



# Medical Assistance in Dying (MAiD) Care Coordination: Navigating Ethics and Access in the Emergence of a New Health Profession

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## Abstract

Medical assistance in dying (MAiD) in Canada is a complex, novel interprofessional practice governed by stringent legal criteria. Often, patients need assistance navigating the system, and MAiD providers/assessors struggle with the administrative challenges of MAiD. Resultantly, the role of the MAiD care coordinator has emerged across the country as a novel practice dedicated to supporting access to MAiD and ensuring compliance with regulatory requirements. However, variability in the roles and responsibilities of MAiD care coordinators across Canada has highlighted the need for accountability and standardization for this practice. This manuscript constitutes a first attempt to describe this emerging role, through discussion of proposed standards of practice, as well as roles and responsibilities, and ethical duties of this emergent professional practice. We detail the core commitments of MAiD care coordinators to patients, providers/assessors and institutions involved in the MAiD process. We address the core competencies that inform the unique skillset required by MAiD care coordinators to facilitate high-quality care, while highlighting the moral and ethical considerations embedded in this work. To illustrate the complexity of the MAiD care coordinator role, case examples involving ethical dilemmas encountered in practice are included. Finally, a code of ethics is proposed to serve as a guide for appropriate professional practice and conduct. This manuscript is intended to illustrate the importance of transparency and accountability for this new role that provides service to vulnerable patients and families; this is especially critical as the ethical complexity of MAiD is likely to increase with future changes in legislation opening MAiD access to new populations.

**Keywords** MAiD · Euthanasia · Care coordinator · Assisted dying · Case coordination · Access · Competencies · Code of ethics · Professional duties

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## Introduction

A new professional role is emerging in the Canadian healthcare system for individuals who coordinate Medical Assistance in Dying (MAiD) services within organizations and regions. The MAiD care coordinator (MCC) role developed concurrently in various institutions and regions across Canada after MAiD legislation came into effect following the passage of amendments to the federal criminal code (called “Bill C-14”) that decriminalized MAiD in 2016 (Beuthin, 2018). The role exists in a variety of institutions, providing Care Coordination in hospitals, in health regions and in entire provinces (North West LHIN, 2021). The aim of this role is to create a sustainable model of MAiD care which supports timely access for patients, provides system navigation, and ensures the rigor of the MAiD process; including adherence to the legal standards. The intention of MAiD Care Coordination is to alleviate components of the heavy administration burden on physicians and nurse practitioners, who carry significant legal and moral risks by engaging in MAiD practice, and to help patients and families navigate access to this new service.

MCCs come from diverse professional backgrounds, such as nursing, psycho-spiritual care, speech-language pathology, and social work. As we write, no specific qualifications, training or credentials exist for this role. Thus, there is a need to define standards of practice and a code of ethics for MAiD Care Coordination for three main reasons:

- (1) The variety of backgrounds mean specific professional colleges do not regulate many of the essential tasks performed by MCCs;
- (2) Patients seeking MAiD are often vulnerable and face challenges in accessing services. They depend upon the professionalism and competencies of MCCs to help them navigate a complex clinical and legal process;
- (3) There are substantive consequences for MAiD providers/assessors<sup>1</sup> if the legal and regulatory obligations intrinsic to the MAiD process are not met, including disciplinary action from their professional college, up to and including criminal charges.

MCCs can have a great deal of power and influence as the primary gatekeepers to MAiD care in many organizations and regions. Additionally, MCCs have commitments to multiple stakeholders including patients and families, MAiD providers/assessors, health professionals providing referrals, and the organizations that employ them. As such, MCCs have to manage competing obligations and priorities, and currently have no practice standards to guide these decisions.

The purpose of this paper is to offer an initial description of the emerging professional practice of MAiD care coordination, specifically: the core commitments; roles and responsibilities; core competencies; ethical issues commonly encountered by

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<sup>1</sup> Note: “MAiD providers/assessors” refers to physicians and nurse practitioners who choose to provide MAiD to eligible patients, as well as the independent assessors who confirm the eligibility of the patients; the affirmation of MAiD eligibility by two independent physicians or nurse practitioners is part of the legal framework for MAiD in Canada.

MCCs; and a proposed code of ethics. These are offered as a preliminary scaffolding for the development of formal professional practice guidelines as MAiD evolves. These proposed guidelines were developed collaboratively over a two year period, from 2019 to 2021, in consultation with MCCs from across Canada, as well as other stakeholders, including operational and medical directors of MAiD services. The purpose of this project is to support high-quality, equitable and fair access to MAiD by ensuring that MCCs are governed by a common set of values and principles specific to their unique role and scope of practice.

## Methods

This work utilized both quantitative and qualitative methods for gathering the perspectives of MCCs on the proposed documents, constituting a mixed-methods approach to stakeholder engagement that was highly reflexive, narrative, and auto-ethnographic in nature.

### Collecting Stakeholder Perspectives

An email invitation describing the purpose of the draft documents was sent to MCCs along with initial drafts of the two proposed documents (Appendix 1, 3: “Roles and Responsibilities of MAiD Care Coordinator” and “Core Competencies of a MAiD Care Coordinator”) and a link to an anonymous, online survey to solicit feedback (see Appendix 4). The survey included demographic questions, Likert Scale questions and open-ended questions. The email invitation was sent to approximately 25 MCCs from across Canada. The email invitation asked the recipient to forward the invitation to other MCCs, constituting a snowball method of sampling. The draft code of ethics (see Table 1 “Code of Ethics for MAiD Care Coordinator”) was created after the survey was fielded so it was circulated amongst MCCs across Canada by email to elicit their thoughts and feedback with respect to its content and applicability. Our stakeholder engagement process constitutes a qualitative participatory approach to understanding the perspectives of MCCs working in diverse contexts across Canada.

### Analysis

Descriptive statistics for the demographic variables and Likert scale questions were analyzed using the Survey Monkey software. The suggestions related to the three different documents (including items to emphasize, items identified as not being part of the respondent’s MCC role, and items to add) were reviewed and discussed at three meetings by the three authors and changes were made to the documents based on consensus. The open-ended responses soliciting general feedback on the documents, as well as the questions about challenges and rewards experienced as a MCC,

**Table 1** Demographic characteristics of survey respondents

Demographic variable	N = 19
Gender n, %	
Female	15 (79)
Male	3 (16)
Prefer not to disclose	1 (5)
Primary profession n, %	
Nurse	7 (37)
Advanced practice nurse	1 (5.3)
Nurse practitioner	1 (5.3)
Nursing director	1 (5.3)
Patient relations consultant/nurse	1 (5.3)
Physician	2 (10.5)
Ethicist	2 (10.5)
Spiritual care/chaplain	1 (5.3)
Social worker	1 (5.3)
Speech language pathologist	1 (5.3)
Director of risk and compliance	1 (5.3)
Length of time worked as a MAiD coordinator n, %	
< 1 year	3 (15.8)
1–3 years	3 (15.8)
3–4 years	7 (36.8)
4 years or longer	6 (31.6)
Setting for the MAiD work n, %	
Hospital-based	12 (63)
Community-based	7 (37)
Province works in n, %	
Ontario	10 (53)
Quebec	5 (26)
British Columbia	4 (21)

and how participants would like to see the MCC role evolve in the future, were analyzed using conventional content analysis (Hseih & Shannon, 2005).

## Outcomes of Stakeholder Engagement

### Demographics

A total of 19 individuals completed the survey. We cannot calculate a response rate as snowball sampling was the primary methodology of distribution and it is unknown how many MCCs received the email invitation.

Over three quarters (79%) of the survey respondents were female and nearly two-thirds (63%) indicated they did MAiD work in the hospital setting. Over two-thirds (68%) had worked as a MAiD Coordinator for 3 or more years and over half (58%)

listed their primary profession as nursing. Survey respondents were from only three provinces: Ontario (53%), Quebec (26%) and British Columbia (21%). Demographic characteristics are summarized in Table 1.

Survey respondents were engaged with reviewing the draft documents and identifying items that were missing or that needed greater emphasis, or items that were not relevant to their practice as a MCC. There were divergent opinions about the Roles and Responsibilities document, with a third (31.2%) identifying roles and responsibilities in the document that were not part of their job as MCCs, and nearly two-thirds (63%) identifying additional roles and responsibilities that were not included in the draft document.

However, there was more consensus around the Core Competencies and Code of Ethics documents: just under a third (31.2%) offered additional items to the draft Core Competencies document and less than a fifth (15.8%) offered additional items for the Code of Ethics. Further elaboration on this data and the feedback provided by stakeholders can be found in Appendix 4. On the whole, however, there was significant agreement amongst participating MCCs with the content of all proposed documents. Feedback and additional items offered by participants were incorporated into the final drafts presented here, based on consensus of the three authors.

## Key Findings and Implementation

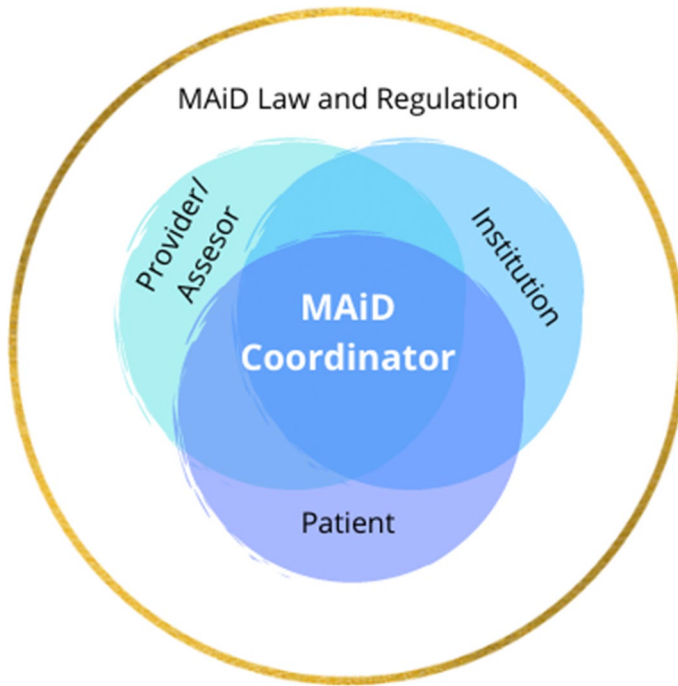
Our experience and findings through consultation with MCCs across the country yielded information about this emerging role that can be categorized in the following five ways: (1) core commitments, roles and responsibilities of the MCC, (2) core competencies of the MCC, (3) ethical issues in MAiD care coordination, (4) code of ethics for MAiD care coordination, and (5) support for MAiD care coordination.

### Core Commitments, Roles and Responsibilities of the MAiD Care Coordinator

The goal of MAiD care coordination is to facilitate patient choice and access to high quality MAiD services within the scope of the law and professional regulations, while ensuring MAiD providers/assessors are supported and institutional policies are followed. Thus, the core commitment of care coordinators is to quality and accountability, balancing the needs and interests of Patient, Provider/Assessor, and Institution within the current legal/regulatory context (see Fig. 1).

**Commitments to Patients** Care coordinators must always be aware that patients seeking MAiD, and their families, can be vulnerable as they are requesting a life-ending procedure due to intolerable suffering. Care coordinators must always be mindful of the legacy of the MAiD process for the family members who accompany their patients through the process.

**Commitments to Providers/Assessors** Being a MAiD provider/assessor is voluntary, and it is often an “add on” to a full-time clinical role. Providers/assessors shoulder many responsibilities in providing MAiD for a patient, including: the emotional



**Fig. 1** Interaction of the core commitments and the law

labour of supporting a patient/family through the dying process; ensuring all legal requirements are met; documenting the process thoroughly; and collaborating with other care providers/assessors. Care coordinators work with MAiD providers/assessors to support their readiness and willingness to step into cases by alleviating administrative burdens and providing support to navigate the complexities of MAiD cases. The relationship between care coordinator and provider/assessor aims to mitigate burdens and risks to ensure the case has a positive legacy for the physician/nurse practitioner.

**Commitments to Institutions** Where MAiD is provided in an institutional context—such as a hospital, long-term care facility, hospice or group practice—the institution usually has its own internal policies and procedures to govern MAiD practice. These may include: standardized forms and guidelines, referral processes, conflict resolution and reporting processes, data collection, discharge or admission pathways, or procedures for procuring appropriate clinical consultations for patients exploring MAiD. Care coordinators must be familiar with the institutional policies and norms governing MAiD practice, and support adherence to these procedures to ensure accountability of the service. In addition, the care coordinator must be familiar with the variety of clinical services offered within the institution and community, and support patients to access appropriate services to assist them as they navigate their care options: such as social work, specialist consultations, palliative care services, psycho-spiritual care,

etc. The other clinicians and teams supporting the patient also frequently need guidance from the MCC, including coaching, education and reporting support.

**Commitment to MAiD Legal and Regulatory Compliance** Because MAiD is governed by the federal criminal code, the practice carries serious legal and professional consequences if compliance is less than perfect, including risks to provider/assessor reputation, to institutional reputation, and legal liability. Care coordinators support providers/assessors and institutions in upholding MAiD standards of practice by addressing barriers to access, ensuring compliance with standards of practice, supporting reporting and documentation requirements, participating in quality improvement activities, etc. Detailed description of the roles and responsibilities of a MCC under each of these core commitments is reflected in Appendix 1.

In summary, MCCs must explicitly acknowledge their commitments to all parties in their role. Their work should not be focused on the completion of MAiD provisions alone, but should balance the patient experience and family expectations, with provider/assessor experience, and compliance with institutional and legal obligations. Success in the MAiD Care Coordination process cannot be measured solely by the number of provisions and eligibility assessments completed—success is demonstrated when the care coordinator has acted as the custodian for a fair, transparent and high-quality process, balancing the interests of all stakeholders. This ensures the sustainability of the MAiD service for future patients. Suggested indicators for evaluating the performance of MCCs could include: the timeliness in responding to a MAiD request; support for clinicians who want to make an effective referral (including those with a conscientious objection); training new clinicians in the assessment process; helping clinical teams facilitate access to the MAiD service by providing education/capacity building; patient/family/provider/assessor experience with the MCCs (re: professionalism, compassion, effectiveness, etc.); tracking and reporting MAiD activities to institutional leaders; providing support and information to patients/families throughout the process; updating policies and guidelines.

### **Core Competencies of a MAiD Care Coordinator**

The unique role of the MCC encompasses a set of core competencies that are not typically seen in a job description or listed in the professional practices of regulatory colleges. Although there is overlap with the core competencies of other health professions, the complexity of the core commitments of this position—at the nexus of patient, provider/assessor, institution and law—requires a unique combination of core competencies to support sustainable, high-quality MAiD practices. An expanded description of the core competencies was developed (Appendix 3) using the Core Competencies of Healthcare Ethics Consultation (Arnold, 2017) as a basis, due to the similarity between the roles of MCCs and Ethics Consultants in terms of the necessity of navigating core commitments to multiple stakeholders in a complex and evolving context. In addition, the typical process that a MCC follows in supporting a patient request for MAiD from initial inquiry to follow-up is detailed in Appendix 2.

**Interpersonal, Critical Thinking, and Process Skills** Analytical and “soft skill” competencies are critical for effectively communicating and fostering positive, trusting relationships in the context of responding to MAiD requests. MCCs must have the capacity to pause and reflect on their own personal limitations and values, while supporting the values and emotions of patients, families, providers/assessors and other health care professionals. Care coordinators must be able to address process barriers and refer problems to appropriate leaders. Managing these complexities requires that the care coordinator identify any resources that may be helpful during the process, and possible solutions within the context.

**Knowledge of MAiD Legislation, Regulations, and Context** It is essential for care coordinators to have a functional knowledge of the current and evolving MAiD legislation, as well as an understanding of the healthcare system to support patients in the MAiD journey. Furthermore, providing high quality care includes understanding related regulations and context, such as: professional rights and obligations, confidentiality, patient autonomy, informed consent, cultural and religious diversity, grieving and bereavement processes, and the provision of care across a range of programs and settings. Finally, a MCC should ensure they are familiar with the code of ethics for their own profession, and guidelines for their own professional conduct relevant to end of life and MAiD practice.

**Evaluative and Quality Improvement Skills** MCCs are often responsible for data collection, process improvement and quality of care, working in collaboration with MAiD providers/assessors. These skills may include: data collection; retrospective review of cases; identifying underlying systems issues and possible barriers to accessing MAiD care; soliciting feedback and developing QI processes.

### **Ethical Issues in MAiD Care Coordination**

This section describes commonly observed ethical challenges encountered by MCCs and proposed methods for navigation through the use of case-studies. Through fictional case studies based on lived experiences, these cases explore the ethical dimensions of the questions that frequently emerge in this professional role, and how these complex issues might be addressed using an ethics framework.

**Case Study 1: Patient does not want his Family to Know he is Going Through MAiD PROCESS** John was diagnosed with lung cancer in 2017. By the time he presented to the MAiD team the cancer had metastasized to several other areas and any treatment he was undergoing was palliative in nature. He is an inpatient on a palliative care ward within the hospital system. John disclosed to the MAiD team that he would like to keep his request for MAiD confidential from his family as they are quite religious and he does not feel that they would be accepting of his desire to receive MAiD at end of life.

It is the job of the MCC to uphold the confidentiality of not only the patient, but also the family, the MAiD providers and the MAiD assessors. The ethical



dilemma in this case then becomes one of addressing how to uphold the confidentiality requested by the patient, counterbalanced by staff expectation that family are actively involved in the patient's end of life choices. Consideration must also be given to the discomfort of the health care team regarding feelings of "hiding" this information from the family.

The first priority for the MCC is upholding the confidentiality that the patient has requested. It is the job of the MCC therefore to: inform the healthcare team of what can be shared with family, and make sure that confidentiality is maintained as per patient's wishes. The MAiD team/care coordinator can offer support to the clinical team as they may be struggling with the inability to openly disclose this decision to family. It is important to use the greater interdisciplinary team in order to provide support to the patient, the family and the staff, such as social work and spiritual care. It may be appropriate to engage with John around his reasoning for not disclosing to family. In some cases, a patient may feel that with support they may be able to speak to their family about their wishes, and their end of life plan.

Confidentiality and duty to the patient are the ethical considerations at the forefront of this case study. In addition, acknowledging the moral distress and concerns of healthcare providers is important. A clash of ethical values related to the dynamics of a MAiD case may lead health care providers to feel challenged in navigating their personal and professional values. It is important that the MCC rely on their core competencies and code of ethics to guide them through these complex situations.

**Case Study 2: Physician is a Conscientious Objector** Dr. Jones is an oncologist and a conscientious objector to MAiD. She has just received a request for MAiD from one of her patients. The relationship that Dr. Jones has with this patient spans many years and she cares deeply about her. She wants to make sure that the patient does not feel abandoned at this vulnerable time. That being said, she also feels strongly that she cannot be involved in the MAiD process. The College of Physicians and Surgeons of Ontario (CPSO) outlines what is required by a physician who conscientiously objects to providing MAiD; making an effective referral is one of the expectations (CPSO, 2022). When Dr. Jones calls the MCC, the anxiety in her voice is obvious. She wants to make sure she is following the rules as outlined by her college and in the legislation but at the same time feels strongly about her own conscience and does not want to participate in MAiD.

It is the job of the MCC to support the physician in making an effective referral to ensure appropriate patient access, while also acknowledging the physician's moral conflict. The MCC also helps the physician to understand their roles and responsibilities legally, such as federal reporting, and their professional college guidelines, including connecting them to appropriate physician peer supports. Finally, once the effective referral is made it is the role of the MCC to allow the physician to be as involved or uninvolved as they feel comfortable in alignment with their personal and professional values.

If the MCC can create a safe and effective place for conscientious objectors to make referrals without judgement, then they are contributing to good patient access. In our experience, a conscientious objector is more likely to refer a patient to an

appropriate MAiD provider or assessor in the future if they feel that their moral values have been respected, while simultaneously being empowered to fulfill their professional obligations.

### **Code of Ethics for the MAiD Care Coordinator Role**

The following proposed code of ethics for the MCC role is informed by the ethical issues experienced by MCCs and the core commitments of the role. We propose that all MCCs also abide by the code of ethics for their primary profession (e.g., social work, psycho-spiritual care, nursing etc.). The code of ethics for the MCC role includes the following components: integrity; autonomy, dignity and access to care, excellence in practice, education and support for colleagues (Table 2).

Each of these ethical considerations are equally important in order to provide best practice from a MAiD care coordination perspective. A MCC who acts without integrity has the possibility of doing harm to themselves, their providing/assessing team, as well as others within the patient's circle of care. Honouring a patient's autonomy and dignity while ensuring that there is transparency in access to care is critical to a patient-driven practice like MAiD. Excellence in practice is important to mitigate the risks involved for all parties given the high-risk nature of MAiD practice. Providing education for MAiD, assessors/providers, clinical teams and patients and families, helps us to achieve excellence in practice. Support for our colleagues helps us to build and maintain a sustainable, resilient practice to ensure access for patients now and in the future.

### **Supports for MAiD Care Coordination**

In order to provide high-quality care coordination, the MAiD coordinator requires a supportive structure, environment and access to appropriate resources. Working in a dyad model of care with several other back-up MAiD coordinators can ensure a more sustainable model of care for coordination. Having two MAiD coordinators work together, where possible, creates space for inter-professional relationships that allow for mutual support, collaboration, knowledge translation, and room to highlight individual professional strengths, making for better overall coordination.

The creation of an interdisciplinary team model has the potential to sustain the Care Coordination role, given that implementing a team-based structure ensures MAiD care coordination isn't delivered in isolation. Care coordinators should have allotted time and budget for their position, rather than attempting to do this work off the side of their desk. Cultivating a culture of respect for the importance of the role of MCC through organizational leadership, teamwork and appropriate working conditions, as well as continuous professional development, is essential for the care coordinator to feel equipped to fulfill the full scope of their responsibilities and the complexity of the issues they navigate.

**Table 2** Proposed code of ethics for MAiD care coordinators

Ethical considerations	Purpose and practice
Integrity	To ensure the integrity of MAiD practice and fundamental adherence to legal and regulatory requirements; to openly inform patients and healthcare professionals about care options, access/limitations to MAiD services, and potential risks and benefits of MAiD; to be trustworthy in supporting the interests of all stakeholders
Autonomy, dignity and access to care	To respect confidentiality, rights and diversity of all persons; advocate for fair and transparent processes for individual patients and providers/assessors; to provide equal access to care to all patients exploring MAiD
Excellence in practice	To work in the best interest of patients and providers/assessors; maintain awareness of best practices and legislation and local policies/procedures in order to ensure accountability and the provision of high-quality care
Effective education	To provide clear and accurate education to health professionals/learners/ patients/families that is unbiased and guided by the legal framework. To provide supportive information and create safe spaces in educational sessions to explore the complexity of MAiD
Support for colleagues	To provide reassurance and support to health professionals across the moral spectrum, ensuring they have the knowledge and resources to provide patient access in accordance with their professional guidelines and the legislation. Provide coaching/debriefing for new MAiD assessors/providers. Reduce the risk of moral injury or moral distress for professionals who have a conscientious objection to MAiD by facilitating respectful effective referrals

## Discussion

Due to the relative novelty of the role of MCC, there is as yet no consensus on how the coordinator role should be defined, and no governing body that coordinators are accountable to for their practice. This paper is a starting point for defining a framework for a high quality, sustainable, and successful case coordination model. It is intended to be a tool to guide the creation of MCC roles, and to help MCCs advocate for additional resources, and advance current practice.

MCCs are beginning to collaborate to advance their practice and create a shared understanding of the roles, responsibilities and ethics of this nascent profession. The creation of the Ontario MAiD coordinator community of practice (COP) in 2021, is one example of how care coordinators are working together to define their role, advocate for more resources and funding, support each other through legislation changes, ensure consistency in practice, and work together on developing policies and procedures. This group could be an additional way to help define the documents proposed herein.

Changes to MAiD criteria and safeguards will continue to challenge the roles of MCCs. For example, opening access to MAiD for individuals without a reasonably foreseeable natural death (non-RFND) in 2021 has increased administrative and coordination burdens for MCCs, highlighted the need for coordinators to complete fair and equitable triaging of new referrals where there are not enough assessors to meet the demand, and challenged coordinators to support more complex patients in navigating a system crippled by the COVID-19 pandemic. The coordination role is

expected to continue to change and evolve over time and additional resources and standards may be required to support the core commitments of MCCs.

This paper has some limitations. It was written by two case coordinators working in an institutional setting with strong leadership, funding and team support, which is not common for all MCCs across Canada. By reaching out to stake holders for feedback on the drafts of these documents, we attempted to correct these biases in order to develop guidance documents that are relevant beyond our context. We acknowledge that we may not have been able to fully capture the viewpoints of care coordination in community or rural settings, as most respondents to our survey were from urban settings. In addition, MCCs from only three provinces participated in our survey (Quebec, BC and Ontario); these provinces do account for over 80% of all MAiD cases in Canada, but nevertheless, it is not clear how relevant these documents are for MCCs in other provinces.

## Conclusion

The purpose of this project was to outline the new role of the MCC in Canada and begin to lay the groundwork for more consistent, ethical and competent practice. In outlining aspects such as core competencies, roles and responsibilities, as well as creating a proposed code of ethics, we have intended to describe and support this emerging practice of MAiD coordination. We have also presented case studies that illustrate the ethical complexity of the MCC role.

Future areas of research about the roles of and responsibilities of MCCs include: differences between local and regionalized MAiD care coordination services; strategies for supporting appropriate access for patients without a reasonably foreseeable natural death including the resources to support this new population; educational and training needs for new MCCs; and options for creating a governing body to oversee MAiD care coordination practice.

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## Appendix 1

### Roles and Responsibilities of MAiD Care Coordinator

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#### Patient

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- Access and system navigation for patient and family
  - Receiving written requests
  - Supporting patient access to info about the legal and institutional process (giving them the request form, FAQ)
  - Help with procuring witness for written request
  - Responding to patient inquiries and educating patients, families, and staff about the process
  - Organizing assessments and other meetings with patient and family and health professionals
  - Provide resources/contacts regarding organ donation at patient's request, where available and applicable
  - Providing a consistent, supportive contact with patient/family re: the MAiD process
  - Trouble-shooting challenges: discharge planning, transfer to another unit
  - Support communication of care needs to other members of the team (family physicians, specialists, MRP, etc.)
  - Connect patient/family to additional resources, including: social worker, psycho-spiritual care, bereavement supports, etc
  - Assist with death choreography/provision planning in accordance with patient's wishes
  - Conduct or support bereavement follow-up

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#### Maid Assessor and provider

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 Patient
 

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## ■ MAiD process and team support

Conduct intake with patient's physician (obtain medical history, review eligibility criteria, and particular dynamics/care needs)

This conversation allows us to provide support regardless of whether a physician/nurse practitioner is a conscientious objector or not as we help them navigate what needs to happen in order to follow legal guidelines and safe practice

I.e.,: Effective referral, federal reporting

The intake document then becomes a tool for the willing provider/assessor to use in order to understand at a quick glance the dynamics of the case

Identify appropriate and willing MAiD provider/assessor team

Flag provider/assessor team and/or physician regarding potential specialist referrals that may be needed (i.e., Palliative care, psychiatry, geriatrics)

Identify appropriate and willing Independent Assessor

Consistent point of contact for MAiD team and clinical team; liaison between teams to ensure continuity of care and clarity of communication re: process

Companion teams on day of MAiD provision:

Preparation and debriefing

In hospital—provide support to in-patient team in the form of answering questions and explaining legal processes etc

Gather and review documentation package for coroner/over sight body

Support referring physicians/nurse practitioners and assessors with federal reporting

## ● Professional education and capacity-building

Coaching and mentorship of new MAiD team members

Coaching and mentorship of independent assessors

Allowing new assessors to step into the role with structural, emotional support

Creating a safe space for physicians/nurse practitioners who want to get involved

Education of health professionals and teams, participation in public education

Report process challenges to director and physician lead

Allowing for supportive response to challenges and service gaps

Identify cases for peer review, support continuing education for the team, quality improvements in processes

## Law/institution

## ● Support for federal reporting

Federal reporting as required in accordance with Health Canada's regulations put in place November 1, 2018

Our role: coaching, providing relevant dates and information, education for physician/nurse practitioner in order to know when to report, ensuring compliance within our organization, record of completed reporting

## ● Abiding by and educating regarding the legal requirements around MAiD care (i.e., Waiver of final consent, independence of witness MAiD request form)

## ● Knowledge of eligibility criteria and safeguards for all patients accessing MAiD

## ● Support for reporting to Coroner, chief medical officer or oversight body for quality assurance

Assist with preparing MAiD documentation package including: MAiD request form, eligibility assessments, consent, provision record, prescription, death certificate, any supporting documentation

## ● Accountability to steering committee/institutional board to ensure quality of care (this will vary depending on employment of provider/assessor/team)

Present data, trends, challenging cases, updated policies/practices, strategic objectives, research and innovation, administrative updates

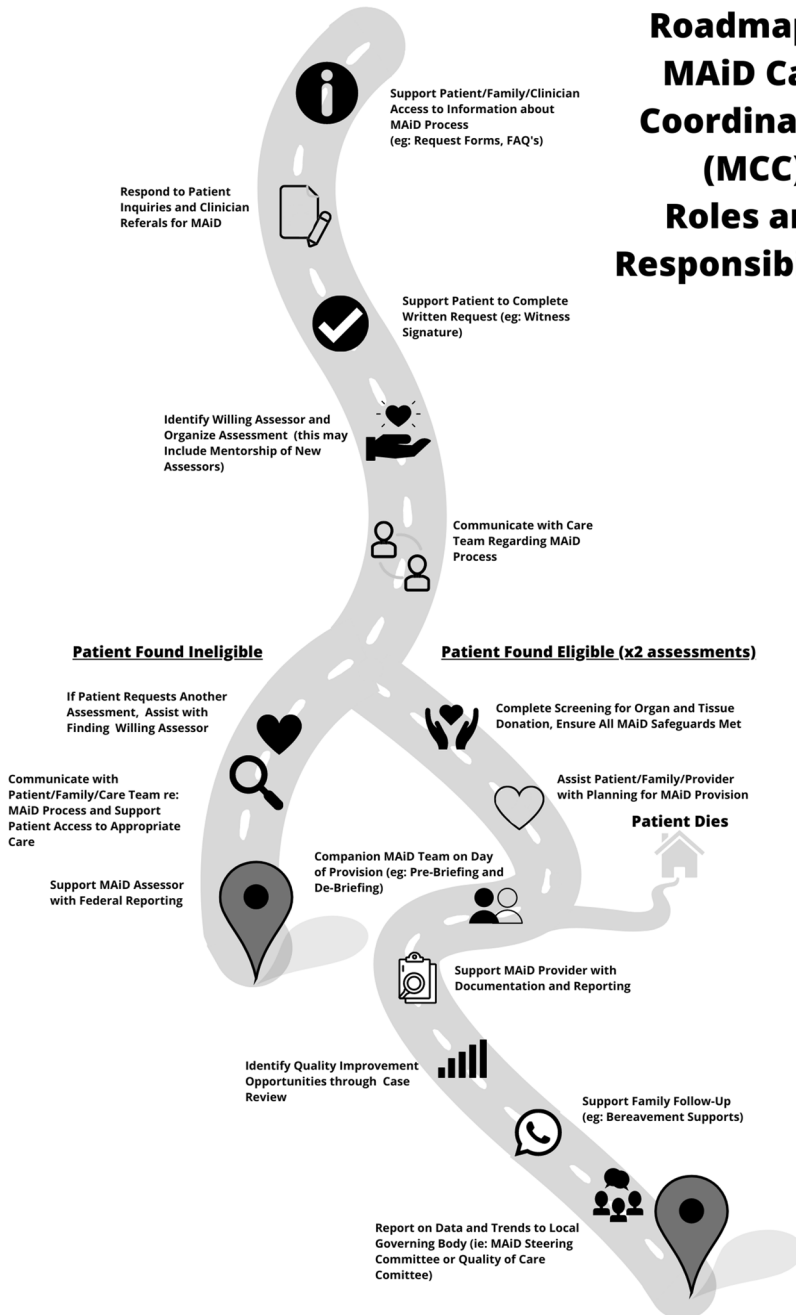
## ● Update MAiD infrastructure to reflect evolution of practice and change in legislation

Collaboration with providers to ensure any policies/procedures within the institution are current

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## Appendix 2

# Roadmap of MAiD Care Coordinator (MCC) Roles and Responsibilities



## Appendix 3

### Core competencies of a MAiD Care Coordinator.

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- Interpersonal, analysis, and process skills: Skills needed to effectively communicate and to develop positive relationships, while successfully responding to MAiD requests
- Recognize and attend to various relational barriers to communication present among those involved in a MAiD case- in particular, suffering, moral distress, and strong emotions
- Communicate and collaborate effectively with other responsible individuals, departments, or divisions within the institution to facilitate MAiD access/care
- Provide clear and supportive education to those who are learning about the MAiD process and legislation
- Recognize and acknowledge personal limitations and possible areas of conflict between personal and moral views, and one's role in a MAiD case (e.g., accepting decisions of a MAiD assessor/provider with which one disagrees, but are ethically and legally acceptable)
- Gain familiarity and achieve comfort with diversity among patients, staff, and institutions and provide care coordination in a respectful manner
- Help identify which structures and resources may be beneficial in the process (e.g., consultants, specific provider/assessor and debriefing support),
- Document referrals clearly and thoughtfully in appropriate service records (as well as in patient health records); summarize and communicate key information to relevant parties to facilitate efficient care coordination
- Evaluative and qualitative improvement skills:  
Skills necessary for the MAiD care coordinator to monitor and improve their own performance (and team's performance) and contribute to improving the quality of MAiD care in the wider institution
- Retrospectively review MAiD services, including review of individual cases; reflect on wider implications of cases and trends; ensure rigor and flexibility in the evaluation process
- Collect data about patient access and quality, including feedback from individuals involved in the MAiD process, and record that data in a systematic fashion to facilitate analysis and reporting to oversight committees
- Identify underlying systems issues and possible structural barriers to MAiD care, identify potential solutions and bring them to the attention of the appropriate institutional resources for resolution
- Core knowledge and clinical context: Understanding common issues, concepts and processes encountered in MAiD
- Recognize the uniqueness of the MAiD process for all parties involved; identify supports available to providers/assessors and patients/families
- Patients' rights, including: rights to access health care resources; disability rights and accommodations; rights to self-determination, treatment refusal, and the right to privacy; the concept of "positive" and "negative" rights and obligations
- Autonomy and informed consent and the importance of providing clear, accessible information; voluntary and involuntary decisions; decision-making capacity; paternalism
- Confidentiality, including the notion of "fiduciary" relationship of professional and patient; exceptions to confidentiality; the duty to warn
- Professionals' rights and duties, including the parameters of conscientious objection and the duty to care
- Understanding of how cultural and religious diversity, as well as biases based on race, ethnicity, gender, and disability, informs the context of end of life options
- Organ donation and transplantation, including procurement and allocation policies as they pertain to MAiD
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Awareness of basic clinical courses of commonly seen illnesses among MAiD patients, and the processes that healthcare professionals employ to evaluate and treat them.
Awareness of grieving process and psychological responses to illness for patients and their families
Basic understanding of how care is provided in range of programs across institutions including: ICU, rehabilitation, palliative care, emergency, oncology, surgery, medicine, elder care, hospice, etc.
Related organizational and facility resources relevant to supporting MAiD services (eg. Patient Relations/Risk Management, Privacy Office, Organ donation Coordinators, Clinical Ethics Committee, Social Work, Spiritual Care, Palliative Care)
Relevant codes of ethics, professional conduct and health law
Clear understanding of current and evolving legislation/regulations pertaining to MAiD; federal and provincial reporting requirements
Codes of ethics and policies from relevant professional organizations (e.g., nursing, social work, spiritual care, physicians)
Local healthcare facility's code of professional conduct
Health law (e.g., Informed consent, organ donation, privacy, federal reporting requirements)
Professionalism (e.g., Disclosure of errors, conflict of interest, truth telling, difficult patients, conscientious objection etc.)

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## Appendix 4

### Analysis of Feedback on Documents from MAiD Care Coordinators in Canada

The frequency of responses related to revising the three documents circulated to MAiD care coordinators across Canada are summarized in Table 3.

### Survey Findings

Responses to the Likert scale questions asking MAiD coordinators their level of agreement with statements indicating that each document reflected their experience with the MAiD coordinator role indicate that all three documents resonate with their experience as a MAiD coordinator. None of the respondents disagreed with any of the statements and only 1 respondent selected the “neither agree or disagree” option.

Nearly two-thirds (63%) agreed and nearly one-third (32%) strongly agreed that the roles and responsibilities document reflected the roles and responsibilities in their position as a MAiD coordinator. For the core competencies document, half (50%) agreed and 44.5% strongly agreed that the document reflects the core competencies in their MAiD coordinator position. Half (50%) of respondents strongly agreed and 44% agreed that the code of ethics document captures the ethical dimensions of the MAiD Coordinator role.

Responses to the three questions asking about the extent to which the three developed documents reflect respondents' MAiD coordinator roles are summarized in Table 4.

Respondents were asked to explain their level of agreement with how much each document reflected their experience in their position.

Over two-thirds (68%) explained their level of agreement with the roles and responsibilities document. The majority indicated that overall, the roles and responsibilities in the document are: “*described well*”, “*accurate*”, “*comprehensive*” and

**Table 3** Frequency of Responses Related to Revising the MCC Core Competencies, Role and Responsibilities, and Code of Ethics

	N = 19 n, % Listed items that should be emphasized more	N = 19 n, % Listed items in the document that were not part of their role as a MAiD coordinator	N = 19 n, % Listed items that were part of their MAiD coordinator role that were not included in the document
Roles and responsibilities	15 (79)	6 (31.2)	12 (63)
Core competencies	8 (42)	1 (5)	6 (31.2)
Code of ethics	12 (63)	1 (5)	3 (15.8)

**Table 4** Assessing the extent to which the three developed documents reflect respondents' MAiD coordinator roles

Please indicate the extent to which you agree with this statement	Strongly agree		Agree		Neither agree or disagree		Disagree		Strongly disagree	
	n, %	n, %	n, %	n, %	n, %	n, %	n, %	n, %	n, %	n, %
The roles and responsibilities described in the document reflect the roles and responsibilities in my position as a MAiD Coordinator. (N = 19)	6	(32)	12	(63)	1	(5.3)	0	0	0	0
The core competencies described in the document reflect the core competencies in my position as a MAiD Coordinator. (N = 18)	8	(44.5)	9	(50)	1	(5.5)	0	0	0	0
The Code of Ethics for a MAiD Coordinator captures the ethical dimensions of the MAiD Coordinator role. (N = 16)	8	(50)	7	(44)	1	(6)	0	0	0	0

“largely representative of my roles/responsibilities”. A few responses noted national differences in the MAiD role: “there is wide variation between these roles nationally” and “there may be differences between provinces.” A few participants also identified how the profession of the coordinator may lead to “slight differences and nuances” in roles and responsibilities.

Nearly two-thirds (63%) of respondents explained their level of agreement with the core competencies document. One response supported the need for this document, “I feel that there has been a considerable amount of work that has gone into the document and even though different organizations use a slightly different framework it is necessary to have core competencies outlined.” Other responses described agreement with the document, “[the document] reflects the competencies and skills needed for the role”, “the stated competencies reflect my reality”, and, “the list is comprehensive.” One respondent suggested adding a competency related to virtual care, “I do think it is important to add something about virtual care as it is looking like COVID will be here for a while. Though virtual care isn’t preferred, there will be times when it is needed and as coordinators, we need to know how to support both the individual requesting MAiD and our MAiD team.”

Over a third (42%) of respondents explained their level of agreement with the Code of Ethics: “it corresponds to my vision of what is needed for the role”, “this list you’ve created seems thorough and exhaustive in capturing the code of ethics for MAiD coordinators to abide by”, and, “this list covers the ethical issue and frameworks within with we work.” One respondent noted, “I am not sure that the code of ethics adds anything that isn’t captured by my professional code of ethics (nursing), but understand a code of ethics may be beneficial when coordinators come from a variety of backgrounds.”

### Challenges, Rewards and Future Vision for the MAiD Coordinator Role

Over three-quarters (79%) of survey respondents shared what they find most challenging about their job as a MAiD Coordinator. These challenges were grouped into the five codes: limited resources, supporting patients and families, moral diversity and conscientious objection, system issues, and general challenges.

Over half (60%) of those who responded to this question identified limited resources as being what they find most challenging about their job as a MAiD coordinator. Limited staff resources were described as being challenging: MAiD assessors, MAiD providers “only a few physicians are interested in providing MAiD services”, and “being the only person (n=1) covering multiple locations and sites.” One response cited “absences of sustainable staffing structures and succession planning” as being the most challenging.

Related to staff resources, limited funding was also cited as a challenge: “the fact that it is unfunded and a side-of-desk job” and, “lack of funding for additional new roles in MAiD.” One coordinator described the lack of resources related to mental health and poverty reduction as the most challenging and explained, “It is hard for me to see people seek MAiD where their suffering comes from mental health or

*poverty. Although they might not be eligible, just the basic knowledge that our system has not supported them is emotionally draining.”*

### **Supporting Patients and Families**

A fifth (20%) of the responses to the question asking what MAiD coordinators find most challenging about their job related to supporting patients and families. *“Adapted response to patients wishes”* and supporting patients who are not eligible for MAiD were listed. One coordinator shared, *“Personally, I find it very difficult when family members are not supportive of (and indeed sometime vehemently opposed to) the patient’s choice to proceed with MAiD.”* A respondent who identified as being fairly new to the role expressed how anticipating *“the right timing for arranging MAiD assessments”* was challenging, and explained how *“patients seem to be putting their requests in too early or too late, so I’ve been learning how to interact with patients and their families regarding appropriate timing (specifically pertaining to intolerable suffering).”*

### **Moral Diversity and Conscientious Objection**

A few survey respondents identified working in the context of moral diversity and conscientious objection as being most challenging. One response explained:

Physicians, staff and families putting up barriers to patients—they need to feel comfortable that they are not doing anything wrong before sending the patient along to the care coordination office. If they are not comfortable with the care option then the patient either never gets to us or has to work very hard while dealing debilitating health issues to fight for access to a legal care option.

Another response highlighted how MAiD Coordinators often are the recipients of moral distress and anger, *“when someone is opposed the moral distress and anger that is expressed. I never know what I will get at the end of the phone when I pick it up, someone either loves me or hates me.”*

Patients experiencing delays or barriers based on *“conscientious objection of organizations”* was also mentioned as being a challenge.

### **System Issues**

One response described how system issues that make it difficult to provide care was most challenging:

This care option is not woven into the fabric of healthcare therefore whenever it comes up with most staff and physicians they are taken out of their routine and it frightens them. Once they feel unease that comes across to the patient and family, and often results in delays with the patient getting access to the care option.

## General Challenges

Responses coded here include:

Taking into account changes in the law, support for the organisation and teams in effective process implementation; that respect the needs and rights of patients

Managing expectations/assumptions of all stakeholders while maintaining compliance with legal safeguards (e.g., asking the coordinator to validate a request form—while this is the legal accountability of a MAiD clinician such as an NP or physician).

Emergency cases are emotionally draining. When people don't learn about MAiD until the "end" or they think we are an emergency service.

Myths—lots of people listen to the news and only hear half of what was said, or remember it wrong. This leads to people thinking the care option is not an option for some people, or getting the process or criteria wrong. This creates barriers for patients.

## Rewards

Nearly 85% of survey respondents shared what they find most rewarding about their job as a MAiD coordinator: supporting patients. Different aspects of supporting patients with MAiD were described including: respecting patient autonomy, providing patient and family-centred care, having conversations with patients about choosing MAiD and about death and dying, coordinating the process and removing barriers for patients. One respondent shared, *“Being able to assist people with their end-of-life wishes by providing the most patient and family-centred care that we could possibly provide.”* Other responses described how *“when the patient says they feel heard and listened to”* and *“being able to carry out a patient’s wishes to have their suffering end.”*

One respondent shared how the experience of supporting their colleagues that oppose MAiD was very rewarding and described:

I had one nurse who was a staunch conscientious objector at the beginning, but after about 2 years she finally volunteered to be a support nurse for the MAiD death. She said she appreciated my way of supporting her, but also the patients and she felt that she was now able to separate her personal and professional self.

Another respondent reflected, *“I am humbled by the kindness and compassion of all involved. I am moved by the gratitude expressed by all involved.”*

## Future Evolution of the MAiD Coordinator Role

Nearly 80% of respondents shared their ideas around how they would like to see the MAiD Coordinator role evolve in the future.

## Integration into End of Life Care

Over half of the respondents identified the need for the MAiD Coordinator Role to be more integrated into EOL care. One MAiD Coordinator described wanting to see the role as more of a consultant/navigator role in the hospital setting with *“much of the MAiD Coordination being delivered at the unit level without much physical presence from the MAiD Coordinator.”* The same respondent identified, *“From a community perspective, I would like to see stronger connections and engagement among MAiD coordination programs along with standardized approaches to ensure optimal access to MAiD.”*

A few respondents described if MAiD was well integrated into end of life care, there might not be the need for a MAiD Coordinator.

A number of responses identified the need to integrate MAiD more fully into end of life care, suggesting

more linkages with palliative care. One coordinator described, *“I would like it to evolve to be part of end of life care provision more generally. Less of a silo. The role of the MAiD coordinator would evolve to become more specialized in providing guidance and support on palliative/EOL care generally (including MAiD) not just for MAiD patients.”*

Similarly, another respondent explained:

I would like care coordinators to be seen as a person to come in and discuss all end of life care options with patients and family. Currently within our Health Authority, MAiD is not considered an end-of-life care option because of the clash with palliative care. It is difficult for patients to understand why there are two different groups talking about end of life. If MAiD could be situated with end-of-life it would be less resource heavy, easier for staff and more understandable for patients and family.

## Develop Expertise in the Field

Some of the responses around evolution of the MAiD Coordinator role in the future identified the need to *“continue to develop the expertise in the field”* and included a suggestion to bring MAiD Coordinators across various jurisdictions *“to share their experiences with one another, in a somewhat structured forum (such as quarterly or annual meetings) to learn together and grow from each other’s experiences.”* Another respondent suggested developing best practice guidelines and more resources for care coordination centers to allow coordinators to spend more time on patient work and less time on administrative work.

Other suggestions for evolution of the role included more provincial funding for MAiD programs to support more coordinator roles and a more coordinated system of care province wide.

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