MEDICAL ASSISTANCE IN DYING IN CANADA

Report on a pan-canadian multidisciplinary planning and dissemination meeting to improve practice documents and plan a research agenda.

Background

While Medical Assistance in Dying (MAiD) has been legal in Canada since June 2016 (1), many eligibility criteria are still challenging to assess, especially unbearable suffering and provision of informed consent (2). A person can receive MAiD if their suffering cannot be relieved under conditions that they consider "acceptable," and informed consent implies that this person has given permission for MAiD after receiving all of the information needed to make their decision: that is, their medical diagnosis, remaining treatments, and available options to relieve suffering, including palliative care (3). The evaluation of unbearable suffering is challenging in other countries where euthanasia and physician-assisted suicide, the practices that constitute MAiD in Canada, are legal (e.g., Netherlands, Belgium, Switzerland); particularly, this suffering is often psychological, existential, and social in nature (4).

There have been discussions of the values underlying the Canadian MAiD legislation, which more liberally favours patients' autonomy and choice in determining what treatments are "acceptable." Other countries require a trial of alternatives as a safeguard, acknowledging that suffering can fluctuate (5). According to the Annual Report on MAiD in Canada, requests are mostly motivated by a combination of psychological, existential and social issues, primarily loss of ability to enjoy and engage in meaningful activities (86%) or to perform activities of daily living (83%), loss of dignity (54%), depression (47-52% in scientific literature (6,7)), pain and other physical symptoms (real or anticipated, e.g., fear of dying in pain)(58%), burdensomeness (36%), loss of (or fear of losing) control of bodily functions (33%), and isolation or loneliness (17%)(8). While evidence-based interventions to alleviate suffering exist in palliative care (9,10), it is unclear how suffering is addressed in MAiD within the Canadian context. The ambiguity in legislation and guidelines, in addition to its impacts on patients and families, can increase the sense of responsibility and moral distress in professionals involved in MAiD (11).

Scoping Review

We conducted a scoping review based on PRISMA - ScR guidelines, to better understand how the Canadian scientific literature (SL) and grey literature (GL) defines, assesses, and manages suffering within the practice of MAiD. This study was funded by the *Quebec Research Network on Palliative and End of Life Care/RQSPAL* and the Centre for Research and Intervention on Suicide, Ethical Issues and End-of-Life Practices (CRISE). Data were collected from six databases for the SL and from federal, provincial, and local organizations for the GL (in the provinces of Quebec, Ontario, and British Columbia). Thematic analyses (12) (SL n=570; GL n=537) using NVivo (20% random articles double-coded with regular team discussions) indicate use of a multidimensional definition of suffering, akin to the concept of total pain (13). The assessment of suffering is based upon the patients' subjective reports, creating ambiguity due to an absence of objective criteria and tools, and lack of structured care pathways. Notably, screening for distress, depression or other symptomatology is not systematically or comprehensively undertaken. Interventions to address suffering are minimally described, with active listening proposed as the primary intervention tool. The interdisciplinary team is generally mentioned but not directly involved in the assessment process. The GL does not refer to evidence-based interventions or clinical practice guidelines known to relieve suffering in palliative care. Professionals other than MAiD assessors/providers are recommended to manage suffering; however, the role of an interdisciplinary team is not clearly described, and the availability of resources are reported as restricted. When educational tools are available, they tend to focus on assessing MAiD eligibility criteria.

Planning and Dissemination Meetings

Objectives. Based on the abovementioned findings of our scoping review, we held a Canadian Institutes of Health Research (CIHR) 2-day pan-Canadian virtual Knowledge Dissemination and Research Planning Initiative on July 14-15, 2022, to: 1) disseminate results of our scoping review to stakeholders, and on this basis 2) discuss challenges in how MAiD eligibility criteria are currently defined and evaluated in clinical practice documents, with a focus on discussing improvements to clinical practice documents in definitions, eligibility evaluation, and treatments offered for suffering, based on embodied knowledge and evidence-based practices in the fields of palliative and end-of-life care; and 3) develop a research agenda on MAiD in Canada that focuses on suffering, in order to promote optimal end-of-life care.

Methods. We were guided by the Dialogue Model (DM)(14), a researcher, clinician, patient and family caregiver participatory method for clinical practice document improvements and setting a future research agenda, based on the knowledge transfer model of Prihodova et al. (2019) (15). This model emphasizes the importance of articulating knowledge transfer through three components: the message, the processes, and the stakeholders. The proposed event made it possible to implement each of these components to ensure an optimal transfer of knowledge. In addition, the DM, which corresponds to the process component of the Prihodova model, includes six steps: 1) exploration through literature search and conversations with stakeholders; 2) consultation and engagement through mutual learning; 3) prioritization, including convergence on key research questions; 4) integration of diverse stakeholder perspectives through discussion; 5) programming the research agenda; and 6) implementation of the research agenda. Our planning and dissemination meetings covered the first four steps. The first part of the meetings comprised talks of evidence-based practices to evaluate MAiD eligibility criteria and available options to relieve suffering, including palliative care, the role of assessment tools, healthcare systems factors, education, and patient/caregiver lived experience (See Program and Speaker Biographies below). The second part of the meetings consisted of breakout rooms within session focus areas to discuss improvements in clinical practice documents and research gaps/priorities.

Meeting participants were researchers, clinicians, policy-makers, patients, and family caregivers; including MAiD, palliative care, and suicide prevention fields. Organizations had expertise in the nature of suffering (physical, psychological, existential/spiritual, social, functional) and experience with interdisciplinary teams. They were reflective of MAiD characteristics according to the Report on MAiD in Canada (8), including medical conditions, MAiD provider characteristics (profession, specialty), and practice settings (province, rural/urban).

Results of the Meetings

After the event, the Zoom recordings were transcribed verbatim and a thematic analysis (12) was conducted to describe a list of 1) key areas of improvement in clinical practice documents concerning suffering in MAiD (definitions, evaluation, management); and 2) key research priorities. The thematic analysis identified a total of 15 overarching themes. Within the themes, 37 items fell under clinical practice document changes and 42 under research priorities. The themes and items are found below.

Delphi Study

We conducted a Delphi study (16-18) to reach a group consensus, within 54 participants of the 2-day pan-Canadian meeting, on key areas of improvement in clinical practice documents and key research priorities. Participants included 23 researchers (43%), 21 clinicians (39%), 9 policymakers (17%), and 1 patient/family caregiver (2%). Researchers and clinicians were a convenience sample from the field of MAiD, palliative care, and suicide prevention. Twenty seven were from the province of Quebec (51%), 13 from Ontario (25%), 10 from British Columbia (19%), 1 from Saskatchewan (2%), 1 from Manitoba (2%) and 1 from Nova Scotia (2%). In three rounds of surveys, we asked people to rate on a scale the degree of importance they placed on the identified 15 themes, 37 changes to Canadian MAiD clinical practice documents and 42 research priorities according to the scale 1=Not important, 2= Slightly important, 3=Moderately important, 4=Important, and 5=Very important. Items were considered to achieve a consensus if at least 70% of participants identified the item as either important or very important (i.e., score of 4 or 5 on the scale). Based on the areas that reached consensus, we are providing key points that can be integrated into current clinical practice documents to improve how we assess and address suffering in the context of a MAiD request.

Clinical Practice Document Changes

Instructions: We have held a 2-day pan-Canadian meeting on suffering in Medical Assistance in Dying (MAiD) on July 14-15, 2022, in which were discussed several changes to clinical practice documents as well as research priorities. We are now asking you to rate the discussed items to be able to identify key actionable priorities, more specifically:

- The importance of each of the 15 themes that were discussed in the meetings as they relate to MAiD in Canada;
- The degree of importance you place on the identified specific changes to Canadian MAiD clinical practice documents. MAiD clinical practice documents are any documents that are produced by organizations with a regulatory role over the practice of MAiD.
- The degree of importance you place on the identified research priorities.

Please rate the degree of importance for each of the themes and specific changes mentioned below according to the scale 1=Not important, 2= Slightly important, 3=Moderately important, 4=Important, and 5=Very important.

1 Not important	**2** Slightly important	**3** Moderately important	**4** Important	**5** Very important

Create a core set of standards and ensuing quality indicators for palliative care specifically in Canada to be integrated into the general monitoring system for end-of-life care.

1	2	3	4	5
Not important	Slightly important	Moderately important	Important	Very important

Rating	Frequency
4.24	79%

There is a need to develop standards and quality indicators for palliative care in Canada, allowing the country to initiate palliative care quality improvement and monitor quality end-of-life care. These indicators would be used throughout the provision of care in all major disease trajectories (e.g., cancer, cardiovascular, neurodegenerative disease). A core set of quality indicators would constitute standards for palliative care that are enforced through Accreditation Canada. These indicators are needed in all places where people receive care for chronic life-threatening illnesses, and need to be assessed again at the time of MAiD requests and can serve to inform care options provided or offered during MAiD assessments. The indicators could then be integrated into the MAiD monitoring system through Health Canada and the Canadian Institute of Health Information.

Clinical practice documents	Rating	Frequency
Integrate standards and quality indicators for palliative care specifically in Canada.	4.24	81%

Research priorities	Rating	Frequency
Develop standards and quality indicators for palliative care in Canada to be integrated into the MAiD monitoring system through Health Canada and the Canadian Institute of Health Information.	4.07	68%

Create a core set of existential / psychosocial indicators to be integrated into the monitoring system for end-of-life care.

1	2	3	4	5
Not important	Slightly important	Moderately important	Important	Very important

According to the Annual Report on MAiD in Canada, MAiD requests are motivated principally by existential and psychological distress. There are validated measures of psychological and existential distress available, and some interventions may be effective to address this distress. Included in palliative care indicators, it would be important to develop a core set of psychosocial care quality indicators with the aim of integration into the MAiD monitoring system.

Rating	Frequency
4.08	70%

Clinical practice documents	Rating	Frequency
Integrate a core set of existential / psychosocial care quality indicators in Canada.	3.97	81%
Include a basic psychosocial needs assessment within the context of a MAiD request, considering both patient and family needs.	4.24	79%
Mention interventions that may be effective to address existential and psychosocial distress in a patient requesting MAID.	4.18	79%

Research priorities	Rating	Frequency
Develop a core set of validated quality indicators for existential / psychosocial care in Canada to be integrated into the MAiD monitoring system.	3.92	74%
Develop effective, scalable and acceptable treatments for existential and psychosocial distress.	4.05	79%
Better understand the perspectives of MAiD clinicians with respect to different forms of suffering, their influence on MAiD requests, and how they change over the course of the MAiD trajectory (psychological, practical/social, existential, physical).	3.89	74%
Better understand the perspectives of patients with respect to different forms of suffering, their influence on MAiD requests, and how they change over the course of the MAiD trajectory (psychological, practical/social, existential, physical).	4.47	95%
Better understand the perspectives of family caregivers with respect to different forms of suffering, their influence on MAiD requests, and how they change over the course of the MAiD trajectory (psychological, practical/social, existential, physical).	3.84	74%
Compare provider and patient/family caregiver perspectives on suffering in MAiD requests.	3.50	53%

Theme 3

Implementing an interdisciplinary approach to the care of a patient requesting MAiD.

1 Not important	2 Slightly important	3 Moderately important	4 Important	5 Very important

The suffering that motivates MAiD requests is due to a combination of physical, psychological, practical/social, and existential issues. Considering the nature of suffering in MAiD, there may be a benefit to integrating an interdisciplinary approach in assessment and management of MAiD requests, including palliative care, psychiatrists, psychologists, social workers, nurse practitioners, physiotherapists, occupational therapists, and spiritual counselors. Continuity of care is a priority.

Rating	Frequency
4.24	76%

Clinical practice documents	Rating	Frequency
Establish clear roles, responsibilities, and clinical pathways for each member of the interdisciplinary care team to assess and address suffering in MAiD requests.	4.08	72%
Consider the central role of a nurse navigator in the creation of interdisciplinary teams.	3.52	58%
Mention that the evaluation of suffering is complex and has a therapeutic component, which requires specific training and skills.	3.69	58%
Integrate follow-up and support for patients found to be ineligible for MAID at the time of the assessment.	4.26	84%
Refer to educational curriculum venues for MAiD assessors and providers that comprehensively covers evaluating and addressing suffering.	4.03	74%

Research priorities	Rating	Frequency
Identify brief, validated, and relevant psychometric measures of suffering that can be integrated into MAiD clinical assessments.	3.67	69%
Better understand MAiD assessors' and providers' knowledge and skills in regard to complex assessments of suffering within MAiD requests.	4.05	74%
Develop an educational curriculum for MAiD assessors and providers that comprehensively covers evaluating and addressing suffering.	4.05	76%
Better understand how doctor-patient communication best practices are applied to conversations around suffering within a MAiD request.	4.23	79%
Identify how family and friends can be best supported through the process of MAiD evaluation, MAiD provision, and post-MAiD.	3.83	62%
Better understand health service utilization when patients are found ineligible for MAID.	4.05	74%

Theme 4

There are evidence-based palliative and supportive care guidelines for management of symptoms and distress, and these could be integrated into the MAiD process of assessment. Screening for distress as the 6th vital sign could be more comprehensively covered with inclusion of clinical pathways.

1	2	3	4	5
Not important	Slightly important	Moderately important	Important	Very important

Rating	Frequency
3.72	Text

Screening for distress could be included in MAiD practice documents, considering the bio-psycho-social-existential nature of suffering underlying MAiD requests. A core set of validated measures for psychological/existential/practical/social distress (e.g., depression, demoralization, dignity, social isolation/loneliness) could be made available to MAiD assessors for use in their evaluation, and MAiD assessors and providers could receive education on evaluation of depression and suicidal ideation. Referencing palliative and supportive care guidelines for symptom and distress management appears important.

Clinical practice documents	Rating	Frequency
Integrate current evidence-based palliative and supportive care guidelines for management of symptoms and distress into the process of MAiD assessment and provision.	3.97	72%
Include screening for distress as the 6th vital sign with inclusion of clinical pathways.	3.54	52%
Include a core set of brief validated measures for psychological, practical/social, and existential distress for MAID assessors to use in their evaluation of MAiD requests.	4.00	79%
Integrate the systematic evaluation of depression and suicidal ideation in the assessment of MAiD requests.	3.92	71%

Research priorities	Rating	Frequency
Identify a validated core set of measures to optimally assess suffering in MAiD requests and orient evidence-based interventions to address this suffering.	3.75	63%

Theme 5

Social determinants of health need to be integrated into the evaluation of MAiD requests.

1 Not important	**2** Slightly important	**3** Moderately important	**4** Important	**5** Very important

Socio-economic deprivation and other forms of structural disadvantage can contribute to suffering, and may be challenging to assess and address. Stigmatization and poor health literacy may also play a role in patients refusing palliative and psychosocial interventions. Different models need to be envisaged to increase access to care.

Rating	Frequency
4.34	79%

Clinical practice documents	Rating	Frequency
Integrate the evaluation of social determinants of health as part of a MAiD assessment.	4.21	76%
Integrate an evaluation of unmet needs related to social determinants of health underlying unbearable suffering and indicate whether treatment and therapies exist and are available to the patient, at the hospital and community levels.	4.18	71%
Establish care models that could be used when resources are lacking to address unbearable suffering.	4.13	71%

Research priorities	Rating	Frequency
Understand the contribution of stigma in patients refusing palliative and psychosocial interventions.	3.66	63%
Understand the contribution of health literacy in patients refusing palliative and psychosocial interventions.	3.68	64%

Theme 6

Develop a model for MAiD that is culturally competent.

1	2	3	4	5
Not important	Slightly important	Moderately important	Important	Very important

Medical education is paying increasing attention to cultural competency and sensitivity to diversity. Considerations of culture and diversity may be important when evaluating how patients, caregivers, and healthcare practitioners envision life, death, suffering, and the role of medicine.

Rating	Frequency
4.29	79%

Clinical practice documents	Rating	Frequency
Address issues of cultural competency and sensitivity to diversity in addressing how patients, caregivers, and healthcare practitioners envision life, death, suffering, and the role of medicine.	4.13	74%

Research priorities	Rating	Frequency
Understand the influence of cultural factors on MAiD requests, use of palliative care services, and the assessment of suffering.	4.16	79%
Understand the impact of social and cultural factors on the interpretation of suffering from the perspective of patients, families, and healthcare practitioners.	4.08	76%

Introducing palliative and psychosocial care services early in the disease trajectory.

1	2	3	4	5
Not important	Slightly important	Moderately important	Important	Very important

Practice guidelines for most serious and incurable illnesses emphasize the importance of early or timely integration of palliative and psychosocial care services. There are barriers to timely integration of palliative and psychosocial care, including stigmata vis-à-vis opioids, palliative care, and mental health. There may be ways to address these barriers, including psychoeducation, patient representatives, and a recovery-oriented approach.

Rating	Frequency
4.54	89%

Clinical practice documents	Rating	Frequency
Consider and discuss a palliative approach as early as the onset of diagnosis.	4.34	89%
Offer psychosocial care for identified distress as early as the onset of diagnosis and at crucial times during the disease trajectory.	4.45	92%
Address stigma towards opioids.	3.55	56%
Address stigma towards palliative care.	3.92	68%
Address stigma towards mental health.	4.21	84%

Research priorities	Rating	Frequency
Determine the impact of an early/timely palliative approach on requests for MAiD.	4.21	85%
Determine the impact of early and timely psychosocial care on requests for MAiD.	4.08	71%
Identify how stigmata affect the provision of optimal care in the context of MAiD.	3.68	61%
Identify how stigmata around opioid use affect the provision of optimal care in the context of MAiD.	3.15	59%
Identify how stigma around palliative care affect the provision of optimal care in the context of MAiD.	3.46	54%
Identify how mental health stigma affect the provision of optimal care in the context of MAiD.	4.21	87%

Theme 8

Offer supportive care for people suffering from non-life-threatening conditions.

1 Not important	**2** Slightly important	**3** Moderately important	**4** Important	**5** Very important

Additional safeguards are needed for patients whose deaths are not reasonably foreseeable, such as consultation of physicians specializing in the disease being treated, a 90-day assessment period, and access to supportive care addressing physical, psychological and existential symptoms with practical support.

Rating	Frequency
4.13	79%

Clinical practice documents	Rating	Frequency
Clarify bio-psycho-social-existential issues associated with intolerable suffering (including social determinants of health) in patients requesting MAiD in the context of life-threatening and non-life-threatening conditions.	4.21	79%
Involve a social worker and other psychosocial professionals when the evaluation reveals that social determinants of health are a significant component of suffering.	4.24	79%
Provide a spiritual or pastoral professionals when the evaluation reveals that social determinants of health are a significant component of suffering.	3.20	61%

Research priorities	Rating	Frequency
Understand suffering in the context of MAiD requests associated with non-life-threatening conditions and how this suffering changes with time.	4.08	76%
Characterize how the nature of suffering in the context of MAiD requests associated with non-life-threatening conditions may be different from that of MAiD requests associated with a life-threatening condition.	3.92	71%
Understand the relative contribution of social determinants of health to suffering underlying track 1 versus track 2 MAiD requests.	4.05	74%
Evaluate whether the inclusion of a social work consultation as part of a MAID assessment may affect the suffering reported by people who request MAID under track 2 criteria.	3.56	51%
Evaluate whether the inclusion of a social work and other psychosocial professional consultations as part of MAiD assessment changes the desire for MAiD in patients suffering from non-life-threatening conditions.	3.91	68%
Describe the psychological and practical/social factors involved in desire for hastened death in patients according to their disease trajectory (e.g., cancer, cardiovascular, neurodegenerative disease).	3.74	60%
Better understand what the public believes is an appropriate response to suffering and whether MAiD is a solution to this suffering.	3.24	52%

Theme 9

Maintaining supportive care during the 90-day wait period until MAiD is performed.

1	2	3	4	5
Not important	Slightly important	Moderately important	Important	Very important

Healthcare providers have an obligation to provide ongoing care, including any indicated treatments, to patients who have requested MAID. Continuity of care may help improve suffering, which is beneficial even if the person ultimately proceeds with MAID.

Rating	Frequency
4.27	86%

Clinical practice documents	Rating	Frequency
▪ Reinforce the importance of providing or continuing support for patients and caregivers during the 90-day wait period via community resources and psychological assistance.	4.13	79%

Research priorities	Rating	Frequency
▪ Develop and evaluate a model of care that emphasizes support throughout the 90-day wait period for people requesting MAiD by track 2.	3.95	72%

Theme 10

Reflect complexity in the evaluation of patients with mental health comorbidities requesting MAiD.

1 Not important	**2** Slightly important	**3** Moderately important	**4** Important	**5** Very important

Patients requesting MAiD may have underlying comorbid psychiatric illnesses that may be unidentified or undertreated by the care team. MAiD assessors and providers are in a position to identify and help manage such illnesses, and ensure that alternatives to MAiD have been offered.

Rating	Frequency
4.26	84%

Clinical practice documents	Rating	Frequency
Integrate diagnostic tools to evaluate mental health comorbidities in patients requesting MAiD.	3.95	74%
Outline the various treatment options (pharmacologic, psychotherapy) available for psychiatric illness and psychological distress.	4.18	76%
Evaluate suicidality, and whether suicidality may be affecting a wish to hasten death.	4.05	74%
Integrate best practices related to the development or improvement of resilience and coping strategies when facing mental health comorbidities.	3.65	59%

Research priorities	Rating	Frequency
Better understand resilience and coping within the context of MAiD requests.	3.42	56%
Evaluate the effect of treating underlying psychiatric illness on suffering reported by people requesting MAiD.	4.03	74%

Theme 11

Normalize palliative care as part of health care in order to help destigmatize it.

1	2	3	4	5
Not important	Slightly important	Moderately important	Important	Very important

The stigma surrounding palliative care may prevent individuals from utilizing palliative care themselves or from enrolling family members. A public health strategy with media campaigns designed to educate the public on palliative care in a way that associates it with life and promotes hopefulness may be helpful in overcoming this stigma.

Rating	Frequency
4.08	74%

Research priorities	Rating	Frequency
Develop a public health strategy on palliative care, with media campaigns designed to educate the public on palliative care in a way that associates it with life and promotes hopefulness.	3.83	66%
Engage national leaders and stakeholders to develop and enact a public health strategy on palliative care.	4.10	74%
Better understand public knowledge and attitudes regarding palliative care.	3.71	61%

Theme 12

Integration of suicide prevention in the MAiD evaluation.

1	2	3	4	5
Not important	Slightly important	Moderately important	Important	Very important

Suicide prevention is an important societal imperative. Although MAiD and suicide can be distinct concepts, people who are eligible for MAiD may also be at risk of suicidality. A MAiD assessment should include an assessment of suicidality, and MAiD providers need to have the necessary skill and training to do this. The is also a need to identify who would be at risk of suicide when denied MAiD.

Rating	Frequency
3.76	61%

Clinical practice documents	Rating	Frequency
Integrate assessments of suicidality into MAiD assessments to identify requesters who are suicidal.	3.81	61%
Underscore the importance of identifying those who would be at risk of suicide if deemed ineligible for MAiD.	4.08	77%

Research priorities	Rating	Frequency
Determine the impact of previous suicide attempts on current suffering, and perceived eligibility for MAID.	3.59	57%
Identify differences and similarities between people requesting MAiD and those who are suicidal.	3.65	57%
Explore the ethical dilemma of offering MAiD for patients during a mental illness episode and the role of suicide prevention in these cases.	3.79	62%

Theme 13

Integrate trauma-informed and recovery-oriented models of care.

1	Not important
2	Slightly important
3	Moderately important
4	Important
5	Very important

Rating	Frequency
3.71	59%

A life-threatening or life-limiting condition may cause psychological trauma by forcing people to adapt to changes in body function, activities, and participation in life roles. Trauma Informed Care "realizes the widespread impact of trauma and understands potential paths for recovery; recognizes the signs and symptoms of trauma in clients, families, staff, and others involved with the system; and responds by fully integrating knowledge about trauma into policies, procedures, and practices, and seeks to actively resist re-traumatization." (Substance Abuse and Mental Health Services Administration, 2014, p. 9) Trauma Informed Care emphasises recovery and healing through six principals: (1) safety, (2) trustworthiness and transparency, (3) peer support, (4) collaboration and mutuality, (5) empowerment, voice, and choice, and (6) cultural, historical, and gender issues (SAMHSA, 2014).

Clinical practice documents	Rating	Frequency
▪ Integrate trauma-informed care in palliative care and MAiD practice.	3.60	55%
▪ Integrate recovery-oriented models in palliative care and MAiD practice.	3.31	57%

Research priorities	Rating	Frequency
▪ Determine whether a trauma-informed approach to MAiD assessments may affect the suffering reported by those requesting MAiD.	3.44	51%
▪ Better understand the contribution of childhood and recent trauma to a patient's request for MAiD.	3.15	64%
▪ Better understand best practices in approaching MAiD assessments from a trauma-informed perspective.	3.36	51%

Offer interventions based on hope, dignity, and maintaining a sense of autonomy/control.

1 Not important	**2** Slightly important	**3** Moderately important	**4** Important	**5** Very important

MAiD requests are often based on existential distress and a loss of a sense of control and autonomy. Interventions focused on these threats may help improve their suffering, whether or not they chose to proceed with MAiD.

Rating	Frequency
4.18	77%

Clinical practice documents	Rating	Frequency
Include dignity measures and exploration of patients' suffering.	4.00	71%
Offer dignity therapy and other therapies that may benefit existential distress.	3.78	61%
Implement explanations related to shared decision-making and advanced directives as a means to foster a sense of control and autonomy.	4.03	77%

Research priorities	Rating	Frequency
Understand what triggers a patient to delay MAiD or change their mind about MAiD following a request.	4.08	82%
Understand how hope and hopelessness are addressed in patients requesting MAiD.	3.95	72%
Understand the extent to which knowledge of certain care processes (e.g., advanced directives, palliative sedation) provide patients with a sense of control and change their minds as to MAiD.	3.86	71%
Understand how the awareness and availability of palliative sedation affects the decision to pursue MAiD.	3.50	52%
Better understand the impact of early conversations around MAiD on a sense of control and the eventual pursuit or not of it.	3.96	72%

Theme 15

Consider the effect of MAiD on healthcare provider burnout and emotional and psychological distress.

1	Not important
2	Slightly important
3	Moderately important
4	Important
5	Very important

Rating	Frequency
4.02	74%

Burnout in healthcare professionals has been increasing, especially following the onset of the COVID-19 pandemic. In the context of MAiD, healthcare providers can sometimes face challenges navigating patients' requests and adapting to changes in Canada's MAiD legislation. Providers may experience distress as a result of participating in MAiD assessment and provision, or as a result of being prevented from participating in MAiD assessment and provision (either through institutional policies or other means). Both participation and non-participation may conflict with a provider's values and beliefs. There is a need to ensure that healthcare providers are supported regardless of their involvement in MAiD.

Clinical practice documents	Rating	Frequency
Integrate strategies to prevent and manage healthcare provider burnout, such as providing organizational and mental health support.	4.04	73%

Research priorities	Rating	Frequency
Understand burnout in MAiD assessors and providers, how suffering is addressed, and the impact on clinical practice.	3.94	73%
Understand how the experience of MAiD providers changes over the years.	3.80	60%
Better understand how the experience of MAiD providers changes according to certain contextual factors such as work setting, disease trajectory, and organizational culture.	3.74	54%

References

- Government of Canada (2018). Medical Assistance in Dying. Retrieved December 14, 2021. https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html
- Downie, J. & Chandler, J.A. (2018). Interpreting Canada's Medical Assistance in Dying Legislation. Retrieved December 14, 2021 from https://irpp.org/wp-content/uploads/2018/03/Interpreting-Canadas-Medical-Assistance-in-Dying-Legislation-MAiD.pdf
- Government of Canada (2016). An Act to ammend the Criminal Code and to make related ammendments to other Acts (medical assistance in dying). Retrieved March 30, 2019. https://laws-lois.justice.gc.ca/fra/LoisAnnuelles/2016_3/TexteComplet.html
- Dees, M., Vernooij, M., Dekkers, W. & van Weel, C. (2010). Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: an integrative review. *Psycho-Oncology, 19*(4), 339-352.
- Mishara, B.L. & Weistuub, D.N. (2013). Premises and evidence in the rhetoric of assisted suicide and euthanasia. *International Journal of Law in Psychiatry, 36*(5-6), 427-435.
- Wilson, K., Dalgleish, T.L., Chochinov, H.M., Chary, S., Gagnon, P.R., MacMillan, K., De Luca, M., O'Shea, F., Kuhl, D. & Fainsinger, R.L. (2016). Mental disorders and the desire for death in patients receiving palliative care for cancer. *BMJ Supportive & Palliative Care, 6*(2), 170-177.
- Hudson, P.L., Kristjanson, L.J., Ashby, M. et al. (2006). Desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines: A systematic review. *Palliative Medicine, 20,* 693-701.
- Government of Canada (2022). Third Annual Report on Medical Assistance in Dying in Canada 2021. Retrieved October 7, 2022 from https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2021.html
- Cherny, N.L., Fallon, M.T., Kaasa, S., Portenoy, R.K & Currow, D.C. (2021). Oxford Textbook of Palliative Medicine. New York, USA: Oxford University Press.
- Chochinov, H.M & Breitbart, W. (2012) Handbook of psychiatry in palliative medicine (2nd Edition). New York, USA: Oxford University Press.
- Dorman, J.D. & Bouchal, S.R. (2020). Moral distress and moral uncertainty in medical assistance in dying: A simultaneous evolutionary concept analysis. *Nursing Forum, 55*(3), 320-330.
- Thorne, S.E. (2017). *Interpretive Description: Qualitative Research for Applied Practice*. Routledge.
- Saunders, C. (1958). Dying of Cancer. *St Thomas' Hospital Gazette, 56*(2), 46.
- Abma, T.A. & Broerse, J.E. (2010). Patient participation as dialogue: Setting research agendas. *Health Expectations, 13*, 160–73.
- Prihodova, L., Guerin, S., Tunney, C. & Kernohan, W.G. (2019). Key components of knowledge transfer and exchange in health services research: Findings from a systematic scoping review. *Journal of Advanced Nursing, 75*(2), 313-326.
- Tricco, A.C., Lillie, E., Zarin, W., O'Brien, K.K., Colquhoun, H. et al. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine*. doi:10.7326/M18-0850
- Hsu, C.C. & Sanford, B.A. (2007). The Delphi Technique. *Practical Assessment, Research & Evaluation, 12*(10), 1-8.
- Hasson, F., Keeney, S. & McKenna, H. (2000). Research guidelines for the Delphi survey technique. *Journal of Advanced Nursing, 32*,1008–15.

GENERAL QUESTIONS

Once we have identified priorities in changes to be made to existing clinical practice guidelines, results will be disseminated in practice and research settings. To support dissemination efforts, we would need your perceptions on the following points:

Eighty-one percent of participants reported that they believed their workplace was moderately willing (46%) or totally willing (35%) to make practice and policy changes regarding how suffering is addressed in regard to MAiD. Seventy-three percent of participants reported that they believe their workplace would be moderately able (54%) or totally able (19%) to make practice and policy changes. Facilitators to implementing the changes to clinical practice documents was clinician and patient partners, standardized continuing education on MAiD practice, improved policy development within each Canadian province by the ministry of health and regulatory colleges, and the CAMAP board. Major barriers to implementing these changes to clinical practice documents was a lack of time and resources, a lack of public and funded mental healthcare, the need for better national leadership, more effort to remove the stigma of healthcare providers and citizens towards MAiD, and fear of mistaking a valid request for MAiD with one based on poor social determinants of health.

1 Not at all willing	**2** Slightly willing	**3** Moderately willing	**4** Totally willing	○

- To what extent do you believe your workplace will be willing to make practice and policy changes?

1 Not at all willing	**2** Slightly willing	**3** Moderately willing	**4** Totally willing	○

- To what extent do you believe your workplace will be able to make practice and policy changes?

- What will be the major facilitators to implementing these changes to clinical practice documents?

- What will be the major barriers to implementing these changes to clinical practice documents?

1 Not at all willing	**2** Slightly willing	**3** Moderately willing	**4** Totally willing	○

- To what extent would you be willing to disseminate these priorities for action in your respective workplaces?

- What would you need from us to be able to effectively disseminate these priorities for action in your respective workplaces (e.g. type of documents, support, activities…)?

Other elements

- If any, please mention other clinical practice document changes that we may have missed that would be important to consider as priorities.

- If any, please mention other research priorities that we may have missed that would be important to consider as priorities.

KEY IMPROVEMENTS TO INTEGRATE IN MAID CLINICAL PRACTICE DOCUMENTS

Based on our meetings and Delphi study, the following are key improvements that could be considered for integration in clinical practice documents with the goal of improving assessing and addressing suffering in the context of a MAiD request. The clinical guidelines referenced mainly relate to oncology, as cancer is the main disease in people requesting MAiD in Canada. These guidelines could generically be considered appropriate for other disease sites. However, other guidelines may exist for other diseases involved in MAiD such as cardiovascular, respiratory, neurological, and organ failure. The items having reached consensus for each of the key improvements described are found at the end of this section.

Screening for distress, basic psychosocial needs assessment, and referral pathways

1

Note: While screening for distress itself did not reach consensus in our Delphi study, we are mentioning it here as a tool to address certain items that reached consensus, such as those referring to the importance of identifying sources of distress, conducting a basic psychosocial needs assessment, and integrating the evaluation of social determinants of health. Screening for distress could be used as an entry point and complementary to the MAiD assessments being done. They could also be carried out systematically by the treating team when a patient is requesting MAiD, to ensure that needs are identified and resources properly presented. The Canadian Problem Checklist includes the items typically covered in social determinants of health screening. More specifically, the items that reached consensus and that would support screening for distress are "Offer psychosocial care for identified distress as early as the onset of diagnosis and at crucial times during the disease trajectory", "Include a basic psychosocial needs assessment within the context of a MAiD request", and "Integrate the evaluation of social determinants of health as part of a MAiD assessment.

Evaluating the attribution of the suffering is an important practice standard. It is important to ensure the suffering is due to the medical condition or state of decline and not primarily or solely due to an unmet psychosocial need. A global evaluation of suffering is key in the context of the known multidimensional nature of suffering. It is considered important to offer psychosocial care for identified distress as early as the onset of diagnosis and at crucial times during the disease trajectory. It is estimated that 30-40% of patients will require specialized professional intervention for symptom management and/or distress during their illness, considered essential to improve outcomes.

Screening for distress has been recommended in medical illness for all patients as early as the onset of diagnosis and at crucial timepoints in the illness trajectory, for example using the Minimum Data Set, including the Edmonton Symptom Assessment System (ESAS-r) and the Canadian Problem Checklist (CPC). Screening for distress could be used within the context of a MAiD request to orient care in a way as to address patient suffering. Screening for distress is typically used to identify psychosocial, practical, and physical concerns. It is followed by a basic biopsychosocial needs assessment and proper referrals to address these concerns, factoring both patient and family needs. It is considered essential to clarify bio-psycho-social-existential issues associated with suffering (including unmet needs related to social determinants of health) in patients requesting MAiD in the context of life-threatening and non-life-threatening conditions. Depression and suicidal ideation would be systematically assessed. It is important to mention that different professionals have different areas of expertise in assessing psychosocial, practical, and physical concerns. This is why working in an integrated multidisciplinary team and using a collaborative care approach can be important in addressing the suffering related to MAiD requests.

In addition to screening for distress, a core set of brief validated measures for psychological, practical/social, and existential distress can be used to complement the evaluation of patients' suffering (for example, the PHQ-9 for depression, the GAD-7 for anxiety, the Brief Pain Inventory for pain, the Patient Dignity Inventory to measure dignity-related distress, items of the PRAPARE screening tool for social determinants of health, a single-item or short-form measure of demoralization, hopelessness, loneliness, and/or burdensomeness). There also exists a measure of unbearability of suffering at the end of life, the State Of Suffering-Five (SOSV) scale, which comprises 69 aspects of suffering in five domains: Medical signs and symptoms; loss of function; personal aspects; aspects of the social environment; and nature and prognosis of disease. Without being diagnostic, these tools alongside a clinical assessment can identify emotional distress and social comorbidities in patients requesting MAiD to ensure proper allocation of resources to support them in the process. One would suggest the integration of diagnostic tools to evaluate mental health comorbidities in patients requesting MAiD. This would include tools to systematically evaluate depression and suicidal ideation, and whether they may be affecting a wish to hasten death.

Patients that are ineligible for MAiD at the time of the assessment can be referred to members of the interdisciplinary team, to address their psychosocial, practical and physical concerns. One ought to assess suicide risk in these situations, through initial screening followed by a more complete evaluation and rapid referral process. Continued support via community resources and psychological assistance could be provided to patients and caregivers during the 90-day wait period for patients requesting MAiD in the context of a non-life-threatening condition.

The tools mentioned above could be integrated within the context of a MAiD assessment. A standard form could be developed with topics to cover during the MAiD assessment to ensure that all domains related to patients' suffering are covered in the assessment. CAMAP is developing educational tools on a comprehensive assessment of suffering in MAiD.

To assist in evaluating suicidality, please see:

- Mental Health Commission of Canada (2023). *Suicide Risk Assessment Toolkit: A resource for healthcare workers and organizations*. Retrieved October 10, 2023 from https://www.mentalhealthcommission.ca/wp-content/uploads/drupal/2021-01/mhcc_cpsi_suicide_risk_assessment_toolkit_eng.pdf.
- American Psychiatric Association (2023). *Assessing and treating suicidal behaviors (A quick reference guide)*. Retrieved October 12, 2023 from https://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/suicide-guide.pdf.

For screening for distress practice guidelines, please see:

- Canadian Partnership Against Cancer (2012). *Screening for distress, the 6th vital sign: A guide to implementing best practices in person-centred care*. Retrieved October 10th, 2023 from https://s22457.pcdn.co/wp-content/uploads/2018/12/Screening-Distress-6th-Vital-Sign-EN.pdf.
- For the ESAS, see: go to www.palliative.org and choose «Assessment Tools» under «Health Professionals.» The ESAS is available in different languages: https://www.cancercare.on.ca/cms/one.aspx?objectId=58189&contextId=1377.

For the assessment of psychosocial health care needs, please see:

- Canadian Partnership Against Cancer / Canadian Association of Psychosocial Oncology (2009). *A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient*. Retrieved October 10th, 2023 from https://www.capo.ca/resources/Documents/Guidelines/1.%20Pan%20Canadian%20Guideline-%20Assessment%20of%20Psychosocial%20Health%20Needs%20of%20the%20Adult%20Cancer%20Patient.pdf.
- Groupe de recherche sur la souffrance psychique et l'AMM Département de psychiatrie, CHUM et CRCHUM (2017). Retrieved December 27, 2023 from https://cms.cmq.org/files/documents/Pratiquer-medecine/fin-de-vie/exploration-souffrance-psychique.pdf.

2

Outlining treatment options for suffering as part of consent

As part of the process of MAiD assessment and provision, as required by law one would outline the various evidence-based treatment options (pharmacologic, psychotherapy, other) available to address unbearable suffering, integrating current palliative and supportive care guidelines for management of symptoms, distress, mental health conditions, and underlying social determinants of health. One could consider and discuss a palliative approach as early as the onset of diagnosis as well as involving a social worker and other psychosocial professionals when the evaluation reveals that social determinants of health are a significant component of suffering. There are several clinical practice guidelines that can aid in addressing suffering and would need to be presented to patients as part of consent for MAiD. As part of consent, one would address stigma towards seeking help for suffering, by providing information, normalizing, and addressing any misconceptions and beliefs (ex. stigma towards mental health and related to consultation of a psychologist, psychiatrist, or social worker, and/or taking anti-depressant medication). While proper staffing is considered key to provide psychosocial care and evidence-based interventions for unbearable suffering, one would suggest mapping out resources in the healthcare network to be able to develop pathways and appropriately refer within the system's access constraints, including at the hospital and community levels. Health care models including stepped-care approaches and task shifting could be recommended in situations when resources are lacking to address unbearable suffering. Clear roles, responsibilities, and clinical pathways are key for each member of the interdisciplinary care team to assess and address suffering in MAiD requests. The interdisciplinary team goes beyond physicians and nurses when suffering is at play, the latter context typically requiring collaborative care approaches.

For palliative care guidelines on symptom management, please see:

- National Comprehensive Cancer Network (NCCN) (2023). *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines)*. Retrieved October 12, 2023 from https://www.nccn.org/guidelines/category_3.

For guidelines on psychosocial distress, please see:

- Canadian Partnership Against Cancer / Canadian Association of Psychosocial Oncology (2015). *Pan-Canadian Practice Guideline: Screening, Assessment and Management of Psychosocial Distress, Depression and Anxiety in Adults with Cancer*. Retrieved October 10, 2023 from https://www.capo.ca/resources/documents/guidelines/3apan-~1.pdf.
- National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology: Distress Management*. v2.2023. Retrieved October 10, 2023 from https://www.nccn.org/professionals/physician_gls/pdf/distress.pdf.
- Andersen BL, DeRubeis RJ, Berman BS, et al. (2014). American Society of Clinical Oncology. Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: an American Society of Clinical Oncology guideline adaptation. *Journal of Clinical Oncology*, 32(15), 1605-1619.

For algorithms for cancer-related distress, depression, and global anxiety, please see:

- Canadian Association of Psychosocial Oncology (2023). *Algorithms for cancer-related distress, depression and global anxiety*. Retrieved October 10, 2023 from https://www.capo.ca/resources/Documents/Guidelines/4.%20Algorithms%20for%20Cancer-related%20Distress,%20Depression%20and%20Global%20Anxiety.pdf.

For the role of psychosocial oncology in Medical Assistance in Dying, please see:

- Canadian Association of Psychosocial Oncology (2017). *Role of psychosocial oncology in medical assistance in dying*. Retrieved October 10, 2023 from https://www.capo.ca/resources/Documents/3.3.%20Medical%20Assistance%20in%20Dying.pdf.

3

Communication and culture

Communication comprises core communication skills, discussing an early palliative approach to care, goals of care and prognosis, discussing treatment options and clinical trials, discussing end of life care, using communication to facilitate family involvement in care, communicating effectively when there are barriers to communication, discussing cost of care, meeting the needs of underserved populations, and clinician training in communication skills. An organized communication framework and their accompanying tools can facilitate these discussions. It is suggested to engage in conversations around shared decision-making and advanced directives to foster a sense of control and autonomy and address struggles around uncertainty of prognosis. Advanced care planning materials can be used as an aid. A central documentation system in which these discussions are noted and accessible to all team members can aid coordination and continuity of care as it pertains to addressing suffering. An interdisciplinary model of care with clear communication can aid in providing best of care as it pertains to assessing and addressing unbearable suffering in the context of a MAiD request. Evaluating and intervening in a culturally competent and sensitive way is key, drawing upon cultural resources and/or cultural brokers to facilitate the dialogue, and addressing how patients, caregivers, and healthcare practitioners envision life, death, suffering, and the role of the health care team.

Please see:

- Advanced Care Planning Canada (2023). Advanced care planning in Canada (It's about conversations, it's about wishes). Retrieved December 11, 2023 from https://www.advancecareplanning.ca
- Gilligan T, Coyle N, Frankel RM, Berry DL, Bohlke K et al. Patient-Clinician Communication: American Society of Clinical Oncology Consensus Guideline. *Journal of Clinical Oncology*, 35, 3618-3632.
- Ariadne Labs (2023). *Serious Illness Conversation Guide*. Retrieved October 12, 2023 from https://www.ariadnelabs.org/wp-content/uploads/2023/05/Serious-Illness-Conversation-Guide.2023-05-18.pdf

4

Standards and quality indicators for palliative care in Canada

Standards and quality indicators for palliative care in Canada can be based on the Framework on Palliative Care in Canada https://healthstandards.org/leading-practices/introduction-to-leading-practices/ and on the Canadian Partnership Against Cancer Palliative Care Competency Framework. https://www.partnershipagainstcancer.ca/topics/palliative-care-competency-framework/background/.

Competencies in palliative care include twelve domains of practice:

1. Principles of a palliative approach to care;
2. Cultural safety and humility;
3. Communication;
4. Optimizing comfort and quality of life;
5. Care planning and collaborative practice;
6. Last days and hours;
7. Loss, grief, and bereavement;
8. Self-care;
9. Professional and ethical practice;
10. Education, evaluation, quality improvement, and research;
11. Advocacy;
12. Virtual care.

The indicators in each domains may vary according to the context of care and populations (e.g., pediatrics).

Please see:

Quality indicators in different population

- Mizuno A, Miyashita M, Hayashi A, Kawai F, Niwa K, Utsunomiya A, Kohsaka S, Kohno T, Yamamoto T, Takayama M & Anzai T (2017). Potential palliative care quality indicators in heart disease patients: a review of the literature. *Journal of Cardiology*, 70(4), 335–341. https://doi.org/10.1016/j.jjcc.2017.02.010
- Walling AM, Ahluwalia SC, Wenger NS, Booth M, Roth CP, Lorenz K, Kanwal F, Dy S, Asch SM & Palliative Care Cirrhosis Quality Expert Panel. (2017). Palliative care quality indicators for patients with end-stage liver disease due to cirrhosis. *Digestive Diseases and Sciences*, 62(1), 84–92. https://doi.org/10.1007/s10620-016-4339-3
- Amador S, Sampson EL, Goodman C & Robinson L (2019). A systematic review and critical appraisal of quality indicators to assess optimal palliative care for older people with dementia. *Palliative Medicine*, 33(4), 415–429. https://doi.org/10.1177/0269216319834227

Quality indicators in different settings

- Dupont C, De Schreye R, Cohen J, De Ridder M, Van den Block L, Deliens L & Leemans K (2021). Pilot study to develop and test palliative care quality indicators for nursing homes. *International Journal of Environmental Research and Public Health*, 18(2). https://doi.org/10.3390/ijerph18020829
- Guthrie DM, Williams N, Beach C, Buzath E, Cohen J, Declercq A, Fisher K, Fries BE, Goodridge D, Hermans K, Hirdes JP, Seow H, Silveira M, Sinnarajah A, Stevens S, Tanuseputro P, Taylor D, Vadeboncoeur C, Martin TLW & Scott J (2022). A multi-stage process to develop quality indicators for community-based palliative care using interrai data. *Plos One*, 17(4). https://doi.org/10.1371/journal.pone.0266569
- Takaoka Y, Hamatani Y, Shibata T, Oishi S, Utsunomiya A, Kawai F, Komiyama N & Mizuno A (2022). Quality indicators of palliative care for cardiovascular intensive care. *Journal of Intensive Care*, 10(1). https://doi.org/10.1186/s40560-022-00607-6

5

Integrate a core set of existential/spiritual and psychosocial care quality indicators in Canada

Considering the high prevalence of psychosocial and existential/spiritual components to a patient's suffering when requesting MAiD, in addition to the palliative care indicators above it is considered essential to integrate a core set of existential/spiritual and psychosocial care quality indicators in Canada. Providing appropriate psychosocial and existential/spiritual services is considered a standard of quality cancer care. Main quality indicators include implementing processes to identify patients' psychosocial and existential/spiritual needs through screening for distress, a further comprehensive needs assessment interview, and plans that link patients with the services they need.

Please see:

- Canadian Partnership Against Cancer / Canadian Association of Psychosocial Oncology (2015). *Pan-Canadian Practice Guideline: Screening, Assessment and Management of Psychosocial Distress, Depression and Anxiety in Adults with Cancer*. Retrieved October 10, 2023 from https://www.capo.ca/resources/Documents/Guidelines/3apan-~1.pdf.
- American Society of Clinical Society (2014). *ASCO guidelines – Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer*. Retrieved October 11, 2023 from https://old-prod.asco.org/sites/new-www.asco.org/files/content-files/practice-and-guidelines/documents/depression-anxiety-summary-of-recs-table.pdf.
- Institute of Medicine (2007). *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. National Academies Press: Washington.
- Jacobsen PB, Shibata D, Siegel EM, Lee JH, Fulp WJ et al. (2011). Evaluating the quality of psychosocial care in outpatient medical oncology settings using performance indicators. *Psycho-Oncology*, 20, 1221-1227.
- Cadotte T, Ismail Z, Moody L & Rugg M (2016). Psychosocial oncology quality indicators prioritization exercise. *Journal of Clinical Oncology*, 34(7), Suppl 7, 277.
- Derendorf L, Stock S, Simic D & Lemmen C (2023). Developing quality indicators for cross-sectoral psycho-oncology in Germany: combining the RAND/UCLA appropriateness method with a Delphi technique. *BMC Health Services Research*, 23, 599.

6

Educational curriculum venues that covers evaluating and addressing suffering

MAiD assessors and providers have access to educational curriculum venues that covers evaluating and addressing suffering. These include the nationally accredited, comprehensive, bilingual, Canadian MAiD Curriculum, offered by the Canadian Association of MAiD Assessors and Providers and other educational avenues on all aspects of suffering from different organizations including in palliative care and psychosocial oncology. It is important to receive continuing education and potentially supervision on how to assess and address unbearable suffering in the context of a MAiD request. One needs to recognize the value of multidisciplinary care and the varied disciplines that are involved in addressing unbearable suffering. Team work is key, as well as an integrated model of care.

Please see:

- Canadian Association of MAiD Assessors and Providers (2023). *Canadian MAiD Curriculum*. Retrieved October 12, 2023 from https://camapcanada.ca/curriculum/curriculum-overview/

Items having reached consensus for each key improvement described above

Key improvement 1

- Offer psychosocial care for identified distress as early as the onset of diagnosis and at crucial times during the disease trajectory.
- Clarify bio-psycho-social-existential issues associated with intolerable suffering (including social determinants of health) in patients requesting MAiD in the context of life-threatening and non-life-threatening conditions.
- Integrate an evaluation of unmet needs related to social determinants of health underlying unbearable suffering and indicate whether treatment and therapies exist and are available to the patient, at the hospital and community levels.
- Include a basic psychosocial needs assessment within the context of a MAiD request, considering both patient and family needs.
- Integrate the systematic evaluation of depression and suicidal ideation in the assessment of MAiD requests.
- Integrate the evaluation of social determinants of health as part of a MAiD assessment.
- Include dignity measures and exploration of patients' suffering.
- Include a core set of brief validated measures for psychological, practical/social, and existential distress for MAID assessors to use in their evaluation of MAiD requests.
- Integrate diagnostic tools to evaluate mental health comorbidities in patients requesting MAiD.
- Integrate the systematic evaluation of depression and suicidal ideation in the assessment of MAiD requests.
- Evaluate suicidality, and whether suicidality may be affecting a wish to hasten death.
- Reinforce the importance of providing or continuing support for patients and caregivers during the 90-day wait period via community resources and psychological assistance.
- Underscore the importance of identifying those who would be at risk of suicide if deemed ineligible for MAiD.
- Integrate follow-up and support for patients found to be ineligible for MAID at the time of the assessment.

Key improvement 2

Items having reached consensus:

- Integrate current evidence-based palliative and supportive care guidelines for management of symptoms and distress into the process of MAiD assessment and provision
- Address stigma towards mental health
- Mention interventions that may be effective to address existential and psychosocial distress in a patient requesting MAID.
- Outline the various treatment options (pharmacologic, psychotherapy) available for psychiatric illness and psychological distress.
- Establish care models that could be used when resources are lacking to address unbearable suffering.
- Establish clear roles, responsibilities, and clinical pathways for each member of the interdisciplinary care team to assess and address suffering in MAiD requests.
- Integrate an evaluation of unmet needs related to social determinants of health underlying unbearable suffering and indicate whether treatment and therapies exist and are available to the patient, at the hospital and community levels.

Key improvement 3

- Implement explanations related to shared decision-making and advanced directives as a means to foster a sense of control and autonomy.
- Address issues of cultural competency and sensitivity to diversity in addressing how patients, caregivers, and healthcare practitioners envision life, death, suffering, and the role of medicine.
- Consider and discuss a palliative approach as early as the onset of diagnosis.

Key improvement 4

- Integrate standards and quality indicators for palliative care specifically in Canada.

Key improvement 5

- Integrate a core set of existential / psychosocial care quality indicators in Canada.

Key improvement 6

- Refer to educational curriculum venues for MAiD assessors and providers that comprehensively covers evaluating and addressing suffering

SPEAKERS BIOGRAPHIES

Medical Assistance in Dying (MAiD) in Canada

A Multidisciplinary Pan-Canadian Knowledge Translation Initiative to Improve Practice Documents and Plan A Research Agenda on Suffering in the Context of a MAiD Request

Chair
Melissa
HENRY, DR.

Associate Professor,
Department of Oncology

Dr. Henry is an Associate Professor in the Gerald Bronfman Department of Oncology. She is a FRQS Senior Clinician-Scientist and a psychologist in the Department of Psychology and in the Louise-Granofsky Psychosocial Oncology Program of the Segal Cancer Centre at the Jewish General Hospital. Her research program aims to better conceptualize early determinants of mental health in oncology, leading to the development and testing of interventions to improve the quality of life of cancer patients. Her work combines translational research with a major focus on advanced cancer and head and neck oncology. She developed the FACT/MBIS McGill Body Image Concern Scale – Head and Neck, part of the internationally known FACT Measurement System. She is Co-Director of the FRQS-funded Quebec Research Group in Palliative and End-of-Life Care (RQSPAL) Axis I on optimizing quality of life, a group comprising of over 200 researchers and students across the province of Quebec. Dr. Henry has received funding from the Canadian Institute for Health Research, the Fonds de recherche Sante - Quebec, Genzyme and Roche. She is a board member of the International Psycho-Oncology Society (IPOS) and has received the IPOS Noemi Fisman Award for Lifetime Clinical Excellence. She has served on World Health Organization Committees. Her international work with IPOS and the World Health Organization involves chairing Training Academies designed to build capacity for psycho-oncology in Africa and more broadly for low-middle-income countries.

Jacquie
LEMAIRE

Jacquie Lemaire is a Senior Policy Advisor in the End-of-Life Care Unit, within the Strategic Policy Branch of Health Canada. The Unit is leading federal health policy development related to medical assistance in dying and palliative care. Since 2016, Jacquie has been involved in MAID policy, including federal MAID legislation, regulations and reporting, federal/provincial/territorial collaboration and research.

Tracy
JOHNSON

Director, Health System Analytics, The Canadian Institute for Health Information

As director of Health System Analytics, Tracy Johnson is responsible and accountable for providing the vision, strategic leadership and client/stakeholder relationships to develop analytical products that address priority health information needs, and promote their use. Prior to joining CIHI in 2005, she worked in quality and risk and hospital management, and prior to that in acute care and rehabilitation as a physiotherapist. She holds a Masters of Business Administration from Schulick School of Management at York University and Bachelor of Science in Physiotherapy from University of Toronto.

Ghislaine
ROULY

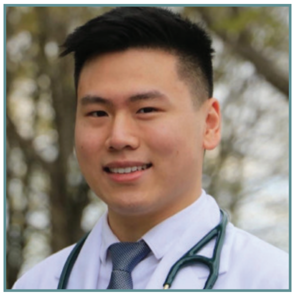
Ghislaine Rouly has been a patient from birth, living with two orphan genetic diseases. She has always been in the health field,(including her first year of Medecine at McGill) where over the years she acquired a unique level of experiential knowledge. Since 2012, at the Faculty of Medicine at the University of Montreal she has been working with the team of the Direction collaboration partenariat patient (DCPP) where she participates in mentoring, giving ethics courses, including the three CSS courses on collaborative practices and also sits on the expert patient committee. In collaboration with Dr. Antoine Boivin, she is working on several research projects, including End-of-Life Care, MAID, also with the Montreal Heart Institute (MHI). She is, also with Dr Boivin, the co-founder of the "Caring Community" and "Compassionate Communities". For more than 50 years, Ghislaine has been involved in end-of-life support and sits on the MAID's governance committees since 2015 and on the Interdisciplinary Support Group (ISG) at the CHUM, at the CIUSSS in the Centre-South and Nord-de-l'Île de Montréal. Since 2016, Ghislaine has worked as a patient partner with the Centre of Excellence on Partnership with Patients and the Public (CEPPP). She is the author and co-author of numerous articles and is involved in research-action with the Canada Research Chair in Partnership with Patients and Communities.

Ali
ALIAS

Ali Alias, MDCM, MSc(PT) is a first-year pediatric resident at McGill University. As per his interest in mental health and end-of-life care, he has been involved in Dr Melissa Henry's Psycho-Oncology lab for the past 6 years and was involved in the Scoping Review that is to be presented during the present meeting on the topic of Suffering within MAiD.

Vanessa
BISSON-GERVAIS

Vanessa Bisson Gervais (she/elle) is a 3rd year medical student at McGill that has been involved within Dr. Melissa Henry's Psycho-Oncology lab since 2020 where she has advanced her interest in the topic of Medical Assistance in Dying. Alongside her medical studies, she stewards engagements in student governance within McGill's Medical Student Society and the Fédération médicale étudiante du Quebec (FMEQ) as political delegate.



Jun
YANG LIU

Jun Yang Liu (he/il) is a 3rd year medical student at McGill that has been involved within Dr. Melissa Henry's Psycho-Oncology lab since 2020 and has been keen on advancing his understanding of the practice of MAiD. Alongside his medical studies, he is engaged in advocacy for patients experiencing with language barriers and in promoting Equity-Diversity-Inclusion principles with medical education.

Brian
MISHARA

Brian Mishara, Director of the Centre for Research and Intervention on Suicide, Ethical Issues and End-of-Life Practices (CRISE), and Psychology Professor at Université du Québec à Montréal (UQAM). has directed national and international suicide prevention NGOs, including the International Association for Suicide Prevention, and works internationally with WHO in training and consulting on national suicide prevention strategies. He held the Bora Laskin National Fellowship in Human Rights Research for studies on assisted suicide and euthanasia. He has published extensively on suicide, gerontology, and ethical issues in suicide prevention and MAID (200+ book chapters and peer-reviewed articles, 11 books). His forthcoming book, with David N. Weisstub, Hard Choices and Practical Ethics: Suicide in the 21st Century, summarizes applied ethics approaches to suicide prevention and medical assistance in dying.

Luc
DELIENS

Luc Deliens, MA, MSc, PhD, is Full Professor of Palliative Care Research, End-of-Life Research Group, Vrije Universiteit Brussel and Ghent University in Belgium. He is member of the Royal Academy of Medicine of Belgium. Since 2000, he is the Director of the End-of-Life Care Research Group, VUB & Ghent University, Belgium (www.endoflifecare.be). He published over 450 papers in medical and public health journals and several book chapters, e.g. for OUP, CUP, Springer etc.

Natalie
EVANS

Dr. Natalie Evans is a Social Scientist with a background in Public Health and Anthropology and a long-term interest in ethics. She is an Assistant Professor at the Department of Ethics, Law and Humanities at AmsterdamUMC and conducts research on complex decision making in health care, aging, palliative care and research integrity. Previous research projects focused on health and social care needs of elderly people living alone in rural Malaysia, patient-physician communication at the end of life, and the influence of culture on end-of-life care.

James
DOWNAR

James Downar is a Critical Care and Palliative Care physician in Ottawa. He is Professor and Head of the Division of Palliative Care at the University of Ottawa, and holds a Clinical Research Chair in Palliative and End of Life Care. He is an adjunct professor at the Australian Centre for Health Law Research at the Queensland University of Technology. He is the co-chair of the Pan-Canadian Palliative Care Research Collaborative and the Treasurer of the Canadian Critical Care Society. He has authored more than 120 peer-reviewed publications, has been principal investigator on more than 20 peer-reviewed grants, and is a former Associated Medical Services Phoenix Fellow. His research interests include communication, decision-making and suffering for seriously ill patients and their families; Palliative Care for the Critically Ill; and Palliative Care for Noncancer Illnesses.

Justin
SANDERS

Dr. Justin Sanders is the Kappy and Eric M. Flanders Chair of Palliative Care and Director of Palliative Care at McGill University. A family and palliative care physician and communication researcher, Dr. Sanders joined the Department of Family Medicine as an Associate Professor of Medicine in 2021, following 8 years at Dana-Farber Cancer Institute, Brigham and Women's Hospital, and the Harvard Medical School. His research and teaching focus on promoting equity in serious illness care through promotion of high-quality communication and authentic healing relationships.

Romayne
GALLAGHER

Dr. Gallagher is a Clinical Professor in the Division of Palliative Care at the University of BC doing teaching and academic writing. She was the founding director of the Division of Palliative Care at the University of BC from 1997 to 2003. During her tenure, Dr. Gallagher established the first public forum on death and dying which ran for 5 years and was replicated by others in North America and Europe. Romayne Gallagher retired from clinical practice in 2018 after 34 years of working in multiple healthcare sectors. She spent 12 years as a family physician doing palliative care consultations before leaving her practice to do full time palliative care in hospitals, long term care and the community. She has been Physician Program Director of Providence Health Care's Hospice Palliative Care program as well as Physician Program Director for the Palliative Care and Residential Care Programs at Providence Health Care. She has over 25 years of experience as a consultant in palliative care. Through her work with the Doctors of BC, Dr. Gallagher helped establish the BC Palliative Care Benefits Program. Dr. Gallagher's other area of clinical and academic interest is chronic pain in older adults. She continues to teach and write about this issue.

Jacynthe
RIVEST

Jacynthe Rivest is an assistant professor in the Department of Psychiatry and Addiction at the University of Montreal and a psychiatrist at the Center Hospitalier de l'Université de Montréal where she provides care to people with cancer with psychiatric comorbidities within an interdisciplinary team. In addition to her clinical duties, Dr. Rivest has research activities in psychosocial oncology and palliative care.

Georgia VRAKAS

Georgia Vrakas is a professor at the Département de psychoeducation of the Université du Québec à Trois-Rivières (UQTR). She obtained her Ph. D. in community psychology at the Université du Québec à Montréal and completed her postdoctorate in public health at the Institut national de santé publique du Québec (INSPQ). She is a member of the Center for Research and Intervention on Suicide, Ethical Issues and End-of-Life Practice (CRISE). Dr. Vrakas is a clinical psychologist as well as a researcher specializing in positive mental health, mental illness and suicide prevention. She also lives with a bipolar disorder and advocates for breaking the stigma around mental illness, addressing the root causes of mental health problems and helping those with mental illnesses live better lives.

Madeline LI

Madeline Li MD PhD is an Associate Professor of Psychiatry at the University of Toronto, and a cancer psychiatrist and Lead of Psychosocial Oncology at the Princess Margaret Cancer Centre in Toronto, Canada. In addition to clinical practice in cancer psychiatry, she conducts collaborative research in the areas of psychoneuroimmunology and psychosocial oncology. She has expertise in end of life care, emotional distress screening and management of mood disorders in cancer. She led the development of the Distress Assessment and Response Tool (DART) program at Princess Margaret and the Medical Assistance in Dying (MAiD) service at the University Health Network in Toronto, and is the scientific lead for the Canadian MAiD Curriculum Development Project whose mandate is to train healthcare professional across Canada in the standardized and safe practice of MAiD.

Isabelle DUMONT

Isabelle Dumont a entre autres travaillé, comme travailleuse sociale, en privée, dans une clinique de médecine familiale (GMF-UMF) et en centre de réadaptation cardiaque. Elle est maintenant professeure régulière à l'École de travail social de l'Université du Québec à Montréal en plus de s'impliquer comme bénévole dans une unité de soins palliatifs. Elle enseigne principalement l'intervention auprès des familles et des proches. Les soins de fin de vie, les soins palliatifs, l'aide médicale à mourir et le deuil font partie de ses principaux champs de recherche et d'intérêts. Isabelle Dumont has worked as a social worker in private practice, in a family medicine clinic (GMF-UMF) and in a cardiac rehabilitation center. She is now a regular professor at the École de travail social de l'Université du Québec à Montréal and is involved as a volunteer in a palliative care unit. She mainly teaches intervention with families and loved ones. Her main areas of research and interest include end-of-life care, palliative care, medical assistance in dying and bereavement.

Harvey
CHOCHINOV

Dr. Harvey Max Chochinov is a Distinguished Professor of Psychiatry at the University of Manitoba and a Senior Scientist at CancerCare Manitoba Research Institute. His research in palliative care has resulted in more than 300 career publications, broaching emotional issues at end of life. He has also led a large program of research on dignity within the healthcare setting. His book, Dignity Therapy: Final Words for Final Days was the 2011 winner of the Prose Award. He is the co-founder of the Canadian Virtual Hospice and editor of The Handbook of Psychiatry in Palliative Medicine (Oxford University Press). He is an Officer in the Order of Canada, and an inducted into the Canadian Medical Hall of Fame.

Stefanie
GREEN

Dr. Stefanie Green spent 10 years in general practice and another 12 years working exclusively in maternity and newborn care before changing her focus in 2016 to medical assistance in dying (MAiD). Dr. Green is the cofounder and current President of the Canadian Association of MAID Assessors and Providers (CAMAP). She is medical advisor to the BC Ministry of Health MAID oversight committee, moderator of CAMAP's national online forum, and has hosted several national conferences on the topic. Beyond her clinical practice, she frequently speaks about MAiD to a wide range of audiences locally, nationally and internationally. She is clinical faculty at the University of British Columbia and the University of Victoria and most recently, is the author of the bestselling book THIS IS ASSISTED DYING, a memoir about her first year providing assisted dying in Canada.

LIST OF CONTRIBUTORS

Justine Albert
Ali Alias
Elizabeth Arpin
Alexandra Beaudin
Vanessa Bisson-Gervais
Mario Blais
Nathalie Boudreault
Valerie Bourgeois-Guerin
Gina Bravo
Glenn Brimacombe
Carl Bromwich
Dr. Alan Chaput
Dr. Janice Chisolm
Harvey Chochinov
Dr. Maria Chung
Audrey Clavet
Philip Crowell
Luc Dargis
Luc Deliens
Geneviève Dorval
James Downar
Julie Dufort
Isabelle Dumont
Patrick Durivage
Pierre Gagnon
Romayne Gallagher
Lynn Gauthier
Valérie Gauthier
Kelsey Goforth
Stéphanie Goulet
David Granovsky
Stefanie Green
Brian Greenfield
Diane Guay
Manon Guay
Mona Gupta
Sally Guy
Maude Hébert
Melissa Henry
Dr. Leonie Herx
Tanya Horsley
Dirk Huyer
Tracy Johnson
Dr. Ebru Kaya
Greg Killough
Geneviève Landry
Andrea Lee
Jacquie Lemaire
Marie-Josée Lewis
Madeline Li
Jun Liu
Helen Long
Stan Marchuk
Isabelle Marcoux
Michael McKenzie
Brian Mishara
Zachary Mokosak
Claudie Morin
Isaiah Muanza
Dr. Viren Naik
Chuks Onwunyi
Barbara Pesut
Laurel Plewes
Dr. Renuka Prasad
Jacynthe Rivest
Stéphane Rivest
Ghislaine Rouly
Justin Sanders
Catharine Schiller
Diane Tapp
François Tardif
Sally Thorne
Lilian Thorpe
Deborah Ummel
Bilkis Vissandjée
Georgia Vrakas
Ellen Wiebe
David Kenneth Wright
Alison Ytsma