

Grief in The Age of Medical Assistance on Dying: Understanding Risk, Support, and Lived Experience

Distress and Crisis Ontario is very pleased to provide Knowledge-user Collaborator support to an application at the Canadian Institutes of Health Research, submitted by lead researcher, Susan Cadell from the School of Social Work, Renison University College at the University of Waterloo.



From the work of our member organizations, we have learned that unfortunately, our society often stigmatizes and minimizes grief. Generally, we avoid grieving people and want grief to be over quickly.

Research in the area of grief is rich, and theory has evolved over the years. One of the newer approaches to grief is the public health model, which identifies categories of grief-related distress and their prevalence. The model was developed in Australia but has not been confirmed in Canada. While much is known about grief in general, we know little about it in the context of Medical Assistance in Dying (MAiD).

Canada is one of the few countries where MAiD is legal. In other jurisdictions where MAiD has been legal for longer, grief has not been a major research focus. This is alarming, considering the impact that end-of-life care has on the family and the challenges that some people face in bereavement. Knowing how MAiD influences grief is essential as we learn about and improve the enactment of this new end-of-life care practice.

There are two overarching research purposes. One is to test the public health model of grief in Canada, and second, to better understand how MAiD impacts grief. The research will achieve these by answering the following questions:

RQ1. What are the proportions of all grievers (both those who did and did not experience a death with MAiD) who evidence low, medium, and high bereavement risk and support needs in Ontario?

RQ2. What is the level of bereavement risk and support needs of grievers in Ontario when death occurs through MAiD?

RQ3. What is the lived experience of grievers when death occurs through MAiD?

The mixed method project has three phases; in phase One, quantitative (RQ1 and RQ2) and qualitative (RQ3) data is collected. To address RQ1 and RQ2, using a cross-sectional approach in Ontario, the province with the largest population and the highest number of MAiD deaths to date, we will survey those who are grieving any kind of death 6 to 32 months earlier.

The piloted survey instruments ask about the supports, perceived needs, and whether these were met. In-depth qualitative interviews will take place simultaneously with people who have experienced a MAiD death.

Phase Two involves combining the analyzed data of the Phase One components to expand the breadth and depth of the overall results. Phase Three involves knowledge transfer and meeting with knowledge users.

The study will use a survey and interviews in Ontario in order to determine levels of risk and understand the lived experience of those who are grieving. Participants will be recruited throughout the province via social media in both English and French. Another advantage of using social media is the advantage of accessing multiple people who are impacted by someone's death. The study will place special emphasis in recruitment on ensuring that the sample includes those who are grieving a MAiD death. Analysis of the survey will include comparing non-assisted deaths to MAiD deaths and general statistics. The results will be classified by risk categories as articulated by the study collaborators who developed the Australian model.

Data will be analyzed and presented at conferences and in public forums as well to the media. The findings will improve understanding of the public health model of grief and will also allow us to better understand MAiD and how its implementation

affects people in the new landscape of Canadian end-of-life care. Ultimately, the research will contribute to the field of end-of-life care by providing evidence to inform the provision of services to those who are grieving.

This project will invite anyone who is bereaved to participate. Death and grieving are not necessarily gendered, but the ways that people express their grief in society can be. Further, the majority of informal caregiving to family members with terminal illness in this country is provided by women, and experiences in caregiving can be influential in shaping the bereavement experience. Further, men are typically under-represented in bereavement research.

The study will account for gender considerations in two ways: the study will make a deliberate attempt to recruit men in the sample, and it will specifically look for similarities and differences in how people of various genders describe their grief. Also, all recruitment materials and other study documents are explicitly inclusive of any person who is grieving regardless of gender, including people who are gender diverse.

We look forward to hearing about the approval of this study project in early 2019 and the prospect of supporting, participating in recruitment and learning from the outcomes of this research. Good luck to Dr. Cadell and the team.