The reflection room: Shifting from death-avoiding to death-discussing
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The Reflection Room

Shifting from death-avoiding to death-discussing

Early observations from a year-long research project

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It’s very difficult to make end of life decisions in a time of crisis

There’s nothing more we can do...

What are our options?
Only 25% of Canadians over age 30 have completed plans for end of life

(Environics Research Group, 2013)
70% of people die in hospital when over 50% want to die at home

(Gauvin, Abelson & Lavis, 2013; Environics Research Group, 2013)
Choice at end of life depends on our ability to talk about death and dying

Canadians don’t talk about death and dying
Fear and denial are very real aspects of how Canadians relate to dying and death.

(Arnup, 2013)
“Medicalization of death”

Created an institutional preference to be sick and curable rather than dying and incurable

Limited exposure to death and the dying process

(Arnup, 2013)
Family structures are changing
Research suggests that people who are exposed to dying are more open to discussing it.

(Goodridge, Quinlan, Venne, Hunter & Surtees, 2013)
(Carr & Khodyakov, 2007)
New approaches to support discussion and planning
New approaches to support discussion and planning

Death denying

Death discussing

Death accepting

Human beings are storytellers

(Sanders & Stappers, 2012)
Storytelling effects

It is more likely that people will discuss dying and death if they are exposed to the reality of death and dying through experience.

Hearing or reading true stories about serious medical conditions can increase the familiarity that appears to be a significant catalyst to discussions about end of life.

Stories can be a catalyst to discussion about end of life.

(Mazanderani, Locock & Powell, 2013)
(Ziebland & Wyke, 2012)
Spirituality Research + Participatory Art

(beforeidie.com, Candy Chang)
How might we use human-centred design and qualitative research to go from being a death-denying society to a death-discussing society?
Canadian Hospice Palliative Care Conference
The invitation to share a story
The Reflection Wall
Every hospital should have a room like this
Expanding the project
Planning points of intervention

WITHIN HEALTHCARE

Hospices
Long Term Care Centres
Conferences
Onsite @ Saint Elizabeth
Hospitals

IN PUBLIC SPACES

Community Events
Community Centres
Libraries
Art Galleries
Shopping Malls
Coffee Shops

ONLINE PLATFORM
(thereflectionroom.ca)
Within Healthcare

Hospice Palliative Care Ontario Conference

Heart House Hospice, Mississauga

St. Paul's Hospital, Sasaktoon
Public Spaces

Death Perceptions Exhibit, Wellington County Museum

Art Gallery of Burlington

Tansley Village Retirement Home, Burlington
200 shared stories
1,100 visitors to the website
What have we learned so far?
Relationships are at the centre of the stories
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.
Experiences remain in our hearts

Human experiences and “moments in time”
"Hi Uncle Pete, it's me, Clare..."

"Oh, Clare, it's so good to just hear your voice!"

across many miles, last conversation by telephone, between a young niece and her dying young uncle
Expressions of gratitude & regret
Promises to do better
Sharing learnings
My one regret is that I was so busy looking after your physical comfort that I didn't talk to you about what you would want for me and the family—or to talk more about how you felt and saw things.

Is others facing the loss of their spouse—talk about the things that really matter...
Death is about life
My reflection

My wife’s death was the single most defining moment in my life. I was with her in the hospital at the moment she passed away and it has changed how I look at living, and dying.
Appreciation for the invitation to reflect
My reflection

Being here, now, and feeling a felt shift because I came here to be still and reflect. Thank you for opening this physical space and the space in me today.
People have complex lives
Embedded in complex social networks
Healthcare professionals work within a complex system
Society that is struggling with how, when and with whom we talk about dying and death

Where are the leverage points?
Read some of the reflections in the Reflection Room

I found reading the other pages on the wall put me more at ease about some of my own reflections that I have in my head. It allowed me to see that most of my reflections were not way out there.
Said the experience made them a bit, or a lot, more comfortable thinking about dying and death

Said the experience made them a bit, or a lot, more likely to talk to family and/or friends about dying and death
Of people that did not read reflections or did not write a reflection, ‘not enough time, maybe later’ was indicated as the primary reason.
Physical space can open emotional space.

Time = ‘space’

People often visited more than once.
There are times and places where the leap is too great.

It’s easy to not accept the invitation.
Two leverage points are emerging

The creation of ‘space’
The sharing of the human experience
Further look at ‘time’ and ‘space’

What do we need to know about creating space within our complex lives that acknowledges the complexity, and commonality, of individual experiences?
Our next steps

20 installations between now and June 2017
Better chance of dying where we want, how we want and with whom we want

Before diagnosis

Let’s talk about what we want...

Health crisis

There’s nothing more we can do...

What are our options?
We invite you to take a moment to reflect on your own experiences with dying and death.

thereflectionroom.ca
The Reflection Room is supported by Saint Elizabeth Health Care

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