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

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Issue	Theoretical foundation	The study
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}	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	We provided 39 non-coercive spaces across Canada to give people an opportunity to tell and read stories about dying. 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 Rooms

Gratitude, promises, regret	Working through grief	Letters to the dead
<p><i>My reflection...</i></p> <p>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.</p> <p><i>My reflection...</i></p> <p>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.</p> <p>Thank you for teaching me this my love.</p> <p><i>My reflection...</i></p> <p>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 curious, 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.</p> <p>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!</p>	<p><i>My reflection...</i></p> <p>Dad, 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.</p> <p><i>My reflection...</i></p> <p>It is a long time since my parents passed. By now, the "how" is long forgotten, although it was painful at the time. But I think though 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. If I can borrow their memory by being like them, I will have lived a good life!</p> <p>Thank Mom & Dad</p> <p><i>My reflection...</i></p> <p>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)</p> <p><i>My reflection...</i></p> <p>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)</p>	<p><i>My reflection...</i></p> <p>My dear family - Mom, Dad, Brothers Michael and Harold.</p> <p>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 -</p> <p><i>My reflection...</i></p> <p>Didn't get to say goodbye to you Dad - your death was too soon & unexpected. Mum wants to join you & I'm trying (only child) to support her quest - but how? Her journey is prolonged & she is so aware; does not wish to enter at LTC home.</p> <p><i>My reflection...</i></p> <p>Funny thing eh! I've been teaching a course on Grief Loss & Death for 21 years, but I was not prepared for the exhibit - too visual, too tactile, were turned on my concepts. Could be because I had too few, but some letters of reflection personalized - one from June to Dad. Funny thing eh!</p>

Results – surveys

70%	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	82%	said they were more likely to think about planning for their own death
Three months later					
73%	said visiting the Reflection Room increased their comfort with talking about dying and death	79%	said they had talked to their family and friends about dying and 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.

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