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Dr. Thorne is Professor Emeritus in the School of Nursing at the University of British Columbia, where her long career in the study of chronic illness and cancer experience from the patient perspective became a natural foundation for turning to the study of MAiD in Canada. In addition to her extensive body of clinical research, she has been active in the development of new approaches to qualitative methods to address the knowledge needs of the applied and practice disciplines.

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# Strategizing a Qualitative Research Agenda for the Evolving Practice of Medical Assistance in Dying (MAiD) in Track 2

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## Introduction

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Since the advent of medical assistance in dying (MAiD) in Canada in June 2016, the qualitative research community has been actively engaged in asking and answering questions related to the human and system complexities associated with its practice. While a broad spectrum of research using a full range of methodological approaches has contributed to an increasingly solid evidence base for best practices and support systems, qualitative inquiry has been used to illuminate and document the nuanced experiences of MAiD seekers, their families, caregivers, communities, and the health care providers supporting these patients and/or directly participating in coordination, assessment and provision. These insights gained from qualitative inquiries have helped strengthen the MAiD community's collective recognition of patterns and trends in the complexities of this practice, offering a basis for interpretation and management as our systems evolve and adapt over time.

## Qualitatively Documenting the MAiD Experience

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Early qualitative inquiry on MAiD in Canada primarily focused on documenting how patients and families were experiencing this new end-of-life option, and how health care providers were encountering what amounted to a radical change in their ability to support patients experiencing intolerable suffering. Initial studies began to document a range of experiences, including those of persons pursuing MAiD,<sup>1,2</sup> family members supporting loved ones through the process,<sup>3</sup> physicians involved in its provision,<sup>4</sup>

and nurses caring for patients who had chosen MAiD.<sup>5</sup> Over time, the priorities evolved to target consideration of specific complexities within the MAiD patient and family experience. This included exploring the nature of suffering experienced by patients pursuing MAiD,<sup>6</sup> the ethical complexities surrounding the final consent,<sup>7</sup> the logistical and emotional challenges for families involved in planning a MAiD death,<sup>8</sup> and the factors complicating bereavement following MAiD.<sup>9,10</sup> Researchers focusing on health care providers examined the evolving dynamics of communication associated with MAiD care<sup>11</sup> and the emotional and moral impact of MAiD on physicians.<sup>12</sup> At the institutional level, studies explored such issues as barriers to delivering high-quality MAiD care in various care contexts and workplaces,<sup>13</sup> experiences with institutional objection,<sup>14</sup> regulatory factors influencing access to MAiD,<sup>15</sup> and the ongoing implications of diverse attitudes to MAiD among health system leaders.<sup>16</sup>

## Considering the Evolving Context with Track 2 MAiD

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The 2021 legislation introduced Track 2 eligibility, extending MAiD access to those whose natural death is not considered 'reasonably foreseeable.' This identified a new population whose experiences warranted examination, documentation, and interpretation by the qualitative research community. Although much of Canada had openly welcomed MAiD as an option for those nearing death who were suffering, the expanded eligibility criteria cast MAiD back into the wider public domain as a highly contentious issue. This shift introduced new concerns for MAiD coordinators, assessors

and providers, as well as for the broader group of health care professionals supporting MAiD-seeking patients.<sup>17,18</sup> While MAiD for mental disorder as a sole underlying medical condition was suspended until (at least) March of 2027, the intrinsic inseparability of body and mind within the human experience has placed many clinicians in the position of conducting complex assessments. These assessments often involve persons whose suffering arises from multiple intersecting health factors that are entwined with societal conditions and social determinants of health. As a result, the complex task of eligibility assessment has expanded beyond discerning whether unresolved suffering was occurring to untangling which of the many contributors to that suffering was most responsible, and determining whether all reasonable means for addressing suffering had been offered to the patient.<sup>19,20</sup> Within this context, interpreting such delicate aspects as capacity and voluntariness grew increasingly complex, not only from a clinical perspective but also in ethical and philosophical terms. At the same time, the potential risks for MAiD providers were being heightened by adversaries within the public arena and professional media. For this commentary, we have chosen on principle not to include examples of this kind of writing, although they are readily accessible through any search engine. Sensationalized fearmongering, which often drives narratives, adds a difficult layer of challenge for assessors and providers, who are already charged with highly complex determinations conducted over a much longer period of time in order to ensure the integrity of their processes and reduce their own personal risk.

While the palliative care community expressed some resistance to MAiD in the early years, this tension gradually resolved as many palliative care practitioners and services had found ways to integrate MAiD into end-of-life options, and alternative access points for MAiD-seeking patients had been established over time.<sup>21</sup> However, with the introduction of Track 2 MAiD, opposition persists within segments of the disability and chronic illness communities. Some individuals favoured the option for an assisted death (over alternative outcomes such as death by suicide or accidental overdose), and others voiced concern that MAiD could become a preferred strategy for Canadian society rather than addressing the well-recognized inadequate and inequitable services for those affected.<sup>19</sup> MAiD assessors and providers were thus confronted with the

decision to engage in a practice that required extraordinary levels of effort and commitment in a context of predictable contention and professional risk. Many health care providers who had contributed effectively to Track 1 MAiD ultimately concluded that they could not accommodate the challenges posed by Track 2.<sup>22</sup> However, as Canadian legislation has been established with the understanding that health care systems are obliged to provide a path toward MAiD access for those meeting eligibility criteria, coordination teams were placed in a position of considerable complexity—managing requests from patients whose lives had been profoundly impacted by their conditions and were seeking an assisted death while facing a shortage of assessors and providers willing to participate. Although these systemic inequities and inadequacies are well known to health professionals, meaningful change requires sustained political will and broad societal commitment; it cannot rest solely on the MAiD community.

## Orienting the Ongoing Qualitative Contribution

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Unlike conventional scientific approaches, in which the ‘discovery’ of new facts drives advancements in practice possibilities, qualitative research systematically documents that which is ‘known’ by human actors within a relevant context in a manner that allows for interpretation of that synthesized knowledge into a coherent pattern of understanding that can be shared and communicated. Although each patient is the expert on their own life and illness, systematically studying that expertise embedded across a wide range of patients in comparable situations generates useful conceptualizations of patient experience that can enhance our capacity to deliver optimal care.<sup>23</sup> Similarly, while MAiD practitioners discern patterns within their own practice domains, systematically analyzing and integrating those patterns into shared interpretations deepens our understanding of commonalities in practice, clarifies the implications of exceptional cases, and enhances the insight we can extract from cross comparisons.

While a single case might be discounted as anecdotal, credible findings based on transparent and rigorous analysis of multiple cases can yield understandings that are increasingly applicable beyond the context in which they were developed (albeit not ‘generalizable’ in the statistical sense).

As the body of qualitative findings grows, the insight produced builds a distinctive contribution to the evidence base for practice. When such findings illuminate the lived experiences of those in a particular situation, place them within a broader context, and translate them into conceptual interpretations that inform future developments in that practice, they provide an important guidance for educational strategies, practice guidelines, program development, and system-level policy directions.

In the context of Track 2 MAiD, the Canadian qualitative research community will continue to document, illuminate, interpret, and explain the experiences of all parties affected by the current and evolving legislation, regulatory guidelines, and health system supports. However, it must increasingly move beyond description toward application, by expanding study size, strengthening representativeness in sampling strategies, and diversifying angles of vision and focus. It must also ensure that those most closely in tune with the evolving complexities—such as MAiD coordinators—are actively involved in shaping research questions and the methodological approaches we take toward answering them. Qualitative researchers must also collaborate closely with the broader research community, integrating patterns emerging from national reports and aligning with emerging evidence regarding alternatives for the relief of suffering in its many forms.

Although the qualitative contribution to MAiD in Canada began with a focus on attitudes and experiences, it is also being extended to address the broader societal narratives and discourses, as these are increasingly complicating the lives of both MAiD seekers and practitioners.<sup>24</sup> Qualitative researchers share a collective obligation to acknowledge the contentious social world in which MAiD decisions and practices evolve and to integrate this understanding into their analyses. Qualitative research is also needed for expanding our understanding of institutional cultural change, including the influence of health leader assumptions, biases, and interests in either supporting or compromising safe and ethical MAiD-related practice.<sup>25</sup> Qualitative work can also help us better understand and manage workforce development, including the creation of team-based systems to support care for patients in increasingly complex health and social circumstances, and its intersections with an overburdened primary and social care system.

While one function of qualitative inquiry in evolving social and health care contexts is to identify aspects requiring practice improvements, it is equally important to acknowledge and provide evidentiary support for developments in practice excellence. Ideally, MAiD practitioners, system leaders, and researchers will collaborate actively to identify issues that deserve further inquiry and where further illumination of the delicate complexities and subtle nuances will substantiate and support best practices and optimal outcomes.

It is of fundamental importance that researchers engaged in qualitative work remain aware of their own positionality. To preserve credibility, qualitative inquiry must remain distinct from political or social advocacy (in either direction) so as not to risk seriously compromising the utility of its contributions. Obvious bias renders any research meaningless or worse, and detracts from confidence in the research enterprise. Instead, we must be deliberate and strategic in selecting what to study, how to study it, and how to articulate findings in a manner that advances the practice field and optimally serves the populations for whom the legislation was intended.

## **Concluding Thoughts**

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Qualitative research has unequivocally demonstrated the exceptional care, attention, and thoughtfulness that the MAiD community has brought to this practice in Canada. It has also illuminated the multiple layers of complexity inherent in MAiD for all concerned, and it has helped establish an evidence base that defines a shared vision of rigorous adherence to safeguards alongside supportive and ethical practice within these evolving complexities.

MAiD was introduced in Canada because Canadians brought forward challenges to its prohibition. The continued expansion of requests for it<sup>26</sup> reflects the choices of informed citizens who, as experts in their own circumstances, health care options, and quality of life possibilities, voluntarily request this option. Since 2016, clarity around the practice has evolved because health care providers and health systems have been deeply committed to ‘getting it right’ both in terms of legal transparency in determining eligibility and safety in delivering MAiD services to eligible Canadians experiencing intolerable suffering.

The advent of MAiD in Canada did not reduce palliative care access; rather, it has clearly contributed to its expansion.<sup>21,27</sup> Similarly, there is

strong hope that the attention it brings to societal inequities and health system inadequacies will stimulate concerted attention toward resolving those issues. Ultimately, MAiD is a story that forces us to fully embrace an understanding of that which can be learned from deep engagement with human experience and human experiential knowledge, and to integrate that knowledge into the health systems and supports we design for the future.

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## Financial Disclosures

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