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

Holyoke, Paul, Oikonen, Karen, Rizzi, Katherine and Sethi, Pam

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Shifting from death-avoiding to death-discussing

Dr. Paul Holyoke, Saint Elizabeth Health Care, Markham
Karen Oikonen, Saint Elizabeth Health Care, Markham
Katherine Rizzi, Saint Elizabeth Health Care, Markham
Pam Sethi, Baycrest, Toronto
Dr. Barry Stephenson, Assistant Professor of Religious Studies at Memorial University of Newfoundland

Abstract

Thinking about dying and death is something we tend not to do, and those who promote Advance Care Planning for the health care in ourlast 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. We will share emerging themes from the research and pose the questions: How might we engage patients and families in shared storytelling as they navigate decision-making at end-of-life? How might collective storytelling about dying and death support the design of human-centred Advance Care Planning experiences?

At the RSD5 Conference we also propose to set-up a Reflection Room pop-up for the duration of the conference and invite people to take a few moments to reflect on their own experiences with dying and death and add them to the reflection wall to continue building the collective story.

Background

More advance care planning is a pan-Canadian goal of the Canadian Hospice Palliative Care Association and the Quality End-of-Life Care Coalition of Canada.[1, 2] Advance care planning is defined as:

> …a process of reflection and communication. It is a time for you to reflect on your values and wishes, and to let people know what kind of health and personal care you would want in the future if you were unable to speak for yourself. It means having discussions with family and friends, especially your Substitute Decision Maker — the person who will speak for you if you cannot speak for yourself. It may also include writing down your wishes, and talking with healthcare providers and financial or legal professionals.[3]

Health care providers are very interested in the outcome of advance care planning – the advance care plan – because a well-formed plan is seen as a way to help avoid unpleasant, rushed, underinformed decisions about care at the end of life (i.e., in the last days and hours before death), and to ensure that care provided to a person in these last days and hours is, to the maximum extent possible, consistent with the patient's wishes.[4]

Given healthcare providers' interest, there has been a heavy focus on initiation, discussion and negotiation of end-of-life goals of care by health care providers. Much research and practice on advance care planning has therefore focused on approaches and techniques for healthcare providers to engage in discussions about advance care planning with their patients and their families.[5] Since healthcare providers usually make contact with patients at the time of recognition of an approaching death, there are considerable efforts to prompt hospital-based providers with effective techniques to engage patients in advance care planning.[5-7]

A recent initiative, The Way Forward,[2] seeks to introduce a palliative approach to chronic disease management, and has introduced the idea that healthcare providers who take a palliative approach should introduce and initiate advance care planning upon diagnosis of a chronic disease rather than nearer the last stages of life.

Research has shown that increasing healthcare providers' comfort with end-of-life discussion tends to make it easier for them to raise the issues. Other research has shown that there is a correlation between patients' knowledge about advance care planning and patients' having advance care plans — but it is not known whether patients who are more inclined to discuss their dying wishes seek out education and complete advance care plans or whether education alone encourages completion of advance care plans.[8]

In a 2015 pan-Canadian study of hospital-based health care providers' perceptions of barriers to their ability to discuss end-of-life care goals with seriously ill patients,[7] the following factors were considered the top four barriers:

(1) family members' or patients' difficulty accepting a poor prognosis,
(2) family members' or patients' difficulty understanding the limitations and complications of life-sustaining treatments,

(3) disagreement among family members about goals of care, and
(4) patients' incapacity to make goals of care decisions.

The providers did not consider their own skills or system factors to be important barriers to these discussions; nonetheless, the researchers called for more training for the health care providers to make them better able to remedy these situations. But the researchers also observed that patients and their families should be helped to be better prepared to make the end of life decisions, and the recommendations were to provide more information of prognoses and life-sustaining treatments. They also suggested that "encouraging patients and their family members to reflect on their preferences, communicate them, and record them in appropriate documents should be a high priority for health care systems" and referred to several websites currently available.

This suggests strongly that discussion, thought and reflection well before a significant illness or disability manifests probably better establishes the appropriate time and frame for discussion about dying and death, and the values and preferences that will come into play as a person approaches dying.

Some researchers and policy makers have considered whether there are broader issues at work that prevent people from thinking about dying and death. In an influential Senate Report from 2010,[9] it was said, "In Canada, we are a death-denying society. We avoid thinking or talking about death." In 1984, sociologist Allan Kellehear[10] argued that at a society level, there is no widespread denying of death, but he did describe various institutional forces that appear to be leading individuals to avoid talking about death. He argued that the "medicalization of death" – and the institutional preference for people to be "sick" and curable rather than "dying" and incurable — appears to have influenced people not to discuss death and dying.
It has been observed that changes in the ability of

science and medicine to prevent death, the rise of a
funeral industry, and the vastly increased availability
of hospitals in the second half of the twentieth century
have distanced people from the experience of death
by relocating the usual site of death from homes to
hospitals, and narrowing the range of people who are
exposed to death to smaller and smaller circles.[11]

A 2013 national poll [12] found that 80% of Canadians
said they were comfortable discussing death, but most
(75%) had not made an advance care plan, largely because
"they hadn't thought about it" (47%). Sixteen per cent,
all over 70 years old, felt they were too young. This poll
suggests that there may be a latent openness to engage
in discussions about values and preferences about dying
and death and that, with appropriate action, that open-
ness might be engaged to help people 'think about it'.

Researchers have observed that familiarity with the
process of dying and death may provide the contextual
factors for people to understand more fully that there
are issues to discuss in advance of the final hours and
days.[8] For example, Carr et al. found that persons
who knew a loved one who had recently experienced
a serious illness or death were more willing to engage
in discussions about end of life care,[13] and they
recommended that health providers wishing to engage
such a person could usefully refer to that story when
discussing end of life planning.

A systematic review suggested that though the
literature is meagre on successful strategies to engage
people in discussions about end of life, those
approaches that do engage people actively are more
likely to provoke fruitful discussion than those that are
more passive (for example, literature and one-way
lectures or information-sharing).[14]

There are many different and innovative ways that
people around the world are endeavouring to engage in
wider community discussions about dying and death.[15]
For example, there are Death Cafés and Compassionate
Communities Café Conversation,[16]. In addition,

there are websites that are focused on issues of dying
and death, with a goal to increase public discussion.
Examples include:

- GYST.com
- OnceI'veGone.com
- Cake (joincake.com)
- Deathoverdinner.org
- Theconversationproject.org
- Begintheconversation.org
- Everplans.com
- Deadsocial.org

These approaches show promise in bringing people
together to discuss death and dying, but it is not known
whether these forums for death-discussing draw people
who are already inclined to engage in these conversations.
If so, they are potentially effective arena, but they may
not be drawing those who are 'death-avoiding'.

Other researchers are focusing on improving "death
literacy," that is, enabling the sharing and acquisition of
the set of skills, knowledge and capacity to gain access
to various aspects of end of life care.[17]

These approaches are, however, generally based on the
discussion of dying and death in the abstract, though
of course, in their conduct, there will undoubtedly be
disclosure of experiences and emotions. A different lens
for creating the conditions for discussions about dying
and death is to focus directly on the stories of those who
have experienced dying and death.[18]

Schenker et al. [19] developed a conceptual model of the
benefits of storytelling for bereaved family members
and an innovative approach to enable storytelling. Those
who participated in the storytelling found the approach
helpful. This affirms other research that has shown that
storytelling can have a positive, healing effect, not only
on the storyteller but also on those who hear or receive
the stories,[19, 20] including when those stories are told or
read online.[21]

Study Design

This study brings together two strands of literature to identify ways to engage people in discussing dying and death before they have a chronic disease diagnosis or a prognosis of imminent death. First, there appears to be an increase in the likelihood that people will discuss dying and death and engage in advance care planning if they are exposed to the reality of death and dying through experience. Second, it appears likely that the hearing or reading stories about serious medical conditions, if they are true stories, can increase the familiarity[20] that appears to be a significant catalyst to discussions about end of life.

The hypothesis for this study is, therefore, that the sharing of stories and experiences about dying and death can be a useful approach to enable people to engage more easily and readily in discussions about dying and death. In turn, being able to discuss dying and death more comfortably, they should be better prepared to think through the issues involved in the end of their own lives.

The Intervention

Human beings are storytellers. When we share our stories, we are able to build understanding of ourselves and others and trigger the imagination for future possibility.[24]

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 was focused on creating a welcoming and relaxing environment and was informed by research findings on spiritual care by Dr. Paul Holyoke, Director of the Saint Elizabeth Research Centre and Dr. Barry Stephenson, Assistant Professor of Religious Studies at Memorial University of Newfoundland. 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 the spirituality research. The intention for the Reflection Room was to adopt a human-centred approach to engage people in reflection and storytelling focussed on experiences with hospice palliative care. With the spirituality research in mind, the Reflection

Reflection wall at the Canadian Hospice Palliative Care Conference in Ottawa, October, 2015
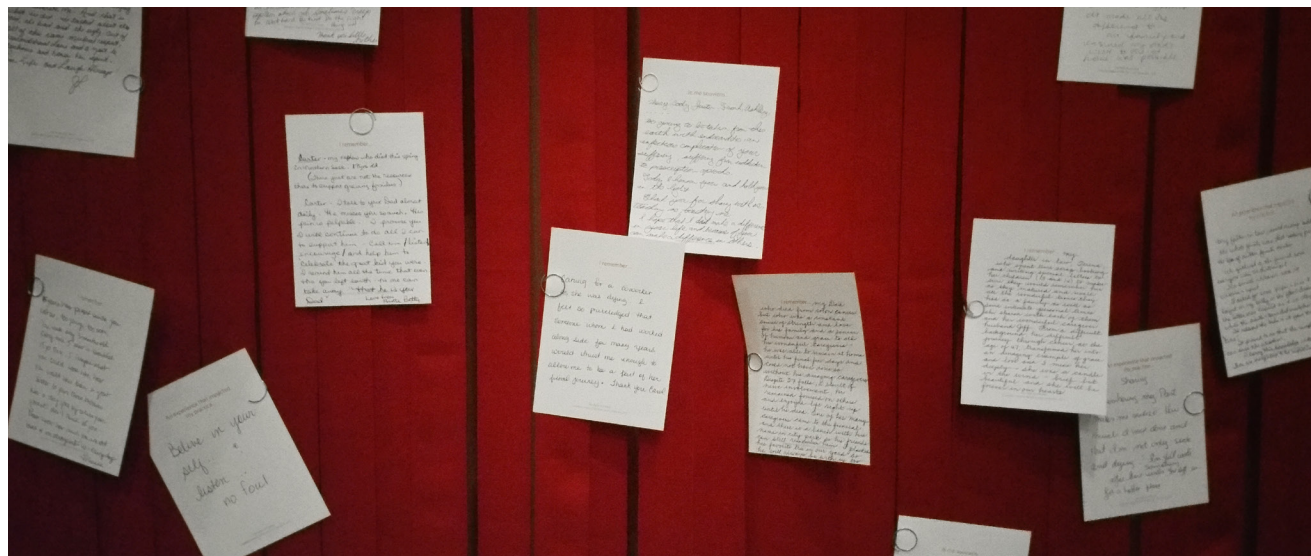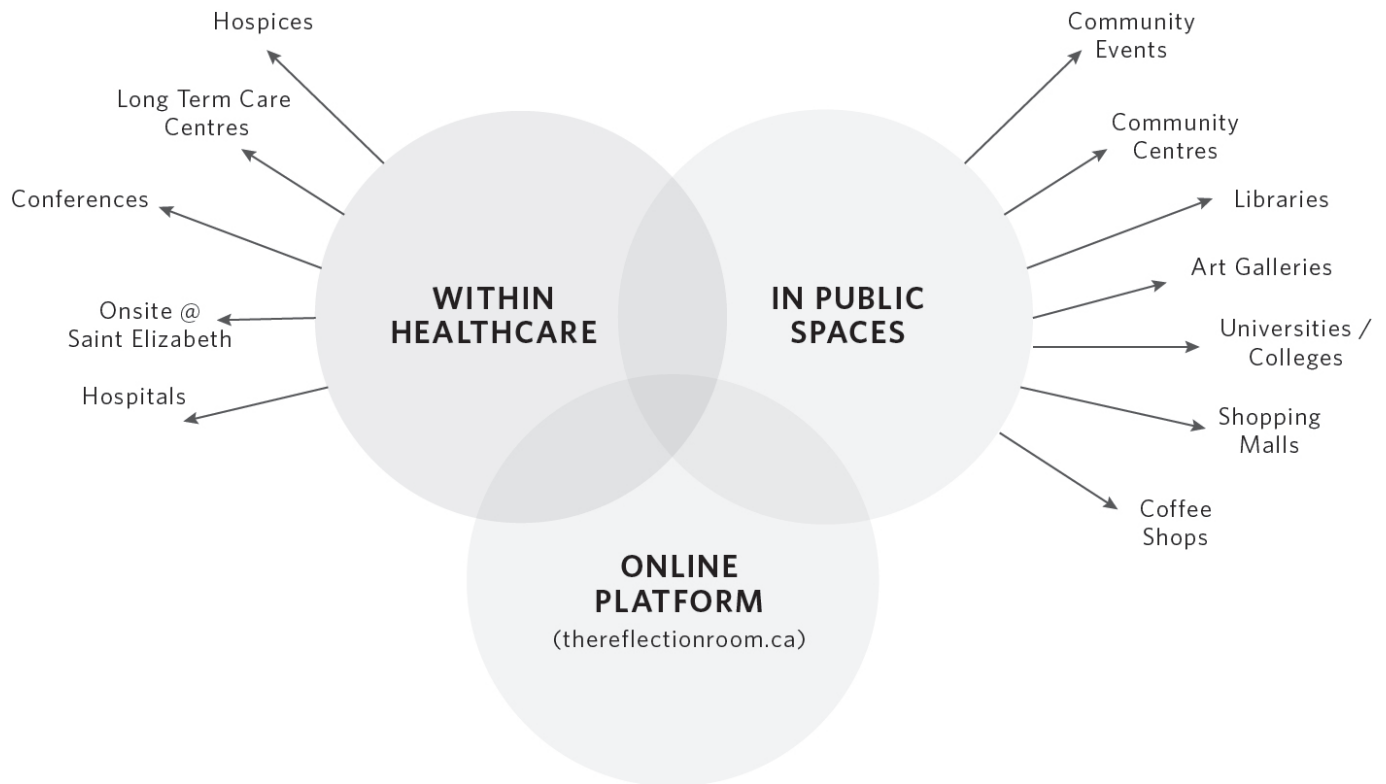
Room was also designed to be an immersive experience informed by the process of generative design research[24] and inspired by the public engagement installations of artist Candy Chang, whose 'Before I die...' series captured the attention of people around the globe[25]. The invitation to share a reflection at the CHPCA conference was meant to provide a unique place for people to tell a story of personal experience and build a collective story of the human experience of dying and death, through reading the stories of others.

Following the CHPCA installation, we have iterated on the Reflection Room experience and have hosted subsequent rooms at the Hospice Palliative Care Conference in 2016, the Toronto Design Offsite 2016 Symposium, in the Service Delivery Centre at Saint Elizabeth in Markham and at a Hike for Hospice outdoor event in Markham.

Expanding the scope of the Reflection Room

Over the course of a year, the research team is inviting collaborative engagement in three ways:

In Public Spaces *(Type A)*
These physical installations of the Reflection Room are purposefully in non-healthcare related locations: rather they will live in the locations of daily life. Although the public conversation on death and dying is increasing, fear and denial are very real aspects of how Canadians relate to death and dying. The public installations of the Reflection might be held in a library, a university or college, an art gallery, a community centre or a shopping mall. Or they might be presented in non-healthcare specific events or conferences such as Toronto Design Offsite in January 2016 and the Relating Systems Thinking and Design Conference in October 2016.

Within Healthcare (*Type B*)

These physical installations of the Reflection Room are directed at clinicians and practitioners who work in hospice palliative care or the broader healthcare sector. Events and locations could be conferences, such as the Hospice Palliative Care Ontario Conference in April 2016, as well as on-site installations at hospices, home care service centres, hospitals or other healthcare related sites.

Online Platform (*Type C*)

TheReflectionRoom.ca serves to create a virtual reflection room where anyone, regardless of their location, will be invited to share a reflection of their experiences with end of life. The online line platform provides space—physical and virtual—for people to share and engage with the stories of others. The focus is on sharing of the human experience and continuing to the build the collective storytelling in support of shifting society's relationship with dying and death from avoiding to discussing.

The differentiation between Type A and Type B is made because there may be a difference between the responses of members of the public and responses of healthcare providers whose work means they encounter dying and death more often.

The goal of the research project is to host up to 50 travelling rooms across Canada, balancing Type A and Type B environments, and supporting each physical installation through the online platform.

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

Initial observation

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

The ongoing engagement process can be viewed online at *thereflectonroom.ca*. We invite you to take a few moments to visit and see the collective story we are building.

I remember... regret

not asking enough questions about your life

not knowing you better

not calling often enough

if I did I would have more (deeper) memories, it hurts me that I don't.

Reflection from the Toronto Design Offsite Symposium, January 2016

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