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The Honourable Marc GarneauThe Honourable Yonah Martin



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• (1835)

[*Translation*]

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

I call this meeting to order.

[*English*]

Welcome to this meeting.

I'm immediately going to hand it over to my colleague co-chair, Senator Martin, if she is ready.

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

[*Translation*]

Welcome.

I would like to begin by welcoming members of the committee, witnesses as well as those watching this meeting on the web.

My name is Yonah Martin, and I am the joint chair of this committee. I am joined by the Honourable Marc Garneau, joint chair of this committee, member of the House of Commons.

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

[*English*]

In regard to the health and safety of everyone taking part in this committee, the Board of Internal Economy requires that committees adhere to the health protocols in effect until June 23, 2022. As joint chairs, we will enforce these measures, and we thank you for your co-operation.

With that, I would like to remind members and witnesses to keep their microphones muted unless recognized by name by one of the joint chairs.

As a reminder, all comments should be addressed through the joint chairs. When speaking, please speak slowly and clearly. Interpretation in this video conference will work like an in-person committee meeting. You have the choice at the bottom of your screen of floor, English or French.

I would like to now welcome our witnesses for this first panel.

As individuals, we have Dr. James Downar, critical care and palliative care physician, and Dr. Pierre Viens, family physician. On

behalf of the Canadian Society of Palliative Care Physicians, we have Dr. Ebru Kaya, president, and in the field of medicine at the University of Toronto.

Thanks to all of you for joining us as we continue our very important study.

We will begin with opening remarks by Dr. Downar, who will be followed by Dr. Viens and Dr. Kaya.

You will each have up to five minutes, which we will time, and I will give you a 30-second warning as that time approaches.

To begin, we have Dr. Downar.

Dr. James Downar (Critical Care and Palliative Care Physician, As an Individual): Thank you very much.

I'll try to keep my comments as brief as I can. I've already sent in some notes for people to follow.

I'm the head of the division of palliative care at the University of Ottawa. I have a clinical research chair in palliative and end-of-life care and a master's degree in ethics.

I've taken an interest in this issue for some time, have served as an expert witness in different cases involving medical assistance in dying and have developed educational materials for medical assistance in dying for different jurisdictions, including Canada and Australia. I've also led a few studies looking at MAID and people who receive medical assistance in dying to understand a bit about their experience and about who these individuals are, but I'm not here representing any organization or agency.

I've previously spoken in favour of legalization of medical assistance in dying, but I'm not here to promote MAID and certainly not to advocate for any position on any of the remaining issues before Parliament about mature minors, advance directives, etc.

The main points I would like to make today really are that I'm very grateful to say that funding for palliative care and support for palliative care research is improving and that there have been some notable successes in that regard. I really want to thank Parliament and Health Canada for that, but I really emphasize the need to continue doing this and to reduce barriers so that we can improve the way we treat suffering among the dying.

I've heard a lot of comments in the previous sessions about the social determinants of health and the vulnerable. I think it's very important to say that we really do need to address social determinants of health, including housing, food security, pharmacare and dental care, because these are important to the health of all Canadians. I think it's important to recognize that these measures are really not about medical assistance in dying at all, because structurally vulnerable individuals are already far less likely to use medical assistance in dying than anybody else. We should do these things simply because they're a good idea and the right thing to do.

There are a lot of narratives about medical assistance in dying in Canada. These are generally driven by ideological or political aims that really have nothing to do with saving lives or protecting the vulnerable. I think we've learned an awful lot over the past 20 years about how medical assistance in dying is provided in different countries, including Canada, and who is requesting it and who is receiving it.

What we know very much is that it is not what has previously been thought. It is heavily driven by something known as existential distress. This is a type of suffering for which we have very little or nothing to offer. We really should be attempting to understand this type of suffering better, to identify new forms of treatment and to support research into identifying new forms of treatment for it, so that we can address this suffering as really the root cause of MAID requests. I think that's something on which everybody—as controversial as this issue might be—can agree.

Finally, I'd like to also mention that our experience through Bill C-14 and Bill C-7 has been that Parliament, in the past, has really been unwilling to address medical assistance in dying and key issues in a proactive way, preferring to let the courts strike down laws and leave the government to replace them. This unfortunately happens usually in a very partisan process—a bit of a circus, almost—in an accelerated time frame and with predictable results.

I really love that there's now a committee like this that's going to be studying some of the important issues and reviewing things. I would really encourage a committee like this to continue operating to try to make sure that the remaining questions about medical assistance in dying are handled in a way similar to what Quebec's parliament does: proactively addressing questions, studying them thoroughly, forming committees to really review evidence and then developing nuanced answers. I'm not suggesting that we should go the same way Quebec has on any issue. I'm simply admiring its process and encouraging us to follow it.

I think we can get into some further discussions around some of the drivers, but I really want to emphasize that there is absolutely no data suggesting that the practice of MAID at this point is driven to any degree by poor access to palliative care, socio-economic deprivation or any isolation. Quite the contrary: The people who receive MAID almost invariably have excellent access and are receiving palliative care far more than the average population. They tend to be very wealthy, privileged, non-institutionalized and married, not widowed or single.

The national reviews on this have shown that the number of people who received MAID and who had trouble accessing disability services and palliative care services is tiny—absolutely minuscule.

That's very reassuring. Obviously, it could be even lower than 1% or 3%, but that's pretty good. Certainly, it would not be accurate to say that it's being driven by a lack of access to services.

I really want to emphasize a bit of information about the research and the successes that have been found in research—

• (1840)

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

Dr. James Downar: Okay.

I had better just wrap it up, my final point here being that if we're going to talk about the vulnerable and the socially deprived, I think we need to emphasize that there are really important things that we as a society and we as a Parliament can do to help those people—things like vaccine mandates, pharmacare, etc.

I really love how much people in Parliament talk about the need to protect the vulnerable. I really wish those sentiments would carry over to important things that would save lives. We've had a hard few years—

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

Dr. James Downar: Thank you.

The Joint Chair (Hon. Yonah Martin): Next is Dr. Pierre Viens.

[*Translation*]

Dr. Pierre Viens (Family Physician , As an Individual): Good evening.

Thank you for welcoming me to this committee.

I have been practising medicine in the field of palliative care for 30 years, and I have administered medical assistance in dying 180 times in the last six years, mostly at home.

I was asked to speak a little about palliative care. At the end of my presentation, I will share with you my views on advance medical directives.

Five percent of patients at the end of life who receive excellent palliative care are still seeking medical assistance in dying. Why? Because existential suffering at the end of life cannot be relieved to the patient's satisfaction by any current conventional palliative approach.

First, we must not forget that any curative or palliative care can be legally refused. Nor should we forget the ethical principle of respect for individual autonomy. The individual is the only one entitled to make decisions about their own end of life and to judge the results of the care given to them.

When palliative care physicians claim that medical assistance in dying would not be necessary if good palliative care were available everywhere, one should first define what is meant by "good" palliative care.

When I assess a request for medical assistance in dying to see if it meets the eligibility criteria, the law recommends that I ensure that the person is aware of the alternative options to medical assistance in dying that are available, including palliative care. When the palliative care physician is about to put the patient under continuous sedation until death, why does the law not require that the patient be made aware of the existence of medical assistance in dying, to allow them a choice, as I am required to do?

I have helped thousands of people to die. I can testify that medical assistance in dying is probably the most compassionate life care, the most respectful of the person and their values, and the most comfortable for them and their family. Medical assistance in dying should be considered appropriate care in a logical continuum of palliative end-of-life care, which can be requested when, in the patient's opinion, all reasonable efforts have been made. It should be made clear in law that medically assisted dying is part of a continuum of palliative care.

The conscientious objection of caregivers to the administration of medical assistance in dying must be maintained, but conscientious objection applies only to the caregiver as an individual. It cannot apply to an institution, a health care facility or a social professional group.

In 2015, the law passed in Quebec allowed hospices not to offer medical assistance in dying. Since then, 50% of them have changed their minds under social pressure from the community. All health care facilities in Canada, public or private, especially if they are partially publicly funded, should be required to offer this care, even if it means bringing in external physicians to implement it.

Finally, it would be necessary for what is meant by "palliative care" to be defined in a way that is more consistent with reality. To think, or even wish, that the intense level of care found in most hospices should be set as the norm is unrealistic and, ultimately, undesirable. Basic palliative care is comfort care. The family doctor who relieves the pain of his elderly patient suffering from generalized cancer at the end of life is providing palliative care. When I report to Health Canada about a medically assisted death that I have performed, I am asked on the reporting form if that person received palliative care and for how long. Let me tell you that the thousands of responses to this question received to date are probably meaningless, because the term "palliative care" has never been defined at the operational level.

I had a few more ideas to share with you about advance medical directives, but since I don't have much time left, I'll try to do it very briefly, if I may.

First, when a person has just been diagnosed with Alzheimer's, the doctor should adequately inform them of the nature of the disease, its course and prognosis, and the possible treatment options. That person could then define in their own words...

• (1845)

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

Dr. Pierre Viens: Five minutes is really not enough.

Thank you.

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

[English]

Next is Dr. Ebru Kaya.

Dr. Ebru Kaya (Associate Professor of Medicine, University of Toronto, President, Canadian Society of Palliative Care Physicians): Thank you for the opportunity to talk about the state of palliative care as part of the statutory review of Canada's current legislation on medical assistance in dying.

I am a palliative care expert with formal training in the field of palliative medicine and the program director for the Royal College of Physicians of Canada's two-year residency program in palliative medicine at the University of Toronto. I am also the president of the Canadian Society of Palliative Care Physicians, which is committed to improving quality and access to palliative care for all Canadians through advocacy, partnerships, research and physician education. We are the national specialty society representing palliative care physicians, and physicians with a special interest in palliative care, throughout Canada.

I work at Toronto General Hospital and provide palliative care to patients who have been diagnosed with a life-threatening illness. Some of my patients have advanced cancer. Others have non-cancer diseases, such as chronic kidney disease and heart failure. I manage their symptoms, whether physical, psychological, social or spiritual.

The vast majority of patients and their families do not understand the role of palliative care. I spend time explaining what we do and who we are, and work on demystifying and destigmatizing our work. It is not uncommon that I have to convince patients that by managing their symptoms, I will not hasten their death. Most patients are often relieved, and are happy to continue to be followed by our palliative care team.

There are times, especially at my initial consultation, when patients tell me that they are considering MAID. It is my job to explore the reasons underlying that request and provide suggestions and support based on my expertise and formal training, not simply call the MAID team. With evidence-based psychotherapeutic options to treat depression, anxiety, demoralization and hopelessness, most patients end up not choosing MAID. This patient-centred "shared care" model of decision-making is a hallmark of quality palliative care.

I also teach and train palliative care residents as well as other clinicians who provide a palliative approach to care based on the patient populations they are looking after. This includes family doctors and specialists, such as cardiologists and nephrologists, and the many interdisciplinary colleagues who work alongside them. This work is incredibly important, as there is evidence from Canada and around the world that a palliative approach to care improves symptoms and quality of life for patients. When there are more complex issues, the way palliative care is presented to patients makes a difference to whether they will accept specialist palliative care services similar to mine.

Palliative care needs to be a distinct service from MAID, with separate funding and resources. Palliative care and MAID need to remain distinct and separate. Our palliative care community has worked hard over the past 40 years to move away from being associated with end-of-life care only. We do not want to go backwards. By separating them, palliative care can continue to be the safeguard as intended. MAID assessors and providers are in a conflict of interest if providing palliative care at the same time. This does not prevent palliative care physicians from practising MAID. However, they should not be providing palliative care alongside MAID for the same patient.

We urgently need investment in palliative care programs that are administered and funded separately from MAID so that we are not competing for the same resources. Many programs have had to divert their already scarce resources to support MAID services. This has made it even more challenging to provide palliative care when there are dire shortages in palliative care experts from coast to coast and, as a result, patients are even less likely to access palliative care. We need clear data around the quality and accessibility of palliative care and who is providing it for patients who choose MAID. This does not currently exist.

We need funding so that every Canadian has a right to high-quality, comprehensive palliative care. Our palliative care residency programs provide outstanding training experience, graduating highly skilled experts in the field. Together we provide education, guidance and clinical support to clinicians providing primary palliative care. Unfortunately, there are not enough residency positions or specialist palliative care physicians in Canada. We urgently need to invest in increasing funding for training programs across the country in order to graduate more specialist palliative care physicians and in education for all doctors who provide a palliative approach to care.

Please refer to the brief we submitted, as well as the one submitted by our past president, Dr. Leonie Herx, for more information.

Thank you.

• (1850)

The Joint Chair (Hon. Yonah Martin): We'll begin our first round of questions with Mr. Cooper for five minutes.

Mr. Michael Cooper (St. Albert—Edmonton, CPC): Thank you very much, Madam Co-Chair.

I am going to direct my questions to Dr. Kaya.

Dr. Kaya, Dr. Downar stated in his testimony that there is really no issue with respect to accessing palliative care services for those who have accessed or are contemplating accessing medical assistance in dying. Would you agree?

Dr. Ebru Kaya: No. The data that Dr. Downar refers to and the data that Health Canada reports is the wrong kind of data. It doesn't lend itself to being able to make these sorts of conclusions. I mean, it's self-reporting.

I have the form in front of me. Essentially, the form asks, "Did the patient receive palliative care, yes or no?", and, "To the best of your knowledge, if the answer is no, was palliative care accessible to the patient, yes or no?". That's not enough.

We need significantly more data. We need to know much more information. We need to understand the quality of health care being provided and how it impacts palliative care. This sort of health admin data does not do it.

We also need to have national standards to measure the quality of palliative care across the country, with reporting to Accreditation Canada so that health authorities are essentially obligated and held accountable.

Thank you.

Mr. Michael Cooper: Thank you for that.

You're right, it is limited to self-reporting, which seems to me to be totally inadequate.

Do you agree that MAID providers are in a conflict of interest in terms of submitting data and that the fact that Health Canada simply relies on MAID providers to assess the state of and access to palliative care in Canada seems to be problematic? Would you agree?

Dr. Ebru Kaya: Completely: I think it doesn't make any sense for the same person to be doing both. We really definitely need to separate this.

Not only is there a conflict of interest, but there is also conflict within our community: We're competing for the same resources.

Health care nurses in Ontario, Alberta, Quebec and Nova Scotia are doing MAID assessments instead of health care. In Ontario, billing codes are used for MAID assessments. Financial incentives created to encourage family doctors to do primary health care are being given to MAID providers instead. MAID providers can also bill for indirect clinical work, such as travel time and paperwork, yet palliative care providers cannot, so there is a lot of conflict within our community, as well as conflict of interest for MAID providers.

Mr. Michael Cooper: Can you speak to the difference between primary palliative care and specialist palliative care? Dr. Herx, in her submission, noted that only about 15% of Canadians have access to specialist palliative care.

Maybe, as you do so, could you expand upon the comment you made with regard to the quality of palliative care in Canada, because it's one thing to say there is access, but if the quality doesn't live up to or match up, what good is that access?

● (1855)

Dr. Ebru Kaya: Thank you.

Primary palliative care providers are doctors such as family doctors who have training in basic palliative care skills and provide a palliative approach to care to their patients, but some patients have more complex needs and require specialist palliative care teams and specialist palliative care doctors like me, who have more advanced training.

Primary palliative care providers are the backbone of palliative care in this country, and we need to support them. We need to ensure that our undergraduate and postgraduate competencies are adopted by all Canadian medical schools and their residency programs so that all doctors who graduate have the basic skills to provide palliative care, but we don't have enough specialist palliative care physicians in our country either. We urgently need to make sure that we fund more residents to complete the advanced training—like me—and we need to ensure that all of the competencies that we have created are integrated into all of our programs.

In addition to that, the quality that you mentioned—

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

Dr. Ebru Kaya: When it comes to being able to figure out what we have and who is doing what in terms of palliative care, we don't have that information. We have no national standards to benchmark palliative care. These do not exist. We need to create these. We don't have that information at the moment.

Mr. Michael Cooper: Thank you very much.

The Joint Chair (Hon. Yonah Martin): Next is Mr. Arseneault for five minutes.

[Translation]

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

I also thank the witnesses for their testimony.

I will address Dr. Viens first, and then Dr. Downar.

I come from an extremely rural area, far from major urban centres. I'm probably the member of parliament from one of the re-

gions in the country with highest average age. I have had experiences of accompanying people in death, including close family members. My sister died very young, at 46. She had decided not to go to a hospice and to die at home, while receiving nursing care there twice a day.

Other people I knew well died after long illnesses in long-term care facilities. In my region, the smaller long-term care facilities have set up a room for palliative care where the family can come. It's more comfortable for the patient and for the family. Our smaller hospitals have set up palliative care rooms on certain floors.

This leads me to ask the following question. In your presentation, Dr. Viens, you said that there has never been a definition of what palliative care is. Some of the documents that I have seen distinguish between quality palliative care and poor palliative care.

For the patient who is at the end of life, what does this mean? How do we define good palliative care?

Dr. Pierre Viens: There are certainly many levels of palliative care. When we think of palliative care, we think especially of hospices where the quality of care is really, let's say, extraordinary. It is so extraordinary that it is impossible to believe that such care could be offered more broadly to the public.

In the beginning, there were mostly very specialized hospices. Now, at least in Quebec, there are good palliative care services in almost every hospital, large or small. I have nothing against that at all. Palliative care is and always will be necessary.

● (1900)

Mr. René Arseneault: What I'm asking you, Dr. Viens, is how to define quality palliative care. How does it differ from palliative care of lesser quality? What does it mean for the patient?

Dr. Pierre Viens: What is palliative care?

Palliative care is comfort care. It is not intended to cure, and patients at the end of life have only comfort care to relieve them.

What is comfort care? It varies in nature. It can be treatment, pain management and management of other physical symptoms, such as nausea, balance problems, and so on. Beyond that, there is the whole category of what is called psychological suffering, including existential suffering at the end of life. There is no pharmaceutical treatment or any other treatment sufficient to meet the needs of these patients. I don't think there ever will be.

I was a doctor in an excellent hospice for 25 years, before I devoted myself exclusively to medical assistance in dying. I had to because in that hospice, when the law was passed...

[English]

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

[Translation]

Dr. Pierre Viens: I will try to summarize, Mr. Arseneault.

In my view, good palliative care is comfort care that is available to people wherever they are, even at home, and is sufficient to meet their needs satisfactorily.

Higher quality palliative care...

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

Mr. René Arseneault: Thank you.

[English]

The Joint Chair (Hon. Yonah Martin): Next is Mr. Thériault for five minutes.

[Translation]

Mr. Luc Thériault (Montcalm, BQ): Thank you very much, Madam Chair.

Dr. Viens, I will let you finish your answer.

You were talking about the accessibility of palliative care.

Dr. Pierre Viens: In my opinion, good palliative care is comfort care that is accessible and satisfactory in the majority of cases.

I will give an example. There are different levels of pain management, but what is important is to make basic treatment techniques and approaches accessible. That's why it's not necessary...

Mr. Luc Thériault: I am sorry to interrupt, but I want to address another aspect of the issue.

Quebec's approach was forward-thinking, in that they implemented end-of-life care legislation under which palliative care is the vehicle for end-of-life care. Rather than debating this, as many do, or pitting palliative care and the request for medical assistance in dying against each other, Quebec has included the emergence of a request for medical assistance in dying within a continuum of end-of-life care.

I assume that this approach is acceptable to you.

Isn't it?

Dr. Pierre Viens: Not only does it suit me, but personally it is the approach I have always used.

Mr. Luc Thériault: Some claim that when palliative care is optimal, it leads to people not seeking medical assistance in dying.

In your 25 years of practice in this field, has this been your experience?

• (1905)

Dr. Pierre Viens: I experienced it profoundly.

When I started working in the field of palliative care, I was working at Maison Michel-Sarrazin.

The Maison Michel-Sarrazin is one of the most renowned homes for quality care. When I started working there, the law on medical assistance in dying did not exist. After a few years, I realized that even with more extensive palliative care, whether in the form of drug therapy or other supportive therapies, we were not able to respond to suffering on a psychological level, such as existential suffering.

To really respond adequately to patients at the end of life who asked us for relief, I always thought that the range of palliative care available was not always sufficient, especially to respond to this well-known existential suffering.

That is why, after the Act respecting end-of-life care came into force in Quebec in 2015, the Collège des médecins du Québec defined medical assistance in dying as being part of the continuum of palliative care. In other words, it is palliative care along with other forms of care. It is intended to respond, at the patient's request, to situations that traditional palliative care does not address.

In my practice, I have never had to deal with a conflict opposing palliative care and medical assistance in dying.

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

Dr. Pierre Viens: I respond to all the MAID requests I receive by providing the best palliative care at my disposal. As I see it, there is no conflict. There's no difference between medical assistance in dying and other palliative care measures.

Mr. Luc Thériault: Thank you.

[English]

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

Next is Mr. Johns for five minutes.

Mr. Alistair MacGregor (Cowichan—Malahat—Langford, NDP): Madam Co-Chair, I'm actually back in the committee.

The Joint Chair (Hon. Yonah Martin): Okay, Mr. MacGregor. Go ahead.

Mr. Alistair MacGregor: Thank you very much.

Thank you, Mr. Johns, for holding a spot for me.

Thank you to our witnesses. I'm sorry I missed your opening statements. Forgive me if I cover some of the same ground, but maybe it can give you a chance to expand on earlier answers.

We had a meeting earlier this week, on Monday, at which the topic of palliative care was also covered. We heard from some of our witnesses that many Canadians do not understand palliative care. In many cases, they are referred to it far too late in their end-of-life stages. They could have been better served had they been aware of it earlier and granted access to it earlier.

Perhaps I'll start with Dr. Kaya and then invite each of you to respond. When it comes to specific recommendations that our committee can be making to the federal government, what can we do to ensure that more people are better informed about palliative care supports that are out there? How can the federal government be supporting provinces to ensure that the information is out there even in remote communities, which may not have the best access the way our big city centres do?

The Joint Chair (Hon. Yonah Martin): Dr. Kaya, please go ahead.

Dr. Ebru Kaya: Thank you.

We definitely need increased funding and resources in palliative care, but it needs to be separate and distinct from MAID. Currently, essentially all of us are competing for the same resources. As I mentioned before, we have palliative care nurses in many of our provinces who are doing MAID assessments instead. My community is distressed. We're burnt out. We're being asked to do more with less. Some of our community members have retired early. Others have left the field.

Really, we need to be able to provide a sustained investment in palliative care. We have some of the best researchers in palliative care here in Canada, but when it comes to our clinical programs, we are way behind other developed nations. That definitely needs to change.

In terms of the communication around this, as national organizations representing palliative care in Canada, we would love to be able to meaningfully engage with our government officials. As the experts in the field, we can help you with the information you need, and the guidance, so that we can work together and improve palliative care in Canada for Canadians together. We can't do this if we're ignored or if we're called at the eleventh hour.

• (1910)

Mr. Alistair MacGregor: Thank you very much.

Go ahead, Dr. Downar.

Dr. James Downar: I absolutely think we do need to continue to redouble our efforts to improve the quantity and quality of palliative care that Canadians receive. As a rule, most Canadians can and should be getting palliative care approaches integrated earlier than they currently are. I think it's important, though, to distinguish this from the MAID question. There really isn't any indication that this is what's driving MAID on any level. When palliative care is involved, it's often involved for quite a substantial amount of time before MAID requests go in and before MAID is provided.

I just want to correct the misconception that this study data comes from only self-reported surveys, which I think Mr. Barrett had asked about before. That's not true. We did a study in Ontario. In Ontario, every single case is reviewed by a nurse investigator working for the office of the chief coroner. Obviously, these are people with no skin in the game who would stand to lose or gain nothing from any of their assessments. Their assessments concurred almost exactly with the same numbers in terms of the involvement of palliative care duration. I think that's really important to state. MAID is provided to maybe 2% or 3% of the population as they die.

The importance of palliative care, social services and improving all of those things that we do for Canada's most vulnerable and Canada's dying are vitally important, because it applies to 97% of the population, the part that doesn't get MAID. I've gone two or three years now without doing a single MAID case. I'm a palliative care physician. Since moving to Ottawa I haven't done it. There's a lot more palliative care to be done out there than there is MAID. That's really where the emphasis should be. I don't think you want to mix and confuse these two.

It's also important to state that the shared pool of resources is a misconception. In Ontario, certainly, there isn't a shared pool of dedicated palliative care resources. It's a physician services budget, one where anyone could bill any amount of codes. It doesn't come at the expense of palliative care. Where there are nurses...

Sorry. I'll stop there. Thank you.

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

Time is up. I will now turn this over to my co-chair for questions from the senators.

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

We'll proceed with questions from senators. These are three-minute rounds.

[*Translation*]

We're going to start with Ms. Mégie.

You have three minutes, Senator.

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

I'm very glad to have palliative care experts with us today. Having been a family physician for 30 years, I am in my element.

My first question is for Dr. Kaya.

First of all, thank you for your opening statement.

You brought up national standards earlier. I think they are needed, but how much of a difference do you think national standards can make in palliative care?

[English]

Dr. Ebru Kaya: Right now we have no way of being able to measure the quality of palliative care services that our patients have access to. By having minimal standards across the board throughout our country, we can essentially hold health authorities accountable by using evidence-based information tools, the latest and greatest from all of our research and all of our researchers, so that we're really holding ourselves to the highest possible level we possibly can to provide the very best for our patients.

• (1915)

[Translation]

Hon. Marie-Françoise Mégie: Thank you, Dr. Kaya.

Dr. Viens, like me, you were in practice before MAID came into force, so you have surely used palliative sedation, one of the items in the palliative care tool box. I thought I detected a hint of disregard for the practice, given the somewhat disdainful way you talked about physicians plunging palliative patients into sedation.

Am I mistaken? If so, could you please explain what you meant?

Dr. Pierre Viens: You are mistaken, because I did not in any way mean to take a disdainful tone.

Throughout my career in palliative care, I have had to use palliative sedation hundreds of times. When MAID came into force, health care professionals working in palliative care appeared not to approve of the practice at all, so people tended to talk about “continuous sedation”.

The Joint Chair (Hon. Marc Garneau): You're almost out of time, Mr. Viens, so please wrap up your comments, if you don't mind.

Dr. Pierre Viens: Right now, I, personally, use palliative sedation when MAID is not possible. Palliative sedation will always have its place.

None of my patients has ever spontaneously chosen palliative sedation over MAID when given a choice between the two. Palliative sedation is an important medical tool, but I use it only when MAID cannot be provided to a patient.

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

[English]

Senator Kutcher, you have three minutes.

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

I have two questions for Dr. Downar.

I will say them quickly and leave you to answer them.

The first is that every part of medicine—being a physician myself—has a balance between specialty and primary care. That's why we have primary, secondary and tertiary care. Not everybody with diabetes needs an endocrinologist for care.

My understanding is that much palliative care is provided by family physicians. Does every patient who needs palliative care require full-speciality palliative care from a palliative care physician or can a properly trained, empathic, primary care physician provide

high-quality palliative care to many patients? That's the first question.

The second one is that, at the risk of confusing palliative care with MAID, there has been discussion that resources provided to provinces have been allocated to MAID instead of to palliative care. I've looked at the federal Library of Parliament data that we just got. Maybe we can put it on the record that federal funding for palliative care has increased substantially since 2017 to 2018. What's your understanding of how this money has been used?

Dr. James Downar: I'll answer your first question. Thank you very much, Senator Kutcher.

As you indicate, a large majority of end-of-life care, and palliative care as well, can be provided by non-specialists. I think that as the complexity of symptoms increases you should involve experts and specialists, as you do for any other problem such as complex diabetes or complex heart problems; you don't need a cardiologist or an endocrinologist unless they're complex. I think that's definitely the case. Certainly, for more complicated physical symptoms, I think you would definitely want to look at an expert and get an expert's involvement.

Unfortunately, when it comes to the main drivers of medical assistance in dying, it almost never relates to physical symptoms—or even less to psychological symptoms—but actually to this existential distress, which is something for which we have little or nothing to offer. That's why it's important to distinguish this, but really, to emphasize and bolster the palliative care sort of pyramid and make sure we have adequate specialist resources for those more complicated symptomatic cases is super important.

In terms of your second question, I'm very impressed that you read through the documents about where the funding is going. I'm glad somebody did. I think it's really important to emphasize that the money comes to the provinces and the provinces decide how it's spent, but there's never a sort of “earmarked” anything in the physicians' services budgets anywhere that “this goes to palliative care and MAID” and you have to fight over it. That's definitely not how it happens.

Some people use the same fee codes for the same activities, but as I said, it's not a zero-sum game. One does not come at the expense of the other. There is sometimes a global cap on physicians' services budgets, but it doesn't mean that MAID happens at the expense of palliative care, and certainly for people who are salaried and do both activities, they almost invariably do MAID in their sort of downtime or on weekends. There's really no suggestion, I think, or no reason to believe, that these resources are being repurposed.

That said, MAID is not the reason that palliative care is under-resourced in Canada. The reason that palliative care is under-resourced in Canada is that palliative care is under-resourced in Canada.

• (1920)

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

[Translation]

We now go to Senator Dalphond for three minutes.

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

Dr. Viens, please keep in mind that I have three minutes, so I will keep my comments brief and I would ask you to do the same, although I realize you have many years of experience.

You brought up an argument often cited by MAID opponents: that the data provided by Health Canada were not reliable.

Do you have any recommendations on how to make the data more reliable? Dr. Downar did say, however, that the coroner's office in Ontario had confirmed the reliability of the figures provided by Health Canada.

Dr. Pierre Viens: The data provided by Health Canada is correct. This refers only to investigative data on palliative care provided to patients prior to medical assistance in dying.

There should be a more precise definition of what palliative care is being referred to when asking if a patient has received palliative care. Is it ordinary care that can be provided by any family physician with some experience and minimal training, or is it more like second- or third-level palliative care such as that provided in hospices?

Personally, I have always answered in the affirmative when asked if the patient to whom I gave medical assistance in dying had received palliative care. Of course he always received it. He received it from his family doctor or from our palliative care team, which, incidentally, is the same team that provides medical assistance in dying. For our part, operationally, we do not differentiate between palliative care and medical assistance in dying.

My comment was mainly about the data on whether palliative care is used or not. The rest of the data is absolutely correct.

Mr. René Arseneault: Mr. Chair, I'd like to raise a point of order.

Dr. Downar mentioned that he had sent a brief to the committee, but I don't think we received it.

I just want to remind him to send it to us, if he hasn't yet.

Dr. James Downar: I sent it this morning. You may not have received it in time for the meeting.

The Joint Chair (Hon. Marc Garneau): As you know, the brief must be translated before it can be distributed.

Thank you, Mr. Arseneault and Dr. Downar.

[English]

Senator Wallin, the floor is yours for three minutes.

Hon. Pamela Wallin (Senator, Saskatchewan, CSG): Thank you very much.

Our time is brief, so I have a quick question for Dr. Downar first, which is picking up on Dr. Viens' point that MAID is not driven by a lack of access to palliative care; they are part of a continuum. Would you describe it that way?

Dr. James Downar: I do see a difference between palliative care and medical assistance in dying, for a variety of reasons, and I think there are a lot of important members of the palliative care community who really feel distinctly uncomfortable with medical assistance in dying. I think it's important to keep a definitional distinction for that purpose.

I think that broadly grouping them under the category of end-of-life care is the most useful distinction. That avoids people having to identify with something with which they have a strong moral disagreement and therefore adopting a sort of peaceful co-existence, as exists in many parts of the world, where some people perform, some people do not, and some people include it as part of their care and others do not. That's what's been going on in Belgium and the Netherlands for years, and it's starting to happen in many parts of Canada too. I think that's probably our future.

• (1925)

Hon. Pamela Wallin: Thanks.

Then I'll get a brief comment from Dr. Viens. You started in your opening remarks to talk a bit about advance requests. Can you give us just a moment on that, particularly on the question of Alzheimer's? I think you started to comment and then time ran out.

Dr. Pierre Viens: This is a question that will require far more than two minutes to answer.

Hon. Pamela Wallin: I understand.

Dr. Pierre Viens: I'm just referring to the recent report of the Quebec National Assembly special commission. It contains I think the very basis of how we should consider advance directives to be included in the medical assistance in dying act.

[Translation]

The current position of the Select Committee on the Evolution of the Act Respecting End-of-Life Care in Quebec is that advanced directives should be reserved for patients who have been newly diagnosed with a cognitive neurodegenerative disease, such as Alzheimer's, and not in any other situation.

I think it's important to set the context. Doing this allows doctors who make a diagnosis of Alzheimer's in a patient to explain in detail what's going on, what the nature of the disease is, what's ahead, what the treatment options are, and so on.

The patient is then able to make an informed decision as to whether they want to risk one day becoming unable to decide their fate and spending the rest of their life in that situation, that kind of agony. This would allow doctors to have advance medical directives that are truly detailed and personalized when they are called upon, 10 years later, to carry out an advance request for medical assistance in dying for a patient who probably won't remember making it. Moreover, the patient would be unable to communicate with the doctor because the dementia would be well established.

It is imperative that the physician be able to rely on advance medical directives that truly reflect the patient's wishes, especially from the perspective of their existential suffering.

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

We'll complete this round with Senator Martin.

Hon. Pamela Wallin: Thank you very much.

The Joint Chair (Hon. Marc Garneau): Senator, you have three minutes.

The Joint Chair (Hon. Yonah Martin): Thank you
My question is for Dr. Kaya.

Under the best of circumstances, often there can be barriers to accessing all sorts of resources and services. Are there people requesting MAID due to a lack of access to resources needed—such as palliative care—and other reasons? It could be language. They may not have family. There are a lot of reasons.

Would you expand on that, please?

Dr. Ebru Kaya: Thank you.

We definitely know of cases where patients have requested MAID because of lack of access to palliative care. This might well be because of language barriers, or it might be because of an inability to articulate what they would like. They're not necessarily health literate.

We also have some special and vulnerable populations. They're not like the people in this room, who are well educated, articulate and capable of essentially informing what they want and being in control of what they want. At the other end of the spectrum, we have vulnerable groups who have difficulties understanding the health care landscape.

If we have difficulty understanding health care, then it is not surprising that these people would have difficulty understanding it, let alone MAID. We really want to be careful about making sure that the information we provide is accessible to everybody, whether that means language issues or access for people living in rural and remote communities who don't have access to the resources and care that they need. There are a lot of complicated issues at play here that we really don't have a good grip on.

• (1930)

The Joint Chair (Hon. Marc Garneau): Thank you very much. That completes our first panel.

I would like to thank Dr. Kaya and Dr. Downar.

[Translation]

I would also like to thank Dr. Viens.

I thank you very much for your testimony tonight. We appreciate your making yourself available for this very important study.

[English]

With that, we will suspend momentarily and set up panel number two.

• (1930)

(Pause)

• (1930)

The Joint Chair (Hon. Marc Garneau): Good evening. Welcome to the second panel as part of our continuing study focusing on palliative care.

For the new witnesses and for any of the new members, this is a reminder that before speaking, please wait until I recognize you by name. I'm one of the co-chairs. My name is Marc Garneau.

This is also a reminder that all comments should be addressed through the joint chairs. When speaking, please speak slowly and clearly. Interpretation in this video conference will work like in an in-person committee meeting. You have the choice at the bottom of your screen of floor, English or French. When you're not speaking, please mute your microphone.

With that, I would like to welcome our three witnesses for this second panel: Dr. Sandy Buchman, chair and medical director, Freeman Centre for the Advancement of Palliative Care, North York General Hospital and past president of the Canadian Medical Association; Dr. Harvey Max Chochinov, distinguished professor of psychiatry, University of Manitoba; and Dr. Marjorie Tremblay, physician.

Welcome to all of you.

We'll start off with each of you being able to address the committee for five minutes.

Dr. Buchman, we'll start with you. You have five minutes.

• (1935)

Dr. Sandy Buchman (Chair and Medical Director, Freeman Centre for the Advancement of Palliative Care, North York General Hospital and Past President, Canadian Medical Association, As an Individual): Good evening, everyone. Thank you for the invitation to participate in this important panel on MAID and palliative care.

First and foremost, with regard to a little on my background, I was trained as a family physician, for 22 years, and I've spent the last 16 years or so as a full-time palliative care physician, working both in hospital ambulatory clinics and home-based palliative care, including palliative care for those living on the homeless continuum. As well, as mentioned by Mr. Garneau, I have a national perspective both as a past history of being president of the Canadian Medical Association and as president of The College of Family Physicians Canada.

I am also a MAID assessor and provider, in addition to my palliative care work. Currently I am building a hospice in Toronto. We only have one general hospice for adults in all of Toronto—we can talk about access to palliative care—and I am also a supporter and founder of a facility to provide medical assistance in dying in Toronto called MAiDHouse.

What I am saying I guess is that I walk two roads, in support of vastly improved access—a strong advocate for palliative care—but support the right of Canadians to assess the eligibility for medical assistance in dying. I went into this profession to alleviate suffering, and after years of reflection came to the feeling that I could do the best in addressing suffering when I encounter the limitations of modern medicine, including the limitations of palliative care, and am able to address my patients' suffering through the provision of MAID. I consider myself a conscientious provider.

I would like to state at the outset that I think there needs to be improved education and training, and perhaps certification both in the fields of palliative care and in the provision of medical assistance in dying. I strongly believe that the most important thing to do—any clinician can do as part of an assessment—when people express the wish to hasten death is to address and explore their suffering in all of its domains.

In palliative care, we follow the teachings of Dame Cicely Saunders, who was one of the original palliative care physicians with a background as a social worker nurse and physician, who started St. Christopher's Hospice in the U.K. in the sixties. She talked about four domains of suffering: the physical, the psychosocial, emotional and the spiritual existential. I believe that too many clinicians in this world of MAID will just prefer when a patient asks for a hastened death...as opposed to exploring their suffering. I believe that's an important competency, and I'm happy to speak to that more.

Ultimately, we need to maintain the rights of Canadians to access medical assistance in dying when their suffering is deemed intolerable and other forms of treatment aren't acceptable.

Thank you, and I look forward to your further questions.

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

We'll now go to Dr. Harvey Chochinov.

Doctor, you have the floor for five minutes.

Dr. Harvey Max Chochinov (Distinguished Professor of Psychiatry, University of Manitoba, As an Individual): Thank you, honourable Chairs.

By way of background, I am a distinguished professor of psychiatry at the University of Manitoba and former chair of the External Panel on Options for a Legislative Response for Carter v. Canada. I'm also a long-time researcher and clinician, who has published extensively on psychosocial matters pertaining to palliative care.

I'd like to use the brief time I have to make five specific points.

Number one, some studies, both in Canada and the United States, imply that medical aid in dying is for the so-called white, wealthy and worried. In other words, these studies suggest that we don't need to be concerned that people seeking to hasten death are vul-

nerable or disenfranchised, but rather are well positioned to make autonomous choices. This is a very narrow and, I would say, problematic interpretation of the data. If we look at MAID deaths reported by Health Canada, most are elderly and fraught with various disabilities and comorbid medical conditions.

However, the most significant concern about this data is that it pertains to patients with less than six months to live or those whose death was reasonably foreseeable.

If you want to look at how vulnerability and hastened death will play out in Canada, we need to look at the Benelux countries or Switzerland, where, like now in Canada, dying or approaching death is not a requirement. In Switzerland, assisted suicide is more common in women—who suffer higher rates of clinical depression—and those who are living alone, divorced or without children. Loneliness and a lack of social support are key vulnerabilities that we can expect to play out in Canadian MAID. Sixty per cent of patients who have received euthanasia for mental illness in the Netherlands were described as socially isolated and lonely.

Like persons with disabilities, we also know that mental illness is associated with a higher rate of poverty and lack of access to critical support services, food and housing security, things that can wear down the human spirit and undermine the desire and wherewithal to go on living.

Number two, it's also claimed that whether you are dying, disabled, mentally ill or chronically suffering, you are free to exercise your autonomy and choose whether you want to live or die.

If someone is standing on an open balcony in a high-rise apartment rapidly being engulfed in hot flames, is it reasonable to say that they have a choice of whether or not to jump? Exercising autonomy means having real and viable options. If you're dying in the absence of quality and available palliative care; if you're disabled but don't have access to supports and services, or social, housing, and employment opportunities; if you have chronic pain or uncontrolled symptoms and don't have timely access to a specialist; if you're struggling with a mental illness and can't find a therapist who is prepared to help you grapple your way towards recovery, can we really say you're exercising an autonomous choice?

Did the 51-year-old Ontario woman with severe sensitivities to chemicals, who chose MAID two weeks ago after failing to find affordable housing free of contaminants, really make an autonomous choice? Or, did she just get tired of being seen as “expendable trash, a complainer, [and] useless”, and out of desperation, jumped.

With regard to number three, individual or person autonomy is like helium: its nature is to expand and occupy whatever space it is given. Look at what's happening in Canada. We've removed “reasonably foreseeable death” and soon will include mental illness. We're now contemplating children and advance directives. If individual autonomy is the driver and we observe what is happening with our European brethren, we will see MAID expand to include life completion and tiredness of life.

Number four, various palliative care researchers, myself included, are advancing the art and science of addressing suffering for patients with life-threatening and life-limiting conditions. While dignity therapy, developed by my group in Winnipeg, or others, such as meaning-centred psychotherapy or calm therapy, are not a panacea for suffering, they are proving to be effective in mitigating distress while enhancing end-of-life experience.

Number five, whatever direction Canada takes on MAID, it must first and foremost support the continued study and ongoing provision of palliative care. Fewer than 2% to 3% of Canadians will ever avail themselves of MAID, yet nearly all Canadians living with a life-threatening or a life-limiting illness could benefit from palliative care even though only a minority will receive it. In instances when there aren't real choices, we must tread carefully into conversations about the right to jump and do all we can to douse the flames of human suffering across Canada.

Thank you.

• (1940)

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

Dr. Tremblay, you have five minutes.

[*Translation*]

Dr. Marjorie Tremblay (Physician, As an Individual): Good evening.

I would first like to thank the members of the committee for inviting me to participate in this meeting.

I am a family physician. I have been providing palliative care for 20 years. I provide it in hospitals, at home and in a hospice. I am the medical director of the Maison de la Sérénité. I am also a researcher on the steering committee of the Quebec Network for Research in Palliative and End-of-Life Care, or RQSPAL, in Quebec.

First of all, I would like to say that I fully support what Dr. Kaya has said. So I'm not going to repeat everything she just said.

I would like to make a slight correction to what Mr. Thériault and Dr. Viens said, when they said that Quebec has made medical assistance in dying part of a continuum of care. If we rely on the Act Respecting End-of-Life Care—we must refer to the act, not its interpretation—the definition is clear. As Dr. Downar said, it is end-of-life care, and in the act it is clearly stated that there is pallia-

tive care and medical assistance in dying. So they are two different entities. This does not mean that just because we make them two different entities, we are opposed to them. It is important to say that. Indeed, every time we make the distinction between the two entities, some people seem to think that we are opposed to them, but that is not the case at all. According to the definition of “palliative care” in the End-of-Life Care Act, it is care related to the respect of a natural process. We are there to alleviate whatever discomfort there is, without hastening death or prolonging life. It is about respect for the natural state of advanced illness.

In 20 years, I have never seen so much confusion about these two concepts as I do now. Tonight, it's clear from listening to you that it all sounds a bit confusing.

When the term “palliative care” is used, far too many people think that it is given for a few hours, days or weeks before a patient dies. Palliative care is not just that. It is indeed end-of-life palliative care, but it has a different option, which is medical assistance in dying. The use of palliative care is a palliative approach and it takes place for months or even years before the patient dies. The palliative approach, which we could call an integrated palliative approach, aims to ensure that the patient with an advanced illness, who begins to have symptoms of discomfort affecting his or her quality of life, can eventually seek palliative care, knowing what it can offer. If they don't know, they can't ask for it, and if the patient feels that it is just end-of-life care, they won't ask for it sooner.

This lack of information results in patients not being identified, and this lack of early identification is costly to the health system. The patient, who should not be in intensive care, given his condition, ends up undergoing a lot of suffering. Instead, they should be in a hospice or simply at home, surrounded by their family, with appropriate care for their condition.

The resources are there, but they are deficient, because the population is aging and the needs are only increasing. So we need to inject money into the system. Above all, it is important to know that the patient's condition and the type of care must be matched so that the patient is in the right place and can access the right resources. You have to protect the quality of life of patients for two, three, four or five years, as long as the patient is going to need it. That's what good palliative care is all about.

One of you asked what is meant by “having good palliative care”. I think it is having access to enough resources, both material and human resources, and having access to all the places that provide such care for all diseases, not just cancer. I am thinking in particular of patients suffering from heart failure. Take the example of a heart failure patient whose heart is quietly dying. He may have two, three or four years to live. If he has symptoms of discomfort, he should have the option of seeing a palliative care physician.

Will this patient be able to access a specialist palliative care doctor? It is quite possible that they will not. This is where we see the need. Indeed, the complexity of cases sometimes requires the ability to access a specialist palliative care physician with experience in this area.

• (1945)

There should be a national awareness campaign about palliative care. Clearly, in Canada, we don't have a good understanding of what palliative care is. We rely on some people's interpretation and say that's what we're doing, when we're kind of misrepresenting what palliative care is.

The Joint Chair (Hon. Marc Garneau): Dr. Tremblay, I would invite you to finish your presentation.

Dr. Marjorie Tremblay: In my work, what people tell me most often is that if they had known what palliative care could offer them, they would have asked for it much sooner. They wouldn't have been afraid to do it.

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

We will now have our question period.

I yield the chair to Senator Martin.

[*English*]

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

The testimonies have all been very insightful. Thank you.

We'll go into questions from both Ms. Vien and MP Gladu.

They're going to split the five minutes, so two and a half minutes each, starting with Madame Vien.

• (1950)

[*Translation*]

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

Dr. Tremblay, you just said that if people had known what palliative care could offer, they would have gone down that road. However, according to data that we have received, many people have made the decision to request medical assistance in dying, even if they had access to palliative care.

In your practice, do you provide medical assistance in dying?

Dr. Marjorie Tremblay: No, I do not, but that does not make me someone who is against medical assistance in dying. It is very important to mention this.

I am in no way against the person's choice, but, as another witness said, to allow for a real choice, the options must be available.

Mrs. Dominique Vien: Clear and comprehensive information about palliative care is needed, and this also applies to the issue of medical assistance in dying.

I don't have much time, Dr. Tremblay. So I'm going to move on to another question.

You mentioned a national awareness campaign on palliative care. What specifically are you thinking about?

Dr. Marjorie Tremblay: I am thinking of a clear definition of what palliative sedation is. Earlier, Dr. Viens said that he administered palliative sedation to patients who could not access medical assistance in dying.

There are very clear criteria that define palliative sedation. There has to be a vital prognosis of no more than two weeks and refractory symptoms that cannot be adequately relieved with medication without the consent of the person or the family. Continuous palliative sedation cannot simply be given because a patient has not reached a point where they can request medical assistance in dying.

Mrs. Dominique Vien: Would the national campaign you envisage be directed to the medical profession and nursing staff? Would this campaign also target the general public?

Dr. Marjorie Tremblay: Yes, absolutely.

[*English*]

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

[*Translation*]

Dr. Marjorie Tremblay: The campaign would target the general public and health professionals, of course, so that everyone could benefit. The issues covered would not be the same, but it would be important that the campaign be targeted to both health professionals and the general public.

Mrs. Dominique Vien: Do you think that a national campaign on the two options available would be equally beneficial?

Dr. Marjorie Tremblay: It would be very beneficial, but I think medical assistance in dying has been publicized enough. At the moment, it's very important to make the distinction between palliative care and medical assistance in dying, and just because you make that distinction doesn't mean you're against medical assistance in dying.

Mrs. Dominique Vien: Thank you very much.

[*English*]

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

Ms. Gladu, you are next.

Ms. Marilyn Gladu (Sarnia—Lambton, CPC): Thank you, Chairs, and thank you to all our witnesses.

I want to talk about palliative care. As a result of the special committee that studied the Carter decision and their recommendation that in the absence of good quality palliative care, you actually don't have a choice, I brought forward Bill C-277 to create a palliative care framework, which I am very proud of.

The government pledged \$6 billion over 10 years in the 2018 budget for palliative care. Sadly, what's happened is that they've spent only \$200,000 of that, and it was bucketed together with MAID, which was never the intent. The World Health Organization has been clear that palliative care does not hasten death; that's a totally different thing from MAID.

My first question is easy and for each of you. We know that the framework was also looking at addressing the 60,000 missing resources in terms of palliative care doctors, nurses and other providers. Would you agree that the government should meet its commitment of \$6 billion over 10 years for palliative care and address the gap of missing resources?

Dr. Buchman, I'll start with you.

Dr. Sandy Buchman: I agree one hundred per cent. It's a shame that the funding did not follow the framework. That's been the consistent place in Canada. We have wonderful plans, but they end up sitting on a shelf because the funding never comes.

When Australia created its assisted dying legislation a couple of years back, they pledged a very significant amount for palliative care at the same time. I think it is incredibly important to do that.

Ms. Marilyn Gladu: Very good.

Dr. Chochinov, do you agree?

Dr. Harvey Max Chochinov: Yes, absolutely.

Again, congratulations on the framework. As Dr. Buchman was saying, the fact is that we don't have the services available for patients and their families. I don't think we can take any comfort in the fact that 15% to 30% of people have access to these resources. It's shameful that we just don't have better care available.

In preparation for today's presentation, I spoke to the head of our medical palliative care program, and, for your information, Winnipeg—a city of about a million people—has not seen an increase for palliative care funding in the last 20 years. We have 16 hospice beds, all located within the perimeter highway—

• (1955)

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

Dr. Harvey Max Chochinov: —and none beyond that in Manitoba, so we're woefully lacking.

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

Next we'll have Dr. Fry for five minutes.

Hon. Hedy Fry (Vancouver Centre, Lib.): Thank you very much, Madam Chair.

I want to thank the witnesses for coming and giving their time so late in the evening.

I listened to the last meeting that we had and this meeting, and I am hearing different stories about palliative care. As a physician, I

think I know what palliative care is, and I have heard some of our palliative care physicians explain what it is. It is a part, at the end of day, of a continuum of care. It is not the same care, and it is not necessarily parallel care, but it is a continuum of care.

I've also heard that there are competing resources. We had our Library of Parliament research some of this first, and I have not necessarily found that to be true.

With regard to money being given by the federal government for palliative care and a framework, that palliative care money goes to provinces. The federal government, except for indigenous people and the armed forces, etc., does not do this itself. It gives it to provinces, so it all depends on where provinces decide to put their money and their priorities. I know in some provinces there isn't enough money for home care within the palliative care system.

However, I would like to understand what happens if—and I'm going to ask Dr. Buchman this—a patient comes to you.... You pointed out three very important parts of end-of-life care: the physical care, the psychosocial care and the existential issue. Now the psychosocial care we understand. It's mostly women and a lot of people who live alone, obviously isolated, etc., but not a lot of people are talking—other than Dr. Viens, who talked about it today—about the existential care, about the fact that you can take away the pain, you can make people comfortable, and you can bring people around them to deal with their loneliness, but at the end of the day, there is that piece, that spiritual part, of a person considering what their options are.

If a patient came to you with a chronic disease and chronic pain, and you went to palliative care with them, and they seemed to be getting the help in the physical and psychosocial arenas.... After a while, patients have their needy sides from an existential point of view that this is not living. This is not quality-of-life care. This is not really living, and they want more, and they want to make a decision to probably end their life on their terms. What would you say to that person? Would you insist that they continue at palliative care or would you explain the options in a simple way, regardless of language, etc., allow them to make that decision and respect the decision of the individual about their person?

The Joint Chair (Hon. Yonah Martin): Two minutes remain.

Dr. Sandy Buchman: We see these patients virtually every day. What happens is that you do everything possible to address their suffering in those domains I referred to before, including existential and spiritual suffering. Part of the frustrations that many of us have with the system is that, if I want to refer for spiritual care or anticipatory grief or even family members for grief and bereavement, the access to those services is very poor. We have long waiting lists.

We have to often take it upon ourselves to address that suffering. I guess I've always worked on the principle that I will do whatever possible to address their suffering, everything short of MAID, but ultimately, if that person insisted that everything we have tried was not acceptable to them, which is consistent with the law, then I would agree to an eligibility assessment for them with regard to medical assistance in dying.

• (2000)

Hon. Hedy Fry: Thank you, Dr. Buchman.

I want to go to Dr. Tremblay.

I think you've also expressed that same sort of sense, that it is about the patient at the end of the day. It's not just about what the physician thinks; it's always going to be about the patient.

Can you tell me what you would do with that patient who went through palliative care and then decided that they wanted to end their suffering?

[*Translation*]

Dr. Marjorie Tremblay: A patient who requests a treatment option that the doctor cannot provide is obliged to go to another source. For example, if a cardiologist needs the opinion of a respirologist, he will seek the opinion of a respirologist. It's that simple.

Some doctors are willing to offer medical assistance in dying and some patients ask for it. It is not for the doctor to say whether it is right or wrong. The doctor must assess the patient. All those who offer medical assistance in dying must do so, and must continue to do so. One does not exclude the other.

[*English*]

Hon. Hedy Fry: Thank you.

Thank you for clarifying it, Dr. Buchman and Dr. Tremblay.

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

Hon. Hedy Fry: I am sorry, Dr. Chochinov, that I could not get to you.

The Joint Chair (Hon. Yonah Martin): We have five minutes.

Next we'll have Monsieur Thériault.

[*Translation*]

Mr. Luc Thériault: Thank you very much, Madam Chair.

Dr. Tremblay, in another forum we can have a debate on Quebec's legislative intent. I would now like to move on to another question.

Palliative care, as conceived by Ms. Cicely Saunders, consists of a holistic approach, accompaniment towards death, relief of pain and suffering on the psychic and physical levels, as well as accompaniment of the family, and this in the most natural environment possible.

When palliative care was started, it did not mean leaving the patient to die in a corner. Palliative care helps to slow down the process of dying when it has irrevocably set in. Patients feel better and do better when they are in a palliative care unit. Sometimes they even have to be taken out of the unit because they cannot stay there

for more than three months. You are right to demand more access to palliative care.

My next question is for Dr. Buchman and Dr. Tremblay.

If a patient at the end of life, who has received very good palliative care, who has been well supported and who feels serene and ready to let go, asks for medical assistance in dying, do you consider this a failure of palliative care?

Why should we separate these two approaches when they are part of a continuum of end-of-life care?

[*English*]

Dr. Sandy Buchman: I don't think that it's a failure of palliative care. It's unlikely a person will just wake up one morning.... But the wish to hasten death is very common in our field. At times, despite our best efforts...like anything in medicine, there are limitations to what we can do. It may be that we are just unable to address the suffering in ways that are acceptable to the patient.

Ultimately, Canadians have that access for eligibility, but it's also true that the presence of the MAID law allows us to deliver palliative care.

I had a patient with HIV and ALS, and he had no use of his upper body or his arms. He was completely dependent on others for feeding and for personal hygiene. He lived on the 22nd floor of a high-rise in Toronto, where I cared for him, and he told me it was the MAID law and his opportunity to choose or to have that choice when he was ready.... Otherwise, he accepted everything that we could do in palliative care. It was the MAID law that allowed him to accept palliative care, or he stated clearly that he would have jumped. The overall answer is that it doesn't happen immediately. We have limitations, and the presence of the MAID law often allows us to deliver excellent palliative care to the best of our ability.

• (2005)

[*Translation*]

Dr. Marjorie Tremblay: There can be many interpretations, and they are related to each person's experience. It is a highly emotional subject. We need to get data and do studies to find out what really motivates patients to ask for medical aid in dying, to understand what is going on.

Similarly, we need indicators in palliative care to be able to understand the bigger picture and understand the situation. If you decide to put a policy in place, you need indicators to monitor the situation. If there are no indicators, how do you know if it's working, if it's going well, or if there are failures and collateral effects?

Mr. Luc Thériault: Are you one of those who think that a patient who applies for medical aid in dying should be excluded from a palliative care unit from the outset?

This is done in some institutions.

Dr. Marjorie Tremblay: In this regard, I would say that patients who are in a palliative care unit need specialized care. So that means that their condition is complex. In my opinion, these beds should be kept. So it's not a question of being for or against, but it's a question of resources. We need to keep these specialized beds and the use of these specialist doctors for complex cases, i.e., cases like these.

Mr. Luc Thériault: If I understood correctly, your answer is “yes”.

[*English*]

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

Next we will have Mr. MacGregor for five minutes.

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

Dr. Buchman, I'd like to direct my questions to you.

You made mention of the fact in your opening statement that you have provided palliative care for homeless people—a very vulnerable population. I think you bring a unique perspective, because you say walk in both lanes. You have also been a MAID assessor and provider.

In your work with the homeless, you're dealing with a very vulnerable population, where the social determinants of their health are very obvious and present. They have had housing insecurity, they often don't know when their next good quality meal will come, and they live a life, on a daily basis, which is full of uncertainties and incredible stress on their health.

When someone has an incurable disease, an irremediable medical condition, and they're either being assessed for access to palliative care or maybe their choice is to go to medical assistance in dying, can you talk a little bit about what effect those social determinants have on their health? Do you often run into conditions where, if that population had earlier access or better access to health care, the state they are in when they first see you could have been prevented?

Dr. Sandy Buchman: I'm going to go right there with the question, and the answer is likely yes.

When an individual's suffering is a conglomeration of their past—they may have had severe trauma earlier in their life—we learn very much about performing trauma-informed histories. There's been a sequence of events, given the social and structural determinants of their life, everything from systemic racism perhaps, to mental health issues and addiction issues, that render them in the situation they are in.

We're working very downstream. I think it's really critically important to look at what's happening upstream very early on, not only the importance of directing the root causes of the social determinants, such as racism, sexism, homophobia, transphobia, colonialism, etc. Those are the roots of the social determinants of health and why it is key that we begin to address them at the roots. For those people who have gone through it, that's why it is so critical that we need equitable access to care, and particularly equitable access to palliative care.

We happen to have a program in downtown Toronto—and there are a handful of them across the country—but for the most part, folks don't have access to the palliative care services, or even the primary care services, the mental health and addiction services that are necessary to serve them. So we're down the road—we're downstream—and all we can do, then, is our very, very best to address their suffering, in all of its domains, as I referred to before.

● (2010)

Mr. Alistair MacGregor: Thank you for that.

In general, when you are meeting patients for the first time to have that very difficult discussion on what their options are, what's your sense of their familiarity with what palliative care involves or what medical assistance in dying involves when you first talk to them? Is that very vulnerable population aware of what those two types of care involve?

Dr. Sandy Buchman: It's hard to generalize, but as a rule, no. Most Canadians aren't really aware of palliative care, for example, until they happen to encounter it themselves or with a family member. The same is true for medical assistance in dying. A lot of the more vulnerable people haven't had the opportunities to have the same kind of education in health literacy as many other more fortunate Canadians. One of the reasons is that it's usually those of higher socio-economic and higher educational status who would opt for medical assistance in dying.

We have to do our best to educate them about their options, and if they express this wish to hasten death, then they have that right, like an option for any medical treatment. In this country they have a right to know about medical assistance in dying, but it's very important that we assess their vulnerability in a comprehensive way. That's why I stressed earlier that our education and competency in being able to assess this comprehensively is a critical issue.

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

At this time, I will ask my co-chair to step back in for questions from the senators.

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

We'll start off with Senator Mégie.

[*Translation*]

Madam Senator, you have the floor for three minutes.

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

I thank the witnesses for their testimony.

I also thank my former colleague Dr. Tremblay for being here with us.

Dr. Tremblay, I know that you worked with the Quebec National Institute of Public Health on palliative care indicators. We have heard and we still hear that we need to improve palliative care, that we need quality palliative care.

Can you tell us about these indicators? What criteria were used to select them? How can these indicators enable various levels of government to improve palliative care?

Dr. Marjorie Tremblay: Thank you, Dr. Mégie.

The latest report is from April 2021. Unfortunately, in Quebec, data on palliative care are very scarce. In this study, which was conducted from 2002 to 2016, we collected data on eight palliative care indicators. These indicators had been used in the past and were reviewed. Of the 10 indicators previously used, we kept eight. In this report we looked at what was happening to the population that could benefit from hospice palliative care. This study did not look at people who were receiving palliative care at home or in settings such as residential and long-term care centres. These indicators provide a lot of information about what is happening in Quebec.

I'll give you an example. Thanks to these indicators, we now know the place of death in Quebec. The main place of death in Quebec is the hospital. Four out of 10 patients likely to benefit from palliative care will visit an emergency room in the last two weeks of their lives. One in 10 people likely to benefit from palliative care will stay in intensive care. These indicators show us that early identification is not happening and that there is no integrated palliative approach.

Patients are said to have access to palliative care, but they actually have access to end-of-life palliative care when a catastrophe or complication occurs and the patient did not know they were going to die. The patient is in shock and distress. That's what it's all about. The patient is in distress because of their imminent death. They are transferred to palliative care, because curative care is no longer possible, and medication is started to relieve their symptoms.

There is a misinterpretation by the general population, and even by some professionals, that a patient receiving morphine will soon die. If the patient had been started on morphine five years earlier for pain or shortness of breath due to heart failure, for example, no one would say that morphine killed him at the end of his life. The myths would stop and people would stop being afraid of drugs. Indicators are extremely important because they allow all responsible authorities to understand the impact of decisions on everyone and to monitor progress.

● (2015)

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

[English]

We will now go to Senator Kutcher.

You have three minutes.

Hon. Stanley Kutcher: Thank you very much, Mr. Chair.

My questions are for Dr. Buchman.

We know that palliative care is inadequately funded and that there are substantial challenges to accessing public palliative care. We also know that access to MAID can be similarly problematic. Both areas are underfunded. Is the solution to fund one over the other by robbing Peter to pay Paul?

The second question is that quality palliative care has been sometimes characterized as needing to be provided by palliative care specialists in hospices. Others have noted that home-based palliative care can be provided by primary care physicians and it can be of very high quality.

What are your thoughts on these issues?

Dr. Sandy Buchman: I'm going to start with the second question first, if I may. I spend most of my time providing home-based palliative care or, as earlier mentioned, on the streets. I'm a very strong believer that the palliative care approach can be provided by primary care physicians, family physicians, nurse practitioners, etc. Probably about 70% of palliative care could be provided by primary care.

Unfortunately, due to many reasons, everything from a lack of sufficient training to even just lack of confidence, to payment models, etc., very few family physicians continue to provide home-based care of any sort, let alone palliative care.

I work very much on models that are just-in-time palliative care, 1-800 palliative care, where a family physician could call a palliative care specialist for just-in-time supports to manage pain crises or delirium in the middle of the night. I believe very strongly in supporting that, and continuing education.

With regard to your second point about inadequate funding, this is a problem throughout the health care system, of course. There is a fixed amount of money. We need to be able to support access to palliative care—hugely. I spend most of my life advocating for that. At the same time, there's inequitable access to medical assistance in dying across the country, and it's becoming even more so, after Bill C-7, and perhaps even in the future, in March 2023, when medical disorders as an underlying condition will be legal.

Having said that, we need huge amounts to be funded, from the very basics with regard to primary care, of course.... We advocated for that prior to the pandemic, with the current Liberal government, and never really got the funding for primary care that's needed. We need to be advocating all the time for sufficient training and access for both palliative care and medical assistance in dying, in my opinion.

[Translation]

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

I now yield the floor to Senator Dalphond.

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

[English]

My question is for Dr. Buchman.

You work with the more vulnerable in society, those who are often isolated and have been left out by society in general. When they come to you, it's because they need palliative care or they want to receive MAID. You are a MAID assessor.

In your practice, have you noticed that this subgroup of most vulnerable persons are acting differently from the other subgroups of people, that they are more reliant on MAID than other groups, because they feel that their lives are worthless?

• (2020)

Dr. Sandy Buchman: No. That has not been my experience at all. In fact, it's very interesting. When I work with the more vulnerable patients, they very much want aggressive medical care.

Often we talk about goals of care, or have end-of-life discussions with our patients, and whether they want to go through resuscitation, more comfort measures. Most of those vulnerable patients have an extreme lack of trust, for many good reasons, in the health care system. They become kind of suspicious if you start talking about maybe proceeding with a "do not resuscitate" or that it might cause more harm than good, etc. In fact, they want everything possible done, even maybe, from another perspective, to their detriment.

The experience with more vulnerable people asking for medical assistance in dying is actually quite uncommon. As known from many data, it's usually those who have a sense of control over their lives, usually higher socio-economic status, Caucasian, etc. All of those factors are very clear.

I would have to say there are patients who have asked for that, and that's when we go into the mode of addressing all of the issues of suffering, including the psychosocial issues and the mental health issues they are experiencing.

[*Translation*]

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

[*English*]

Go ahead, Senator Wallin.

Hon. Pamela Wallin: Thank you very much.

I have two questions to Dr. Buchman.

We have heard other testimony from professionals in the field of palliative care that somehow, when we get to the end of palliative care, it is not their responsibility to really offer the MAID option or to even have that discussion at the front end of opting for palliative care.

I keep coming back to this, and I'm not sure it's the right word, but do we have to on some level see this as a continuum and have that conversation at the front end?

You also said something that interested me and that is that the presence of a MAID option allows people to take on palliative care because they know there is another option if that doesn't work.

Dr. Sandy Buchman: A very interesting and challenging question is when to introduce the option or bring up the idea of MAID. In some jurisdictions such as in Australia, where I've spoken with regard to this, they prohibit physicians from bringing up the option of medical assistance in dying.

There's a power differential between physicians and our patients. They can be very influenced by that kind of authority. On the other hand, of course, it's like talking about cancer and not saying that

there's a chemotherapy option available, so fully informed consent of what's available to a patient I think becomes critical as is their moral and ethical right to have all the information that's available.

This is where I go back to competency and skill in how we share information. Ultimately, yes, I think patients have the right to have full knowledge and information about it. When that is introduced is where skill and the best professional judgment come in.

For some patients, as you explore their various options and see where they're going, and as you work, as I said, towards trying to address their suffering—I keep coming back to it because it's key—we find that the majority of patients will accept what you are offering, but there's always going to be a subset who absolutely find whatever treatment you offer unacceptable. At that time, I think it's incumbent upon us as professionals to let them know that there is such an option as an eligibility assessment for MAID. I do not say they have a right to MAID; I say they have an eligibility assessment option for MAID. I think it's a key difference.

Hon. Pamela Wallin: I went through this process with a friend recently. It was almost the opposite way. She said to her doctors, when the diagnosis was terminal, that she wanted the MAID option, and then they had the discussion with her about using palliative treatment in the interim to maximize her quality of life until her chosen date.

• (2025)

Dr. Sandy Buchman: For that patient, it sounds like that was the best course for them. It sounds very reasonable.

Hon. Pamela Wallin: Thanks very much.

The Joint Chair (Hon. Marc Garneau): We'll now go to Senator Martin.

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

My question will be for Dr. Chochinov.

I thought the examples you gave us really help us understand what true autonomy means and how important it is for patients to have that real choice.

Dr. Chochinov, can you tell us about the kind of suffering you see in end-of-life patients? What else could be done to better remediate suffering in end-of-life patients?

Dr. Harvey Max Chochinov: I've heard several times today and from various different witnesses the idea that there really is nothing we can do for existential distress, that there is no effective treatment and that there's no effective approach. I have to say, I've been working in palliative care for the last 35 years exclusively in the area of looking at end-of-life distress, existential distress, psychiatric and psychological distress.

For 15 years, I've been the co-editor of the *Handbook of Psychiatry in Palliative Medicine*, psychosocial care for the terminally ill. This is a book that will be coming out in its third edition this coming September with 45 chapters from various different experts around the world, so the idea that there is nothing that can be done is really something that I have to take exception to.

There is a massive literature that is out there looking at ways in which we can start to mitigate end-of-life distress. I'm also the co-editor of a regular journal called *Palliative & Supportive Care*, a journal that is entirely devoted to addressing end-of-life distress of the existential kind. This notion that MAID is the only card in our deck I think is terribly unjustified, and there are various different approaches that are available.

For instance, one of the things that causes a great deal of suffering in patients nearing end of life is an undermining of their sense of personhood, an assault on their sense of dignity, if you will, so we find ways to try to affirm personhood. This has us looking at everything from the attitudes and disposition of the health care provider, teaching them and training them that their own outlook and their own disposition can have a profound influence on the patient's sense of well-being and sense of dignity, to more formatted kinds of interventions.

One intervention we call the patient dignity question, where we ask about what we would need known about that individual in order to take the best care of them possible. It's an opportunity to put personhood on the radar.

Then there are a number of psychotherapies. I mentioned in my brief that I've developed dignity therapy, which is based on generativity and giving people an opportunity to leave a legacy. Gary

Rodin in Toronto is developing CALM therapy, and Bill Breitbart at Memorial Sloan Kettering has been looking at meaning-centred therapy.

I would not want to leave the committee with the impression that this notion that there is nothing to be done about existential distress. Unequivocally, obviously, that is being done with some intent or purpose that I can't claim to understand, but we need to understand. We need to know that there's a whole cadre of professionals around the world. This is not just a Winnipeg event or a Canada event; this is a global effort to try to address, understand and mitigate distress that is being tested, by the way, with research, including randomized control trials that show its efficacy.

The Joint Chair (Hon. Yonah Martin): That's a good way to end this panel.

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

I'm afraid we're at the end of our hour, but it has been very, very helpful to hear you, Dr. Chochinov, Dr. Buchman and Dr. Tremblay. Thank you for taking part of your day to answer our questions. This will help us in what is a very important and difficult issue, as you've all clearly pointed out. We very much appreciate it. Thank you very much for coming.

With that, for the members of the committee, it looks like we will be meeting two times next week, on Monday night, of course, and it looks like Thursday as well. We will be focusing on advance requests.

I would like to adjourn this meeting. Thank you.

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