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The Honourable Marc Garneau The Honourable Yonah Martin



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• (0845)

[*Translation*]

The Joint Chair (Hon. Marc Garneau (Notre-Dame-de-Grâce—Westmount, Lib.)): Good morning, everyone.

I call to order meeting number 19 of the Special Joint Committee on Medical Assistance in Dying. Welcome to the members of the committee, the witnesses and the members of the public watching this meeting on the Internet.

My name is Marc Garneau, and I am the committee vice-chair from the House of Commons. With me is the Hon. Yonah Martin, the committee vice-chair from the Senate.

Today, we are continuing our statutory review of provisions of the Criminal Code relating to medical assistance in dying and their application.

[*English*]

I would like to remind members and witnesses to keep their microphones muted unless they are recognized by name by one of the joint chairs. All comments should be addressed through the joint chairs.

When speaking, please speak slowly and clearly. Interpretation in this video conference will work as it does in an in-person committee meeting. You have a choice at the bottom of your screen. You can probably see the interpretation button that gives you the choice of “floor”, “English” or “French”.

With that, I would like to welcome our witnesses for our first panel. They are here to discuss the state of palliative care in Canada.

[*Translation*]

As an individual, we welcome Dr. Geneviève Dechêne, who is a family physician.

[*English*]

We have Dr. James Downar, professor and head, division of palliative care at the University of Ottawa.

We have Mr. Spencer Hawkswell from TheraPsil, president and chief executive officer.

Thank you for joining us this morning. We will begin with opening remarks. Each of you will have five minutes to speak, and we'll start with Dr. Dechêne.

[*Translation*]

Go ahead, Dr. Dechêne.

Dr. Geneviève Dechêne (Family Doctor, As an Individual): Thank you for allowing me to address the Special Joint Committee on Medical Assistance in Dying.

As a physician specializing in home-based palliative care, I would like to talk to you about the lack of home access, both for palliative care and for medical assistance in dying.

I am speaking to you this morning as an expert in home-based palliative care who has been practising in Quebec for 35 years, and this home-based care covers seniors' residences. In Quebec, clinicians have unfortunately so far failed to convince decision makers of the importance of giving people access to comprehensive palliative care at home. I am talking about multi-professional palliative care teams. These teams should include at least the basic duo of a nurse and a physician, who work as a team to provide 24-hour care. In Quebec, we use the term “intensive team”.

These teams are experts in palliative care and have demonstrated their efficiency. Hospitalizations are reduced by 65%, and 64% of the deaths of patients under care are at home. These figures are good and comparable to those of the palliative care teams of the main English-Canadian and European authorities. Unfortunately, Quebec clinicians are still trying to get people to accept the average length of palliative medical care for end-of-life patients at home, which is eight months, not seven days, as set by Quebec authorities in 2019.

International evidence shows that home-based palliative nursing care is enhanced care. This is the expertise of clinical nurses with undergraduate degrees who are dedicated to this practice. These nurses are given additional training and time to care for these difficult cases and support patients' loved ones, who are very actively involved in home care. It's not a basic nursing practice, and it's not a hospital practice at all.

We also know that not all physicians have the training and experience they need to relieve patients' suffering in the last year of their lives. These patients are indeed complex and unstable. This is not a basic medical practice.

It has been shown in several recognized scientific publications that palliative care physicians provide better and faster relief to patients, at a lower cost to the health care system. Despite this, there is still a serious shortage of home-based palliative care physicians in Quebec. This is clearly a medical desert that affects 80% to 85% of all Quebecers at the end of their lives.

Home care clinicians were hoping that comprehensive palliative care would finally be implemented in all care settings, including at home, along with medical assistance in dying, with the implementation in 2015 of Quebec's legislation on end-of-life care. In order to meet the criteria of this legislation, every effort must be made to relieve the patient before proceeding with medical assistance in dying, be it physical or psychological suffering. However, priority was given to medical assistance in dying, not palliative care, which is absurd, because both are in fact—and I emphasize both—complementary and essential.

I will now talk about the accepted metric for measuring access to home-based palliative care and the rate of death at home. Quebec's home death rate is the lowest in the western world. It stands at 12%, compared to an average of 30% elsewhere in Canada and Europe. We are experiencing this on a daily basis in our overwhelmed emergency rooms. The data show that at least 70% of Quebecers want to be treated and die at home. In Quebec, our family doctors devote a very significant part of their working hours to the hospital.

During our first home visit, patients very often talk to us about medical assistance in dying because they are suffering. Many don't even know that their prognosis is less than 12 months, especially in cases of non-cancer diseases. They tell us of their exhaustion and despair at the persistent suffering they are facing, after repeated stays in crowded emergency rooms. When palliative care teams are present at home, the suffering is managed intensively until it is relieved, and few patients choose medical assistance in dying.

Theoretically, the Act respecting end-of-life care stipulates that palliative care, as well as medical assistance in dying, should be available to all Quebecers who want it, in all care settings, including at home. However, that is not the case in Quebec. Inequity in access to palliative care at home and medical assistance in dying persists, with most other provinces prioritizing home care over hospital care.

● (0850)

In Quebec, in 2022, the place of our death is determined by our postal code. We can and must do better.

In order to do so, we will need to get out of a health care model that is hospital-based and accept the fact that here in the West, the end of a life is a long journey which requires expert medical care and enhanced nursing.

Thank you.

The Joint Chair (Hon. Marc Garneau): Thank you, Dr. Dechêne.

[*English*]

We will now go to Dr. James Downar.

Dr. Downar, you will have five minutes.

Dr. James Downar (Professor and Head, Division of Palliative Care, University of Ottawa, As an Individual): Thank you, Mr. Chair.

I really appreciate the opportunity to speak before you again, and I want to thank Dr. Dechêne for her comments, which were largely focused on home care. I will try to keep my comments focused on

the hospital just so I don't repeat what she was saying, but I agree with what she was saying.

I've provided some material in my—

[*Translation*]

Mr. Luc Thériault (Montcalm, BQ): Mr. Chair, we have to do something about the sound. The volume is much too high here in the room and I can't hear the interpreters.

[*English*]

The Joint Chair (Hon. Marc Garneau): Just stand by, Dr. Downar.

Dr. James Downar: That's no problem.

The Joint Chair (Hon. Marc Garneau): Can we lower the volume in the room here? Very good.

I'm sorry, Dr. Downar; we're just making a little adjustment to the sound. It's nothing to do with you.

Dr. James Downar: That's no problem.

The Joint Chair (Hon. Marc Garneau): Please carry on.

Dr. James Downar: I have small children, so I'm used to telling people to use their inside voices.

The main point I want to communicate today is that it's important to acknowledge that there have been important improvements in funding and in support for palliative care in many, many parts of the country. This is a start; it needs to continue.

I think a lot of the more acute crises that we are experiencing—

[*Translation*]

Mr. Luc Thériault: Mr. Chair, I am sorry...

[*English*]

The Joint Chair (Hon. Marc Garneau): Hold on again, please.

[*Translation*]

Mr. Luc Thériault: Mr. Chair, I do apologize to the witness.

I do not want to make a fuss, but I can't hear the interpretation.

[*English*]

The Joint Chair (Hon. Marc Garneau): We've lost translation momentarily. Hold on, Dr. Downar.

[*Translation*]

Dr. James Downar: No problem.

I can continue my presentation in French, if need be.

[*English*]

The Joint Chair (Hon. Marc Garneau): Okay, we have it back on. Carry on in English or French, whichever you prefer.

Dr. James Downar: This is going to be a fun morning.

I think it's very important to point out that a lot of the crises we are experiencing right now in palliative care and palliative care provision are related a generalized lack of person power across the health care system, especially in home care. We need more nurses and we need more personal support workers in particular, but most importantly, we need to add to our labour pool in those areas without stealing from other areas. By simply throwing money at palliative care, stealing staff from hospitals or from long-term care, we're just going to move one crisis into another place, and we've done that a few times during the pandemic, so just be careful.

I think it's important to recognize that in a lot of the crisis, even before the pandemic, the lack of funding, the inadequate number of palliative care beds and the inadequate amount of palliative care home resources had a very important upstream effect on the health care system as a whole. Probably one in five or one in six patients admitted to a hospital were simply waiting to go to another facility, another bed that didn't exist. The result was a heavy contribution to overwhelming our acute care facilities.

The even sadder part is that the beds in all the places they were waiting to go are cheaper than the beds they were occupying in acute care. We just published a C.D. Howe report a year ago suggesting that if you just took the patients who were in the final 90 days of their life, and that's almost half of the patients who are at so-called alternative level of care, or ALC patients, in hospital and moved those people to the beds they were waiting for, you would save hundreds of millions of dollars a year while improving care for those patients and alleviating the health care crisis. The acute care crisis is predominantly an end-of-life care crisis, and that's what we really need to focus on right now.

I think I also want to highlight the importance of improving support and funding for palliative care research in this country. We have definitely had an increase in the previous couple of years. A large amount of funding was given to the pan-Canadian palliative care research collaborative and a large amount of funding was given to the palliative care institute in Alberta. These are great starts; please keep going, because we really do need to improve our ability to treat many types of suffering, and in particular existential suffering, which is very common. It is the number one factor in people requesting medical assistance in dying, and there is currently no proven therapy to address that type of suffering. It is very important. We have promising therapies; we just need some support to help do that research and start to advance our field.

Improving palliative care is a moral imperative for all Canadians, independent of medical assistance in dying. Only the tiniest minority of Canadians choose medical assistance in dying at the end of life, and 98% of those people receive or have access to palliative care. There are many people who don't have access to palliative care or don't get good palliative care. They're not getting MAID either. This really isn't about MAID; this is about improving end-of-life care for all Canadians.

Maybe I'll just say that I think there is probably an opportunity to answer questions, so I'll just bring my opening comments to a close with that.

Thank you.

• (0855)

The Joint Chair (Hon. Marc Garneau): Thank you, Dr. Downar.

We'll now go to Mr. Hawkswell from TheraPsil.

Sir, you have five minutes. Please go ahead.

Mr. Spencer Hawkswell (President and Chief Executive Officer, TheraPsil): Thank you.

I'm a patient-rights advocate and the CEO at TheraPsil, a non-profit dedicated to supporting patients in accessing psilocybin, a substance commonly found in what's otherwise known as magic mushrooms that has an amazing ability to help people through the therapeutic process. It usually has been used in studies to help people with end-of-life distress.

I'm here today to advocate on behalf of a number of our constituents and patients who have the right to die in Canada with medical assistance in dying, but currently are being denied their right to try psilocybin. Specifically, I will refer to a patient, Janis Hughes, who is a 65-year-old woman in Manitoba with stage 4 breast cancer and an advocate with a two-year prognosis who in her own words states, "It is not only patronizing but an infringement upon my charter rights to have a Canadian government deny me access to psilocybin, a substance that has helped me with my palliative care treatment and end-of-life distress while allowing me at the same time only one alternative—medical assistance in dying."

To relate what this has to do with MAID, it is about improving palliative care and adjunct or prior therapies.

The last time psilocybin was brought up in this meeting, it was shot down as a pseudo-science for its lack of research and not having much to do with medical assistance in dying. However, first in relation to the research, I might remind everyone that there is actually quite a bit of research behind psilocybin, specific research coming out of Johns Hopkins and NYU, that far surpasses much of the research that was done for medical cannabis and perhaps medical assistance in dying. These were both legalized on the basis of human rights, and that is what we are talking about here today—a human rights issue in need of compassion.

Second, to answer how MAID is connected to the psilocybin issue, the people whom I represent, such as Ms. Hughes, are directly affected by this committee. Psilocybin access is currently available through the special access program to those who have failed every other treatment, leaving MAID as one of their only alternatives if psilocybin is not allowed. This represents a woeful incongruity in our health care system. I believe that if this committee is made aware of this incongruity, they may see a situation in which we're allowing people to die before they're able to try substances such as psilocybin that might help them alleviate end-of-life distress and help with their palliative care before MAID.

Where is the compassion? Why is there not a more patient-centred approach when constituents and stakeholders of the actions of this committee are being told that they are being denied prior or adjunct treatments to MAID?

I am personally a big supporter of medical assistance in dying and have agreed with everything I've heard so far. We must move it forward quickly, but we must also see it in the context of palliative care in Canada, especially where patients are being denied access to other therapies.

Bill C-14 and Bill C-7 required establishing this committee in the House of Commons and Senate to conduct a comprehensive review of the Criminal Code, MAID provisions and their application and issues relating to mental illness and the state of palliative care in Canada. I believe that we are talking about the state of palliative care in Canada.

I am here to defend Canadians with mental illness and those struggling to receive adequate palliative care. Our health care system prides itself on being patient-centred and giving people the right to die after the Carter proclamation—if you don't have the right to die, then whose body is it? At the same time, it will limit these same Canadians by expanding MAID while ignoring issues related to adjunct or prior treatments, such as psilocybin access.

I believe that this is unconscionable. Given the constituents affected by this committee, this review will be subject to broader options relating to medical death while their request to seek treatment such as psilocybin to better their quality of life is being ignored.

I don't believe that the members of this committee should let such a thing happen. I'm asking for your compassion and support for people like Janis. I believe that Canadians who have the right to die should similarly have the right to try psilocybin and perhaps other controlled substances prior to MAID.

I believe, however, that we should start with psilocybin access, given the robust research. We should expect this to increase to other treatments and substances that may hold other grounding.

I'm urging this committee to add in its report that regulations for medical psilocybin access for those seeking MAID should be given a priority and that it should be a possible prior treatment for a number of Canadians seeking this. I do not intend in any way to slow down any of the other work that is being done on MAID and on other issues; rather, I encourage the expansion of other alternative treatments at the same time. Again, I am referring to psilocybin.

I am here to defend people like Ms. Janis Hughes and hundreds of other patients who have reached out to our organization and who are feeling disheartened that we might make MAID available in as little as three days while someone like Ms. Hughes has waited seven months for access to psilocybin and has been forced to break the law to access it.

• (0900)

I do not believe that this reflects well upon the state of palliative care in Canada, and I believe that, similar to the comments made by Dr. Downar, this is simply a reflection of other therapies—adjunct and prior therapies—that need to be made available while our MAID committee is expanding possible options for medical assistance in dying.

Please consider it. Thank you.

The Joint Chair (Hon. Marc Garneau): Thank you, Mr. Hawkswell.

We'll now go to questions, and I'll hand it over to my co-chair, Senator Martin.

The Joint Chair (Hon. Yonah Martin (Senator, British Columbia, C)): Thank you, Mr. Co-Chair.

Thank you to our witnesses for your testimony today.

We'll go into our first round of questions. We will begin with Madame Vien for five minutes.

[*Translation*]

Mrs. Dominique Vien (Bellechasse—Les Etchemins—Lévis, CPC): Thank you very much, Madam Chair.

Hello, everyone. I would like to thank the witnesses for being here this morning.

Good day to you, Dr. Dechêne.

Dr. Geneviève Dechêne: Hello.

Mrs. Dominique Vien: Welcome to our committee.

I read a very interesting article about Nova Home Care in Verdun that you authored and that was published, if memory serves, in 2021. You brought up a fascinating point and I will come back to it later.

To start with, you have expressed a lot of doubt about access to home care. You spoke about how this access was inequitable. You did not pull any punches by stating that the place of our death is determined by our postal code.

Dr. Geneviève Dechêne: In Quebec.

Mrs. Dominique Vien: Indeed, in Quebec.

Dr. Geneviève Dechêne: Yes.

Mrs. Dominique Vien: Dr. Dechêne, what is difficult, is it accessing home care or is it accessing home-based palliative care?

• (0905)

Dr. Geneviève Dechêne: Thank you for that fantastic question.

In Quebec, we have local community service centres, called CLSC. They are wonderful places, which offer excellent home care. They have nurses, occupational therapists and physiotherapists on staff. Every category of health professionals is represented, apart from doctors. It's absurd, I know.

For purely political reasons, and probably union-related ones, for 35 years now, doctors have not been included in this exemplary multidisciplinary health care model which is the CLSC. However, in the case of palliative care, we can't offer it without doctors. I am not talking about a person's last seven days on earth, but rather of palliative care, which is comforting care given during the last year of life, as I stated earlier.

For example, let's say we have a person who suffers from heart failure, which patients, who frequently find themselves choking, sometimes call "water on the lungs." The medication dosage has to be changed constantly, whether administered intravenously or orally. We change the dosage from one day to the next, and sometimes twice a day. It can be done over the telephone, or during one of our visits, so that we make sure that the patient enjoys a good quality of life and does not choke.

What can our wonderful home care nurses do...

Mrs. Dominique Vien: Dr. Dechêne, I have very little time.

You're speaking of...

Dr. Geneviève Dechêne: As I just said, the problem is that there are no doctors in the CLSCs.

Mrs. Dominique Vien: You said this was for political reasons and also union-related ones. According to you, there is a seemingly simple and much less costly solution.

What is the problem, in this case? I'm having trouble wrapping my head around it. I would have thought that it might rather be a question of training, or doctors having the necessary skills or being sufficiently at ease with offering this type of care.

Dr. Geneviève Dechêne: No, not at all.

Mrs. Dominique Vien: You spoke of political reasons and union-related ones.

Dr. Geneviève Dechêne: Yes, absolutely.

I really liked Dr. Downar's comment when he explained that actually, palliative care constitutes an improved practice in all care settings, not only at home. Not all family doctors, such as pediatricians, for example, can say that they are experts in palliative care, especially in a home setting.

The problem is not training, however, because doctors can't even be hired in order to offer palliative home care through our CLSCs. There is a fundamental problem here.

Mrs. Dominique Vien: If I understand you correctly, the government has the solution within its reach, but as you say, you have not been able to convince it to make home care a priority.

Dr. Geneviève Dechêne: Yes.

Mrs. Dominique Vien: You waxed lyrical about the Nova Home Care program.

What is it exactly?

Can it be used elsewhere in Quebec? I think that is what you are looking to do, from what I understood.

Dr. Geneviève Dechêne: That's correct.

In English-speaking Canada, Nova is a well-known organization because it is now a distinct subsidiary of the Victorian Order of Nurses, the VON, whose wonderful community nurses support the public health care system's home care nurses. The VON is already present in almost all of the English-speaking provinces in Canada.

Our equivalent of the VON is called Nova Home Care. The organization offers tremendous support and knowledge to nurses who are already offering home care through our CLSCs.

To come back to your question, you are indeed right, we would certainly be happy if community nursing groups specializing in palliative home care could offer their support and mentorship everywhere in Quebec.

Mrs. Dominique Vien: How could that happen, Dr. Dechêne?

I understand that only Verdun's CLSC benefits from this support, and that is in an urban setting. Am I wrong?

Dr. Geneviève Dechêne: Nova Home Care is already working with 19 CLSCs in the Greater Montreal region. There are other nursing groups, such as the Palliative Home-Care Society of Greater Montreal, in the eastern part of Montreal. Unfortunately, these expert nursing groups do not offer their services in many regions in Quebec because they do not all enjoy the same accreditation or subsidies for the important work that they do.

By the way, Nova Home Care and other similar groups cost less to the health care system than the nurses working within the public system. They actually represent a very interesting model that could help the public system.

The Joint Chair (Hon. Yonah Martin): Thank you.

[*English*]

Next we have Madame Brière for five minutes.

Mrs. Élisabeth Brière (Sherbrooke, Lib.): Thank you, Madame Joint Chair.

[*Translation*]

I would like to thank all the witnesses for being here.

Doctor Dechêne, thank you for your comments. I would like to ask you a particular question without using up all my speaking time.

You are making a distinction between a family medicine practice and a CLSC by stating that there are no doctors who work in the CLSCs, is that correct?

Dr. Geneviève Dechêne: Yes, absolutely. They are two completely different entities. You're right.

Mrs. Élisabeth Brière: Thank you.

You said that expert care is required. Can you explain to us in concrete terms what palliative home care requires in terms of resources?

• (0910)

Dr. Geneviève Dechêne: Thank you for that excellent question.

As a practitioner of family medicine, you can have an enhanced practice. You don't have to go back to medical school, but rather undertake a two to three month-long practicum, and then be supervised by your peers, i.e., doctors who do this type of work, for a three-month period. After these two three-month periods, a doctor is able to practise in a different area than family medicine.

I also have my own practice. My pager does not buzz at 2:00 a.m. for my practice patients. They are not hemorrhaging, they are not choking and they are not crying out in pain at 2:00 a.m. They are in a very stable condition and suffer much less, overall. I would say that it's almost a hospital practice in a home setting.

When we work at the hospital, we are woken up at night for our patients who have been hospitalized. The same thing goes for home-based palliative care. I really want to underscore this point: patients whose condition is unstable and who need complex medical care need to have a doctor on call 24 hours a day, otherwise they will just keep on going to the ER.

I would like once again to say thank you to Dr. Downar. This is the biggest medical crisis the health care system is facing everywhere in Canada.

[English]

If only you knew, Dr. Downar, how much worse it is in the province of Quebec.

[Translation]

Our statistics on deaths in the home show this, because we only have 12% of deaths taking place in the home. It is a very low percentage, compared to what we see elsewhere in Canada, which is 30%.

Mrs. Élisabeth Brière: Thank you.

So what do we need in practical terms? Let's say that I'm coming to the end of my life and I'm living at home. Will a nurse come stay with me 24 hours a day?

Dr. Geneviève Dechêne: No. As I said in my presentation, caregivers play an active role. This means that hospital-based doctors may not be comfortable with home care if they do not have a framework and are not supervised. Caregivers are given the responsibility of administering opiates by injection, giving medication and checking vital signs. Of course, not all patients can stay home until the end, but we manage to keep between 64 and 65% of patients at home and we accompany them until the end.

The nurses are already working. We have them everywhere in Quebec and they are extremely competent. They are fantastic, consummate professionals. They have a bachelor's degree and are

trained in palliative care, but who can they call at 9:00 a.m. on a Friday morning if the patient is choking, when there is no on-call medical staff 24 hours a day, which for us means an intensive palliative care team? That is what we are lacking in Quebec.

[English]

Mrs. Élisabeth Brière: Dr. Downar, would you like to add something?

[Translation]

Dr. James Downar: If I may, I would like to add some quick comments on the situation outside of Quebec. There are problems everywhere in Canada, but we have a few ways of filling the gaps in the system.

Here in Ontario, there are many teams and various models to support patients at home. You asked what it would take to help those patients at home. As Dr. Dechêne said, oftentimes, there aren't enough doctors in the community who make house calls. It is therefore important to have a team which has the necessary skills to meet patients' needs. That could be a nurse practitioner.

For example, nurse practitioners or nurses who have the necessary skill set are able to meet the needs of patients. A family doctor can be supported by a consultant specialist who would be on call to give advice in order to help manage certain situations. In the case of patients whose needs are more complex, teams of doctors specialized in palliative care can make house calls. Often, though, these specialists are only present in urban communities, as you stated.

There are many models. As Dr. Dechêne said, it is important to find models that offer rewards. It is sometimes difficult for doctors to earn a good living when they make house calls, because house calls don't pay very much. Remuneration schemes do exist, however, especially in Ontario.

• (0915)

The Joint Chair (Hon. Yonah Martin): Thank you very much.

[English]

We'll now go to Monsieur Thériault for five minutes.

[Translation]

Mr. Luc Thériault: Thank you, Madam Chair.

My question is for Dr. Dechêne.

It is most refreshing to hear what you have to say, given that Quebec's Act Respecting End-of-Life Care was brought into being in order to put an end to the argument opposing palliative care and medical assistance in dying. This is most interesting because your comments are entirely based on this aspect and validate my own opinion on the subject.

What is the situation currently? We have a hospital-based system. This means that a person's last moments usually take place in a hospital. From what I understand from your presentation, if there were palliative care on offer and everyone had access to it, there would be no more medical assistance in dying because no one would request it. That is the argument used by those that oppose medical assistance in dying.

Could you be brief in your reply, because I have a few more questions to ask.

Dr. Geneviève Dechêne: You are absolutely right.

In Quebec, the proportion of all deaths by MAID is at 3.4%, and I believe that we will get to the Belgian or Swiss average, which is 4% to 5%. I agree with this, because we have to respect the will of our patients.

I will be brief. If patients, as it often happens, do ask for MAID because no doctor is available to ease their pain, then that is less acceptable to me.

Mr. Luc Thériault: All right.

Correct me if I'm wrong or if you don't agree with what I'm going to say, but in the end, medical assistance in dying should be seen as part of the continuum of care.

People sometimes say that patients request medical assistance in dying because palliative care is missing. A dying patient does not have access to palliative care and therefore requests medical assistance in dying.

But palliative care, when seen as part and parcel of accompanying a person toward death, and I would also ask that you define this notion, could be such that at a given time, a patient may be ready to let go. Because that patient has received good palliative care, has been well supported on his or her journey toward death and is completely at peace, that person could then decide that today is the day that he or she lets go and would like to depart this earth.

The example I've given you does not constitute a failure of palliative care. It could be seen as a success story for palliative care because, all of a sudden, the patient is completely at ease with letting go and requests MAID.

Do you agree with this?

Dr. Geneviève Dechêne: The words “let go” don't sit well with me because 96% or 97% of our patients do not request MAID. I'm not ready to say that they “hung on.” The expression doesn't sit well with me. I think we should see the end of our life as...

Mr. Luc Thériault: Pardon me for interrupting you.

Someone told me that an approach based on self-determination is actually a very controlling approach to death, because that person wants to control his or her death till the very end. The person told me that we are obsessed with controlling death and that is the reason people are requesting MAID. But really, when a person gets up in the morning and feels totally at peace with his or her decision to go, that is letting go. It does not exclude a person who wants to keep on living until the end. That is not the issue here.

Dr. Geneviève Dechêne: The vast majority of people want to continue living until the very end because they know that we will be there, that we are there to reassure them and that we will know how to ease their pain during the care journey up until the end.

I would like to state as well that because we are not lacking nurses and doctors, the patients that are being accompanied do not feel abandoned by the health care system. I would add that we offer palliative care elsewhere in Quebec, in addition to Verdun. Other municipalities are also well served. A good portion of requests for

MAID are made due to psychiatric or psychological disorders, and not physical ones. We regularly offer palliative sedation to people who are tired and suffering to help them sleep and often, so that they do not wake up again.

MAID is another issue, it is not part of the continuum of palliative care. It is an essential and complementary addition to palliative care. That's the way that I see things.

Mr. Luc Thériault: I'm not sure that I've understood. Are you saying that when palliative care is good, there's no desire to request MAID?

Dr. Geneviève Dechêne: No, quite the contrary. I'm sorry, I must have not expressed myself clearly. When palliative care is good, approximately 96% of patients do not request MAID. I said 96%, not 100%.

• (0920)

Mr. Luc Thériault: In those cases, there is no request for MAID.

Dr. Geneviève Dechêne: Actually, those patients talked to us about it many times, and they said that they felt better and relieved in the end, and they had an acceptable quality of life until the end.

Three to four per cent of our patients receive medical assistance in dying. I'd like to add that those patients often decide in advance to receive MAID before they have physical pain or shortness of breath, but they are experiencing significant psychological pain. Also, they absolutely need to control the decision regarding the day, the hour and the minute of their death, and we have to respect that.

[English]

The Joint Chair (Hon. Yonah Martin): Thank you very much.

Last, we'll have Mr. MacGregor. You have five minutes.

Mr. Alistair MacGregor (Cowichan—Malahat—Langford, NDP): Thank you, Madam Chair.

Thank you to all of our witnesses for appearing today.

Mr. Hawkswell, I'd like to direct my questions to you if I may. It's good to see you join our committee today. I really did appreciate how your comments were focused on a patient-centred approach. We, as a committee, have previously had Dr. Valorie Masuda appear before us, who's one of my constituents. She's a palliative care physician and she has seen first-hand with her patients how psilocybin in a controlled environment has definitely relieved their anxiety, the existential dread they feel when they are approaching the end of their life, and has allowed them to focus on that part of their life with friends and family present and with a much more sound mind.

You mentioned the research from Johns Hopkins. I'm just reading their website. I'll quote it:

Research to date [demonstrates] safety of psilocybin in regulated spaces facilitated by medical [teams] over a series of guided sessions; and as a part of cognitive behavioural therapy, psilocybin helps in reducing anxiety in some cancer patients, and in facilitating even smoking cessation for some.

Can you add a little bit more to what that research is pointing towards, and later on would you be able to submit some of that research to this committee so that we can consider it as we're approaching our final report?

Mr. Spencer Hawkswell: I can absolutely submit some research and opinion pieces from the patients and doctors if you would like. I believe they're very helpful and outline more patient-centred cases in which both patients and health care professionals, as well as families, have been helped by this.

I will just add a bit more on the use of psilocybin and what we've seen in close to 100 treatments that our organization has helped facilitate with doctors such as Dr. Val Masuda.

Psilocybin, the compound, alone does not alleviate much of the end-of-life distress. It's commonly referred to as that, but it is the combination of anxiety, depression and hopelessness that a patient faces when they're told that they're going to die. Again, this does not affect every cancer patient, but some of the literature reviews we've done—which we will also try to include—show that about 2,800 Canadians every year fall into this category of treatment-resistant depression or anxiety due to an end-of-life diagnosis.

What the psilocybin does, coupled with psychotherapy, which is what you're referring to and what Johns Hopkins was referring to, when it is conducted with clinicians in a safe space—and that space can be the patient's home, where many of the treatments have been done—is to aid in the psychotherapeutic process. It allows people to let their guard down. In many cases, it allows the therapist to actually do the work that they need to do.

For many people the psychotherapeutic process is hindered by lies that people tell themselves and by fears. In many cases, the patients coming out of these experiences are reporting that they are no longer afraid of death or that they feel a oneness with the universe. It is essentially years of psychotherapy packed into a single session with the help of medicine.

Mr. Alistair MacGregor: Thank you.

I have limited time left. Psychedelics Canada is asking for three key things. They want more federal government research into this by the Canadian Institutes for Health Research; they want clear, effective and evidence-based regulations; and they want a pharmacist compounding psychedelic substances under Health Canada's special access program.

Can you add a little bit more to that and put it in the context of the barriers you have faced under current regulations? What kind of recommendations would you like to see this committee make in its final report so that we are making sure that end-of-life care truly is a patient-centred approach?

● (0925)

The Joint Chair (Hon. Yonah Martin): You have just under one minute.

Mr. Spencer Hawkswell: I'll be very quick, then, and will comment on the special access program and regulations.

First, the special access program, which was amended in January of this year to facilitate psilocybin use, is a complete and total failure. Eighteen patients have been granted access. Val Masuda, the

doctor of one of your constituents, can attest to the fact that SAP was a failure. Health Canada is now telling us and many of the doctors and patients that they are to not use the SAP and to use clinical trials, which is wrong here.

We need regulations. We need medical regulations. Our organization has written those medical regulations and submitted them to the ministers of health. Those medical regulations fall right in line with the medical cannabis regulations, which, again, are based upon human rights. That's what we're looking for—the human right to try psilocybin, especially for those for whom it works.

Mr. Alistair MacGregor: Thank you.

The Joint Chair (Hon. Yonah Martin): Thank you very much.

Now we'll go to our round of questions from the senators.

I will turn this over to my co-chair.

The Joint Chair (Hon. Marc Garneau): Thank you, Senator Martin.

We'll begin with Senator Mégie.

[*Translation*]

Senator, you have the floor for three minutes.

Hon. Marie-Françoise Mégie (Senator, Quebec (Rougemont), ISG): Thank you, Mr. Chair.

My first question is for Dr. Dechêne.

Good morning, Dr. Dechêne.

Dr. Geneviève Dechêne: Good morning, Senator Mégie.

Hon. Marie-Françoise Mégie: The notes that we get, which are reports, articles and even legislation, refer to palliative care and end-of-life care. That can really confuse people who don't work in the field.

Could you please explain the difference between “palliative care”, because you talked about the final 12 months of life, and “end-of-life care”?

Dr. Geneviève Dechêne: That's a very good question. Thank you, Senator Mégie.

The Collège des médecins du Québec helped us draft the definition. It produced a document I was happy to help write, *Medical Care in the Last Days of Life*. In the last week of life, patients do not receive palliative care, they receive care for the last seven days of life.

Palliative care is all types of care given to someone with a guarded prognosis, who has an incurable terminal illness and is in agony. Take, for example, a heart failure patient. I challenge even the top cardiologists to determine the day and time of death of a patient with an enlarged heart. Death can come the next day or eight months after their checkup. These patients choke regularly. They need opiates to relieve their shortness of breath. That's what palliative care is. It's care often given in conjunction with acute care. Palliative care should not be seen as something that blocks and prevents acute medical care. I can give my heart failure patient diuretics to get rid of excess water, but also morphine to relieve their shortness of breath. So palliative care is provided over a long period of time, months, but rarely years. In the Western world, people rarely die of pneumonia. We die of chronic terminal illness.

Hon. Marie-Françoise Mégie: We also have something we wanted to clarify at some point with a witness.

How would you define “good palliative care”, or comprehensive palliative care as you call it in your document?

Dr. Geneviève Dechêne: The World Health Organisation and the Canadian Hospice Palliative Care Association have defined “good palliative care”. All professions must be involved. There is the core team, the first step in the staircase, represented by the nurse and physician, who must be available in all care settings with 24-hour coverage. The core team should also be surrounded by other health care professionals, that is, nutritionists, social workers and the all-important home care workers, who provide all the hygiene care and help patients eat and get around. These are inter-professional teams.

That's what we call “good palliative care”.

The Joint Chair (Hon. Marc Garneau): Thank you, Senator Mégie.

Hon. Marie-Françoise Mégie: Do I have any time left?

The Joint Chair (Hon. Marc Garneau): No, you had three minutes.

Senator Kutcher, you also have three minutes.

[*English*]

Hon. Stanley Kutcher (Senator, Nova Scotia, ISG): Thank you very much, Mr. Chair.

Thanks to all the witnesses. Just as an observation, gosh, three minutes goes fast.

Our family has had personal experience with excellent home-based palliative care. I agree that improving home-based palliative care is essential to providing more end-of-life choices. We've known for decades that health human resources across Canada are inadequate in all kinds of health care, including in palliative health care. This is not unique to palliative care.

Dr. Downar, we've also heard arguments that MAID funding is stealing resources that were originally directed for palliative care, or that funding for MAID is causing deficits in funding for palliative care, that funding is being specifically directed to MAID instead of palliative care. Can I have your thoughts on these concerns?

• (0930)

Dr. James Downar: I have heard these claims too, but I don't think there's really any basis for them. I think in most cases in many parts of the country, palliative care funding is increasing, and increasing quite substantially. My own division in Ottawa has roughly doubled in size, including a large increase in salaried positions over the past few years. I think that has largely been the case in much of Ontario.

I know that it's not the case across the country, and I'm not claiming that it is, but definitely there has been a substantial increase, I think, in funding for staff and funding for beds, which unfortunately we're just generally missing staff for and can't always fill. That's super-important to state.

In terms of resources and our resources being stolen, I think it's also important to remember that if somebody is at end of life and is suffering, and they are getting resources, I find it hard to understand why people would say that it's an inappropriate use of palliative resources. I'd really regret if any member of the palliative care community would say that it's stealing resources. The resources belong to the patients. They are patient resources, not my resources and not anyone else's resources. They are for them. If they are nearing the end of life and suffering, and the resources go to them, good. The fact that they have chosen MAID shouldn't make them ineligible for resources.

Hon. Stanley Kutcher: Dr. Dechêne, thank you so much for being here. Your sister is a great senator.

Dr. Geneviève Dechêne: I agree.

Hon. Stanley Kutcher: Could you give us your comments on what Dr. Downar told us? What is your perspective on that?

Dr. Geneviève Dechêne: I would not add a word more.

Thank you, Dr. Downar. I agree completely with you.

Dr. James Downar: Is that why you get all the questions—because your sister is a senator?

Voices: Oh, oh!

Dr. Geneviève Dechêne: Well, she supervises me. I have to give short answers, so I'm trying to do so.

Hon. Stanley Kutcher: I think I have 48 seconds left.

The Joint Chair (Hon. Marc Garneau): You have 18 seconds left.

Hon. Stanley Kutcher: Oh, dear.

We have seen chaos in nursing homes during the pandemic. Do you think we should recommend a pan-Canadian approach to improving care for our elderly? That would be for everyone who's elderly—not just at end of life, but for all elderly people in this country.

[*Translation*]

Dr. Geneviève Dechêne: I'm going to answer in French because it's a delicate matter.

Health care is a provincial jurisdiction. In other words, health care decisions are to be made by the provinces .

In my opinion, Canadians should receive a minimum level of care from coast to coast. I'm talking about palliative care, but also geriatric care and in long-term care facilities.

The Joint Chair (Hon. Marc Garneau): Thank you very much.

I will now turn the floor over to Senator Dalphond for three minutes.

Hon. Pierre Dalphond (Senator, Quebec (De Lorimier), PSG): Thank you, Mr. Chair.

My questions are for Dr. Downar and Dr. Dechêne.

We've talked about the fact that 98% of those who have had access to MAiD were receiving palliative care. We also spoke of the lack of resources related to access to palliative care.

Would you say that individuals who have access to palliative home care are less likely to choose MAiD than those who don't?

Quebec appears to have a lower rate than Ontario, but I'd like to hear about the Ontario experience first.

Dr. James Downar: Thank you for your question.

We know that individuals who have received palliative home care and patients who receive MAiD are the same people. If a study were conducted with these groups, it would clearly demonstrate that these are the same people. So it's hard to say whether it's access to palliative home care that determines if people will seek out MAiD.

Dr. Geneviève Dechêne: I'd like to add something.

Hon. Pierre Dalphond: Do we distinguish between individuals who are at home and those who are in the hospital due to a shortage of suitable hospice beds?

Dr. James Downar: I'm not going to lie to you. We don't really have any data on the subject. However, we do know that the fact that people live in an urban or rural community has no incidence on the rate of MAiD requests. The rate doesn't change. A number of studies have shown that we have no reason to believe that access to palliative home care determines whether an individual will request MAiD.

It's important to understand that the reason people request MAiD is primarily because they are experiencing existential and other pain that we can't really treat effectively as hospice workers. That's why even those who are likely getting the best palliative care in the country are going to request MAiD anyway.

• (0935)

Hon. Pierre Dalphond: Thank you.

I believe Dr. Dechêne wanted to add something.

The Joint Chair (Hon. Marc Garneau): You have the floor, Dr. Dechêne.

Dr. Geneviève Dechêne: The data you're talking about is Canadian.

Surprisingly, in Quebec, despite the fact that a report was produced four years after the Act respecting end-of-life care was adopted, no data is available on comprehensive palliative care. We know whether nurses are involved or not, but that's it.

We couldn't even answer your question in Quebec, and I think that's a shame.

Hon. Pierre Dalphond: Thank you.

The Joint Chair (Hon. Marc Garneau): We will now go to questions from Senator Martin.

Senator, you have the floor for three minutes.

[*English*]

The Joint Chair (Hon. Yonah Martin): Thank you very much. Thank you to all of our witnesses.

Dr. Dechêne, you've really helped me and us understand the importance of quality home care, especially quality home care and palliative care.

I want to give you the rest of my time to go into any of the key recommendations that you would have for our committee to ensure that people aren't being pushed to access MAiD due to a lack of access to home care, palliative care, chronic pain services and mental health services.

Would you go into the key recommendations that you have for our committee?

[*Translation*]

Dr. Geneviève Dechêne: Thank you for that really great question.

I have a dream that comprehensive palliative care will one day be available Canada-wide, not just in Quebec, and therefore, all the professionals I just mentioned will be present. As Dr. Downar was saying, the physician can provide care in the home or over the telephone, but we need comprehensive teams so that patients at the end of life have access to medical and nursing care as well as the full range of other professional care they need. I want to make it clear that access to this care is critical whether or not cancer is involved, because non-cancer diseases are always overlooked and they account for half of deaths. Everyone should have access to that care, both those who need more and those who need less.

I'd like to reiterate that MAiD is a complement to good palliative care, not a continuum of care. Also, I believe that more people will request MAiD. We have an average of 3.4% medically assisted deaths in Quebec. So that has gone up and I think it will continue to go up. Quebec is ahead of several Canadian provinces in that respect. I'm not making any value judgements because I feel the most important thing is that we respond to patient requests.

[*English*]

The Joint Chair (Hon. Yonah Martin): I saw Dr. Downar's hand. Did you want to add something to that?

Dr. James Downar: I wanted to respond to something Mr. Hawkswell said previously. I'm sorry; I don't know if this is a good time for that.

The Joint Chair (Hon. Yonah Martin): Dr. Dechêne, it seems that what's happening in Quebec in terms of home care and palliative care is about the fact that there's a lack of access and not enough specialists. Are you aware if this is a problem across Canada?

Dr. Geneviève Dechêne: No, I'm not aware. I'm just speaking for Quebec. I have not studied the other provinces.

Nothing is perfect anywhere in Canada, but obviously the figures we have of the number of patients dying at home show that Quebec is far worse as far as access to palliative care is concerned.

Our guess—but the government is not working on this data, unfortunately—is that 85%, maybe even 90%, of all patients in their last year of life who are unable to go to a hospital or clinic to have their medical care have no medical care at home. That's a lot.

The Joint Chair (Hon. Yonah Martin): I would think the same issues are prevalent in other provinces and territories as well.

Thank you very much.

Dr. Geneviève Dechêne: Thank you.

The Joint Chair (Hon. Marc Garneau): Thank you, Senator.

[*Translation*]

Unfortunately, time is going by so quickly and we're now at the end of our first panel. I'd like to thank the witnesses for appearing this morning.

Thank you, Dr. Dechêne, Dr. Downar and Mr. Hawkswell.

[*English*]

Thank you for coming and providing testimony this morning and answering our questions. We very much appreciate it.

With that, committee, we will suspend for a few minutes to move to our next panel.

Hon. Stanley Kutcher: Excuse me, Chair; could I ask a question?

• (0940)

The Joint Chair (Hon. Marc Garneau): Go ahead, Senator Kutcher.

Hon. Stanley Kutcher: Thank you.

Dr. Downar was wanting to make a comment.

Dr. James Downar: It's a very quick one. I promise.

Hon. Stanley Kutcher: You can say it or put it in writing to us. Either way is good.

The Joint Chair (Hon. Marc Garneau): I think probably it's best to put in writing.

We would appreciate it, Dr. Downar. We have to stay within the protocols of this meeting. Please send it to the committee.

Dr. James Downar: Thank you. It's about regulations.

The Joint Chair (Hon. Marc Garneau): Thank you.

With that, we'll suspend.

• (0940)

(Pause)

• (0945)

[*Translation*]

The Joint Chair (Hon. Marc Garneau): Hello again.

We will now resume our work with our second group of witnesses.

[*English*]

I would like to make a few comments for the benefit of our new witnesses. These are housekeeping rules.

Before speaking, please wait until one of the co-chairs recognizes you by name.

This is a reminder that all comments should be addressed through the joint chairs.

When speaking, please speak slowly and clearly. This is for the benefit of our interpreters. Interpretation in this video conference will work like an in-person committee meeting. If you're remote, you have the choice at the bottom of your screen of floor, English or French. The little globe is the interpretation button. When you're not speaking, please keep your microphone on mute.

With that, I would like to welcome our witnesses for the second panel. Again, we're looking at palliative care.

We have online with us Dr. José Pereira, professor and the director of the division of palliative care at the department of family medicine at McMaster University. We have in the room with us Mr. Mike Kekewich, director of the Champlain Regional MAID Network and the Champlain Centre for Health Care Ethics.

I'm not sure I see him yet, but we're hoping to have Dr. Louis Roy.

[*Translation*]

Dr. Roy represents the Collège des médecins du Québec. He should be arriving any minute now.

[*English*]

With that, thank you all for joining us.

We will start with opening remarks from our three witnesses. We will start with Dr. Pereira. Each witness will have five minutes for opening comments before we go to questions.

Dr. Pereira, you have the microphone for five minutes.

Dr. José Pereira (Professor and Director, Division of Palliative Care, Department of Family Medicine, McMaster University, As an Individual): Thank you, honourable chairs, and thank you to the committee for the invitation to discuss palliative care in Canada.

As you've heard, I'm professor and director of palliative care at McMaster University, and I'm also co-founder and scientific officer of Pallium Canada.

I have dedicated most of my career to improving palliative care in Canada and abroad, and I've worked in different clinical, education, research and leadership roles in several Canadian jurisdictions. I am pleased to appear before you to share my experiences in the science on palliative care.

I'd like to briefly highlight three areas related to palliative care in our country: access and availability, education, and funding.

While we have seen noteworthy improvements across all three areas in the last two decades, many gaps still exist. We cannot say today that all Canadians have access to palliative care. In fact, many still do not. The good news is that there are examples of excellence in all these areas across the country, and there are solutions as well.

Let me start with access to palliative care and palliative care services.

On average, only about 30% to 50% of Canadians who need palliative care have access to it or receive it, whether it is delivered by palliative care specialists or by other health care professionals. On average, only about 15% to 25% of patients have access to specialist palliative care teams to address more complex needs. In many rural and remote areas of the country, there is no access to specialist palliative care, and many of the health care professionals serving those populations, just like their urban colleagues, lack core palliative care skills.

A growing body of research shows that palliative care should be initiated early in the illness, not just in the last days or weeks of life. It improves quality of life and reduces anxiety and depression, caregiver distress, hospitalizations and, importantly, health care costs.

Despite this, we consistently see palliative care activated very late in the illness. I see that often in my clinical practice, and studies confirm this.

Whether you'll get the palliative care you need depends largely on where you live, what you're dying from and how close you are to death. Some areas have excellent access; others have almost nothing. You're also less likely to receive palliative care if you're poor, indigenous, homeless or incarcerated.

The availability of access to key palliative care services is still a patchwork across our country. For example, experts propose at least 10 palliative care in-patient beds for every 100,000 inhabitants. This includes palliative care units and hospice beds. Many jurisdictions across the country do not attain these standards. Some do; many don't. Many hospitals across the country do not have sufficient palliative care physicians and nurses, and many communities do not have adequately staffed palliative care specialist teams to

support family physicians and home care nurses to provide home and community-based palliative care.

The COVID-19 pandemic has had a major impact on the home care workforce. We struggle to discharge patients from hospital, because there is a lack of home care with palliative care supports. Canadians need assistance in living and supports. This is a crisis.

The pandemic has also highlighted chronic deficiencies in the integration of palliative care into long-term care homes, but again there are centres of excellence.

In the area of education, we have too few palliative care specialists in the country and too few training positions for new palliative care specialists. However, all the palliative care needs of a population cannot be met by palliative care specialists alone.

We must train our professionals in primary care and across many specialty areas to provide a palliative care approach. This has been highlighted in the government's 2018 framework on palliative care.

Many learners across the health professions are still graduating without core skills. In Canada, for example, fewer than one in three medical students completes palliative care clinical rotations during their training. In residency training, only 60% of family medicine trainees completed clinical rotations, and the numbers are low in other specialty areas.

Many practising professionals in primary care and across different specialty areas do not have core palliative care skills. Interestingly, in a study of 10 OECD countries, only 42% of primary care practices in Canada felt prepared to provide palliative care. The number was 80% in the U.K.

To help address this gap, Pallium Canada, a non-profit organization that I co-founded 22 years ago, has trained over 40,000 health care professionals across the country on the palliative care approach. We also now train carers and help build compassion community programs. This still represents less than 6% of the workforce.

Funding is needed to spread these initiatives. The public also needs to be educated on what palliative care actually is and what it can offer.

This finally brings me to funding. Sustained and adequate funding by federal, provincial and territorial governments is needed to ensure access to palliative care services and education. Too often, it's piecemeal.

• (0950)

We applaud some provincial governments, such as the Government of Alberta, which has recently invested in palliative care training en masse, and the Nova Scotia government, which is training PSWs on a large scale.

Federal funding is required to provide the necessary infrastructure and resources to implement the key priorities outlined in the "Framework on Palliative Care in Canada".

Thank you very much, honourable chairs.

The Joint Chair (Hon. Marc Garneau): Thank you, Dr. Pereira.

[Translation]

We will now hear from Dr. Louis Roy, who will deliver his opening remarks.

Dr. Roy, you have the floor for five minutes.

Dr. Louis Roy (Physician, Collège des médecins du Québec): Good morning. Thank you for having me. I'm sorry I'm a little late. I was having some minor technical issues.

I'm here today to share the thoughts of the Collège des médecins du Québec, where I've been working for the past year and a half.

The Joint Chair (Hon. Marc Garneau): Sorry to interrupt you, but we're having interpretation and sound quality issues.

• (0955)

Dr. Louis Roy: Hello?

The Joint Chair (Hon. Marc Garneau): On your screen, have you selected your headset as the audio input? It's going through your computer right now.

Do you know how to do that?

Dr. Louis Roy: I'll check. The headset should be selected.

The Joint Chair (Hon. Marc Garneau): I can ask a technician to contact you.

Dr. Louis Roy: Is that better now?

The Joint Chair (Hon. Marc Garneau): No. A technician will contact you. We will go on to Mr. Kekewich and come back to you after him, Dr. Roy.

Dr. Louis Roy: Okay, thank you.

[English]

The Joint Chair (Hon. Marc Garneau): With that, Mr. Kekewich, if you are ready, the floor is yours for five minutes.

Mr. Mike Kekewich (Director, Champlain Regional MAID Network, Champlain Centre for Health Care Ethics, The Ottawa Hospital): Thank you very much, Mr. Chair and members of this committee.

Good morning, and good morning to my fellow panellists as well.

I'm the director of the Champlain Regional MAID Network here in Ottawa. We provide care to patients throughout the Champlain region, going from roughly Pembroke all the way to Hawkesbury. I'm also the director of the Champlain Centre for Health Care Ethics, both of which are hosted at the Ottawa Hospital here in town.

I'd like to make a few comments on what we're presently experiencing with respect to MAID, and then I'll talk a little bit about palliative care, given that's the subject of today's discussion.

First I want to comment on the most recent data from Health Canada, which shows that MAID continues to grow quite substantially from year to year, now representing 3.3% of deaths in Canada. We're seeing the same trend in our region and in this province, and it's very clear that more and more Canadians are inquiring about and accessing this service. I think we could continue to expect those numbers to grow as eligibility changes over time in terms of the law.

I do want to take just a quick moment to formally acknowledge the hard work of the clinicians across the country who are supporting patients and families through these very difficult decisions, particularly during this pandemic response period.

Ultimately, physicians; nurse practitioners; MAID navigators, as they're called, or coordinators; and other dedicated health care professionals are critical to the delivery of compassionate and high-quality care to patients who are requesting MAID.

I believe it's worth noting quickly that those who are actually assessing patients and providing MAID may not be as big a group of clinicians as people might think. In 2021, the total number of clinicians who provided at least one MAID procedure was 1,577, which initially sounds like a fairly comfortable number, but 35% provided only one MAID procedure, while just over 16% provided more than 10.

This is a challenge. It's a lot of stress on this dedicated group of clinicians. There were over 10,000 MAID provisions in 2021, and obviously there were a lot more assessments of patients moving through this process. There continues to be a substantial need for service from this group of clinicians.

In terms of palliative care, I would like to make a few comments.

Obviously I agree with the previous panellists. I had the opportunity to sit here and listen to them. Palliative care is an essential and critical service for Canadians and particularly for those who are considering MAID. I strongly believe—and have for many years—that MAID and palliative care are not mutually exclusive.

In my experience, many patients who are requesting MAID have historically received, or are currently receiving, very high-quality palliative care services that help them manage their suffering in a variety of ways. Many patients who are not receiving palliative care when requesting MAID are referred in that direction to give them the best possible care, regardless of what decision they ultimately make. Even for patients who ultimately do receive MAID, it's often the case that they continue to receive palliative care up until their final days to help alleviate their suffering, because MAID providers primarily act as consultants; they don't take over all of the responsibilities for caring for patients, in most cases.

I was encouraged to see in federal reporting over the last number of years that over 80% of MAID recipients had in fact received palliative care, with many of them receiving those services for one month or more, which I think is noteworthy.

In 2021, palliative care was identified as being accessible to 88% of those who received MAID in Canada, which I think is very encouraging.

- (1000)

Other localized studies and reports on this topic show, with some variability, that most patients requesting MAID were receiving palliative care or had access to it. I think it may also be the case that the introduction of the waiver of final consent, which was part of Bill C-7, might have the effect of patients continuing to receive palliative care up until their final days, because historically some patients had been concerned about the requirement that they maintain capacity at the time that MAID is ultimately provided.

Obviously I'm encouraged by the data. I think there's still room for disagreement in terms of what would represent adequate access to palliative care for these patients; I don't feel particularly qualified to answer that question, but I believe that there is probably no such thing as too much access to palliative care services, and I think that probably transcends the conversation around patients who are requesting MAID, because it appears that they actually have quite good access to those services.

I will stop there. I am happy to receive any questions after the next panellist.

The Joint Chair (Hon. Marc Garneau): Thank you, Mr. Kekewich.

[*Translation*]

Now we will go back to Dr. Roy.

Dr. Roy, you have the floor for five minutes.

Dr. Louis Roy: Perfect, thank you.

I'm here to present the position of the Collège des médecins du Québec, where I've been working for a year and a half as an inspector in the Professional Inspection Division.

In light of the progress being made in granting access to medical assistance in dying and developments over the past few years, the Collège struck a working committee made up of clinicians. The committee began reflecting on MAiD in April 2021 and submitted its report in December 2021. The report was then endorsed by the board of directors.

I will now outline the findings and recommendations of the committee and the board.

First—and this has to do with the federal government, but also the Quebec provincial government—the Collège would like to note the harmonization issues between Quebec and Canadian law. The mismatch in choosing certain words causes confusion among health care providers.

For example, the Canadian legislation talks about an “illness, disease or disability”, while the Quebec legislation does not. It's causing many issues when it comes to interpreting the law. In addition, it could disqualify people who would normally be entitled to MAiD, based on which side of the Ottawa River they call home.

With respect to access to care, the working committee first looked into access to MAiD for persons with neurocognitive disorders, or progressive dementias. The committee and the Collège's board of directors supported advance requests when an individual becomes aware that they inevitably risk losing their faculties due to a progressive illness. People must therefore be able to submit an advance MAiD request, even if that means it is made several years prior to taking any action.

The second area for consideration had to do with MAiD individuals presenting a mental health issue only. Once again, the board of directors endorsed the recommendation that MAiD should only be available to people with a serious and persistent mental health condition for which treatment has been attempted and for which the individual sees no other outcome. Of course, this requires further thought about how to implement it. We need to make sure that the law is interpreted correctly and access to care respects people. We also need to make sure that all the necessary and possible care has been offered to an individual with mental health issues. In our current health care system, we know that access to mental health care can be problematic.

The third area for consideration was access to MAiD for emancipated minors between the ages of 14 and 17.

With support from the board of directors, the committee recommended that emancipated minors be able to apply for MAiD in conjunction with their parental authority or guardian. The pain that these young people may suffer must be taken into account; the suffering may become intolerable and it may no longer make sense in certain situations. The same is true for babies from birth to one year of age who come into the world with severe deformities and very serious syndromes for which the chances of survival are virtually nil, and which will cause so much pain that a decision must be made to not allow the child to suffer. In that respect, the committee highlighted the Netherlands' and other countries' experience. This avenue could be explored.

Finally, the committee considered the burden of living some elderly people carry. In geriatrics, we call it failure to thrive. For these individuals, life no longer makes any sense. Among other things, the fragility of life, diminished physical capabilities and existential pain become intolerable burdens. The committee and the Collège endorsed the idea of undertaking thorough reflection on this.

• (1005)

This is a topic that remains sensitive for the public and one for which we currently do not have clear answers on our side. Yet we want to be able to continue to have a joint reflection with learned societies and the general public to see under what circumstances this may be an option.

So I've presented to you here quickly, in a few minutes, the result of the reflections of the college's working committee, reflections that have been endorsed by its board of directors. The committee's work lasted six months, but it followed many years of reflection and work around this topic.

I am available to answer questions from committee members and provide clarifications.

The Joint Chair (Hon. Marc Garneau): Thank you, Dr. Roy.
[English]

I will now turn it over to my co-chair, Senator Martin.

The Joint Chair (Hon. Yonah Martin): Thank you.

Thank you, all three of you, for your testimonies. It will be very helpful to our committee work.

We'll begin our first round of questions with five minutes for Mr. Barrett.

Mr. Michael Barrett (Leeds—Grenville—Thousand Islands and Rideau Lakes, CPC): Thanks very much, Madam Chair.

Thank you to the witnesses for your time.

My first question is for Dr. Pereira.

Since MAID was legalized, have you had any experience of being prevented or impeded from applying a palliative care approach for someone who could have benefited from it?

Dr. José Pereira: Yes, I have, and I've also had colleagues share similar experiences. I'll give you an example.

I was working for two years in a palliative care unit in my region, and in the palliative care unit, MAID is done. Patients are referred from other hospitals and other settings to the units to receive MAID. There were some occasions on which I saw patients I thought could benefit from palliative care, in that the treatment, the palliation, they received was suboptimal, and we could optimize it, but I was made to feel that I was obstructing access to it.

I think that does happen, and if you speak to colleagues, you will hear those examples.

That reminds me that I think a previous speaker said that most people who are requesting MAID are receiving palliative care. There are examples in which they arrive in palliative care units, and

therefore on paper they are in a palliative care setting. However, they are not receiving palliative care; they are awaiting MAID.

I think we need to look at those numbers a bit more cautiously and closely.

• (1010)

Mr. Michael Barrett: To pick up on something you said there, the distinction between palliative care and medical assistance in dying is one that has been noted by the board of directors of the Canadian Society of Palliative Care Physicians. International associations of palliative care state that distinction. Can you comment, then, on the intrusion of MAID into palliative care in the Canadian context, please?

Dr. José Pereira: Yes. It's not only professional societies or associations of palliative care; it's also the World Health Organization that doesn't see MAID as part of it.

I believe that there is a distinction between the two. I understand that in a democratic society one can have access to it, but it doesn't mean that they have to be associated.

What I've seen is confusion around the two. For example, a few weeks ago I had a patient who had very advanced dementia and was on hemodialysis. She was in the final stages of her life and was still receiving hemodialysis. I met with the family and said that we needed to consider stopping hemodialysis, since it was not being helpful anymore. The family were very upset because they felt that I was promoting MAID. I had to spend a lot of time explaining that this is not MAID and we don't do MAID.

I also think that linking the two causes confusion. We are trying to move palliative care to earlier in the illness trajectory. This has been known since 2002. There's an emerging body of evidence showing the benefits of palliative care that is started months before the end of life. I think associating it with MAID keeps linking it to the very end of life.

I have seen resources being diverted. In one of the peripheral areas of the region that I live in, there have been nurses and nurse practitioners assigned to do MAID assistance, and therefore not enough health care professionals to assist patients for their palliative care needs and to address palliative care.

Mr. Michael Barrett: Okay. To paraphrase, you would say that end-of-life resources that are going to MAID are in some cases being provided at the expense of palliative care offerings. Is that correct?

Dr. José Pereira: Yes, Madam Chair, I would agree with that—

Mr. Michael Barrett: Okay—

Dr. José Pereira: —in some cases.

Mr. Michael Barrett: Madam Chair, how much time do I have left?

The Joint Chair (Hon. Yonah Martin): You have 30 seconds.

Mr. Michael Barrett: Okay.

Could you briefly speak to Canada's palliative care approach as compared to international examples that you have personal experience with, please?

Dr. José Pereira: Yes, certainly.

A study of world rankings has been published recently. There was a large Economist study done and published in 2015. Canada stands at about 10th or 12th on the list overall, but we start dropping in certain areas. For example, in funding for private care resources, we've dropped down to the 20th spot, so there's room for improvement.

Many other jurisdictions, such as the United Kingdom and Australia, put a lot of effort into ensuring they have enough specialist palliative care services and specialist palliative care teams, and they also build up what we refer to as the primary part of care. In other words, all health care professionals caring for patients with cancer, heart diseases, lung diseases and renal diseases, etc., have those core skills—

The Joint Chair (Hon. Yonah Martin): Thank you.

Dr. José Pereira: —and in Canada, we still have a long way to go to ensure that is occurring.

The Joint Chair (Hon. Yonah Martin): Okay. Thank you very much.

Next we will have Monsieur Arseneault for five minutes.

[*Translation*]

Mr. René Arseneault (Madawaska—Restigouche, Lib.): Thank you, Madam Chair.

I thank the witnesses for being here, including those from the first panel, if they are still watching us. It has been really enlightening.

I will address you first, Dr. Roy. The data that we have in the annual reports on medical assistance in dying for the last three years is quite telling in terms of the proportion of people who request medical assistance in dying versus those who request palliative care. What was feared does not seem to be happening—that is, 82% or 83% of the people who requested medical assistance in dying were receiving palliative care. They decided to leave of their own free will, with medical assistance in dying. We also know from the same data that 89% of those who chose not to use palliative care had access to it.

You have been working in palliative care for 22 years. Can you tell us what explains why someone would want to receive medical assistance in dying without necessarily wanting to use palliative care?

• (1015)

Dr. Louis Roy: Thank you for that question, Mr. Arseneault.

In this case, I will put on my clinician hat. That stage of my career ended when I joined the Collège des médecins du Québec, but I still had a long career as a clinician. I have also worked extensively in palliative care, participated in the implementation of medical assistance in dying, and administered medical assistance in dying to many patients myself.

To answer your question, I can speak from my experience as a clinician in Quebec, particularly in Quebec City, where I was, among other things, head of palliative care at the university hospital. The vast majority of people, as you said based on your numbers, had access to palliative care when they requested medical assistance in dying. You really have to look at it as a continuum of care. When medical assistance in dying was implemented in Quebec, we put a lot of emphasis on the fact that palliative care must be present.

It should be remembered that legislation was passed in Quebec a number of years ago, so that palliative care would not be optional in institutions. All public institutions must have a program or plan to provide palliative care, which is not the case everywhere in Canada and which is completely different from what I had experienced some 15 years before the passing of that legislation. I had even been told by someone in an administrative position that my palliative care business was irrelevant to the mission of their institution—

Mr. René Arseneault: Dr. Roy, I'm sorry to interrupt, but I really don't have much time.

What makes a person choose to obtain medical assistance in dying bypassing palliative care?

Dr. Louis Roy: In my experience, most people who directly request medical assistance in dying have already come a long way and are at a stage where palliative care is not the outcome they envision. This can particularly affect people who have a neurodegenerative disease and who see themselves declining. I'm thinking of amyotrophic lateral sclerosis, ALS, also known as Lou Gehrig's disease, among others. They receive care, but it cannot necessarily be called palliative care. Although they have support, these people have chosen a critical juncture past which they do not want to receive intensive palliative care, but rather receive medical assistance in dying.

Mr. René Arseneault: Thank you very much.

Dr. Pereira, could you tell me very quickly if you agree with what Dr. Roy just said about palliative care and medical aid in dying being part of a continuum of health care?

[*English*]

Dr. José Pereira: Madam Chair, I would disagree. With regard to the 80% access, I think we need to stop and look more closely at that number. We don't know what the quality of the palliative care is there. Often it is very late. Often people have suffered for months and months, leading to suffering that then reaches a point where palliative care is finally suggested.

[*Translation*]

Mr. René Arseneault: Have you read and understood the Supreme Court of Canada's Carter decision, which led to the availability of medical assistance in dying in Canada?

[*English*]

Dr. José Pereira: I have read it through, and I was actually part of it, so I am very much aware of it. I think it's important—

[Translation]

Mr. René Arseneault: Dr. Pereira, would you agree that the patient is at the centre of the decision in this case?

• (1020)

[English]

The Joint Chair (Hon. Yonah Martin): Answer very briefly, Dr. Pereira.

Dr. José Pereira: Madam Chair, I think it's important to say that autonomy and the patient being at the centre of the care have always been a foundational piece of palliative care.

I think we need to ask ourselves whether there are limitations as well. Are there things that we are missing? Are there opportunities that we are missing?

[Translation]

Mr. René Arseneault: Okay. My time is up.

Thank you all.

[English]

The Joint Chair (Hon. Yonah Martin): Thank you very much.

Next, we'll have Mr. Thériault for five minutes.

[Translation]

Mr. Luc Thériault: Thank you, Madam Chair.

I will go to Dr. Roy.

During your opening remarks, you talked to us about harmonizing legislation. So I assume you were referring to the harmonization of Bill C-7 and the Quebec bill, the Act respecting end-of-life care.

You talked about the concepts of illness, disease and disability. It seems to me that the Criminal Code and Bill C-7 are pretty clear. What is the problem that makes you talk about harmonizing legislation?

Dr. Louis Roy: The problem is that, in the Quebec bill, the notion of disability is not recognized as a possibility for requesting medical assistance in dying. In French, a distinction seems to be made between an individual who suffers from a progressive disease and a person who has a physical disability.

The simplest example of a physical disability is the case of a person who becomes quadriplegic as a result of a car accident and who must receive constant care from everyone, both for hygiene and nutrition. However, this is not a progressive issue.

In medical terms, as currently worded, the Quebec bill considers that this person suffers from a disability, not a disease that will progress, which prevents them from qualifying to receive medical assistance in dying. If the individual wants to receive it, they must "find a disease", if you will pardon the expression, that will be progressive. It's really a matter of determining whether another condition is present that causes a health condition to progress.

Mr. Luc Thériault: In short, it is not at all a case like Truchon and Gladu where, in the end, the disability is induced not by an accident, but by a progressive disease.

Dr. Louis Roy: Yes, exactly.

Mr. Luc Thériault: Okay.

You talked about mental illness and mental disorders. We've just finished this segment, but I'm going to take advantage of your time with the committee. Have you read the expert panel's report?

Dr. Louis Roy: Yes.

Mr. Luc Thériault: The report states that the assessment should be done by a psychiatrist who is independent of the treatment team. Do you think this is realistic, given the resource situation on the ground in Quebec?

Dr. Louis Roy: That's a great question.

I agree with you, the resource situation means that there is already some difficulty in accessing mental health care. The difficulty that stands out is making sure an independent assessment is obtained.

Since the therapist may have been meeting with a patient for several years, the therapeutic relationship could be tinged with certain elements. Having an independent third party confirm the opinion of the treating physician appears to be a source of safety to ensure that one is not moving a little too quickly or missing something important.

Mr. Luc Thériault: The question is whether we will be ready to implement the legislation by March 2023. Indeed, the legislation currently contains a sunset provision.

Do you think we will be able to move forward? That was more my question.

Dr. Louis Roy: I am not an expert on the whole issue of access to mental health care, but I believe that, if something is to be implemented, the system needs to be able to take the necessary steps to allow access and accessibility.

Mr. Luc Thériault: Okay.

The report also talks about the idea of implementing a prospective oversight process. Yet that oversight is retrospective in the case of the Commission on end-of-life care in Quebec.

In this case, oversight would be prospective. This implies that, following the entire process, a step would be added. Mandatorily, not as needed, a committee would decide whether or not the patient and the assessment have addressed all the requirements.

Do you think this plan is realistic and can be implemented quickly?

• (1025)

Dr. Louis Roy: I will express my personal opinion, which is not necessarily that of the Collège des médecins du Québec. The implementation of such a measure is going to pose some challenges. The application of a prospective measure should, in my opinion, be reserved for contentious, less clear or specific cases.

Then it will be necessary to clearly define within the legislation what will need to be specified.

The Joint Chair (Hon. Yonah Martin): Thank you very much.

[English]

Thank you.

Next we'll have Mr. MacGregor. You have five minutes.

Mr. Alistair MacGregor: Thank you, Madam Co-Chair.

Dr. Pereira, I'd like to start with you. In the previous panel, we had a witness from TheraPsil who was talking about the research that's going on in Johns Hopkins University into psilocybin therapy used in a very controlled environment with cognitive behavioural therapy. One of my own constituents, palliative care physician Dr. Valorie Masuda, has been granted access to this through special exemptions from Health Canada, and she has reported remarkable success in helping patients who are in palliative care overcome their anxiety.

Do you have any thoughts to offer on this research?

There have been calls not only for additional funding into the research, but also to tackle Health Canada's overly complicated and restrictive rules. I want you to answer this in the theme of a patient-centred approach, if we are trying to help patients at the end of their life in palliative care meet their end in a safe and controlled way such that they are not filled with anxiety.

Do you have any thoughts on this?

Dr. José Pereira: Mr. Chair, I'd like to thank the member for that excellent question.

I think what that illustrates is that contrary to what a previous panellist said, which was that there are no solutions or approaches to addressing existential distress, there are, and there are growing numbers of them. One of them in this class of medications is psilocybin.

I've been monitoring the literature coming out, and the results are quite amazing for many persons. They get significant relief from existential suffering as a result of that therapy. Many people as well benefit from approaches such as dignity-conserving care developed by Professor Chochinov.

I would argue that yes, there are approaches to address existential distress. I've seen that in my own practice with my own teams, and it makes a difference, so I think we have to be careful about making assertions that there are no treatments or approaches. Obviously there's not the panacea yet, but we are stretching out. We're improving every year on how we can address these needs.

Mr. Alistair MacGregor: Thank you for that.

To the Champlain Regional MAID Network, am I correct here that your areas of service include not only the city of Ottawa, but also Renfrew County; Stormont, Dundas and Glengarry; Prescott and Russell; and north Lanark?

Is that correct? I see it is.

We've heard comments about the challenges that exist for rural Canadians in accessing service. Can you add anything to what you've heard, based on your own personal experience, and compare patients who live in the city of Ottawa to Canadians who live in those more rural areas that your network also serves?

Mr. Mike Kekewich: Yes, certainly there are some differences in terms of the experience of living in smaller communities and the types of institutions that exist in those communities.

Not that there were many things that were positive about the pandemic, but thankfully, one thing was that virtual care became a very normal modality for providing linkages between patients and providers. I think we were able to mitigate more effectively some of those disparities, to the extent that they exist, by pairing people with services that they needed.

I wouldn't say it's perfect by any stretch of the imagination. I also don't know that I would say that even all rural communities are the same in terms of their access. I think we're making some progress, though. I appreciate the question.

● (1030)

Mr. Alistair MacGregor: Thank you.

Dr. Pereira, I'd like to return to you for my last minute. You talked about how not enough physicians are getting palliative care training. In your observation, how are our medical schools meeting this challenge, especially when you fast-forward 10 or 20 years and look at the demographics of Canadian society? How are the colleges of physicians and surgeons meeting this challenge?

Also, do you have any thoughts about specific regions of Canada that may have a higher-than-average elderly population? I've spoken to members of the provincial legislature in Nova Scotia. They have a very high elderly population, and they don't think the current funding model adequately looks after their particular needs as a province.

The Joint Chair (Hon. Yonah Martin): Please be very brief, Dr. Pereira.

Dr. José Pereira: All right.

The authorities that oversee the medical schools and residency programs have incorporated palliative care as a core competency, but we struggle as educators to get palliative care content inside the curriculum to get our rotations done. There are a number of barriers, and one of them is insufficient faculty. There absolutely is a lack of palliative care specialists.

I know the Champlain region very well. I worked there for a few years. In Petawawa, for example, the family health team trained up the whole team to provide a palliative care approach, and it's made a very big difference, but there are still many areas across the country—and you've highlighted some of those rural areas—where there aren't enough resources.

I've also helped in New Brunswick, trying to build the palliative care capacity there—

The Joint Chair (Hon. Yonah Martin): Thank you, Dr. Pereira.

It's now over to you, Mr. Co-Chair.

The Joint Chair (Hon. Marc Garneau): Thank you, Senator Martin.

We'll now proceed with the Senate questions, beginning with Senator Mégie.

[*Translation*]

Senator Mégie, you have the floor for three minutes.

Hon. Marie-Françoise Mégie: Thank you, Mr. Chair.

I am happy to be taking the floor after my colleague Mr. MacGregor because his question is the same as one of mine.

It is increasingly noticeable that the public and all professionals are receiving a lot of information about the implementation of the medical assistance in dying program. However, when I was practising medicine, I noticed that the population knew nothing about palliative care. People who were offered palliative care were resistant to it.

Today, palliative care is still contrasted with medical assistance in dying. What could be done to educate the public about what palliative care is, as is done for medical assistance in dying?

How could provincial colleges of physicians better educate professionals about palliative care, so that they can advise people about either option when the time comes?

Dr. Roy, has the Collège des médecins du Québec ever thought about that?

Dr. Louis Roy: Thank you, Senator Mégie.

Yes, a lot of thought has been put into that.

On that note, I would say that the problem of information about access to palliative care goes back a long way. It also comes from the fear of talking about death, of talking about topics that are not easy.

I think the shortcut to medical assistance in dying was taken not because it was necessarily easier to talk about it, in terms of public information, but because it was something new for the press and the media. There was something new to put out there, whereas when you want to talk about palliative care, you have all the problems of what you are going to say, who you are going to say it to, and how you are going to say it.

On the public side, we really need some very targeted, but also well-organized, press campaign elements to explain to people what palliative care is.

I noticed in my long experience in palliative care that the best ambassadors to talk about it well are the families and loved ones of people who have received it. They are the best people to do it. They can say that their mother or aunt received palliative care, that it was a positive experience, and that this person received care, comfort, and relief.

On the physician side, Dr. Pereira talked about this. Medical schools are getting into it, but they definitely need to continue to [*technical difficulties*]. Obviously, all of this fits into an increasingly heavy curriculum in medicine where it is difficult to tell future medical students that they are going to have to add one or two years

of study to successfully cover everything. We need to successfully condense everything even more.

Obviously, our medical students need to be confronted with the fact that everyone is going to die someday, but they also need to be exposed to palliative care during their training.

• (1035)

The Joint Chair (Hon. Marc Garneau): Thank you, senator.

[*English*]

Please proceed, Senator Kutcher.

Hon. Stanley Kutcher: Thank you, Chair.

Thank you to the witnesses.

Before I ask my questions, I would ask the chair if he could request that Dr. Pereira provide this committee with a written report supporting his opinion that, one, people are being provided MAID instead of access to palliative care when they want palliative care; two, the data that shows that people who are receiving MAID have received suboptimal palliative care; and three, that resources are being diverted from palliative care to MAID provisions outside the usual ongoing annual reallocation of resources in the health care system.

I have questions for both Dr. Kekewich and Dr. Roy.

Dr. Kekewich, you raised a concern about the possibility of a real shortfall in the health care workforce that can provide MAID and palliative care. Both are very important. How can that human resource problem be addressed by the federal government? Can you think about whether targeted health care transfer funds might be part of that solution?

Dr. Roy, would regulatory bodies have within their jurisdiction the ability to require that MAID providers must have completed a national training program in MAID assessment and delivery?

Go ahead, Dr. Kekewich.

Mr. Mike Kekewich: That's an excellent question. I think it's something we've struggled with, quite frankly, in terms of what the strategies look like.

I think one of the interesting things about MAID is that most clinicians who are providing MAID are not doing it full time; they are doing it in addition to other work that they're committed to, so it has to be rewarding for them. It has to be meaningful for them.

I think certainly the volumes are one thing, in terms of their increase over time, and the complexity may also increase over time, as new patient populations start requesting it. I think there have been some innovative attempts to develop MAID coordination services that really support clinicians. It can be very administratively burdensome to have a large caseload of patients, for example.

I think focusing on those types of strategies, so that there's a team that's supporting patients—not just the clinician on their own, but a team of nurses, social workers and perhaps other specialists who could be available to give support—would be helpful.

Hon. Stanley Kutcher: Thank you for that.

Dr. Roy, please go ahead.

Dr. Louis Roy: Thank you for your question.

If you don't mind, I will continue in French to make sure that I make my [*Technical difficulty—Editor*] more clearly.

[*Translation*]

With regard to palliative care, obviously, we have come a long way, as there was initially no training. Initiatives were organized locally all over. At the national level, a working group is setting up a training program on medical assistance in dying for physicians and nurse practitioners. This program, whose modules I am helping review, is expected to be in place by the spring of 2023. In terms of training physicians and nurses in medical assistance in dying, I think the pieces are gradually falling into place. It should have been done before, but at the very least, work is being done.

One thing remains to be done and remains a very worthwhile element to me. In my field, very few physicians are opposed to medical assistance in dying. A lot of physicians say that they don't feel capable of administering it, but they understand their patient very well and so they will redirect them to someone who has the training and feels physically, psychologically, and morally ready to do it. So there is that dichotomy, but overall I would say that—

• (1040)

The Joint Chair (Hon. Marc Garneau): Thank you, Dr. Roy.

Senator Dalphond, the floor is yours.

Hon. Pierre Dalphond: Thank you, Mr. Chair.

Dr. Kekewich, you have done a lot of analysis and research on the data, which is evidence-based and available. Is there any data indicating that people chose medical assistance in dying because of the poor quality of palliative care they were receiving?

I am asking this question because you said that 80% of the people who have requested medical assistance in dying were already receiving palliative care.

[*English*]

Mr. Mike Kekewich: I have not seen anything to reflect that specific concern. I think I would agree to some extent with Dr. Pereira that there are limitations in terms of the data, and I believe that Health Canada is going to be collecting more specific data on palliative care involvement to help inform these types of discussions.

I'm not aware of any reports that support that claim, but the reality also is that it's not the case that 100% of patients receive palliative care, right? I think it goes back to understanding what adequate access to palliative care looks like.

[*Translation*]

Hon. Pierre Dalphond: My time is limited, so I'm going to ask you my second question. This one will be more related to ethics, since you are also an expert in that area. I understand that the whole issue of medical assistance in dying and that of continuous palliative sedation raise ethical questions. We see that these are accentuated when it comes to medical assistance in dying for mental disorders.

Do you think these justifications are admissible, given the vulnerability of these individuals, and how can they be countered?

[*English*]

Mr. Mike Kekewich: I think that's a very difficult.... Are you talking about mental illness as a sole underlying medical condition?

Hon. Pierre Dalphond: Yes.

Mr. Mike Kekewich: Yes, in preparation, we've had a lot of conversation about that.

Certainly I'd be lying if I said that there wasn't apprehension about how we're going to be able to effectively support some of these patients. I think it perhaps goes back to another comment, which is that we're talking a lot about palliative care, but patients also require timely, ongoing access to other services in terms of mental health supports, complex pain and other specialized care. I think we need to make sure that we recognize that not all of these patients are going to receive MAID. What, then, is the support for these patients to make sure that their care is good?

Hon. Pierre Dalphond: Thank you.

[*Translation*]

The Joint Chair (Hon. Marc Garneau): Thank you, Senator Dalphond.

[*English*]

We'll go to Senator Martin for three minutes.

The Joint Chair (Hon. Yonah Martin): My first question is for Dr. Pereira.

What is meant by specialist palliative care versus the palliative approach to care, as outlined in the “Framework on Palliative Care in Canada”? Why is that so important with respect to providing access to palliative care, and where does Canada stand on that?

Dr. José Pereira: If you look at jurisdictions that have done very well in exercising palliative care, they've developed specialist palliative care services and have also ensured that all health care professionals are getting basic training so that they can identify earlier the patients who would benefit from palliative care. They can start addressing the psychosocial, spiritual and physical distress those patients are experiencing, and as a result, patients then have a lot more access to palliative care.

There was an earlier assertion that there has been considerable funding going into palliative care across the country. That may be true in some jurisdictions, but not in all. In my region, for example, we don't have enough specialist funding for specialist palliative care physicians. I know of another hospital in Ontario that has been trying for years to get extra funding to build palliative care specialists.

We also struggle with funding to make sure that we train up health care professionals in practice, the very professionals who are going to be asked by patients “What choices do I have?” and “What are my options?” When they don't know what palliative care is, when they keep equating it to only the very end of life and when the patients and the public still think of palliative care only at the very end of life, we have a problem, and I think we do need to address that.

The Joint Chair (Hon. Yonah Martin): Speaking of training, I see how important it will be to have training, and really for all the people in the system if we're expanding MAID, because we'll need these professionals. To what extent has palliative care education been integrated into medical, nursing and social work training programs in Canada?

• (1045)

Dr. José Pereira: Mr. Chair, I think we've come a long way in the last two decades. I've been doing palliative care since 1995, and over the years I've worked really hard to try to get palliative care integrated into curricula. It's a real challenge, and Dr. Roy alluded to some of that challenge as well, but there are ways of doing it.

I think it's unacceptable that specialists in internal medicine, cardiology, nephrology and respirology don't get core palliative care training. How can they inform their patients with the options appropriately when they don't have that training?

I think it's still not adequate that only 30% of medical students across the country have clinical rotations. We're not even speaking about nursing schools, because in nursing schools there are still major gaps in the curricula. We need resources. We need funding. I've experienced many push-backs, largely around how we don't have the resources, we don't have the space and we don't have the time, but we do, actually, and we can be innovative. There are examples across the country of how that can happen.

Thank you.

The Joint Chair (Hon. Marc Garneau): Thank you, Senator Martin.

This brings our panel to an end.

Just before I finish, this is for you, Dr. Pereira. You probably heard the request from Senator Kutcher: Could you provide documentation that supports some of the points you raised during your opening remarks and in answering questions? Are you in a position to do that?

Dr. José Pereira: Yes, sir, I am. It would take a few days, because I have some family priorities I have to deal with.

The Joint Chair (Hon. Marc Garneau): That's fine. Thank you for providing that additional information.

With that, thank you, Dr. Pereira.

[*Translation*]

Thank you, Dr. Roy.

[*English*]

Thank you, Mr. Kekewich, for appearing in front of the committee this morning. We very much appreciate it and are continuing our analysis of the theme of palliative care in the context of medical assistance in dying. Thank you very much for your appearances this morning.

With that, for the committee, our next meeting is Tuesday, the 18th. We won't be here next week, of course. We'll continue with the study of palliative care.

Thank you very much.

This meeting is adjourned.

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