

The Reflection Room®: Creating Space for Pausing, Reflecting, and Storytelling at the End-of-Life

The COVID-19 pandemic created a tremendous amount of collective loss and grieving that requires care and support.¹ This was as true in residential long-term care (LTC) homes, which continue to experience pandemic-related challenges, as in hospitals and among the general public.² Through the Reflection Room® project, our interdisciplinary team of researchers partnered with LTC homes in Ontario to create physical spaces to pause, reflect, connect, and process grief. The Reflection Room uses quiet reflection and storytelling to generate open dialogue about dying, death, and grief in a way that is accessible, anonymous, and adaptable to community needs.



The Reflection Room® is an evidence-based, participatory art installation that provides an immersive space for visitors to read stories written by others and write and share their own stories on the topic of dying, death, and/or grief. Visitors are invited to “pause, reflect, and share” although engagement with the Room is self-directed and open-ended.

Project Overview

Many LTC home communities were seriously affected by COVID-19.³ On top of the stress from COVID-19 infections and deaths, staff have experienced burnout and low morale,⁴ and some homes with outbreaks must continue to restrict residents’ movements, isolate residents in their rooms, and limit activities such as social functions to reduce risk of spread.⁵ Many within these communities have reflected on the trauma³ the

pandemic has caused. Ontario’s Long-Term Care COVID-19 Commission Final Report⁶ has recommended reforms and counselling services. However, with the immense levels of grief, and feelings of helplessness, regret, and sadness, there is also a need for innovative and timely support for LTC communities.

The Reflection Room pilot project was created in 2016 by the SE Research Centre, led by Dr. Paul

Holyoke from the Centre and Dr. Barry Stephenson from Memorial University of Newfoundland. The goal of the project was to support people in community and health care settings to talk about dying and death.⁷ A research study from 2016-2018 evaluated the impact of 25 Reflection Room installations across Canada. We found the installations created space for expressing emotions (e.g., love and regret) and making sense of experiences related to dying and death such as making meaning of the mystery of mortality; dying and death; and feeling that connections with the soul/spirit/memories can continue after physical death.⁷

Adapting to COVID-19

During the pandemic, the Reflection Room project was adapted to address experiences of loss and grief in LTC homes in Ontario, Canada. The pilot version of Reflection Room project was found to increase visitors' comfort talking about dying and death,⁷ and we thought it might be possible to invite reflections on experiences during the pandemic. The idea behind this is that people able to name their experiences with grief and loss are often able to process and transform their grief.⁸ With grief being under-supported in most areas, it was important to find an innovative and engaging way to support grief and loss in LTC homes.

In this version of the Reflection Room project, an easy-to-set-up 'kit' was designed that incorporated instructions and materials (e.g., Reflection Cards, a red curtain to display Reflection Cards, candles, etc.) at no cost, so that LTC homes could install a Reflection Room adapted to their space. The invitation to visitors was to *"write about your experiences or thoughts about what has happened for you over the course of the pandemic"*.

Supported by Ontario Health's Central Region, Family Councils Ontario and Saint Elizabeth Foundation, a Reflection Room was installed in 32 LTC homes across Ontario, with 19 more still hoping to install a Room.

To understand how a Reflection Room might support pandemic-related grief, we analyzed data from 1) Reflection cards written by people in LTC homes; 2) a survey from staff, residents, and caregivers; and 3) interviews and surveys from staff who set up the Room.

Feasibility and Adaptability

We found that the Reflection Room as designed for this iteration was feasible and adaptable. The Room took little time for staff of LTC homes to set up, promote, and maintain. It was also reported that the Room was adaptable to the various settings, and was installed in various creative places within LTC homes (e.g., chapel, recreation room, meeting room, solarium) and integrated into existing services such as memorials for those who had died.

Pandemic Related Grief Stories

Reflection Cards written by LTC home community members shared stories about the pandemic, including stories about overload (e.g., burnout), loss (e.g., loss of meaningful activities), and restoration (e.g., wanting to return to normal). Additionally, they shared stories about pandemic-related learnings (e.g., the importance of time together), and gratitude (e.g., for receiving good care).

Support for Grieving

Most staff, residents, and caregivers (n=98) recommend the Reflection Room to others because it supports grieving and well-being. These communities felt the Reflection Room was helpful by 1) Offering a quiet restful place; 2) Providing an outlet for thoughts and emotions; 3) Allowing people to reflect and process; 4) Providing additional support; 5) Supporting community building and connection; and 6) Supporting wellbeing for individuals and communities.

What are we doing now?

The research portion of this project has ended, yet dissemination of the work continues. The Saint Elizabeth Foundation is working with various Canadian organizations to distribute Reflection Room "kits" so there can be installations of this

arts-based storytelling initiative that supports grieving and well-being for Canadians, especially in a post-pandemic future.

What will be the (anticipated) impact?

The expectation is that installation of the Reflection Room in various spaces will support communities to grieve and cope together through pausing, reflecting, and sharing stories. The Room may also increase peoples' understanding of grief and activities that can support their grieving through end-of-life journeys.

Visit TheReflectionRoom.ca to read reflections from our installations across Canada:



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References

1. Torrens-Burton, A., Goss, S., Sutton, E., Barawi, K., Longo, M., Seddon, K., Carduff, E., Farnell, D. J. J., Nelson, A., Byrne, A., Phillips, R., Selman, L. E., & Harrop, E. (2022). 'It was brutal. It still is': a qualitative analysis of the challenges of bereavement during the COVID-19 pandemic reported in two national surveys. *Palliative care and Social Practice*, 16, 26323524221092456.
2. Capaldi, C. A., Liu, L., Ooi, L. L., & Roberts, K. C. (2022). At-a-glance-Self-rated mental health, community belonging, life satisfaction and perceived change in mental health among adults during the second and third waves of the COVID-19 pandemic in Canada. *Health Promotion and Chronic Disease Prevention in Canada: Research, Policy and Practice*, 42(5), 218.
3. Chu, C. H., Yee, A. V., & Stamatopoulos, V. (2022). "It's the worst thing I've ever been put through in my life": the trauma experienced by essential family caregivers of loved ones in long-term care during the COVID-19 pandemic in Canada. *International Journal of Qualitative Studies on Health and Well-being*, 17(1), 2075532.
4. Yau, B., Vijn, R., Prairie, J., McKee, G., & Schwandt, M. (2021). Lived experiences of frontline workers and leaders during COVID-19 outbreaks in long-term care: A qualitative study. *American Journal of Infection Control*, 49(8), 978-984.
5. Stall, N. M., Brown, K. A., & Maltsev, A. (2021). COVID-19 and Ontario's long-term care homes. *Journal of Elder Policy*, 1(3), 65-110.
6. Government of Ontario (2022). *Long-Term Care COVID-19 Commission: Final report and progress on interim recommendations*. <https://files.ontario.ca/mltc-ltcc-final-report-en-2021-04-30.pdf>
7. Carter, C., Giosa, J., Rizzi, K., Oikonen, K., Stephenson, B., & Holyoke, P. (2023). The Reflection Room®: Moving from Death-Avoiding to Death-Discussing. *OMEGA-Journal of Death and Dying*, 00302228231192163. <https://doi.org/10.1177/00302228231192163>
8. Canadian Mental Health Association (n.d.). *Loss and grief during the COVID-19 pandemic*. <https://ontario.cmha.ca/documents/loss-and-grief-during-the-covid-19-pandemic>