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#### How is the Medical Assistance in Dying (MAiD) process carried out? A qualitative process model flowchart study

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#### How is the Medical Assistance in Dying (MAiD) process carried out? A qualitative process model flowchart study

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### Abstract

**Objectives:** The aims of this study are: 1. To create a flowchart process model of how MAiD occurs and, 2. To detail how healthcare professionals are involved at each stage. The research questions are: How is the MAiD process carried out and which professionals are involved at which points? and Which roles and activities do professionals carry out during the MAiD process?

**Design:** Qualitative process model flowchart study with semi-structured interviews. **Setting:** Primary and secondary care in Nova Scotia, Canada.

**Participants:** Twelve physicians, three nurse practitioners, six nurses, six pharmacists and five healthcare administrators and advocates. Interviewees self-selected to participate in the study. Participants were included if they participate in MAiD (e.g., conduct assessments, provide MAiD, fill prescriptions, insert IVs, organize care, etc.).

**Results:** The flowchart process model details 5 stages of how MAiD occurs: 1. Starting the MAiD Process, 2. MAiD Assessments, 3. MAiD Preparation (hospital in-patient, hospital outpatient, non-hospital), 4. Day of MAiD and 5. Post-MAiD (hospital in-patient and out-patient, non-hospital, after leaving setting). Nineteen points where the process could stop or be delayed were identified (e.g., no local clinicians or pharmacists participate, patient does not meet criteria). MAiD differs slightly by location and multiple types of professionals from different organizations are involved at different points in the process.

**Conclusions:** Our study adds knowledge about the variety of activities and roles of different professionals in the MAiD process, which have not been documented in the international literature. Clinicians and pharmacists spend significant additional time to participate in and coordinate MAiD, raising questions about its sustainability and uncompensated costs. The process model flowchart identifies where MAiD can be delayed or stop, signalling where resources, training and relationship-building may need to occur. Knowing where potential delays can occur can help clinicians, administrators and policymakers in other jurisdictions improve MAiD.

#### Strengths and limitations of this study

- Our novel flowchart process model of medical assistance in dying outlines professionals' roles and activities, the points at which they are involved and where delays/stops can occur.
- Our findings provide an opportunity for other jurisdictions to learn how medical assistance in dying works as well as compare and contrast their model.
- As this study occurred in one Canadian province, it does not enable us to generalize the findings to other provinces or internationally.

**Keywords**: Euthanasia, Active, Voluntary; Qualitative research; Outcome and Process Assessment, Health Care; Professional Role

### Background

Medical assistance in dying (MAiD) has been legal in Canada for over 4 years [1, 2]. Many of the initial *ad hoc* processes and procedures that healthcare professionals developed to implement it while professional College policies, health authority policies and processes were being developed are still being used today [3, 4, 5, 6, 7, 8]. For example, the press described MAiD in the Canadian province of Ontario as "*an ad hoc, scattershot mess. Policies were hammered out in email chains and over casual conversations*" [9], and in Nova Scotia (NS) as "*We have a small set of providers, but we can't possibly keep up with the patient demand*" [10]. It is difficult, however, to evaluate and improve a new health service without understanding how it is carried out. With Canada's MAiD criteria expanding (i.e., an advance directive for those who will lose capacity can be included and the "reasonably foreseeable" death requirement will be removed) [11, 12, 13, 14], there is a pressing need to evaluate and improve the process. The objectives of this study are to create a flowchart process model of how MAiD occurs and detail where and how healthcare professionals are involved. Our research questions are: How is the MAiD process carried out and which professionals are involved at which points? and Which roles and activities do professionals carry out during the MAiD process?

Many of today's healthcare services are designed around interdependent roles – that is, professionals organize interdependent work around their responsibilities and activities [15]. Process theory examines the sequences and stages of activities and events as they occur [16, 17, 18]. Some processes emerge as they are implemented and may not be written down, causing an issue for quality improvement. With MAiD, events such as appointments often occur in a linear fashion, that is, in a certain order, and a person requesting the service needs to meet specific criteria in order to move from one stage to another [16]. Internationally, there is little documentation about how MAiD occurs, which professionals are involved at which points and how the process is organized [19]. The 8 jurisdictions that have MAiD, Australia, Belgium, Canada, Colombia, Luxembourg, The Netherlands, Switzerland, and 8 states in the United States [20, 21], collect statistics about number of deaths, gender, etc. but this data does not provide adequate information to evaluate and improve the service.

Providers and health systems are actively working to improve the MAiD experiences of patients, families and professionals [22, 23, 24, 25], but it remains challenging to improve its implementation without knowing what the process looks like. Studies describing professional roles, expectations and knowledge gaps [8, 13, 26, 27, 28, 29] or how MAiD was implemented [3, 4, 8, 30, 31, 32, 33, 34] provide few details about the process itself (e.g., how work is coordinated between professionals, which professional(s) do which activities and when, etc.) [12, 19, 34, 35, 36, 37, 38]. Knowing how MAiD occurs helps us better understand how new health services are implemented. Our identification of gaps and inefficiencies in the process is timely given that lawmakers will be expanding eligibility criteria for MAiD, yet the number of physicians and nurse practitioners (NP) that provide it is not growing [39]. Patients, health professionals and policymakers want to improve the MAiD service [37, 38] but lack standard best practice guidelines and training [34, 35]. This study provides details about how the MAiD process is being implemented, from beginning to end, and identifies areas for improvement.

#### Methods

#### **Design and setting**

A qualitative process model flowchart study for MAiD was conducted in the province of NS, Canada because MAiD is centrally coordinated and the researchers reside there. As the lead researcher specializes in interviews, first-hand accounts from those involved in MAiD were the most appropriate to piece together how the process occurs. Using semi-structured interviews, we asked those involved in the MAiD process (e.g., assessors, providers, administrators) to describe their MAiD roles, activities and at what points they are involved [16, 40, 41].

#### Recruitment and sample

Participants were recruited through: 1. emails to the NS MAiD providers' list-serv (convenience sample), 2. emails to professional colleges, associations and organizations and 3. snowball sampling [42] by asking authors and participants to forward study information to colleagues involved with MAiD. Recruitment continued until no new information was found.

The sample included health professionals who are involved in MAiD: physicians and NP (hereafter, clinicians), nurses, pharmacists and health administrators. The study was approved by the Nova Scotia Health Authority Research Ethics Board (Study Protocol ID: #1022997) and data were securely collected and stored using the approved protocol. Participants received written study information and completed an electronic or written consent form. To ensure confidentiality, participant characteristics are presented at a group level, and quotations are anonymized by profession and interview number.

#### **Data collection**

The data were collected using a semi-structured, pre-tested interview guide in-person in a private location, by telephone or Microsoft Teams® [see Additional file 1]. The interview guide was pilot tested with 3 clinicians. To obtain details about how and when they are involved and their interactions with other professionals, participants were asked open-ended questions about their MAiD role and activities [43]. Interviewers probed responses and made field notes. Interviews were audio-recorded, professionally transcribed in simple verbatim (e.g., um, ah and pauses were not transcribed) and stored in password-protected Microsoft Word® documents on a secure server [44, 45, 46]. As JM is the MAA, NP is the MNN, GG is a MAiD provider, they were not involved in data collection to help preserve participants' anonymity. To achieve saturation, data was collected until no new information about the process was found.

\*\* ADDITIONAL FILE 1 ABOUT HERE \*\*

#### Data analysis

After each interview was completed, data were iteratively coded and checked using constant comparison during six phases [3, 16, 47]: (1) reading each interview and coding passages about MAiD roles, activities and stages; (2) creating a draft flowchart process model with stages and outlining professionals', roles and activities in each stage; (3) continuing to conduct and code interviews, then incorporating new or revised information into the draft flowchart process model (drawn using Microsoft PowerPoint®); (4) inviting all participants to critique the flowchart process model and incorporating their recommendations and changes (5) finalizing the flowchart process model and (6) writing the article.

#### Results

Thirty-two professionals participated in 1-2 hour interviews (Table 1). Figure 1 has the process model detailing professionals' MAiD roles and activities. Nineteen places were identified where the process can be delayed or stop, depicted by a red octagon (Figure 1). Table 2 has quotes about how NS professionals' view the MAiD process and their role.

\*\* INSERT TABLE 1 ABOUT HERE \*\*

\*\* INSERT FIGURE 1 ABOUT HERE \*\*

\*\* INSERT TABLE 2 ABOUT HERE \*\*

#### 1. Starting the MAiD Process

Patients explore MAiD for many reasons [34, 48, 49, 50] and often find out about it through the media, Dying with Dignity (DWD), or the NSH website. When they are exploring MAiD, NS patients may do their own research, call the MAiD nurse navigator (MNN) or visit a clinician (e.g., family clinician, surgeon, nurse practitioner) to obtain more information. The clinician may give a patient MAiD information or send a patient referral to the MNN. Some patients may first seek information about MAiD, then visit a clinician again for a MAiD assessment referral. If the clinician is a conscientious objector or is not comfortable participating in MAiD, they will transfer the patient to another clinician, send a referral to the MNN or ask the patient to contact the MNN. If the MNN does not receive a referral, she will follow-up with the clinician.

The MNN's role is central. As paperwork or phone calls are received, the MNN contacts with the patient for an intake interview to explain the MAiD process, offer support, explain resources (i.e., palliative care, home care) and understand the patient's goals. The MNN may email or mail the patient information (e.g., Advanced Directive Guides, MAiD and Palliative Care information). The MNN sends MAiD documentation (e.g., referral, nursing intake notes, clinical notes) to assessing clinicians. The MNN remains in contact with the patient, family and their circle of care throughout the process.

Anytime, patients may decide not to continue with MAiD and pursue options such as palliative care; patients may pursue multiple options simultaneously. If the clinician the patient visited will not do the first MAiD assessment, the patient or clinician contact the MNN who helps streamline and organize the process. The MNN then emails the NS MAiD list-serv to request assessors. Finding assessors may take time due to the small number of providers, their lack of time and/or their inability to travel. Some clinicians will only assess their own patients but do not provide MAiD. Some clinicians said patients must bring up MAiD, not them, suggesting the NSH needs to educate clinicians about how the process works. If a patient mentions MAiD to staff, they will refer the patient to a clinician, the MNN or a manager in their facility.

Although clinicians and the MNN prefer the MAiD consent form is signed after the first assessment, some patients download it from the NSH website and sign it in advance. As patients are often quite ill, they may have difficulty finding two independent witnesses to observe them signing the MAiD consent form. To find independent witnesses, the MNN will contact Dying with Dignity (DWD) which has a national network of volunteer witnesses. If the MAiD consent form is not signed before the first assessment, the clinician will give it to the patient.

Delays can happen if patients have to wait for an appointment with a clinician to discuss MAiD. If a patient initially meets with a non-MAiD provider or conscientious objector, they have to be referred/transferred to another clinician and make another appointment, which could delay their Assessments. A common delay is finding two independent people to witness the consent form signing.

#### 2. MAiD Assessments

The clinician arranges the patient's first MAiD assessment and continues communicating with the MNN. This assessment can occur in the patient's home, hospice, hospital, nursing home or clinician's office. Assessments can take 45 minutes-5 hours depending on the location and the case complexity. The first assessor discusses the MAiD process with the patient (and their family and/or supports, depending on the patient's wishes), including legislation, criteria and timeline. The clinician also provides the patient with the College of Clinicians and Surgeons of Nova Scotia Professional Standard Regarding Medical Assistance in Dying. The clinician completes the MAiD assessment form, sends it to the MNN and may dictate notes for their records. If the first assessor finds the patient is not eligible for MAiD, the patient may ask the MNN to arrange a second and third assessment. If the second and third assessors indicate the patient is ineligible for MAiD, the process is finished.

If the first assessor indicates the patient is eligible for MAiD, the MNN or clinician arranges the second assessment. The second assessor often provides or reviews the consent form, returns their assessment form to the MNN and may dictate notes. If both assessments indicate the patient meets MAiD criteria, the patient decides when MAiD occurs – it could occur hours, days or months later. If neither assessor provides MAiD, the patient decides to wait, the original assessors are not available or the patient requests MAiD during a busy time (e.g., summer or December), the MNN helps find a provider who will re-assess the patient to ensure they still meet MAiD criteria. When patients decide to wait, the MNN checks in with them and receives regular updates from their circle of care. The MNN keeps relevant health care providers informed about the patient's goals and health status. Sometimes the patient does not have MAiD because they die, change their mind or lose competency.

Numerous delays can occur or the process could end during this stage. If the two assessors do not agree a patient meets MAiD criteria, a third assessment will be done. The process stops if a patient does not meet MAiD criteria, dies, changes their mind or loses competency. The 10-day waiting period can be waived for patients about to lose competency and MAiD provided more quickly. If the first or second assessor cannot provide MAiD, it may be delayed while the MNN finds another provider, who then may need to re-assess the patient.

#### 3a. MAiD Preparation – Hospital In-Patient

For in-patients, the clinician and MNN ask hospital staff (e.g., a nurse manager, nurse director) to find a private room and a nurse comfortable with inserting the 2 IVs for MAiD, one to be used and one back-up. The 2 IVs are usually inserted by a hospital nurse who also gathers supplies (e.g., syringes, needles, IV solution, IV pole, tubing, etc.). The clinician alerts the hospital pharmacy about the upcoming procedure and sends a pre-printed MAiD order (PPO). If the hospital does not have a pharmacy, the pharmacy does not have the medications or the pharmacist(s) will not fill the PPO, the MNN and/or clinician will coordinate the MAiD medications with a community or another hospital pharmacy. The other pharmacy may courier medications to the hospital. Two to five pharmacists fill the PPO and double-check the two sets

of medications according to their protocol [51]. Two MAiD medication kits are prepared in case anything unforeseen occurs (e.g., broken bottle). Clinicians typically pick up the medications 24-48 hours after the PPO is submitted, but pharmacies may make exceptions for urgent cases. For patients preferring anonymity, a ghost/shadow chart may be used to conceal their identity.

#### **3b.** MAiD Preparation – Hospital Out-Patient

A nurse manager, charge nurse, facility lead or MAiD provider helps ensure out-patients are registered and admitted, a location is identified and staff are coordinated. Some hospitals have specific wards or rooms for MAiD out-patients after hours since these are often used during the day. A hospital nurse often inserts the IVs and gathers MAiD supplies; an anesthesiologist may insert the IVs. The MNN may provide support and MAiD education to ward staff. The same pharmacy processes and ghost charting occur as in 3a.

#### **3c. MAiD Preparation – Non-Hospital**

MAiD may also occur in the community (i.e., a patient's home), long-term care, nursing home or a hospice. The clinician and MNN often work together to contact Continuing Care (i.e., the Victoria Order of Nurses) to insert the IVs. A VON nurse manager will find a nurse comfortable with MAiD. Typically, MNN sends all the MAiD docs to VON and confirms they can meet the need. The clinician coordinates the medication order with a community pharmacy and may discuss further with a pharmacist unfamiliar or uncomfortable with MAiD. One to three pharmacists prepare and double-check the two MAiD medications. The clinician usually picks up the MAiD medications 24-48 hours later. If the pharmacy does not have MAiD supplies and the clinician may obtain these from their hospital or facility. The MNN and MAA are currently working on making MAiD kits available for all clinicians.

In stage 3, there may be delays if a nurse cannot be found to insert the IVs or the hospital pharmacy will not fill the PPO. The clinician or MNN may need to coordinate with another pharmacy or find a willing pharmacist. MAiD may be delayed

#### 4. Day of MAiD

The MAiD process can take several hours. The clinician picks-up the MAiD medications from the pharmacy and gathers supplies. They may drive to the patient's location and, in some cases, fly or walk. Some may participate in religious services, celebrations of life or farewells before or after MAiD, but not all clinicians are comfortable with this. Where possible, a nurse (or clinician) inserts the two IVs close to the procedure time to decrease having to reinsert them in dehydrated and very ill patients. IVs are not placed in patients with central (Hickman) or PICC lines. A VON nurse inserts IVs in long-term care. The nurse may stay for the procedure, if they are comfortable, if the patient/family wants them there and/or they have time. Some nurses will return for the procedure if the IVs are placed earlier. Hospital nurses often arrive 1-2 hours before the procedure and stay with the family and body after MAiD.

The clinician will draw up the syringes with medications (Table 3). After determining the patient has the capacity to request MAiD, the clinician explains the procedure including: what each medication does (if the patient wishes to know), the dying process and potential medication responses (i.e., twitching). The clinician asks the patient if they wish to have MAiD. If the patient says no, MAiD does not occur. If the patient says yes, the clinician administers the medications over 10-15 minutes. If a patient does not have capacity to request MAiD, the procedure does not occur.

A clinician may be delayed picking up the prescription if MAiD is being rushed or a participating pharmacist cannot fill it. This can affect when the clinician arrives for the provision. How the clinician travels to the MAiD location can also delay the process, especially if they are flying or driving. The MAiD process can be stopped if the patient chooses not to have MAiD or if the patient has lost capacity and cannot consent to have the procedure done.

#### 5a. Post-MAiD – Hospital In-Patient or Out-Patient

The clinician records the medications and time given, the patient's time of death and completes the death certificate. The clinician and/or nurse may wait with the family, participate in a family event or leave. Ward staff follow the protocols for post-mortem care and may contact security to transfer the body to the morgue. Or, the family may contact a funeral home to remove the body from the floor. The death certificate goes with the body. A manager or the hospital may provide staff debriefing. There may be delays waiting for the funeral home or security to collect the body, especially if they were not notified in advance.

#### 5b. Post-MAiD – Non-Hospital

The clinician records the medications and time given, the time of death and completes the death certificate. The clinician and/or nurse may wait with the family, participate in a family event or leave. At home, the family will contact the funeral home to remove the body. In long-term care, the family, security or staff arrange for the funeral home to collect the body. The death certificate goes with the body. The family may want to spend time with the body before calling the funeral home and/or may not have notified the funeral home in advance, which can lead to lengthy delays.

#### 5c. Post-MAiD After Leaving Setting

The clinician documents the procedure and sends the MNN information including: people present, medications given and dose, times the medication was pushed, time of death and notes about the procedure and/or family difficulties. They return all used and unused medications to the pharmacy, which disposes them, input information into the national MAiD database online and may dictate notes. Some clinicians debrief with colleagues. Clinicians may bill Medical Service Insurance (MSI) up to 8 hours for MAiD assessments and procedure. Clinicians send travel expenses to the MAA who submits these to NSH for reimbursement. Nurses are usually paid overtime by their organization and typically debrief with a nursing manager/director but not always. The MNN collects and submits MAiD statistics to the NSH and follows-up with the family, sometimes connecting them with community supports. The MNN and MAA collect and save MAiD documentation and the MNN closes the case.

There may be delays entering data into the national registry and returning the MAiD medications to the pharmacy. It takes time to submit billing and travel reimbursement information and to receive reimbursement from NSH and MSI. Some clinicians have never been reimbursed for time or travel.

#### Discussion

This study's flowchart process model indicates how multiple professionals work together and are involved at each stage of MAiD [15,16-18]. Clinicians, mainly working evenings and weekends, assess patient eligibility, write and pickup prescriptions, gather supplies, and organize and provide MAiD. Nurses', often being paid overtime, insert IVs and support the patient and their

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supports before and after the procedure. Health administrators organize the process as part of their workload. Pharmacists, within regular work hours, fill prescriptions and dispose of medications after MAiD. The process differs slightly by location and in-patient/out-patient status. We identified multiple points where MAiD could be delayed or stopped [17].

Some of our processes were similar to others such as having a central coordinator, a variety of professionals being involved at different stages and MAiD being available in multiple locations [8, 27, 28, 30, 33, 34, 55]. Some Ontario regions coordinate MAiD centrally [3, 4]. Other processes were different such as not having a centralized pharmacy, clinicians making arrangements with patients and fewer health professions are involved (e.g., no social workers, spiritual advisors, psychologists) [27, 52]. Most MAiD assessments and procedures are conducted on evenings and weekends, outside regular hours. Nurses are paid overtime for participating in MAiD, unless it is during their regular shift [34]. Some of our clinicians considered MAiD "volunteer work", since setting up billing codes and coordinating government and insurance payments can be difficult [32]. Many devoted significant amounts of, mainly unpaid, time coordinating MAiD but did not consider this sustainable [33, 32]. NS could learn from Manitoba where a single MAiD team serves the entire province [51].

Our clinicians learned to ask about family dynamics to prevent difficult situations, such as arguments on the day of MAiD or a wrongful death lawsuit. Thus, including spiritual providers, social and mental health professionals, psychiatrists and psychologists could be beneficial [3, 8, 27, 51, 52, 53]. Along with offering support, inserting the IVs and documenting the process, our nurses want to meet patients and their supports before the day of MAiD [27, 56]. Pharmacy technicians cannot prepare MAiD medications [54], thus pharmacists incorporate an additional 1-5 hours into their regular workload. This is unusually long to fill a prescription. The Northwest Territories, Manitoba and Alberta have dedicated MAiD pharmacies [57]. Pharmacists do not provide MAiD supplies (e.g., tubing and syringes) and some clinicians scramble to collect or "steal" supplies from their workplace. Some regions provide supplies with the MAiD medications [3] but some do not.

**Limitations**. This study occurred in one Canadian province, thus we cannot generalize to other provinces or internationally [59, 60]. However, the results could be helpful to other jurisdictions seeking to evaluate and improve MAiD. Although this study has a smaller sample size for each group of professionals [58], we continued recruiting until no new information was found (i.e., data saturation). To address sample and selection bias, as self-selected participants may not represent the views of all professionals [42, 58], we recruited across the province from different professionals during different times of the year.

**Implications for clinicians and policymakers**. This study builds on MAiD research [12, 28] by detailing the process from beginning to end. Our findings about the roles and activities of professionals could help inform MAiD practice nationally and internationally. We identified issues such as clinicians' additional time to pick up and drop off medications, travel to the patient, input data and bill hours. Other jurisdictions may consider the benefits of centrally coordinating communication between professionals and administrators to avoid miscommunication or missed communication.

Our identification of delays/stop points and resources are high priorities for improving MAiD. Delays and stop points can limit patients' access to and receiving MAiD. Resources include professionals' time and supplies. Providing assistance to set up reimbursement codes and processes could save clinicians' from using personal time without compensation. Having centralized coordination and a central pharmacy providing a MAiD kit with medications and

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supplies are vital to help ensure delays are minimized and resources are used efficiently. If professional colleges allowed pharmacy technicians to assist with MAiD prescriptions, this would significantly reduce pharmacists' time. Pharmacists' professional colleges should be concerned since they are not compensated for hours of additional work to prepare and dispose MAiD medications.

**Future research**. This study contributes to research about healthcare process models. Future researchers could compare and contrast process models from other jurisdictions with this study [42, 16] which could be used to improve MAiD internationally. To better understand each profession's contributions to and time for MAiD, researchers could conduct participant observations to detail what they do throughout the process. Studies reveal a wide variety of professionals participate in MAiD [3, 8], hence conducting interviews with them could provide further insights into the process. Since patients and their informal supports are involved throughout MAiD, our model their insights could be added to improved the flowchart process model.

#### Conclusion

This study adds knowledge about the variety of activities and roles that multiple professionals have throughout the entire MAiD process – these have not been studied in the international literature. Clinicians and pharmacists spend significant additional time to participate in and coordinate MAiD, raising questions about its sustainability and uncompensated costs. Our identification of where potential delays can occur can help clinicians, administrators and policymakers improve MAiD and be of interest to other jurisdictions implementing it.

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#### Footnotes

**Author contributions** ETC and SK conceived, designed, drafted and wrote the article, JY, GG, JM and NP critiqued, revised and edited it. All authors read and approved the final manuscript.

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**Data sharing statement** We do not have ethics approval to make raw data from this study available for sharing.

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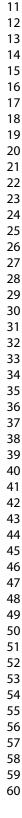
#### Table 1: Participant characteristics

	Number (%) of participants <i>n</i> = 32
Physicians	
Family medicine	6 (18.8)
Palliative care / critical care	4 (12.5)
Emergency medicine	2 (6.3)
Nurse Practitioners	3 (9.4)
Nurses	
Hospital	3 (9.4)
Long-term care / nursing home	1 (3.1)
Victoria Order of Nurses (VON)	2 (6.3)
Pharmacists	
Community	2 (6.3)
Hospital	4 (12.5)
Health Administrators / Advocates	5 (15.6)
Hospital Health Administrators / Advocates	

Table 2:
Professionals' quotes about their MAiD role and tasks

Quotes from	MAiD	professionals
Quotes nom		professionals

	<b>Physicians</b> With an approximation of the procedure is probably shout $-6$ to 8 hours of work in a maximum function of the shout $-6$ to 8 hours of work in a maximum function.
	With an assessment and the charting and the procedure is probably about 6 to 8 hours of work in a mor
	t was more involved at the beginning when things weren't as clear. And it depends on the case too. Some a
	nore straightforward than others. I would say it's about 8 hours of work. So I'd have to fit that in on weeke
	nd evenings. So it's just the procedure would take several hours on a weekend. And then the assessment w
	e several hours usually in an evening as well But then the actual billing code right now, it's still capped
	ours for an assessment and 2 hours for a procedure. And almost all of my procedures have been longer. So
	ust chosen to bill for 2 hours of my work and the rest is not paid." Physician 1
	The main tension we have is the cap on the hours. So just totally unrealistic. I mean the amount of time the
	pent to do these cases. I mean some of the cases are straightforward. You know, it's in the hospital, you go
	he assessment takes an hour, you come out, you give the order to the pharmacy, the nurse is ready, you con
	ack for the procedure, it takes an hour. Like sometimes it's very straightforward. But some cases, especial
	ney're at home or they're in the periphery, are very complex. Sometimes the assessment can take a long til
y	ou might have to speak to multiple family members to answer questions just to make sure it's the right de
fc	or the patient. Plus, you have to be coordinating with VON to get the IV set up and the pharmacy - which
p	robably never had to organize the medications. And then getting back and forth with the patient as they so
p	rogress and checking in on how they are And then the driving of going out to Amherst or, you know
Ň	New Glasgow Right now it's 2 hours for the assessment and 2 hours for the procedure Yeah. So the
ca	ap. And you don't want people to rush it All of us kind of treat this as volunteer work." Physician 2
	When you go to see a patient, you never know if it's going to be a half hour assessment or a 2 hour assess
	When you go to do the procedure, it could be a 15 minute procedure and done, it could be multiple hours. S
	ort of have to be willing to be flexible. And so in fitting in time, you sort of have to make sure that whatev
	ad booked after you might not get to and you might get there – it just depends." Physician 3
	And it's possible to have a self-referral system. And it doesn't need to involve family doctors. There could
	There are many ways to go about doing this that everybody can be happy and not block any patient from ha
	f they want it." Physician 4
	Each MAiD case is taking probably a minimum of 5 or 6 hours of time. That's 5 or 6 patients that I cou
	n that time. So we were never resourced to consider taking on MAiD. And that's probably the most practic
	ssue." Physician 5
	the procedure itself is fairly quick once everything is set up. But generally it takes hours in order to go through the procedure itself is fairly quick once everything is set up. But generally it takes hours in order to go through the procedure itself is fairly quick once everything is set up. But generally it takes hours in order to go through the procedure itself is fairly quick once everything is set up. But generally it takes hours in order to go through the procedure itself is fairly quick once everything is set up. But generally it takes hours in order to go through the procedure itself is fairly quick once everything is set up. But generally it takes hours in order to go through the procedure itself is fairly quick once everything is set up. But generally it takes hours in order to go through the procedure itself is fairly quick once everything is set up. But generally it takes hours in order to go through the procedure itself is fairly quick once everything is set up. But generally it takes hours in order to go through the procedure itself is fairly quick once everything is set up. But generally it takes hours in order to go through the procedure itself is fairly quick once everything its set up. But generally its takes hours in order to go through the procedure its set up. But generally
ťŀ	his very personal process with this individual. Sometimes they're very straightforward. Other times You
	now, I've heard stories of very elaborate events that have been planned around medical assistance in dying
	m astounded and I'm stunned by the clinicians that will do this on a regular basis and take hours and hour
	ours of their personal time." Physician 6
	When I'm assessing somebody, I'm usually generating the consult, right. The patient's come to me. I've s
	nem. I've said, okay, I'm going to be the assessor 1. Off to you guys – you find assessor #2, and, you know
	vith all the rest of it." Physician 7
	when MAiD came up, I thought 'well it's legal!'. It's people have the right to ask for this and nobody in
	ommunity was willing to provide this service. I knew that I couldn't be available to do the actual procedu
	ut I did know that I had no difficulty whatsoever doing the opinion pieces, MAiD 1 or MAiD 2 [assessme
	and then I was having the conversations, discussing if the people met the criteria as outlined by our licensi
	ody in Nova Scotia, and you know completing the paperwork. And facilitating the actual procedure of
	oordinating the the healthcare team members who needed to be part and parcel of the procedure becaus
	here's this huge reliance on pharmacists and nursing staff and community funeral homes and so on, to be s
	hat the whole procedure is done properly at that time, I was one of two people who would do a MAiD
	onsultation." Physician 8
	colleague "very quickly becomes attached to the patients they're such neat patients, and their families
	eat, and because that initial interview often times you get to know them so much, you talk about their l
	ou get to know where their moral compass lies and what their general feelings about life and death and su
	nd quality are. And the family often really wants you to know and love that person the same way that they
V	ou get a lot of that background in a really short period of time. And then typically I do my procedure on a



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different day, and so going back in to meet the family again and see them for the procedure, there's often so much relief to see you and they're so pleased. ... sometimes if the patient has some sort of functional decline or symptom management issues in between, you've talked to the family a few times to help them navigate that and make sure that their quality is maintained while they're waiting for their procedure, so I think you become attached to the families very, very quickly" Physician 9

"the physicality of the procedure takes about 15 minutes. That's the actual giving of the medications. But between getting the medication...picking up the medications, drawing everything up, getting yourself ready to do the procedure, going in, seeing the family, making sure they're all set and ready to go, it usually takes about two hours or so. Now, again, it really varies. Sometimes you go in and there's like they don't want to chat, they just want to go and get it done. And so they don't take as long. I had one situation where I walked in and there was a party going on in the house. And I said, "I'll go down to the back room," where they wanted me, and I waited for two hours before the patient came into the room, and then performed the procedure. So I mean upwards of three hours, I guess, depending on if you're waiting. But otherwise are usually around two hours between the time of going to get the medications, get everything drawn up." Physician 10

"two days after the [MAiD] Assessment, the family phoned and said, "Come now. You know, he's starting to get confused." ... And then there was a brief ... kerfuffle getting the other assessor to agree to move it up, and scrambling to learn how to get the drugs from the drug store. And tried to get the VON in, and it being too late - the nurses do the IV. And then going and stealing IV equipment from the emergency department ... I don't do IVs very often. So worrying that I was going to go to this house to do a MAiD procedure and not be able to get the IV." Physician 11

"if it's an in-house assessment, I'll schedule it for the late afternoon/evening, like starting at 4:30 or 5:00. And then it goes until about 6:30 or so. The procedures can be done within a half hour to 40 minutes. I go in and have a chat with them and make sure that they still have capacity and that they know why I'm there. And if they still want the procedure. I'll say, okay, have some time with your family or whoever is there. And I'll go get my medications ready, and then I'll come back and ask them again if they want me to proceed or give them that last chance to rescind." Physician 12

#### **Nurse Practitioners**

"there's a fair amount of phone calls and logistics. So if I've agreed to do the provision for a patient, so I've had to do one of the assessments and if ... they've had two assessments that agree that they meet the criteria, then I ask the patient to decide on a time and a place, and we talk about when and where that might be, and usually that's done in concert with the patient ... So if it's at home it's easy ... If it's not at home, it means having a patient admitted to the hospital or going through ambulatory care, then that would take phone calls and arranging. If somebody was at home ... which the majority of cases I've been involved have been home deaths. So, that would mean I would send the prescription in to the pharmacy, call the pharmacist and make sure it was received. I would fax requests into VON for the IV's to get inserted the day of the planned procedure. ... I would coordinate this with the patient and their family to make sure that the time and place was all arranged, and they wanted to go ahead. I would pick up the medications at the pharmacy, I would usually prepare them here in my office so that when I arrive at the patient's home everything is all drawn up. ... I don't like to be fumbling in somebody's dark bedroom with big syringes and vials and so I have a system, I get it all ready in my office. I have a plastic tote, little small tote, and all the paperwork ... So, I like to have it all ready to roll and then I arrive at the patients home ... the morning of the procedure. After the procedure I have to sign the death certificate and do the paperwork ... and then return the unused medications to the pharmacy. So there's a fair amount of kind of little detailly stuff." Nurse Practitioner 1

"I've been involved with MAiD two more times. ... I don't want to do the second assessment. .... So I did it [once], and I am okay with that. And I don't have any moral distress with it. Even though I get choked up about it, it's only because I remember the patient, and I remember how deeply I felt about [them] and helping [them] die comfortably. ... if we're going to be providers, we have to help people get access to what they want, even if we, because of our beliefs, our faith would not do that ourselves. And Lord only knows whether I would or not when that came to me. ... I feel right now that that would not be something I would choose to do because of my faith, and I wouldn't want to go any deeper down a road than first assessment..." Nurse Practitioner 2

"there's nobody else to provide it. I do have a full practice but sometimes I'll do this on my off time. I try to include it in my day. My manager is very supportive of me doing this. But, you know, I went to ... before to see a case, which is an hour away. But I do get reimbursed for my expenses. Mind you, it did take me a year to get my travel claim figured out.... The doctors get paid for doing this. The nurse practitioners don't. ... I think they're trying to lobby to get us paid. Like we get paid for our travel expenses. So I can send that in. But I know the

Nur	
But kind [loca getti was.	ent out and I got the [MAiD] policies and I had them sitting on my desk. But there was no meaning ir once we had the [MAiD] requests, I had two months. But I had already written the paper and I had alr of went through all of that. So it was I just basically stole the policies and procedures from [locatio ation] and another [location] and put them all together The mechanics weren't the important thing ng the fact sheet right and getting to that audience, that you could talk to them in their language. And For me it was the relational piece that was more important than the mechanics." Nurse 1
dow Care we g have to pa	when we get a referral come in for MAID, we havewhichever manager's area All of HRM, we be n into 4 areas. And there's a nurse manager for each area. So we take the referral and work with Cont to ensure that alleverything's there – the consents are there, that we have everything we need. And go through the client's schedule in the computer to find a nurse that has been there the most so that we e somebody that the client or the family knows. And then we reach out to the nurses to see if they are articipate. Because it's their choice to do it. And I'd say probably 60% are willing." Nurse 2
	not a simple IV. It's not a little tiny one. You have to be able to Like to put an IV in that is as big a thetist would use. So big." Nurse 3
"As	a nurse, I can't push those drugs. I can't order the drugs. I can't go and get the drugs. I can't push the am there as a patient support and a family support." Nurse 4
"we cow enco You migl impo it do	were under the impression that we weren't supposed to be sharing the fact that we are participating in orkers and things like that. So there's not a lot of professional like interprofessional support. And we buraged to do that just because they didn't want the public knowing like where things were taking place know, because it was presented to us as like, "Well, there might be a death notice in the paper and so in put together that you just participated in this thing. So that's what that family chose. So it's really portant to not tell anyone that youbecause their decision needs to be kept private." Which I understar we make it difficult to process." Nurse 5
abou are f	basically what we were told when MAID became law was that if patients voiced wanting more inform at it, you know, we don't really have an opinion per se because You know, I don't know if my cowo for or against." Nurse 6
	rmacists
	e drugs themselves are often in pharmacies, just not either in the quantity or the dosing that we need." macist 1
you orde sure	but 5 to 7 hours. And that [putting together first MAiD kit] was over several days. And that was a proc know, calling places, calling the other pharmacy, finding the drugs, calling our wholesaler to find out ring the right ones, data entering the information, getting the bins together, you know, with labelling. we have a spot in the fridge. Making sure all of our staff are aware. Like it was a very time consumin eavour." Pharmacist 2
	t generally that collecting of drugs and organizing, that would be a technician job." Pharmacist 3
	t if it wasn't evident in the chart that yes, the patient was getting MAID on this date then I wouldn't essarily know unless the team sought me out to let me know." Pharmacist 4
"Tec one syste MA labe prese the c to pr	chnicians are not involved with this [MAiD prescriptions] at all So other orders, we would Let's of them is a heart medication pill that they don't already have on the floor. So I send pretty much through the technicians to say send this to the floor And then the technicians take it from there. With ID, it's 100% pharmacist-run. So we enter the prescriptions that were ordered and then we're picking is, we're packaging it up and we're checking it Let's just say I'm the pharmacist who checked it [cription] Usually it's the clinicians are okay to come and get it. And then there's additional information rovide, education we need to provide and basically just we go through the medications." Pharmacist 5
	in do a regular order in probably 20 seconds, depending how easy it is. A MAID can be like well over "" Pharmacist 6
	lth Administrators
	think of something that we may struggle with is probably making sure the staffs' schedule of that day re of personal values." Admin 1

"So the biggest challenge would I guess be that as with every new job there's a steep learning curve and making the new connections new working relationships developing them and in building trusts among those you work with." Admin 2

"My biggest concern is there are people who want MAID but they are unable to access the system because the doctors won't put their names forward. We have had phone calls of people that said my doctor won't refer so we had to call them back and explain that there is a duty to transfer the name of a patient requesting and they shouldn't disallow the request to occur ... but how many people out there that are actually that sick and are not being allowed to refer." Admin 3

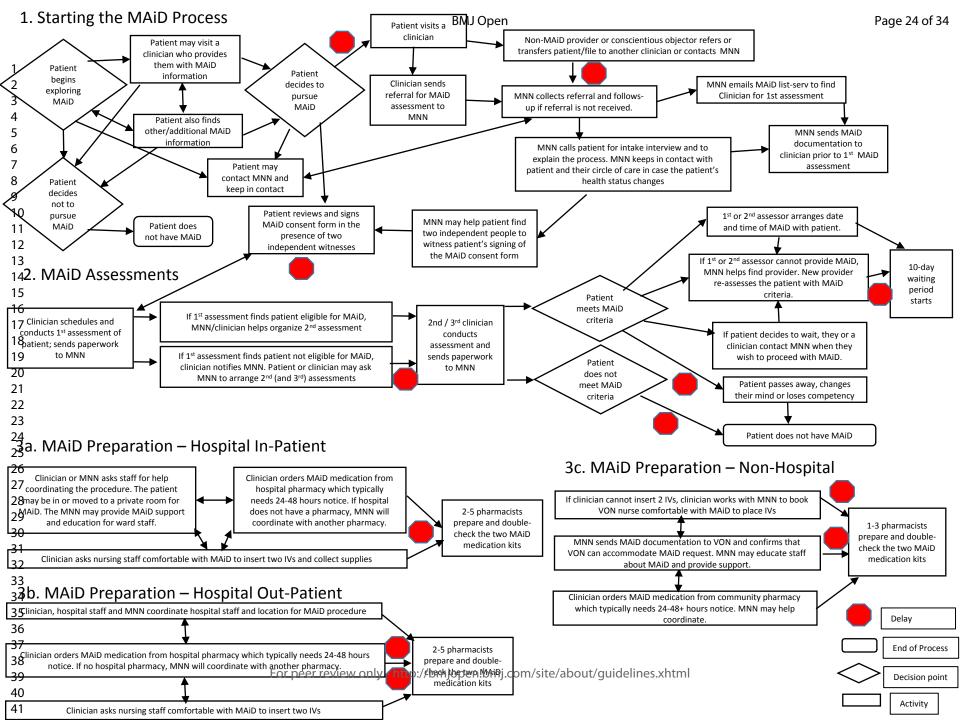
"If I get a call now and somebody says there's a MAID case and they're interested in whatever date, I really have to drop everything and try to organize the space, the date, the staff." Admin 4

"I think Canada can have the absolute best assisted dying regimen in the world. We can show people how it can be done, how it can be done well. And we just need to make some changes to do that. And so I feel it's still worth trying. ... I'm in a transition in the sense that I have to recognize there's some things that are my wheelhouse and there are a lot of things related to this [MAiD] that are not my wheelhouse. And I need to let others do it, right. For a long time I was pretty alone in this field, trying to make this change. And so you just feel like, "Oh, it's on my shoulders. I've got to keep going, I've got to keep doing it". And at the first CAMAP meeting, it was the most extraordinary feeling because I was in a room... with all these people. And this is what they do. And it was this incredible sense of relief and release and a sense of okay, you know, this is in good hands. Different people are going to be doing these different things. So now what I try and focus on are the things that I can do. So ... there's an issue right now of whether nurses can raise the issue. ... Or the faith-based institutions, publicly funded faithbased institutions ... there's a way in which it's my wheelhouse" Admin 5

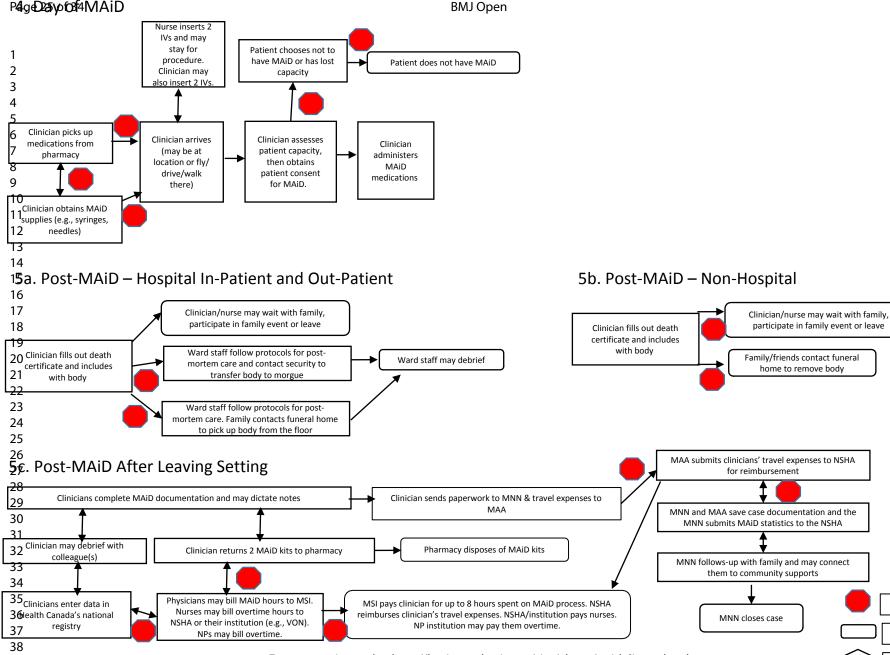
Table 3:	
Medications	used in MAiD in NS

- 1<sup>st</sup> medication, a sedative to help relax the patient. The patient typically falls asleep in 30-60 seconds.
- 2<sup>nd</sup> medication, a numbing agent to prevent the patient from feeling any vein discomfort from the subsequent medications.
- 3<sup>rd</sup> medication, a coma-inducing agent.
- 4<sup>th</sup> medication, a muscle relaxant which stops breathing and heart function. It usually takes 2-6 minutes to stop the patient's heart.

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#### P4geDayof3f4MAiD



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participate in family event or leave

Delay

End of Process

Decision point

Activity

home to remove body

40

39

# Interview Guide

Version 3 – 19 February 2019

I am interested in finding more about your involvement with medical assistance in dying, MAiD; how this has affected your practice and your perceptions of yourself as a health care provider. I want to study MAiD from your point of view.

I also want you to know that you are freely able to withdraw your consent at any time and you may choose not to answer any questions you are not comfortable with. Do you have one hour available today to talk with me?

## **Current Professional Role**

- 1. Please describe what you currently do as a physician / pharmacist / nurse / health care administrator (or in your job).
- 2. Tell me about how your role came to include MAiD. or How did you become involved with MAiD?
  - a. When did you start assessing MAiD patients and/or performing MAiD?
- 3. How many MAiD procedures have you been involved in since you started?
  - a. Did your patients play a role in your getting involved with MAiD?
  - b. Are the MAiD patients you have been involved with your own patients or patients you know well and see regularly?
- 4. How much time a month do you spend participating in MAiD and assessments?
  - a. Are you thinking about expanding the time you spend on MAiD assessments and procedures?
  - b. Do you travel to provide MAiD? If so, how far and how often?
  - c. Where have your MAiD assessments and procedures occurred: at patient's home, the hospital, your office, other?
  - d. How do you set up MAiD assessments and procedures with nursing, pharmacists and administrators? Does anyone help you with this?
  - e. How do you schedule MAiD into your current practice? If you provide it on your own time, is it on evenings and weekends?
  - f. Nurses: Why did you decide to participate in the MAiD procedure?
- 5. Why is it important for you to offer MAiD in NS?
- 6. Have you taken any MAiD training? If so, where or with whom?
  - a. Have you joined Dying with Dignity? Have you taken their training?
- 7. Have you developed or found any support systems for yourself now that you are involved with MAiD? Do you feel you need any additional support systems for yourself personally?
  - a. Some people are worried that professionals involved in MAiD will burn-out. Is this a concern for you? If so, is there anything you are doing to prevent burning out?
- 8. Are you a MAiD mentor in Nova Scotia?
  - a. If so, how did you become involved?
  - b. Can you tell me more about your role as a mentor

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2	
3 4	9. We've heard that some health care professionals had trouble billing for MAiD. What
4 5	processes did you go through to bill for MAiD and receive remuneration?
6	10. Do you think the remuneration for MAiD is adequate and covers your costs?
7	11. What are you doing differently now in your job than you did before MAiD was legal?
8	How has your role changed since it became legal?
9	12. Has participating in MAID changed how you think about yourself as a professional?
10	a. If so, in which ways?
11 12	b. If not, why do you think it hasn't changed the way you think about yourself as a
12	professional?
14	13. Do you think participating in MAiD has changed your professional role or practice?
15	a. If so, what do you do differently in your role or practice?
16	b. If not, why hasn't your role or practice changed?
17	14. Are there any ways you think MAiD in NS could be improved or different?
18	
19 20	Professional's Colleagues
20	15. How do your colleagues feel about your being a MAiD provider?
22	a. Do you feel that the small number of health professionals participating in MAiD
23	in NS puts an additional burden on you? If so, tell me more about that.
24	16. Do you work with different professionals or are you involved in different ways with other
25	professionals than you did before you practiced MAiD?
26	a. If so, tell me more about which professionals you now work with and how your
27 28	relationship has changed.
28 29	b. Some interviewees mentioned that their communication with other professionals
30	increased quite a bit after they became involved with MAiD, has this happened to
31	you?
32	17. Do any of your professional colleagues (either within the same profession or in another
33	profession) participate in MAiD?
34	a. Which professions are they?
35 36	18. Do you know what your fellow professionals who practice MAiD are doing differently
37	now than they did before it was legal?
38	19. Which professionals do you think should provide MAiD in NS?
39	
40	Professional's Patient's Family
41	20. What type of support do the families of the patient's you provide MAiD for have?
42	21. What type of support would you suggest could be most helpful for the families, both
43 44	before and after MAiD?
45	
46	Professional's Organization
47	22. In your experience, what kinds of changes were required to implement MAiD in your
48	practice or organization? What kinds of changes do you think your organization needs to
49	make so that it is easier for you to participate in MAiD?
50	a. Did you have any say or input into making or implementing these changes to
51 52	provide MAiD in your organization?
53	23. Can you tell me about what your organization is doing differently now than it did before
54	MAiD was introduced?
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59 60	For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml
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## Additional Comments, Questions or Thoughts

- 24. Is there anything that you want to talk about regarding MAiD and your professional role that we did not discuss?
- 25. If we were to expand this study across Canada, which provinces would you recommend we start with?
- 26. Do you have any questions for us about the research?
- 27. Would you be willing to send information about our study to your colleagues?

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#### COREQ – Crumley et al.

Domain 1: Research team and reflexivity	
Personal Characteristics	
1. Interviewer/facilitator	ETC and JY conducted the interviews
Which author/s conducted the interview or	
focus group?	
2. Credentials What were the researcher's	ETC has a PhD
credentials? E.g. PhD, MD	JY has a BSc
3. Occupation What was their occupation	ETC is an assistant professor
at the time of the study?	JY is a medical student
4. Gender Was the researcher male or	ETC is a woman
female - this is sex not gender?	JY is a man
5. Experience and training What experience or training did the researcher have?	ETC has conducted 120+ interviews with healt professionals since 2007 and published peer- reviewed articles with this data. She has completed several qualitative research courses, teaches qualitative methods. Her PhD was an ethnography.
	JY was extensively trained by ETC. With ETC JY listened to all the interviews ETC had conducted, coded them and helped develop themes. He listened to ETC conducting a live interview, then they talked and critiqued the interview after. Then ETC listened to him conducting live interviews and they talked and critiqued each interview after. He also read qualitative methods articles.
Relationship with participants	
6. Relationship established Was a relationship established prior to study commencement?	Neither ETC nor JY knew any of the participan prior to the study.
7. Participant knowledge of the interviewer What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	All participants were emailed the consent form along with the research protocol guidelines, which were approved by the Nova Scotia Healt Research Ethics Board. Both documents give information about the researcher and why the research is being conducted. In her email signature and on her webpage, ETC has links to her bio, Google Scholar and CV so potential participants can look at these. The interview guide also has information about why the research is being conducted, which is read to al participants at the beginning of the interview.

	ETC contacted all potential participants via email and let them know that JY is a medical student who she trained. ETC then asked participants if JY could interview them, none declined.
8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	ETC is a social scientist who has conducted health research since 1999 and interviews since 2007. Interviewees were informed of this so they were aware she did not have a clinical degree. Using her qualitative skills, she was able to ask 'naïve' and in-depth clarifying questions to participants which produced some rich descriptions and helped minimize bias.
	JY is a medical student. He was able to ask 'naïve' questions and in-depth clarifying questions which produced some rich descriptions and helped minimize bias.
Domain 2: study design	
Theoretical framework	
9. Methodological orientation and Theory What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	The Data Analysis section explains how semi- structured interviews and thematic analyses were conducted. These analyses were informed by iterative qualitative analysis and constant comparison. Process theory informed the theoretical approach.
Participant selection	
10. Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball	Convenience sampling was used as professionals contacted were on the list of MAiD assessors and providers, maintained by the Medical Affairs Advisor. The researchers do not have access to this list. Professional organizations and colleges also emailed their members the study information and participants opted to take the study. At the end of each interview, we used snowball sampling and some participants sent study information to their colleagues.
11. Method of approach How were participants approached? e.g. face-to-face, telephone, mail, email	Participants were approached via email and the study was also mentioned during video conference meetings.
12. Sample size How many participants were in the study?	32
13. Non-participation How many people refused to participate or dropped out? Reasons?	Since the study information was sent out to a list of MAiD assessors and providers which is constantly changing (clinicians join while others leave/take a break), it is not possible to know how many refused to participate. At the time of

	article submission, there were 48 physicians at 8 NPs who assess and provide MAiD - we interviewed 12 physicians and 3 NP. Professional organizations do not track member who participate in MAiD (e.g., pharmacy or nursing college) and this number also changes frequently. Thus, we do not know the total poor of pharmacists, health administrators and nurs who refused to participate or who do not participate in MAiD at all.
Setting	
14. Setting of data collection Where was the data collected? e.g. home, clinic, workplace	Nova Scotia, Canada. Data was collected in the participant's office, interviewer's office, over t phone or via secure video (e.g., Microsoft Teams).
15. Presence of non-participants Was anyone else present besides the participants and researchers?	If the person was in their home for the phone of video interview, it is possible they were not in private location with a closed door.
16. Description of sample What are the important characteristics of the sample? e.g. demographic data, date	Table 1 outlines the information collected about participants who were from different professions, organizations and geographic locations
Data collection	
17. Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested?	The semi-structured interview guide was pilot tested on 3 clinicians. If requested, the intervie guide was provided to interviewees in advance We used open-ended questions and also probed participants' answers.
18. Repeat interviews Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording Did the research use audio or visual recording to collect the data?	All interviews were audio-recorded and the on in Teams were video-recorded. We only used t audio-recording for all interviews, not the vide recording.
20. Field notes Were field notes made during and/or after the interview or focus group?	ETC and JY made field notes during the interview
21. Duration What was the duration of the interviews or focus group?	Each interview was approximately 1 hour, som were up to 2 hours.
22. Data saturation Was data saturation discussed?	Yes
23. Transcripts returned Were transcripts returned to participants for comment and/or correction?	No. No participants requested to see their transcript.
Domain 3: analysis and findings Data analysis	

24. Number of data coders How many data coders coded the data?	SK and ETC independently coded the first 10 interviews. ETC and JY coded the next 22 interviews, the first 3 together, then divided up the rest.
25. Description of the coding tree Did authors provide a description of the coding tree?	Our process model and stages were used as the coding tree. We compared and contrasted new data to the process model, revising it as data was collected.
26. Derivation of themes Were themes identified in advance or derived from the data?	Because GG is a MAiD provider and ETC and SK had considerable knowledge about MAiD, our collective knowledge helped us initially sort data into different stages/themes. The process model and its stages were derived from the data. All participants were sent the process model and article and offered the opportunity to provide feedback.
27. Software What software, if applicable, was used to manage the data?	Microsoft Word was used to manage the data and Microsoft Powerpoint was used to draw the process model.
28. Participant checking Did participants provide feedback on the findings?	Yes. The final process model was emailed to all interviewees inviting them to critique it.
Reporting	
29. Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	Yes. Table 2 has quotations from each provider by identifier, that illustrate MAiD.
30. Data and findings consistent Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes Were major themes clearly presented in the findings?	Yes
32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?	Yes

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## Standards for Reporting Qualitative Research (SRQR)\*

http://www.equator-network.org/reporting-guidelines/srqr/

Page

Title and abstract	
<b>Title</b> - Concise description of the nature and topic of the study. Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
<b>Abstract</b> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2

## Introduction

<b>Problem formulation</b> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	3
<b>Purpose or research question</b> - Purpose of the study and specific objectives or questions	3

## Methods

<b>Qualitative approach and research paradigm</b> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	4
<b>Researcher characteristics and reflexivity</b> - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	4
Context - Setting/site and salient contextual factors; rationale**	4
<b>Sampling strategy</b> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	4
<b>Ethical issues pertaining to human subjects</b> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	4
<b>Data collection methods</b> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	4

<b>Data collection instruments and technologies</b> - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	4
<b>Units of study</b> - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	4
<b>Data processing -</b> Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	4
<b>Data analysis -</b> Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	4
<b>Techniques to enhance trustworthiness</b> - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	4
ults/findings	
<b>Synthesis and interpretation</b> - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or	5-8

	<b>Synthesis and interpretation</b> - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or	5-8	
	integration with prior research or theory		
	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts,	Table 2, Figure	
	photographs) to substantiate analytic findings	1	
Disc	cussion		

## Discussion

cussion	
Integration with prior work, implications, transferability, and	
contribution(s) to the field - Short summary of main findings; explanation	
of how findings and conclusions connect to, support, elaborate on, or	8-10
challenge conclusions of earlier scholarship; discussion of scope of	0-10
application/generalizability; identification of unique contribution(s) to	
scholarship in a discipline or field	
Limitations - Trustworthiness and limitations of findings	9

Other

<b>Conflicts of interest</b> - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	10
<b>Funding</b> - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	10

\*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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2	**The rationale should briefly discuss the justification for choosing that theory, approach,
3	method, or technique rather than other options available, the assumptions and limitations
4	implicit in those choices, and how those choices influence study conclusions and
5	transferability. As appropriate, the rationale for several items might be discussed together.
6 7	
8	<u>Reference:</u>
9	O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for
10	reporting qualitative research: a synthesis of recommendations. Acad
11	Med 2014;89(9). DOI: 10.1097/ACM.000000000000388
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# How is the Medical Assistance in Dying (MAID) process carried out in Nova Scotia, Canada? A qualitative process model flowchart study

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# How is the Medical Assistance in Dying (MAID) process carried out in Nova Scotia, Canada? A qualitative process model flowchart study

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\*Correspondence: Ellen T. Crumley

# Abstract

**Objectives:** The aims of this study are: 1. To create a flowchart process model of how medical assistance in dying (MAID) occurs in Nova Scotia (NS), Canada and, 2. To detail how NS healthcare professionals are involved in each stage of MAID. The research questions are: How is the MAID process carried out and which professionals are involved at which points? and Which roles and activities do professionals carry out during MAID?

**Design:** Qualitative process model flowchart study with semi-structured interviews. **Setting:** Primary and secondary care in Nova Scotia, Canada.

**Participants:** Thirty-two interviewees self-selected to participate (12 physicians, 3 nurse practitioners (NP), 6 nurses, 6 pharmacists and 5 healthcare administrators and advocates). Participants were included if they conduct assessments, provide MAID, fill prescriptions, insert IVs, organize care, etc.

Results: The flowchart process model details five stages of how MAID occurs in NS: 1. Starting the MAID Process, 2. MAID Assessments, 3. MAID Preparation (hospital in-patient, hospital outpatient, non-hospital), 4. Day of MAID and 5. Post-MAID (hospital in-patient and outpatient, non-hospital, after leaving setting). Nineteen points where the process could stop or be delayed were identified. MAID differs slightly by location and multiple professionals from different organizations are involved at different points. Some physicians and NP provide MAID for free as they cannot be reimbursed or find it too difficult to be reimbursed.
 Conclusions: Our study adds knowledge about the MAiD activities and roles of NS professionals, which are not documented in the international literature. Clinicians and pharmacists spend significant additional time to participate, raising questions about MAID 's sustainability and uncompensated costs. The process model flowchart identifies where MAID can stop or be delayed, signalling where resources, training and relationship-building may need to occur. Knowing where potential delays can occur can help clinicians, administrators and

policymakers in other jurisdictions improve MAID.

# Strengths and limitations of this study

- Our novel flowchart process model of medical assistance in dying in Nova Scotia, Canada outlines professionals' roles and activities, the points at which they are involved and where delays/stops can occur.
- Our findings from Nova Scotia, Canada provide an opportunity for other jurisdictions to learn how medical assistance in dying works as well as compare and contrast their model.
- As this study occurred in one Canadian province, Nova Scotia, it does not enable us to generalize the findings to other provinces or internationally.

**Keywords**: Euthanasia, Active, Voluntary; Qualitative research; Outcome and Process Assessment, Health Care; Professional Role

# Background

Medical assistance in dying (MAID) has been legal in Canada for over 4 years [1, 2]. Although MAID includes both assisted suicide and euthanasia, most Canadians have chosen euthanasia [3]. Many of the initial *ad hoc* processes and procedures that healthcare professionals developed to implement it while professional College policies, health authority policies and processes were being developed are still being used today [4, 5, 6, 7, 8, 9]. In 2017 when the MAID process was first being set up, the press described it in the provinces of Ontario and Nova Scotia (NS), respectively, as:

"an ad hoc, scattershot mess. Policies were hammered out in email chains and over casual conversations" [10]

"We have a small set of providers, but we can't possibly keep up with the patient demand" [11].

It is difficult, however, to evaluate and improve a new health service without understanding how it is carried out. Canada's MAID criteria is currently being debated and the legislation may be expanding: advance consent for those who will lose capacity may be included and the "reasonably foreseeable" death requirement may be removed [12, 13, 14, 15]. The latest national poll found Canadians support advance consent (82%) and removing "reasonably foreseeable" (71%) [16]. Thus, there is a pressing need to evaluate and improve the process. The objectives of this study are to create a flowchart process model of how MAID occurs and detail where and how healthcare professionals are involved in NS's process. Our research questions are: How is the MAID process carried out and which professionals are involved at which points? and Which roles and activities do professionals carry out during the MAID process?

Many of today's healthcare services are designed around interdependent roles – that is, professionals organize interdependent work around their responsibilities and activities [17]. Process theory examines the sequences and stages of activities and events as they occur [18, 19, 20]. Some processes emerge as they are implemented and may not be written down, causing an issue for quality improvement. With MAID, events such as appointments often occur in a linear fashion, that is, in a certain order, and a person requesting the service needs to meet specific criteria in order to move from one stage to another [18]. Internationally, there is little documentation about how MAID occurs, which professionals are involved at which points and how the process is organized [21]. The 8 jurisdictions that have assisted suicide and/or euthanasia, Australia (Victoria and Western Australia recently legalized assisted suicide and euthanasia), Belgium, Canada, Colombia, Luxembourg, The Netherlands, Switzerland, and 8 states in the United States [22, 23], collect descriptive statistics about number of deaths, gender, etc. However, additional data is needed to evaluate and improve the service (e.g., feedback from providers, patients and families, analyses of the process including its policy, functionality, efficiency, effectiveness, impacts and sustainability, etc.) [24].

Canadian providers and health systems are actively working to improve the MAID experiences of patients, families and professionals [25, 26, 27, 28], but it remains challenging to improve its implementation without knowing what the process looks like. Studies describing professional roles, expectations and knowledge gaps [9, 15, 29, 30, 31, 32] or how MAID was implemented [4, 5, 9, 33, 34, 35, 36, 37] provide few details about the process itself (e.g., how work is coordinated between professionals, which professional(s) do which activities and when, etc.) [14, 21, 37, 38, 39, 40, 41]. The process involved in the provision of MAID in one province can help us better understand how new health services are implemented. Our identification of gaps and inefficiencies in the process is timely given that lawmakers will be expanding eligibility criteria for MAID, yet the number of physicians and nurse practitioners (NP) that provide it is

not growing in NS [42]. National best practice guidelines and training are available [38]. Patients, health professionals and policymakers want to improve the MAID service [40, 41]. This study provides details about how the MAID process is being implemented in NS, from beginning to end, and identifies areas for improvement.

# Methods

# Design and setting

A qualitative process model flowchart study for MAID was conducted in the province of NS in Canada because MAID is centrally coordinated and the researchers reside there. As the lead researcher specializes in interviews, first-hand accounts from those involved in MAID were the most appropriate to piece together how the process occurs. Using semi-structured interviews, we asked those involved in the MAID process (e.g., assessors, providers, administrators) to describe their roles, activities and at what points they are involved [18, 43, 44].

### **Recruitment and sample**

Participants were recruited through: 1. emails to the NS MAID providers' list-serv (convenience sample), 2. emails to professional colleges, associations and organizations and 3. snowball sampling [45] by asking authors and participants to forward study information to colleagues involved with MAID.

The sample included health professionals who are involved in MAID: physicians and NP (hereafter, clinicians), nurses, pharmacists and health administrators. The study was approved by the Nova Scotia Health Authority Research Ethics Board (Study Protocol ID: #1022997) and data were securely collected and stored using the approved protocol. Participants received written study information and completed an electronic or written consent form. To ensure confidentiality, participant characteristics are presented at a group level, and quotations are anonymized by profession and interview number.

# **Data collection**

ETC collected data from 29 participants using a semi-structured, pre-tested interview guide inperson in a private location, by telephone or Microsoft Teams® [see Additional file 1]. JY, a medical student, was trained by ETC and conducted 3 of the interviews under her supervision. The interview guide was pilot tested with 3 clinicians. To obtain details about how and when they are involved and their interactions with other professionals, participants were asked openended questions about their MAID role and activities [46]. Interviewers probed participants' responses by asking follow-up questions and also made field notes. Interviews were audiorecorded, professionally transcribed in simple verbatim (e.g., um, ah and pauses were not transcribed) and stored in password-protected Microsoft Word® documents on a secure server [47, 48, 49]. As JM is the Medical Affairs Advisor (MAA), NP is the MAID Nurse Navigator (MNN), GG is a MAID provider, they were not involved in data collection to help preserve participants' anonymity. To achieve saturation, data was collected until no new information about the process was found.

# \*\* ADDITIONAL FILE 1 ABOUT HERE \*\*

# Data analysis

After each interview was completed, data were iteratively coded and checked using constant comparison during six phases [4, 18, 50]: (1) reading each interview and coding passages about MAID roles, activities and stages; (2) creating a draft flowchart process model with stages and outlining professionals', roles and activities in each stage; (3) continuing to conduct and code interviews, then incorporating new or revised information into the draft flowchart process model (drawn using Microsoft PowerPoint®); (4) inviting all participants to critique the flowchart process model and incorporating their recommendations and changes (5) finalizing the flowchart process model and (6) writing the article.

# Patient and Public Involvement

Patients and or public were not involved in this research.

# Results

Thirty-two professionals participated in 1-2 hour interviews (Table 1). Figure 1 has the process model detailing professionals' MAID roles and activities as well as the places where the process may stop or be delayed, depicted by a red octagon. Table 2 has quotes about how NS professionals' view the MAID process and their role.

Table 1 Participant characteristics	
Type of professional	Number (%) of participants $n = 32$
Physicians	
Family medicine	6 (18.8)
Palliative care / critical care	4 (12.5)
Emergency medicine	2 (6.3)
Nurse Practitioners	3 (9.4)
Nurses	
Hospital	3 (9.4)
Long-term care / nursing home	1 (3.1)
Victoria Order of Nurses (VON)	2 (6.3)
Pharmacists	
Community	2 (6.3)
Hospital	4 (12.5)
Health Administrators / Advocates	5 (15.6)

\*\* INSERT Figure 1. The MAID process in NS, Canada ABOUT HERE \*\*

Ta	ble	2	Prof	essi	ion	als	° c	juotes	about	the	MAID	proces	S
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Logistics & scheduling

"when MAID came up, I thought 'well it's legal!". It's... people have the right to ask for this and nobody in my community was willing to provide this service. I knew that I couldn't be available to do the actual procedure, ... And facilitating the actual procedure of coordinating the ... the healthcare team members who needed to be part and parcel of the procedure because there's this huge reliance on pharmacists and nursing staff and community funeral homes and so on, to be sure that the whole procedure is done properly. ... at that time, I was one of two people who would do a MAID consultation." Physician 8

"I don't do IVs very often. So worrying that I was going to go to this house to do a MAID procedure and not be able to get the IV." Physician 11

"procedures can be done within a half hour to 40 minutes. I go in and have a chat with them and make sure that they still have capacity and that they know why I'm there. And if they still want the procedure. I'll say, okay,

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have some time with your family or whoever is there. And I'll go get my medications ready, and then I'll come back and ask them again if they want me to proceed or give them that last chance to rescind." Physician 12 "there's a fair amount of phone calls and logistics. So if I've agreed to do the provision for a patient, so I've had to do one of the assessments and if ... they've had two assessments that agree that they meet the criteria, then I ask the patient to decide on a time and a place, and we talk about when and where that might be, and usually that's done in concert with the patient ... So if it's at home it's easy ... If it's not at home, it means having a patient admitted to the hospital or going through ambulatory care, then that would take phone calls and arranging. ... I don't like to be fumbling in somebody's dark bedroom with big syringes and vials and so I have a system, I get it all ready in my office. I have a plastic tote, little small tote, and all the paperwork ... So, I like to have it all ready to roll and then I arrive at the patients home ... the morning of the procedure. After the procedure I have to sign the death certificate and do the paperwork ... and then return the unused medications to the pharmacy. So there's a fair amount of kind of little detailly stuff." Nurse Practitioner 1

"In our first [MAID] case ... a CCA [Continuing Care Assistant] had struggles. ... We respect people's decisions all of the time. ... And so perhaps our staff are better prepared because of those autonomous choices, like we have ethical conversations around them, when people make decision of to not have treatment or suspend treatment and how do we support staff at that point through that. ... if I think of something that we may struggle with is probably making sure the staffs' schedule of that [MAID] day are aware of personal values. So if we had a Muslim RN, we have to change shifts. It is being conscious of that from an administrative staffing scheduling perspective that we had thought 'We don't put people in difficult situation'". Admin 1

"If I get a call now and somebody says there's a MAID case and they're interested in whatever date, I really have to drop everything and try to organize the space, the date, the staff." Admin 4

"The drugs themselves are often in pharmacies, just not either in the quantity or the dosing that we need." Pharmacist 1

#### Process

"When I'm assessing somebody, I'm usually generating the consult, right. The patient's come to me. I've seen them. I've said, okay, I'm going to be the assessor 1. Off to you guys – you find assessor #2, and, you know, deal with all the rest of it." Physician 7

"I provide them [clinicians] basic information about the case. And then they would get back to me ... "I'll take this case" ... I do the assignments of physicians to the case, forward patient information ... about the referral. They will do the assessment and then report back to me. And I will arrange for the second assessment to take place with another care provider ... Once those assessments agree that ... the patient meets the criteria for the MAID, we would walk the patient around the details of time, location, circumstance for the procedure. So then the procedure happens and the physicians and nurse practitioners take care of the specific details relative to the location and the medication protocol ... the procedure is completed and practitioners send the information to me and I capture that in the office and then close the case." Admin 2

#### Relationships

"they're such neat patients, and their families are so neat, and because that initial interview often times ... you get to know them so much, you talk about their life and you get to know where their moral compass lies and what their general feelings about life and death and suffering and quality are. And the family often really wants you to know and love that person the same way that they do, so you get a lot of that background in a really short period of time. And then typically I do my procedure on a different day, and so going back in to meet the family again and see them for the procedure, there's often so much relief to see you and they're so pleased. ... sometimes if the patient has some sort of functional decline or symptom management issues in between, you've talked to the family a few times to help them navigate that and make sure that their quality is maintained while they're waiting for their procedure, so I think you become attached to the families very, very quickly" Physician 9

#### Time and compensation

"When you go to see a patient, you never know if it's going to be a half hour assessment or a 2 hour assessment. Physician 3

"Each MAID case is taking probably a minimum of 5 or 6 hours of time. That's 5 or 6 ... patients that I could see in that time. So we were never resourced to consider taking on MAID. And that's probably the most practical issue." Physician 5

"the procedure itself is fairly quick once everything is set up. But generally it takes hours in order to go through this very personal process with this individual. Sometimes they're very straightforward. Other times... You know, I've heard stories of very elaborate events that have been planned around medical assistance in dying. ... I am astounded and I'm stunned by the clinicians that will do this on a regular basis and take hours and hours and hours of their personal time." Physician 6 "about 5 to 7 hours. And that [putting together first MAID kit] was over several days. And that was a process of, you know, calling places, calling the other pharmacy, finding the drugs, calling our wholesaler to find out if we're ordering the right ones, data entering the information, getting the bins together, you know, with labelling. Making sure we have a spot in the fridge. Making sure all of our staff are aware. Like it was a very time-consuming endeavour." Pharmacist 2

#### **Policy & legislation**

 "I went out and I got the [MAID] policies and I had them sitting on my desk. But there was no meaning in them. But once we had the [MAID] requests, I had two months. But I had already written the paper and I had already kind of went through all of that. So it was... I just basically stole the policies and procedures from [location] and [location] and another [location] and put them all together. ... The mechanics weren't the important thing. It was getting the fact sheet right and getting to that audience, that you could talk to them in their language. And that was... For me it was the relational piece that was more important than the mechanics." Nurse 1

"I think Canada can have the absolute best assisted dying regimen in the world. We can show people how it can be done, how it can be done well. And we just need to make some changes to do that. And so I feel it's still worth trying. ... I'm in a transition in the sense that I have to recognize there's some things that are my wheelhouse and there are a lot of things related to this [MAID] that are not my wheelhouse. And I need to let others do it, right. For a long time I was pretty alone in this field, trying to make this change. And so you just feel like, "Oh, it's on my shoulders. I've got to keep going, I've got to keep doing it". And at the first CAMAP [Canadian Association of MAID Assessors and Providers] meeting, it was the most extraordinary feeling because I was in a room... with all these people. And this is what they do. And it was this incredible sense of relief and release and a sense of okay, you know, this is in good hands. Different people are going to be doing these different things. So now what I try and focus on are the things that I can do. So ... there's an issue right now of whether nurses can raise the issue. ... Or the faith-based institutions, publicly funded faith-based institutions ... there's a way in which it's my wheelhouse" Admin 5

#### Role

"I've been involved with MAID two more times. ... I don't want to do the second assessment. .... I did it [once], and I am okay with that. And I don't have any moral distress with it. Even though I get choked up about it, it's only because I remember the patient, and I remember how deeply I felt about [them] and helping [them] die comfortably. ... if we're going to be providers, we have to help people get access to what they want, even if we, because of our beliefs, our faith would not do that ourselves. ... I wouldn't want to go any deeper down a road than first assessment.." Nurse Practitioner 2

"As a nurse, I can't push those drugs. I can't order the drugs. I can't go and get the drugs. I can't push the drugs. So I am there as a patient support and a family support." Nurse 4

"Technicians are not involved with this [MAID prescriptions] at all. ... So other orders, we would... Let's just say one of them is a heart medication pill that they don't already have on the floor. So I send pretty much through the system to the technicians to say send this to the floor. ... And then the technicians take it from there. With the MAID, it's 100% pharmacist-run. So we enter the prescriptions that were ordered and then we're picking up the labels, we're packaging it up and we're checking it. ... Let's just say I'm the pharmacist who checked it [MAID prescription]. ... Usually it's the clinician who picks it up but there are a few options. But because we can't leave the dispensary, usually the clinicians are okay to come and get it. And then there's additional information we need to provide, education we need to provide and basically just we go through the medications." Pharmacist 5

#### Secrecy & privacy

"we were under the impression that we weren't supposed to be sharing the fact that we are participating in it with coworkers and things like that. So there's not a lot of professional ... like interprofessional support. And we were encouraged to do that just because they didn't want the public knowing like where things were taking place or... You know, because it was presented to us as like, "Well, there might be a death notice in the paper and someone might put together that you just participated in this thing. So that's what that family chose. So it's really important to not tell anyone that you...because their decision needs to be kept private." Which I understand. But it does make it difficult to process." Nurse 5

"So basically what we were told when MAID became law was that if patients voiced wanting more information about it, you know, we don't really have an opinion per se because... You know, I don't know if my coworkers are for or against." Nurse 6

"I also regard it [MAID] as a very private confidential process. And I know we've really struggled with that in the distribution side ... whether it should be at a higher level of confidentiality than everything else we do. And everything we do is confidential. But if one person is handling a MAID, do all 5 pharmacists in the dispensary need to know about that MAID? ... So I guess in the back of my mind I kind of thought, well, clinically I am not

 required to counsel the patient. They haven't asked me to do that, and they didn't, you know, tell me of this decision. That may have been the intent, you know. But at the same time ... it's part of the therapeutic plan that wasn't well documented like every other process that we work on as a team is." Pharmacist 4

# 1. Starting the MAID Process

Patients explore MAID for many reasons [37, 51, 52, 53] and often find out about it through the media, Dying with Dignity (DWD), a "national human-rights charity committed to improving quality of dying, [and] protecting end-of-life rights," [54] or the Nova Scotia Health (NSH) website. When they are exploring MAID, NS patients may do their own research, call the MNN or visit a clinician (e.g., family clinician, surgeon, nurse practitioner) to obtain more information. The clinician may give a patient MAID information or send a patient referral to the MNN. Some patients may first seek information about MAID, then visit a clinician again for a MAID assessment referral. If the clinician has a conscientious objection or is not comfortable participating in MAID, they will transfer the patient to another clinician, send a referral to the MNN or ask the patient to contact the MNN. If the MNN does not receive a referral, they will follow-up with the clinician. One physician suggested this could be improved by having "a self-referral system. And it doesn't need to involve family doctors." An administrator also noted that:

"My biggest concern is there are people who want MAID but they are unable to access the system because the doctors won't put their names forward. We have had phone calls of people that said my doctor won't refer so we had to call them [doctor] back and explain that there is a duty to transfer the name of a patient requesting and they shouldn't disallow the request to occur." (Admin 3)

The MNN's role is central. As paperwork or phone calls are received, the MNN contacts the patient for an intake interview to explain the MAID process, offer support, explain resources (i.e., palliative care, home care) and seeks to understand the patient's goals. The MNN may email or mail the patient information (e.g., Advanced Directive Guides, MAID and Palliative Care information). The MNN sends MAID documentation (e.g., referral, nursing intake notes, clinical notes) to assessing clinicians. The MNN remains in contact with the patient, family and their circle of care throughout the process. One administrator detailed the process:

"Referrals come in typically from family doctors but occasionally specialists ... the patient arrives at a point where they are considering MAID as an option and discuss that with their physicians ... So the physicians would make referrals to this office [MNN]. It's generally faxed to us ... And I get the referral. I'll capture the basic patient information that is required as part of our reporting to the federal government. ... and then inform the MAID provider team. ... a group of physicians, nurse practitioners ... who do the assessments and perform the procedure. ... through an email. (Admin 2)

At any time, patients may decide not to continue with MAID and pursue options such as palliative care; patients may pursue multiple options simultaneously. If the clinician the patient initially visited will not do the first MAID assessment, the patient or clinician contact the MNN who helps streamline and organize the process. As discussed in the quote above, the MNN then emails the NS MAID list-serv to request assessors. Finding assessors may take time due to the small number of NS clinicians who participate in MAID, their lack of time and/or their inability to travel. Some clinicians will only assess their own patients but do not provide MAID. Some clinicians about how the process works. As one nurse practitioner said "I only bring up MAID if

they ask me about it. Like if a patient comes in and wants to know about MAID, I'll explain it." If a patient mentions MAID to staff, they will refer the patient to a clinician, the MNN or a manager in their facility.

Although clinicians and the MNN prefer the MAID consent form is signed after the first assessment, some patients download it from the NSH website and sign it in advance. As patients are often quite ill, they may have difficulty finding two independent witnesses to observe them signing the MAID consent form. To find independent witnesses, the MNN will contact DWD which has a national network of volunteer witnesses. If the MAID consent form is not signed before the first assessment, the clinician will give it to the patient. Two physicians shared their experiences with consent:

"I go through the consent and kind of the little conundrums or difficulties with getting consent" (Physician 10)

"Sometimes the patient has signed their request. Other times they're waiting and trying to get witnesses lined up. So most times when I'm involved, I've assessed them, I'm usually not there when witnesses are signing. But they're making the request." (Physician 7)

Delays can happen if patients have to wait for an appointment with a clinician to discuss MAID. If a patient initially meets with a non-MAID provider or conscientious objector, they have to be referred/transferred to another clinician and make another appointment, which could delay their Assessments. A common delay is finding two independent people to witness the consent form signing.

#### 2. MAID Assessments

The clinician arranges the patient's first MAID assessment and continues communicating with the MNN. This assessment can occur in the patient's home, hospice, hospital, nursing home or clinician's office. Assessments can take 45 minutes-5 hours depending on the location and the case complexity. As one physician described:

"if it's an in-house assessment, I'll schedule it for the late afternoon/evening, like starting at 4:30 or 5:00. And then it goes until about 6:30 or so." (Physician 12)

The first assessor discusses the MAID process with the patient (and their family and/or supports, depending on the patient's wishes), including legislation, criteria and timeline. The clinician also provides the patient with the College of Clinicians and Surgeons of Nova Scotia Professional Standard Regarding Medical Assistance in Dying. The clinician completes the MAID assessment form, sends it to the MNN and may dictate notes for their records:

"I had no difficulty whatsoever doing the ... MAID 1 or MAID 2 [assessment]. And then I was having the conversations, discussing if the people met the criteria as outlined by our licensing body in Nova Scotia, and ... completing the paperwork." (Physician 8)

"so there's the assessment piece, we have a checklist form that we fill. But it doesn't give enough history. So most of us will dictate a note. ... Both assessments and the consent all have to get copied and sent into the central office for MAID. So they have to have a record of it. Which is nothing but it's still paperwork that has to happen." (Physician 3)

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If the first assessor finds the patient is not eligible for MAID, the patient may ask the MNN to arrange a second and third assessment. If the second and third assessors indicate the patient is ineligible for MAID, the process is finished in NS. Although it is more rare, some patients may go to another province or country to be assessed for assisted dying or euthanasia eligibility.

If the first assessor indicates the patient is eligible for MAID, the MNN or clinician arranges the second assessment. The second assessor often provides or reviews the consent form, returns their assessment form to the MNN and may dictate notes. If both assessments indicate the patient meets MAID criteria, the patient decides when MAID occurs – it could occur hours, days or months later. If neither assessor provides MAID, the patient decides to wait, the original assessors are not available or the patient requests MAID during a busy time (e.g., summer or December), the MNN helps find a provider who will re-assess the patient to ensure they still meet MAID criteria. When patients decide to wait, the MNN checks in with them and receives regular updates from their circle of care. The MNN keeps relevant health care providers informed about the patient's goals and health status. Sometimes the patient does not have MAID because they die, change their mind or lose competency.

Numerous delays can occur or the process could end during this stage. If the two assessors do not agree a patient meets MAID criteria, a third assessment will be done. The process stops if a patient does not meet MAID criteria, dies, changes their mind or loses competency. As Physician 11 describes, the 10-day waiting period can be waived for patients about to lose capacity or their imminent death and MAID will be provided before the 10 days have passed:

"two days after the [MAID] Assessment, the family phoned and said, "Come now. You know, he's starting to get confused." ... And then there was a brief ... kerfuffle getting the other assessor to agree to move it up, and scrambling to learn how to get the drugs from the drugstore. And tried to get the VON in, and it being too late - the nurses do the IV. And then going and stealing IV equipment from the emergency department. (Physician 11)

If the first or second assessor cannot provide MAID, it may be delayed while the MNN finds another provider, who then may need to re-assess the patient.

#### **3a. MAID Preparation – Hospital In-Patient**

For in-patients, the clinician and MNN ask hospital staff (e.g., a nurse manager, nurse director) to find a private room and a nurse comfortable with inserting the 2 IVs for MAID, one to be used and one back-up. The 2 IVs are usually inserted by a hospital nurse who also gathers supplies (e.g., syringes, needles, IV solution, IV pole, tubing, etc.). The clinician alerts the hospital pharmacy about the upcoming procedure and sends a pre-printed MAID order (PPO). If the hospital does not have a pharmacy, the pharmacy does not have the medications or the pharmacist(s) will not fill the PPO, the MNN and/or clinician will coordinate the MAID medications with a community or another hospital pharmacy. The other pharmacy may courier medications to the hospital. Two to five pharmacists fill the PPO and double-check the two sets of medications according to their protocol [51] because: pharmacists change shifts (i.e., the MAID PPO may be partially filled when the shift changes), MAID PPO are filled when: pharmacists have additional time (i.e., another pharmacist may take over the PPO if the other pharmacist is busy), because there are numerous checks on the MAID medications and NS

pharmacy technicians cannot fill the MAID PPO. The latter issue results in additional work for NS pharmacists:

"the biggest thing is actually doing the collecting of the drugs. ... I would never be the one to go and collect the drugs and ... put them together in the bags. That would usually be a technician job after a pharmacist okayed the order and felt comfortable with it, and said, "Okay, these are the drugs that we're using. Proceed with this." But in this step [MAID PPO], we're actually the ones who are collecting the drugs as well. ... we do keep everything [MAID medications] like actually in a box. So we don't have that initial like trying to make sure that the drugs are appropriate. We do have them for when MAID orders do come up. So we have them separated." (Pharmacist 3)

The time to fill a MAID PPO is significant and pharmacists receive no additional compensation (i.e., community pharmacists receive a small dispensing fee but hospital pharmacists do not):

"I can do a regular order in probably 20 seconds, depending how easy it is. A MAID can be like well over an hour." (Pharmacist 6)

Two MAID medication kits are prepared in case anything unforeseen occurs (e.g., broken bottle). Clinicians typically pick up the medications 24-48 hours after the PPO is submitted, but pharmacies may make exceptions for urgent cases. For patients preferring anonymity, a ghost/shadow chart may be used to conceal their identity.

### **3b. MAID Preparation – Hospital Out-Patient**

A nurse manager, charge nurse, facility lead or MAID provider helps ensure out-patients are registered and admitted, a location is identified and staff are coordinated. Some hospitals have specific wards or rooms for MAID out-patients after hours since these are often used during the day:

"we have a place ... if people want to just come in and have it [MAID] done in hospital. So we've done a number that way as well. ... We tend to do it after hours. We have a clinic area that's got some nice rooms. And so we tend to do it after hours when they're not busy. And it's a nice room. Families can be there." (Physician 3)

A hospital nurse often inserts the IVs and gathers MAID supplies; an anesthesiologist may insert the IVs. The MNN may provide support and MAID education to ward staff. The same pharmacy processes and ghost charting occur as in 3a MAID Preparation – Hospital In-Patient.

#### **3c. MAID Preparation – Non-Hospital**

MAID may also occur in the community (i.e., a patient's home), long-term care, nursing home or a hospice. A lot of coordination and steps are involved:

"If somebody was at home ... I would send the prescription in to the [community] pharmacy, call the pharmacist and make sure it was received. I would fax requests into VON for the IV's to get inserted the day of the planned procedure. ... I would coordinate this with the patient and their family to make sure that the time and place was all arranged, and they wanted to go ahead. I would pick up the medications at the pharmacy, I would usually prepare them here in my office so that when I arrive at the patient's home everything is all drawn up." (Nurse Practitioner 1)

The clinician and MNN often work together to contact Continuing Care (i.e., the Victoria Order of Nurses) to insert the IVs. A VON nurse manager will find a nurse who does not have a conscientious objection to inserting the IVs. One nurse described the IV:

"It's not a simple IV. It's not a little tiny one. You have to be able to... to put an IV in that is as big as an anesthetist would use. So big. (Nurse 3).

Typically, MNN sends all the MAID docs to VON and confirms they can meet the need. A VON manager provided details:

"when we get a referral come in for MAID ... we break it down into 4 areas, there's a nurse manager for each area. So we take the referral and work with Continuing Care to ensure that ... the consents are there, that we have everything we need. And then we go through the client's schedule ... to find a nurse that has been there the most so that we can have somebody that the client or the family knows. And then we reach out to the nurses to see if they are willing to participate. Because it's their choice to do it. And I'd say probably 60% are willing." (Nurse 2)

The clinician coordinates the medication order with a community pharmacy and may discuss further with a pharmacist unfamiliar or uncomfortable with MAID. One to three pharmacists prepare and double-check the two MAID medications. The clinician usually picks up the MAID medications 24-48 hours later. If the pharmacy does not have MAID supplies and the clinician may obtain these from their hospital or facility. The MNN and MAA are currently working on making MAID kits available for all clinicians.

In stage 3, there may be delays if a nurse cannot be found to insert the IVs or the hospital pharmacy will not fill the PPO. The clinician or MNN may need to coordinate with another pharmacy or find a willing pharmacist. MAID may be delayed

# 4. Day of MAID

Depending on where MAID is occurring, the MAID process can take several hours:

"some of the cases are straightforward. You know, it's in the hospital, you go in, the assessment takes an hour, you come out, you give the order to the pharmacy, the nurse is ready, you come back for the procedure, it takes an hour. ... But some cases, especially if they're at home or they're in the periphery, are very complex. ... you have to be coordinating with VON to get the IV set up and the pharmacy – which has probably never had to organize the medications. And then getting back and forth with the patient as they sort of progress and checking in on how they are. ... And then the driving" (Physician 2)

The clinician picks-up the MAID medications from the pharmacy and gathers supplies. They may drive to the patient's location and, in some cases, fly or walk. Some may participate in religious services, celebrations of life or farewells before or after MAID, but not all clinicians are comfortable with this. As one physician recounted:

"the procedure takes about 15 minutes. That's the actual giving of the medications. But between getting the medication...picking up the medications, drawing everything up, getting yourself ready to do the procedure, going in, seeing the family, making sure they're all set and ready to go, it usually takes about two hours or so. ... Sometimes you go in and ... they don't want to chat, they just want to go and get it done. And so they don't take as long. I had one situation where I walked in and there was a party going on in the house. And I said, "I'll go down to the back room," where they wanted me, and I waited for two hours before the patient came into the room, and then performed the procedure." (Physician 10)

Where possible, a nurse (or clinician) inserts the two IVs close to the procedure time to decrease having to reinsert them in dehydrated and very ill patients. IVs are not placed in patients with central (Hickman) or PICC lines. A VON nurse inserts IVs in long-term care. The nurse may stay for the procedure, if they are comfortable, if the patient/family wants them there and/or they have time. Some nurses will return for the procedure if the IVs are placed earlier. Hospital nurses often arrive 1-2 hours before the procedure and stay with the family and body after MAID.

The clinician will draw up the syringes with medications (Table 3). After determining the patient has the capacity to request MAID, the clinician explains the procedure including: what each medication does (if the patient wishes to know), the dying process and potential medication responses (i.e., twitching). The clinician asks the patient if they wish to have MAID. If the patient says no, MAID does not occur. If the patient says yes, the clinician administers the medications over 10-15 minutes. If a patient does not have the capacity to consent to MAID, the procedure does not occur, although this may change with the revised legislation.

Table 3Medications used for MAID in NS

- 1<sup>st</sup> medication, a sedative to help relax the patient. The patient typically falls asleep in 30-60 seconds.
- 2<sup>nd</sup> medication, a numbing agent to prevent the patient from feeling any vein discomfort from the subsequent medications.
- 3<sup>rd</sup> medication, a coma-inducing agent.
- 4<sup>th</sup> medication, a muscle relaxant which stops breathing and heart function. It usually takes 2-6 minutes to stop the patient's heart.

A clinician may be delayed picking up the prescription if MAID is being rushed or a participating pharmacist cannot fill it. This can affect when the clinician arrives for the provision. How the clinician travels to the MAID location can also delay the process, especially if they are flying or driving. The MAID process can be stopped if the patient chooses not to have MAID or if the patient has lost capacity and cannot consent to the procedure. One physician described their time and compensation:

"With an assessment and the charting and the procedure is probably about ... 6 to 8 hours of work in a month. ... it depends on the case too. Some are more straightforward than others. I would say it's about 8 hours of work. So I'd have to fit that in on weekends and evenings. ... But then the actual billing code right now, it's still capped at 2 hours for an assessment and 2 hours for a procedure. And almost all of my procedures have been longer. So I've just chosen to bill for 2 hours of my work and the rest is not paid." (Physician 1).

Another physician talked about being flexible:

"When you go to do the procedure, it could be a 15 minute procedure and done, it could be multiple hours. So you sort of have to be willing to be flexible... have to make sure that whatever you had booked after you might not get to and you might get there – it just depends." (Physician 3)

Some NPs have had a different experience:

"sometimes I'll do this on my off time. I try to include it in my day. My manager is very supportive of me doing this. ... I went ... to see a case, which is an hour away. But I do get reimbursed for my expenses. Mind you, it did take me a year to get my travel claim figured out.... The doctors get paid for doing this. The nurse practitioners don't. ... I think they're trying to lobby to get us paid. Like we get paid for our travel expenses. So I can send that in. But I know the physicians bill for doing a MAID case, like doing assessments. But we don't get paid. I mean you know, I'm going all hours of the day, the weekends, right." (Nurse Practitioner 3)

# 5a. Post-MAID – Hospital In-Patient or Out-Patient

The clinician records the medications and time given, the patient's time of death and completes the death certificate. The clinician and/or nurse may wait with the family, participate in a family event or leave. Ward staff follow the protocols for post-mortem care and, although this may not be the usual process in many organizations, may contact security to transfer the body to the morgue. Or, the family may contact a funeral home to remove the body from the floor. The death certificate goes with the body. A manager or the hospital may provide staff debriefing. There may be delays waiting for the funeral home or security to collect the body, especially if they were not notified in advance of the death:

"If you're doing them [MAID] in hospital after hours, we have to actually ask for security to come and take the body away. Or if you're at home, sometimes the family is not comfortable waiting there with the body themselves until the funeral home comes. So you have to hang around with them. We had one time here where the family did not want the body to go to the morgue. They didn't tell us that beforehand. ... We had to wait 3  $\frac{1}{2}$  hours for the funeral home to come and pick the body up." (Physician 3)

# **5b.** Post-MAID – Non-Hospital

The clinician records the medications and time given, the time of death and completes the death certificate. The clinician and/or nurse may wait with the family, participate in a family event or leave. At home, the family will contact the funeral home to remove the body. In long-term care, the family, security or staff arrange for the funeral home to collect the body. The death certificate goes with the body. The family may want to spend time with the body before calling the funeral home and/or may not have notified the funeral home in advance, which can lead to lengthy delays.

# 5c. Post-MAID After Leaving Setting

The clinician documents the procedure and sends the MNN information including: people present, medications given and dose, times the medication was pushed, time of death and notes about the procedure and/or family difficulties. They return all used and unused medications to the pharmacy, input information into the national MAID database online and may dictate notes. Some clinicians debrief with colleagues. Clinicians may bill Medical Service Insurance (MSI) up to 8 hours for MAID assessments and procedure. Clinicians send travel expenses to the MAA who submits these to NSH for reimbursement. Nurses are usually paid overtime by their organization and typically debrief with a nursing manager/director but not always. The MNN collects and submits MAID statistics to the NSH and follows-up with the family, sometimes connecting them with community supports. The MNN and MAA collect and save MAID documentation and the MNN closes the case.

The pharmacy or practitioner disposes the used MAID medications. Some hospital pharmacies store and re-use the backup medications if they have not left their premises. Other pharmacies discard both sets of medications as they do not know how and where the medications were stored, what conditions they were exposed to, who they might have come into contact with, etc. One pharmacist detailed what happens with the medications:

ETC: "So how would the physician or nurse practitioner dispose of what they had used?" Pharmacist 3: "That would go back to whatever their typical disposing protocol would be. There shouldn't be any leftover drug, I wouldn't think. So it would probably just need to be disposed of the vials and the packaging and that type of thing. So for us, we're only taking back drugs that haven't been opened or used at all." ETC: "And then what happens on intake of the [MAID] kit?"

Pharmacist 3: "We would just put it back. We would just disassemble the kit, put the drugs back. Except for one that's refrigerated that we have to dispose of. ... It would only be stable for 30 days or so [after leaving the pharmacy]. ... We would just dispose of it."

There may be delays with the physician entering data into the national registry and returning the MAID medications to the pharmacy. It takes them time to submit billing and travel reimbursement information and to receive reimbursement from NSH and MSI. Some clinicians have never been reimbursed for time or travel.

#### Discussion

This study's flowchart process model indicates how multiple professionals work together and are involved at each stage of MAID [17, 18, 19, 20]. Clinicians, mainly working evenings and weekends, assess patient eligibility, write and pickup prescriptions, gather supplies, and organize and provide MAID. Some clinicians are reimbursed, while others are not (e.g., depending on their contract, some NP cannot be reimbursed for MAID and must participate outside working hours; some physicians provide MAID for free outside working hours). To compare, Medicare in Oregon pays for assisted suicide for terminally ill people with low income but does not specify who pays the physician for participating (e.g., insurance companies) [55, 56]. As well, physicians in the Netherlands are compensated by the patient's insurance company but Belgian physicians do not receive compensation [57]. US patients pay from \$0-\$8000 USD and there may be additional fees for medications, mileage and complex procedures (personal communication, Dr. Lonny Shavelson, 2021). UK patients having assisted dying in Switzerland pay between £6500-15000 [58]. In Switzerland, physicians receive their regular wage and provide assisted dying during regular work hours (personal communication, Dr. Erika Preisig, 2021). In Australia, physicians receive fee-for-service and provide assisted dving outside of regular work hours, typically in the patient's home (personal communication, Dr. Alida Lancee, 2021). Nurses, often being paid overtime, support the patient and their supports before and after the procedure as well as insert IVs. Health administrators organize the process as part of their workload. Pharmacists, within regular work hours, fill prescriptions and dispose of medications after MAID. The process differs slightly by location and in-patient/out-patient status. We identified multiple points where MAID could be delayed or stopped [19].

Some NS processes were similar to others such as having a central coordinator, a variety of professionals being involved at different stages and MAID being available in multiple locations [9, 30, 31, 33, 36, 37, 59]. Some Ontario regions coordinate MAID centrally [4, 5]. Other processes were different such as not having a centralized pharmacy, clinicians making arrangements with patients and fewer health professions are involved (e.g., no social workers,

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spiritual advisors, psychologists) [30, 60]. Most MAID assessments and procedures are conducted on evenings and weekends, outside regular hours. Nurses are paid overtime for participating in MAID, unless it is during their regular shift [37]. Some of our clinicians considered MAID "volunteer work", since setting up billing codes and coordinating government and insurance payments can be difficult [35]. Many devoted significant amounts of, mainly unpaid, time coordinating MAID but did not consider this sustainable [35, 36]. NS could learn from other provinces, including Manitoba where a single MAID team serves the entire province [61].

Our clinicians learned to ask about family dynamics to prevent difficult situations, such as arguments on the day of MAID or a wrongful death lawsuit. Thus, including spiritual providers, social and mental health professionals, psychiatrists and psychologists could be beneficial [4, 9, 30, 60, 61, 62]. Along with offering support, inserting the IVs and documenting the process, our nurses want to meet patients and their supports before the day of MAID [30, 63]. Pharmacy technicians in NS cannot prepare MAID medications [64], thus pharmacists incorporate an additional 1-5 hours into their regular workload. This is unusually long to fill a prescription. The Northwest Territories, Manitoba and Alberta have dedicated MAID pharmacies [65]. Pharmacists do not provide MAID supplies (e.g., tubing and syringes) and some clinicians scramble to collect or "steal" supplies from their workplace. Some regions provide supplies with the MAID medications [4] but some do not.

**Limitations**. This study occurred in one Canadian province, thus we cannot generalize to other provinces or internationally [66, 67]. However, the results could be helpful to other jurisdictions seeking to evaluate and improve MAID. Although this study has a smaller sample size for each group of professionals [68], we continued recruiting until no new information was found (i.e., data saturation). To address sample and selection bias, as self-selected participants may not represent the views of all professionals [45, 68], we recruited across the province from different professionals during different times of the year.

**Implications for clinicians and policymakers**. This study builds on MAID research [3-6, 26-28, 30-32, 34, 48, 61] by detailing the process in NS from beginning to end. Our findings about the roles and activities of professionals could help inform MAID practice in the rest of Canada and internationally. We identified issues such as clinicians' additional time to pick up and drop off medications, travel to the patient, input data and bill hours. Other jurisdictions may consider the benefits of centrally coordinating communication between professionals and administrators to avoid miscommunication or missed communication.

Our identification of delays/stop points and resources are high priorities for improving MAID. Delays and stop points can limit patients' access to and receiving MAID. Resources include professionals' time and supplies. Providing assistance to set up reimbursement codes and processes could save clinicians' from using personal time without compensation. Having centralized coordination and a central pharmacy providing a MAID kit with medications and supplies are vital to help ensure delays are minimized and resources are used efficiently. If professional colleges allowed pharmacy technicians to assist with MAID prescriptions, this would significantly reduce pharmacists' time. Pharmacists' professional colleges should be concerned since their professionals are not compensated for hours of additional work to prepare and dispose MAID medications.

**Future research**. This study contributes to research about healthcare process models. Future researchers could compare and contrast process models from other jurisdictions with this study [18, 45] which could be used to improve MAID internationally. To better understand each profession's contributions to and time for MAID, researchers could conduct participant observations to detail what they do throughout the process. Studies reveal a wide variety of professionals participate in MAID [3, 8], hence conducting interviews with them could provide further insights into the process. Since patients and their informal supports are involved throughout MAID, their insights could be added to improve the flowchart process model. As many jurisdictions are integrating patient-centered care, MAID administrators should consider the value of incorporating this approach.

# Conclusion

This study adds knowledge about the variety of activities and roles that multiple professionals have throughout the entire MAID process in Nova Scotia, Canada – these have not been studied in the international literature. Clinicians spend significant time to participate in and coordinate MAID. There are serious questions about the NS model's sustainability due to potential for burnout and clinicians ceasing to provide MAID since the model relies on them working additional (uncompensated) hours on evenings and weekends. Issues could also be raised about the ethics of sustaining a volunteer model which depends on unpaid work, personal time and inefficient workflow. The Nova Scotia College of Pharmacists should consider allowing pharmacy technicians to help prepare MAID medications as pharmacists also spend significant time preparing and checking MAID PPO. Our identification of where potential delays can occur can help clinicians, administrators and policymakers improve MAID and be of interest to other jurisdictions implementing it.

# Footnotes

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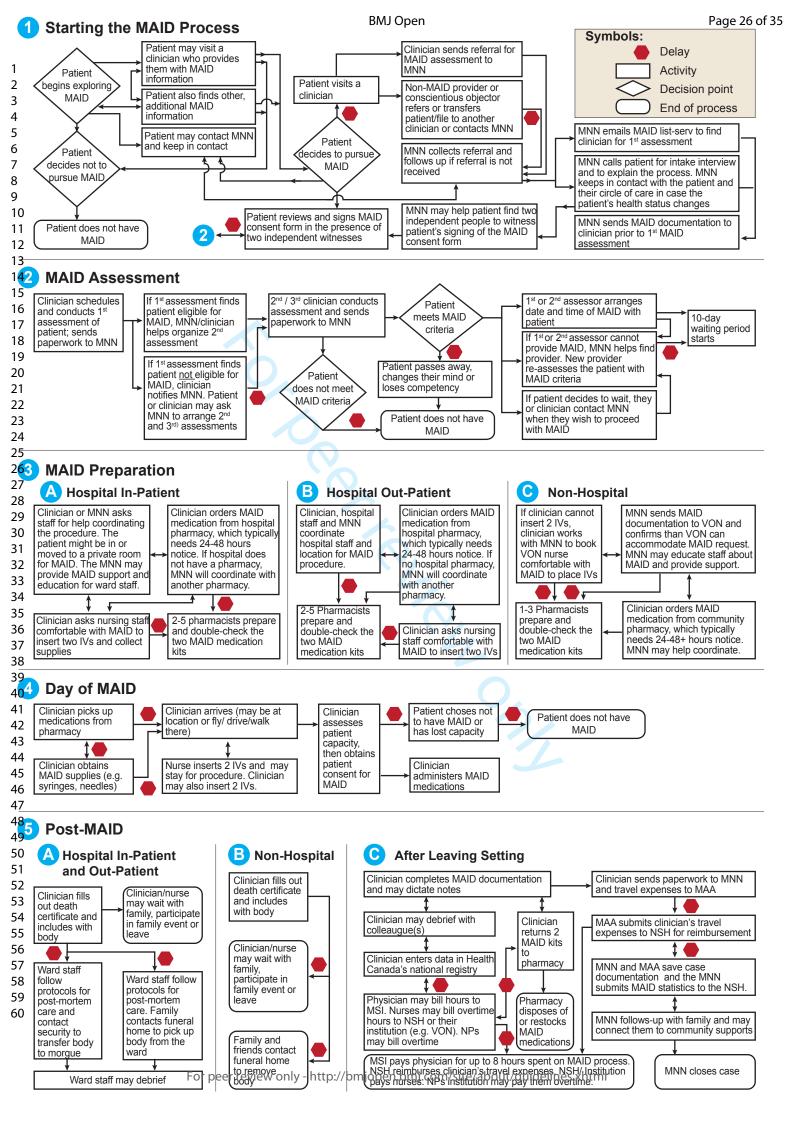
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3	
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6	
7	I am interested in fir
8	
9	how this has affecte
9 10	want to study MAiE
10	
12	I also want you to k
13	may choose not to a
13	available today to ta
15	available today to ta
16	<b>Current Profession</b>
17	
18	1. Please descri
19	administrato
20	2. Tell me abou
21	with MAiD?
22	a. When
23	3. How many M
24	a. Did y
25	•
26	
27	you k
28	4. How much t
29	a. Are y
30	proce
31	b. Do y
32	c. When
33	the h
34	d. How
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36	and a
37	e. How
38	own
39	f. Nurs
40	5. Why is it im
41	6. Have you tal
42	a. Have
43	7. Have you de
44 45	with MAiD?
45 46	
40 47	personally?
47 48	a. Some
48 49	this a
49 50	out?
50	8. Are you a M
52	a. If so,
53	b. Can
54	U. Call
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59	Romeo file number 1022997.

# **Interview Guide**

Version 3 – 19 February 2019

nding more about your involvement with medical assistance in dying, MAiD; d your practice and your perceptions of yourself as a health care provider. I ) from your point of view.

now that you are freely able to withdraw your consent at any time and you inswer any questions you are not comfortable with. Do you have one hour lk with me?

# al Role

- ibe what you currently do as a physician / pharmacist / nurse / health care or (or in your job).
- ut how your role came to include MAiD. or How did you become involved
  - n did you start assessing MAiD patients and/or performing MAiD?
- MAiD procedures have you been involved in since you started?
  - your patients play a role in your getting involved with MAiD?
  - the MAiD patients you have been involved with your own patients or patients know well and see regularly?
- ime a month do you spend participating in MAiD and assessments?
  - you thinking about expanding the time you spend on MAiD assessments and edures?
  - ou travel to provide MAiD? If so, how far and how often?
  - re have your MAiD assessments and procedures occurred: at patient's home, ospital, your office, other?
  - do you set up MAiD assessments and procedures with nursing, pharmacists dministrators? Does anyone help you with this?
  - do you schedule MAiD into your current practice? If you provide it on your time, is it on evenings and weekends?
  - es: Why did you decide to participate in the MAiD procedure?
  - portant for you to offer MAiD in NS?
- ken any MAiD training? If so, where or with whom?
  - you joined Dying with Dignity? Have you taken their training?
- veloped or found any support systems for yourself now that you are involved Do you feel you need any additional support systems for yourself
  - e people are worried that professionals involved in MAiD will burn-out. Is a concern for you? If so, is there anything you are doing to prevent burning
- AiD mentor in Nova Scotia?
  - how did you become involved?
  - you tell me more about your role as a mentor

- 9. We've heard that some health care professionals had trouble billing for MAiD. What processes did you go through to bill for MAiD and receive remuneration?
- 10. Do you think the remuneration for MAiD is adequate and covers your costs?
- 11. What are you doing differently now in your job than you did before MAiD was legal? How has your role changed since it became legal?
- 12. Has participating in MAID changed how you think about yourself as a professional?
  - a. If so, in which ways?
  - b. If not, why do you think it hasn't changed the way you think about yourself as a professional?
- 13. Do you think participating in MAiD has changed your professional role or practice?
  - a. If so, what do you do differently in your role or practice?
  - b. If not, why hasn't your role or practice changed?
- 14. Are there any ways you think MAiD in NS could be improved or different?

# **Professional's Colleagues**

- 15. How do your colleagues feel about your being a MAiD provider?
  - a. Do you feel that the small number of health professionals participating in MAiD in NS puts an additional burden on you? If so, tell me more about that.
- 16. Do you work with different professionals or are you involved in different ways with other professionals than you did before you practiced MAiD?
  - a. If so, tell me more about which professionals you now work with and how your relationship has changed.
  - b. Some interviewees mentioned that their communication with other professionals increased quite a bit after they became involved with MAiD, has this happened to you?
- 17. Do any of your professional colleagues (either within the same profession or in another profession) participate in MAiD?
  - a. Which professions are they?
- 18. Do you know what your fellow professionals who practice MAiD are doing differently now than they did before it was legal?
- 19. Which professionals do you think should provide MAiD in NS?

# **Professional's Patient's Family**

- 20. What type of support do the families of the patient's you provide MAiD for have?
- 21. What type of support would you suggest could be most helpful for the families, both before and after MAiD?

# **Professional's Organization**

- 22. In your experience, what kinds of changes were required to implement MAiD in your practice or organization? What kinds of changes do you think your organization needs to make so that it is easier for you to participate in MAiD?
  - a. Did you have any say or input into making or implementing these changes to provide MAiD in your organization?
- 23. Can you tell me about what your organization is doing differently now than it did before MAiD was introduced?

Romeo file number 1022997. Version 03. Date: 19 February 2019

# Additional Comments, Questions or Thoughts

- 24. Is there anything that you want to talk about regarding MAiD and your professional role that we did not discuss?
- 25. If we were to expand this study across Canada, which provinces would you recommend we start with?
- 26. Do you have any questions for us about the research?
- 27. Would you be willing to send information about our study to your colleagues?

to beet terien only

# COREQ – Crumley et al.

1: Research team and reflexivity	
1 Characteristics	
viewer/facilitator	ETC and JY conducted the interviews
author/s conducted the interview or	
oup?	
entials What were the researcher's	ETC has a PhD
als? E.g. PhD, MD	JY has a BSc
pation What was their occupation	ETC is an assistant professor
me of the study?	JY is a medical student
er Was the researcher male or	Interviewers:
or was the rescarcher mate or	ETC is a woman (gender)
	JY is a man (gender)
rience and training What	ETC has conducted 120+ interviews with health
nce or training did the researcher	professionals since 2007 and published peer-
	reviewed articles with this data. She has
	completed several qualitative research courses,
	teaches qualitative methods. Her PhD was an
	ethnography.
	JY was extensively trained by ETC. With ETC,
	JY listened to all the interviews ETC had
	conducted, coded them and helped develop
	themes. He listened to ETC conducting a live
	interview, then they talked and critiqued the
	interview after. Then ETC listened to him
	conducting live interviews and they talked and
	critiqued each interview after. He also read
	qualitative methods articles.
ship with participants	
ionship established Was a	Neither ETC nor JY knew any of the participants
ship established prior to study	prior to the study.
ncement?	
cipant knowledge of the interviewer	All participants were emailed the consent form
1 0	
	which were approved by the Nova Scotia Health
	information about the researcher and why the
	research is being conducted. In her email
	signature and on her webpage, ETC has links to
	her bio, Google Scholar and CV so potential
	participants can look at these. The interview
	guide also has information about why the
	research is being conducted, which is read to all
	participants at the beginning of the interview.
ncement?	All participants were emailed the consent forr along with the research protocol guidelines, which were approved by the Nova Scotia Hea Research Ethics Board. Both documents give information about the researcher and why the research is being conducted. In her email signature and on her webpage, ETC has links her bio, Google Scholar and CV so potential participants can look at these. The interview guide also has information about why the research is being conducted, which is read to

	ETC contacted all potential participants via email and let them know that JY is a medical student who she trained. ETC then asked participants if JY could interview them, none declined.
8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	ETC is a social scientist who has conducted heal research since 1999 and interviews since 2007. Interviewees were informed of this so they were aware she did not have a clinical degree. Using H qualitative skills, she was able to ask 'naïve' and in-depth clarifying questions to participants which produced some rich descriptions and helped minimize bias.
Ó	JY is a medical student. He was able to ask 'naïve' questions and in-depth clarifying question which produced some rich descriptions and help minimize bias.
Domain 2: study design	
Theoretical framework	
9. Methodological orientation and Theory What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	The Data Analysis section explains how semi- structured interviews and thematic analyses were conducted. These analyses were informed by iterative qualitative analysis and constant comparison. Process theory informed the theoretical approach.
Participant selection	
10. Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball	Convenience sampling was used as professions contacted were on the list of MAiD assessors and providers, maintained by the Medical Affairs Advisor. The researchers do not have access to this list. Professional organizations as colleges also emailed their members the study information and participants opted to take the study. At the end of each interview, we used snowball sampling and some participants sent study information to their colleagues.
11. Method of approach How were participants approached? e.g. face-to-face, telephone, mail, email	Participants were approached via email and the study was also mentioned during video conference meetings.
12. Sample size How many participants were in the study?	32
13. Non-participation How many people refused to participate or dropped out? Reasons?	Since the study information was sent out to a line of MAiD assessors and providers which is constantly changing (clinicians join while othe leave/take a break), it is not possible to know

	how many refused to participate. At the time of article submission, there were 48 physicians and 8 NPs who assess and provide MAiD - we interviewed 12 physicians and 3 NP. Professional organizations do not track members who participate in MAiD (e.g., pharmacy or nursing college) and this number also changes frequently. Thus, we do not know the total pool of pharmacists, health administrators and nurses who refused to participate or who do not participate in MAiD at all.
Setting	
14. Setting of data collection Where was the data collected? e.g. home, clinic, workplace	Nova Scotia, Canada. Data was collected in the participant's office, interviewer's office, over the phone or via secure video (e.g., Microsoft Teams).
15. Presence of non-participants Was anyone else present besides the participants and researchers?	If the person was in their home for the phone or video interview, it is possible they were not in a private location with a closed door.
16. Description of sample What are the important characteristics of the sample? e.g. demographic data, date	Table 1 outlines the information collected about participants who were from different professions, organizations and geographic locations
Data collection	
17. Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested?	The semi-structured interview guide was pilot tested on 3 clinicians. If requested, the interview guide was provided to interviewees in advance. We used open-ended questions and also probed participants' answers.
18. Repeat interviews Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording Did the research use audio or visual recording to collect the data?	All interviews were audio-recorded and the ones in Teams were video-recorded. We only used the audio-recording for all interviews, not the video- recording.
20. Field notes Were field notes made during and/or after the interview or focus group?	ETC and JY made field notes during the interview
21. Duration What was the duration of the interviews or focus group?	Each interview was approximately 1 hour, some were up to 2 hours.
22. Data saturation Was data saturation discussed?	Yes
23. Transcripts returned Were transcripts returned to participants for comment and/or correction?	No. No participants requested to see their transcript.
Domain 3: analysis and findings	

Data analysis	
24. Number of data coders How many data coders coded the data?	SK and ETC independently coded the first 10 interviews. ETC and JY coded the next 22 interviews, the first 3 together, then divided u the rest.
25. Description of the coding tree Did authors provide a description of the coding tree?	Our process model and stages were used as the coding tree. We compared and contrasted new data to the process model, revising it as data v collected.
26. Derivation of themes Were themes identified in advance or derived from the data?	Because GG is a MAiD provider and ETC and SK had considerable knowledge about MAiD our collective knowledge helped us initially so data into different stages/themes. The process model and its stages were derived from the da All participants were sent the process model a article and offered the opportunity to provide feedback.
27. Software What software, if applicable, was used to manage the data?	Microsoft Word was used to manage the data and Microsoft Powerpoint was used to draw the process model.
28. Participant checking Did participants provide feedback on the findings?	Yes. The final process model was emailed to a interviewees inviting them to critique it.
Reporting	
29. Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	Yes. Table 2 has quotations from each provide by identifier, that illustrate MAiD.
30. Data and findings consistent Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes Were major themes clearly presented in the findings?	Yes
32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?	Yes

Page

# Standards for Reporting Qualitative Research (SRQR)\*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract	
<b>Title</b> - Concise description of the nature and topic of the study. Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	; 1
<b>Abstract</b> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2

# Introduction

<b>Problem formulation</b> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	3
<b>Purpose or research question</b> - Purpose of the study and specific objectives or questions	3
thods	

# Methods

<b>Qualitative approach and research paradigm</b> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	4
<b>Researcher characteristics and reflexivity</b> - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	4
Context - Setting/site and salient contextual factors; rationale**	4
<b>Sampling strategy</b> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	4
<b>Ethical issues pertaining to human subjects</b> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	4
<b>Data collection methods</b> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	4

		1
1	Data collection instruments and technologies - Description of instrume	ents
1	(e.g., interview guides, questionnaires) and devices (e.g., audio recorders	а — — — — — — — — — — — — — — — — — — —
2	used for data collection; if/how the instrument(s) changed over the course	
3 4		
4 5	the study	
6	<b>Units of study</b> - Number and relevant characteristics of participants,	
7	documents, or events included in the study; level of participation (could l	he 4
8	reported in results)	
9		unin d
10	Data processing - Methods for processing data prior to and during analy	'SIS,
11	including transcription, data entry, data management and security,	4
12	verification of data integrity, data coding, and anonymization/de-	
13	identification of excerpts	
14	Data analysis - Process by which inferences, themes, etc., were identifie	b
15		
16	and developed, including the researchers involved in data analysis; usual	Iy T
17	references a specific paradigm or approach; rationale**	
18	Techniques to enhance trustworthiness - Techniques to enhance	
19	trustworthiness and credibility of data analysis (e.g., member checking, a	udit 4
20	trail, triangulation); rationale**	
21		
22		
23	Results/findings	
24	Synthesis and interpretation - Main findings (e.g., interpretations,	
25	inferences, and themes); might include development of a theory or mode	l, or 5-8
26	integration with prior research or theory	
27 28	Links to empirical data - Evidence (e.g., quotes, field notes, text excerp	ots, Table 2, Figure
20	photographs) to substantiate analytic findings	
30	photographis) to substantiate anarytic findings	I
31		
32	Discussion	
32 33	Integration with prior work, implications, transferability, and	
33 34	<b>Integration with prior work, implications, transferability, and</b> <b>contribution(s) to the field -</b> Short summary of main findings; explanation	ion
33 34 35	Integration with prior work, implications, transferability, and	
33 34 35 36	<b>Integration with prior work, implications, transferability, and</b> <b>contribution(s) to the field -</b> Short summary of main findings; explanation	ion 8-10
33 34 35 36 37	<b>Integration with prior work, implications, transferability, and</b> <b>contribution(s) to the field -</b> Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of	
33 34 35 36 37 38	<b>Integration with prior work, implications, transferability, and</b> <b>contribution(s) to the field -</b> Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to	
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33 34 35 36 37 38 39 40	<b>Integration with prior work, implications, transferability, and</b> <b>contribution(s) to the field -</b> Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to	
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\*\*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

### **Reference:**

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Acad Med* 2014;89(9). DOI: 10.1097/ACM.00000000000388

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## How is the Medical Assistance in Dying (MAID) process carried out in Nova Scotia, Canada? A qualitative process model flowchart study

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## How is the Medical Assistance in Dying (MAID) process carried out in Nova Scotia, Canada? A qualitative process model flowchart study

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## Abstract

**Objectives:** The aims of this study are: 1. To create a flowchart process model of how medical assistance in dying (MAID) occurs in Nova Scotia (NS), Canada and, 2. To detail how NS healthcare professionals are involved in each stage of MAID. The research questions are: How is the MAID process carried out and which professionals are involved at which points? and Which roles and activities do professionals carry out during MAID?

**Design:** Qualitative process model flowchart study with semi-structured interviews. **Setting:** Primary and secondary care in Nova Scotia, Canada.

**Participants:** Thirty-two interviewees self-selected to participate (12 physicians, 3 nurse practitioners (NP), 6 nurses, 6 pharmacists and 5 healthcare administrators and advocates). Participants were included if they conduct assessments, provide MAID, fill prescriptions, insert IVs, organize care, etc.

Results: The flowchart process model details five stages of how MAID occurs in NS: 1. Starting the MAID Process, 2. MAID Assessments, 3. MAID Preparation (hospital in-patient, hospital outpatient, non-hospital), 4. Day of MAID and 5. Post-MAID (hospital in-patient and outpatient, non-hospital, after leaving setting). Nineteen points where the process could stop or be delayed were identified. MAID differs slightly by location and multiple professionals from different organizations are involved at different points. Some physicians and NP provide MAID for free as they cannot be reimbursed or find it too difficult to be reimbursed.
 Conclusions: Our study adds knowledge about the MAID activities and roles of NS professionals, which are not documented in the international literature. Clinicians and pharmacists spend significant additional time to participate, raising questions about MAID's sustainability and uncompensated costs. The process model flowchart identifies where MAID can stop or be delayed, signalling where resources, training and relationship-building may need

to occur. Knowing where potential delays can occur can help clinicians, administrators and policymakers in other jurisdictions improve MAID.

## Strengths and limitations of this study

- Our novel flowchart process model of medical assistance in dying in Nova Scotia, Canada outlines professionals' roles and activities, the points at which they are involved and where delays/stops can occur.
- Our findings from Nova Scotia, Canada provide an opportunity for other jurisdictions to learn how medical assistance in dying works as well as compare and contrast their model.
- As this study occurred in one Canadian province, Nova Scotia, it does not enable us to generalize the findings to other provinces or internationally.

**Keywords**: Euthanasia, Active, Voluntary; Qualitative research; Outcome and Process Assessment, Health Care; Professional Role

## Background

 Medical assistance in dying (MAID) has been legal in Canada for over 4 years [1, 2]. Although MAID includes both assisted suicide and euthanasia, most Canadians have chosen euthanasia [3]. Many of the initial *ad hoc* processes and procedures that healthcare professionals developed to implement it while professional College policies, health authority policies and processes were being developed are still being used today [4, 5, 6, 7, 8, 9]. In 2017 when the MAID process was first being set up, the press described it in the provinces of Ontario and Nova Scotia (NS), respectively, as:

"an ad hoc, scattershot mess. Policies were hammered out in email chains and over casual conversations" [10]

"We have a small set of providers, but we can't possibly keep up with the patient demand" [11].

It is difficult, however, to evaluate and improve a new health service without understanding how it is carried out. Canada's MAID criteria is currently being debated and the legislation may be expanding: advance consent for those who will lose capacity may be included and the "reasonably foreseeable" death requirement may be removed [12, 13, 14, 15]. The latest national poll found Canadians support advance consent (82%) and removing "reasonably foreseeable" (71%) in the legislation [16]. Thus, there is a pressing need to evaluate and improve the process. The objectives of this study are to create a flowchart process model of how MAID occurs and detail where and how healthcare professionals are involved in NS's process. Our research questions are: How is the MAID process carried out and which professionals are involved at which points? and Which roles and activities do professionals carry out during the MAID process?

Many of today's healthcare services are designed around interdependent roles – that is, professionals organize interdependent work around their responsibilities and activities [17]. Process theory examines the sequences and stages of activities and events as they occur [18, 19, 20]. Some processes emerge as they are implemented and may not be written down, causing an issue for quality improvement. With MAID, events such as appointments often occur in a linear fashion, that is, in a certain order, and a person requesting the service needs to meet specific criteria in order to move from one stage to another [18]. Internationally, there is little documentation about how MAID occurs, which professionals are involved at which points and how the process is organized [21]. The 8 jurisdictions that have assisted suicide and/or euthanasia, Australia (Victoria and Western Australia recently legalized assisted suicide and euthanasia), Belgium, Canada, Colombia, Luxembourg, The Netherlands, Switzerland, and 8 states in the United States [22, 23], collect descriptive statistics about number of deaths, gender, etc. However, additional data is needed to evaluate and improve the service (e.g., feedback from providers, patients and families, analyses of the process including its policy, functionality, efficiency, effectiveness, impacts and sustainability, etc.) [24].

Canadian providers and health systems are actively working to improve the MAID experiences of patients, families and professionals [25, 26, 27, 28], but it remains challenging to improve its implementation without knowing what the process looks like. Studies describing professional roles, expectations and knowledge gaps [9, 15, 29, 30, 31, 32] or how MAID was implemented [4, 5, 9, 33, 34, 35, 36, 37] provide few details about the process itself (e.g., how work is coordinated between professionals, which professional(s) do which activities and when, etc.) [14, 21, 37, 38, 39, 40, 41]. The process involved in the provision of MAID in one province can help us better understand how new health services are implemented. Our identification of gaps and inefficiencies in the process is timely given that lawmakers will be expanding eligibility

criteria for MAID, yet the number of physicians and nurse practitioners (NP) that provide it is not growing in NS [42]. National best practice guidelines and training are available [38].
Patients, health professionals and policymakers want to improve the MAID service [40, 41]. This study provides details about how the MAID process is being implemented in NS, from beginning to end, and identifies areas for improvement.

## Methods

## Design and setting

A qualitative process model flowchart study for MAID was conducted in the province of NS in Canada because MAID is centrally coordinated and the researchers reside there. As the lead researcher specializes in interviews, first-hand accounts from those involved in MAID were the most appropriate to piece together how the process occurs. Using semi-structured interviews, we asked those involved in the MAID process (e.g., assessors, providers, administrators) to describe their roles, activities and at what points they are involved [18, 43, 44].

## **Recruitment and sample**

Participants were recruited through: 1. emails to the NS MAID providers' list-serv (convenience sample), 2. emails to professional colleges, associations and organizations and 3. snowball sampling [45] by asking authors and participants to forward study information to colleagues involved with MAID.

The sample included health professionals who are involved in MAID: physicians and NP (hereafter, clinicians), nurses, pharmacists and health administrators. The study was approved by the Nova Scotia Health Authority Research Ethics Board (Study Protocol ID: #1022997) and data were securely collected and stored using the approved protocol. Participants received written study information and completed an electronic or written consent form. To ensure confidentiality, participant characteristics are presented at a group level, and quotations are anonymized by profession and interview number.

## **Data collection**

ETC collected data from 29 participants using a semi-structured, pre-tested interview guide inperson in a private location, by telephone or Microsoft Teams® [see Additional file 1]. JY, a medical student, was trained by ETC and conducted 3 of the interviews under her supervision. The interview guide was pilot tested with 3 clinicians. To obtain details about how and when they are involved and their interactions with other professionals, participants were asked openended questions about their MAID role and activities [46]. Interviewers probed participants' responses by asking follow-up questions and also made field notes. Interviews were audiorecorded, professionally transcribed in simple verbatim (e.g., um, ah and pauses were not transcribed) and stored in password-protected Microsoft Word® documents on a secure server [47, 48, 49]. As JM is the Medical Affairs Advisor (MAA), NP is the MAID Nurse Navigator (MNN), GG is a MAID provider, they were not involved in data collection to help preserve participants' anonymity. To achieve saturation, data was collected until no new information about the process was found.

## \*\* ADDITIONAL FILE 1 ABOUT HERE \*\*

## Data analysis

After each interview was completed, data were iteratively coded and checked using constant comparison during six phases [4, 18, 50]: (1) reading each interview and coding passages about MAID roles, activities and stages; (2) creating a draft flowchart process model with stages and outlining professionals', roles and activities in each stage; (3) continuing to conduct and code interviews, then incorporating new or revised information into the draft flowchart process model (drawn using Microsoft PowerPoint®); (4) inviting all participants to critique the flowchart process model and incorporating their recommendations and changes (5) finalizing the flowchart process model and (6) writing the article.

## Patient and Public Involvement

Patients and or public were not involved in this research.

## Results

Thirty-two professionals participated in 1-2 hour interviews (Table 1). Figure 1 has the process model detailing professionals' MAID roles and activities as well as the places where the process may stop or be delayed, depicted by a red octagon. Table 2 has quotes about how NS professionals' view the MAID process and their role.

Type of professional	Number (%) of participants $n = 32$
Physicians	
Family medicine	6 (18.8)
Palliative care / critical care	4 (12.5)
Emergency medicine	2 (6.3)
Nurse Practitioners	3 (9.4)
Nurses	
Hospital	3 (9.4)
Long-term care / nursing home	1 (3.1)
Victoria Order of Nurses (VON)	2 (6.3)
Pharmacists	
Community	2 (6.3)
Hospital	4 (12.5)
Health Administrators / Advocates	5 (15.6)

## \*\* INSERT Figure 1. The MAID process in NS, Canada ABOUT HERE \*\*

Logistics & scheduling "when MAID came up, I thought 'well it's legal!' people have the right to ask for this and nobody in my community was willing to provide this service. I knew that I couldn't be available to do the actual procedure, and facilitating the actual procedure of coordinating the healthcare team members there's this huge reliance on pharmacists and nursing staff and community funeral homes and so on, to be sure that the whole procedure is done properly at that time, I was one of two people who would do a MAID consultation." Physician 8	Table 2 Professionals' que	otes about the MAID process
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"I don't do IVs very often. So worrying that I was going to go to this house to do a MAID procedure and not be able to get the IV." Physician 11

"procedures can be done within a half hour to 40 minutes. I go in and have a chat with them and make sure that they still have capacity and that they know why I'm there. And if they still want the procedure. I'll say, okay,

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1	
2	
3 4	have some time with your family or whoever is there. And I'll go get my medications ready, and then I'll come
5	back and ask them again if they want me to proceed or give them that last chance to rescind." Physician 12 "there's a fair amount of phone calls and logistics. So if I've agreed to do the provision for a patient, so I've had
6	to do one of the assessments and if they've had two assessments that agree that they meet the criteria, then I
7	ask the patient to decide on a time and a place, and we talk about when and where that might be So if it's at
8	home it's easy If it's not at home, it means having a patient admitted to the hospital or going through
9	ambulatory care, then that would take phone calls and arranging I don't like to be fumbling in somebody's
10	dark bedroom with big syringes and vials and so I have a system, I get it all ready in my office. I have a plastic
11	tote and all the paperwork So, I like to have it all ready to roll and then I arrive at the patients home the
12	morning of the procedure. After the procedure I have to sign the death certificate and do the paperwork and
13	then return the unused medications to the pharmacy. So there's a fair amount of little detailly stuff." Nurse
14	Practitioner 1
15	"In our first [MAID] case a CCA [Continuing Care Assistant] had struggles We respect people's decisions
16	all of the time And so perhaps our staff are better prepared because of those autonomous choices, like we have ethical conversations around them, when people make decision to not have treatment or suspend treatment and
17	how do we support staff at that point something that we may struggle with is probably making sure the staffs'
18	schedule of that [MAID] day are aware of personal values. So if we had a Muslim RN, we have to change shifts.
19	It is being conscious of that from an administrative staffing scheduling perspective that we had thought 'We don't
20	put people in difficult situation <sup>3</sup> . Admin 1
21	"If I get a call now and somebody says there's a MAID case and they're interested in whatever date, I really have
22 23	to drop everything and try to organize the space, the date, the staff." Admin 4
23 24	"The drugs themselves are often in pharmacies, just not either in the quantity or the dosing that we need."
25	Pharmacist 1
26	Process
27	"When I'm assessing somebody, I'm usually generating the consult, right. The patient's come to me. I've seen them. I've said, okay, I'm going to be the assessor 1. Off to you guys – you find assessor #2, and, you know, deal
28	with all the rest of it." Physician 7
29	"I provide them [clinicians] basic information about the case. And then they would get back to me "I'll take
30	this case" I do the assignments of physicians to the case, forward patient information about the referral.
31	They will do the assessment and then report back to me. And I will arrange for the second assessment to take
32	place Once those assessments agree that the patient meets the criteria for the MAID, we would walk the
33	patient around the details of time, location, circumstance for the procedure. So then the procedure happens and
34	the physicians and nurse practitioners take care of the specific details relative to the location and the medication
35	protocol the procedure is completed and practitioners send the information to me and I capture that in the office
36	and then close the case." Admin 2 Relationships
37	"they're such neat patients, and their families are so neat, and the initial interview you get to know them so
38	much, you talk about their life and you get to know where their moral compass lies and what their general
39	feelings about life and death and suffering and quality are. And the family often really wants you to know and
40	love that person the same way that they do, so you get a lot of that background in a really short period of time.
41 42	And then typically I do my procedure on a different day, and so going back in to meet the family again and see
42	them for the procedure, there's often so much relief to see you and they're so pleased sometimes if the patient
43 44	has some sort of functional decline or symptom management issues in between, you've talked to the family a few
45	times to help them navigate that and make sure that their quality is maintained while they're waiting for their
46	procedure, so I think you become attached to the families very, very quickly" Physician 9
47	<b>Time and compensation</b> "When you go to see a patient, you never know if it's going to be a half hour assessment or a 2 hour assessment.
48	Physician 3
49	"Each MAID case is taking probably a minimum of 5 or 6 hours of time. That's 5 or 6 patients that I could see
50	in that time. So we were never resourced to consider taking on MAID. And that's probably the most practical
51	issue." Physician 5
52	"the procedure itself is fairly quick once everything is set up. But generally it takes hours in order to go through
53	this very personal process with this individual. Sometimes they're very straightforward. Other times You
54	know, I've heard stories of very elaborate events that have been planned around medical assistance in dying I
55	am astounded and I'm stunned by the clinicians that will do this on a regular basis and take hours and hours and
56	hours of their personal time." Physician 6
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59	For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml
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"about 5 to 7 hours. And that [putting together first MAID kit] was over several days. And that was a process of, you know, calling places, calling the other pharmacy, finding the drugs, calling our wholesaler to find out if we're ordering the right ones, data entering the information, getting the bins together, you know, with labelling. Making sure we have a spot in the fridge. Making sure all of our staff are aware. Like it was a very time-consuming endeavour." Pharmacist 2

#### **Policy & legislation**

 "I went out and I got the [MAID] policies ... But there was no meaning in them. But once we had the [MAID] requests, I had two months. But I had already written the paper and I had already kind of went through all of that. ... I just basically stole the policies and procedures from [location] and [location] and another [location] and put them all together. ... The mechanics weren't the important thing. It was getting the fact sheet right and getting to that audience, that you could talk to them in their language. ... For me it was the relational piece that was more important than the mechanics." Nurse 1

"I think Canada can have the absolute best assisted dying regimen in the world. We can show people how it can be done, how it can be done well. And we just need to make some changes to do that. ... I'm in a transition in the sense that I have to recognize there's some things that are my wheelhouse and there are a lot of things related to this [MAID] that are not my wheelhouse and I need to let others do it, right. For a long time I was pretty alone in this field, trying to make this change. And so you just feel like, "Oh, it's on my shoulders. I've got to keep going, I've got to keep doing it". And at the first CAMAP [Canadian Association of MAID Assessors and Providers] meeting, it was the most extraordinary feeling because I was ... with all these people and this is what they do. And it was this incredible sense of relief and release and a sense of okay, you know, this is in good hands. ... So now what I try and focus on are the things that I can do. ... there's an issue right now of whether nurses can raise the issue. ... Or the faith-based institutions, publicly funded faith-based institutions ... there's a way in which it's my wheelhouse" Admin 5

#### Role

"I've been involved with MAID two more times. ... I don't want to do the second assessment. .... I did it [once], and I am okay with that. And I don't have any moral distress with it. Even though I get choked up about it, it's only because I remember the patient, and I remember how deeply I felt about [them] and helping [them] die comfortably. ... if we're going to be providers, we have to help people get access to what they want, even if we, because of our beliefs, our faith would not do that ourselves. ... I wouldn't want to go any deeper down a road than first assessment..." Nurse Practitioner 2

"As a nurse, I can't push those drugs. I can't order the drugs. I can't go and get the drugs. I can't push the drugs. So I am there as a patient support and a family support." Nurse 4

"Technicians are not involved with this [MAID prescriptions] at all. ... So other orders, ... I send pretty much through the system to the technicians to say send this to the floor. ... And then the technicians take it from there. With the MAID, it's 100% pharmacist-run. So we enter the prescriptions that were ordered and then we're picking up the labels, we're packaging it up and we're checking it. ... Let's just say I'm the pharmacist who checked it [MAID prescription]. ... Usually it's the clinician who picks it up but there are a few options. But because we can't leave the dispensary, usually the clinicians are okay to come and get it. And then there's additional information we need to provide, education ... and basically we go through the medications." Pharmacist 5

#### Secrecy & privacy

"we were under the impression that we weren't supposed to be sharing the fact that we are participating in it with coworkers and things like that. So there's not a lot of ... interprofessional support. And we were encouraged to do that just because they didn't want the public knowing like where things were taking place ... it was presented to us as like, "Well, there might be a death notice in the paper and someone might put together that you just participated in this thing. So that's what that family chose. So it's really important to not tell anyone that you...because their decision needs to be kept private." Which I understand. But it does make it difficult to process." Nurse 5

"So basically what we were told when MAID became law was that if patients voiced wanting more information about it, you know, we don't really have an opinion per se because... You know, I don't know if my coworkers are for or against." Nurse 6

"I also regard it [MAID] as a very private confidential process. And I know we've really struggled with that in the distribution side ... whether it should be at a higher level of confidentiality than everything else we do. And everything we do is confidential. But if one person is handling a MAID, do all 5 pharmacists in the dispensary need to know about that MAID? ... clinically I am not required to counsel the patient. They haven't asked me to do that, and they didn't, you know, tell me of this decision. That may have been the intent, you know. But at the

same time ... it's part of the therapeutic plan that wasn't well documented like every other process that we work on as a team is." Pharmacist 4

#### 1. Starting the MAID Process

Patients explore MAID for many reasons [37, 51, 52, 53] and often find out about it through the media, Dying with Dignity (DWD), a "national human-rights charity committed to improving quality of dying, [and] protecting end-of-life rights," [54] or the Nova Scotia Health (NSH) website. When they are exploring MAID, NS patients may do their own research, call the MNN or visit a clinician (e.g., family clinician, surgeon, nurse practitioner) to obtain more information. The clinician may give a patient MAID information or send a patient referral to the MNN. Some patients may first seek information about MAID, then visit a clinician again for a MAID assessment referral. If the clinician has a conscientious objection or is not comfortable participating in MAID, they will transfer the patient to another clinician, send a referral to the MNN or ask the patient to contact the MNN. If the MNN does not receive a referral, they will follow-up with the clinician. One physician suggested this could be improved by having "a self-referral system. And it doesn't need to involve family doctors." An administrator also noted that:

"My biggest concern is there are people who want MAID but they are unable to access the system because the doctors won't put their names forward. We have had phone calls of people that said my doctor won't refer so we had to call them [doctor] back and explain that there is a duty to transfer the name of a patient requesting and they shouldn't disallow the request to occur." (Admin 3)

The MNN's role is central. As paperwork or phone calls are received, the MNN contacts the patient for an intake interview to explain the MAID process, offer support, explain resources (i.e., palliative care, home care) and seeks to understand the patient's goals. The MNN may email or mail the patient information (e.g., Advanced Directive Guides, MAID and Palliative Care information). The MNN sends MAID documentation (e.g., referral, nursing intake notes, clinical notes) to assessing clinicians. The MNN remains in contact with the patient, family and their circle of care throughout the process. One administrator detailed the process:

"Referrals come in typically from family doctors but occasionally specialists ... the patient arrives at a point where they are considering MAID as an option and discuss that with their physicians ... So the physicians would make referrals to this office [MNN]. It's generally faxed to us ... And I get the referral. I'll capture the basic patient information that is required as part of our reporting to the federal government. ... and then inform the MAID provider team. ... a group of physicians, nurse practitioners ... who do the assessments and perform the procedure. ... through an email. (Admin 2)

At any time, patients may decide not to continue with MAID and pursue options such as palliative care; patients may pursue multiple options simultaneously. If the clinician the patient initially visited will not do the first MAID assessment, the patient or clinician contact the MNN who helps streamline and organize the process. As discussed in the quote above, the MNN then emails the NS MAID list-serv to request assessors. Finding assessors may take time due to the small number of NS clinicians who participate in MAID, their lack of time and/or their inability to travel. Some clinicians will only assess their own patients but do not provide MAID. Some clinicians about how the process works. As one nurse practitioner said "I only bring up MAID if they ask me about it. Like if a patient comes in and wants to know about MAID, I'll explain it."

If a patient mentions MAID to staff, they will refer the patient to a clinician, the MNN or a manager in their facility.

Although clinicians and the MNN prefer the MAID consent form is signed after the first assessment, some patients download it from the NSH website and sign it in advance. As patients are often quite ill, they may have difficulty finding two independent witnesses to observe them signing the MAID consent form. To find independent witnesses, the MNN will contact DWD which has a national network of volunteer witnesses. If the MAID consent form is not signed before the first assessment, the clinician will give it to the patient. Two physicians shared their experiences with consent:

"I go through the consent and kind of the little conundrums or difficulties with getting consent" (Physician 10)

"Sometimes the patient has signed their request. Other times they're waiting and trying to get witnesses lined up. So most times when I'm involved, I've assessed them, I'm usually not there when witnesses are signing. But they're making the request." (Physician 7)

Delays can happen if patients have to wait for an appointment with a clinician to discuss MAID. If a patient initially meets with a non-MAID provider or conscientious objector, they have to be referred/transferred to another clinician and make another appointment, which could delay their Assessments. A common delay is finding two independent people to witness the consent form signing.

#### 2. MAID Assessments

The clinician arranges the patient's first MAID assessment and continues communicating with the MNN. This assessment can occur in the patient's home, hospice, hospital, nursing home or clinician's office. Assessments can take 45 minutes-5 hours depending on the location and the case complexity. As one physician described:

"if it's an in-house assessment, I'll schedule it for the late afternoon/evening, like starting at 4:30 or 5:00. And then it goes until about 6:30 or so." (Physician 12)

The first assessor discusses the MAID process with the patient (and their family and/or supports, depending on the patient's wishes), including legislation, criteria and timeline. The clinician also provides the patient with the College of Clinicians and Surgeons of Nova Scotia Professional Standard Regarding Medical Assistance in Dying. The clinician completes the MAID assessment form, sends it to the MNN and may dictate notes for their records:

"I had no difficulty whatsoever doing the ... MAID 1 or MAID 2 [assessment]. And then I was having the conversations, discussing if the people met the criteria as outlined by our licensing body in Nova Scotia, and ... completing the paperwork." (Physician 8)

"so there's the assessment piece, we have a checklist form that we fill. But it doesn't give enough history. So most of us will dictate a note. ... Both assessments and the consent all have to get copied and sent into the central office for MAID. So they have to have a record of it. Which is nothing but it's still paperwork that has to happen." (Physician 3)

If the first assessor finds the patient is not eligible for MAID, the patient may ask the MNN to arrange a second and third assessment. If the second and third assessors indicate the patient is

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ineligible for MAID, the process is finished in NS. Although it is more rare, some patients may go to another province or country to be assessed for assisted dying or euthanasia eligibility.

If the first assessor indicates the patient is eligible for MAID, the MNN or clinician arranges the second assessment. The second assessor often provides or reviews the consent form, returns their assessment form to the MNN and may dictate notes. If both assessments indicate the patient meets MAID criteria, the patient decides when MAID occurs – it could occur hours, days or months later. Sometimes, neither assessor provides MAID, the patient decides to wait, the original assessors are not available or the patient requests MAID during a busy time (e.g., summer or December). If MAID is delayed for a significant amount of time or another provider is needed, the MNN helps find a provider to re-assess the patient to ensure they still meet MAID criteria. When patients decide to wait, the MNN checks in with them and receives regular updates from their circle of care. The MNN keeps relevant health care providers informed about the patient's goals and health status.

Numerous delays can occur or the process could end during this stage. If the two assessors do not agree a patient meets MAID criteria, a third assessment will be done. The process stops if a patient does not meet MAID criteria, dies, changes their mind or loses competency. As Physician 11 describes, the 10-day waiting period can be waived for patients about to lose capacity or their imminent death and MAID will be provided before the 10 days have passed:

"two days after the [MAID] Assessment, the family phoned and said, "Come now. You know, he's starting to get confused." ... And then there was a brief ... kerfuffle getting the other assessor to agree to move it up, and scrambling to learn how to get the drugs from the drugstore. And tried to get the VON in, and it being too late - the nurses do the IV. And then going and stealing IV equipment from the emergency department. (Physician 11)

If the first or second assessor cannot provide MAID, it may be delayed while the MNN finds another provider, who then may need to re-assess the patient.

#### **3a. MAID Preparation – Hospital In-Patient**

For in-patients, the clinician and MNN ask hospital staff (e.g., a nurse manager, nurse director) to find a private room and a nurse comfortable with inserting the 2 IVs for MAID, one to be used and one back-up. The 2 IVs are usually inserted by a hospital nurse who also gathers supplies (e.g., syringes, needles, IV solution, IV pole, tubing, etc.). The clinician alerts the hospital pharmacy about the upcoming procedure and sends a pre-printed MAID order (PPO). If the hospital does not have a pharmacy, the pharmacy does not have the medications or the pharmacist(s) will not fill the PPO, the MNN and/or clinician will coordinate the MAID medications with a community or another hospital pharmacy. The other pharmacy may courier medications to the hospital. Two to five pharmacists fill the MAID PPO which is time-consuming for several reasons: shift changes (i.e., the MAID PPO may be partially filled when the shift changes), MAID PPO are filled in-between regular work (i.e., another pharmacist may take over the PPO if the other one is busy) and the two sets of medications need to be double-checked according to pharmacy protocol. [51] Because NS pharmacy technicians cannot fill the MAID PPO, this results in additional work for NS pharmacists:

"the biggest thing is actually doing the collecting of the drugs. ... I would never be the one to go and collect the drugs and ... put them together in the bags. That would usually be a technician job after a pharmacist okayed the order and felt comfortable with it, and said, "Okay, these are the drugs that we're using. Proceed with this." But in this step [MAID PPO], we're actually the ones who are collecting the drugs as well. ... we do keep everything [MAID medications] like actually in a box. So we don't have that initial like trying to make sure that the drugs are appropriate. We do have them for when MAID orders do come up. So we have them separated." (Pharmacist 3)

The time to fill a MAID PPO is significant and pharmacists receive no additional compensation (i.e., community pharmacists receive a small dispensing fee but hospital pharmacists do not):

"I can do a regular order in probably 20 seconds, depending how easy it is. A MAID can be like well over an hour." (Pharmacist 6)

Two MAID medication kits are prepared in case anything unforeseen occurs (e.g., broken bottle). Clinicians typically pick up the medications 24-48 hours after the PPO is submitted, but pharmacies may make exceptions for urgent cases. For patients preferring anonymity, a ghost/shadow chart may be used to conceal their identity.

## **3b. MAID Preparation – Hospital Out-Patient**

A nurse manager, charge nurse, facility lead or MAID provider helps ensure out-patients are registered and admitted, a location is identified and staff are coordinated. Some hospitals have specific wards or rooms for MAID out-patients after hours since these are often used during the day:

"we have a place ... if people want to just come in and have it [MAID] done in hospital. So we've done a number that way as well. ... We tend to do it after hours. We have a clinic area that's got some nice rooms. And so we tend to do it after hours when they're not busy. And it's a nice room. Families can be there." (Physician 3)

A hospital nurse often inserts the IVs and gathers MAID supplies; an anesthesiologist may insert the IVs. The MNN may provide support and MAID education to ward staff. The same pharmacy processes and ghost charting occur as in 3a MAID Preparation – Hospital In-Patient.

## **3c. MAID Preparation – Non-Hospital**

MAID may also occur in the community (i.e., a patient's home), long-term care, nursing home or a hospice. A lot of coordination and steps are involved:

"If somebody was at home ... I would send the prescription in to the [community] pharmacy, call the pharmacist and make sure it was received. I would fax requests into VON for the IV's to get inserted the day of the planned procedure. ... I would coordinate this with the patient and their family to make sure that the time and place was all arranged, and they wanted to go ahead. I would pick up the medications at the pharmacy, I would usually prepare them here in my office so that when I arrive at the patient's home everything is all drawn up." (Nurse Practitioner 1)

The clinician and MNN often work together to contact Continuing Care (i.e., the Victoria Order of Nurses) to insert the IVs. A VON nurse manager will find a nurse who does not have a conscientious objection to inserting the IVs. One nurse described the IV:

"It's not a simple IV. It's not a little tiny one. You have to be able to... to put an IV in that is as big as an anesthetist would use. So big. (Nurse 3).

Typically, MNN sends all the MAID docs to VON and confirms they can meet the need. A VON manager provided details:

"when we get a referral come in for MAID ... we break it down into 4 areas, there's a nurse manager for each area. So we take the referral and work with Continuing Care to ensure that ... the consents are there, that we have everything we need. And then we go through the client's schedule ... to find a nurse that has been there the most so that we can have somebody that the client or the family knows. And then we reach out to the nurses to see if they are willing to participate. Because it's their choice to do it. And I'd say probably 60% are willing." (Nurse 2)

The clinician coordinates the medication order with a community pharmacy and may discuss further with a pharmacist unfamiliar or uncomfortable with MAID. One to three pharmacists prepare and double-check the two MAID medications. The clinician usually picks up the MAID medications 24-48 hours later. If the pharmacy does not have MAID supplies and the clinician may obtain these from their hospital or facility. The MNN and MAA are currently working on making MAID kits available for all clinicians.

In stage 3, there may be delays if a nurse cannot be found to insert the IVs or the hospital pharmacy will not fill the PPO. The clinician or MNN may need to coordinate with another pharmacy or find a willing pharmacist. MAID may be delayed

## 4. Day of MAID

Depending on where MAID is occurring, the MAID process can take several hours:

"some of the cases are straightforward. You know, it's in the hospital, you go in, the assessment takes an hour, you come out, you give the order to the pharmacy, the nurse is ready, you come back for the procedure, it takes an hour. ... But some cases, especially if they're at home or they're in the periphery, are very complex. ... you have to be coordinating with VON to get the IV set up and the pharmacy – which has probably never had to organize the medications. And then getting back and forth with the patient as they sort of progress and checking in on how they are. ... And then the driving" (Physician 2)

The clinician picks-up the MAID medications from the pharmacy and gathers supplies. They may drive to the patient's location and, in some cases, fly or walk. Some may participate in religious services, celebrations of life or farewells before or after MAID, but not all clinicians are comfortable with this. As one physician recounted:

"the procedure takes about 15 minutes. That's the actual giving of the medications. But between getting the medication...picking up the medications, drawing everything up, getting yourself ready to do the procedure, going in, seeing the family, making sure they're all set and ready to go, it usually takes about two hours or so. ... Sometimes you go in and ... they don't want to chat, they just want to go and get it done. And so they don't take as long. I had one situation where I walked in and there was a party going on in the house. And I said, "I'll go down to the back room," where they wanted me, and I waited for two hours before the patient came into the room, and then performed the procedure." (Physician 10)

Where possible, a nurse (or clinician) inserts the two IVs close to the procedure time to decrease having to reinsert them in dehydrated and very ill patients. IVs are not placed in patients with

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central (Hickman) or PICC lines. A VON nurse inserts IVs in long-term care. The nurse may stay for the procedure, if they are comfortable, if the patient/family wants them there and/or they have time. Some nurses will return for the procedure if the IVs are placed earlier. Hospital nurses often arrive 1-2 hours before the procedure and stay with the family and body after MAID.

The clinician will draw up the syringes with medications (Table 3). After determining the patient has the capacity to request MAID, the clinician explains the procedure including: what each medication does (if the patient wishes to know), the dying process and potential medication responses (i.e., twitching). The clinician asks the patient if they wish to have MAID. If the patient says no, MAID does not occur. If the patient says yes, the clinician administers the medications over 10-15 minutes. If a patient does not have the capacity to consent to MAID, the procedure does not occur, although this may change with the revised legislation.

Table 3Medications used for MAID in NS

- 1<sup>st</sup> medication, a sedative to help relax the patient. The patient typically falls asleep in 30-60 seconds.
- 2<sup>nd</sup> medication, a numbing agent to prevent the patient from feeling any vein discomfort from the subsequent medications.
- 3<sup>rd</sup> medication, a coma-inducing agent.
- 4<sup>th</sup> medication, a muscle relaxant which stops breathing and heart function. It usually takes 2-6 minutes to stop the patient's heart.

A clinician may be delayed picking up the prescription if MAID is being rushed or a participating pharmacist cannot fill it. This can affect when the clinician arrives for the provision. How the clinician travels to the MAID location can also delay the process, especially if they are flying or driving. The MAID process can be stopped if the patient chooses not to have MAID or if the patient has lost capacity and cannot consent to the procedure. One physician described their time and compensation:

"With an assessment and the charting and the procedure is probably about ... 6 to 8 hours of work in a month. ... it depends on the case too. Some are more straightforward than others. I would say it's about 8 hours of work. So I'd have to fit that in on weekends and evenings. ... But then the actual billing code right now, it's still capped at 2 hours for an assessment and 2 hours for a procedure. And almost all of my procedures have been longer. So I've just chosen to bill for 2 hours of my work and the rest is not paid." (Physician 1).

## Another physician talked about being flexible:

"When you go to do the procedure, it could be a 15 minute procedure and done, it could be multiple hours. So you sort of have to be willing to be flexible... have to make sure that whatever you had booked after you might not get to and you might get there – it just depends." (Physician 3)

#### Some NPs have had a different experience:

"sometimes I'll do this on my off time. I try to include it in my day. My manager is very supportive of me doing this. ... I went ... to see a case, which is an hour away. But I do get reimbursed for my expenses. Mind you, it did take me a year to get my travel claim figured out.... The doctors get paid for doing this. The nurse practitioners don't. ... I think they're trying to lobby to get us paid. Like we get paid for our travel expenses. So I

can send that in. But I know the physicians bill for doing a MAID case, like doing assessments. But we don't get paid. I mean you know, I'm going all hours of the day, the weekends, right." (Nurse Practitioner 3)

## 5a. Post-MAID – Hospital In-Patient or Out-Patient

The clinician records the medications and time given, the patient's time of death and completes the death certificate. The clinician and/or nurse may wait with the family, participate in a family event or leave. Ward staff follow the protocols for post-mortem care and, although this may not be the usual process in many organizations, may contact security to transfer the body to the morgue. Or, the family may contact a funeral home to remove the body from the floor. The death certificate goes with the body. A manager or the hospital may provide staff debriefing. There may be delays waiting for the funeral home or security to collect the body, especially if they were not notified in advance of the death:

"If you're doing them [MAID] in hospital after hours, we have to actually ask for security to come and take the body away. Or if you're at home, sometimes the family is not comfortable waiting there with the body themselves until the funeral home comes. So you have to hang around with them. We had one time here where the family did not want the body to go to the morgue. They didn't tell us that beforehand. ... We had to wait 3  $\frac{1}{2}$  hours for the funeral home to come and pick the body up." (Physician 3)

## **5b.** Post-MAID – Non-Hospital

The clinician records the medications and time given, the time of death and completes the death certificate. The clinician and/or nurse may wait with the family, participate in a family event or leave. At home, the family will contact the funeral home to remove the body. In long-term care, the family, security or staff arrange for the funeral home to collect the body. The death certificate goes with the body. The family may want to spend time with the body before calling the funeral home and/or may not have notified the funeral home in advance, which can lead to lengthy delays.

## 5c. Post-MAID After Leaving Setting

The clinician documents the procedure and sends the MNN information including people present, medications given and dose, times the medication was pushed, time of death and notes about the procedure and/or family difficulties. They return all used and unused medications to the pharmacy, input information into the national MAID database online and may dictate notes. Some clinicians debrief with colleagues. Clinicians may bill Medical Service Insurance (MSI) up to 8 hours for MAID assessments and procedure. Clinicians send travel expenses to the MAA who submits these to NSH for reimbursement. Nurses are usually paid overtime by their organization and typically debrief with a nursing manager/director but not always. The MNN collects and submits MAID statistics to the NSH and follows-up with the family, sometimes connecting them with community supports. The MNN and MAA collect and save MAID documentation and the MNN closes the case.

The pharmacy or practitioner disposes the used MAID medications. Some hospital pharmacies store and re-use the backup medications if they have not left their premises. Other pharmacies discard both sets of medications as they do not know how and where the medications were stored, what conditions they were exposed to, who they might have come into contact with, etc. One pharmacist detailed what happens with the medications:

ETC: "So how would the physician or nurse practitioner dispose of what they had used?" Pharmacist 3: "That would go back to whatever their typical disposing protocol would be. There shouldn't be any leftover drug, I wouldn't think. So it would probably just need to be disposed of the vials and the packaging and that type of thing. So for us, we're only taking back drugs that haven't been opened or used at all." ETC: "And then what happens on intake of the [MAID] kit?" Pharmacist 3: "We would just put it back. We would just disassemble the kit, put the drugs back. Except for one that's refrigerated that we have to dispose of. ... It would only be stable for 30 days or so [after leaving the pharmacy]. ... We would just dispose of it."

There may be delays with the physician entering data into the national registry and returning the MAID medications to the pharmacy. It takes them time to submit billing and travel reimbursement information and to receive reimbursement from NSH and MSI. Some clinicians have never been reimbursed for time or travel.

#### Discussion

This study's flowchart process model indicates how multiple professionals work together and are involved at each stage of MAID [17, 18, 19, 20]. Clinicians, mainly working evenings and weekends, assess patient eligibility, write and pickup prescriptions, gather supplies, and organize and provide MAID. Some clinicians are reimbursed, while others are not (e.g., depending on their contract, some NP cannot be reimbursed for MAID and must participate outside working hours; some physicians provide MAID for free outside working hours). To compare, Medicare in Oregon pays for assisted suicide for terminally ill people with low income but does not specify who pays the physician for participating (e.g., insurance companies) [55, 56]. As well, physicians in the Netherlands are compensated by the patient's insurance company but Belgian physicians do not receive compensation [57]. US patients pay from \$0-\$8000 USD and there may be additional fees for medications, mileage and complex procedures (personal communication, Dr. Lonny Shavelson, 2021). UK patients having assisted dying in Switzerland pay between £6500-15000 [58]. In Switzerland, physicians receive their regular wage and provide assisted dying during regular work hours (personal communication, Dr. Erika Preisig, 2021). In Australia, physicians receive fee-for-service and provide assisted dying outside of regular work hours, typically in the patient's home (personal communication, Dr. Alida Lancee, 2021). Nurses, often being paid overtime, support the patient and their supports before and after the procedure as well as insert IVs. Health administrators organize the process as part of their workload. Pharmacists, within regular work hours, fill prescriptions and dispose of medications after MAID. The process differs slightly by location and in-patient/out-patient status. We identified multiple points where MAID could be delayed or stopped [19].

Some NS processes were similar to others such as having a central coordinator, a variety of professionals being involved at different stages and MAID being available in multiple locations [9, 30, 31, 33, 36, 37, 59]. Some Ontario regions coordinate MAID centrally [4, 5]. Other processes were different such as not having a centralized pharmacy, clinicians making arrangements with patients and fewer health professions are involved (e.g., no social workers, spiritual advisors, psychologists) [30, 60]. Most MAID assessments and procedures are conducted on evenings and weekends, outside regular hours. Nurses are paid overtime for participating in MAID, unless it is during their regular shift [37]. Some of our clinicians considered MAID "volunteer work", since setting up billing codes and coordinating government and insurance payments can be difficult [35]. Many devoted significant amounts of, mainly unpaid, time coordinating MAID but did not consider this sustainable [35, 36]. NS could learn

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from other provinces, including Manitoba where a single MAID team serves the entire province [61].

Our clinicians learned to ask about family dynamics to prevent difficult situations, such as arguments on the day of MAID or a wrongful death lawsuit. Thus, including spiritual providers, social and mental health professionals, psychiatrists and psychologists could be beneficial [4, 9, 30, 60, 61, 62]. Along with offering support, inserting the IVs and documenting the process, our nurses want to meet patients and their supports before the day of MAID to get to know the person having MAID and in case there are family issues [30, 63]. Pharmacy technicians in NS cannot prepare MAID medications [64], thus pharmacists incorporate an additional 1-5 hours into their regular workload. This is unusually long to fill a prescription. The Northwest Territories, Manitoba and Alberta have dedicated MAID pharmacies [65]. Pharmacists do not provide MAID supplies (e.g., tubing and syringes) and some clinicians scramble to collect or "steal" supplies from their workplace. Some regions provide supplies with the MAID medications [4] but some do not.

**Limitations**. This study occurred in one Canadian province, thus we cannot generalize to other provinces or internationally [66, 67]. However, the results could be helpful to other jurisdictions seeking to evaluate and improve MAID. Although this study has a smaller sample size for each group of professionals [68], we continued recruiting until no new information was found (i.e., data saturation). To address sample and selection bias, as self-selected participants may not represent the views of all professionals [45, 68], we recruited across the province from different professionals during different times of the year.

**Implications for clinicians and policymakers**. This study builds on MAID research [3-6, 26-28, 30-32, 34, 48, 61] by detailing the process in NS from beginning to end. Our findings about the roles and activities of professionals could help inform MAID practice in the rest of Canada and internationally. We identified issues such as clinicians' additional time to pick up and drop off medications, travel to the patient, input data and bill hours. Other jurisdictions may consider the benefits of centrally coordinating communication between professionals and administrators to avoid miscommunication or missed communication.

Our identification of delays/stop points and resources are high priorities for improving MAID. Delays and stop points can limit patients' access to and receiving MAID. Resources include professionals' time and supplies. Providing assistance to set up reimbursement codes and processes could save clinicians' from using personal time without compensation. Having centralized coordination and a central pharmacy providing a MAID kit with medications and supplies are vital to help ensure delays are minimized and resources are used efficiently. If professional colleges allowed pharmacy technicians to assist with MAID prescriptions, this would significantly reduce pharmacists' time. Pharmacists' professional colleges should be concerned since their professionals are not compensated for hours of additional work to prepare and dispose MAID medications.

**Future research**. This study contributes to research about healthcare process models. Future researchers could compare and contrast process models from other jurisdictions with this study [18, 45] which could be used to improve MAID internationally. To better understand each profession's contributions to and time for MAID, researchers could conduct participant observations to detail what they do throughout the process. Studies reveal a wide variety of professionals participate in MAID [3, 8], hence conducting interviews with them could provide further insights into the process. Since patients and their informal supports are involved throughout MAID, their insights could be added to improve the flowchart process model. As many jurisdictions are integrating patient-centered care, MAID administrators should consider the value of incorporating this approach.

## Conclusion

This study adds knowledge about the variety of activities and roles that multiple professionals have throughout the entire MAID process in Nova Scotia, Canada - these have not been studied in the international literature. Clinicians spend significant time to participate in and coordinate MAID. There are serious questions about the NS model's sustainability due to potential for burnout and clinicians ceasing to provide MAID since the model relies on them working additional (uncompensated) hours on evenings and weekends. Issues could also be raised about the ethics of sustaining a volunteer model which depends on unpaid work, personal time and inefficient workflow. The Nova Scotia College of Pharmacists should consider allowing pharmacy technicians to help prepare MAID medications as pharmacists also spend significant time preparing and checking MAID PPO. Our identification of where potential delays can occur can help clinicians, administrators and policymakers improve MAID and be of interest to other jurisdictions implementing it. Leitung ...

## Footnotes

**Author contributions** ETC and SK conceived, designed, drafted and wrote the article, JY, GG, JM and NP critiqued, revised and edited it. All authors read and approved the final manuscript.

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Provenance and peer review Not commissioned; externally peer reviewed.

**Data sharing statement** We do not have ethics approval to make raw data from this study available for sharing.

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Word count: 4898 words

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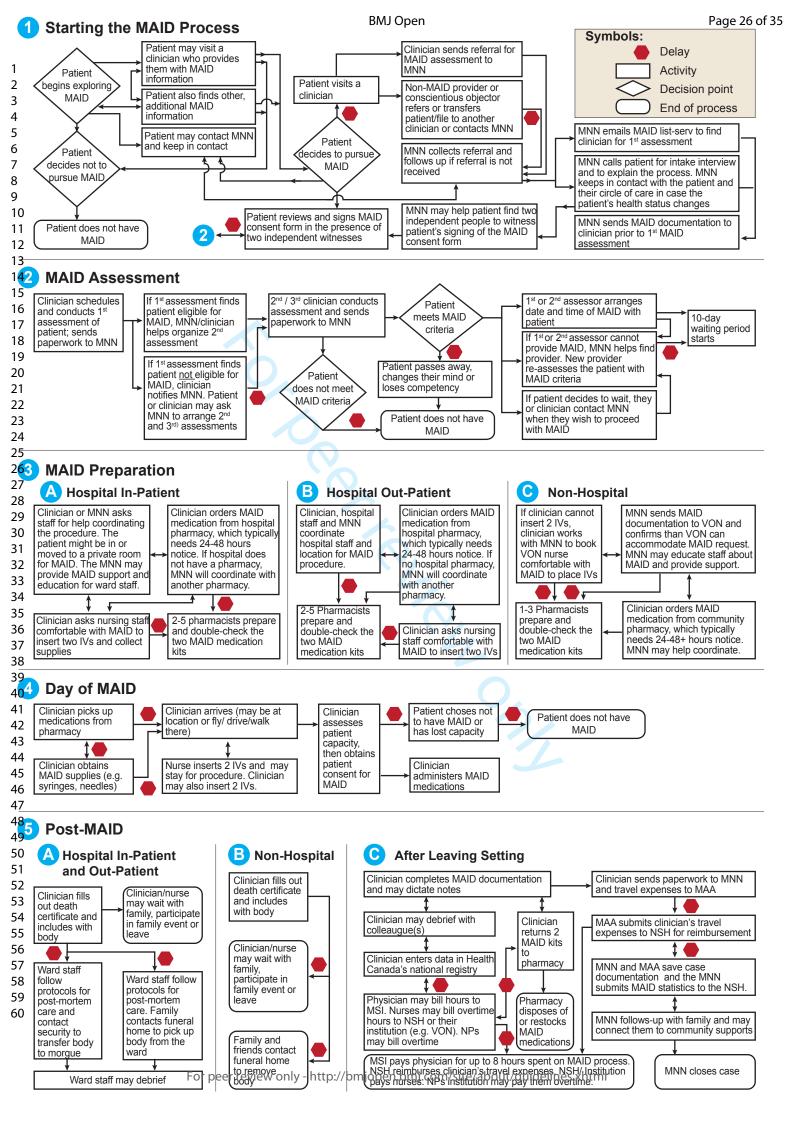
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## **Interview Guide**

Version 3 – 19 February 2019

nding more about your involvement with medical assistance in dying, MAiD; d your practice and your perceptions of yourself as a health care provider. I ) from your point of view.

now that you are freely able to withdraw your consent at any time and you inswer any questions you are not comfortable with. Do you have one hour lk with me?

## al Role

- ibe what you currently do as a physician / pharmacist / nurse / health care or (or in your job).
- ut how your role came to include MAiD. or How did you become involved
  - n did you start assessing MAiD patients and/or performing MAiD?
- MAiD procedures have you been involved in since you started?
  - your patients play a role in your getting involved with MAiD?
  - the MAiD patients you have been involved with your own patients or patients know well and see regularly?
- ime a month do you spend participating in MAiD and assessments?
  - you thinking about expanding the time you spend on MAiD assessments and edures?
  - ou travel to provide MAiD? If so, how far and how often?
  - re have your MAiD assessments and procedures occurred: at patient's home, ospital, your office, other?
  - do you set up MAiD assessments and procedures with nursing, pharmacists dministrators? Does anyone help you with this?
  - do you schedule MAiD into your current practice? If you provide it on your time, is it on evenings and weekends?
  - es: Why did you decide to participate in the MAiD procedure?
  - portant for you to offer MAiD in NS?
- ken any MAiD training? If so, where or with whom?
  - you joined Dying with Dignity? Have you taken their training?
- veloped or found any support systems for yourself now that you are involved Do you feel you need any additional support systems for yourself
  - e people are worried that professionals involved in MAiD will burn-out. Is a concern for you? If so, is there anything you are doing to prevent burning
- AiD mentor in Nova Scotia?
  - how did you become involved?
  - you tell me more about your role as a mentor

- 9. We've heard that some health care professionals had trouble billing for MAiD. What processes did you go through to bill for MAiD and receive remuneration?
- 10. Do you think the remuneration for MAiD is adequate and covers your costs?
- 11. What are you doing differently now in your job than you did before MAiD was legal? How has your role changed since it became legal?
- 12. Has participating in MAID changed how you think about yourself as a professional?
  - a. If so, in which ways?
  - b. If not, why do you think it hasn't changed the way you think about yourself as a professional?
- 13. Do you think participating in MAiD has changed your professional role or practice?
  - a. If so, what do you do differently in your role or practice?
  - b. If not, why hasn't your role or practice changed?
- 14. Are there any ways you think MAiD in NS could be improved or different?

## **Professional's Colleagues**

- 15. How do your colleagues feel about your being a MAiD provider?
  - a. Do you feel that the small number of health professionals participating in MAiD in NS puts an additional burden on you? If so, tell me more about that.
- 16. Do you work with different professionals or are you involved in different ways with other professionals than you did before you practiced MAiD?
  - a. If so, tell me more about which professionals you now work with and how your relationship has changed.
  - b. Some interviewees mentioned that their communication with other professionals increased quite a bit after they became involved with MAiD, has this happened to you?
- 17. Do any of your professional colleagues (either within the same profession or in another profession) participate in MAiD?
  - a. Which professions are they?
- 18. Do you know what your fellow professionals who practice MAiD are doing differently now than they did before it was legal?
- 19. Which professionals do you think should provide MAiD in NS?

## **Professional's Patient's Family**

- 20. What type of support do the families of the patient's you provide MAiD for have?
- 21. What type of support would you suggest could be most helpful for the families, both before and after MAiD?

## **Professional's Organization**

- 22. In your experience, what kinds of changes were required to implement MAiD in your practice or organization? What kinds of changes do you think your organization needs to make so that it is easier for you to participate in MAiD?
  - a. Did you have any say or input into making or implementing these changes to provide MAiD in your organization?
- 23. Can you tell me about what your organization is doing differently now than it did before MAiD was introduced?

Romeo file number 1022997. Version 03. Date: 19 February 2019

## Additional Comments, Questions or Thoughts

- 24. Is there anything that you want to talk about regarding MAiD and your professional role that we did not discuss?
- 25. If we were to expand this study across Canada, which provinces would you recommend we start with?
- 26. Do you have any questions for us about the research?
- 27. Would you be willing to send information about our study to your colleagues?

to beet terien only

## COREQ – Crumley et al.

1: Research team and reflexivity	
1 Characteristics	
viewer/facilitator	ETC and JY conducted the interviews
author/s conducted the interview or	
oup?	
entials What were the researcher's	ETC has a PhD
als? E.g. PhD, MD	JY has a BSc
pation What was their occupation	ETC is an assistant professor
me of the study?	JY is a medical student
er Was the researcher male or	Interviewers:
or was the rescalence male of	ETC is a woman (gender)
	JY is a man (gender)
rience and training What	ETC has conducted 120+ interviews with health
nce or training did the researcher	professionals since 2007 and published peer-
	reviewed articles with this data. She has
	completed several qualitative research courses,
	teaches qualitative methods. Her PhD was an
	ethnography.
	JY was extensively trained by ETC. With ETC,
	JY listened to all the interviews ETC had
	conducted, coded them and helped develop
	themes. He listened to ETC conducting a live
	interview, then they talked and critiqued the
	interview after. Then ETC listened to him
	conducting live interviews and they talked and
	critiqued each interview after. He also read
	qualitative methods articles.
ship with participants	
ionship established Was a	Neither ETC nor JY knew any of the participants
ship established prior to study	prior to the study.
ncement?	
cipant knowledge of the interviewer	All participants were emailed the consent form
	which were approved by the Nova Scotia Health
	information about the researcher and why the
	research is being conducted. In her email
	signature and on her webpage, ETC has links to
	her bio, Google Scholar and CV so potential
	participants can look at these. The interview
	guide also has information about why the
	research is being conducted, which is read to all
	participants at the beginning of the interview.
ncement?	All participants were emailed the consent forr along with the research protocol guidelines, which were approved by the Nova Scotia Hea Research Ethics Board. Both documents give information about the researcher and why the research is being conducted. In her email signature and on her webpage, ETC has links her bio, Google Scholar and CV so potential participants can look at these. The interview guide also has information about why the research is being conducted, which is read to

	ETC contacted all potential participants via email and let them know that JY is a medical student who she trained. ETC then asked participants if JY could interview them, none declined.
8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	ETC is a social scientist who has conducted heal research since 1999 and interviews since 2007. Interviewees were informed of this so they were aware she did not have a clinical degree. Using H qualitative skills, she was able to ask 'naïve' and in-depth clarifying questions to participants which produced some rich descriptions and helped minimize bias.
Ó	JY is a medical student. He was able to ask 'naïve' questions and in-depth clarifying question which produced some rich descriptions and help minimize bias.
Domain 2: study design	
Theoretical framework	
9. Methodological orientation and Theory What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	The Data Analysis section explains how semi- structured interviews and thematic analyses were conducted. These analyses were informed by iterative qualitative analysis and constant comparison. Process theory informed the theoretical approach.
Participant selection	
10. Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball	Convenience sampling was used as professions contacted were on the list of MAiD assessors and providers, maintained by the Medical Affairs Advisor. The researchers do not have access to this list. Professional organizations as colleges also emailed their members the study information and participants opted to take the study. At the end of each interview, we used snowball sampling and some participants sent study information to their colleagues.
11. Method of approach How were participants approached? e.g. face-to-face, telephone, mail, email	Participants were approached via email and the study was also mentioned during video conference meetings.
12. Sample size How many participants were in the study?	32
13. Non-participation How many people refused to participate or dropped out? Reasons?	Since the study information was sent out to a line of MAiD assessors and providers which is constantly changing (clinicians join while othe leave/take a break), it is not possible to know

	how many refused to participate. At the time of article submission, there were 48 physicians and 8 NPs who assess and provide MAiD - we interviewed 12 physicians and 3 NP. Professional organizations do not track members who participate in MAiD (e.g., pharmacy or nursing college) and this number also changes frequently. Thus, we do not know the total pool of pharmacists, health administrators and nurses who refused to participate or who do not participate in MAiD at all.
Setting	
14. Setting of data collection Where was the data collected? e.g. home, clinic, workplace	Nova Scotia, Canada. Data was collected in the participant's office, interviewer's office, over the phone or via secure video (e.g., Microsoft Teams).
15. Presence of non-participants Was anyone else present besides the participants and researchers?	If the person was in their home for the phone or video interview, it is possible they were not in a private location with a closed door.
16. Description of sample What are the important characteristics of the sample? e.g. demographic data, date	Table 1 outlines the information collected about participants who were from different professions, organizations and geographic locations
Data collection	
17. Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested?	The semi-structured interview guide was pilot tested on 3 clinicians. If requested, the interview guide was provided to interviewees in advance. We used open-ended questions and also probed participants' answers.
18. Repeat interviews Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording Did the research use audio or visual recording to collect the data?	All interviews were audio-recorded and the ones in Teams were video-recorded. We only used the audio-recording for all interviews, not the video- recording.
20. Field notes Were field notes made during and/or after the interview or focus group?	ETC and JY made field notes during the interview
21. Duration What was the duration of the interviews or focus group?	Each interview was approximately 1 hour, some were up to 2 hours.
22. Data saturation Was data saturation discussed?	Yes
23. Transcripts returned Were transcripts returned to participants for comment and/or correction?	No. No participants requested to see their transcript.
Domain 3: analysis and findings	

Data analysis	
24. Number of data coders How many data coders coded the data?	SK and ETC independently coded the first 10 interviews. ETC and JY coded the next 22 interviews, the first 3 together, then divided u the rest.
25. Description of the coding tree Did authors provide a description of the coding tree?	Our process model and stages were used as the coding tree. We compared and contrasted new data to the process model, revising it as data v collected.
26. Derivation of themes Were themes identified in advance or derived from the data?	Because GG is a MAiD provider and ETC and SK had considerable knowledge about MAiD our collective knowledge helped us initially so data into different stages/themes. The process model and its stages were derived from the da All participants were sent the process model a article and offered the opportunity to provide feedback.
27. Software What software, if applicable, was used to manage the data?	Microsoft Word was used to manage the data and Microsoft Powerpoint was used to draw the process model.
28. Participant checking Did participants provide feedback on the findings?	Yes. The final process model was emailed to a interviewees inviting them to critique it.
Reporting	
29. Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	Yes. Table 2 has quotations from each provide by identifier, that illustrate MAiD.
30. Data and findings consistent Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes Were major themes clearly presented in the findings?	Yes
32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?	Yes

Page

## Standards for Reporting Qualitative Research (SRQR)\*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract	
<b>Title</b> - Concise description of the nature and topic of the study. Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	; 1
<b>Abstract</b> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2

## Introduction

<b>Problem formulation</b> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	3
<b>Purpose or research question</b> - Purpose of the study and specific objectives or questions	3
thods	

## Methods

<b>Qualitative approach and research paradigm</b> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	4
<b>Researcher characteristics and reflexivity</b> - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	4
Context - Setting/site and salient contextual factors; rationale**	4
<b>Sampling strategy</b> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	4
<b>Ethical issues pertaining to human subjects</b> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	4
<b>Data collection methods</b> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	4

		1
1	Data collection instruments and technologies - Description of instruments	
1	(e.g., interview guides, questionnaires) and devices (e.g., audio recorders)	
2	used for data collection; if/how the instrument(s) changed over the course of	4
3		
4 5	the study	
6	<b>Units of study</b> - Number and relevant characteristics of participants,	
7	documents, or events included in the study; level of participation (could be	4
8	reported in results)	
9		
10	<b>Data processing -</b> Methods for processing data prior to and during analysis,	
11	including transcription, data entry, data management and security,	4
12	verification of data integrity, data coding, and anonymization/de-	
13	identification of excerpts	
14	Data analysis - Process by which inferences, themes, etc., were identified	
15		4
16	and developed, including the researchers involved in data analysis; usually	Т
17	references a specific paradigm or approach; rationale**	
18	Techniques to enhance trustworthiness - Techniques to enhance	
19	trustworthiness and credibility of data analysis (e.g., member checking, audit	4
20	trail, triangulation); rationale**	
21		
22		
23	Results/findings	
24	Synthesis and interpretation - Main findings (e.g., interpretations,	
25	inferences, and themes); might include development of a theory or model, or	5-8
26 27	integration with prior research or theory	
27 28	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts,	Table 2, Figure
20	photographs) to substantiate analytic findings	1
30	photographs) to substantiate analytic midnigs	1
31		
32	Discussion	1
	Integration with prior work, implications, transferability, and	
32 33 34	<b>Integration with prior work, implications, transferability, and</b> <b>contribution(s) to the field -</b> Short summary of main findings; explanation	
32 33 34 35	Integration with prior work, implications, transferability, and	8 10
32 33 34 35 36	<b>Integration with prior work, implications, transferability, and</b> <b>contribution(s) to the field -</b> Short summary of main findings; explanation	8-10
32 33 34 35 36 37	<b>Integration with prior work, implications, transferability, and</b> <b>contribution(s) to the field -</b> Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of	8-10
32 33 34 35 36 37 38	<b>Integration with prior work, implications, transferability, and</b> <b>contribution(s) to the field -</b> Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to	8-10
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\*\*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

#### **Reference:**

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Acad Med* 2014;89(9). DOI: 10.1097/ACM.00000000000388

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