

The Reflection Room: Participatory art installations to move us from death-denying to death-discussing

Paul Holyoke, PhD, SE Research Centre, SE Health, Canada
Barry Stephenson, PhD, Dept of Religious Studies, Memorial University, Canada
Contact: paulholyoke@sehc.com, bstephenson@mun.ca

Issue

Choice at end of life depends on talking about dying.¹
Fear and denial are part of the reluctance to talk about death.^{2,3}

Theoretical foundation

People are more likely to discuss death if they are exposed to it through experience.^{4,5}
Hearing or reading stories can increase the familiarity with dying and be a catalyst to talking about dying.⁵

The study

We have provided 33 spaces across Canada to give people an opportunity to tell and read stories about dying and death. Visitors to “pop-up” Reflection Rooms can read others’ stories, leave a reflection, or simply enjoy the space. A survey collects data on comfort about talking about dying.

Installations – examples



Results – themes from stories left in the Reflection Room

Gratitude, promises, regret

My reflection...
I will always remember my father's death. It was a painful ending to a noble life. His life had its share of difficulties. His death was hard too at the end. But he stayed as long as he could for us. Love you.

My reflection...
I find myself hesitant to leave this room. I have read every note and while there are lessons, regrets and loss in some, this room is ~~over~~ overflowing with love. It is timeless and transcends our earthly bodies and minds. Our connections to our loved ones are eternal.
Thank you for teaching me this my love.

My reflection...
You both helped me so much, during your lives (together), and after your lives as well. You both helped provide a basis for my understanding of the world, one that is compassionate and anxious, but also profoundly affected by what you experienced as children. I miss you both, but I'm happy that you don't have to see what the world is becoming, again.

I wish I had loved my husband more. I did the best I could. I still talk to him every night and tell him that I loved him. He doesn't answer me back!

Working through grief

My reflection...
Paul, I'll never know the relationship we could have had over the last 10 years not speaking. I couldn't look you in the eye and feel safe anymore after the pain you put me through. Without your apology, I still live in the past. I've moved away and still miss what was never there. I keep your letter "Love you too much not to see you happy so please be happy and love me back! Dad." I'm not happy, but I love you too. Words unspoken.

I wrote a reflection, but couldn't post it when I was done. I ripped it up and discarded it. But I do feel this was extremely helpful. It brought me some closure and peace. Thank you for this. (comment from a survey form)

I loved the fact that at first I could not stay in the room.... It brought out too many emotions. After going back several times, I felt calm and I was able to think, reflect and feel better. I am a person who believes in talking and expressing wishes around death, but this was a healing process for me also. (comment from a survey form)

My reflection...
It is a long time since my parents passed. By now, the "loss" is long forgotten, although it was painful at the time. But I think them every day for the gift of generosity, caring and that magical ability to look beyond themselves. They were both active in the community, always helping others. It was the very act of thoughtfulness which resulted in the best form of help. I can honour their memory by being like them. I will have lived a good life!
Thank Mom & Dad

Letters to the dead

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

My reflection...
Funny thing ah! I've teaching a course on Grief Loss & Death for 21 years, but I was not prepared for the exhibit - too visual, the tables were turned on my concepts. Could be because I had too fun, but some letters of reflection penetrated - the one from June to Dad. Funny thing ah!

My reflection...
My dear family - Mom Dad, Brothers Michael and Harold.
I am the remaining one. Miss each of you even though I know you're in a better place. Wish I could have done more with love -

My reflection...
Didn't get to say goodbye to you Dad - your death was too soon & unexpected. Mum wants to join you & I'm crying (only child) & support her just - not how? Her journey is prolonged & she is so aware; does not wish to enter at LTC home.

Results – surveys

70% said visiting the Reflection Room increased their comfort with talking about dying and death

Three months later...

73% said visiting the Reflection Room increased their comfort with talking about dying and death

79% said they were more likely to talk to their family and friends about dying and death

79% said they had talked to their family and friends about dying and death

82% said they were more likely to think about planning for their own death

28% said they had started about planning for their own dying and death

Discussion

Physical space and time open emotional space to become more comfortable about talking about death. Helping more people move from discussion to planning requires more investigation.



References: 1. Quality End-of-Life Care Coalition of Canada: Blueprint for action 2010 to 2020. Ottawa: Quality End-of-Life Care Coalition of Canada; 2010. 2. Carstairs S: Raising the bar: a roadmap for the future of palliative care in Canada. Ottawa: The Senate of Canada; 2010. 3. Arup K: Death, dying and Canadian families. Ottawa: Vanier Institute of the Family; 2013. 4. Goodridge D, Quinlan E, Venne R, Hunter P, Surtees D: Planning for serious illness by the general public: a population-based survey. ISRN family medicine, 2013, Article ID 483673. <http://dx.doi.org/10.5402/2013/483673>. 5. Carr D, Khodyakov D: End-of-Life Health Care Planning Among Young-Old Adults: An Assessment of Psychosocial Influences. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences 2007, 62(2):S135-S141. 6. Abba K, Byrne P, Horton S, Lloyd-Williams M: Interventions to encourage discussion of end-of-life preferences between members of the general population and the people closest to them-a systematic literature review. BMC palliative care 2013, 12(1):1. 7. Mazanderani F, Locock L, Powell J: Biographical value: towards a conceptualisation of the commodification of illness narratives in contemporary healthcare. Sociology of health & illness 2013, 35(6):891-905.