



MAiD to Last: Creating a Care Ecology for Sustainable Medical Assistance in Dying Services

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Abstract

This paper depicts a case study of an organizational strategy for the promotion of ethical practice when introducing a new, high-risk, ethically-charged medical practice like Medical Assistance in Dying (MAiD). We describe the development of an interprofessional program that enables the delivery of high-quality, whole-person MAiD care that is values-based and sustainable. A “care ecology” strategy recognizes the interconnected web of relationships and structures necessary to support a quality experience of MAiD for patients, families, and clinicians. This program exemplifies a care ecology approach that addresses common barriers to entry to MAiD practice, and also meets the needs of a variety of stakeholders through the creation of patient and family resources, team supports, standards of practice, professional development opportunities, organizational infrastructure, and community partnerships. We also describe how a thriving care ecology evolves to remain resilient, and to enable integration as the needs of the organization, team and program change over time. The design and development of this program may be adapted to other jurisdictions and organizations where MAiD is introduced, or where new patient populations become eligible for MAiD. This care ecology model may also be applicable to the creation of sustainable programs that provide other morally controversial or novel clinical services.

Keywords MAiD · Medical Assistance in Dying · Physician Assisted Dying · Hospitals · Organizational ethics · Interprofessional · Quality · Team

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Introduction

The theme of this volume centers on the practical ethics of delivering Medical Assistance in Dying (MAiD) and the lessons learned in the first 6 years since the emergence of this novel clinical practice in Canada in 2016. Other papers explore: the political and legal history that led to the decriminalization of MAiD in Canada and Quebec (Bouthillier et al., 2022; Downie, 2022); a method for addressing the introduction of MAiD as an organizational ethics challenge (Frolic & Miller, 2022); and the results of a stakeholder engagement process to assess the readiness of a hospital system for MAiD, including the specific needs clinical staff identified as important in designing a values-based, high-quality approach to MAiD care (Frolic et al., 2022a). In this paper, we describe how we put the results of that needs assessment process into practice, developing a sustainable, integrated and quality-focused MAiD program based on an ecological approach to clinical service design.

Program design for a novel, complex, and morally controversial practice like MAiD is especially important in the hospital sector. In community settings, MAiD providers are often solo practitioners and have a high degree of autonomy with few bureaucratic hurdles to providing MAiD. By contrast, in a hospital context where team-based care is the norm, a patient seeking MAiD often interacts with multiple programs (i.e., oncology and palliative care and infectious disease) and dozens of healthcare professionals over the course of their hospital stay and MAiD process. The clinical teams caring for a patient exploring the option of MAiD require (especially in the early days of the practice) education about MAiD, standards of practice to facilitate referrals and care coordination, clarification of their roles and responsibilities, and support for reflective practice regarding their own values and feelings about MAiD. In addition, hospital systems often demand structural supports for any new high-risk practice, including: evidence of compliance with legal and professional requirements through standardized and authorized forms, protocols, and practices; quality control and oversight committees to manage risk and ensure a positive patient experience; human resource management to support staff; and data management structures to track patient volumes, trends and gaps in service.

This paper proceeds in three parts. First, we describe the barriers to entry to MAiD practice in Canada for physicians and nurse practitioners who provide MAiD after assessing legal eligibility and complying with all procedural safeguards (“MAiD providers”), or who conduct independent assessments (or second opinions) of eligibility for MAiD (“MAiD assessors”). Second, we describe the model of a “care ecology” and its relevance to designing sustainable, adaptable and resilient healthcare services in challenging, trauma-exposed clinical contexts. Third, we provide an overview of the resources and structures we developed through the Assisted Dying Resource and Assessment Service (ADRAS) at Hamilton Health Sciences (HHS) to create a care ecology for MAiD practice. We hope this paper can serve as a model for other organizations in Canada and in other jurisdictions embarking on the process of creating or renewing an institutional MAiD program, especially in light of increases in demand and complexity of MAiD cases. In addition, the care ecology approach described here may inform the design of other novel and morally

controversial clinical services within organizations, with the goal of supporting high-performance in the context of high-risk practice.

Background

MAiD in Organizational Contexts: A Sustainability Challenge

In 2015 MAiD was illegal in Canada; by the end of 2020 21,589 Canadians had died with MAiD, accounting for 2.5% of all deaths in this country (Government of Canada, 2020). However, the “success” of MAiD as it becomes a more common practice also poses a challenge as the number of new MAiD providers is not keeping pace with the increase in demand for MAiD (Frolic & Oliphant, 2022).

MAiD provision in hospitals is rare in other jurisdictions where voluntary active euthanasia or physician assisted suicide is legalized. In places like Oregon assisted suicide is self-administered at home, while in places like the Netherlands that practice euthanasia, it is almost exclusively provided by the patient’s own family physician in their home or residence (personal correspondence with M. Dees in 2016). However, in Canada 60% of all deaths occur in hospitals (Statistics Canada, 2021), and the second federal report on MAiD practice in Canada (Government of Canada, 2020) indicates that in 2020, less than half of cases were performed in private residences, with most MAiD cases occurring in hospitals (28%) or Palliative Care Facilities (21%) or Residential Care Facilities (7%), in spite of the pandemic which kept so many patients away from hospitals and other healthcare institutions.

In addition, the changes to MAiD legislation in Canada in 2021 (Government of Canada, 2020) opened access to new patient populations, specifically patients who meet all eligibility criteria but who do not have a “reasonably foreseeable natural death”. This expanded criterion means that healthcare facilities in Canada that have never entertained a request for assisted dying from a patient—such as rehabilitation hospitals, in-patient mental health facilities, residences for disabled persons, addiction treatment centers, chronic pain clinics, etc.—will soon be confronted with the challenge of responding appropriately to patient requests for MAiD. Healthcare organizations need to develop strategies to create and maintain sustainable access to MAiD in anticipation of this increase in demand and in the complexity of MAiD cases as new populations begin to request MAiD, including patients with mental illness as the sole underlying condition motivating their MAiD request, starting in March 2023.

Research into the factors that influence clinicians to become MAiD providers indicates that organizational support for the practice, including administrative support, peer support and leadership support, have a big influence on engagement (Oliphant & Frolic, 2020; Rutherford, 2020). Our goal in this paper is to describe the development of a hospital-based MAiD program that delivers MAiD through an interprofessional team called the Assisted Dying Resource and Assessment Service

(ADRAS). We describe how an ecological approach to program design has enabled us to address barriers to entry to practice in order to recruit and sustain a team that delivers high-quality, whole person, evidence-based MAiD care. This approach has enabled ADRAS to meet increases in demand for MAiD; adapt to changes in legislation and regulation; integrate MAiD into clinical care across a complex, multi-site health system; and maintain the resilience and engagement of an interprofessional team even through the COVID-19 pandemic and its aftermath.¹

Barriers to Entry to MAiD Practice

It is natural for a new clinical practice to take time to take hold in medical culture. And while there is evidence emerging that MAiD providers find the work of MAiD meaningful, fulfilling and compatible with their core professional commitments (Oliphant & Frolic, 2020; Rutherford, 2020), MAiD also presents a variety of barriers and challenges that may dissuade clinicians from entering this practice. These barriers include: legal risks; clinical and administrative challenges; and social and intrapersonal challenges (see also Bouthillier & Opatrny, 2019).

Legal Risks for MAiD Assessors and Providers

MAiD practice in Canada is governed by specific provisions within the federal Criminal Code which: create exemptions from the offences of culpable homicide; define specific eligibility criteria and procedural safeguards that must be respected before medical assistance in dying may be provided to a person; require the reporting of information about MAiD practice to the federal Minister of Health; and create new offences and penalties for failing to comply with the safeguards or for failing to provide the required information, which may include imprisonment (Parliament of Canada, 2016). In addition to these requirements under federal law, provincial health authorities may also require MAiD assessors and providers to complete forms of documentation and/or report their MAiD cases for review and oversight. For example, the Coroner's Act of Ontario requires physicians and nurse practitioners who provide MAiD to notify the Office of the Chief Coroner of the death, and provide the coroner/investigator with the facts and circumstances of the death.² Once a death is reported, the coroner/investigator will determine whether it is appropriate to investigate the death. If issues with compliance with the law, regulations and/or regulatory college policies (College of Physicians & Surgeons of Ontario, 2016) are identified, a structured approach to respond to concerns regarding compliance will be undertaken by the coroner. Noncompliance may result in written warnings to the MAiD

¹ This model of MAiD care was recognized with a Palliative Care Innovation Award from the Canadian Foundation for Healthcare Improvement in 2017–2018.

² Further clarification on the role of the coroner and coroner's office can be found at <http://www.mcscs.jus.gov.on.ca/english/Deathinvestigations/OfficeChiefCoroner/Publicationsandreports/MedicalAssistanceDyingUpdate.html>.

provider for minor infractions, or reports to the regulatory body and/or the police for major infractions. Note, however, that the Office of the Coroner only offers *retrospective* case review after the patient has received MAiD; they do not offer guidance or advice to practitioners in advance of the death. Thus, a MAiD provider who has questions or concerns about how to comply with the law in a particular case must find their own advisors to assist them prior a MAiD provision.

The highly regulated and compliance-focused nature of MAiD practice may be a barrier to entry for many nurse practitioners and physicians who may be sympathetic to the needs of patients requesting MAiD. However, other aspects of the legal and regulatory framework surrounding MAiD may amplify the legal risks in the minds of prospective assessors and providers. These include:

- *Subjectivity of clinical eligibility criteria:* Persons are only eligible for MAiD if they have a “grievous and irremediable medical condition”, which is a legal term not clearly defined in clinical practice. In addition, there is significant ambiguity surrounding other criteria, including “advanced state of irreversible decline in capability” and “enduring physical or psychological suffering that is intolerable”. No objective test can determine whether a patient meets these criteria, rather a professional must rely on their clinical judgement, which may feel challenging for novice practitioners (Parliament of Canada, 2016).
- *Capacity assessment:* Persons receiving MAiD must give informed consent, understand and consider the alternatives to MAiD (especially palliative care), and be capable of directing their end of life care. Patients seeking MAiD are often acutely ill and medically fragile, and may have fluctuating capacity throughout the process, making the assessment of capacity at each step potentially challenging.
- *Voluntariness:* Persons receiving MAiD must demonstrate they have made a voluntary request for medical assistance in dying that was not made as a result of external pressure. It is not clear what may constitute “external pressure” in the context of patients who may be totally reliant on care from others to meet their basic needs, nor is it clear how MAiD providers ought to assess voluntariness, which is not a typical part of clinical practice.
- *No MAiD assessment standards of practice:* At the outset of this practice there were no published best practice standards for conducting MAiD assessments of eligibility by any regulatory body. Novice clinicians would have to discern for themselves: what questions must be asked; how to establish therapeutic rapport; how to involve families in the process; how to interpret the patient’s suffering and whether other options have been adequately explored, etc. Without clear assessment guides or standards, the risk of noncompliance with regulatory requirements increases.
- *Incongruent assessments:* A person receiving MAiD must have two assessments from independent physicians/nurse practitioners confirming their eligibility. However, it is not clear how clinicians should reconcile incongruent findings of eligibility (i.e., when one finds the patient eligible, and others find the patient ineligible). Such incongruence may trigger a deeper investigation by the Coroner/regulatory body, and increase perceived legal risks for all clinicians involved.

- *Reporting requirements:* MAiD is the only clinical practice requiring reporting of patient referrals, assessments and outcomes to the federal government, with significant sanctions for failure to report.

The legal and regulatory requirements surrounding MAiD practice—in combination with the ambiguity of the clinical and procedural eligibility criteria, the lack of standards of practice, and stringent reporting requirements—may all pose significant barriers to entry to practice for clinicians based on the perception that MAiD is a legally and professionally high-risk practice (see also Bouthillier & Opatrny, 2019).

Clinical Challenges for MAiD Assessors and Providers

As of 2022, there are no competency-based barriers to entry to practice for MAiD providers and assessors in most parts of Canada. Any clinician with a valid medical or nurse practitioner license may decide to include MAiD in their practice. There are as yet no standardized curricula,³ no required practical training or clinical supervision, and no exams or credentialing processes. Many MAiD providers are either self-taught or rely on peer support or mentoring to become familiar with the practice and its complex regulations. While this theoretically makes it easy for new clinicians to enter the field, the lack of formal educational pathways itself creates a barrier to entry, especially for providers in rural or remote communities without access to peer support from an experienced MAiD provider.

It is important to note that patients with a wide range of diagnoses may request MAiD: patients with cancer; ALS and other neurological conditions; cardio-vascular or pulmonary disease; infectious diseases; frailty; dementia; auto-immune disorders; and even rare or orphan diseases may ask for help to die. Some conditions have more predictable prognoses while others have more variable courses and symptoms. MAiD providers have to know enough about the patient's illness and the local health system, to be able to determine if their suffering is grievous and irremediable, if their natural death is reasonably foreseeable or not, and if there are other treatment options available to the patient to relieve suffering. MAiD providers often communicate with multiple care providers involved with the patient (i.e., primary care, palliative care, specialists) to clarify the patient's clinical status, and may need to seek consultation from a specialist with expertise in the patient's condition, which is a legal requirement for patients without a reasonably foreseeable natural death. Timely access to specialists is challenging in many communities across Canada, creating another barrier.

While MAiD assessments are cognitively demanding, requiring the synthesis of complex dynamics between the patient's clinical presentation, prognosis, options, wishes and values, MAiD patients also are nested in a social/familial network and

³ The Canadian Association of MAiD Assessors and Providers (CAMAP) is developing a national curriculum to provide standardized hybrid on-line/in-person training in MAiD practice, to be launched in 2022/2023.

frequently present with complex psycho-social needs. Patients themselves may express religious or moral ambivalence about their desire for MAiD; experience significant psychological and existential suffering as well as physical discomfort; have a concurrent mental illness such as depression or anxiety; express fears about death and dying; or articulate concerns about how their family/friends/community are responding to their illness and their request for MAiD. In addition, the family/community surrounding a patient may have their own fears, worries, moral ambivalence, anticipatory grief, social pressures and caregiving responsibilities that require emotional support from the MAiD provider (Frolic et al., 2020). Sometimes there are overt tensions between family members that may need containment. The MAiD provider must also educate the family about how the patient will die and is present with the family immediately after the death during their immediate grief response. Thus, a MAiD provider must be prepared for the significant emotional labor that goes along with supporting a patient and family through the dying process.

Administrative Challenges for MAiD Assessors and Providers

A frequent complaint heard amongst MAiD providers is the significant administrative burdens associated with MAiD practice (Frolic et al., 2022b; Simpson-Tirone et al., 2022), including:

- Coordinating communication with specialists, and other care providers.
- Gathering information from multiple medical records across different healthcare institutions.
- Ensuring the patient has completed the required written request/consent forms and that they are appropriately witnessed.
- Finding a willing and available independent MAiD assessor.
- Coordinating appropriate time/location of assessments with patients and families.
- Completing detailed documentation of assessments of eligibility (which may be pages long).
- Following up with patients/families throughout the process.
- Reporting MAiD activities to the federal Ministry of Health.
- Communicating with the provincial authorities, such as a coroner, after completing cases.
- Traveling to patients homes or other institutions outside of the clinician's usual place of work.

These burdens will be particularly heavy for novice practitioners who have to learn the regulatory, reporting, and documentation systems and gradually develop their own routines to manage the many details of this practice. In some provinces, financial remuneration for MAiD providers and assessors is not commensurate with the time the practice requires, creating another barrier to entry to practice, especially for many nurse practitioners.

Social and Intrapersonal Challenges for MAiD Assessors and Providers

Making the decision to become a MAiD provider or assessor is not an easy one for many clinicians. Although MAiD has become increasingly socially acceptable within Canadian society over the first 6 years of practice, MAiD providers may face stigmatization and isolation within their communities. For providers who work in medical cultures that see death as a failure and direct participation in a patient's death as anathema to the fiduciary duties of a healthcare practitioner, the professional barriers may be significant. Some specialties in hospitals may be dominated by objectors to MAiD, making it challenging professionally to opt into MAiD practice. Participating in MAiD could lead to conflicts with colleagues and even impact academic advancement. In smaller communities MAiD providers may be “outed” and face ostracism; other patients may leave their practice if they find out their physician or nurse practitioner is a MAiD provider. The history of violence against abortion providers in North America, and fears for their own physical safety, are often cited as concerns raised by novice MAiD practitioners. And of course, MAiD providers have their own friends and families who may not approve of their participation in a clinical practice unfairly cast as taboo.

In addition to these social barriers, clinicians often encounter intrapersonal or psycho-emotional challenges to participating in MAiD. Participating in assisted dying requires providers to listen to stories of patients' grievous and irremediable medical conditions and intolerable suffering. And, they are not only present at but facilitators of the patient's death. This direct encounter with loss, suffering, grief and death, while deeply meaningful, nevertheless exposes providers to vicarious trauma. This may evoke emotional responses in the MAiD provider related to their own experiences of illness and loss. In addition, MAiD providers may experience moral ambivalence about certain MAiD cases, for example where the patient or family are perceived as aggressive or manipulative, or where the patient has certain characteristics that trigger countertransference. Without access to reliable peer support or mentorship, a supportive family, personal psychological supports or a professional community to debrief cases with, it may be challenging for even willing clinicians to overcome these intrapersonal barriers to MAiD practice.

Not all of these barriers will be experienced by all MAiD assessors and providers, and some may be mitigated for practitioners who are later in their careers or who have strong professional networks of support. But many of these challenges are difficult to overcome in the absence of significant social, administrative, and organizational support. In addition, the expansion of the option of MAiD to new populations in 2021—specifically to patients who don't have a reasonably foreseeable natural death, who often suffer with multiple co-morbid chronic conditions, as well as mental illness—will likely amplify these barriers to entry as these patients are more complex and have more required procedural safeguards that must be followed.

We propose the strategy of a “care ecology” as one way to structure MAiD services to reduce barriers to entry for new MAiD practitioners, to promote the resilience and retention of current practitioners, and to continuously build capacity to ensure sustainable access to care for patients seeking MAiD now and in the future.

Table 1 Assisted Dying Resource and Assessment Service (ADRAS) Team Charter

Purpose: The purpose of ADRAS is to provide a centralized consultation and referral service to responsibly and compassionately manage patient inquiries and requests for assisted dying, and to support clinical teams caring for these patients

Mandate: To provide expert and effective consultation services using an interprofessional team model in alignment with legislative/regulatory requirements, professional practice guidelines and emerging best practices, and in collaboration with community partners. ADRAS provides service to HHS inpatients and outpatients, following and supporting the patient, family and healthcare team from first inquiry to the provision of assisted dying, tailoring its services to the specific needs of each situation

Roles and responsibilities

- Develop policies and resources to ensure consistency and transparency of MAiD services, and comply with all professional and legal requirements (i.e. documentation standards and forms)
- Provide standardized, high-quality MAiD assessments and provisions
- Utilize an interprofessional team structure to enable whole-person, compassionate care for patients and families
- Build capacity for responding to patient MAiD requests amongst clinical teams through coaching, education and collaboration
- Use a trauma-informed approach to create resources and practices that promote MAiD provider resilience and engagement (including mindfulness, peer support, psychological support and case debriefing)
- Practice continuous quality improvement through data tracking and engaging multiple stakeholders in the evaluation of our practice (families, clinical teams, leaders, ADRAS members, etc.)

Team structure^a

Team members: ADRAS members from diverse professions and specialties participate in MAiD practices (assessment, provision, team meetings, professional development)

Leadership: Operational Director and Physician Lead facilitate operational and clinical functions and team culture

Care coordinators: Provide case coordination of MAiD referrals from first contact to follow-up; facilitate communication with other care teams; educate patients/families/clinicians about MAiD; ensure compliance with standards; promote continuous quality improvement (see Simpson-Tirone et al., 2022)

^aAll ADRAS members have a primary appointment in another clinical program and devote 7–15 work hours/month to MAiD work. The only roles dedicated to MAiD care are the operational director (0.3 FTE); physician lead (0.1 FTE) and care coordinators (0.8 FTE). Thus, although the MAiD care ecology is robust, it is not financially resource-intensive.

Methods

Our hospital, Hamilton Health Sciences (HHS), undertook an organizational ethics engagement (Frolic & Miller, 2022) and stakeholder needs assessment project (Frolic et al., 2022a) in 2015–2016 to inform the design of the MAiD program. Based on the results, we designed—with input from senior executives, clinical leaders and ethicists—an interprofessional, team-based approach to MAiD care, modeled on the interprofessional ethics consultation team structure at HHS that was recognized by Accreditation Canada as a leading practice. This team, called the Assisted Dying Resource and Assessment Service (ADRAS), was recruited and launched just before MAiD legislation was passed in June 2016. Its membership comprises: physicians from multiple specialties, nurses and nurse practitioners, social workers, spiritual care providers, ethicists, speech language pathology, psychology and pharmacy.

The goal in creating ADRAS was to develop a high-quality, values-based, sustainable and integrated model of assisted dying that meets the needs of diverse stakeholders across our tertiary, multi-site health system, as described in Table 1.

In 2018, after the first 2 years of MAiD practice, we undertook a program evaluation study to understand how well ADRAS was meeting its goals and mandate through a mixed-methods approach that engaged diverse stakeholders impacted by the implementation of MAiD at HHS, including: frontline clinical staff and physicians, families of patients who received MAiD, and senior leaders (see Frolic et al., 2022b for a detailed description of this study). In addition, ADRAS team members were invited by the research team to participate in two focus groups; four physicians and nine healthcare professionals participated. The facilitator used a semi-structured focus group guide to generate discussion and reflections from participants about their experiences as members of the MAiD program. The transcripts were analyzed by members of the research team (AO and AF) to identify key concepts and themes related to the structure and function of the ADRAS team, and the impact of involvement with MAiD on its diverse members. The results of this study, excerpted below, supported further evolution of our team-based model of care, and the resources developed to support recruitment, retention and resilience within the ADRAS team.

Findings

Care Ecology: A Model for Sustainable Healthcare Practice

Concurrent with the development of the MAiD program, the HHS Office of Clinical & Organizational Ethics embarked on a project to create an evidence-informed theoretical model for developing a compassionate, resilient workforce in healthcare, specifically in trauma-exposed environments. Recognizing the epidemic of burnout and compassion fatigue amongst healthcare workers (even before the COVID-19 pandemic), the project involved a literature review on occupational stress, focusing on the neuroscience of stress, trauma-exposure and post-traumatic growth, and the influence of organizational culture on resilience, empathy and quality of worklife. The model created is intended to inform strategic planning and program design and to generate recommendations for integration of pragmatic resources, structures and practices to enable healthcare organizations to foster a resilient workforce, and one that embodies the emotional intelligence needed to provide a patient experience that is compassionate and delivers whole person care (Tikas & Frolic, 2018).

The model we developed uses the metaphor of *ecology* to describe the delivery of care in hospital settings and the structures needed to sustain resilience and compassion in a trauma-exposed workforce. Ecological models consider the relations between individuals and their environments to understand the multifaceted and interconnected effects of personal and contextual factors that impact function and well-being. An ecological model of care recognizes that all acts of care are carried out within a dynamic system of relationships that span across space and structures, each layer of relationship influencing all others in both subtle and direct ways. As Bruce Jennings puts it, “Care begins with the recognition of symbiotic interdependence

and then intervenes in—interrupts—an ongoing form of life in order to be present to the need, vulnerability, and suffering it contains” (Jennings, 2017, p. 11).

Thus the model of a “care ecology” is the “network of relationships, systems, resources and processes that enables the flourishing of care for self [as healthcare practitioner], patient/family, colleagues, learners, teams, and the healthcare system. Well-being of one part of the care ecology is always connected to well-being of every other part” (Tikasz & Frolic, 2018, p. 11). This model of care recognizes that both givers and receivers of care are constantly engaged in interdependent structures across all levels of a health system that can either enhance or deplete care. Thus, the only way to truly create a sustainable and resilient healthcare workforce is by cultivating an ethos of care and enabling structures of care across the ecology: from patient to provider to team to organization to community. In addition, a care ecology shifts clinical service models away from relying on acts of individual heroism which may deliver short-term results but are limited in scope and impact and can deplete the healthcare practitioner and damage relationships in ways that have long-term detrimental impacts on the system’s capacity to deliver care. A care ecology is a system where whole person care emerges from the properties of the network itself, not from the individual actions of any one member. Such a network effect has strong irreducible properties and is anti-fragile, and thus its benefits to both patients and healthcare providers cannot be derived from any individual alone (Norman, 2021).

A Care Ecology for MAiD

The ADRAS team served as a living laboratory for putting this care ecology model into practice. Through an iterative process of development that has unfolded from the decriminalization of MAiD in 2015 to the present day (see Appendix 1 for a timeline of development), the ADRAS team has created a model of practice that attends to the interconnected web of systems and relationships that enable care. This model has led to the development of a suite of resources, tools and infrastructure designed to overcome barriers to entry to practice for MAiD providers and assessors and promote a sustainable MAiD program that is adaptable to changes in legislation and practice, increased demand and expanded patient populations.

The patient is the heart of MAiD care. Under Canadian law, only the patient may initiate a MAiD request, and the capable patient directs every step of the process,⁴ deciding when to proceed and when to pause or abandon the process. MAiD patients become the center of an intense social and emotional process that includes telling the story of their illness, their treatments, their suffering and their intention to die to two independent nurse practitioners or physicians who assess their eligibility for MAiD and ensure appropriate procedural safeguards are met. If found eligible, and if they choose to proceed with MAiD, patients then engage in various forms of social and emotional labour, including: making final arrangements; explaining their

⁴ Substitute decision-makers have no standing when it comes to MAiD; they cannot request MAiD nor consent to MAiD on behalf of a patient. The patient must be capable through both assessments of eligibility and must be capable to give informed consent to the procedure itself.

choice for MAiD to family/friends; saying good-bye; orchestrating the timing, location, and social/spiritual aspects of their death in collaboration with their MAiD provider and community (a process we have termed “death choreography”); and finally, undertaking the medical procedure that ends in their death.

MAiD is, at its foundation, an expression of patient autonomy. However, because MAiD is a strictly regulated procedure of enormous consequence to all parties, the enactment of a patient’s autonomy is dependent on the collaboration of all other levels of the care ecology surrounding the patient. Recognizing this obstacle, the ADRAS team has evolved a range of tools, practices and processes to support an integrated ecology of care that meets the unique needs of individual patients and families and promotes program sustainability and adaptation over time. The ADRAS care ecology integrates the needs and resources of: the patient, family, clinical team caring for the patient, MAiD team, organization and community partners. This is depicted in Fig. 1 and described in detail in Table 2 in Appendix 2.

Team Experience of MAiD Care Ecology

At the outset of the development of our MAiD program, it was recognized that providing MAiD is trauma-exposed work that carries significant social, emotional, professional, and legal risks for practitioners. Thus, the implementation of resources, processes, and practices to remove barriers to entry to MAiD practice, and to support the resilience, engagement and well-being of MAiD practitioners was hardwired into the design of the care ecology. Focus groups with thirteen ADRAS team members in 2018 revealed a number of contributors to the sustainability and engagement of the team; these are summarized below.

- (1) *Meaning of MAiD care:* ADRAS team members reported feeling energized by the meaningfulness of the practice. As one physician put it, “But I would say that this experience of working with people at the end of their lives, and providing this service to patients and their families, is probably the most important work I’ve ever done. And it is the most gratifying work that I’ve ever done...and I’d like people to understand that this isn’t the underbelly of medicine. It’s not something that... has to be done but we can’t feel proud of”. Another physician said: “in healthcare you see so many awful deaths and just to see people have a dignified, peaceful death is...is very gratifying.” A nurse appreciated how ADRAS practices whole person care, “We get to actually spend as long as we want with our patients, not, ‘Oh my gosh, there’s a patient coming in 5 minutes. You’d better hurry up and get that consent’. ...So that this whole...whole person model has been the best healthcare model that I’ve ever been a part of, for me as a healthcare person”. Another physician even reported that the ADRAS model of care has positively impacted other aspects of her clinical practice: “it has, to some extent, had an effect and permeated back into some of my other practice so, you know...there’s times I’ve recognized more that, okay, I need to be a little bit more attentive, focused in on the patient, what they’re saying to me now, in my clinic because this is an important thing...and I think that I’ve...that ability to do that has been sharpened and developed and focused in this work, to some extent”.

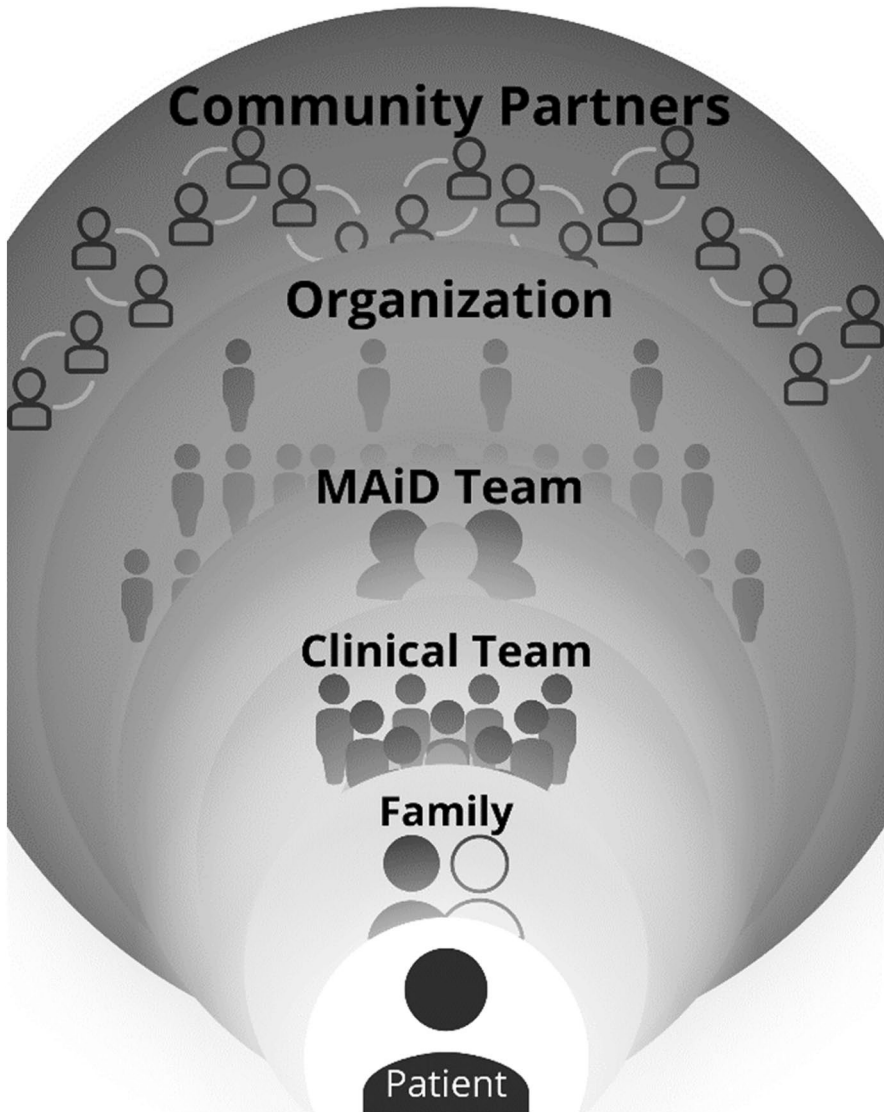


Fig. 1 MAiD Care Ecology Model. *Community Partner Supports*: advocate for/facilitate MAiD care across hospital/community/region; local and national research, policy-making, practice standards and education collaborations. *Organization Supports*: infrastructure and resources to enable sustainable, accountable, high-quality MAiD hospital services (forms, protocols, leader support, etc.). *MAiD Team Supports*: interprofessional MAiD service provides whole-person care to patient and family; care coordination; structures enable team member engagement/resilience/development. *Clinical Team Supports*: facilitate referrals of patient requests for MAiD; support collaboration with ADRAS to enhance patient quality of life and explore all care options. *Family Supports*: education on MAiD process; emotional support; “death choreography”; bereavement support. *Patient Supports*: timely access to MAiD services using narrative, patient-centred approach; honoring the emotional, social, spiritual, and physical needs of the patient through the assessment and dying process

- (2) *Teamwork and collaboration*: Another theme was around the strength of the interprofessional model of care. A physician reported: “I’ve always felt, like, because of the diversity of skillsets that people bring, that you know, I have a lot of confidence that, no matter what happens, this team will be able to adapt and...and meet any sort of challenges that come that way. And in comparison to, you know, thinking about how daunting, you know, MAiD would be if you were doing it entirely on your own”. Similarly, a nurse reported: “this is the way healthcare should be, multidisciplinary, interdisciplinary...using all aspects of self”. A social worker also commented, “the support is palpable and I think that whole, like, care for the carer really has such tremendous personal impact that it creates a healthy environment... It feels very safe”.
- (3) *Resilience resources*: Both physicians and other health professionals appreciated the resilience practices integrated into the team structures. As one physician commented, “we actually debrief right after the [MAiD] provision...it has so much discussion with that that even when there’s difficult things, all that does is build resilience and just makes you want to be further part of the team and be further involved. Whereas, if you had bad experiences on your own, I think people would do two or three of them and then they would feel, ‘I can’t do this anymore’. And you’d burn out much easier”. Another nurse suggested, “something that I think is truly amazing is...is how we come together as a team and build resiliency because a lot of people are getting burnt out, say, in other organizations and in the community”.
- (4) *Administrative and leadership support*: Another theme was the importance of having a leadership structure to create infrastructure to help manage the uncertainties of a new practice, and to support optimal team function. As one social worker pointed out, “I think we’ve been really fortunate to have the level of commitment with [leaders] who’ve gone above and beyond in terms of checking in with people...in my mind, sustainability includes having some dedicated leaders who can manage those administrative, operational challenges”.

Since the time of this program evaluation, ADRAS has continued to evolve its care ecology and resilience resources to include: dedicated psychological support; annual team retreats; education in moral injury prevention and mentorship in managing complex cases from a colleague in the Netherlands. Team members continue to report commitment to and fulfillment through their work with the MAiD program. In the 6 years since the creation of ADRAS, the majority of the original team members have remained engaged even over the course of the COVID-19 pandemic and its aftermath, and we have successfully recruited and retained 25 new members to join the team since we first launched in 2016.

Discussion

In spite of the significant barriers to entry to practice for new MAiD assessors and providers in Canada, and the continuing increase in demand for MAiD services, a care ecology strategy implemented at a tertiary, multi-site academic hospital

has proven effective in developing and maintaining a high-quality and sustainable MAiD program that delivers on the promise of whole person care, provider resilience and operational integrity. The results of our program evaluation project that received feedback from multiple stakeholders impacted by MAiD services (Frolic et al., 2022b) indicate high satisfaction with the program from clinical teams, senior leaders and ADRAS members themselves. In addition, ADRAS receives consistent positive feedback regarding the whole person care the team delivers from families during our bereavement follow-up calls.

This ecological model of MAiD care has supported the retention of MAiD providers and assessors over a tumultuous 6 years of practice that included a global pandemic in 2020–2022, as well as major changes to Canadian MAiD law in 2021. Its organizational infrastructure enabled adaptation of the team's practices to new legislation, safeguards, and regulatory requirements, to mitigate risks and ensure compliance. ADRAS has not only sustained MAiD practice, but it has grown MAiD capacity in the Hamilton community, providing formal training, coaching and mentorship in MAiD assessment to over 100 physicians and nurse practitioners across our region. This care ecology model will enable sustainable access to MAiD even as demand increases and new populations seek MAiD services through ongoing collaborations with community partners.

Critics of a care ecology strategy may point to the significant investment of resources required to design and deliver this model of care. The greatest investment of resource was during the design and build phases of ADRAS, from 2016 to 2017; at that time the operational director (AF) and physician lead (PM) dedicated approximately half their work hours to this project. However, that early investment developed infrastructure that is self-sustaining: now ADRAS has only two part-time care coordinators and the operational director and physician lead work the equivalent of approximately a day a week to sustain the program. Interprofessional ADRAS team members are remunerated from their clinical units, so costs are dispersed across the organization, making the financial investment relatively modest. In this way, a care ecology approach to MAiD is both efficient and cost effective. And while not all MAiD programs have the organizational resources available within a tertiary, academic health system, the care ecology model is scalable to different contexts. The model could be expanded to strengthen interconnections and develop infrastructure across communities or regions, or it could be contracted to focus on developing a care ecology within a small primary care practice or community hospital.

Conclusion

Healthcare ethics as a field has historically focused on the ethical issues surrounding individual patient cases or organizational policies. However, ethics has much to contribute in addressing health system issues such as: anticipating and addressing challenges in patient access to care; identifying barriers to entry to practice where there are unmet healthcare needs; recognizing and naming the risks associated with providing care that is morally controversial, legally perilous and/or trauma-exposed, and advocating to proactively address these risks; mapping the relational

connections across a care ecology; and participating in the co-design of clinical services to enable care that is patient-centered, as well as safe and sustainable for providers. Given the increasing demand for MAiD care in general, and the increasing complexity of cases introduced through the inclusion of new patient populations by law in 2021, MAiD providers may face greater moral uncertainty and legal challenges, and greater personal risk of moral injury, vicarious trauma, and burnout. Designing MAiD services using a care ecology model may be one strategy to ensure patients requesting MAiD receive safe, high-quality care, while also promoting the psychological safety and engagement of providers. Ethics programs may also consider how they could adapt this strategy to support the design and sustainability of their own services, and consider the ecological dimensions of care when consulting on new and controversial organizational practices. Future research may explore the return on investment of a care ecology model, as well as its application to other high-risk, trauma-exposed clinical services.

Appendix 1: Timeline of the Development of the Assisted Dying Resource and Assessment Service (ADRAS) Care Ecology

- *2015 Exploring and Preparing:* February: Supreme Court of Canada *Carter v Canada* decision decriminalizes physician assisted dying (suspended for 1 year); **Winter:** author (AF) travels to the Netherlands, conducts interviews with Dutch euthanasia providers to understand the experience of the practice and identify supportive structures; **Summer:** Hamilton Health Sciences (HHS) leadership endorsement of Physician Assisted Dying Readiness Assessment Project (PADRAP), co-led by Office of Clinical & Organizational Ethics and Medical Advisory Committee; **Fall:** Creation of interprofessional PADRAP Working Group; Research Ethics Board-approved PADRAP survey and focus groups with staff and physicians to understand needs and values of staff and physicians related to the impending introduction of assisted dying.
- *2016 Creating and Initiating:* **Winter:** Completion of PADRAP study and analysis; report provided to hospital medical and executive leadership; **Spring:** Board of Directors approves that HHS will provide assisted dying through the development of an interprofessional, voluntary Assisted Dying Resource and Assessment Service (ADRAS); initial ADRAS recruitment results in 12 member interprofessional team; ADRAS hosts regional symposium on MAiD practice with Dutch guest faculty; Medical Assistance in Dying (MAiD) legislation introduced and debated by Parliament; **Summer/Fall:** MAiD legislation passed into law by Parliament, becomes accessible to Canadians; ADRAS develops team strategy of care, as well as medication protocols and practice guides; first MAiD cases completed by ADRAS; hospital-wide education on MAiD law and process.
- *2017 Consolidating and Expanding:* **Winter:** development of checklists, resources and tools to standardize ADRAS MAiD assessment and provision practices, as well as patient education resources; MAiD Care Coordinator role created; formalization of ADRAS physician lead role; Assisted Dying Steer-

ing Committee formed to provide oversight and promote quality improvement; **Spring**: recruitment and training of second ADRAS cohort (6 members); development of bereavement follow-up process for families; **Summer**: ADRAS Awarded Palliative Care Innovation Award by Canadian Foundation for Healthcare Innovation (CFHI); **Fall**: developed transfer process to accept MAiD patients from local faith-based healthcare organizations and community.

- *2018 Integrating and Sustaining*: **Winter**: initiated program evaluation project (funded by CFHI) using mixed methods design to measure stakeholder experiences of ADRAS and its quality of care; **Spring**: Based on program evaluation results and increase in cases, a sustainability strategy is developed to increase care coordination support; MAiD program is integrated into the palliative care department and reports to the Medical Chief of Palliative Care; third ADRAS team cohort recruited and trained (5 members); **Fall**: second part-time MAiD coordinator hired; federal reporting requirements initiated; initiation of a regional MAiD community of practice of community and hospital providers to identify and address common practice challenges.
- *2019–2021 Reflecting and Responding*: **2019**: Designated outpatient space identified and designed for MAiD procedures for patients requiring transfer from community or other health facilities; Research conducted with bereaved families to explore the legacy of a MAiD death; ADRAS offers training on complex cases with Dutch mentor to community partners, in anticipation of the striking down of the “reasonably foreseeable natural death” eligibility criteria; **2020**: ADRAS adapts practice to the context of COVID-19 pandemic as team members are redeployed to COVID response; creates virtual MAiD assessment processes; community partnership facilitates referrals of outpatients seeking MAiD who wish to avoid hospital admission; federal MAiD law deliberated by federal government, including allowing access to MAiD for patients without a reasonably foreseeable natural death and mental disorder as sole underlying condition, along with changes to other procedural safeguards; **2021**: creation of a community of practice of stakeholders across the region to promote community partnerships and anticipate/address barriers to access to MAiD for new patient populations; new MAiD legislation passed; ADRAS collaborates with legal counsel and community partners to update all policies and procedures to comply with new legislation; ADRAS members co-lead provincial communities of practice for ethicists supporting MAiD and MAiD Care Coordinators in Ontario to address ethical and procedural issues arising from new MAiD legislation and increasing demand for MAiD services.

Appendix 2

See Table 2.

Table 2 Overview of MAiD Care Ecology Model**Patient supports provided by ADRAS**

When patient inquires about MAiD option, ADRAS provides patient education about the MAiD process, including FAQs, criteria, safeguards and the medical procedure

Coordination of care and communication between all clinical services caring for the patient to facilitate timely access to MAiD

Facilitates independent witnesses to sign MAiD request forms

Uses a narrative approach to MAiD assessments, privileging the patient's voice and values, while supporting interpretation of the legal eligibility criteria. Promotes whole person care and patient autonomy by probing all dimensions of suffering (physical, emotional, social and existential), exploring options to enhance quality of life, supporting mortality acceptance, and ensuring that the choice for MAiD is voluntary and informed

“Death choreography”: ADRAS team supports a patient-centred dying process by traveling to the patient's location of choice and integrating the MAiD procedure into rituals of dying that are meaningful to the patient and family

Family supports provided by ADRAS

Provides education about the MAiD process and psycho-emotional support before, during and after the MAiD procedure, in collaboration with the clinical care team

Assists in planning the “death choreography”, including referrals to social work, spiritual care or community religious resources

Offers follow-up call 1–3 months after the patient's procedure to receive family feedback on their MAiD experience, and to provide referrals to bereavement resources

Clinical team supports provided by ADRAS

Receives referrals so that physicians and nurse practitioners who object to MAiD or who are unable to provide MAiD can make efficient and effective referral to a competent care team

Collaborates with other services to ensure patient has considered all treatment options and to support optimal symptom management and quality of life for patient, such as palliative care, spiritual care, communication supports, etc

Offers coaching to physicians and nurse practitioners who are willing to provide independent MAiD assessments for their patients

Provides education about the law and practice of MAiD and how clinicians can support patients exploring the option of MAiD

Facilitates case debriefing after a MAiD procedure to provide hospital staff who cared for the patient with an opportunity for reflective practice and peer support

ADRAS team supports

Integrates peer support and interprofessional practice into every aspect of care; Our philosophy is team members are “never alone”—all MAiD assessments and provisions done in pairs (one physician/nurse practitioner and another health professional)

Supports psychological safety and resilience through: mindfulness, procedural pauses before cases and debriefing afterwards, celebrations and team retreats

Care coordinators facilitate communication and offer logistics support to ease administrative burdens and ensure compliance with legal/regulatory requirements; distributes workload and cases to support sustainability of human resources

Enables capacity-building through bi-annual recruitment of new members, using formal mentorship model as well as simulation-based training to develop competence and confidence in novice MAiD providers

Promotes high-quality, reliable care that complies with legal/regulatory standards through the development of protocols, forms, checklists, practice guides, etc

Engages in continuous quality improvement through monthly team meetings; case debriefing; QI processes; discussion of emerging trends and issues

Table 2 (continued)**Organizational supports for MAiD**

The Assisted Dying Steering Committee is comprised of senior hospital leaders. ADRAS reports quarterly to the Steering Committee which provides oversight, strategic alignment, resource allocation, and organizational accountability

ADRAS has leadership support in the form of an operational director to manage the clinical operations, team and staff, and a physician lead to support clinical practice and innovation. The MAiD program reports to the Chief of Palliative Care and Family Medicine who provides medical oversight and facilitates integration of MAiD with the palliative care program

ADRAS has access to legal and ethics consultation to address complex cases as well as address areas of risk or changes in policy, practice or law

Community partnerships supporting MAiD

ADRAS has an explicit partnership with a local family health team to facilitate efficient referrals/transfers of patients between hospital and community settings

ADRAS participates in a community of practice with other providers across the region to address systemic challenges, advocate for sustainable resources and develop shared processes/tools and educational strategies to enhance regional MAiD capacity

ADRAS collaborates with researchers both locally and nationally to advance new knowledge and enhance MAiD practice and education

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Declarations

Conflict of interest The authors have no conflict of interest to declare.

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