

Medical Assistance in Dying: Policy, Practice, and Ethical Implications for Nursing

Barbara Pesut PhD, RN

Professor School of Nursing UBC

Canada Research Chair in Health, Ethics, and Diversity

Research Exchange Group in Palliative and End of Life
Care, NLCAHR

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Objectives

- Understand how contextual factors influence how MAiD is being enacted and experienced by nurses.
- Gain knowledge of what nurses consider to be good nursing care in the context of MAiD.
- Analyze the moral tensions that characterize nurses' involvement, or non-involvement, in MAiD.

MAiD Legislation

- Medical Assistance in Dying (MAiD) was legalized in June, 2016 through Bill C-14.
- MAiD is defined as a) the administration by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death.

A Legislated Approach to MAiD

- The ‘hardest’ approach to assisted death. Legislation, as opposed to decriminalization, brings particular responsibilities

“There is a specific binding law (high in obligation), a precise, specific, clear rule for every practice (high in precision), and the designated third party to which the state delegates authority is the legislature (high in delegation).” Luzon.

For a more comprehensive discussion of this see Schiller, Pesut., Roussel & Greig. *But It’s legal isn’t it. Law and Ethics in Nursing Practice Related to Medical Assistance in Dying.* Nursing Philosophy. Published online August 20, 2019

Eligibility Criteria for MAiD

- Eligible for health services funded by the federal government or a province or territory.
- 18 years of age and mentally competent.
- Grievous and irremedial medical condition as defined by:
 - Serious illness, disease, or disability
 - Advanced state of decline that cannot be reversed
 - Experience unbearable physical or mental suffering that cannot be relieved under conditions considered acceptable to the patient
 - Be at a point where natural death has become **reasonably foreseeable** but not required to be fatal or terminal.
 - Quebec supreme court has recently struck down the reasonably foreseeable requirement.
- Able to make a voluntary request and give informed consent.

Examples of Safeguards from *Bill C-14*

- ✓ Eligibility for MAiD must be determined by two practitioners, either physicians or nurse practitioners, who are independent of one another (the second practitioner must also be independent of the patient).
- ✓ Once the patient has been determined to be eligible, he or she must then submit a written request for MAiD in the presence of two independent witnesses.
- ✓ Ten day waiting period, although this can be waived in certain clinical circumstances.
- ✓ Must be able to provide consent immediately prior to the procedure.

Prevalence as of October 31, 2018

Total number between December 10, 2015 and October 31, 2018: 6,749

Self-administered deaths: 6 reported.

NP administered: 4-7%

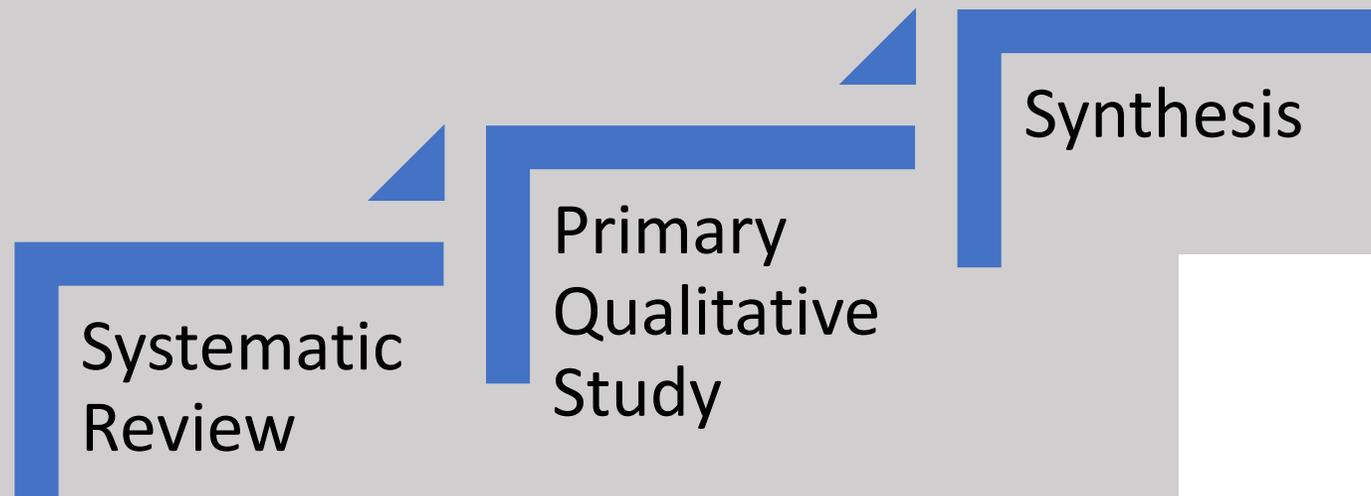
Average age: 72-73

Men: 49-53%

Vast majority occurring in Ontario and BC and in the hospital or home (roughly 80%).

The Study

Purpose: To explore the policy, practice and ethical implications of MAiD for nursing



The Team

- Sally Thorne Co-PI – Qualitative metasynthesis; communication
- Josette Roussel Co-PI – Senior Nurse Advisor, Policy, Advocacy and Strategy, CNA
- Catharine Schiller – Lawyer and Nurse
- Michael Burgess – Medical Ethicist
- Janet Storch – Nursing Ethicist
- Robert Janke – Information Scientist
- Kenneth Chambaere – Sociologist and MAiD expert Belgium
- Carol Tishelman – Palliative care expert Sweden
- Trainees – Madeleine Greig, Adam Fulton

Findings: Policy Literature

- Seventeen regulatory documents reviewed from all provinces and territories – great variability in the amount of direction provided.
- Nursing responsibilities included assisting in assessment of patient competency; providing information about MAiD to patients and families; coordinating the MAiD process; preparing equipment and intravenous access for medication delivery; coordinating and informing healthcare personnel related to the MAiD procedure; documenting nursing care provided; supporting patients and significant others; and providing post death care.
- Highlighted safety concerns: counseling, administering, informed consent, documenting, safeguards.

Findings: Ethics Literature

- Forty-three articles identified that answered a focused ethical inquiry related to assisted death and nursing
- Arguments
 - Nature of nursing
 - Principles, concepts, and theories
 - Moral consistency
 - Social good
- Paucity of literature from Canada; majority from the United States

Literature Findings: Nurses' Experiences

- Six qualitative articles representing nurses' experiences with assisted dying.
- Data from 55 nurses from Canada, Belgium, and the Netherlands
 - Nurses perform a central role in discerning and negotiating initial patient inquiries about assisted death.
 - Even in contexts where nurses are not assessors and providers, nurses provide the 'wrap around' care for patients, families, and other healthcare providers.
 - Participating in assisted death was impactful for nurses and required significant personal and professional moral work.



Canadian Nurses' Experiences

A Qualitative Study

Demographics (n=59)

<u>Province</u> British Columbia: n=28 (48%) Ontario: n=16 (27%) Manitoba: n=7 (12%) Alberta: n=5 (9%) Newfoundland and Labrador: n=5 (3%) Saskatchewan: n = 1 (2%)	<u>Years Worked</u> 2-4 years: n=4 (7%) 5-9 years: n=10 (17%) 10-14 years: n=13 (22%) 15-19 years: n=4 (7%) 20-24 years: n=6 (10%) >25 years: n=22 (38%)	<u>Work Context</u> Home & Community: n=32 (54%) Acute Care: n=10 (17%) LTC: n=5 (9%) Hospice: n=4 (7%) Clinic: n=3 (5%) Other: n=5 (9%)
<u>Designation</u> Registered Nurse: n=43 (73%) Nurse Practitioner: n=13 (22%) Clinical Nurse Specialist: n=3 (5%)	<u>Spiritual or Religious</u> Religious or Spiritual: n=33 (56%) Neither: n=15 (25%) Spiritual but not Religious: n=11 (19%)	<u>Age</u> 25-44: n=27 (46%) 45-64: n=29 (49%) > 65: n= 3 (5%)
<u>Ethnicity</u> Caucasian: n=57 (97%) Other: n=2 (3%)	<u>Conscientious Objection</u> No: n=50 (85%) Yes: n=9 (15%)	<u>Gender</u> Female: n=56 (95%) Male: n=3 (5%)



Nursing Work

How are contextual factors influencing nurses' work and experiences?

Systems and Influential Leaders

- Wide variability in practice supports.
- Influential leaders set the tone.
- Influential role of physicians.
- Concerns about access to palliative care.

We use this rhetoric that it's somebody's right to die and I don't want to debate that part but I think it's also their right to have access to care done by clinicians who are knowledgeable about palliative care. This is the crazy thing for me to consider... it's a shame and it's something that I grieve to think that our system, as it is, can contribute so much to the suffering of somebody on so many different levels....on top of whatever illness process that is causing suffering. But that our health care system contributes to suffering, and is doing nothing about our own contribution to that suffering, but then uses that very suffering to activate access to MAiD. It's absolutely ridiculous to me.

Two's a Team

- Two persons are required to ensure adequate support of patients.
- Providers are often working in isolation.
- Nursing plays an important role in continuity of care when MAiD is provided by “outsiders”.
- Relationships among team members are important to well-being during an impactful provision.
- Inadvertent exclusions of important team members, largely because of privacy reasons, leads to distress.

So, you have these pairs of teams and I think it speaks to the powerfulness of the experience. You need to work with a team that you're trusting in. Right?

What struck me about that day was my physician colleague, how his hands were shaking. And I remember putting my hand on his shoulder and just kind of nodding because we were there together and he had never done this before but we had spent a lot of time together previously.

Her request was not to tell any of the staff members until afterwards. Her care aides took that very poorly because they didn't know. They were with her right to the last minute and it was a normal day. They took her to dinner, they took her out for a smoke, they took her back to her room. But then, they were told that she had died.

Patient-centered aspirations in a complex system.

- Nurses are the ‘go to’ individuals to get the final act of healthcare “right”.
- Priority tasks must be completed in a timely, patient-centered manner.
- Requirements: organized referrals, willing assessors and providers, paperwork and records, physical space.
- Negotiating timing may be labour intensive.

I don't find the provisions so emotionally draining, but it's more the logistics and it's a lot of work. The logistics of filling in 16 pieces of paper and making sure they're all correct so you don't get into trouble because the consequences are pretty significant. Then there's organizing the pharmacy, going to pick up the medication, and organizing with the family, organizing with the nurse. Like, there is so much that goes into it. And that part can be so draining. And making it all happen as it should, you know, so that everything lines up. So, I think it's important not to do too many cases. And that's what I've been focusing on, making sure I'm not taking too much on.

Legislative Complexities

- Difficulties in having continuity in assessors and providers when there are time delays.
- Determining eligibility can be a challenge and it takes mentorship to develop expertise.
- These challenges are exacerbated by the tension between precise and risk-tailored reporting requirements and variability in clinical judgment.

About a month after I saw her for a secondary assessment I realized I've now become her primary provider. But because it's been so long I don't know whether to sign the Form C or not because she actually doesn't have intolerable suffering at this point in time. She goes out for lunch every day with her friends like she's always done. But what happens if next week things turn upside down for her? Somebody else is going to have to come in and do the whole secondary assessment again.

The sense is that we have to prove that what we did was okay and that it was right. Our fear is that they're going to challenge us or ask a question that we won't have an answer to. That will put us in a position of feeling like, "Uh oh. What did I do now?"

Conscientious Objection

Policies specifying what is allowed under conscientious objection vary across the country.

Many nurses in our study remained undecided. Decisions to no longer take part may occur after a number of experiences.

Decisions were based upon a variety of factors.

Embedding MAiD responsibilities within currently existing employment roles were intensely problematic.

I remember when this started 2 and a half years ago. It was assumed that if you were a conscientious objector the supervisor was obligated to accommodate you as long as you did not abandon the patient. But now that it is more ubiquitous, it is so normalized that it is not at all clear where conscientious objectors can stop.

Its' been a difficult issue to discuss in a safe and productive way. People assume they know what you will be comfortable with and that you have nothing useful to contribute to the plan of care.

The way our initial policies were written anyone in this position would have to provide education about MAiD and perform assessments.

We feel like we are abandoning the patient when they need us the most

Nursing Art

What constitutes good nursing care in the context of MAiD?



Legacy Conversations

NP Assessors and Providers

- Immediate and deep intimacy established because of the complexity of the issue.
- Direct and blunt approach is best.
- Complicating factors of mental health, homelessness, diminished social skills.

Registered Nurses

- Nurses are not certain of their role and boundaries.
- Time is a barrier to good assessments of requests.
- Challenges of determining the correct referral path (e.g., palliative, social work, MAiD team).

Artful Principles



Make yourself small and invisible

We kind of figured out how to work together in trying to make ourselves as small as possible in the room because this is never about the provider, it's always about the family. And so, I've been on my hands and knees at the bedside exchanging syringes of medication.

You're trying to make yourself invisible. You need their arm to inject the medications and do the pieces you have to do but really this is their last moment.

Make the act inconspicuous

I think it's really nice to be able to go to a completely separate place to draw up medication. To do that in front of the family, it just felt so crass. I remember shifting my body around trying to hide what we were doing because to me it just seemed that for them to see that just didn't seem right.

Take your emotional cue from the patient and family

It was quite funny. I mean, it was a very emotional time because we were so close with the family physically, as they were saying their final goodbyes, we were having a bit of a hard time keeping it together but we literally had to move ourselves onto this king bed just to reach the IV line. And his daughters were teasing him about being in bed with his providers.

Make it patient-centered

Why don't we kind of set the scene? I want you to think about who you would like to have with you. What you would like to be doing when this is going on? Where you would like to be? Would you like to be in your bedroom, would you like to be in a favourite chair, would you like to be sitting outside on your deck? Who do you want surrounding you? Would you want some music to be played? All of these things help them set the scene because I look at this as a good experience, as strange as that may sound. I want to help them... to provide them with a good death and that involved a lot of things around it.

Is there anything... any other experiences I can facilitate for you because, you know, on this date, at this time, you will be taking your last breath.

Anticipate problems

Achieving rapid intravenous access a significant source of nurses' stress!

I do an on-phone risk assessment because I'm going into somebody's home. I ask them specific things about weapons in the home or any animals that could be a danger to me and I make light of it. I just say, "I have to ask you a couple of questions that seem really silly but it's...It's for the safety of people going into your home."

Then, after not too long a period of time, I realized, I've been nursing for 40 years, I can start IVs, it's not an issue. Why put the person through this the day before. So, you know, that was just an evolving thing.

Teach everyone what to expect

I go into quite a bit of detail about the day of the provision and what to expect and, you know, things to think about. You know, which medications are administered, how long they take, you know, how... the coroner's involvement because that's an unusual experience for most people, they don't have to know about that 99% of the time.

Watch and intervene

If the patient's head starts to droop or the patient looks uncomfortable don't feel afraid to move the patient to make them look more comfortable. Patients and family members have said to me "Thank you for moving his head. He looked like he was drowning or he's flopped over and has hit the bed."

And if you see a family member that looks like they're distressed, then go and talk to them. Don't feel like you can't say things during the assisted death.

Developing nursing competence

- Traditional methods of education not particularly useful.

I feel like I'm living grounded theory.

- Just-in-time mentorship most effective.

This is not a learning experience [for students].

- Supportive presence, with backup, at first death.

*There isn't an appetite for knowing about this
until there is an appetite.*

- Specialized debriefing is essential



Nurses' Moral Journeys

What moral tensions characterize nurses' response to MAiD in the Canadian context?

Moral Responses: Riding an Elephant



Photo by C. Rayban on Unsplash

A Different Death

- Orchestrating a unique patient-centered experience is priority (nature, music, luxury, intimacy).
- Stark transitions from life to death are new for nurses. The greying of the patients is particularly impactful.
- Early death without obvious suffering.

They've been beautiful experiences and I know we kind of chuckle to ourselves when we talk about how beautiful some of these experiences have been.

One of my first experiences was with a patient who was very awake and alert. I consciously made the effort to say goodbye to him before it and then afterwards came in and cared for him after death. And it was just so fast. It's not the normal process and it's hard to take it all in and process it the normal way you would.

There's this feeling you get that I'm helping to relieve your suffering but if you can't connect to that suffering then I think that makes it difficult because that's what soothes you, right?

Impactful across a Spectrum

I found the whole experience to be incredibly profound and very fit for nurses to do.

Every circumstance is different and so, to me, it doesn't matter how many experiences I've had, there is a bit of nervousness prior to doing the next person.

*They are going to end their lives and, you know, there's a courage in that, you know,
it's very humbling*

Impactful across a Spectrum

Because even though I didn't know the patient, I couldn't figure out why I cried and I was very upset because in my twenty years' experience of watching people die, usually I'm not the cause of it. Because generally, I've been told I'm cool and collected, you know. But I was very upset. I couldn't even get in the car and drive. Like, literally, I was just sitting there and going, I need to think about doing this before I can figure if I'm fit to actually operate a car because my brain is literally overloaded... emotionally overloaded.

It was an emotional experience, not a sad emotional experience because, you know, she made the choice and it was her choice. But I found myself crying afterwards in my car and it was just the overload of emotion, I just needed to just let that go.

So, "The Night Before Christmas" is being read. The kids are dictating the book, the dog's under her arms, I'm giving medications to end life and the experience is bonkers. So, where is the psychologist in this room? Where is the social worker in this room? Who do I turn to?

Willingness to Participate: Morally Relevant Factors

➤ Family & Community

Your family needs to be supportive of you if this is something you want to participate in. Because it brings up feelings and dilemmas and you need a place to discuss that.

➤ Professional Experiences

The patient said to me, 'dying isn't supposed to hurt like this. I am in pain. And it broke my heart

➤ Proximity

I definitely believe in choice at end of life. But I never thought I would be part of hastening that end of life. Who wants to play God. I don't really want to play God. You can watch someone skydive but do you want to skydive yourself?

Moral Waypoint

Patient Choice, Control and
Certainty

The ability to have choice and control is an empowering gift. There is no reason to make people suffer unnecessarily. It's just common sense and I don't understand why it is so controversial.

This is what has cushioned me psychologically in being able to understand that this individual truly has no doubts about what they are doing and this is absolutely what they wanted.

Moral Waypoint

It's not about me....

This is about validating them as a person. So that turns everything around. It is all about them, it's not about me. And that's why I can suffer silently when these things occur because it is not about me.

Moral Waypoint

Nurse's role in alleviating suffering

They are most vulnerable and alone. They say they find no meaning in their suffering and are tired of enduring it. It doesn't require a lot of mental gymnastics. If we can't get them comfortable then we have an ethical responsibility to do MAiD.

When we are talking about people's voices and hearing what they are asking for, what they are telling us, is that they're suffering, suffering so badly that they want to end their life. And what you do when you extinguish that voice is that it no longer exists.

Moral Waypoint

Moral Consistency:

Removal of life support

Self versus clinician
administered

I don't think practitioners who remove someone from life support consider themselves to be killing someone either.

It's not me giving the medication. But in terms of being judged, how am I going to be judged at the end of life? It would still be me signing off on allowing that person to do that because I've arranged the medications. So, it's not that much different you know.

Moral Waypoint

Peace and Gratitude

It's very peaceful. So that helps me in the psychology of things.

You get a warm and fuzzy from somebody or you get a hug from a family member or something. That's a reward in itself.

Every patient I've ever encountered has been truly grateful that they have this opportunity to do this.

After the provision he looked at me and he was, like, "I don't know how you do this" and I kind of wasn't sure which way he was going with that comment because most people have thanked us and he did but before he did that, he said, "You guys are kind of like executioners." And I was, like, "Oh, my God" and I kind of haven't been able to shake that out of my brain.

Moral Waypoint
Reflections on the Afterlife

I don't follow a formal religion but I think there must be some patterns we don't understand and if we are intervening, could we possibly be putting things off track?

That always lurks in your mind. Are we playing God? It's a very serious thing, right?

Conclusions

- Nurses, both RNs and NPs, have important roles and responsibilities in ensuring high quality care in the process of considering and implementing MAiD.
- Practice supports need to be commensurate with the precision and obligations of a legislated approach to assisted death.
- MAiD has a significant impact on nurses, across levels of involvement or non-involvement.
 - Artful nursing practice is developing and needs to be shared.
 - Competence and confidence is developed organically.

Recommendations

- ✓ Ensure that nursing practice supports are developed and made readily available – even (and perhaps especially) in those contexts where the perception is that they are not required.
- ✓ Provide supported venues for conversations about the ongoing emotional and moral work.
- ✓ Recognize the importance of the early conversations about MAiD and prepare nurses with best practices.
- ✓ Set an organizational climate that allows for a full range of healthcare provider, client, and family moral responses to MAiD.
- ✓ Establish better mechanisms to facilitate nurses' decisions to not take part in MAiD

Next Steps

STRS – EOL: A longitudinal study
of strategies to relieve suffering
(CIHR Project grant 2020-2026)

Palliative Care

Palliative Sedation

VSED



Conversation

We are seeking to interview health care providers who have experience with the changing nature of end of life practices including PC, PS, MAiD and VSED.

For further information about this study or our current study contact barb.pesut@ubc.ca

