Design for Care Conversations

a qualitative research project about choices and care at end-of-life

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Master of Design
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Submitted to OCAD University in partial fulfillment of the requirements
for the degree of Master of Design in Strategic Foresight and Innovation
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ABSTRACT

This research investigates strategies to enhance communication between healthcare providers, older adults, and their caregivers, with a particular focus on the role of Social Prescribing at end of life. Preliminary findings suggest a significant communication gap within the healthcare system, compounded by insufficient training for healthcare providers. This gap poses a barrier to delivering compassionate and meaningful care. The study aims to explore these deficiencies in the context of end-of-life care communication.

Keywords: Social Prescribing, End of Life Care, Healthy Ageing, Digital Framework, Social Connectedness, Health Equity

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Death, my soulmate!

Death, my soulmate
Me and she, inseparable
Together, with life
We two, together!

We are the best of buddies
Matching each other, step for step
Through the groove each day
We walk the same path, together!

The confluence of life and death
A wondrous union
This beautiful gift of nature
A priceless treasure of life!

Teaches us to grapple with life
Guides us smoothly over the vicissitudes
Is the secret of life
As life merges into death!

—Sitalakshmi Rajagopalan

Translated from Hindi to English by Rahul Rajagopalan

This poem was written 4 years ago by my 80 year old mother-in -law when she was briefly ill. She wrote this in the hospital while undergoing her treatment. Writing this brought her comfort and a positive feeling as she tackled her health issues and recovered completely.

part

1

INTRODUCTION

Personal Background

It all started many years ago....

My brush with social design happened over 15 years ago when I completed my 1st Masters in Graphic Design from UCLAN, Preston, UK. My final project was a personal yet compelling one—exploring storytelling as a therapy for Alzheimer Caregivers. My grandmother had Alzheimer's and was taken care of by my grandfather first and later by my parents. My father was their only child, and culturally felt responsible to take care of his parents. Despite my grandfather not comfortable with the idea of moving from Delhi in the North to Coimbatore down south of India, he was left with no choice as it was getting very hard on him to be the sole caregiver for his wife. As the illness progressed he found it extremely challenging to manage chores in the house and take care of him and his wife. Like a typical Indian husband, he was not used to working in the kitchen. He did not know how to cook. At 70 he was himself unprepared to take on this role as a caregiver. In retrospect, I would question that did he even know what it entailed? How the illness would progress? Did my grandmother know what Alzheimer's was? How it would change her life as well as my grandfather's?

My father was a retired Army doctor, while he knew about Dementia and Alzheimer's and how the illness would take course this was not just a medical thing. It involved his mother. He was their only son and he dearly loved her. It was extremely painful for him to see his mother's identity slip away slowly. Anticipatory grief brought many feelings and emotions such as a sense of loss, guilt, helplessness, pain and even heartbreak. It was difficult to predict how long this would last. My grandmother was a yoga teacher and kept good physical health. But as the illness progressed things changed over the 10 years.

Having studied in an Army college and then serving the Army for over 35 years, my dad had left his home at 18. Now that his mother was seriously ill and he himself was retired he felt as his duty to look after her and be there for her. When the move finally happened and my grandparents started living with my parents in the south many things changed. The family was revolved around my grandmother, scheduling tasks around her care schedule. My mother became the primary caregiver, alongwith my father and my grandfather. My grandmother would often speak in Hindi instead of Tamil confusing the physical and geographical location of the place. We are culturally Tamilians (from South of India) but my grandparents migrated to Delhi (North of India) several years ago. So having lived in the North for so long my grandmother couldn't remember or connect that she now lived in the South of India with her son. Every time my father returned from somewhere outside she would think he has come back home on holidays and welcome him just like he did during his service days. After some time, we let her believe that and didn't correct the fact that she indeed was living with him.

Having seen their experience first-hand I wanted to capture their story, emotions, lifestyle into a graphical format. The final outcome was a book: rectangular in shape yet conveying the circularity of the disease *(oldest memories are the last to fade, my grandmother too went back to her childhood right before she passed away).* It can be read in 4 different ways: from either end or from the middle one can explore either side. I also used my grandmother's well-worn cotton saree as the cover and back cover of the book. Tactile in nature the book was more than a storehouse of memories. It was quite experiential and was permanently exhibited at the Alzheimer's Society, Preston as well as across all libraries in Lancashire County. That is when I realized how a personal story made connections with people across different cultures. The notes people left in the visitors' book were evident enough that it made an impact in their lives and that in turn made a big impact on me.

And now...

I was inspired to pursue this research after recently witnessing the helplessness of two close friends. One was grieving the loss of her husband after a prolonged illness, yet unable to express her sorrow within her family. The other is currently coping with stress and anxiety as her mother undergoes cancer treatment, while struggling to communicate her anticipatory grief with her only older brother. In both situations, they faced difficulty in speaking about their grief and in finding support systems outside of their families to help them manage the emotional struggles. Although I could see the pain they were experiencing, I felt unsure of what to say or do that might bring them even a small measure of peace.

My personal interest and professional experience as a healer through energy and body work brought me to the concept of Social Prescribing. It was fascinating for me to see that there was a formal "prescription" of care that was holistic, non-medical and so person-centred. Social Prescribing is a holistic approach to healthcare that brings together the social and medical models of health and wellness. It provides a formal pathway for health providers to address the diverse determinants of health, using the familiar and trusted process of writing a prescription. (Alliance for Healthier Communities, n.d.). I then wondered what it meant if we could use Social Prescribing during end-of-life.

Student Service Design Challenge

I also was a finalist in a Global Student Service Design Challenge (organized by Service Design College) with 4 other team members. Through the months of Jan-June 2024 while we worked on the challenge, we were able to translate our class theories on systems thinking and foresight into practice. Our challenge was "How to turn the tide of the fragmented healthcare system" in Ontario. We utilized different system mapping tools (Iterative Inquiry, Actors Map, Causes Diagram etc) to undertake the primary healthcare journey through the eyes of the patient. This helped us map out the stakeholders in the system and what their relationship is with each other. It also helped us identify the bottlenecks and barriers faced by the patient. Overall, it helped us develop a deeper, and more holistic understanding of Ontario's complex healthcare system to identify tipping points at which interventions can be applied. These interventions were drawn from Donella Meadows theories on leverage points. We then conducted over 19 interviews with patients, healthcare professionals, and experts and identified pain points mapped to each moment of the patient's care journey. The insights from the interviews helped identify themes emerging from current patient experience. Our final solution was a digital platform with integrated care that was patient centric that also helped in easing pressure for the healthcare providers. We ended with a foresight report for 2044 showcasing 4 future scenarios.

Experience at the Health Design Studio

While I learnt to apply these tools to a real-world problem, I also joined the Health Design Studio at OCAD as a research assistant helping with projects related to end-of-life, death and dying. Through work at the Health Design Studio I assisted with the installation and exhibition at Evergreen BrickWorks for their Annual Good Mourning Festival 2024. I was also part of the curatorial team selecting art pieces on the topic of grief, death and dying for the Dying Series an exhibition which is part of the annual Design TO festival (Jan 24th-Feb 02 2025).

Shaping the Research Project

This research project on *Improving Care Conversations in end-of-life between Healthcare Providers and Older Adults and their Caregivers while exploring the role of Social Prescribing* has emerged from these varied experiences. I have been very interested to see how non-medical interventions can help in holistic health and well-being of which I am a strong believer.

To this end, an internship with **Canadian Institute of Social Prescribing** (July-Sep 2024) was extremely valuable. I assisted in desk research and design for creating a Training Roadmap for Social Prescribing (SP) in Canada. This gave me a deep insight into the current practices of SP in Canada as well as possible opportunity areas for my own research.

I also recently joined **The Patient Revolution** as a Fellow completing their foundation course. That taught me about kind and meaningful care and how to create mini-revolutions to steer away from industrial care and make healthcare more humane and people-centered as it should be.

My project incorporates a service design approach to investigate the issue from a human-centred perspective.

The research insights are drawn from a triangulation of data from primary research (participatory art exhibitions, interviews); secondary research (literature review from articles, podcasts, youtube videos, social media); as well as lived experience (personal stories, experience of the medical system in Canada, internship with the Canadian Institute of Social Prescribing). It will also contribute to real world solutions by addressing the gaps in equitable access to care specifically in end-of-life care integrating social prescribing with the individual's health plans

AGEING IN CANADA

"The two big unfixables are aging and dying. You can't fix those" **(Gawande, 2014)**

Canada is ageing rapidly. The rapid growth expected among Canada's senior population in the coming years is one of the "most significant demographic trends" in the country's history, says demographer Doug Norris (Ferreira, CTV News, 2023). Canada is home to nearly 13,500 centenarians, a 43 per cent increase compared to 2018, according to the latest data from Statistics Canada

In Ontario specifically, by 2029, the portion of the population over the age of 65 is expected to jump by around 650,000 people representing a 23% increase. (Ageing in Canada, CTV News, 2024). Those over 75 in Ontario are also projected to jump by 27% which translares into another 350,000 seniors. (Ageing in Canada, CTV News, 2024). As the baby boomer population increases so does the pressure on the healthcare system and the complex needs of the older adults.

As people age, they are more likely to develop conditions that impinge upon their ability to live as they wish – frailty, chronic conditions or morbidities, and dementia become especially prevalent as of age 85. (Agewell Report, Drummond et al, 2020).

A significant number of seniors are waiting in hospitals for an alternate level of care (ALC) – care they can receive elsewhere – such as home care services, long-term care, or access to primary care. Across Ontario, more than 4,500 patients are waiting in hospitals for other types of care due to a lack of capacity across the health care system. (Ontario Hospital Association, Seniors Care, oha.com/news/ontarios-aging-population-preparing-for-the-future).

While the Ontario government promised around a billion dollars in new funding for the sector, Home Care Ontario states that only a fraction of this has reached the agencies providing services for the aging population. (Ferreira, CTV News, 2023).

According to the 2020 Ageing Well Report by Drummond, Sinclair and Bergen, the great majority of seniors want to age well and in place, in homes and communities they can call their own. However Only 6 percent of Canadians receive publicly funded home care services for which rationing has driven long and lengthening wait lists. (Ageing Well, Drummond et al, 2020).

The aging population and potential lack of sufficient home care are a concern because of the potential ripple effect on hospitals. With an aging population potentially needing emergency rooms more often without adequate home care, this puts further strain on a hospital system where care in an emergency setting is more expensive than preventative home care. Ontario has already experienced more than 200 instances of unplanned emergency room closures in the last couple of years. (Ferreira, CTV News, 2023)

Older adults deserve to live with dignity in the way they want to live and where they want to live.

Social Isolation and Loneliness in Older Adults in Canada

Canadian Coalition for Senior's Mental Health conducted a pan-Canadian survey in 2023 to gather insights on the attitudes, experiences, knowledge and ideas of people working directly with older adults, regarding the topic of social isolation and loneliness.

When asked about barriers impacting their ability to address social isolation and loneliness, the top three barriers identified by respondents were a lack community resources, insufficient system/organizational funding to put appropriate interventions into place, and a lack of organizational/administrative support.

In referring to the lack of community resources, respondents shared:

"There is not enough variety in the types of resources to meet people's unique needs. Not all resources are appropriate for all people so there are limitations as to what to offer folks."
--Occupational Therapist

"There is a lack of resources available in the community for low income/fixed income older adults experiencing social isolation/ loneliness, including free/low cost, accessible options."
- Other Social Service Professional

(Canadian Coalition for Seniors' Mental Health. 2023)

Drummond et all in the Agewell Report advocate for Healthy Ageing, that is supported by these inter-related components of life:

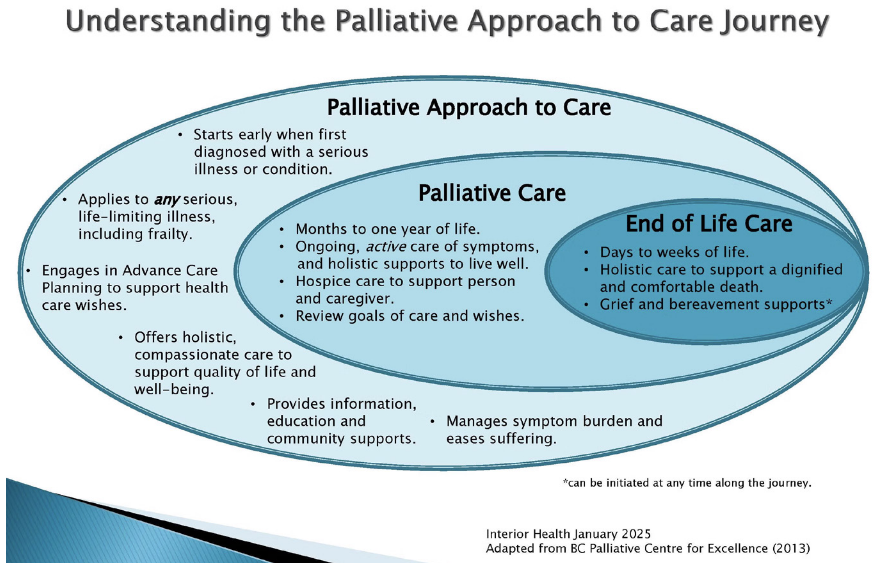
- Housing needs to ensure seniors have options that are flexible and adjustable as their other needs change with age;
- Lifestyle needs such as good nutrition, regular rest and recreation, and the maintenance of healthy habits;
- Social needs that reinforce confidence in the continuing support of family, friends, neighbours, and communities;
- Care needs to alleviate physical and mental limitations often brought on by progressive failure of ageing bodily systems and/or chronic disease.

They suggest that healthy aging "… will require a major policy change, a shift in the status quo, putting emphasis on the housing, lifestyle, and social needs of the elderly equal to that now given to meeting their care."

Canada describes healthy aging as "an ongoing process of optimizing opportunities to enhance and maintain physical, social and mental health as well as independence and quality of life over the life course" (Public Health Agency of Canada, 2010). (Canada.ca, Seniors Council)

PALLIATIVE CARE IN ONTARIO

"Palliative Care–a very important field but poorly understood–while it includes it is not limited to end of life care. It is not limited to hospice. It is simply about living well at any stage."
(Miller, 2015)


Understanding the Palliative Approach to Care Journey

Palliative Approach to Care
- Starts early when first diagnosed with a serious illness or condition.
- Applies to ***any*** serious, life-limiting illness, including frailty.
- Engages in Advance Care Planning to support health care wishes.
- Offers holistic, compassionate care to support quality of life and well-being.
- Provides information, education and community supports.
- Manages symptom burden and eases suffering.

Palliative Care
- Months to one year of life.
- Ongoing, *active* care of symptoms, and holistic supports to live well.
- Hospice care to support person and caregiver.
- Review goals of care and wishes.

End of Life Care
- Days to weeks of life.
- Holistic care to support a dignified and comfortable death.
- Grief and bereavement supports*

*can be initiated at any time along the journey.

Interior Health January 2025
Adapted from BC Palliative Centre for Excellence (2013)

Image source: *A Palliative Care Overview. Interior Health (https://www.interiorhealth.ca/health-and-wellness/palliative-and-end-of-life-care/palliative-care-overview)*

Palliative Care Landscape in Ontario

The palliative care landscape in Ontario is undergoing a major transformation in light of changing demographic trends, particularly the increasing proportion of older adults. By 2021, nearly one in four Ontario residents were aged 65 and older, a demographic shift that will further escalate the demand for palliative care services as the incidence of chronic illnesses and complex medical needs rises in this age group (Dorans et al., 2024).

In Ontario the number of individuals aged 65 and over is expected to almost double from 2.6 million in 2020 to 4.5 million by 2046 (Ontario Provincial Framework for Palliative Care, 2021)

As the demographic shift happens it also puts pressure and creates challenges in the healthcare system in Ontario. One of the key issues in palliative care accessibility is the unequal distribution of the services across the region. Particularly, individuals in rural regions face significant barriers to accessing these necessary services (Tan et al., 2023) Schuurman et al., 2020). The disparity is exacerbated by the limited number of specialists, as only about 2% of palliative care specialists are located in rural areas, necessitating the reliance on generalist practitioners who might not have specialized training (Webber et al., 2021).

Furthermore, the concept of community-driven palliative care services is gaining traction, particularly in First Nations communities where existing resources are insufficient (Seow et al., 2024).

Communication and Decision-making in Palliative Care

We will all have to deal with end-of-life-care decisions at some point in our lives. With the rising ageing population, this complex decision making will only increase in the future.

As per the 2021 poll conducted by Advanced Care Planning, Canada, even though 77% of Canadians think it's important to talk to their health care providers about their wishes, only 7% said they had done so. On top of it current crisis in the lack of family doctors available leaves hardly any choice for Ontarians (1 in 4 Ontarians will be without a family doctor by 2026 (Ontario College of Family Physicians, 2023).

Although the significance and benefits of end-of-life communication have been recognised, such conversations do not occur commonly during visits between and among terminally ill patients, their families and their healthcare providers (Chen et al, 2023). A lack of communication and open conversations leads to anxiety, stress, uncertainty and more questions, creating barriers between the patients, their caregivers and healthcare providers.

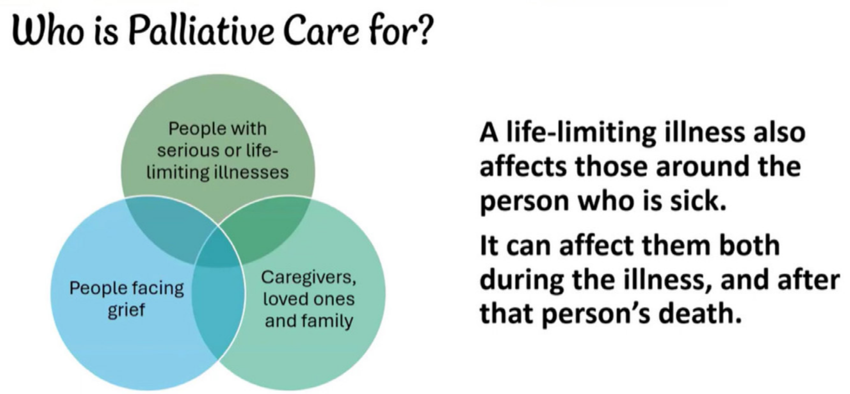
In Ontario, Palliative care is delivered in all care settings, including the following (Palliative and End-of-Life Care, Ontario.ca):
- individual homes
- residential and community-based hospices
- long-term care homes
- hospitals

The use of standardized assessment tools like the Edmonton Symptom Assessment System (ESAS) has been shown to facilitate communication among healthcare providers and patients regarding symptoms and palliative needs (Barbera et al., 2020; Tan et al., 2023). Additionally, research highlights that palliative care referrals are often delayed, with many patients referred only when they are nearing death, which limits the potential for meaningful discussions and planning (Gitau et al., 2023; Harasym et al., 2020). Data from recent studies suggest that only about half of individuals expected to die within three months received home care support, highlighting substantial unmet needs (Murmann et al., 2024).

Cultural and language factors also complicate communication dynamics at the end of life. There is evidence suggesting that language concordance between patients and healthcare providers can significantly affect the quality of care received (Seale et al., 2022; Lee et al., 2023). Within the culturally diverse community language barriers can pose significant challenges in decision making, and choices at end-of-life.

Furthermore, untrained healthcare providers can impede these critical serious illness conversations. Trust and relationship building are some of the key attributes in building a safe and open space for discussions. Training and education in palliative care for healthcare professionals are critical for improving their confidence in discussing end-of-life care topics with patients and families (Gill et al., 2024). Ongoing education and support significantly enhance the ability of clinicians to engage patients in these sensitive conversations, which is essential given the emotional and ethical complexities surrounding end-of-life decisions (Shamon et al., 2023).

Tools to support communication between care settings (such as primary care, hospitals, home care and long-term care homes), may reduce care fragmentation and reduce need for individuals and their loved ones to repeat their stories to each provider (Ontario Provincial Framework for Palliative Care, 2021).



Who is Palliative Care for?

A life-limiting illness also affects those around the person who is sick.

It can affect them both during the illness, and after that person's death.

Image source: *Screenshot from a YouTube webinar: The Palliative Effect: A Caregiving Conversation organised by the Canadian Hospice Palliative Care Association (https://www.youtube.com/watch?v=Jd4xpdlZCfw)*

SOCIAL PRESCRIBING

Moving from “What’s the matter with you?” to asking, “What matters to you?

Alliance for Healthier Communities describes Social Prescribing as a holistic approach to healthcare that brings together the social and medical models of health and wellness. It provides a formal pathway for health providers to address the diverse determinants of health, using the familiar and trusted process of writing a prescription.

We are all familiar with medical prescriptions where the physicians prescribe medicines or treatment based on the patient interaction with them. However Social Prescribing dives deeper by looking at the patient story as a whole.

> **Social prescribing is a model that enables health care providers and social service professionals to connect individuals with non-clinical supports and community resources that address individual and community needs based on the social determinants of health.**
>
> **- Canadian Institute of Social Prescribing**

Kate Mulligan, founder and director of the Canadian Institute of Social Prescribing talks in an interview on The Social CTV in detail about what Social Prescribing is and how important it is to have this social engagement. She talks about flipping the script of a typical clinical healthcare visit by changing the question “what is the matter with you” to “what matters to you?” and connecting individuals with non-medical, non-clinical supports that can improve their well-being. These supports include activities like spending time in nature, engaging in arts and culture, pet therapy, and connecting with other people. (Kate Mulligan in The Social CTV, 2025). Kate Mulligan states that 80% of our health and well-being is determined outside of the healthcare system in the community through factors like housing, food, income, connectedness, a sense of belonging, and a sense of purpose. Social prescribing focuses on these social determinants of health by providing a formalised way to build community connections and identifying resources and activities tailored around individual needs (The Social CTV, 2025).

Social Determinants of Health

Our health is governed not just by our lifestyle choices or ancestory or genes but also by our surroundings, nutrition, housing etc that all have an important role to play in our well-being. Social determinants of health refer to a specific group of social and economic factors within the broader determinants of health. (Government of Canada, canada.ca)

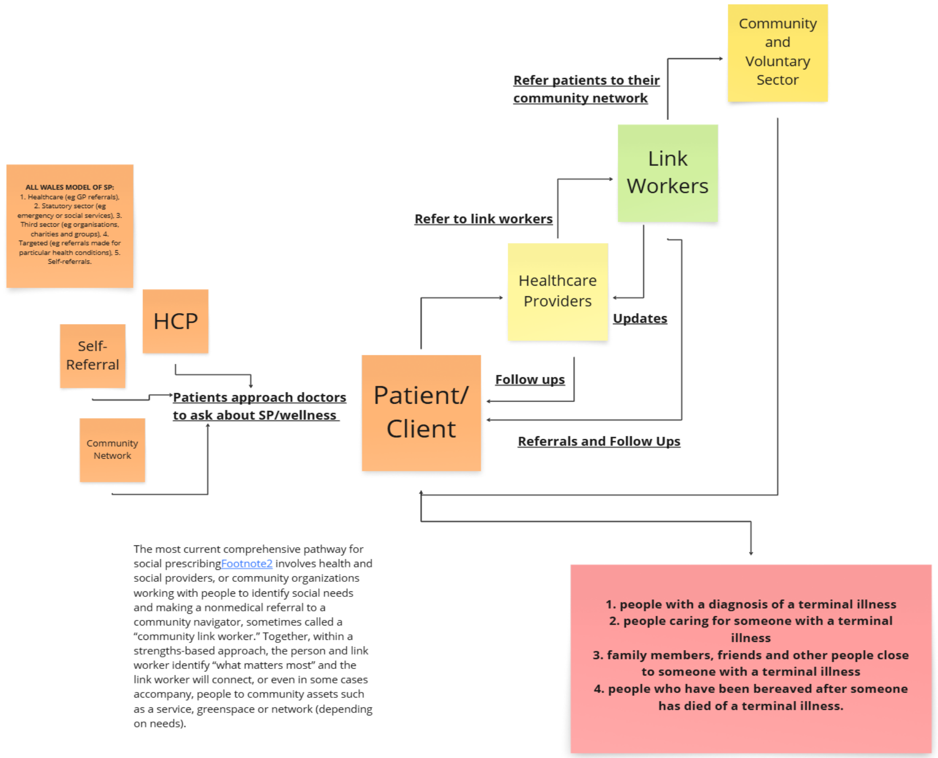
The Canadian Government in their website states: Determinants of health are the broad range of personal, social, economic and environmental factors that determine individual and population health. The main determinants of health include:

Income and social status
Employment and working conditions
Education and literacy
Childhood experiences
Physical environments
Social supports and coping skills
Healthy behaviours
Access to health services
Biology and genetic endowment
Gender
Culture
Race / Racism
(Government of Canada, canada.ca)

Health Equity

> *Health equity is a cornerstone of effective social prescribing. Simply referring a client to a recreational program or encouraging them to visit an art gallery is not enough. Successfully implementing a social prescribing program means removing the barriers clients experience to doing these things. These barriers may be economic, geographical, interpersonal, or psychological. Social prescribing is about listening deeply, providing necessary supports, and empowering people to be co-creators in improving their own health and wellbeing.* (Alliance for Healthier Communities, allianceon.org)

Social Prescribing Practices



ALL WALES MODEL OF SP:
1. Healthcare (eg GP referrals), 2. Statutory sector (eg emergency or social services), 3. Third sector (eg organisations, charities and groups), 4. Targeted (eg referrals made for particular health conditions), 5. Self-referrals.

The most current comprehensive pathway for social prescribingFootnote2 involves health and social providers, or community organizations working with people to identify social needs and making a nonmedical referral to a community navigator, sometimes called a “community link worker.” Together, within a strengths-based approach, the person and link worker identify “what matters most” and the link worker will connect, or even in some cases accompany, people to community assets such as a service, greenspace or network (depending on needs).

1. people with a diagnosis of a terminal illness
2. people caring for someone with a terminal illness
3. family members, friends and other people close to someone with a terminal illness
4. people who have been bereaved after someone has died of a terminal illness.

Illustration 1: *The Social Prescribing stakeholder interaction and touchpoints. This was created during the CISP internship (July-Sep 2024)*

Social Prescribing practices involve healthcare providers referring their patients/clients to Community Connectors or Link Workers. These individuals have a 1x1 conversation understanding patient’s needs and preferences and then connect them with relevant community-based supports. This is particularly important and useful where patients may be having non-specific symptoms, like loneliness, that are difficult to tackle in a clinical setting. By addressing these underlying social factors, social prescribing aims to improve

Cost wise Kate says "if we put one community connector or link worker into every community across Canada it would still cost us far less than 1% of the overall Canadian Healthcare spending... for every dollar that you invest in Social Prescribing you get a return on investment of more than $4 in healthcare cost savings."

overall health, reduce the need for frequent healthcare visits, and enhance individuals' sense of connection and purpose within their communities. Pilot projects have shown promising results, including a 40% decrease in self-reported loneliness and reports from healthcare providers of patients visiting them less often. Therefore, social prescribing broadens the scope of healthcare to encompass the social, emotional, and community-based aspects of well-being, moving beyond a purely clinical model. (The Social CTV, 2025)

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Social Prescribing Around the World

As of 2024, social prescribing initiatives span at least 31 countries across Europe, Asia, North America, and Australia .... England was the first to integrate it into national health policy in 2019. Other countries are rapidly adopting and scaling these approaches. (Global Report, International Social Prescribing Collaborative (ISPC), 2024.)

Social Prescribing for palliative care and/or end-of-life is still not very prevalent although a few examples can be seen.

The Healthy End of Life Program (HELP) is an initiative of the Public Health Palliative Care Unit of La Trobe University, Australia. The HELP Palliative Care Social Prescribing Service Model was designed to help normalise the practice of asking for and receiving help from one's personal network at the end of life by making it both acceptable and easy to do so. (Healthy End of Life Program). HELP utilises an individual's personal connections to build a social support network that's able to consistently and reliably help out with everyday tasks – taking care of the little things day-to-day that can make a big difference to emotional well–being and overall quality of life during this vulnerable period in a person's life. (Healthy End of Life Program). They also offer "conversation starters" to help start conversations between healthcare providers and patients and caregivers.

Marie Curie Response: Marie Curie Support and Care for People with Terminal Illness offers Social Prescribing services in Scotland. These range from sports and physical activities to lesiure activities like music, painting etc. They say "Social relations and maintaining community networks can be a fundamental part of enriching the life of someone living with a terminal illness and approaching the end of life. Health and wellbeing is determined and defined by a range of factors, not just the medical care they receive." (Marie Curie Response). As people are navigating complex emotions while dealing with terminal illness, it can make people feel socially isolated and lonely. When you're dying, you should still be able to live, and live the life you want. People sometimes need support to do that and this is where social prescribing can help. (Marie Curie Response).

In Canada Social Prescribing for end-of-life is still not explored much although social prescribing for older adults is an area of focus promoting Healthy Ageing. A study published by the Public Health Agency of Canada, indicated that older adults desire SP programs that respect their ability to maintain their autonomy and independence, aid and facilitate the development of connectedness and belonging, are built on a foundation of trust and relationship-building in interactions with providers and link workers, and prioritize the person and thus personalize SP to the unique needs of each individual. (Yu. C et al, 2023)

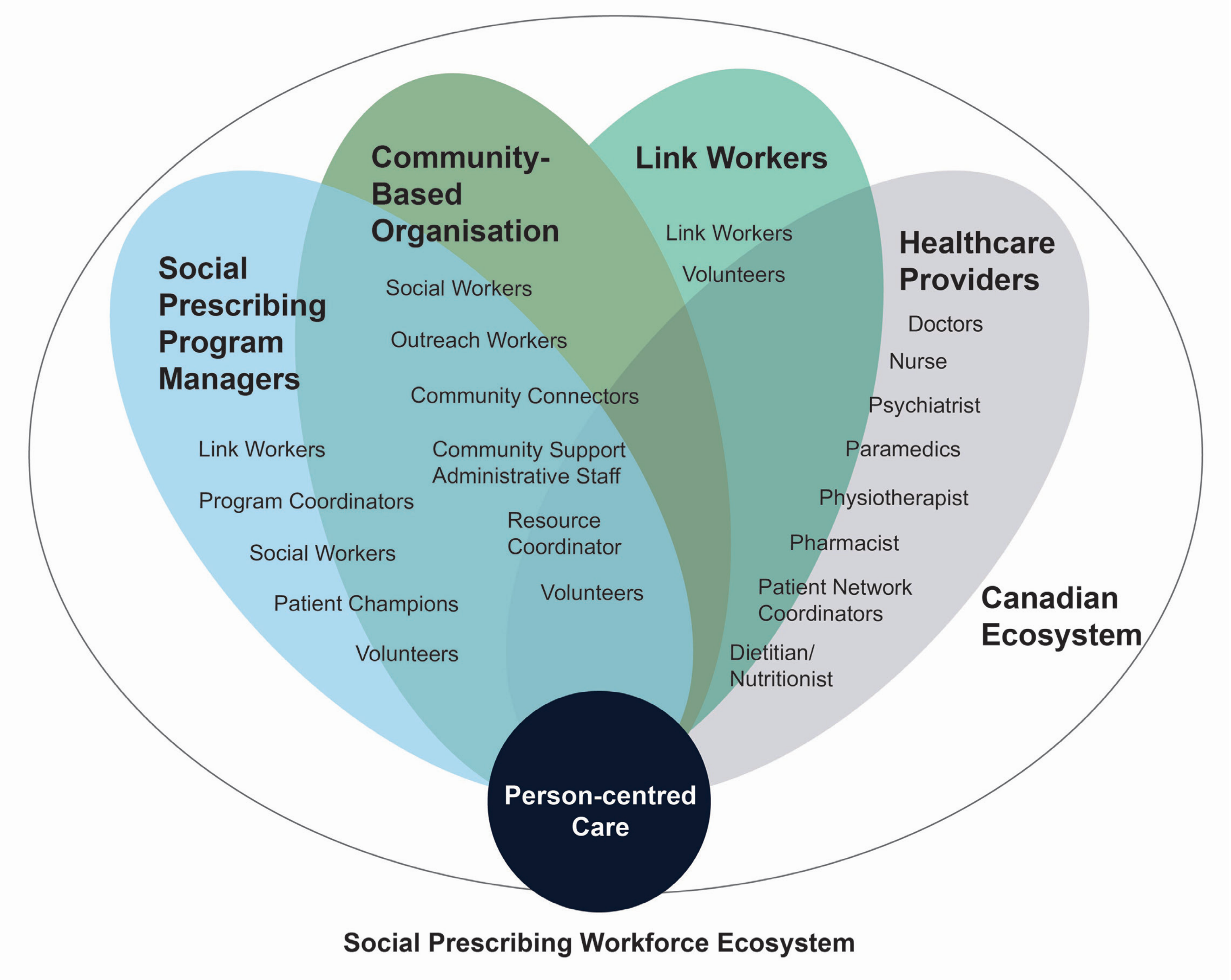

Illustration 2: *The Social Prescribing Workforce Ecosystem. Illustration created as part of my CISP internship July-Sep 2024. This was a visual representation of how the workforce is interconnected.*

Social Prescribing Workforce

Social prescribing (SP) involves a diverse, interconnected and collaborating workforce, comprising healthcare providers, community-based organizations, link workers and social prescribing program managers, each playing a crucial role in providing person-centred care that appropriately and proactively connects individuals to resources that support their social wellbeing. Each role uniquely supports the integration of health and social care through collaboration and community development. (Canadian Institute of Social Prescribing, Training Roadmap, socialprescribing.ca/social-prescribing-training-roadmap)

As a formal referral pathway, social prescribing bridges the gap between health/clinical care and social services. It emphasizes person-centred care, co-creation, and equity empowering individuals to take charge of their health and well-being. (Strengthening Care: A Toolkit for Caregiver-Focused Social Prescribing CISP, 2025) part

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SETTING THE CONTEXT

Looking into ways to improve care conversations between healthcare providers with older adults and their caregivers while exploring the role of Social Prescribing, I find there is a communication gap, a lack of training for healthcare providers in the industrial healthcare system that proves to be a barrier in offering kind and meaningful care. I will look into examining the gap in end-of-life care communication. The project aims to build a resource toolkit for better care communication benefitting not only the healthcare providers but also older adults deserving dignity, empathy and care right upto the end of their lives.

As a design researcher studying systems design, foresight and inclusive design, as well as working on health design projects at university, I was inspired to take some action to address this gap. Having grown up in a large family with lots of elder family members who were well looked after at home, I strongly feel every individual deserves a right to good and personalised care. The concept of Social Prescribing appealed to me as it puts patient/client at the centre of care and works on the concept of what matters most to you rather that what is the matter with you. Just by changing this perspective of offering care, ensures patient needs are addressed

For most people scariest thing about death is not being dead, it is dying or suffering (Miller, 2015). We don't know how we will die or when we will die, the only thing with certainty we can say is that one day we will. We know, from research what's most important to people who are closer to death: comfort, feeling unburdened and unburdening to those they love; existential peace, and a sense of wonderment and spirituality (Miller, 2015).

Social Prescribing support services can help people stay connected to their communities, and stay connected with support system that they need especially at their most vulnerable moments. Looking at death from a holistic angle embracing all the emotions it brings can make it a little less scary.

RESEARCH QUESTION

How might we support healthcare providers to improve care conversations with older adults in end-of-life while exploring the potential role of Social Prescribing?

Secondary Research Questions:

- What are the current challenges faced by healthcare providers while communicating with older adults in end-of-life in palliative care?
- What are the perspectives of caregivers in receiving end-of-life communication from healthcare providers?
- How might we track the benefits of using Social Prescribing with the existing health plans of older adults in end-of-life?
- How might we support caregivers and older adults to enhance agency, empowerment, and dignity in end-of-life care?
- How might we normalise care conversations around end-of-life?

RESEARCH OBJECTIVE

The primary objective of this project is to develop a social prescribing resource toolkit that fosters improved communication in care settings at end-of-life. The toolkit aims to support providers, caregivers, family members, and older adults to receive care characterized by dignity, empathy, and respect throughout the end-of-life process.

SERVICE DESIGN METHODOLOGY

A service design methodology (Stickdorn et al., 2018) was used to better understand older adults and their social prescribing needs. Qualitative data was gathered through interviews, analyzed using thematic analysis (Braun and Clarke, 2006) to identify recurring patterns and overarching themes in relation to social prescribing. In addition, Narrative Analysis (Reissman, 1993) will be applied to human stories sourced from a diverse literature review, including texts, podcasts such as "Thoughts in Passing – Portraits and Stories at the End of Life with Claudia Biçen" (Hullet, 2024), and online interviews. Two participatory art installations were exhibited in public spaces to gather data. The results from these three research techniques have informed the development of archetypes (Hanington and Martin, 2012), which serve as the basis for prototyping a toolkit for social prescribing at end of life.

A service design methodology using the Double Diamond framework with 4 stages: Discover, Define, Develop and Deliver was used for this research project. This approach seems the best fit as [Service design] uses a holistic and highly collaborative approach to generate value for both the service user and the service provider throughout the service's lifecycle (Service Design Network, 2019). Since the philosophy of Social Prescribing is "What Matters to You" it feels apt to keep this service approach with patient at the centre of the solution while understanding the system around which they navigate care.

Discover Phase:

Desk research: This was an important aspect of research to understand current practices as well as what has already been done. It also informed me about the gaps in the study.

Literature review: The literature review included several journal articles, books, interview podcasts by several subject matter experts, social media insights from YouTube and Instagram. This allowed me to get a better understanding of the palliative care landscape in Canada as well as the emotional impact of grief, death and dying. The insights from the desk research and literature review helped me identify subject matter experts for the interviews.

Participatory Art Installation: As part of initial data gathering I had also set up 2 participatory art installations—first one at Evergreen Brickworks, Toronto as part of their Good Mourning festival and second one at Brampton Civic Hospital, Brampton during the inauguration of the William Osler Innovation Lab. This research invited members of the public to reflect on choices related to end-of-life through the means of a prompt as part of the installation. Engaging the public in this open dialogue gave a space to talk about a topic that is often considered a taboo: death:

Activity: Activity A: Participatory Public Exhibit: Members of the public had the opportunity to engage in participatory materials at a panel (board mounted on a stand) covering topics of "what matters most to you in end-of-life" with cross-cutting themes of decline, death, and grieving. In addition to open ended and public interaction with the materials of the exhibit, I was also available at Evergreen Brickworks during event managing materials and answering any questions.

Activity B: Exit Survey (unfacilitated) on postcard The survey consisted of a short questionnaire and took approximately 5 minutes to complete. It asked about experience with end-of-life either in a professional capacity or in a personal capacity. No personal identifiers or details were captured. Filling out the survey was voluntary.

Materials: Blank tags, pens, colors, drawing pins were provided near the board. The board itself was mounted on a stand.

Data was collected and thematically analysed from the short comments on the tags and feedback from survey with short questionnaire. Tags from both the events were collected, sorted and then analysed.

As the research involved human participants on a sensitive topic, a Research Ethics Board approval was sought both for the interviews and the installation and approved by OCAD University's Ethics Committee for Research Involving Human Subjects prior to entering any field work.

Subject Matter Expert Interviews: After the literature review, I conducted semi-structured expert interviews with 4 experts. The experts were people working closely with caregivers, grief counselor and social prescribing managers. The interviews were conducted online via Microsoft Teams. The interview process helped me get a deeper understanding of how death and dying impacts people, what does loss and bereavement mean, how people cope with grief, what are the different kinds of grief as well as the current support available to people. It helped me develop the research scope and also contextualise how the different stakeholders access care whether they are caregivers or carereceivers.

Participant Recruitment: I recruited the participants through my personal network as well as professional network from the Health Design Studio as well as the Canadian Institute of Social Prescribing. Participants that expressed an interest to be part of the research were sent a formal invitation from the university email id. An informed consent form was also sent before the interview so that the participants could read in advance and sign them. Before the interviews I also talked about the benefits and risks associated with the participation and also informed that it was not compulsory to answer all the questions. They were also informed they could withdraw at any point during the interview. There were 5 healthcare providers (2 palliative care physicians and 3 clinical nurse specialists all from Ontario); and 2 caregivers recruited for the interviews.

The criteria for recruiting the healthcare providers was they were working in the palliative care set up in Ontario and experienced with older adults. The criteria for caregivers was their experience in caring for older adults. Both caregivers were taking care of their parent. While one caregiver had already lost their parent, the other was still taking care of her parent. Both are based in Ontario.

Define Phase: Data from the previous step was analysed to understand the relationships, complexities, needs and challenges and emerging themes and trends.

Affinity Diagram and Insight Generation: An affinity diagram is a collection of large amounts of data that is organized into groups or themes based on their relationships (interaction-design.org). To analyse and synthesise the data I marked the data points from the interviews on the word file and then added them to sticky notes. The emerging themes were color coded. Each of the sticky notes was then clustered to the themes using affinity diagramming to gather insights.

I had several themes and sub-themes that validated many of the problems that emerged through the research findings. The next step was to create Insight Statements, succinct sentences that will point the way forward (IDEO.org, 2015). Insight statements are incredibly valuable as they'll help frame How Might We questions (IDEO.org, 2015).

Problem Framing: The next step was to reframe those insights as generative questions (IDEO.org, 2015). How Might We questions are innovative approaches to finding solutions. How Might We format suggests that a solution is possible and because they offer the chance to answer them in a variety of ways (IDEO.org, 2015). I reframed the question using the "How Might We" statements to suggest possible solutions and future recommendations.

Develop Phase: The next step was to design cultural probes. Cultural probes as an approach to qualitative user research where face-to-face research is impractical or inappropriate (Interaction Design Foundation - IxDF, 2022). I had planned to create and send out cultural probe for caregivers asking open-ended questions to get a better insight from their lived experiences of caring for older adults in end-of-life.

Co-design has been increasingly adopted in healthcare settings to involve patients and professionals in service improvement (Boyd et al., 2012). I had planned a co-design session with stakeholders such as healthcare providers, caregivers, link workers, social prescribing managers etc to co-create and brainstorm ideas for a social prescribing resource toolkit.

However due to my own health issues through the year and a double surgery followed by recovery time I was not able to conduct the cultural probe for caregivers nor a co-design workshop session with different stakeholders. I however drafted a design for both tools and was able to get a service design team based out of Barcelona to review the same as well and give their valuable feedback to develop it into an actionable item for the future.

Participants and Limitations:

Participants:

Due to sensitivity of the topic I was not able to interview older adults in end-of-life directly. I relied on the lived experiences of caregivers and insights shared by the healthcare providers working with older adults in end of life. A total of 11 interviews were conducted:

10 online via Teams

1 via phone

The participant breakdown was as follows:

5 healthcare providers: 2 palliative care physicians and 3 clinical nurse specialists all from Ontario

2 caregivers

4 subject matter experts

Limitations:

Due to time limitation there was not much diversity in the interviews of caregivers. For future development of the research a more diverse range of caregiver interviews such as from different cultures, different socio-economic status, gender etc should be considered.

Due to my own health issues and surgeries I got a setback of not being able to actively conduct the research during November and December and later in February and March. I was therefore unable to conduct the co-design workshop to test out any ideas.

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FINDINGS, INSIGHTS AND OBSERVATIONS

Building on the secondary research interviews were conducted with healthcare providers that included palliative care physcians and nurses, to get a better understanding of palliative care services available to older adults in end-of-life as well as challenges faced by older adults and their families and caregivers when receiving difficult communication.

Caregivers were also interviewed to get their lived experience in navigating the healthcare system in Ontario, and any communication barriers they might have faced during the care journey.

Participant interviews:

Healthcare providers: 5

Caregivers: 2

Experts: 4 including grief counselor, social prescribing managers, caregiver navigation manager and an additional informal interview with service designers who have worked in the field of end-of-life care

Thematic analysis (Braun and Clarke, 2006) was used to identify patterns and generate insights that reflect the fragmented healthcare navigation, the emotional, social, psychological impact that death and dying has on families and lack of access to support systems that are available to make this journey less difficult than it already is. A final set of 10 themes which are grouped under 5 broad themes are presented below.

THEME 1:
TOO LITTLE, TOO LATE

Older adults in end of life and their caregivers and family members need access and information to palliative care early on in the care journey to ensure full support and informed decision-making right uptil the end.

There is a misconception about the term palliative care. There is a lack of direction and guidance from the GPs to the patients and their family/caregivers; a lack of awareness about support systems that are available; a lot of fear and anxiety in talking about death and dying and availing the palliative care services as it is often misconstrued as something that is offered at the end-of-life. General fear about talking about death due to cultural reasons (*I will invite death if I talk about it*) and a lack of space to have these conversations creates further barriers in having early conversations about choices at end of life. The palliative care doctors and nurses through the interviews talked about the fear and misconception people have when approaching them. They also talked about how the palliative care services are often introduced very late in the care journey of the person. The caregivers expressed a lack of knowledge about any support services available and when one respondent expressed a desire for palliative care for her mother, her GP didn't think she qualified for the same.

1.1 Delayed and Insufficient Engagement with Palliative Care

> *"So palliative care is often left until the person is more actively dying and they're in their last couple of weeks of dying." (Expert 2)*

> *"So I think you know a lot of people think of it as very much end of life care, but not necessarily. You know, I think often they say that the best time to introduce palliative care is really from the very beginning when you're meeting someone for the first time. And I think, you know, patients sometimes have a hard time with that word. I think that they often wait till it's too late, probably because they're scared to have those conversations or they don't know how to explain what it really is to patients or they get that pushback from patients saying, Oh my gosh, I'm not palliative. Like how dare you sort of say that I'm not giving up?" (HCP2)*

All the participant interviews revealed that there was not enough engagement with palliative care. The patients were not referred in time from the healthcare providers to palliative care as they didn't think it was time yet. A lack of information on the additional support available puts more pressure on the caregivers causing stress, anxiety and confusion.

1.2 Value of Early and Meaningful Conversations

> *"So I think doing more advanced care planning is important so that people aren't so overwhelmed when they actually do come to their end of life to have (these conversations)." (HCP4)*

> *"At least even just with a little bit of advanced care planning. It's sort of like the seeds are planted around different pieces that come up at end of life, like people, a lot of people don't realize, like hospices are, you know, covered by the government. You don't have to pay to go to a public care unit or a Hospice, you know. So just different practical pieces that people might help relay some relief. Some people's like stress and anxiety around, you know, what kind of care that is available to them at the end of life if we prepare people a bit earlier." (HCP4)*

Participants emphasized the need for advance care planning and having early conversations about end of life to make the process less stressful and be better prepared. With practical knowledge about what resources and funding are currently available, the patients and their caregivers will face less stress and anxiety.

> *"Palliative care, in my mind is a supportive type of care that just helps patients to palliate symptoms." (HCP2).*

However Palliative care is frequently viewed as solely end-of-life care and is often initiated late in the illness trajectory, missing opportunities for earlier holistic support. This misconception prevents patients and families from benefiting from symptom management and quality-of-life improvements earlier in their journey.

A lack of marketing attributes to this misconception as one of the participants says:

> *"We have a huge marketing problem. I think when patients and families think about palliative care, they think about end of life care, death and dying when in fact that's really not at all what we do. We really focus on optimizing quality of life at any stage of illness. (HCP 3)"*

The GPs are themselves not equipped to handle the conversations and often pass it on to other team to handle the conversations:

> *"I think just even making the health care providers more comfortable was talking about end of life care. They're not sure how to have that conversation or, you know, they feel like it's opening up a Pandora's box or whatever, and they don't know how to respond to, you know, what's going to come out on the other end." (HCP4)*

> *"So I think a lot of medical personnel are unequipped. Often times they'll tell you in the hospital format, social work gets called in for these conversations." (Expert 2)*

The stress and anxiety in the patients and family/caregivers increase more so when they have to deal with new people they haven't talked to ever.

> *"Patients who have been dealing with nurses and doctors who have a multi-relationship with those professionals to all of a sudden be handed off to some virtual stranger to have some of the hardest conversations they're going to have." (Expert 2)*

There is a lack of advance information or preparedness from the medical side to guide on support that is available:

> *"So I feel like, yeah, they should have maybe had a worker that could have come in and assessed right away our needs and guided us through what was going to happen and kind of like a spokesman for us, you know, that because everywhere we went we felt like we were fighting and we didn't even really know what we were fighting for because we didn't know*

> *what, we didn't know anything, you know. (Caregiver 1)*

Family members sometimes advocate for themselves but are not always successful.

> *"I wanted to get palliative care involved as well, like given my background. I thought it would be nice to have my mom on their radar. Doctor so and so doesn't feel your mother is appropriate for palliative care. Because she doesn't have cancer. So this is a real education deficit on the part of the GP. People who don't have a cancer diagnosis kind of don't get the same level of attention. That people with cancer do. And I think this is just a general misunderstanding of chronic illness, you know." (Caregiver 2)*

There is also a feeling amongst people that when you refer to palliative care you give up hope or stop fighting:

> *"Often I think leaves families feeling like, you know, this is often something I hear too. Like we've given up or we you know. We're defeated, 'cause. There's so much warrior and fighting, messaging and medical with health. This is right versus if we could bring these conversations up earlier." (Expert 2)*

> *"Often times I hear well, the doctor is insane, you know, or the nurses aren't saying that they're dying. So why would I say that they're dying?" (Expert 2)*

Or when the treatments are no longer working:

> *"Sometimes we do get consulted for people who We have to do a lot of explaining and our people or their families are very afraid to see palliative care providers because they think that saying that they can't have any other disease modifying treatments or they can't, you know that we're expecting them to die within days or weeks." (HCP5)*

Older adults in end of life and their caregivers and family members need access and information to palliative care early on in the care journey to ensure full support and informed decision-making right uptil the end.

Initiating conversations about serious illness, prognosis, and end-of-life wishes earlier is crucial for informed decision-making and reducing distress. Advanced care planning plays a significant role in facilitating these conversations.

General stigma and fear around death and dying prevent people from having early conversations. The respondents expressed that often people are scared to hurt the feelings or upset their family.

> *"Family members being afraid to to say, like, what do you want in death? I often hear well, I'm afraid to bring it up because I don't want to upset them or I don't hurt them or I don't want to scare them. And so as a result. Well, those conversations often get laughed until the person's actively dying in front of us."*

> *"I just think that these conversations need time and I'm not sure they get the time they deserve." (Expert 2)*

There was also the notion that if we don't talk about death then we don't make it real:

> *"There's a there is a denial piece. more like if we don't say it aloud and we don't make it real, then we can have more time. (Expert 2)"*

Advanced care planning was suggested and emphasised by the respondents. The benefits of having early conversations meant feeling less overwhelmed and possibly being aware of practicalities to navigate the healthcare system when the time comes.

There is this big myth that hospice is a death sentence. When a person chooses to start hospice services or they're choosing end-of-life care this is not a death sentence. Instead they are choosing to accept. They are choosing to accept that we live finite lives, that we are mortal beings, that we don't have this infinite lifespan. They are choosing to accept that their body is where it is at this given time. But more important when someone is choosing hospice care, when they are choosing to start hospice or end-of-life care services they are choosing dignity. They are choosing comfort. They are choosing quality of life. They are choosing to take control of the end of their life and live as well as they can for as long as they can and they are saying yes to what is serving them and they're saying no to what isno longer helping them, benefitting them or serving them in this time. There is no reason to place judgement on a person for choosing hospice care services. It is not giving up, it is not choosing a death sentence. It is choosing quality of life and a dignified death.

- Katie Duncan, Nursing Practitioner, and an end-of-life Coach, Death Care Coach, Instagram, 2025

> *"So I think doing. More advanced care planning is important so that people aren't so overwhelmed when they actually do come to their end of life to have." (HCP4)*

> *"I love advanced care planning that may not come as surprise. In that it allows us to start the conversation outside of crisis in a meaningful way where we have the ability to be thoughtful around the choices" (Expert 2)*

A respondent from their lived experience also shared the importance of knowing the choices early on to make the right decisions as early as possible.

> *"One of the things that I would. Probably advise people to do that. We didn't do soon enough. Like we waited until she declined and then we started looking at long term care. We probably should have done it 10 years ago, but I mean, that's just kind of a human phenomenon, right, like we Don't always kind of think ahead because the long term care situation right now is not good. And even if we have her on two waiting lists, but the only people getting into long term care right now are people who are considered in a that they're in a crisis situation. And what crisis looks like is bed bound and not able to feed themselves. And she's not considered crisis. I could be wrong, but the likelihood of her getting an offer a bad offer is very, very low. No, it's not gonna happen. (Caregiver 2)"*

This theme showed the general misconception about palliative care, lack of access to information both from the medical side as well as the patient and caregiver side. Stigma and fear around palliative care hinders people from having any kind of conversation. Sammy Winemakersays founder of the Waiting Room Revolution says the "P" word is loaded and often when she is going to have a conversation with the families she doesn't introduce herself as a palliative care physcian because often the conversation then just stops there. (from the podcast Caregiver's Compass: Episode: Debunking the common misconceptions around palliative care and advocating for awareness about Palliative Care, 2024).

This misconception and lack of awareness is also apparent in the family physicians due to a lack of training and general discomfort about talking about palliative care as one of the options alongside treatment.

Dr Matthew Tyler, Palliative Care Physician and founder of "How to Train Your Doctor" constantly talks about knowing the difference between hospice and pallaiative care, he advocates for the patients and their families to be armed with this information themselves. He says "It's important YOU know the difference because you can get palliative care support as son as you are diagnosed--and many doctors still don't know this!" (Tyler, How to Train Your Doctor, Instagram, https://www.instagram.com/howtotrainyourdoctor/reel/DHoo05dM643/)

The theme also highlighted the value of having early conversations to know what the choices are, to take better decisions in end of life and reduce the overwhelm and anxiety.Although doctors, nurses, and allied health professionals know more about illness and mortality than most people, many are uncomfortable talking about the possibility of decline (Winemaker and Seow, 2023). Not having early conversations can have repurcussions later. Consequently, patients and their families make many important decisions about treatments, work and family life with only partial information. (Winemaker and Seow, *Hope for the Best, Plan for the Rest*, 2023). This causes further mistrust in the system, in the doctors and leads to disappointment and frustration and regret.

There is a need to build awareness around Palliative Care, give it a new branding if you will. This training is needed for the healthcare providers across the system maybe even starting from medical school so that when they interact with patients and their caregivers they are armed with the right information. It is important to steer away from the fear and stigma and create a safe space to have conversations that support in the journey of care.

"I think people think palliative care is about dying and death, and by accepting it, you're giving up hope," (Seow, 2025)

THEME 2:
LOST IN THE WOODS

Older adults and their caregivers need a healthcare system that has clear directions for them to navigate through the care journey and an effective communication system that is honest, transparent and empathetic.

2.1 Complex and Fragmented Healthcare Navigation

Navigating the healthcare system during serious illness and end of life is challenging due to its complexity, fragmentation, and lack of seamless communication between different parts of the system.

Respondents felt an absence of someone trustworthy they could connect with or talk to:

> *"I think it would have been nice to have someone central. It could have kind of stepped us through each situation. Yeah, yeah. So I mean, I know in the end, like, it was everything. All the communication seems to have been quite broken."(Caregiver 1)*

> *"I think there's still lots of gaps in in that communication." and "So it's the communication needed is quite a lot in terms of continuing to get that buy in and that trust with healthcare teams." (Expert 3)*

Not being able to have a proper conversation or discussion also disrupted the relation between the caregivers and the doctors thereby causing further barrier in communication. Respondent also felt a lack of empathy when dealing with the older adult:

> *"We didn't have a great relationship with our family doctor after the diagnosis.... because we felt that he had passed her (mom) off, that she was older and she was just complaining all the time. And when we talked about treatment, he made it clear that treatment wasn't an option, that it was too far gone. And everything else, it just moved so fast that we didn't even really get to see the cancer doctor, because by the time the appointment that we were to see him, it was really just gone too far." (Caregiver 1)*

Furthermore a systemic breakdown in communication was expressed by the respondents.

> *"Part of it is our systems don't speak to each other. The biggest gap is hospital to hospital. The communication now I find is not terrible 'cause. There are provincial systems that link hospital data. But primary care data remains largely invisible." (HCP5)*

Some respondents also discussed about the lack of information about the access to resources that they have:

> *"I know more about what I can advocate for because. Of the work that I do and the fact that I work so closely with the healthcare system, that if I wasn't at certain meetings with my family, my family would have no idea that they could have access to the resources that we have and it wouldn't be that." (Expert 2)*

> *(Accessing available resources) "it's one of those pieces where if you don't know or if you don't have a healthcare provider in your corner who's advocating, then it is really hard to get those resources." (Expert 2)*

2.2 Training and Support for Healthcare Professionals

Another sub-theme that emerged was the lack of training and support available for Healthcare providers. There is a need for adequate training and resources to develop effective communication skills for sensitive conversations related to serious illness and end of life.

Respondents talked about not having a framework for communication and that can be a concerning situation:

> *"It's very scary when you don't have a framework or you aren't given opportunities to learn about and practice and hone skills within a framework to communicate in high stakes situations." (HCP3)*

A lack of opportunity to practice communication skills was also expressed:

> *"What we haven't been taught to do, or what some of us may have been taught to do, but having been given ample opportunity to practice, to observe it, to hone our skills in a way that we have been for, let's say, physical skills, for example. Our opportunities to learn how to communicate and be good communicators and be better communicators." (HCP3)*

> *"I think there's like a lot that could be done around not just, you know, communication skills around end of life because it's, you know, that's just like the one piece." (HCP4)*

There was a desire to have the communication skills not just for the palliative care physicians but across the board so that the language of care remains the same when the patient is hearing the information whether from their GPs or from the palliative care physicians:

> *"And it shouldn't be that only palliative care trainees get this. It should be bread and butter training for every single clinician starting from you know, undergrad." (HCP3)*

2.3 Need for Cultural Sensitivity and Language Access

Addressing the diverse cultural and linguistic backgrounds of patients and families is essential for effective communication and respectful care. Language barriers can significantly impede communication. Healthcare respondents talked about how older adults will trust what the medical team is saying and follow the instructions without questioning as that is the culture they have grown up with:

> *"Older adults they have more trust sometimes in the medical team they'll be like Doctor knows best and they just you just tell me what to do and I'll do it." (HCP4)*

Therefore it is really important that the older adults and their families truly understand what is going on. Here sometimes the cultural barriers come into play where the children or family members do not want to disclose the details to the patients to avoid more stress but for healthcare providers this can be challenging:

> *"But there's some families where and this is really challenging, where the the kids or the family don't want us to disclose the reality to the patient. And that's really challenging*

> *because the setting we're in is often to discuss decision making." (HCP2)*
>
> *"So often the family thinks they're protecting their their loved one, and they're actually, you know, not. They're all just living in, sort of a fabrication, so that is sometimes, I think, a relief for everybody when that comes out that actually we all know." (HCP2)*

Similarly language barriers can also impede clear and good communication. Healthcare providers in the palliative care ensure that the patient and their families understand what is going on:

> *"Ensure that if patients can't speak English, we always have an in person translator. And if we can't have an in person translator, we have to use one over the phone. Unless one of our teammates speaks the exact language. For example Mandarin like one of our physicians spoke Mandarin yesterday. making sure we have good communication.*
>
> *Before and we never do an assessment unless we have a translator. If they are unable to speak English, we don't." (HCP1)*
>
> *"And in one case fairly recently where the patient did understand some English but didn't communicate well. I'd asked about a medical intervention. And I could see her shaking her head. And the son was speaking to her and I could see her shaking her head and going. And then I said to him, what question did you ask her that it looks like she was saying no. And he kind of looked half sheepish. So I asked if she wanted the medical intervention. But he wasn't going to translate that. But her body language was so explicit." (HCP5)*

But sometimes using family translators can be challenging and misdirecting. There is no way to ensure if the critical information and decision making is communicated effectively both ways:

> *"We have a bad tendency to use family translators. I know in some cases and believe in others that that may result in communications challenges that would be different if we could speak the language. 'Cause, occasionally someone will speak for 10 minutes and they will, and then you'll get like a like a five word translation. And it's like I said, it was a little bit more nuanced to that answer. " (HCP 5)*
>
> *"Well, what does this mean for this patient? Shouldn't they be able to have a translator that's external to their family to ensure that the information's being relayed in the way that they need it to be relayed? Someone professional. To do this, and also sometimes information provided from the doctor to the caregiver, depending on how sensitive it it is, they might hold back some information from the patient right to not worry them, to not stress them. We see all these things. So that's another thing that we can see as a role for a caregiver and what that interaction might look like. (Expert1)*

This theme covers the broken systemic and communication challenges faced by both healthcare providers and older adults and their caregivers while the caregivers/family members carry the additional burden of translating critical information whether accurately or not. But these broken links further exacerbate the decision-making capabilities of the older adults.

Several respondents shared the systemic tensions and barriers to access information seamlessly. Instead of transitioning smoothly from their trusted GP or family physician to another specialist or the palliative care team, the transition feels abrupt, devoid of empathy and care leaving the patients and their family members confused, drained out, disappointed and frustrated.

My personal experience with the Ontario Healthcare System

I had a first hand experience of interaction with the healthcare system here in Ontario last November when I developed severe abdominal pain. I had an underlying condition of a large fibroid and a hernia that was due for a non-emergency surgery which I had planned in December in India. Since this was the first time I was experiencing pain I rushed to the doctor nearby. Since I don't have a family doctor here I went to a walk in clinic where the doctor asked me to go immediately to Emergency thinking ther hernia or fibroid might be causing an issue. When I reached the Emergency at a nearby well known hospital, the admission procedure itself took about an hour plus. I was accompanied by my brother which was a huge help. I was given a wheelchair as I was unable to walk. The pain was excruciating but I spent the next 12 hours on the wheelchair. In between doctors would come, assign some tests, I was taken for the ultrasound, blood tests etc and because I had 2 issues I was looked at by two teams: The gynae team and the general surgery. I was given pain killers to manage the pain. Every 2-3 hours there was someone coming with a new task or instruction. After midnight a nurse directed me to a stretcher in the corridor and asked me to rest for the night. Next day I was given a room and I spent 4-5 days there as the doctors investigated whether it was an emergency enough reason for me to get the surgery done right away or could it be done in India. Both sets of doctors gave their view that it is not an emergency situaton. The hernia and fibroid have not changed status since the last tests in India so it is ok for you to go to India and get the surgery done. Next thing I was told by the nurse that I will be discharged soon. I was so puzled because here the doctors were running tests, I had not yet started on solid food or walking properly but the nurse was talking about being discharged. The doctors finally did discharge me after 5 days and prescribed solid food, never mind that I was still not able to eat much. They never did diagnose the reason for this pain but just cleared me for the surgery. During the time I was admitted I had to be given morphine for the pain and that makes you drowsy. Several times the doctors came and told me something it was just a blur. I had to process the information later on about what they actually said.

Throughout my experience at the hospital I realised how distant the communication was. There was no information on when the doctors will visit, how long to wait, what are the next steps. Before the next action such as dischatge plan or follow up there was no conversations explaining anything. I just felt frustrated and disappointed and wanted to head back home. The pain eventually subsided over the next several weeks with ice pack massages. Later on in India, my doctor informed me that the abdominal muscle had probably ruptured due to the fibroid.

The broken linkages in the system and consequent communication barriers call for an urgent attention. Training skills and policy level changes need to be implemented with sincerity, urgency and committment. Everyone deserves dignity in care, and end-of-life conversations are even more critical to handle as people navigate the emotional, social and psychological aspect of it. They need guidance, they need someone to actively listen to what they are saying and possibly what they are not saying too.

THEME 3:
DEATH AS A HOLISTIC EXPERIENCE

Death is a natural part of our life. It is a universal experience but there is a stigma and fear in talking about it with our families, communities, or healthcare providers. There is a need to normalise conversations around death and offer support within our communities to cope with death and grief.

3.1 Emotional and Psychological Impact of Serious Illness and End-of-Life:

The experience of serious illness and conversations around it evoke intense emotions, including grief, fear, anxiety, and uncertainty, for both patients and their families. Not only is one navigating the medical part of it but dealing with a lot of emotions, grief, anger, frustration, questions. Respondents feel the current medical model is not equipped to offer care to handle these:

> *"You know, the fact that death has moved into a medical model and a hospitalized notion, and it's so far away from family care." (Expert 2)*

At the same time palliative care physicians are trained to watch out for non-verbal cues to assist the patient and/or their families to address what they need:

> *"You know, sometimes you enter a room in a patient's lying on their side and. You know, they kind of just lie there curled up in a ball and they don't really wanna. They're very withdrawn, you know? So that's like, you know, so it's all it's responding to those cues around cause nursing is a lot about attuning to patient's needs. And I know following their lead and following their cues as well. So if they're, you know, curled up in a ball and not really wanting to engage, you know, figuring out, is there anything in that moment that we need to address?" (HCP4)*

> *"What they need are people to attend to. The emotion that that comes from receiving a life limiting or a serious illness diagnosis." (HCP 3)*

The palliative care respondents also mentioned when they interview patients they try to address how the illness is impacting them overall:

> *"...as part of my interviewing, I wanna make sure that I touch upon physical symptoms and emotional and spiritual symptoms and needs as well. So that would be just asking You know how the illness is impacting them, their family, Others around them if they are feeling stressed, anxious, worried, scared, depressed. My goal is to help optimize their quality of life." (HCP 3)*

While the caregivers expressed the pain of not knowing anything:

> *"These are the doctors you will see or you can see, but we got nothing, nothing, you know, so it was like you just, and you rely on internet, which is terrible, because it just gives you a whole lot of options that aren't options here." (Caregiver 1)*

Navigating a serious illness can bring up a lot of emotions. Our body prepares itself:

> *"Oftentimes an experience, maybe a feeling is shock. It's such a protective feeling. It's meant to be there to support us having to navigate something hard." (Expert 2)*

> *"Sadness, sometimes despair. So heartbreak. Like, you know, I have to talk about sadness as like this very superficial feeling that, like, I might feel sad that I didn't get to finish my lunch. But you know, if someone I care about is dying, I'm going to feel heartbroken. Sad. That's not really a deep enough emotional." (Expert 2)*

> *"Confusion is often an experience that people are having, and again, that that makes sense when shock is there and it's trying to like support us." (Expert 2)*

Tackling anger and frustration from the patients can be quite normal:

> *"So the sign for us, we see it quite often are obviously emotional and frustration and anger. And we sure that we don't get the anger that comes out at us. We have to make sure that it's not because they're angry at us, they're angry or frustrated with the patient's situation most of the time." (HCP 1)*

Therefore it is good to have someone with you for not just supporting but to also ensuring that the information is being processed accurately:

> *"We really encourage all of our patients to bring someone with them to their appointment. Not just for, you know, logistical reasons, but to have a second set of ears to listen and also to have someone else be present because those conversations are very heavy sometimes and they're hard for people to process." (HCP 2)*

Dealing with the concept of death and dying brings up heavy and hard feelings and lots of emotions that sometimes are hard to cope with. As our physical body is dealing with the illness (in the patient) or the news of the illness (for the family or caregiver) we need to account for the emotions it brings with it. Having access to support that can help us cope with grief (dealing with the news, anticipatory grief etc) can prove beneficial in managing it to some extent.

3.2 Potential of Social Prescribing (Though not yet fully explored in End-of-Life Care):

Social prescribing is recognized as a holistic approach to connect individuals with non-medical supports that could potentially benefit caregivers and even patients in palliative care by addressing social needs. However, its application in palliative and end-of-life care is not yet well-explored.

Respondents describe Social Prescribing as a holistic way of looking at healthcare:

> *"Social Prescribing it is a holistic way of looking at healthcare and of ensuring that we are looking at all indicators of health and the whole person." (Expert 4)*

Some respondents referred to different ways of getting the patients in supportive care involved in activities:

> *"Even though these patients are being seen in supportive care, we try to ensure that they get out of bed everyday if they're not extremely in end of life." (HCP 1)*

Or engage volunteer services to tackle loneliness and social isolation:

> *"we do have volunteer programs where they will call patients and talk to them when they're lonely or they're feeling sad." (HCP1)*

Social Prescribing can also be small gestures but can go a long way in providing support to the family such as:

> *"One thing that I've seen in my family is when my father-in-law was end of life, my mother-in-law was provided with a prescription to a grief support group, and it was anticipatory grief as well as post loss. Like she had all of us and her family, but. She needed somewhere to go to just talk out how she was feeling, her fears, what she was going through. And then she knew that she could take that time just for herself. While she did that, and then on her way home, you know, sometimes she would have a coffee with a friend" (Expert 1)*

> *"They're gonna lose someone they love. So I think just having somewhere to go to talk through really heavy feelings she had was so amazing for her." (Expert 1)*

But some of the respondents also mentioned that it is not very well advertised so people are not aware of the support services that are available:

> *"One of the great things about social prescribing is, you know, in I think a lot of support services in our country have like a communications or marketing problem that nobody knows that they're there so having a great opportunity in social prescribing is just like the thing already exists, making more people aware." (Expert 4)*

Social Prescribing is especially not been the focus around end-of life care or palliative care:

> *"I'll be honest, we haven't had a lot of kind of social prescribing for palliative or end of life care. That haven't been our focus with our social prescribing work." (Expert 3)*

Although the respondents do identify its potential and prevention of future healthcare crisis but acknowledge it is not yet explored:

> *"That's also not to say I don't think there's potential. There's potential for social prescribing to benefit that population (older adults), but it just hasn't been a focus of our project." (Expert 3)*

> *"It's really trying to look at older adults that are still living in the community. Where we're able to maybe prevent those future healthcare crisis or declines and things." (Expert 3)*

Particularly caregivers could benefit from availing such supports to avoid burn out if they knew where to access these from. At the moment they are not aware that there is a way to share their caregiving load:

> *"Yeah, like I imagine that a lot of people don't really know what supports are available. And you know, there's a whole literature I haven't read it, but there's a whole literature caregiver burnout, you know." (Caregiver 2)*

> *" I don't know that people are always aware of how they can lighten their own loads, you know. " (Caregiver 2)*

However currently the healthcare providers themselves are not entirely convinced that Social Prescribing works as one of the respondents mentioned so they might not be referring to these support systems themselves:

> *"I think it's around like that trust and that understanding of the services being provided, right? Like, I don't think there's that buy in from all the healthcare providers about like, oh, this is going to really help my patients." (Expert 3)*

Whenever I die, whenever that happens, I hope my family and friends will honor me and honor my legacy by using the words death, dying, died, dead. I hope they'll use the D word because it is not a scary word, it is not a taboo word, it is a real word. It is the reality that we live mortal lives and we don't have infinite lifespans. I hope they don't use the words passed or passed away or any other euphemism to describe died or dead. Because again my legacy is that dying is normal. That it's an expected thing and it's a normal thing and it's not something we need to be afraid of talking about. I also hope they honor my legacy and honor me by not saying that I was a fighter or that I fought a good fight or that I was a survivor. I hope they don't say that. Instead I hope they say that man she lived a really good life. That loved hard, that she was loved, that she lived well and with a good heart, and I also want them to know that whenever I die, I'm okay and I want them to keep living and to keep living well and loving well and laughing well too.

- Katie Duncan, Nursing Practitioner, and an end-of-life Coach, Death Care Coach, Instagram, 2025

While the potential of Social Prescribing is acknowledged and by nature it looks at a person holistically so takes care of the social needs of a person, the lack of advertising, marketing, general awareness about the services and lack of training for the healthcare providers to refer their patients to Social prescribing support in their community causes a barrier to access these services.

3.3 Importance of Holistic, Person-Centered Care

A need for care that addresses the physical, emotional, social, and spiritual well-being of both the patient and their family is uniformly emphasized. Person-centered care values individual preferences and goals.

End-of-life care conversations especially need to be centered around the person's wishes and goals. Respecting an individual's choices right till the end is especially important:

> *"And to understand what patients want, if they're 100, do they want treatment? They might. And then, so why should we? Why should we stop them from having treatment if they're 100? Our approach is not to prescribe medications for everything. Our approach is actually de-prescribe if possible." (HCP1)*

Palliative care plays a crucial role in managing symptoms but also taking care of the person's needs and desire as well as understanding what's going on within their family:

> *"Palliative care, in my mind is a supportive type of care that just helps patients to palliate symptoms. And manage their, you know, their physical symptoms but also social symptoms or spiritual in the context of having a life limiting disease." (HCP2)*

> *"We in the palliative approach to care, we do in depth assessments regarding symptoms and also just placing a person within like a holistic perspective, really understanding what's going on within the person and their family as well, because a unit of care just isn't the patient, it's their family or their whoever they've defined as their family." (HCP4)*

By looking at a patient holistically, the palliative care team felt that it empowers the patient and makes them feel heard and seen:

> *"I think having these conversations in clinics like ours where it's really holistic and comprehensive and you're looking at the full person versus just looking at their specific disease. And giving that empowers patients in itself like we have so many patients saying like just coming. Being asked all these questions, it's so refreshing. Like you're actually asking about these parts of my life. You're not just asking about my disease, so that in itself makes people feel seen and gives them a bit more, you know?" (HCP2)*

On the contrary, the caregivers in the interaction with their GPs and primary care physicians felt unseen. They found the healthcare system lacking in empathy and person-centred care:

> *"You're a person, not a number, not just a name. You are a person, a whole person. And I don't think that's addressed in the healthcare system as much as it should be." (Caregiver 1)*

> *"Communication and the social aspect is probably the thing that Is missing and the personal touch." (Caregiver 1)*

While having end of life conversations it is important to factor in not just the patients but their families and caregivers. It will be important to watch over what is going on there and address any social, emotional and psychological aspects of dealing with serious illness conversations. It will also be important to direct them towards any support that they might need to manage themselves.

THEME 4: UNSEEN AND UNHEARD: THE CAREGIVER STORY

Caregivers play a vital but often overwhelming role, facing emotional, physical, and financial strain. They often lack adequate support, information, and recognition within the healthcare system.

4.1: Significant Burden on Caregivers

Caregivers need support and recognition that empowers them and makes them seen and heard. From taking on the role of translators to making sure the appointments are kept the caregivers have a lot of responsibility on their hands. Sometimes the role of being a caregiver comes unexpectedly and one might not be prepared for it.

Respondents shared that Caregivers role in healthcare often goes unrecognised although their contribution is invaluable:

> *"People are seeing the benefits of caregivers too, right? So if you don't have caregivers, what happens to our health system? What happens to our Community support system? What happens to individuals who are at risk living at home alone?" (Expert 1)*

They also shared that caregivers are not always included in the conversations even though they might be accompanying the patient. It is upto the healthcare provider who decides whether to include them or not in the conversations:

> *"Sometimes a caregiver will actually be seen and included in a conversation. Other times they're kind of just sitting to the side, listening and jumping in when they need to. There are still instances, however, where caregiver is not allowed into a space." (Expert 1)*

> *"Many older adults would report that they just don't always feel heard and seen". (Expert 1)*

Caregivers shared that the role of being a caregiver is stressful and can be something they don't have a choice with:

> *"It's been particularly stressful for me assuming this role because I did not have a close relationship with my mother...at all. In fact, she wasn't a very kind person to me when I was growing up…. we didn't establish like a mother daughter bond... And so now I've been thrown into this role to care for this woman... Who didn't really care for me? So yeah, it's that's been the number one stress for me." (Caregiver 2)*

> " *And so I don't know that people and there is I think in some cultures I imagine there is an expectation that your kids are going to take care of you, you know. That's a really big ask like that is really hard and a lot of caregivers work full time or I don't know, maybe some of them have to leave their jobs to do this like." (Caregiver 2)*

Sometimes labeling with the term 'caregiver' is also not what they are comfortable with. Culturally it can be a role that is taken on naturally by children for their parents:

> *"Even the terminology of caregiver is not something that everyone feels describes who they are, right?". "A lot of people will never say that they're a caregiver. They're a son, a daughter, a partner, a friend". (Expert 1)*

> *"This is not a word in my language, in my, in my home language. This is not anything that we would describe". "This is just what we do for each other, right?". "With indigenous communities, they've also shared something similar. Don't label me why do we have to label everything and everyone. This is a western viewpoint". (Expert 1)*

When caregivers are themselves older adults, respondents shared their own share of challenges from struggling to look after themselves or neglecting their own health:

> *"We're hearing a lot anecdotally and also seeing through this, how many couples or siblings are getting stuck in a situation where both of them are aging and both of them, the one who has traditionally been the caregiver for the other, is now also having like normal aging related health issues or mobility issues. But who is who is left to be their caregiver?" (Expert 4)*

> *"Another thing that happens is that sometimes older adults, especially in a caring role, will be dealing with their own health conditions just as they age. Certain things change for them, but they don't have the time to focus on those health conditions of their own". (Expert 1)*

> *"I think it's sometimes harder with caregivers. To get them to see the importance of caring for themselves and of getting systems in place to give them respite care and to give them some relief." (Expert 2)*

While taking care of themselves is important often caregivers will not do so as they are afraid of losing special moments with the person they are caring for:

> *Like the burden on the person's health is real and but it could be a hard conversation to get them to take care of themselves because there is a sacredness in caring for love as they get frail or sick and die. (Expert 2)*

> *"I didn't look after myself because I knew it was only a short time and I was dedicating every minute that I had to her, you know?" (Caregiver 1)*

And even if they did want to take care of themselves often these support services are not easily available or accessible:

> *"59% of over 65 caregivers said it was difficult to find information about supports. They needed 55% said. It's difficult to get affordable local support. 19% of all caregivers are over the age of 65. 37 are between 45 and 64 and 67% of care recipients are over the age of 65." (Expert 4)*

> *"The other thing that caregivers are really needing and what they look for is mental health supports for themselves. Respite and home care is the number one thing people are always calling for as well." (Expert 1)*

Respondents mentioned how caregivers desperately need these support care for themselves as it is quite stressful:

> “ *And one of the big things that people reach out to us about on our helpline and other services is how on Earth can I work with my family like we're all caring for someone and we're all playing a role. But man is this stressful.” (Expert 1)*

> *“What supports could be modified slightly or even just capacity built to support both the patient and the caregiver, seeing them more as a unit when someone has a caregiver in their life.” (Expert 1)*

Another challenge faced by the caregivers was ascertaining how long they will be caring for, sometimes it was difficult to put a timeline which further impacted their time away from work:

> *“One thing caregivers will share is I know that I need to take some time off work and I need to just be there and I want to be there. But I don't know how long to tell my work. I'm going to be off for”. (Expert 1)*

Respondent also shared the financial burden faced by caregivers and a lack of support available in that area:

> *“Yeah. So I think the main ones, number one, financial, absolutely. We don't have a caregiver benefit in Canada like we like you see in the United States or like, yeah, we don't have that here, right”. “But what we do have is a caregiver tax credit that people can apply for, and we also have an EI benefit where you can take a certain number of weeks off to cares for someone and get employment insurance if you have enough insurable earnings banked. So that's what people are dealing with”. (Expert 1)*

> *“You gotta pay out of pocket and not everyone has assets to liquidate in order to support that, right?”. (Expert 1)*

To sum up, the role of caregivers can come unexpectedly or planned but it comes with a lot of responsibility and decision making. As an older adult caregiver the role can be more demanding as it is easy to neglect one's own health and one might not have the resources or support to take care of oneself. In addition to coping with anticipatory grief, the burden of caregiving can be managing appointments, transportation to and fro the appointments, financial burdens, managing work (and kids if applicable), mental health etc. Access to additional support for caregivers is not easily available or visible.

Data Highlights from Caring in Canada: Survey insights from caregivers and care providers across Canada (Canadian Centre for Caregiving Excellence, 2025) clearly state the challenges faced by caregivers today:

Caregiving takes a toll on a caregiver's wellbeing. Senior caregivers are experiencing the impact of caregiving on their well-being. Nearly half (46%) said that they were tired as a result of caregiving, while 25% reported sleep disrup-tions and 18% reported depression.

Caregivers are working an “extra-shift.” Caregivers provide an average of 5.1 hours of care a day, adding up to over 30 hours of unpaid care, or almost the equivalent of a full-time job.

Many caregivers are 65+ and may also need care. Nearly one in five caregivers are over the age of 65. Senior caregivers are least likely to access any services or supports to help their responsibilities – from home modifications, to respite or transportation services.

Unable to access to support services: Caregivers 65 and older were the only age group that was significantly more likely to have not accessed any services or supports—such as home modifications, respite services or transportation services—in the past year. During that same time period, only a quarter of senior caregivers sought out information about caregiver supports, and even fewer (21%) attempted to access them.

THEME 5: MY MAGIC WAND

As part of the interview the last question was a reflective one that asked respondents to share what was missing from their toolkit of care. If they did have that particular thing it would have been easier to navigate the healthcare journey in the end-of-life care.

Almost all the respondents shared that a common resource tool was missing from their toolkit of care, a sort of collection of support services that are available for older adults and their caregivers.

> *“ I think it's hugely important to have this information like a hub somewhere with this information would I think, really empower a lot of people.” (Caregiver 2)*

> *“I would like a toolkit full of every possible resource in Toronto. More social resources because we're always digging and finding and looking on the Internet and our social worker is amazing. But I'm always looking for types of social resources across the GTA or anywhere because we get patients like Thunder Bay down to like Niagara Falls to from I would.” (HCP 1)*

> *“Like a toolkit of social resources for patients for all different types of different things out there that are non prescribing. Volunteer programs where they will call patients and talk to them when they're lonely or they're feeling sad.” (HCP 1)*

> *“Yeah, it would be great to have like a resource booklet for seniors, for caregivers like it's just kind of trial and error.” (Caregiver 2)*

There was also a desire to have patient navigators or people who can specifically offer support or advocate for the patients:

> *“It would be amazing to have patient navigators who are people who specifically work with patients who are like socially vulnerable or have cognitive issues and like, help them navigate the healthcare system and that kind of thing, because that is a really, you know, it's not common, but when it happens, it's a really, really difficult challenge.” (HCP2)*

Or community and patient support that offer more space for conversations and human connections:

> *“I think with the loss of Community we need some form of support or like circle around People to provide. More opportunities for conversation, more opportunities to connect.” (Expert 2)*

> *“Like a toolkit of social resources for patients for all different types of different things out there that are non prescribing. Volunteer programs where they will call patients and talk to them when they're lonely or they're feeling sad.” (HCP 1)*

> *"Well missing from that (toolkit) so I think communication and the social aspect is probably the thing that is missing and the personal touch maybe. You are a person, a whole person. And I don't think that's addressed in the healthcare system as much as it should be." (Caregiver 1)*

> *"I might wanna look into and I don't even know if this exists is because it's expensive hiring privately and I wonder if there are volunteers I don't know. You know, when I'm looking at, what other supports are out there that we could be using to support my mom that don't cost money or don't cost a lot of money. And I maybe I should look and see if there are kind of volunteers who would just come in and check on her. Just another pair of eyes on her 'cause I wonder if there are more supports out there that that I'm not aware of." (Caregiver 2)*

One respondent also advocated for a decision making tool:

> *"A sort of decision making tool that I'm that I'm trying to find and that would be super helpful in our setting." (HCP2)*

Some respondents brought up systemic gaps that just do not have the space for integrated care so a call out to make changes to accommodate a holistic and person-centerd care:

> *"A broader allied health support system, which allows us to bring some of these things in psychological supports, spiritual supports and those community supports, but in community settings cause hospitals have even in hospitals they're limited, but in the community those are very, very limited." (HCP5)*

> *"I would like blame it on the system more than my own toolkit like because I feel like my toolkit of care is full. But the system doesn't accept my toolkit of care. So I feel like, you know, talking about love and I feel like the palliative approach to care being so holistic and us being like, you know, right, the right now the priority is just like, you know, I always say that sometimes like at the end Say to people like, oh, like, love is the best medicine right now. Or you really have to just focus on loving your father right now. That's the most important thing you can do right now. Or, you know, but these are just things that like, you know. So I feel like, but I feel like those kinds of things aren't sort of like built into the education or the system. The system doesn't sort of like I mean it doesn't vary those things, but it's just kind of like it's sort of like a medical, you know, it is a medicalized system." (HCP 4)*

> *"So I guess it would be like if I had a magic wand, it would be, you know, broadening the systems. Sort of encompassing and valuing, you know the actual humanistic toolkit of care, which is, you know, very deep. You know rich and complex rather than you know, because it's very narrow minded. "(HCP 4)*

Or the System's lack of capacity to fulfil the client's care needs irrespective of where they are located:

> *"Big thing right now is capacity." and "It's purely about capacity and I think the other thing though, when we think for more of the client perspective are really, really big barrier or thing that's missing is access to transportation, so the link worker can suggest a bunch of different programs and services for someone to attend if they don't have the transportation to get there, then they're not gonna get connected to that, right? So, especially in rural communities I think that's just such a big barrier where there's just such a lack of transportation. (Expert 3)*

One of the respondents also wished for more investment and policy level changes and real commitment to make these changes a reality:

> *"I am missing Investment and commitment from the top to prioritize this work. We need investment and prioritization and a real commitment of dollars and cents towards this work." (HCP3)*

There is a strong desire expressed by all stakeholders (healthcare providers including palliative care nurses), caregivers, social prescribing experts for having a resource toolkit that connects them to community resources available for end of life, older adults and caregivers. There is a want of human connection in the current healthcare set up and a desire to bring about a change that accounts for community and human connection that possibly unites everyone in their vulnerable moment.

PARTICIPATORY ART INSTALLATION: EVERGREEN BRICKWORKS AND BRAMPTON CIVIC HOSPITAL

The complexities of death and dying encompass not only medical and psychological dimensions but also social, ethical, and existential considerations. Traditional approaches to end-of-life care often fail to address the holistic needs of individuals and their families, leading to gaps in support and understanding. In contrast, participatory design promotes an inclusive framework that empowers individuals to articulate their values, beliefs, and preferences regarding end-of-life decisions. It has the power to bring diverse voices to one place. That is why I decided to have a couple in different locations to get a sense of what mattered to people.

Using an inductive research analysis approach I asked a question that also is one of the key principles of Social Prescribing: **"What Matters Most to you at the End-of-Life and Why?"**

Note: *A separate REB application from OCAD University was applied and approved for the participatory art installations*

The first participatory installation was part of the Good Mourning festival at Evergreen Brickworks, Toronto on 2nd November 2024. This festival is a chance for people to "embrace the full spectrum of human emotion" and celebrate mourning in a community, connected space.

There was a wide range of people that came to the festival, extremely diverse group of people from different ages and different cultures. There were several other interactive exhibits at the festival.

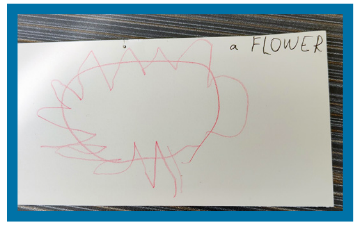
I found that people stopped by and reflected on the prompt on the board and responded on the tags that were provided. There were quite a few drawings on the board as well drawn by children, in some cases for a grandparent that had died.

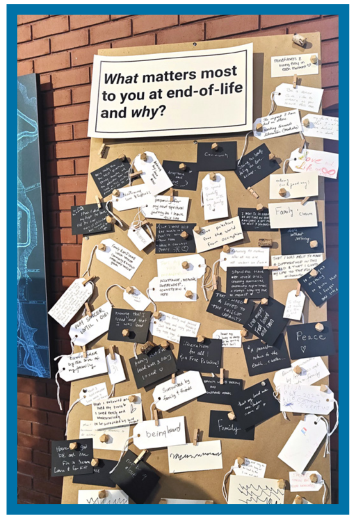
The second participatory installation was at the inaugural ceremony of the William Osler Innovation Lab at Brampton Civic Hospital. I was personally not able to attend the event due to a health issue but received feedback that the interactive installation received a good response.

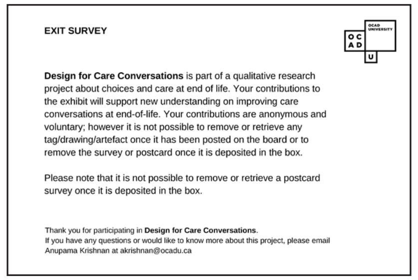
There were exit surveys kept at both locations. It was a voluntary exercise if anyone wanted to share their experience of the installation.

TABLE 1.1 Participatory Art Installation Details

Event Detai;s	Number of Responses	Goal of the Event
• Venue: Evergreen Brick Works • Date: Saturday, 02 Nov 2024 • Event: The Good Mourning Festival • Demographics: Wide ranging; public event. young kids to older adults	• 70 tags • 4 Exit survey responses	• The first exhibit was designed as an exploratory research tool to gather data. The prompt "What matters most to you and why?" was based off a key component of social prescribing where instead of asking "what is the matter with you?" we ask "what matters to you?"
• Venue: Brampton Civic Hospital, Atrium • Date: Monday, 18th Nov 2024 (till 22nd Nov) • Event: Celebrate Research Week 2024. Inauguration of the William Osler Research innovation lab • Demography: On 18th event will be attended by 100 people, in the field of healthcare, researchers, academics, students etc	• 60 tags • 3 Exit survey responses	• The same prompt as Evergreen Brickworks was used but unlike a public space of relaxation this was in a hospital set up. As it was part of an inaugural event at the Brampton Civic Hospital the audience was diverse in the sense there were doctors, other healthcare providers, experts, students, researchers apart from the regular hospital staff.





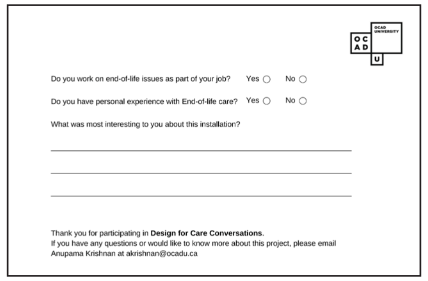


EXIT SURVEY

Design for Care Conversations is part of a qualitative research project about choices and care at end of life. Your contributions to the exhibit will support new understanding on improving care conversations at end-of-life. Your contributions are anonymous and voluntary; however it is not possible to remove or retrieve any tag/drawing/artefact once it has been posted on the board or to remove the survey or postcard once it is deposited in the box.

Please note that it is not possible to remove or retrieve a postcard survey once it is deposited in the box.

Thank you for participating in **Design for Care Conversations**.
If you have any questions or would like to know more about this project, please email Anupama Krishnan at akrishnan@ocadu.ca



Do you work on end-of-life issues as part of your job? Yes ○ No ○

Do you have personal experience with End-of-life care? Yes ○ No ○

What was most interesting to you about this installation?

Thank you for participating in **Design for Care Conversations**.
If you have any questions or would like to know more about this project, please email Anupama Krishnan at akrishnan@ocadu.ca

The exit survey had a question: What was most interesting about the installation: Respondents shared:

"Building awareness"

"Very interactive and reflective, collective insights"

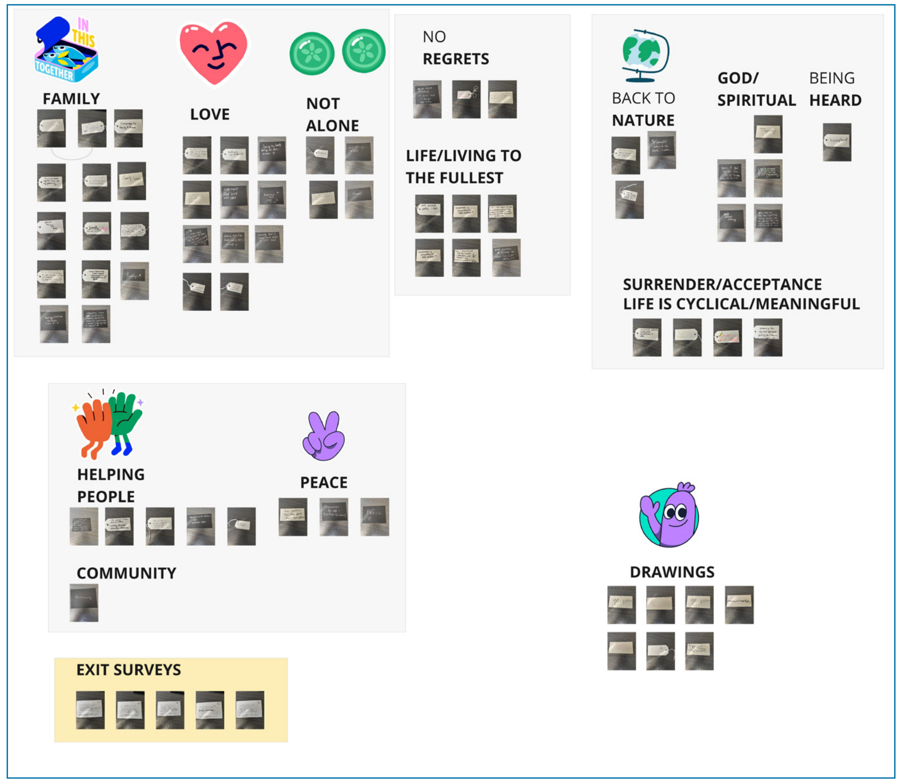
"Everything I find useful: not only the "education" or information but the conversation–good job!"

"Reading others thoughts being asked the questions. Leaving my voice for others too."

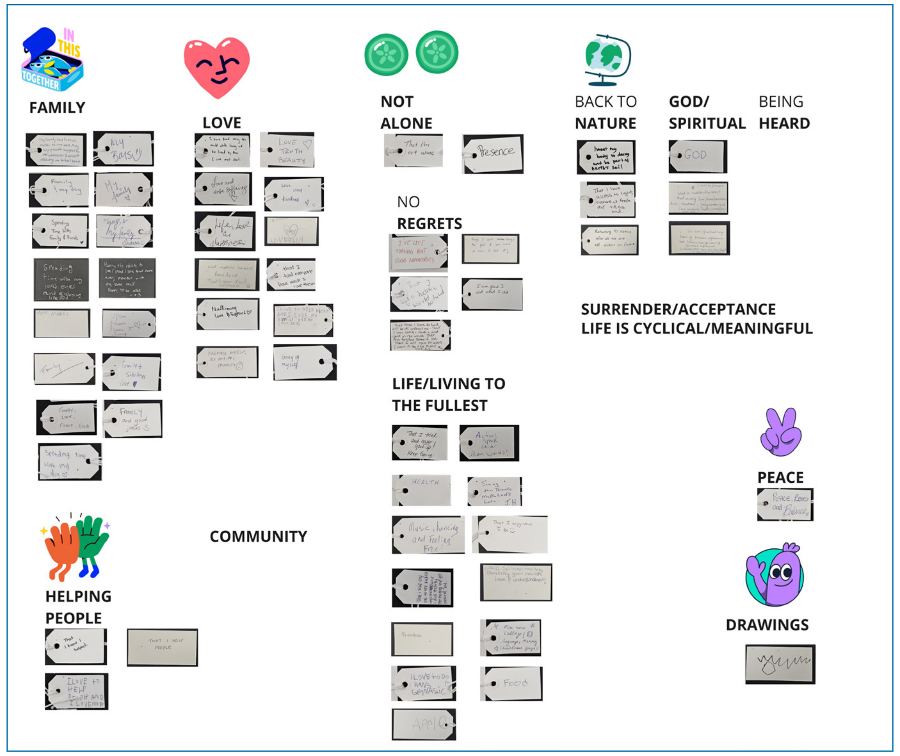
Thematic Analysis

Once the tags were available from both installations, I sorted and grouped them into themes. There were a few overlapping themes and some of them appeared in one location but not in the other. I then created a tabular data (Table 1.2) to compare the two.

From the collective themes, I created a broader theme where I could group a few sub-themes together.



Themes from Evergreen BrickWorks, Toronto



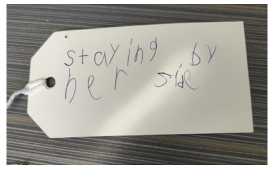
Themes from Brampton Civic Hospital

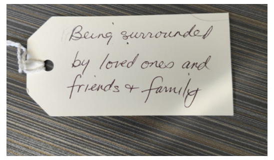
TABLE 1.2 Comparison of Themes from both the participatory art installation

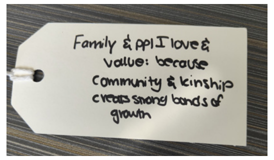
Themes	Evergreen Brickworks	Brampton Civic Hospital
• Theme 1: sub theme Family	• 14	• 15
• Theme 1: sub theme Love	• 11	• 12
• Theme 1: sub theme Not Alone	• 4	• 2
• Theme 2: sub theme No Regrets	• 2	• 5
• Theme 2: sub theme Live Life to the Fullest	• 6	• 13
• Theme 3: sub theme Back to Nature	• 3	• 3
• Theme 3: sub theme God/Spiritual	• 6	• 3
• Theme 3: sub theme Being Heard	• 1	• 0
• Theme 3: sub theme Surrender/Acceptance/Life is Cyclical/Meaningful	• 4	• 0
• Theme 4: sub theme Helping People	• 5	• 3
• Theme 4: sub theme Community	• 1	• 0
• Theme 4: sub theme Peace	• 3	• 1
• Drawings	• 7	• 1

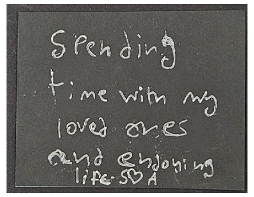
Theme 1: Family, Love and Belonging

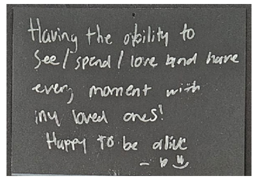
The theme shows how people value family, what matters most to them is to be with their loved ones, to be able to say good bye and stay close to them. It also highlighted that people didn't want to be alone. This was the largest theme that appeared across both the locations reaffirming the importance of families and being around the people who matter most to us.

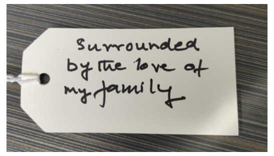

staying by
her side

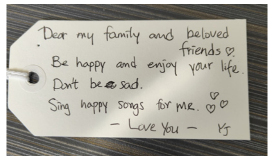

Being surrounded
by loved ones and
friends + family


Family & ppl I love &
value: because
community & kinship
creats strong bonds of
growth

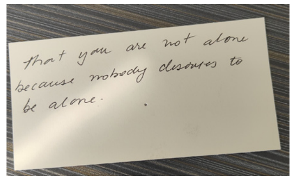

Spending
time with my
loved ones
and enjoying
life. S♡A


Having the ability to
See / spend / love and have
every moment with
my loved ones!
Happy to be alive


Surrounded
by the love of
my family

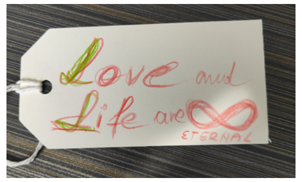

Dear my family and beloved
friends ♡
Be happy and enjoy your life.
Don't be sad.
Sing happy songs for me. ♡♡♡
– Love You – YJ

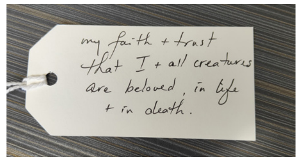

Spending time
with loved ones,
creating memories,
embracing experiences
+ always staying true
to myself ♥

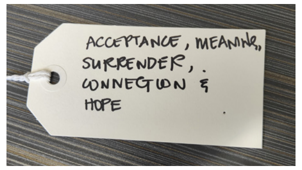

that you are not alone
because nobody deserves to
be alone.

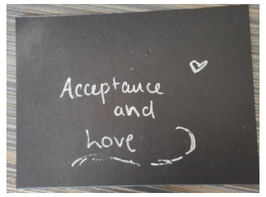
Theme 2: Philosophical Reflections on Life

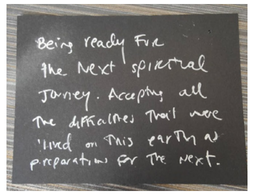
This theme shares philosophical aspects of our lives. From a desire to merge with the earth, an acknowledgement that "we are visitors on this earth", there is also a reflection on the cyclical nature of life such as being reborn. There is also an acceptance in what happens. This theme reflects an interconnectedness of beings and objects in nature.

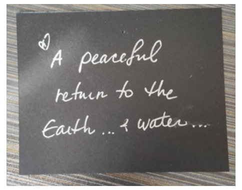

Love and
Life are ∞
ETERNAL

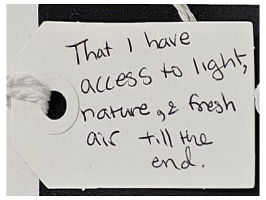

my faith + trust
that I + all creatures
are beloved, in life
+ in death.

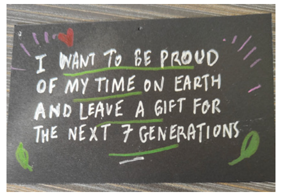

ACCEPTANCE, MEANING,
SURRENDER,
CONNECTION &
HOPE

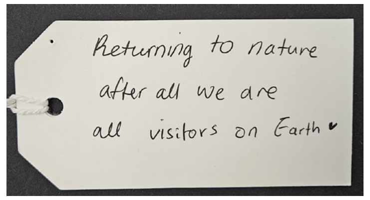

Acceptance ♡
and
love


Being ready For
the Next spiritual
Journey. Accepting all
The difficulties That were
lived on This earth as
preparation for The next.


A peaceful
return to the
Earth … & water…

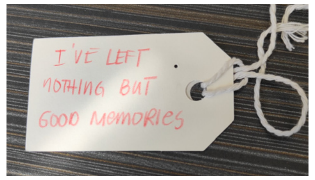

That I have
access to light,
nature, & fresh
air till the
end.

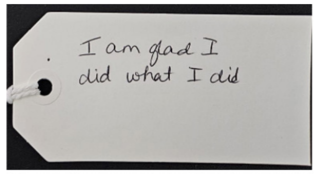

I WANT TO BE PROUD
OF MY TIME ON EARTH
AND LEAVE A GIFT FOR
THE NEXT 7 GENERATIONS

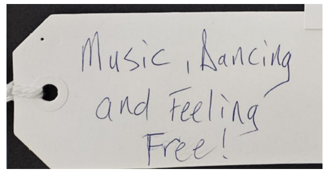

Returning to nature
after all we are
all visitors on Earth ♥

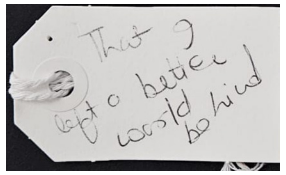
Theme 3: A Life with No Regrets

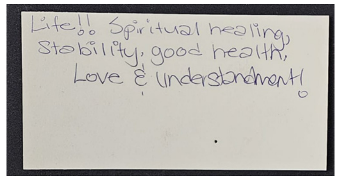
This theme talks about how people don't want to have any regrets in life whether it comes up as leaving only good memories or a slightly spiritual way of thanking God for everything that has been provided and utlised. There is also the concept of living life to the full or maximum capacity.

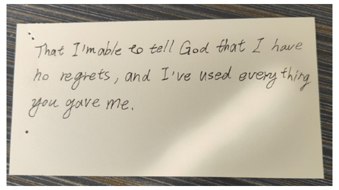

I'VE LEFT
NOTHING BUT
GOOD MEMORIES

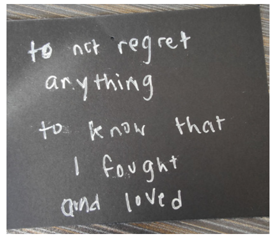

I am glad I
did what I did

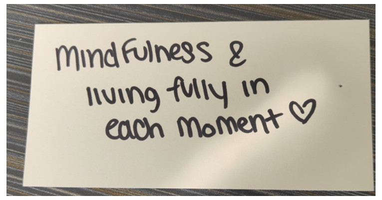

Music, Dancing
and Feeling
Free!


That I
left a better
world
behind


Life!! Spiritual healing,
Stability, good health,
Love & Understandment!

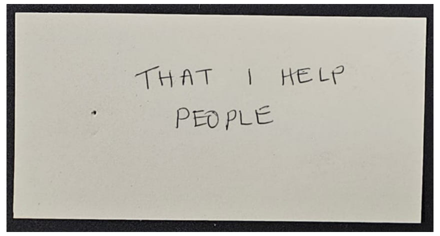

That I'm able to tell God that I have
no regrets, and I've used everything
you gave me.


to not regret
anything
to know that
I fought
and loved

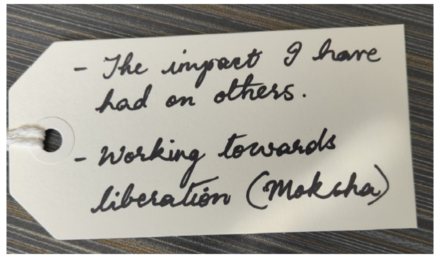

Mindfulness &
living fully in
each Moment ♡

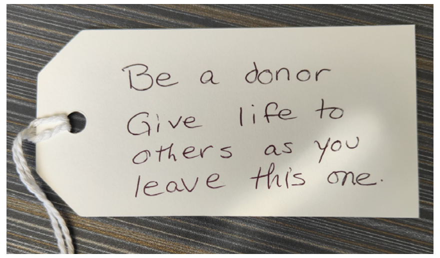
Theme 4: Connection to the Community

This theme talks about helping the community and giving back in some way such as being a donor or rooting for peace within the community.

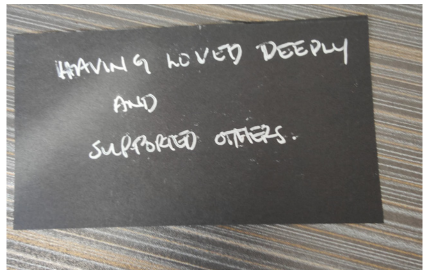

THAT I HELP
PEOPLE


That
I know I
helped.


- The impact I have
had on others.
- Working towards
liberation (Moksha)


Be a donor
Give life to
others as you
leave this one.


Community


HAVING LOVED DEEPLY
AND
SUPPORTED OTHERS.

Takeaway from the installations

The responses gathered from both the installations clearly indicated that what matters most to people in end-of-life was being around their loved ones, surrounded by family, pets, friends or anyone that mattered most to them. People also indicated that they didn't want to be alone or isolated. There was a running theme of having no regrets which again meant that people possibly want a sense of resolution and closure.

Social connection is really important to human beings. Especially since the pandemic people have been struggling with social isolation and loneliness. The disconnection from each other can cause stress and anxiety. Organisations like GenWell in Canada stress on the Human Connection Movement. According to them,

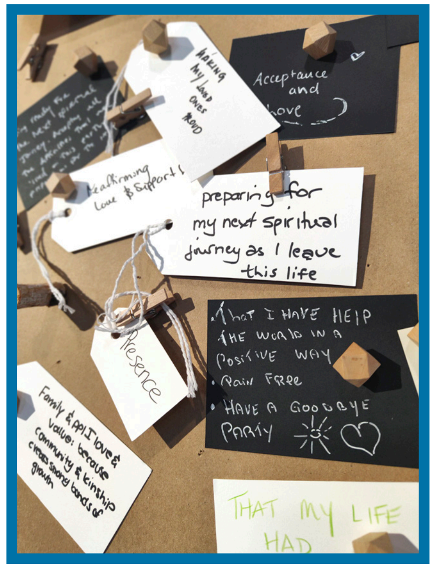
A Human Connection is the exchange between two people that are paying attention to one another. It includes:

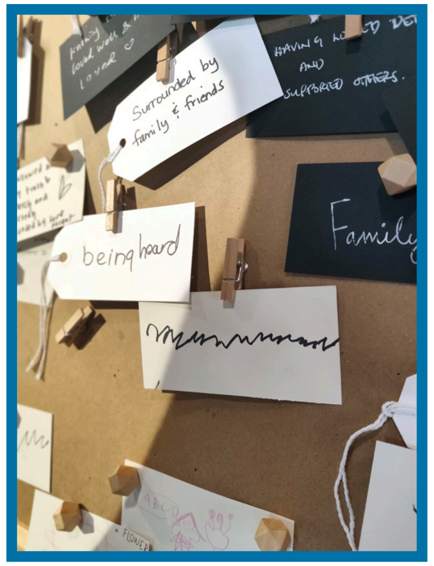
- Any interaction we have like a wave, smile, head nod or conversation

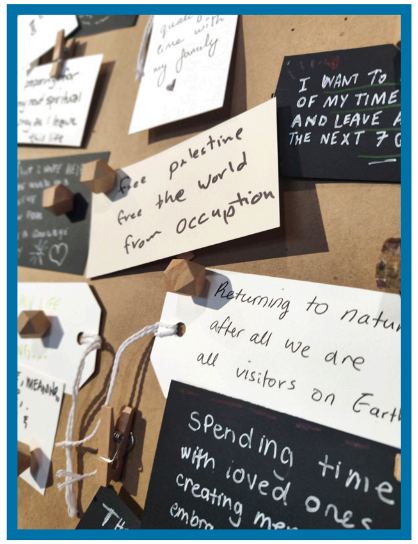
- The sense of acceptance, belonging, safety, trust, mutual understanding, empathy, support and shared purpose/value we get in connection
(Genwell Human Connection Movement, genwell.ca)

This human connection is especially important in the end-of-life. Whether you are caring for someone in end-of-life or are yourself in that situation, you need someone to talk to, a support system that can offer emotional, social, psychological strength.

A photographic collage from the particpatory installations







REDEFINING THE PROBLEM STATEMENT

Based on the interview insights there was a need to look at the existing problem statement and redefine it

Earlier statement: **How might we support healthcare providers to improve care conversations with older adults in end-of-life while exploring the potential role of Social Prescribing?**

Serious illness conversations evoke intense emotions including anxiety, stress, confusion, uncertainty. And caregivers and patients don't have the tools to navigate the healthcare system nor the necessary guidance or conversation with their physicians to help manage this. The care quality can change while transitioning from one care system to the other (primary to palliative care to home care etc). In between there might be several diagnostic tests or decisions about further treatment to align with the patient's goal of care. Caregivers might also be dealing with questions about length of care, duration of illness, how the illness trajectory might change etc. Is it then possible to introduce social prescribing services during this care journey to support the physical, emotional, social and spiritual well-being of both patient and their family?

Need Statement

Caregivers need a way to navigate the healthcare system so they can feel less overwhelmed

What if caregivers and patients were prescribed moments of joy—music, poetry, nature, companionship—as part of care?

What if there was a pool of volunteer support services available for caregivers and their families that could be accessed easily through healthcare providers or an online portal?

Opportunity Statement

"Older adults and their caregivers often face end-of-life experiences that lack emotional and holistic support and timely guidance. By fostering a culture of person-centred care through meaningful conversations and improved access to resources, we can create more compassionate, supportive end-of-life journeys."

How might we accomodate the social, emotional, psychological needs of older adults and caregivers to create a more compassionate, supportive end-of-life holistic care?

part

4

RECOMMENDATIONS AND FUTURE PLANS

Through the interviews and the initial participatory installations, I got a better understanding of the lived experience of people. Overall 5 themes emerged from the interviews and 4 themes emerged from the participatory installation that provided valuable insights into end-of-life care experiences.

I would have liked to conduct a cultural probe for caregivers to get a better understanding and deeper insight into the lived experiences of a caregiver. Cultural probes as an approach to qualitative user research where face-to-face research is impractical or inappropriate (Interaction Design Foundation - IxDF, 2022). Whether someone is caring for an older adult in end-of-life currently or has lost someone they cared for, whether the person was suffering from a terminal illness like cancer or a progressive illness like Dementia, these experiences can offer valuable insights about what is needed on priority and what support is currently missing.

Co-design methodology is a design-led process with a set of creative and participatory principles, practices, and tools. (Health Design Studio, Online Co-Design Toolkit, OCAD. I would have liked to plan a co-design session with stakeholders from the healthcare system and caregivers with prompts similar to the participatory art installation to brainstorm on what is missing and who is missing from the care discussions.

Due to my own health issues in November-December and consequent surgeries in February there was a time limitation to organise these.

In my future plans therefore I recommend these activities to build on a "Social Prescribing Resource Toolkit"

THE SOCIAL PRESCRIBING RESOURCE TOOLKIT FOR END-OF-LIFE

The Social Prescribing Resource toolkit for End-of-Life is offered as a resource guide for older adults in end-of-life and their caregivers. Social Prescribing looks at a person's health and well being holistically and is person-centered. It aims to share resources and community and volunteer services that are available for older adults and caregivers. Link workers or community connectors work closely with the healthcare provider and the person to tailor a personalized care. They also do follow up and evaluate services to report back to the healthcare provider to integrate care and plan the next steps.

The support services offered can address current gaps and challenges faced by older adults and caregivers such as Social Isolation and Loneliness, Financial guidance, Transportation to name a few.

It can also help connect caregivers to health and well-being support such as art activities, or grief support groups or peer support groups.

The Social Prescribing Resource Toolkit for End-of-Life is aimed to:

- Build Connections: Between healthcare providers, older adults and caregivers to offer a space for having conversations about end-of-life;
- Share Resources: List Resources and support systems related to palliative care and end-of-life care that are available;
- Offer Directions to Navigate the palliative care journey to make transitions from one care system to the other easier.

Creating the Version Zero of the Toolkit:

The building blocks for the toolkit will be created through a co-design workshop with stakeholders. Stakeholders include healthcare providers, link workers, social prescribing managers, and caregivers.

The stakeholders will be asked to bring the tools they currently use as well as thoughts and questions about resources they feel are missing.

An activity with 3 prompts will be conducted first to gather information about personal choices at end-of-life:

Prompt 1: What matters most to you at end-of-life?

Prompt 2: What can I tell my family today to make this wish come true?

Prompt 3: Who else do I need to talk with to make my wish come true?

Using collected themes from the workshop and earlier participatory installations pick up 2-3 prominent themes (Social isolation, loneliness, regret etc) and discuss what resources will be useful to work around these? Who are the people who can help. Who is currently missing from the care plan? Who are the people critical conversations should take place with (GPs etc) making transitions to the specialists or palliative care team smoother?

Personas to keep in mind when building the toolkit. These 4 personas are built based on motivation to use the resources and access to social and community support. Healthcare providers will need to connect with the person to assess the motivation level and refer to a link worker as needed.

Persona 1

- Low on Motivation

- Low on Access to Social and Community Support

Persona 2

- High on Motivation

- Low on Access to Social and Community Support

Persona 3

- Low on Motivation

- High on Access to Social and Community Support

Persona 4

- High on Motivation

- High on Access to Social and Community Support

Create the building blocks on which the version zero of Social Prescribing Toolkit for End-of-Life will be created *(which persona will it be for?)*


Persona 1
- Low on Motivation
- Low on Access to Social and Community Support

Persona 2
- High on Motivation
- Low on Access to Social and Community Support

Persona 3
- Low on Motivation
- High on Access to Social and Community Support

Persona 4
- High on Motivation
- High on Access to Social and Community Support

Persona 4 could have the potential to take the SP journey forward by being the signposters or

Activities
- Talking about SP: What it is and how it can help the clients
- Understanding the barriers to access to improve accessibility
- Motivational interviews to evaluate the clients needs and direct accordingly

- **Possible Barriers**

https://www.healthwatchshropshire.co.uk/sites/healthwatchshropshire.co.uk/files/hws_report_for_sp_-_exploring_barriers_280319_v3.pdf

Carers don't have time for SP. Worried who will take care of the patients if they are gone.

Language barrier? Connecting with people who speak the same language

People are shy or afraid to talk to their doctor. They need to discuss the issue with someone else (autism, mental health issue, rural areas, any other cases)

Is SP accessible and easily available

Activities
- Helping clients get more aware about SP activities in their community
- HCP can connect to link workers for further information and accessibility to services
- Giving more information about SP, benefits, process including feedback and follow ups
- Connecting to other community workers/sign posters who can share the benefits of receiving SP

Activities
- Motivational interviews to get clients to use SP
- HCP can connect to Link workers to talk more in details and evaluate the situation.
- Get an understanding of barriers to access services
- Talking to other community members who have benefited from using SP

Activities
- Awareness of SP, its benefits
- Follow up and feedback for further improvement in the SP services
- These clients could be potential candidates to signpost about SP services within their community
- Volunteer training program

Illustration 3: *An impact map sketch based on motivation on self-care and Access to social and community support.*

CULTURAL PROBE FOR CAREGIVERS

Two tools were additionally designed to support the creation of the Social Prescribing Resource toolkit: A Cultural Probe for Caregivers and an EOL Activation Piece. Data from both is meant to get more insight into "What matters most to you in end-of-life?"

Based on the interview insights it was apparent that patients and families and caregivers were navigating a complex healthcare system while dealing with the emotional, social and psychological aspect of coping with grief and a life limiting serious illness. Death and dying is more of a medical issue and missing the human component. Caregivers carry the burden of caring for the family member/person and sometimes are themselves older adults often forced to neglect their own health. They undergo stress and anxiety and are unaware of support systems available to them.

I created an empathy map from the interview and research insights:

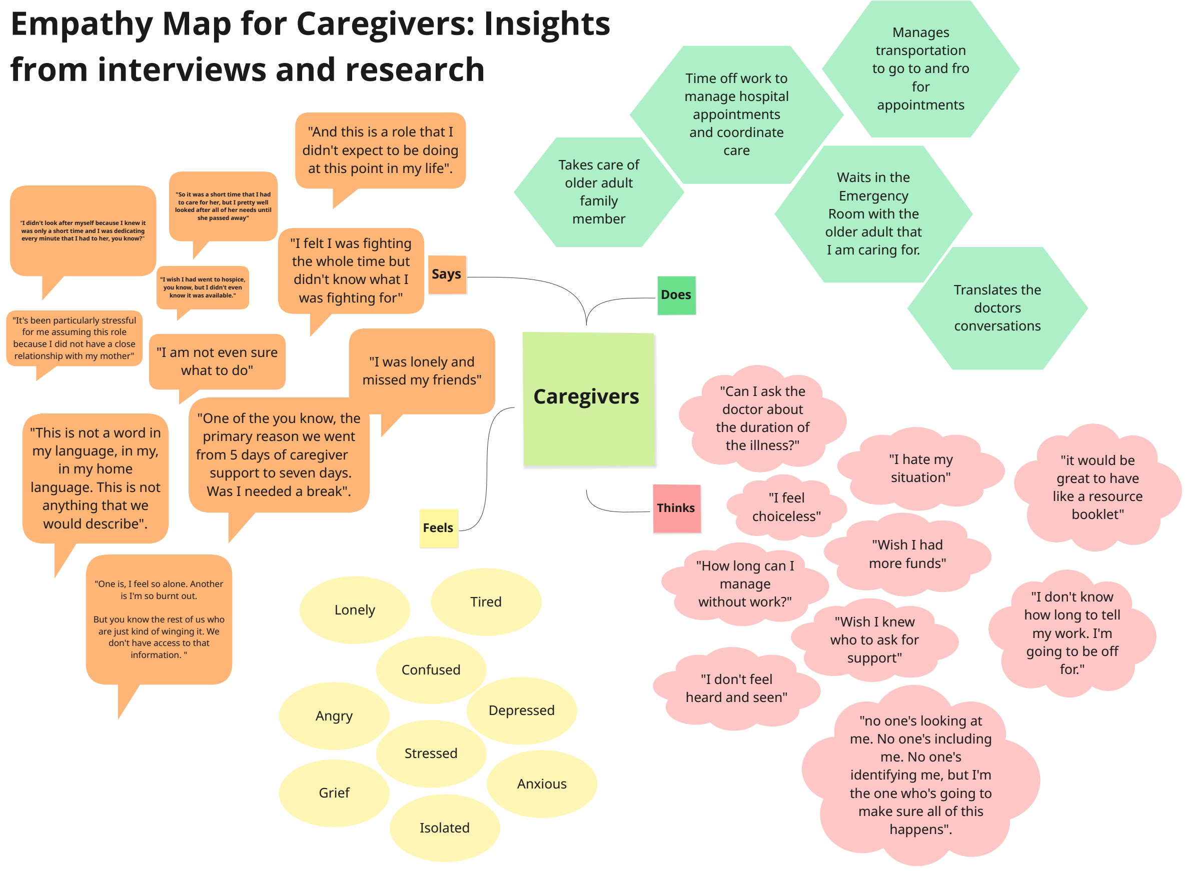


Illustration 4: *An empathy map for caregivers created using research insights fom interviews and literature review*

To get a deeper insight into what caregivers experience and how the grief changes their experience of caregiving I planned a cultural probe to follow up with questions after.

What are Cultural Probes?

Interaction Design Foundation defines Cultural probes as an approach to qualitative user research where face-to-face research is impractical or inappropriate (Interaction Design Foundation - IxDF, 2022). They consist of prompts, questions and instructions along with artifacts for recording thoughts and feelings. The artifacts may be as simple as a diary or as elaborate as a single-use camera. (Interaction Design Foundation - IxDF, 2022)

Goal of the Probe

My cultural probe asks the user 10 questions. with the following goals in mind:

- ❍ To identify gaps and opportunities of the caregiving experience
- ❍ To understand the needs of the caregivers
- ❍ To create a resource guide for other caregivers

Questions

Q1: Start with basics:

1. Caring for (Relationship): Father/Grandfather/Mother etc
2. Age:
3. Your Age:
4. Caring Since: (number of months/years)

(Purpose: Gives data on who they care for most/age of the client and their age)

Q2: My biggest challenge through this caregiving experience?

(Purpose: Gives data in identifying challenges)

Q3: Greatest discovery about myself (The good, bad and ugly)….

Example: "I didn't know I had this much empathy" "Oh I hate cleaning the poop!"

(Purpose: Reflect on a person's capacity. Helps acknowledge themselves)

Q4: Describe something that still brings you joy

(Purpose: Reflect on happy moments, actions, part of the day, phrases etc)

Q5: How am I experiencing grief?

(Purpose: Acknowledge the grief experienced by the person and gather information on how grief can impact a person, therefore what support might be useful for them)

Q6: What do I perceive I require?

(Purpose: Data can show insights on gaps and consequentially opportunities)

Q7: What do I perceive the person I am caring for requires?

(Purpose: Reflection on what's missing from the patient perspective. Data on gaps and opportunities)

Q8: Best advice I ever received...

(Purpose: Sharing tips for other caregivers)

Q9: Best advice I can give others...

(Purpose: To share stories that can possibly heal, and be a learning experience for others. Also shows you are not alone doing this.)

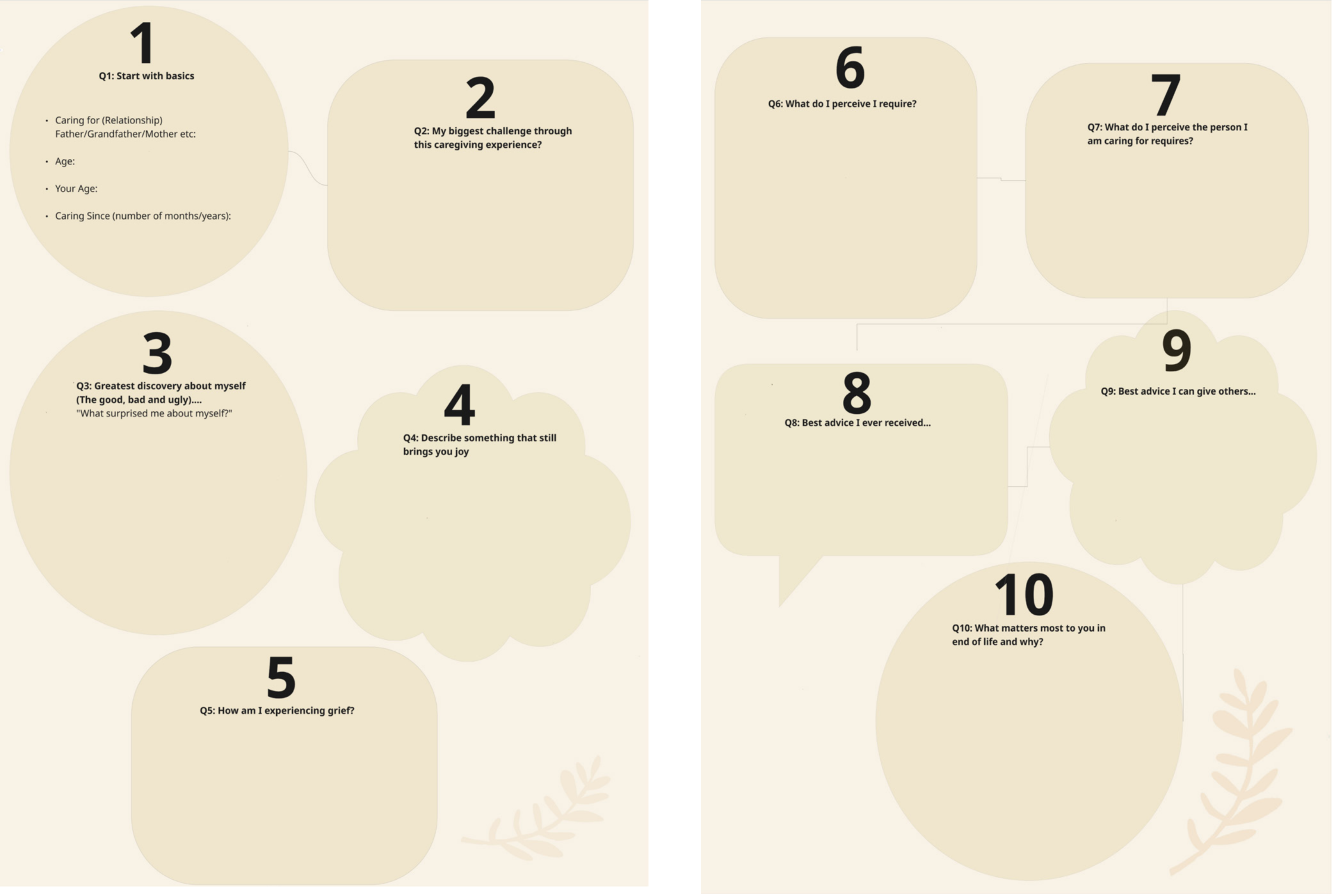
Q10: What matters most to you in end of life and why?

(Purpose: To understand a person's wish and generate themes that emerge as common or different across the participants)

Participant Recruitment

Participants will be recruited via my personal network-caregivers who were already part of the interviews, as well as through a "Call for Volunteer Particpants" poster advertisement in "Voices of Caregivers" an online space managed by the Ontario Caregiver Association that is a network platform for caregivers to engage with each other or learn from each other's experiences.

Sample Design of the Cultural Probe with Ten Questions:



END-OF-LIFE: ACTIVATION PIECE

The End-of-Life Acrivation Piece is designed to reflect and encourage conversations about death, dying, choices at end-of-life and who should be there when you make the choice.

The activation piece has 3 prompts:

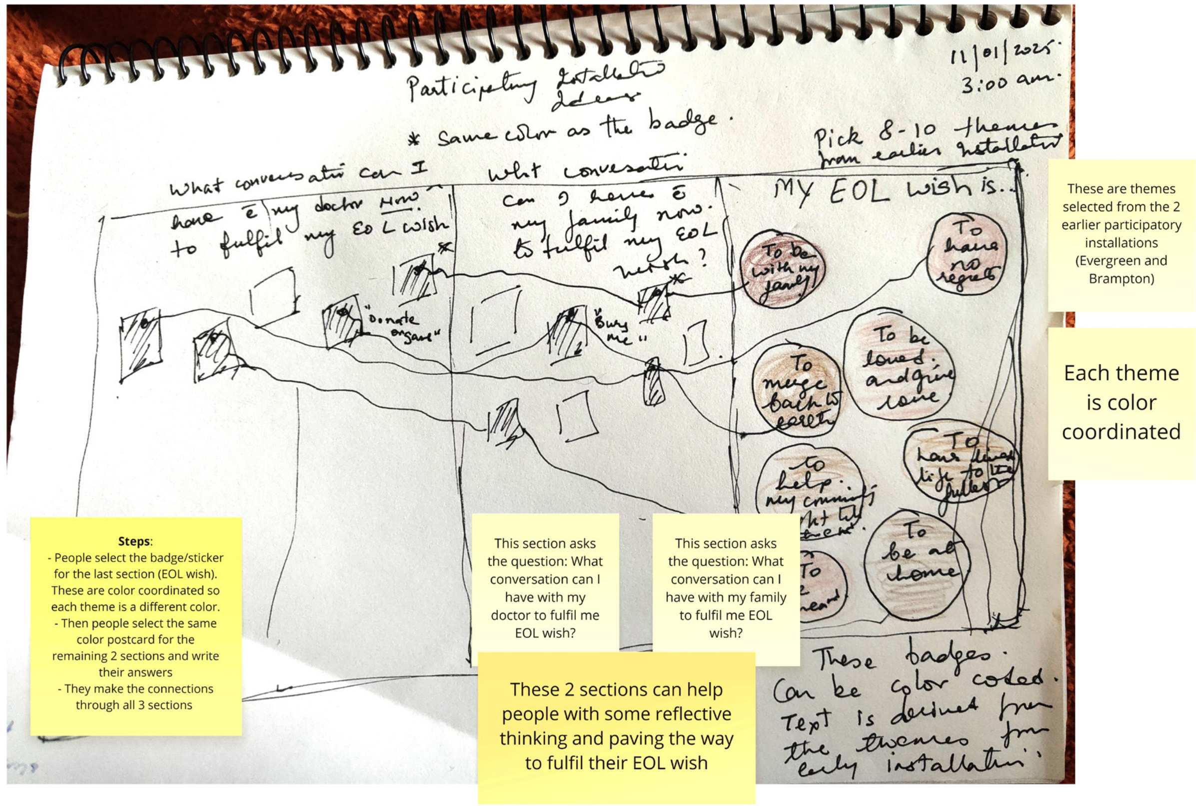
Prompt 1: What matters most to you at end-of-life?

Prompt 2: What can I tell my family today to make my wish come true?

Prompt 3: Who else do I need to talk with today to make my wish come true?

Each individual is required to answer all the 3 questions. The tags will be color coded or linked in a way so that an individual's response is mapped for the 3 questions. Data analysis later will reveal prevalent themes and corresponding needs of the person.

The purpose of this activation is not only to gather data but use the data later as part of the co-design session to build the Social Prescribing resource toolkit.



These are themes selected from the 2 earlier participatory installations (Evergreen and Brampton)

Each theme is color coordinated

Steps:
- People select the badge/sticker for the last section (EOL wish). These are color coordinated so each theme is a different color.
- Then people select the same color postcard for the remaining 2 sections and write their answers
- They make the connections through all 3 sections

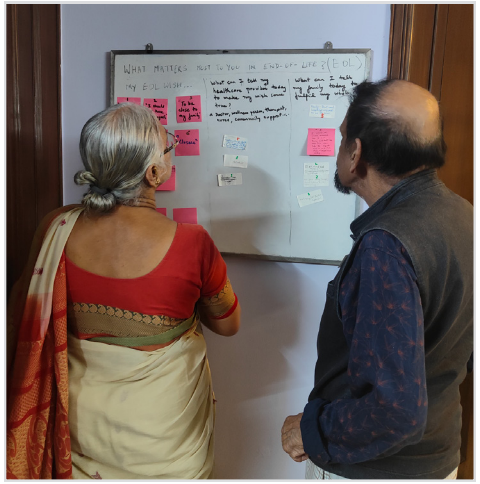
This section asks the question: What conversation can I have with my doctor to fulfil me EOL wish?

This section asks the question: What conversation can I have with my family to fulfil me EOL wish?

These 2 sections can help people with some reflective thinking and paving the way to fulfil their EOL wish

Image: *A first draft of the EOL activation piece and how each prompt will be linked together*

As a test I carried out a low-fidelty model of this activation piece at home with my family in India. And came up with some interesting insights.



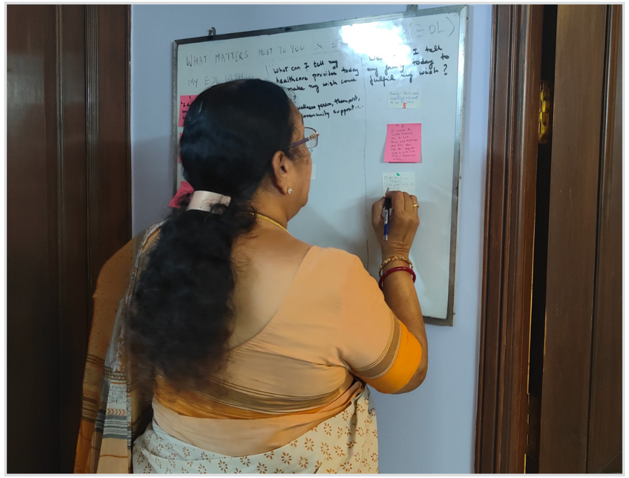
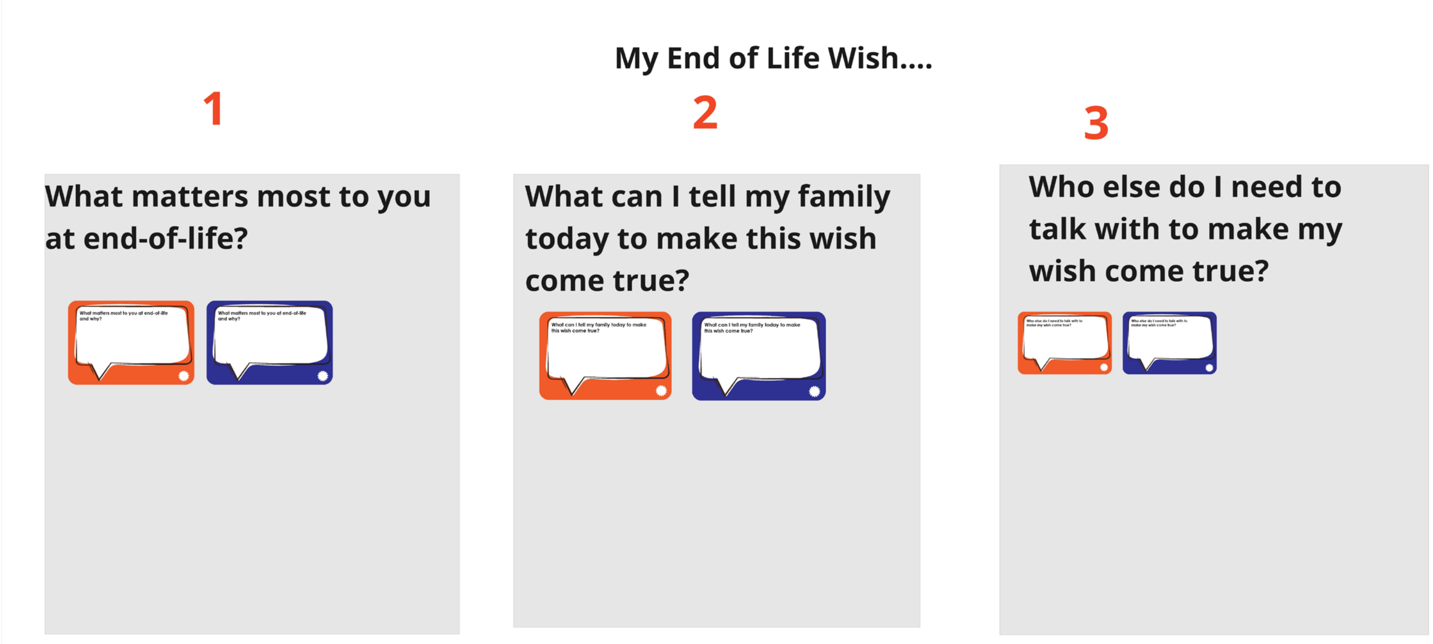


TABLE 1.3 End of Life Activation Piece: Trial with family

Goal of the Interactive Piece	Number of Responses	Observations
• To observe how the audience interacts with the piece. • To observe the questions and thoughts people may have • To note any confusion or doubts about the piece itself (the practical working of it especially connecting the 3 columns together) • Getting the family to talk about EOL	• Number of participants: 9 • Age': Above 65: 5; Above 50 and below 65: 3; Below 50: 1	• Overall family enjoyed the exercise. It was emotional for some of them. • There was an initial surprise expressed by them on the EOL topic. Eg: "Why EOL now itself?" "We want to live much longer." "It is not for young people" • One family member was not able to connect how is the family going to fulfil my EOL wish. "That is on me to work on myself to fulfil my wish." • They were all mostly wanting to write privately and stick their answers on the board so that the others don't know who has written what • Sparked an interesting discussion around EOL wishes and decisions.
• **DESIGN** • Low fidelty piece using whiteboard, markers and post it notes and pens • On 6 sticky notes I had written recurring themes that emerged from the previous art installations at Evergreen Brickworks and Brampton. • The 6 themes were numbered 1-6 and blank post its with the numbers were provided to participants. • If they selected theme 1 from column 1, then they could choose 2 blank post its with number 1 written on it and answer columns 2 and 3.		• **THEMES EMERGING** • No hospitalisation • Prefer to be at home with family and loved ones • No rituals • Die peacefully • Die at home • Family's support is critical and much needed • Helping the community
		• **CHALLENGES WITH THE PIECE** • The numbered themes caused a confusion. • Also pre-existing themes (drawn from earlier exhibitions) limited the thought process • **SUGGESTIONS FOR FUTURE UPDATES:** • Not to number the themes. Think of alternative ways to connect the 3 columns. • Not to have pre-existing themes at all as it feels restrictive • Move family prompt to 2nd column and Healthcare providers to the last column • Have a takeaway with the activation piece

Based on the above experiment, I made some changes to the design and decision on how to connect the 3 columns. All 3 columns will be blank so each individual has the freedom to record their own preferred theme and related answers. The tags are color coded so a set of 3 orange tags, 3 blue tags etc. Only when this activation piece is further tested will I be able to modify and come up with a more refined solution.

The Social Prescribing Resource Toolkit is envisaged as the takeaway from the EOL activation piece, something that an individual can carry back with them. Till such time that the resource toolkit is designed and made available, a reflective bookmark with an action prompt is a suggested takeaway so that people can remind themselves of their wish and who they would like to talk to.



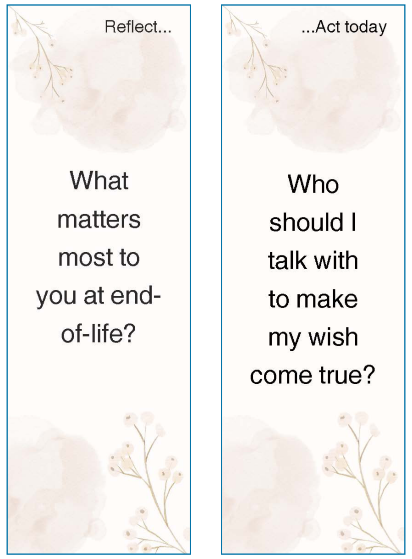


Image: *Front and back sample design of the proposed bookmark*

CONCLUSION

This MRP focused on exploring the potential role of social prescribing in improving care conversations in end-of-life. The preliminary literature review consisted of studies existing in current communication practices between healthcare providers and patients who are in palliative care and their family members/caregivers. The studies were based in Canada as well as some other parts of the world. The Ministry of Health's Ontario Provincial Framework for Palliative Care highlights "how death, dying, grief, and bereavement are all part of life and how everyone can benefit from advance conversations about planning and goals of care (Ontario Provincial Framework for Palliative Care, 2021). The framework report also identified that while "early introduction of advance care planning (ACP) / goals of care (GOC) discussions can improve quality of life" it was often happening late and clinicians were not feeling prepared or lacked adequate skills to have such conversations (Ontario Provincial Framework for Palliative Care, 2021). My study confirmed that the palliative care referrals were coming very late in the care plan and in some cases were not even considered as part of the treatment plan. Conversations between the primary healthcare providers and older adults in end-of-life as well as their caregivers were not happening openly. In my study participants indicated that even when they suggested palliative care, it was disregarded and in one case there was no explanation or suggestion about palliative care at all. What also emerged prominently from the study was the stress and burden of care being undertaken by caregivers. There was emotional, physical, mental stress in coping with caregiving for their family members. Caregiving was not necessarily a choice but something that fell upon them as expressed by one of the partcipant. This is backed by recent survey conducted by the Canadian Centre for Caregiving Excellence in their report Caring in Canada: Survey insights from caregivers and care providers across Canada (Canadian Centre for Caregiving Excellence, 2025). They highlight that impact of caregiving affects the well-being for senior caregivers where 69% reported being tired as a result of caregiving over 5+ hours per day. Other impacts was being overwhelmed, sleep disruptions, depression, fair or poor physical health (Canadian Centre for Caregiving Excellence, 2025).

Furthermore, the concept of Social Prescribing is fairly new and its benefits are still to be fully measured and evaluated. While historically, there have been many models of care focused on connecting people to non-medical supports, but these models have only recently united under the term "social prescribing" (Durden, 2023). The participants in my study expressed mixed awareness about Social Prescribing. While some of the healthcare practitioners in the palliative care had briefly heard about it they were not fully aware. However they did acknowledge the benefits of having a holistic care plan that considered patients at the centre of care and aligns with the goal of the person. There was also a desire expressed by healthcare providers as well as caregivers to have access to resources and support in the community that could help them in the end-of-life care journey. As per the survey insights from the Canadian Centre for Caregiving Excellence, 59% said it was difficult to find information about caregiver support while 55% who attempted to access affordable local services found it difficult to do so (Canadian Centre for Caregiving Excellence, 2025).

This research journey has been exciting, challenging, daunting and exhilirating as well! I started off with some apprehension as I was not familiar with the end-of-life topic but the more I learnt the more I shed my own apprehensions, thoughts, points of view about death and dying. Even when I was interviewing participants I drew so many parallels from my own family stories, the struggle of caregiving, taking care of someone you love, the anxiety, burden but also wanting to do it all was all so familiar.

Social Prescribing is still a new territory. There is evidence of its social, psychologucal and economic benefits and the beautiful part about this service is that it is community-focused and people-focused. People are always at the centre of care. There is not much evidence on how it can impact End-of-Life care yet but from my research it was evident that people need holistic care and support while navigating end-of-life. As they tackle social isolation. loneliness, burden of care, coping with grief, coping with their lives, they look forward to having a support service they can count on that is free, accessible and available easily. They want to know they are not alone in this. And this is something needs further investigation.

As this beautiful journey comes to an end, I hope to continue my work in this field learning more about death, dying and grief and working on building the Social Prescribing Resource toolkit.

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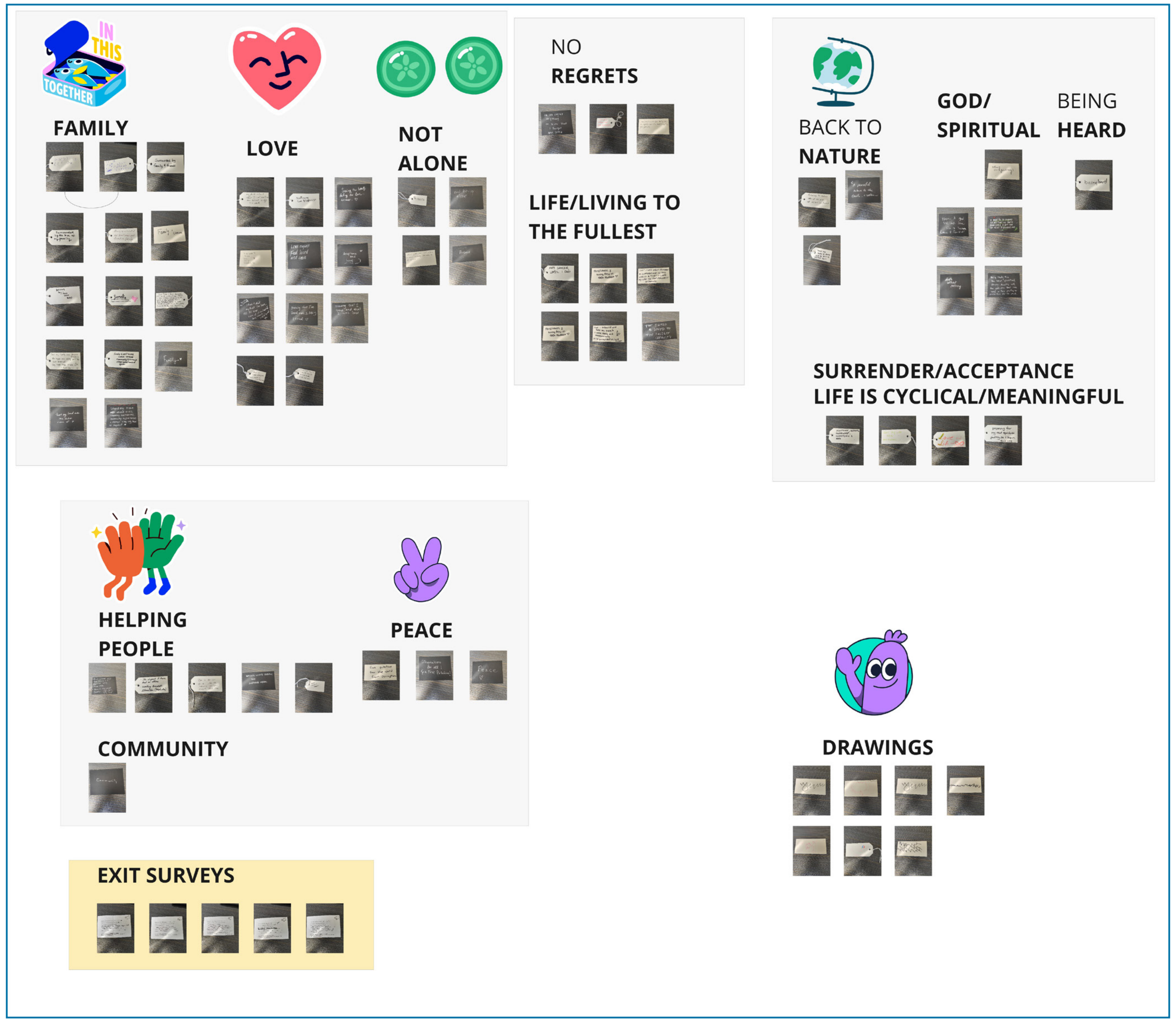
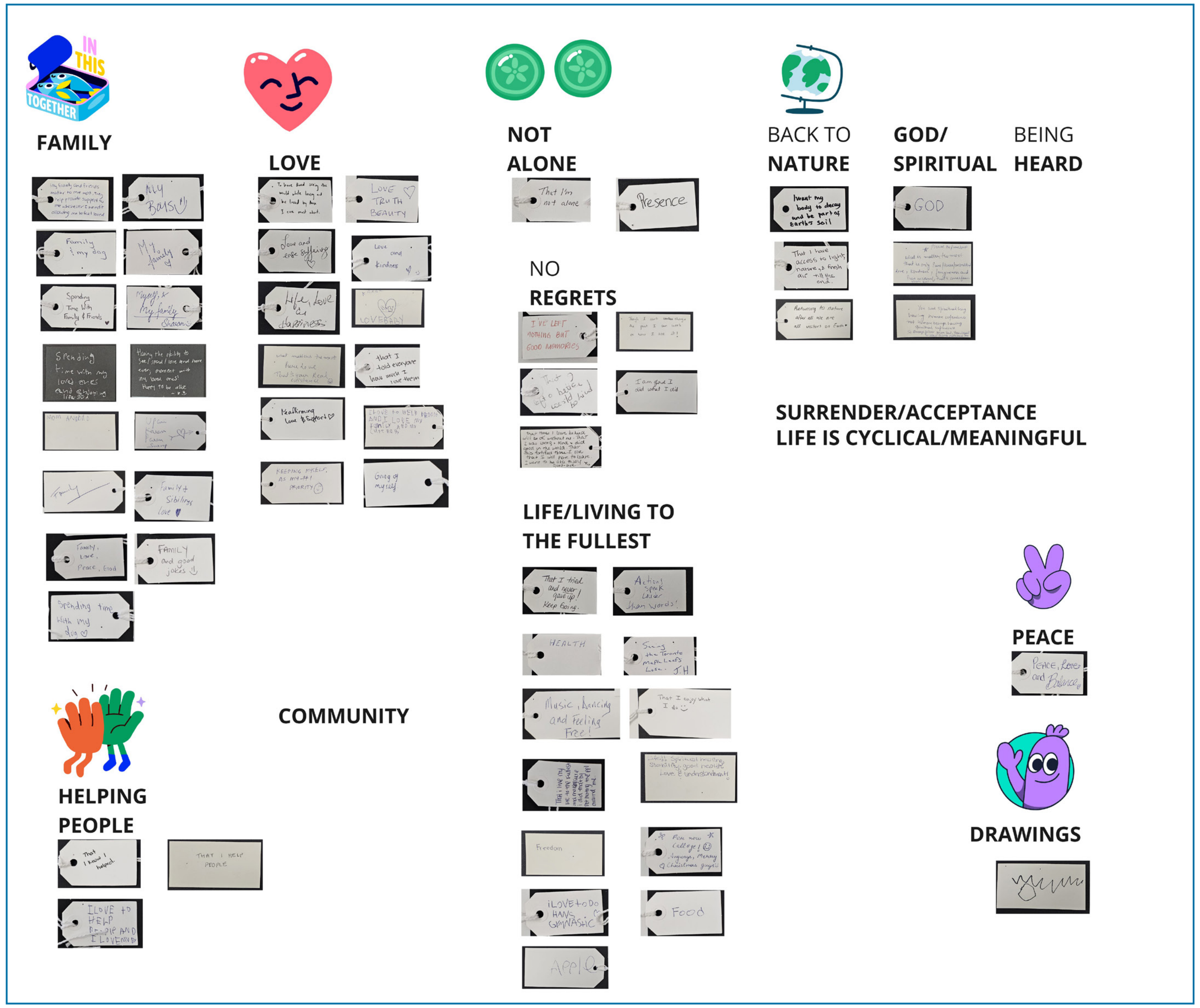
Appendices

Appendix A: Larger-sized images of the participatory art installations at Evergreen Brickworks, Toronto and Brampton Civic Hospital



Themes from Evergreen BrickWorks, Toronto



Themes from Brampton Civic Hospital

Appendix B: Larger-sized images of the sample design of the cultural probe for caregivers

1

Q1: Start with basics

- Caring for (Relationship) Father/Grandfather/Mother etc:
- Age:
- Your Age:
- Caring Since (number of months/years):

2

Q2: My biggest challenge through this caregiving experience?

3

Q3: Greatest discovery about myself (The good, bad and ugly)....
"What surprised me about myself?"

4

Q4: Describe something that still brings you joy

5

Q5: How am I experiencing grief?

Sample Design of the Cultural Probe with Ten Questions

6

Q6: What do I perceive I require?

7

Q7: What do I perceive the person I am caring for requires?

8

Q8: Best advice I ever received...

9

Q9: Best advice I can give others...

10

Q10: What matters most to you in end of life and why?

Sample Design of the Cultural Probe with Ten Questions

“We can’t solve for death, meanwhile we can design towards it.”
— **BJ Miller,** *Ted Talk, 2015*