About the Authors

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Dr. Sarah Broder practiced as a clinical Respirologist and ICU physician for over 25 years at Penticton Regional Hospital. She has recently transitioned her practice to support hospice care at Moog and Friends. She has been a strong advocate for advance care planning and has provided compassionate end of life care her whole career. She has served as Senior Medical Director for IH Palliative Care and End of Life Services since 2020. She sits on the Provincial MAiD Operational and Oversight Committees and has supported IH Bi-monthly MAiD Case Review Rounds since 2021.

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Marta Simpson-Tirone holds a Master of Theological Studies. She originally came into health care as a Psycho-Spiritual Practitioner. She is a Registered Psycho-Therapist with the College of Registered Psychotherapists of Ontario (CRPO) an Associate member of the Canadian Association of Spiritual Care (CASC) and is the medical assistance in dying (MAiD) Care Coordinator for Hamilton Health Sciences (HHS). Marta has been a member of the Assisted Dying Resource and Assessment Service (ADRAS) at HHS since its inception in 2016. She is the former co-chair of the Ontario MAiD Coordinators Community of Practice. The current co-chair for the Greater Hamilton Health Network (GHHN) MAiD Steering Committee. A member of the Canadian Association of MAiD Assessors and Providers (CAMAP) and a previous member of the Curriculum Review Committee for CAMAP's National MAiD Curriculum. She has consulted to Health Canada on issues related to MAiD such as the reporting regulations and led the MAiD Coordinator National conference at the Canadian Association of MAiD Assessors and Providers National Conference in 2023. She has published internationally on the role of MAiD Coordinator and is known nationally as a leader in MAiD coordination practice.

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What Does an Ideal Model for Medical Assistance in Dying (MAiD) Coordination Look Like?

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Introduction

Medical Assistance in Dying (MAiD) is a legal medical procedure in Canada governed by federal and in some instances, provincial laws. MAiD is permitted under strict legal and procedural safeguards for individuals who meet specific eligibility criteria.[1] When MAiD is done well, the MAiD team works not only to ensure that all federally legislated requirements are met in a timely, efficient, and effective manner, but also that the person requesting MAiD is kept at the centre of the care circle ensuring compassionate patient care is reflected throughout the process. The coordination of MAiD Care differs across provinces, territories, regions, and organizations within these areas. Some provinces have MAiD Coordination Centres (MCCs) where all MAiD requests filter through for the entire province. Other provinces have similar concepts but are regionally organised. There are some areas in the Canada where access to MAiD coordination depends on specific organisations individual MAiD response and whether or not they have MAiD teams with coordinators. Even the title attributed to these role(s) vary across and within these areas. MAiD Care Coordinator, MAiD Coordinator, Nurse MAiD Navigator are just a few examples of the various titles attributed to MAiD coordination in Canada. However, despite the differences, one common thread unites ideal MAiD Coordination: its essential and pivotal role in helping to reduce barriers to MAiD care. The authors of this paper advocate for the 'ideal' scenario, which would involve standardizing access to aspects of MAiD coordination across all provinces in the form of a MAiD Coordination Center (MCC). This ideal scenario would ensure access to consistent education, clinical leadership, interprofessional involvement, supportive data/quality improvement oversight initiatives, and the actual process of coordination for all involved in MAiD care. Ideally, giving all health care providers and patients involved in MAiD Care access to standardized supports while maintaining the flexibility to respond to the nuances of their specific region or organization. Acknowledging the need for localized coordination and provincial, territorial difference will ensure the diversity that exists across Canada's healthcare and within each region can be honoured.

Education

One of the most important roles of an ideal MCC is serving as a reliable place to ask for information about MAiD. Since social media can spread misinformation (and even disinformation) about MAiD, the MCC can act as a regional educational hub for all involved in MAiD. MAiD coordinators across the country manage a high volume of basic inquiries, addressing questions regarding the eligibility criteria for MAiD and guiding individuals on how to request an assessment for MAiD within their region. MAiD coordinators come from a variety of health care backgrounds, including nursing and social work, yet they are universally compassionate, patient-centred people who treat each requestor of information as a unique individual. Whether the request comes from a Health Care Provider or a Health Care Consumer, MAiD coordinators provide a safe space to ask questions, receive honest answers, and achieve an effective referral for assessment.

An exceptional MAiD Coordination Centre recognizes educational gaps that exist not only in the public, but also within the healthcare community. They help to fill these gaps with reliable, timely, and factual information. For instance, when MAiD first became available in British Columbia in 2016, coordinators at the

Interior Health region (IH) MCC recognized the need for an online educational brochure. Collaborating with a family member who had experienced MAiD, they developed a brochure[1] that provided information about the process from the patient's perspective, shared links to resources for the family, and explained what was going on behind the scenes. As legislation has evolved, so too have these resources. The MCC in IH was the catalyst to making this type of educational support a reality.

MAiD coordinators can offer support and expertise to clinicians new to MAiD, and facilitate mentorship by connecting them with more experienced MAiD providers. Within many areas, MAiD coordinators currently serve as the experts, as not all primary care clinicians have the appropriate scope of knowledge required to navigate evolving federally legislated eligibility criteria. The introduction of an MCC would ensure this support was available to all MAiD care providers.

Clinical Leadership

A Medical Director (MD) or Clinical Lead (CL) has a vital role as part of an ideal MCC. This individual should also serve as a MAiD assessor/provider and support the MAiD coordinator(s) in various ways throughout the coordination process. The MD/CL can lead educational initiatives, ensure effective recruitment/on-boarding and help create tools to support a sustainable workload. Creating sustainability for the health care providers involved in MAiD Care is an essential task as the number of requests for assessment have consistently increased year over year across Canada.[3] The MD/CL also brings an assessor/provider lens to the creation of MAiD policies and procedures at the organizational, regional, and even provincial levels.

Interprofessional Involvement

Wherever MAiD care takes place, the coordinator works to ensure the appropriate interprofessional team members are present, recognizing that each location has unique support needs. As an example, with 37.2 % of MAiD provisions occurring in private residences across Canada,[3] MCCs often facilitate nursing support for intravenous placement.[4] As a member of an Interprofessional team, one author can attest to the potential an Interprofessional team has to enhance the experience not only for patients in the various supports that can be offered, but also for assessors/providers. Access to interprofessional teams allows assessor/providers to consult with various health care professionals with more ease, bringing multiple specialty perspectives to the assessment when needed.

Another example of interprofessional collaboration is the process by which MAiD coordinators refer eligible and interested patients to the provincial organ donation service once fully approved for MAiD. The MCC then works with the patient, the provincial donation service, the hospital system(s) and the MAiD providing team to enable organ donation after MAiD provisions for those who are eligible and willing. Adding access to interprofessional supports and collaborations is an important component of an ideal MCC as it helps to further patient wishes.

Data/Quality Improvement Oversight

MAiD coordinators have the most comprehensive understanding of what is happening locally within their regions with respect to MAiD. However, to gain an overview across larger regions, it is paramount to compile information from multiple areas to compare how MAiD is provided, and to whom, within the individual regions, provinces and/or territories. Within British Columbia, for example, oversight occurs at both the regional health authority and provincial levels. All completed MAiD assessment paperwork is collated and reviewed, creating a detailed data set. This is possible because MAiD coordinators input all relevant data into their regional MAiD databases and crosscheck with the province to ensure that all documentation is provided for review. This process enables both regional and provincial comparisons regarding who is accessing MAiD for end-of-life care, and the underlying medical problems of those individuals. When one health authority stands out, with respect to one aspect of MAiD Care or lack of access to MAiD care this data analysis process enables a more thorough review. Using the data collected by the regional health authorities, British Columbia can determine where to focus additional education, and when to involve more clinicians. Without the MCC in BC, that collates information across a region, conducting this level of detailed analysis would not be possible. Therefore, an ideal MCC should have the capability to collect and analyze regional data to support quality improvement initiatives at the local, regional,

and provincial/territorial levels. Collecting this information would allow an ideal MCC to revise their resources in order to make the necessary adjustments to clinical care for example.

Act of Coordination

Some communities and acute care hospitals have their own triage/referral systems for managing MAiD requests as they come in.[5] These systems allow patients to move seamlessly through the MAiD process, interweaving MAiD into the organization's existing policies and procedures. Coordinators functioning in these scenarios work directly with patients, providing consistency of care for them and their family throughout the MAiD pathway. However, for the average person wanting assessment for MAiD, this mosaic of MAiD care can be a daunting challenge, especially for those unfamiliar with the healthcare system within which they are receiving care or those receiving care in a setting where MAiD coordination is not already established. The ideal MCC would include a, centralized referral mechanism and secure medical record storage for all required MAiD documentation. This would ensure a standardized process for tracking MAiD requests, as requestors move between community and hospital settings. Everyone supporting the process would know where the information is stored and could review it as needed. Additionally, the ideal MCC would also maintain a directory of MAiD assessors, providers, and experts available for consultation in each area. Local coordinators could upload documentation and request as much, or as little, support throughout the process as needed.

British Columbia is close to achieving a fully coordinated system for MAiD assessments, with 73% of all MAiD requests managed through the five regional health authority-based MCCs.[6] Within each MCC, the MAiD coordinators review the requestors' paperwork, such as their MAiD request form, for completeness. The MAiD request is then triaged/prioritized based on underlying medical problems and readiness to move forward. The MCC contacts the primary care provider to determine if they are willing to serve as either the first assessor or the prescriber (often known as Primary Assessor in other areas of the country). If the primary care provider declines to take on one of these roles, the MCC refers to a list of other health care providers within the community who are willing to take on requests outside their own practice. The coordinator then assembles the necessary assessors to review the request and conduct eligibility assessments. If expert opinion(s) are needed to support a provider's decision, the MCC will provide advice on which experts to approach.

Each step within the MAiD coordination process presents its own unique challenges. A centralized MCC, accessible to all assessors, providers and patients would help ensure that all patients have better access to assessment and that assessors and providers have standardized access to support. This is particularly an issue in remote and rural communities where MAiD assessors may be scarce. An ideal MCC could help arrange for video-assisted assessments, for example. In some regions of Canada, MCCs fund assessor travel to rural and remote regions, making MAiD a viable option for end-of-life care regardless of location. Currently, travel support is not consistent across the country due to provincial variations in funding.

Conclusion

MAiD coordination plays an important role in helping to diminish barriers for MAiD care. The authors believe that a MAiD Coordination Center should have reliable education, clinical leadership, interprofessional involvement, data/quality improvement oversite initiatives, and the coordination process itself built into the standard design. Ideally, all MAiD assessors, providers/prescribers, and coordinators would have access to the support of a MCCs while maintaining the flexibility to respond to the nuances of their specific region or organization. This approach acknowledges the need for localized coordination and provincial differences, ensuring diversity across Canada's healthcare is honoured in the pursuit of excellent MAiD Care.

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