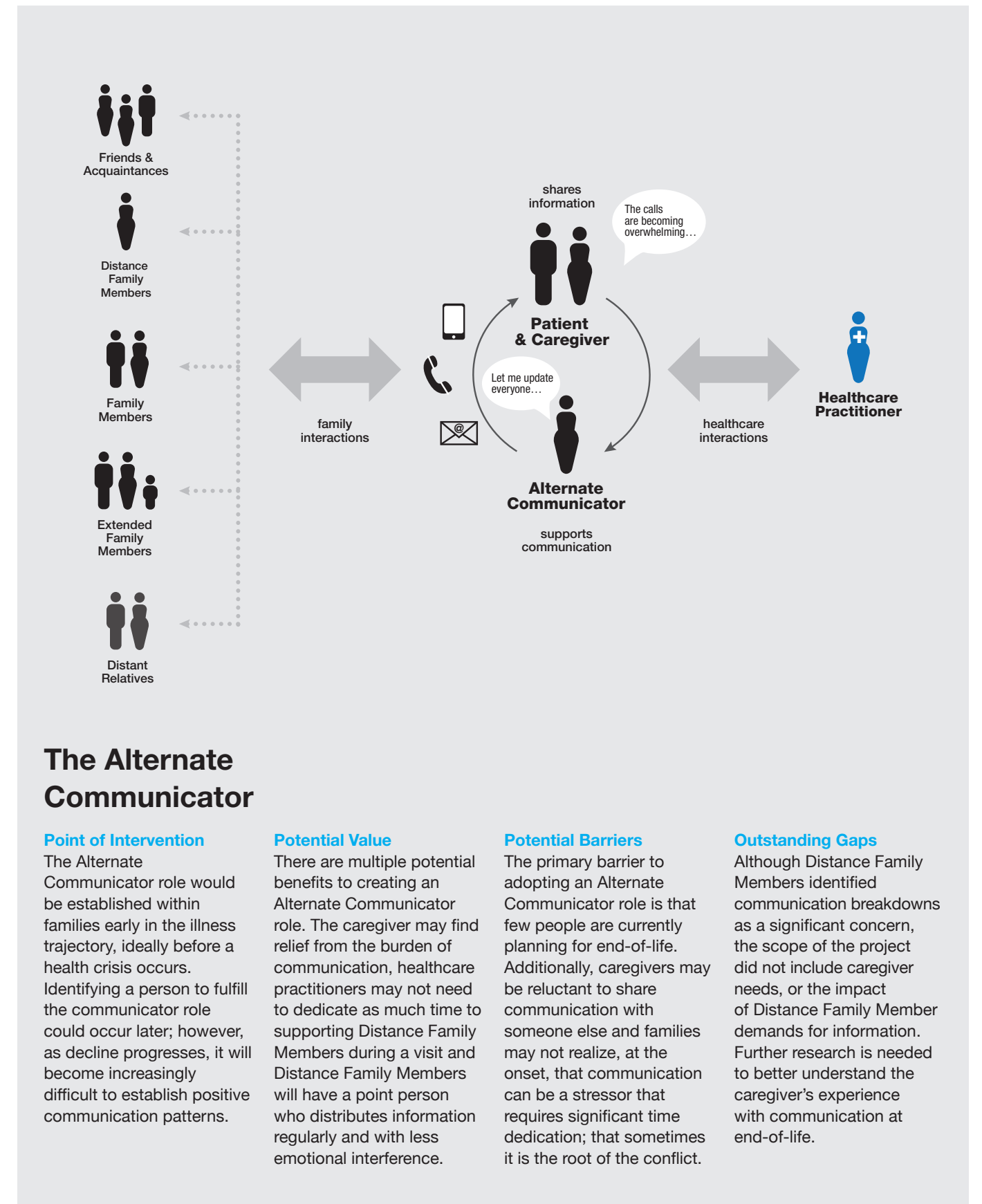
The Alternate Communicator

Point of Intervention
The Alternate Communicator role would be established within families early in the illness trajectory, ideally before a health crisis occurs. Identifying a person to fulfill the communicator role could occur later; however, as decline progresses, it will become increasingly difficult to establish positive communication patterns.

Potential Value
There are multiple potential benefits to creating an Alternate Communicator role. The caregiver may find relief from the burden of communication, healthcare practitioners may not need to dedicate as much time to supporting Distance Family Members during a visit and Distance Family Members will have a point person who distributes information regularly and with less emotional interference.

Potential Barriers
The primary barrier to adopting an Alternate Communicator role is that few people are currently planning for end-of-life. Additionally, caregivers may be reluctant to share communication with someone else and families may not realize, at the onset, that communication can be a stressor that requires significant time dedication; that sometimes it is the root of the conflict.

Outstanding Gaps
Although Distance Family Members identified communication breakdowns as a significant concern, the scope of the project did not include caregiver needs, or the impact of Distance Family Member demands for information. Further research is needed to better understand the caregiver's experience with communication at end-of-life.

PROPOSED INTERVENTIONS

Both interventions require discussion and planning for adoption. How might we encourage families to discuss end-of-life?

Figure 13

LIVINGHOPE FRAMEWORK: THE FIVE STAGES

The LivingHOPE framework is adaptive and encourages reflection, sharing and updating.

Five stages diagram inspired by Dubberly's Service Design Process noted on page 23 (Dubberly & Evenson, 2010).


reflect → identify → share → gather → formalize

PROPOSED INTERVENTION 3

LivingHOPE™

Form a Circle

LivingHOPE™ is a guide for family Advance Care Planning that prioritizes hope and supports sharing among family members. LivingHOPE begins by asking people to reflect on what they hope for themselves if they were to be diagnosed with a life-limiting illness, and also what they hope for the people that mean the most to them. Rather than focusing conversations about end-of-life on medical decision-making, LivingHOPE provides an accessible framework to initiate conversations by reflecting on hope first. This approach acknowledges the importance of maintaining hope for a cure in the face of a life-limiting diagnosis, while providing an accessible entry point to a topic that is difficult for much of society accept.

LivingHOPE provides a path to hope for a cure, while simultaneously sharing with family that, in the end, there may be a hope for no pain, or the hope to be surrounded by family at home. By encouraging open dialogues about end-of-life, people are able to establish principles for end-of-life decision-making that will inform medical decisions later.

LivingHOPE is meant to engage family in open dialogues, before a health crisis occurs. "These are really important conversations that should not be happening in the last week of life" (Gawande, 2014).

LivingHOPE Network

LivingHOPE is a multi-platform planning network that provides touchpoints to facilitate conversations, both face-to-face and digitally. A network is initiated by one person who creates a private circle of hope to share hopes and facilitate discussion on end-of-life.

Reflection is supported in two formats: a physical notebook and a corresponding mobile app. Framing questions are provided to guide the process of thinking about end-of-life from the perspective of hope and encouraging people to consider who they would want in their circle and how much information they would like to share. Both formats are supported by a secure website.

LivingHOPE accommodates both synchronous and asynchronous conversation, ensuring that families who are geographically apart are able

to engage in conversation without the need to be in the same location. The option for asynchronous exchange also provides a safe space to open the conversation about end-of-life where it might otherwise be avoided.

Connecting Families

Communication and exchange of hopes between family members is a critical element of LivingHOPE. It can also be the bridge between opposing ideas. A parent may hope that they spare their adult children from the day-to-day difficulties of living with advanced cancer. However, adult children may want to know about the day-to-day experience, so they feel connected to their parent's journey. LivingHOPE establishes a foundation to share viewpoints, build understanding and reduce conflict.

The LivingHOPE framework is a living document that establishes end-of-life principles for adaptive decision-making. It encourages ongoing reflection and facilitates changing perspectives.
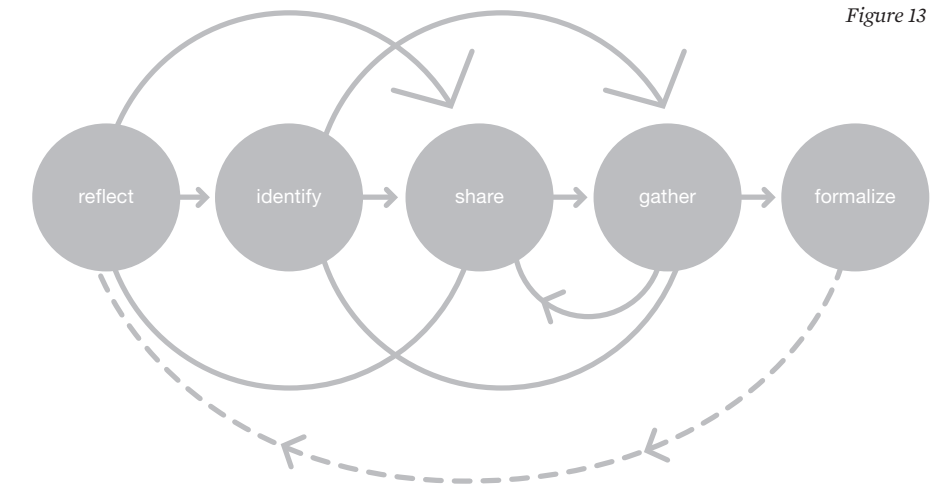
LivingHOPE Framework

It starts with one person downloading the app or printing the notebook to begin considering their own wishes for end-of-life. The framework has five steps that can be revisited at any time.

Reflect
People are asked to consider what they might hope for themselves and for their family if they were to be diagnosed with a life-limiting illness. They are encouraged to reflect on how hope might change and create principles for how they would want to approach end-of-life as a foundation for defining what is important to them. Topics to consider include:
• Who do you hope will always know how you are doing?
• How do you hope to spend your final days? Where do you hope to be?
• Who do you hope will care for you?
• What do you love that you hope to keep doing as long as possible?
• What do you hope for your family after you die?

Identify
Consider who should be in the LivingHOPE network. Who might take on important roles, such as decision-making and communication? You might begin with a spouse, adult children or a best friend.

Share
Share your hopes with at least one person who you've identified to be in your network. LivingHOPE is a reciprocal framework—encourage people to share their hopes with you. The purpose is to discuss, and build trust and a mutual understanding. Ask people to fulfill important roles and ensure that they understand what is important to you.

Gather
Invite others into your network. Be sure to extend the conversation into the family circle that includes the people you identified as most important. Everyone in the network should understand your principles and know who has specific roles. Outline what is important to you.

Formalize
Be clear about what you hope for and ensure that it is recorded within your network of the secure website. It is important that once end-of-life principles have been established, they are recorded and understood. Once formalized, principles can be shared with relevant practitioners, such as family doctors, to ensure that principles inform all conversations on end-of-life.

Reflect
LivingHOPE can always be revised, updated and re-shared. If your situation changes, reflect on your hopes and update your network.

Next Steps

There are a number of different tools available to encourage Advance Care Planning. However, most do not address family communication or the challenge of distance. In order to understand how a family Advance Care Planning tool might be adopted, it will be important to engage family members—including those diagnosed with an illness, caregivers, local and distance family members—in co-design workshops to develop the LivingHOPE framework. Workshops should also include healthcare practitioners to ensure that the framework is developed to create principles that can inform decision-making on end-of-life care.

Next steps will include establishing a partnership with a healthcare organization, such as Saint Elizabeth, to facilitate further research and collaborate on the development of a working prototype to test viability with patients, families and practitioners in both a medical and home environment.

Figure 14

PROPOSED INTERVENTION 3

LivingHOPE™

LivingHOPE is designed to provide a foundation for families to talk about end-of-life wishes. Ideally introduced before a health crisis, the framework brings families together, either in-person or virtually, synchronously or asynchronously, and adapts to each family's established communication patterns. LivingHOPE establishes principles for end-of-life that inform decision-making and can be shared with healthcare practitioners when necessary.
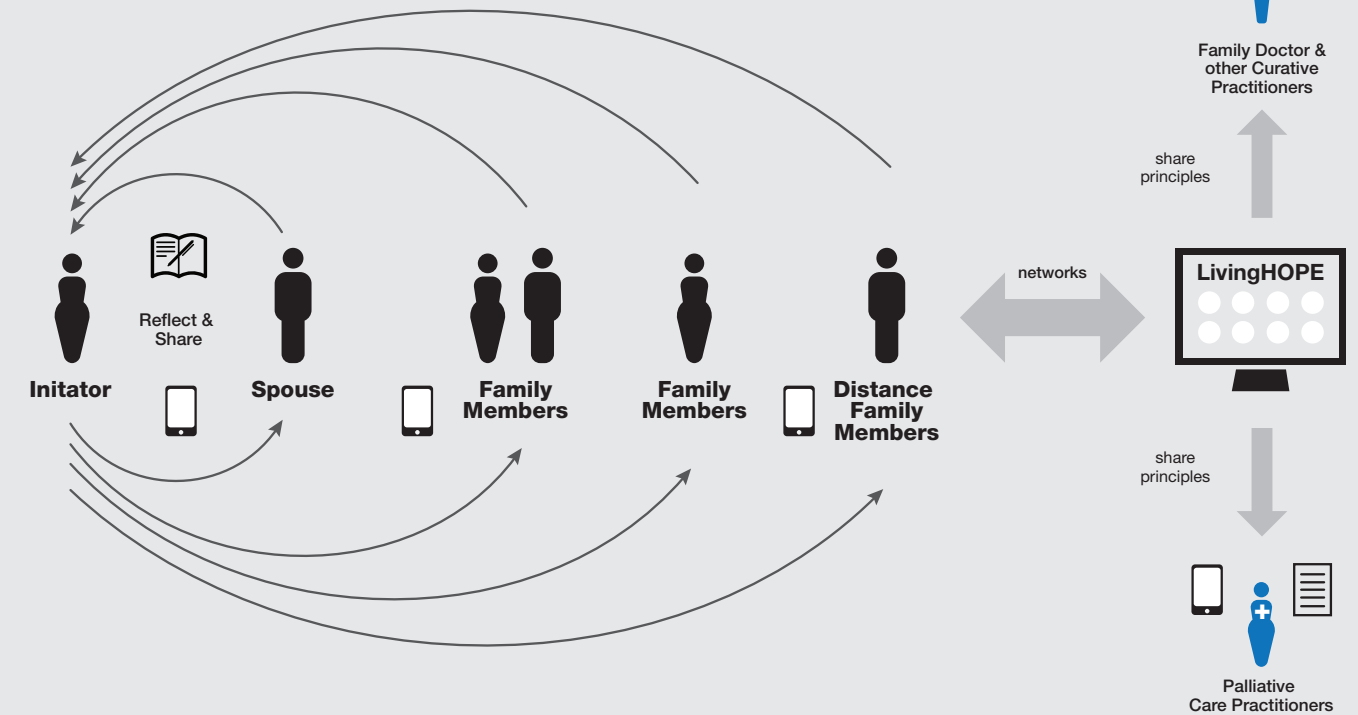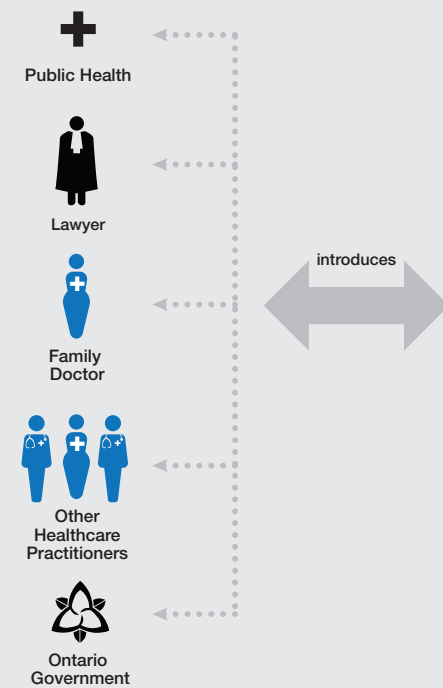

Public Health

Lawyer

Family Doctor

Other Healthcare Practitioners

Ontario Government

introduces

Reflect & Share

Initator   Spouse   Family Members   Family Members   Distance Family Members

networks

LivingHOPE

share principles

Family Doctor & other Curative Practitioners

share principles

Palliative Care Practitioners

LivingHOPE: Family Advance Care Planning

Points of Intervention

LivingHOPE should be introduced early in the illness trajectory, ideally before an illness is diagnosed. As making decisions about end-of-life is very difficult when also faced with a life-limiting illness, conversations should be encouraged when people are well and have the time and space to reflect on their hopes and share them with family.

Although possible to introduce at any point, there are a number of specific intervention points to consider including: the annual checkup with a family doctor, the first visit to a specialist after diagnosis and any arrival in the ER. LivingHOPE could also be positioned as a Public Health initiative that is widely promoted by educating people on the benefits to families of planning early.

There are also touch points outside of healthcare that might be considered for distribution of the framework. Lawyers that handle estate planning, wills and Power of Attorney documents could also distribute information on LivingHOPE. Although lawyers would not be expected to guide end-of-life conversations, they could direct clients to information available online.

The Government of Ontario could also promote Advance Care Planning, such as LivingHOPE, as part of the tax-filing process, and consider offering a tax incentive to people who have completed Advance Care Plans. Although government intervention might be considered unlikely, the potential for savings to the healthcare system, as the population ages, could be great (however, exact savings to the system would require further research).

Potential Value

For families that engage with LivingHOPE, the benefits are many. Individuals faced with a life-limiting illness will have a platform to communicate end-of-life principles to inform decision-making throughout their journey. Caregivers and family members will have a clear understanding of the patient's end-of-life principles. For those families where distance is a factor, a plan for ensuring access to information can

be established long before a crisis occurs. Early planning that includes family members has the potential to mitigate conflict later in the illness trajectory.

There is no doubt that healthcare providers agree that Advance Care Planning is critical for end-of-life and can reduce uncertainly, minimize strain on healthcare practitioners and carry the potential to save time and resources.

Potential Barriers

The most significant barrier to adopting LivingHOPE is the same barrier that all Advance Care Plans face—stigma and fear about death and dying. There are many different options to engage in planning for end-of-life and there will be no one-size-fits-everyone solution. However, by focusing on hope at the onset, rather than tactics, LivingHOPE aims to engage people in a more accessible way and encourage family planning and sharing.

Outstanding Gaps

Healthcare practitioners feel strongly that doing an Advance Care Plan is critical for patients who want to maintain autonomy at end-of-life. Positioning hope as a leverage point for framing end-of-life planning would need to be explored further by engaging with families in how to best frame the LivingHOPE platform. As well, inclusion of professional support within the platform, to guide conversations if needed, should be explored.

CHAPTER 7

Looking Forward…

The Ontario healthcare system is wrestling with the challenge of meeting the needs of an aging population, while acknowledging existing financial limitations. The increasing number of people living at a distance from family creates added complexities to the delivery of palliative care services currently marred by a lack of consistency and inequitable access. There is an increasing need to engage caregivers and family members to better understand how we might provide support and services for end-of-life.

By adopting a design research approach, including an eye to future shifts, we are able to identify the needs of family members at a distance during palliative care, and propose a suite of tools to manage communication and build understanding and acceptance.

Human-centred design provides the opportunity to encourage end-of-life discussion far in advance of a health crisis. By facilitating sharing among family members, we can plan for communication that not only supports Distance Family Members' needs, but also supports patients and caregivers. Ultimately, it will mitigate pressures on healthcare practitioners and the healthcare system as a whole.

Process image:
Project research was captured on a large wall to support visualization and sensemaking across different phases of the major research project.

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Process image:
Thematic sorting, based on a Grounded Theory approach, was adopted to separately process two sets of data: Distance Family Members and healthcare practitioners.

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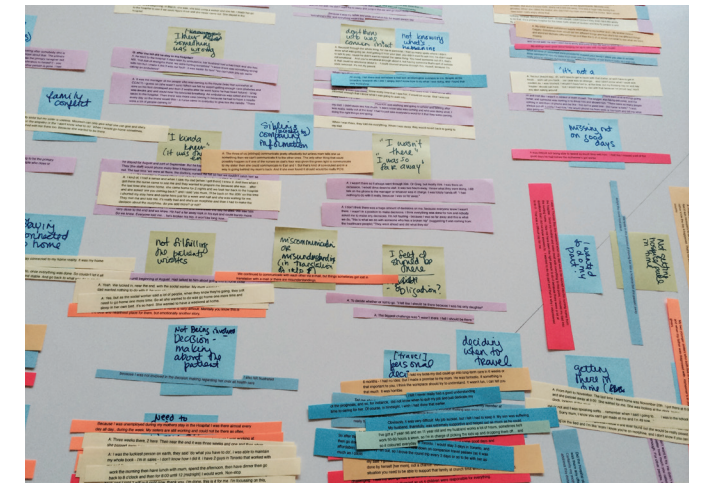
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Process image:
Subsequent sorting was done
by aggregating initial themes
into higher-level interpretations
of the data.

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Appendix A:
Glossary of Terms

The following terminology is relevant to this research project.

Acute Care Hospital
"A hospital that offers short-term, intensive inpatient treatment and care to patients with serious health problems. An acute care hospital can provide palliative care to patients in a designed palliative care unit or in regular beds throughout the hospital." (Office of the Auditor General of Ontario, 2015)

Advance Care Planning
Advance Care Planning is a process that includes reflecting on one's values and determining what your wishes are for end-of-life, including whether you would want specific medical interventions to prolong life. An Advance care plan also includes the selection of an Alternate or Substitute Decision-maker—someone who would make medical decisions on your behalf if you were unable to speak for yourself. Legal and financial documentation is often included in the process of Advance Care Planning. (Advancecareplanning.ca, 2015)

Canadian Hospice Palliative Care Association (CHPCA)
"A national association that advocates for good-quality palliative care, including end-of-life care. This includes promoting public policy, education and awareness of palliative care." (Office of the Auditor General of Ontario, 2015)

Caregiver/Family Caregiver/Informal Caregiver
An individual that provides unpaid, ongoing care, support and/or assistance to another person—family member or anyone in their larger social network—due to a life-limiting illness. (Gauvin, Abelson & Lavis, 2013)

Community Care Access Centre (CCAC)
Community Care Access Centres (CCACs) are community agencies funded by the Ministry of Health and Long-Term Care through the corresponding regional LHIN. There are fourteen CCACs in the province of Ontario, one for each LHIN. They are responsible for providing Ontarians access to home care services and community care, providing information and making referrals to community-related services, managing admissions to long-term care facilities as well as facilitating placements in adult day programs, supportive housing, chronic care hospitals and rehabilitation hospitals. (Government of Ontario, 2011)

Family
The term 'family' applies to anyone in the patient's core family structure or sharing/social network that they have selected to provide care. This may include family members, friends, neighbours or any person with a 'legal, genetic and/or emotional relationship to the person.' (Canadian Hospice Palliative Care Association, 2014)

Goals of Care
"Describes people's goals for their care and should include treatment of the disease and/or symptom management. In some cases, it includes limits on the interventions that people want, such as 'do not resuscitate' orders." (Canadian Hospice Palliative Care Association, 2014)

Hospice
"A home-like facility that provides palliative care to terminally ill people and their families. Residential hospices provide accommodation for people who do not require hospital-based care, but either cannot be cared for at home or do not wish to remain at home, in the last weeks or months of life." (Office of the Auditor General of Ontario, 2015)

Hospice Palliative Care Ontario (HPCO)
"An organization that...promotes awareness, education and best practices in the provision of palliative care in Ontario. Its member organizations deliver palliative care services in Ontario." (Office of the Auditor General of Ontario, 2015)

Life-limiting Illness
A life-limiting illness is an "illness that can be reasonably expected to case the death of an individual within a foreseeable future." (Williams, Kelley, Dykeman & DeMiglio, 2014)

Local Health Integration Network (LHIN)
The fourteen Local Health Integration Networks (LHINs) were created in 2006 to plan, integrate and fund local healthcare services in each of fourteen geographic regions in Ontario. The LHINs are fully-funded and legislated by the Ministry of Health and Long-Term Care. (Government of Ontario, 2011)

Ministry of Health and Long-Term Care (MOHLTC)
The Ontario ministry whose mandate is to build a sustainable public heath care system in Ontario. The LHINs were created in order to allow the ministry to take on a stewardship role. "This new stewardship role will mean that the ministry will provide overall direction and leadership for the system, focusing on planning, and on guiding resources to bring value to the health system. The ministry will be less involved when it comes to the actual delivery of health care." (Health.gov.on.ca, 2015)

Palliative Care
"An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems—physical, psychosocial and spiritual." (Canadian Hospice Palliative Care Association, 2014) For the purposes of this research project, 'palliative care', 'hospice care', 'hospice palliative care' and 'end-of-life care' have the same meaning.

Patient and Family-Centred Care
Patient and Family Centred Care is an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among health care providers, patients, and families, which results in better health outcomes, wiser allocation of resources and greater patient and family satisfaction. (Stiff, Foster, Speller & Anas, 2013)

Palliative Performance Scale (PPS)
An assessment tool that measures a patient's functional status and assigns a score. The lower the score, the less time the patient is estimated to have remaining to live. The scale provides a way to measure progressive decline over the course of a patient's illness." (Office of the Auditor General of Ontario, 2015) The PPS score is often a factor in determining access to a hospice or palliative unit bed, as well as the number of hours allocated to support in the home.

Personal Support Worker (PSW)
"Provides non-medical care to patients, which may include assistance with tasks of daily living such as personal hygiene and eating, as well as homemaking, such as changing bed linens and meal preparation." (Office of the Auditor General of Ontario, 2015)

Quality End-of-Life Care Coalition of Canada (QELCCC)
A national coalition that believes "all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice." The coalition has 35 members and associate members that advocate for a national strategy on palliative and end-of-life care supported by sustainable funding (qelccc.ca, 2015).

Quality Hospice Palliative Care Coalition of Ontario (QHPCCO)
"Quality Hospice Palliative care Coalition of Ontario is a coalition comprised of provincial organizations and associations that represent organizations and individuals providing hospice palliative care; universities that conduct palliative care research; and family caregivers with an interest in hospice palliative care." (Government of Ontario, 2011)

Appendix B:
Literature Review

The Literature Review

The literature review conducted as part of the independent study included research of secondary sources from two perspectives: technology for communication and the medical perspective, including social work and nursing, as they related to palliative care.

The methodology for the literature review included beginning with a key word search using 'word bundles' for each word in the research statement: palliative, remote, communication and family. By making use of a range of databases, I was able to find articles with a varied perspective on the topic which lead to establishing inclusion criteria to narrow down an initial broad list sources to a field of approximately 180 references. In order to sort the larger field of references, two methods were used: an online citation manager and an adapted card sorting methodology that included creating a physical research wall to pin-up references under the broader categorizations of medical, technology and family.

Although sociology of the family was originally in the scope of context for the literature review, it the complexity of the topic quickly became apparent. It was decided that an exploration of family would be re-directed to a foresight methodology in a later phase of the research to ensure the project recognized current trends in the changing Canadian family.

Through reviewing, comparing and sorting in both analogue and digital formats, the references were narrowed down to approximately 40 articles for consideration. After reading the culled list, a final group of 20 key articles were chosen to form the basis for the initial identification of opportunity gaps. The core findings have been categorized and summarized under two perspectives: technology and medical which includes nursing and social work.

Medical Perspective

The philosophy of palliative care is to include the family in the care and decision-making around the patient (Kristjanson and Aoun, 2004). In this context the definition of family should be inclusive of relatives or friends that provide support or help to the patient, yet are not always in close geographic proximity (Bevan and Sparks, 2010). In patient care, there is a noted distinction between individual patient-centred care which puts the patient at the centre of the medical care and family-centred care (King and Quill, 2006) which acknowledges the patient as part of a larger social or sharing network (Pang et al, 2013)

In contrast to the ideal concept of family-centred care is the reality that family members are often "hidden patients" (Kristjanson and Aoun, 2004) as their needs are largely under-served and do not address the issues of financial stress, expectation and demands of daily life. A core person in this context is the local caregiver. Defined as the person closest to the patient who provides the most face-to-face support (Bevan and Sparks, 2010), they often take on the role of conduit for the distribution of information to distance family members and the larger sharing network (Pang et al, 2013).

When it comes to communication with family members who are distanced, there is a lack of research regarding their needs (Bevan and Sparks, 2010), as well as what is required to facilitate inclusion in the palliative care process. It is also worth noting that distance family members are often not considered at all when discussing patient needs and condition (Lautrette et al, 2007). This appeared to be especially true in the research on family conferences.

An additional challenge in this area is the lack of a common understanding for how distance is defined as well as what the meaning of 'mediated communication' is in a medical or palliative setting, as well as the challenge of understanding the family system and changing family dynamic. How do family conflicts affect the ability of distance family members to receive information on a loved one when they rely on other caregivers for updates? (Bevan and Sparks, 2010)

(Harris et al, 2009) acknowledges that "treatments and physicians come and go, but the family is often the primary support unit for the cancer patient." With this in mind, and the growing influence technology has on how families communicate with each other, it is critical to understand the research that focuses on use of technology for communication in a medical or palliative care environment.

Technology Perspective

Review of the technology references revealed that face-to-face communication when dealing with healthcare issues is still the preferred method of communication for family members (Bevan and Sparks, 2010). Although other synchronous methods of communication are employed, such as telephone and video, people still choose an in-person conversation when possible. Interestingly, even though video has the advantage of a visual, it is least preferred method of contact (Pang et al, 2013). And despite other, newer, communication tools the telephone is the next most used point of contact.

Alternatively, email is the most used asynchronous communication tool among text/SMS, postal mail and social media options such as Facebook. (Tee et al, 2008) Asynchronous communication has advantages for communicating details and exchanging information in a direct way, that is different than the time commitment often associated with synchronous communication.

(Moffatt, 2012) and (Pang et al, 2012) both suggest a context for the decision to use which tool in what circumstance. (Moffatt, 2012) proposes there are three types of support—physical, emotional and social—which each require different communication. (Pang et al, 2013) discusses informative, supportive and evaluative communication. These are important distinction in the context why family members choose certain methods of communication with other members of the sharing network.

From the family user perspective, availability and reliability are two potential barriers to the adoption of new communication technology as is the amount of effort required (Tee et al, 2008). Acquiring resources (hardware or software) and a steep learning curve would both be deterrents to accepting new methods of communication, especially in a time of stress which is a possibility in a health crisis or palliative care (Moffatt, 2013).

(Tee et al, 2008) reveal that "our findings suggest that new technology must delicately balance the assistance it provides without creating additional burdens or obligations, while at the same time being easy to use without trivializing the interaction." It is important to remember these parameters when considering the use of technology facilitated communication in the context of palliative care.

The Emergence of Privacy and a Universal Concern

A common thread across all of the sources identified as part of the literature review was the issue of privacy. It is important to recognize the patient's need to control how much information about their condition is shared and with whom (Moncur et al, 2010), even if it's with members of their immediate family. Hospitals and healthcare organization have a legal requirement to ensure the privacy of their patients is respected and upheld and the use of more modern methods of communication that are facilitated by technology are often restricted to ensure privacy is secure (Brecher, 2013). From a communication point of view, family members select their methods of communication with privacy as a key consideration (Pang et al, 2013).

For any future innovation to be accepted and embraced—both by the families and the medical community—privacy will need to be a core consideration of any proposed intervention to support the distance family member.

Possible Opportunities for Innovation

After a review of the selected articles and the creation of a corresponding visual map (see page opposite page), four possible opportunities for innovation have been identified.

1. Distance Family Member Needs

There is a need for further research on the specific needs of distance family members in a palliative care setting. Research on communication to families is often in exclusion of distance family members (Bevan and Sparks, 2010) and assumes communication will be facilitated by the primary caregiver. Understanding the needs of distance family members, as well as the impact these needs might have on both the medical system and the family system, especially the primary caregiver, is integral to this major research project.

2. A Communication Family Ecosystem

Exploration of existing families communication patterns, facilitated by technology, during end-of-life or palliative care is also an area with potential for innovation. Rather than creating a new technology (Saslis-Lagoudakis et al, 2006) to encourage family connectedness, creation of an ecosystem that aligned to existing family patterns (Tee et al, 2008) might have the potential to integrate well in the family system without creating a learning curve that would result in a barrier to adoption (Ferguson and Moffatt et al, 2013).

3. The Family Conference

Although there is substantial research on the family conference in palliative care, there appears to be an information gap in the area of identifying, acknowledging and including distance family members (Oliver et al, 2010). Further research is needed to determine if protocols exist in hospital, hospice or palliative care units but are not part of current academic research. The role of technology to connect distance family members to the family conference is an area of interest.

4. Technology Protocols

Protocols for technology use to facilitate connection of family members to patients in a medical environment is the fourth area of focus. Expert interviews would be important to determine the extend of technology protocols and the inclusive nature as it relates to distance family members. How families are identified and assessed for distanced needs is also critical information. Where technology protocols are not in place, it is important to understand the barriers— for the hospital or medical facility— and the family, that prevent use of technology communication tools.

The knowledge gained from the literature review, and the identified gaps, served as the foundation for framing the Major Research Project. Although all four areas are worthy of further investigation, it was determined that understanding the needs of this emerging, and under-represented, group would be the first critical step in determining appropriate interventions any of the remaining three problem areas.

As such, the following two primary questions are intended to frame the Major Research Project:

What are the needs of family members who are a distance from a loved one during palliative care?

How might we better meet the needs of family members who are at a distance during palliative care in Ontario?

Appendix B:
Visual Map Illustrating Literature Review
Findings and Identified Gaps

Appendix C:
Methodology

ASPIRE	GATHER	CREATE	REFLECT	SHARE	CHANGE
	informs	influences	enables		socializes
	D	**I**	**K**	**W**	

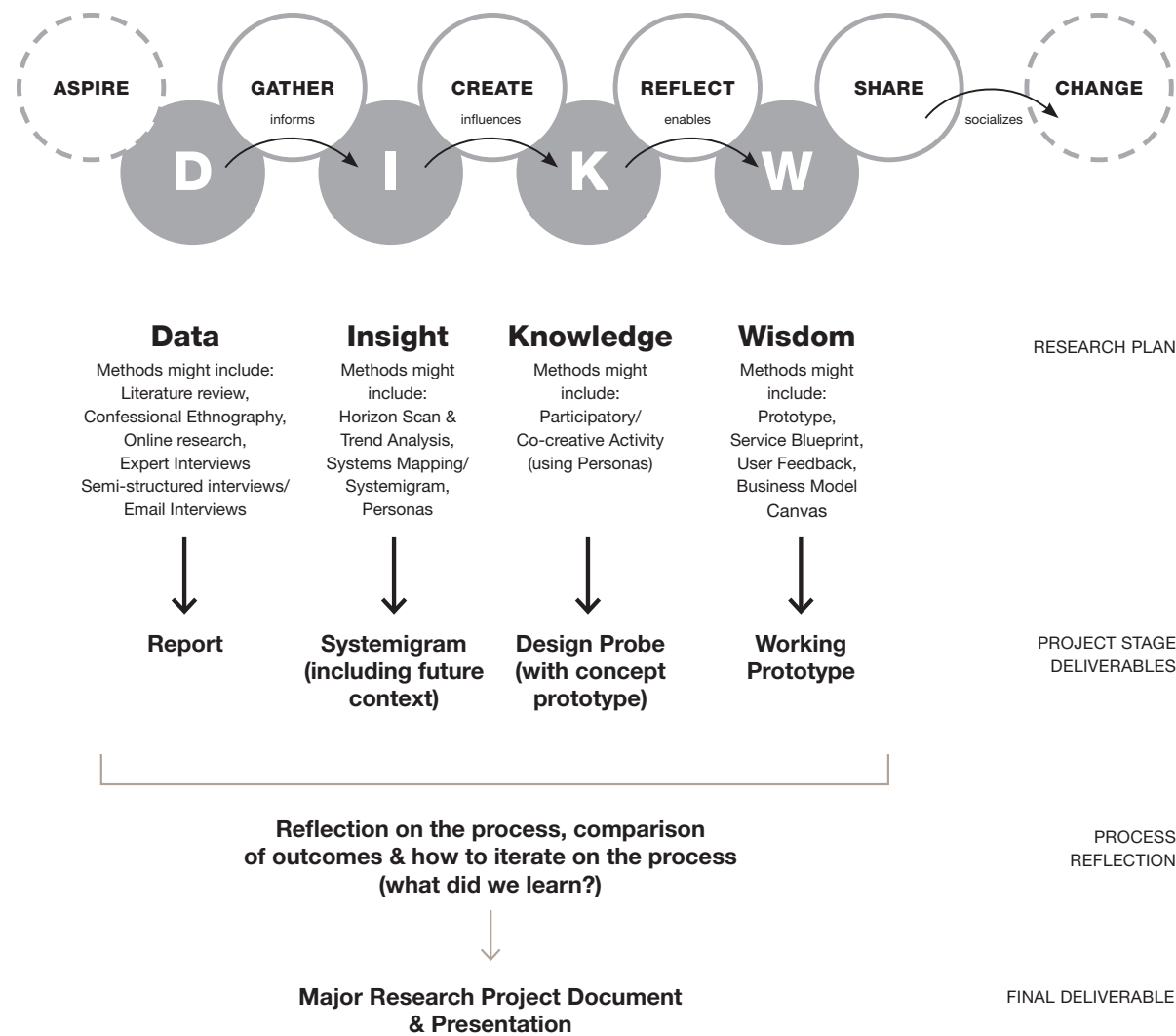| **Data**	**Insight**	**Knowledge**	**Wisdom**	RESEARCH PLAN
Methods might include: Literature review, Confessional Ethnography, Online research, Expert Interviews Semi-structured interviews/ Email Interviews	Methods might include: Horizon Scan & Trend Analysis, Systems Mapping/ Systemigram, Personas	Methods might include: Participatory/ Co-creative Activity (using Personas)	Methods might include: Prototype, Service Blueprint, User Feedback, Business Model Canvas	
Report	**Systemigram (including future context)**	**Design Probe (with concept prototype)**	**Working Prototype**	PROJECT STAGE DELIVERABLES

Reflection on the process, comparison of outcomes & how to iterate on the process (what did we learn?)   PROCESS REFLECTION

Major Research Project Document & Presentation   FINAL DELIVERABLE

Reflection on the Project Plan

This project began with high aspirations and although valuable insights were achieved, time constraints and unanticipated delays in early stages, limited the overall scope of the project. Following the methodology as planned, the project will now circle back to earlier stages to build on each of the three proposed interventions as follows:

Personas

Personas, including the family, Distance Family Member and representative Healthcare Practitioner roles, should be developed.

Participatory Activity

Engaging users as co-creators is an important aspect of a service design methodology and should be part of the next steps in the project development. A small group of participants—stakeholders relevant to the intervention—should be invited to participate in co-design workshops to further develop proposed interventions.

Future Service Blueprint

Building on insights from the participatory activities, a future-facing service blueprint should be developed to further test the intervention ideas.

Business Model Canvas

The Business Model Canvas (Osterwalder, Pigneur & Clark, 2010) should be used as a tool to test viability of each of the three proposed prototypes.

Further Research

A number of opportunities emerged during the course of the project for further research.

The Daughter from California

The Daughter from California was a common theme that emerged from the Healthcare Practitioner interviews, however there was little research available on the concept, and what was available, was from the healthcare perspective. Further research on the evolution of The Daughter from California Syndrome identified in 1991 (Molloy, Clarnette, Braun, Eisemann & Sneiderman, 1991) and current experiences of the Distance Family Member would be of interest.

The Male Voice

The changing role of men in the family is also worth further research. As none of the Distance Family Members interviewed as part of this project were male, future research should aim to be inclusive of the male voice and acknowledge the shift in gender roles and family caregiving responsibilities.
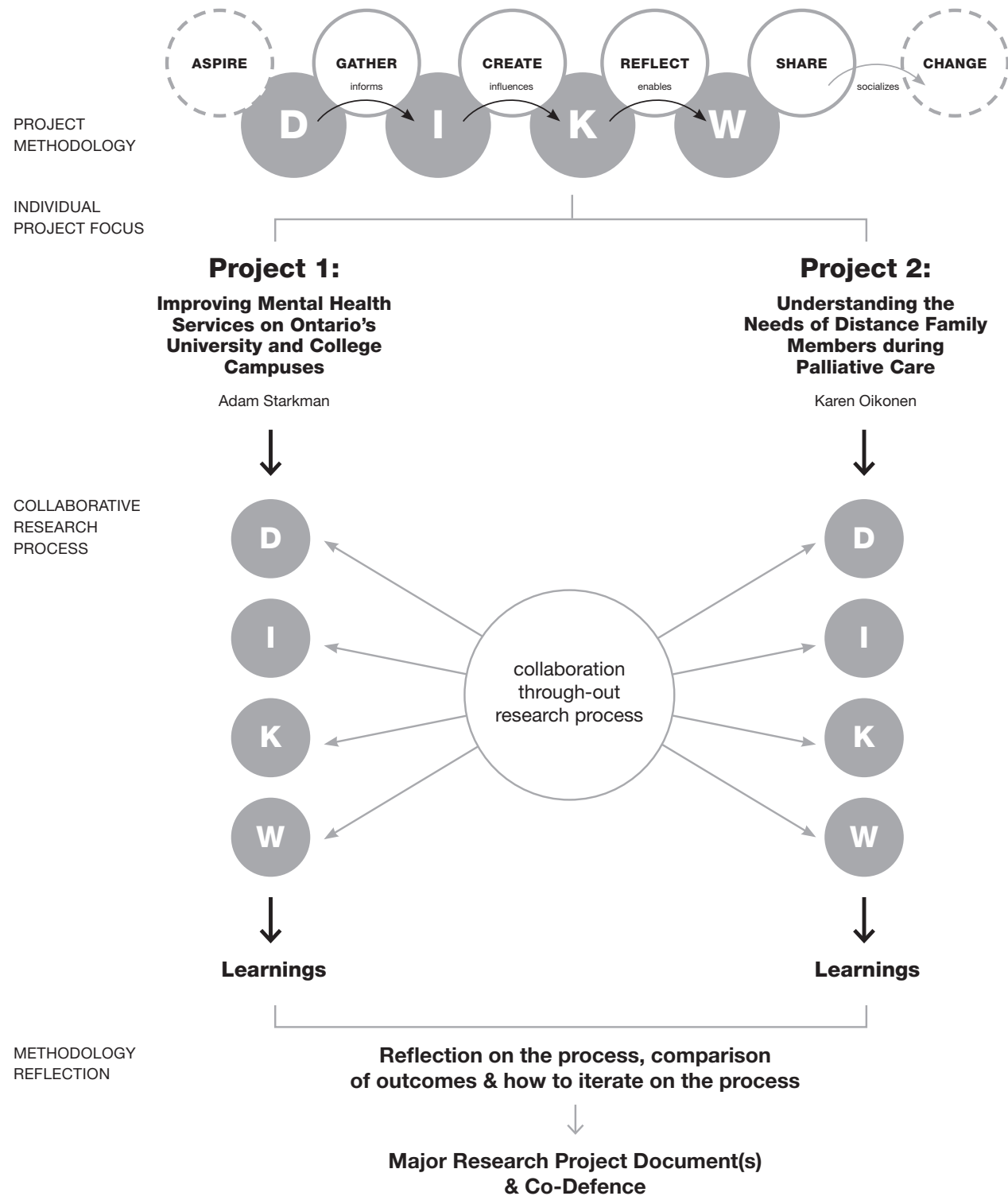
Impact on Families

Research with families was not included in the scope of this project, however should be considered in the next stages. The impact of the Distance Family Member should be captured from the perspective of the caregiver and other local family members. Participatory activities should aim to engage representation from the broader family network. Due to the sensitivity of the topic, it will be beneficial to design future research to support small groups of family members, including the patient, in the their homes where they are most comfortable. Recruitment will benefit from the continued support of a healthcare provider such as Saint Elizabeth to gain access to both families receiving in-home support and healthcare practitioners working in the home.

Going Forward

Although this document fulfills the requirements for the Major Research Project, it does not signal the end of my engagement with the topic. There is no question that I choose to research the Distance Family Member for deeply personal reasons. Through-out this process, I have come to realize how important it will be to address the needs of families during the end-of-life experience, especially as the aging demographic intersects with changing family structures and geographic shifting proximities. I plan to continue working on the project topic with the hopes of making a positive impact in the future.

Appendix C:
Initial Plan for Project Collaboration
and Reflection

ASPIRE   GATHER   CREATE   REFLECT   SHARE   CHANGE
          informs   influences enables   socializes

D   I   K   W

PROJECT
METHODOLOGY

INDIVIDUAL
PROJECT FOCUS

Project 1:
**Improving Mental Health
Services on Ontario's
University and College
Campuses**

Adam Starkman

Project 2:
**Understanding the
Needs of Distance Family
Members during
Palliative Care**

Karen Oikonen

COLLABORATIVE
RESEARCH
PROCESS

D   D
I   collaboration   I
               through-out
K   research process   K
W   W

Learnings   **Learnings**

METHODOLOGY
REFLECTION

**Reflection on the process, comparison
of outcomes & how to iterate on the process**

**Major Research Project Document(s)
& Co-Defence**

Reflecting on the Methodology
The methodology for this project was developed in collaboration with fellow Strategic Foresight and Innovation student, Adam Starkman. We were both working on topics within the healthcare sector in Ontario and wanted to adopt a service design approach. Our original project plan included collaboration throughout our projects—developing the methodology and then tackling each of our individual projects with the methods outlines. We had planned to discuss and compare our learnings as our projects progressed, identifying any similarities to working within the Ontario healthcare system. However, there were a few challenges along the way that ultimately changed our initial plan of presenting the project outcomes together—different project topics, but joint learnings on a service design methodology for healthcare.

Research Ethics Board
When working with a topic that engages human participants in a healthcare context—especially where vulnerability is a concern—preparations for Research Ethics Board (REB) applications, and consequent revisions and approval, can take a considerable amount of time.

Upon reflection, it is important for REB applications be submitted as early as possible and project plan should account for possible revisions and delays. Researchers should not expect a fast turnaround and should plan for the completion of work on the MRP that is not reliant on REB approval. Adam and I received REB approval many weeks apart and, as such, it was difficult to re-align our projects after the delay.

However, challenges and the possibility of a lengthy approval process should not deter researchers from planning projects, within the healthcare space, that include engaging people with lived experiences. Although expert interviews are an important piece of the research, the voice of the people who use the healthcare system are often not heard enough, and offer a valuable point-of-view.

Recruitment
Identifying participants for the research presented two challenges. Due to the sensitivity of the topic, Distance Family Members were recruited through known social networks and, although there were many interested potential participants at the onset they later decided against participating in the study. As such, the recruitment phase for Distance Family Members took months and should have been accounted for in the project planning. In practice, the interviewing of Distance Family Members required time and space, and due to the sensitivity of the topic, could not be rushed. As well, my own proximity to the topic often resulted in the need to take time away from the research due to the emotional intensity of the project, which ultimately extended the project timeline.

Recruitment of practitioners was often made possible through Saint Elizabeth, secondary advisor on the project. This proved to be invaluable for gaining access to healthcare practitioners working with patients and families at end-of-life. Medical practitioners—nurses, doctors, social workers—have busy schedules and it can be difficult for them to make time to participate in research. I am grateful to the practitioners who were generous with their time, and agreed to be interviewed as part of this project. As I am not embedded within the healthcare system, but rather approached the topic from the 'outside', as someone with lived experience, it was critical to gain access to practitioners.

Appendix D:
Interview Guides

Distance Family Member Interview Guide

Thank you for agreeing to be interviewed today. My name is Karen Oikonen and this is my colleague Adam Starkman. As you may remember from our contact with you before, we are graduate students in OCADU's Strategic Foresight and Innovation program. The primary goal of this project is to understand the experiences and needs of family members who were at a distance from a loved one when they were in palliative care or end-of-life. We are holding interviews with family members who have had this experience. There is no obligation to disclose any personal health information of the person who went through palliative care, we are primarily interested in your experience of this process from a distance. The insights gained from this interview will contribute to my (Karen's) Major Research Project which is the final requirement for completion of my Master of Design degree. We are also working with Saint Elizabeth, a leading non-profit organization in delivering health care services in people's homes and communities, and hope to make this study available to the wider palliative care community through publication where appropriate.

The interview is anticipated to be between 30 and 40 minutes. Just a reminder that it is voluntary and you may ask questions throughout the interview, skip questions, come back to questions or leave some unanswered. You may also end the interview at any time. Your responses will be kept confidential, and any statements selected for the purposes of reporting will be not be attributed to you directly. We usually will simply identify a quote with the role someone has e.g. spouse, nurse, daughter/son and sometimes a pseudonym.

Have you had the chance to read over the Information Sheet and Consent Form? Do you have any questions about the study? Are you comfortable with us audio recording this interview? (Y/N) If you agree to this interview and the audio recording, please sign this consent form [verbal consent if interview is done by phone].

The recording will only be used for our purpose to review the conversation. Adam and I will also be taking notes throughout our conversation.

A note about language, for the purposes of this interview, palliative care might also refer to other end-of-life experiences such as hospital, hospice or dying at home.

Are you ready to get started with the interview? I will turn on the audio recorder now.

Thank you for agreeing to participate in this interview.

Introduction
What is your age and gender?
Do you work in healthcare yourself?
How long have you lived in the area where you currently live?
How long ago was your experience with palliative care?
What was your relationship with the person in palliative care?
Tell me about the situation, where you lived, where they lived...?
Was your loved one in hospital? Hospice? At Home? Or...?

Experience being at a distance
What was your everyday experience like being at a distance from your loved one when they were in palliative care or at end-of-life?

What were some of the challenges to being in a different geographic location?

What challenges/pressures had the most impact? Why?

What services or resources were provided to support your family? Were you able to access those services?

What did the hospital or hospice or palliative care environment do to include you in the palliative care process?

Looking back, was there anything that could have made this [process/experience] more manageable?

What were the biggest challenges to being at a distance when dealing with various aspects of the healthcare system or with healthcare professionals?

Tell me about some of the decision-making that you faced, specific to you as a family member at a distance. What was the most challenging? Why?

What was your experience with information? Receiving or exchanging?

Reflecting on your experience, what were the biggest frustrations that were a result of you not being in the same geographic location as your loved one?

From your perspective, how might we better meet the needs of distance family members with a loved one at end-of-life?

Is there a particular story that you would like to share with us to help us understand better or anything else you would like to add?

Closing
Thank you very much for participating in this interview. This conversation helps us better understand the perspective of family members and will inform our thinking as we begin to develop ideas about how to better support the needs of people at a distance during the palliative care and end-of-life experience.

If you would like to see the final version of the project, I would be happy to share that with you. Would you like me to email you a copy after it is complete? Thank you again for sharing your experience with us, I appreciate your willingness to share your thoughts and experiences and they will be very helpful as we move forward.

Thank you again.

Healthcare Practitioner Interview Guide

Thank you for agreeing to be interviewed today. My name is Karen Oikonen and this is my colleague Adam Starkman. We are graduate students in OCADU's Strategic Foresight and Innovation program. The primary goal of this project is to understand the experiences and needs of family members who were at a distance from a loved one when they were in palliative or end-of-life care.

We are holding interviews with medical practitioners [or insert nurse/social worker/palliative care nurse/oncologist here] who have experience with patients in palliative care or end-of-life who might also have had families members in another geographic location or were unable to be physically present. The insights gained from this interview will contribute to my (Karen's) Major Research Project which is the final requirement for completion of my Master of Design degree. We are also working with Saint Elizabeth, a leading non-profit organization in delivering health care services in people's homes and communities, and hope to make this study available to the wider palliative care community through publication where appropriate.

The interview is anticipated to be approximately 1 hour. It is voluntary and you may ask questions throughout the interview, skip questions, come back to questions or leave some unanswered. You may also end the interview at any time. Your responses will be kept confidential, and any statements selected for the purposes of reporting will be anonymized and attributed to a pseudonym.

Have you had the chance to read over the consent form? Do you have any questions about the consent form? Are you comfortable with us audio recording this interview? (Y/N) If you agree to this interview and the audio recording, please sign this consent form (verbal consent if interview is done by phone).

The recording will only be used for our purpose to review the conversation. Adam and I will also be taking notes throughout our conversation.

For the purposes of this interview, palliative care might also refer to other end-of-life experiences such as hospital, hospice or dying at home.

Are you ready to get started with the interview? I will turn on the audio recorder now.

Thank you for agreeing to participate in this interview.

Questions for expert interviewees
What is your role and where are you employed?

How long have your held this position? How long have you worked in healthcare?

What types of contact do you have with the families of patients in palliative care or end-of-life?

What has been your experience working with patients that have a family member at a distance?

Does your institution have any programs for families of patients in palliative care? How are family members at a distance included?

What information is exchanged before and during palliative care? How might this be different in the future?

What might be the role of technology for addressing distance family member needs?

What are the challenges that healthcare providers face when working with patients that have family members at a distance? How was this different 5 years ago? How might it be different 5 years from now?

What are the challenges in the healthcare system that might be barrier to providing services for distance family members?

How might family members at a distance be better supported before, during and after palliative care?

What programs do you know of work well to address the needs of distance family members?

What do you observe as the most important needs expressed by distance family members? What are their biggest challenges?

Is there anything else we should know?

Closing
Thank you very much for participating in this interview. This conversation helps us better understand the perspective of professionals working in healthcare and will inform our thinking as we begin to develop ideas about how to better support the needs of people at a distance during the palliative care and end-of-life experience.

If you would like to see the final version of the project, I would be happy to share that with you. Would you like me to email you a copy after it is complete? [Y/N] Thank you again for sharing your expertise and knowledge with us, I appreciate your willingness to share your thoughts and experiences and they will be very helpful as we move forward.

Thank you again.

About the Author
Karen Oikonen is a design researcher, service designer and educator. Pairing an eye for detail with critical thinking, she has always approached design work from a human-centred perspective. She has over 18 years of professional experience contributing to inter-disciplinary teams in a number of capacities, including design research, engagement, systems thinking, foresight, art direction and design.

Karen holds a Bachelor of Interior Design from the University of Manitoba, and a Master of Design degree in Strategic Foresight and Innovation from OCAD University.

Karen is focused on applying a human-centred design approach to emerging challenges presented by an aging population, with particular interest in meeting the needs of patients and families during the end-of-life experience.

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"Hope is everything.
It's not something
we ever want to take
away from people."

– Social Worker