



RESEARCH ON THE RUN

End of Life Care

The Reflection Room: Moving from death-denying to death-discussing

Thinking about dying and death is something we tend not to do, and those who promote Advance Care Planning for our last days, hours and minutes would like us, to do more. How could we go from being a death-avoiding society to a death-discussing society?

I remember...

Hey Mom Thank you
For the experience I
had with you at the
end of your life.
For all the things I
could have done that
I did not do and to
help the end of your
journey I am sorry
I hope I can have an
impact in other ways.
I love you forever

Project overview

Thinking about dying and death is something we tend not to do, and those who promote Advance Care Planning for the health care in our last days, hours and minutes would like us to do more. However, planning requires us to think about how we want to live our final days and then share those wishes with others. This research proposes the question: How might we use human-centred design and qualitative research to go from being a death-avoiding society to a death-discussing society?

Human beings are storytellers. Understanding complex challenges through narrative builds empathy. Stories also trigger the imagination for future possibility. We propose that providing places for storytelling — and places for reading the stories of others — might trigger more thinking and break through the social complexity that can be a barrier to discussing dying and death.

As part of a year-long research project, we are creating “Reflection Rooms” — both short-term physical spaces across Canada and an online website — where people are invited to write their stories about dying and death and read the stories of others.

Research questions:

1. How might we engage patients and families in shared storytelling as they navigate decision-making at end-of-life?
2. How might collective storytelling about dying and death support the design of human-centred Advance Care Planning experiences?

What are we doing?

At the 2015 Canadian Hospice Palliative Care Conference in Ottawa, we invited attendees to visit the Reflection Room to pause, recharge and remember an experience with hospice palliative care over the past year.

The design of the Reflection Room focused on creating a welcoming and relaxing environment and many elements within the room, such as the use of sound for relaxation and the inclusion of elements of nature, were based on themes that emerged from an earlier spirituality research project.

With the spirituality research in mind, the Reflection Room was also designed to be an immersive experience informed by the process of generative design research and inspired by the public engagement installations of artist Candy Chang.

The intention for the Reflection Room was to adopt a human-centred approach to engage people in reflection and storytelling focused on experiences with hospice palliative care.

Following the CHPCA installation, we iterated on the Reflection Room experience and have hosted several Reflection Rooms across Ontario.

Until December 2017, the research team is inviting people to participate in the Reflection Room in three ways:

- Public Spaces (e.g. libraries, art galleries, etc.)
- Healthcare settings (e.g. conferences, hospice, hospitals, etc.)
- Online (thereflectionroom.ca)

What are our initial findings?

Over the course of the first five installations, many visitors to the room had the opportunity to take a few quiet moments, as well as to write reflections on a card and pin it to the ribbon wall. After each installation, reflection cards are scanned, transcribed and posted to thereflectionroom.ca. Through this process, the research team observed a number of emerging themes:

- Human experiences and “moments in time” were a focus—a conversation with a patient; playing on the floor with a child; receiving a note from a family member.
- Experiences remain in our hearts even though years or decades have passed.
- Relationships are at the centre of the stories whether with a patient, a colleague, a father, mother, brother, sister or friend.
- Expressions of gratitude — for people, experiences, memories — are central.
- Feelings of regret run deep.
- Real appreciation for the invitation to reflect and remember.

Next Steps:

- Planning for approximately 20 travelling Reflection Rooms to be installed in locations across Canada, in both healthcare and public locations
- Stories shared in travelling rooms are transcribed and posted on thereflectionroom.ca
- Ongoing analysis of emerging themes over the next year, culminating in December 2017

How was the research funded?

This research is being funded by the Saint Elizabeth Research Centre.

For more information on this project, please contact:

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About the Saint Elizabeth Research Centre

Saint Elizabeth Health Care has made a strategic commitment to research — \$10 million over 10 years.

At the Saint Elizabeth Research Centre, we study the needs of people, their caregivers, and health care providers to develop innovative solutions to improve health and care experiences across the continuum/ more effective approaches to care. The Research Centre has four areas of focus: integrated care and transitions, end of life care, caregivers and person and family centred care.

Our goal is to improve people’s health and care. We work on innovative solutions for tough problems.

We see *possibilities* everywhere.