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Standing Committee on General Government

Comité permanent des affaires gouvernementales

Compassionate Care Act, 2020

Loi de 2020 sur les soins
de compassion

1st Session
42nd Parliament
Tuesday 24 November 2020

1re session
42e législature
Mardi 24 novembre 2020

Chair: Goldie Ghamari
Clerk: Isaiah Thorning

Présidente : Goldie Ghamari
Greffier : Isaiah Thorning

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Tuesday 24 November 2020

LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

STANDING COMMITTEE ON GENERAL GOVERNMENT

COMITÉ PERMANENT DES AFFAIRES GOUVERNEMENTALES

Tuesday 24 November 2020

Mardi 24 novembre 2020

The committee met at 0900 in room 151 and by video conference.

COMPASSIONATE CARE ACT, 2020

LOI DE 2020 SUR LES SOINS DE COMPASSION

Consideration of the following bill:

Bill 3, An Act providing for the development of a provincial framework on hospice palliative care / Projet de loi 3, Loi prévoyant l'élaboration d'un cadre provincial des soins palliatifs.

The Chair (Ms. Goldie Ghamari): Good morning, everyone. The Standing Committee on General Government will now come to order. We are here to resume public hearings on Bill 3, An Act providing for the development of a provincial framework on hospice palliative care.

We have the following members in the room: MPP Gélinas and MPP Oosterhoff. The following members are participating remotely: MPP Bob Bailey, MPP Chris Glover and MPP Amy Fee.

We have a new addition. MPP McDonell, can you please confirm that you are MPP McDonell and that you are present in Ontario?

Mr. Jim McDonell: Yes, it's MPP Jim McDonell. I'm in Toronto, Ontario.

The Chair (Ms. Goldie Ghamari): Perfect. Thank you very much.

We are also joined by staff from legislative research, Hansard, and broadcast and recording.

To make sure that everyone can understand what is going on, it is important that all participants speak slowly and clearly. Please wait until I recognize you before starting to speak. Since it could take a little time for your audio and video to come up after I recognize you, please take a brief pause before beginning. As always, all comments should go through the Chair.

Once again, in order to ensure optimal sound quality, members participating via Zoom are encouraged to use headphones and/or microphones if possible. Are there any questions before we begin?

Our presenters today have been grouped in threes for each one-hour time slot. Each presenter will have seven minutes for their presentation. After we have heard from all three presenters, the remaining 39 minutes of the time slot will be for questions from members of the committee. The time for questions will be broken down into two rounds of seven and a half minutes for government members, two rounds of seven and a half minutes for the official opposition and two rounds of four and a half minutes for the independent members as a group. Are there any questions?

ALZHEIMER SOCIETY OF NIAGARA REGION

DR. JOSÉ PEREIRA

MATTHEWS HOUSE HOSPICE

The Chair (Ms. Goldie Ghamari): I will now call upon our first set of presenters. We have the Alzheimer Society of Niagara Region, José Pereira and Matthews House Hospice. Each of you will have seven minutes for your presentation. I will give you a one-minute warning before your time is up.

At this time, I'd like to ask the Alzheimer Society of Niagara Region to please state your names for the record and then you may begin. You have seven minutes.

Ms. Sarah Putman: Good morning. Thank you for my invitation to share. My name is Sarah Putman. I'm the manager of education services with the Alzheimer Society of Niagara Region. Across Ontario, 29 Alzheimer Societies serve over 160,000 clients each year, including both people living with dementia and their care partners. In every community in the province, the Alzheimer Society is an integrated part of the health care system. We offer system navigation, adult day programs, counselling, social recreation, caregiver education and in-home respite, among many other programs.

When a member of the family is diagnosed with a dementia or Alzheimer's disease, it means the family dynamic is irreversibly altered and all family members are likely to be deeply affected. Dementia is an illness for which there is not a cure.

The Alzheimer Society believes that when seniors living with dementia reach a terminal stage, a palliative approach to care will improve the quality of living and dying for both patients and their families. However, research suggests that compared with seniors without a dementia diagnosis, seniors with dementia are less likely to be referred to palliative care teams, are prescribed fewer palliative care medications and are infrequently referred to and/or are denied access to hospice care.

There are many reasons for this lack of palliative care. They may include difficulties in assessing needs of persons who cannot always speak for themselves or express what they need, difficulty in predicting time to death for persons who live with dementia, communication barriers between health specialists and between providers and families, and that dementia in particular is not always seen as a palliative care issue by some health care providers.

The Canadian Institute for Health Information found that over 10,000 seniors with dementia died in acute care hospitals in 2015. More than half were identified as having palliative care needs, and 21% were hospitalized primarily just for palliative care. The same study found that in 2015, the number of seniors who died in Canadian long-term care and had a record of receiving hospice palliative care was only one in 20.

Although long-term-care homes provide end-of-life care, it is not typical intense palliative care that would be present in a person's home or in hospices. Staff at long-term-care homes may also not have a dedicated resource or the specialized skills and knowledge required to provide palliative care.

Palliative care improves the quality of life throughout the treatment of serious illnesses by providing practical, emotional and spiritual support. Hospice care places a high value on dignity, respect and the wishes of the person who is ill, as well as the needs of the person's loved ones.

On a very personal note, I have witnessed first-hand the difference appropriate hospice and palliative care brings to end-of-life care. My family struggled to support my grandfather in hospital at the end of his life. He was ineligible for long-term care due to medical needs and unable to access hospice care. This resulted in his final days being filled with busy nursing staff, a less-than-optimal environment of beeping machines, wires and tubes, a lack of education and support for our grieving family and a constant feeling of fighting the system for a peaceful end of life for him. Despite a long two-month battle of attempting to get him out of hospital to die with dignity, we were unsuccessful, and unfortunately he died alone in the night, because no one was able to call us.

This is a very stark contrast to my grandmother who, with no small amount of family advocacy, was one of the lucky few who was able to access a hospice bed in Niagara, where she received appropriate comfort measures, a peaceful environment, and our family was given the support and education needed to cope with the loss. Having appropriately trained doctors, nurses and volunteers and a supportive environment allowed our family to focus on what we needed to and not on a battle with the system.

Currently, there are only 16 hospice beds available to serve our entire Niagara region, with a population of over 450,000. It's the mission of the Alzheimer Society of Niagara Region to advocate for and with persons with dementia and their care partners and to provide access to a diverse range of appropriate resources and supports. This includes supports for end of life. The Alzheimer Society of Niagara Region fully endorses the development of a provincial framework designed to support and improve access to hospice palliative care through hospitals, home care, long-term-care homes and hospices.

Thank you so much for having me this morning.

The Chair (Ms. Goldie Ghamari): Thank you very much for your presentation.

We'll now turn to José Pereira. Please state your name for the record and you may begin. You'll have seven minutes. Thank you.

Dr. José Pereira: Good morning. Thank you very much for the opportunity to present to this committee in support of Bill 3. My name is José Pereira. I'm a palliative care physician and professor and director of the division of palliative care in the department of family medicine at McMaster University. I'm also the scientific officer and co-founder of Pallium Canada.

I've worked in different clinical settings, including home care, hospices, palliative care units and hospitals. I am also an educator, researcher, and I've led regional and provincial palliative care programs. To be very honest, I did not think 25 years ago, when I first trained in palliative care, that a quarter of a century later, I would still have to be advocating for palliative care. We have made many strides over the last two decades, and we do have much to celebrate; I want to stress that. But sadly, there are still too many gaps. I therefore applaud and thank the sponsors and supporters of this bill.

I still witness too many patients not receiving adequate pain control or palliative care, patients receiving palliative care too late, being taken to emergency departments in the last days and weeks of life and dying in hospitals because of shortages of hospice beds. I've also seen patients with severe pain being cared for in general medical wards when they could be better cared for in a palliative care unit.

Too many medicine and nursing learners continue to graduate without core palliative care skills because we cannot get airtime in their curriculum. We cannot get the funding to access ready-made courses. Just in the last few weeks, I've been trying to find $5,000 to access ready-made courseware for 600 medical students at my university, when it will cost tens of thousands of dollars and lots of precious time to develop courses and online modules from scratch. So far, I have been unsuccessful.

At the start of the COVID-19 pandemic, I was asked to co-lead a task group in the Hamilton region to organize community-based palliative care services. We were not able to merge three different groups to form a single go-to service. Why? Because the funding did not allow it. The physicians were paid by different funding models, some of which were inappropriate for the work at hand. Some were receiving funding to be on-call; others, no funding at all.

In the city hospital designated as the regional COVID-19 hospital, there's only one palliative care physician and one palliative care nurse. National and international standards call for at least double that, but there are not enough positions for that hospital that are funded by what we call an alternative funding plan, or AFP. There is also no funding to pay palliative care doctors to provide on-call after-hours coverage for that hospital. Yet in the hospital across town, there is such funding. Why the discrepancies and the inequities?

0910

These problems are neither limited to Hamilton nor are they new. They've been going on for many years. They occur across the province. I can give you many examples where palliative care services cannot be organized properly because of inappropriate funding models and a lack of trained palliative care physicians, nurses and other professions. Opportunities have been missed to fix these issues over the last decade, but we have seen encouraging developments in the last few months. I implore the government and the Ontario Medical Association to accelerate these efforts.

It is a privilege to work in palliative care, but it is not always easy work. These funding inequities and gaps make it difficult to recruit new doctors, to retain experienced ones who are increasingly feeling demoralized and exhausted, and to undertake important work like teaching and system improvements.

While we do need more specialist palliative care positions and services, it cannot be only about more specialist palliative care teams. All health care professionals who care for persons with serious illnesses need core palliative competencies. There is wisdom in the saying, "Teach them to fish and they will have fish for a lifetime." In this case, teach and support them to do palliative care, and many more people will receive it.

Ontario is lagging Alberta and countries like the United Kingdom, the Netherlands and Australia in this regard. We have also tended to focus on single components of what is a whole system. When we purchase a car, we don't ask for a car with only one excellent tire; we ask for a car that has all four tires, all the components to function. So why is it that with respect to palliative care, we tend to focus only on one component at a time? More hospice beds and better hospice funding are desperately needed, but we also need palliative care unit beds in hospitals and more home care resources. If we close palliative care unit beds, where will we care for patients with complex needs who are not at the end of life, but need in-patient care?

The lack of funding not only threatens the important components of the palliative care system and palliative care research in our province, it also creates a scramble for what funding does exist. This is resulting in some unnecessary duplication of efforts. Instead of funding groups to come together to collaborate on areas like training long-term-care staff, for example, and to join forces to improve and spread what we already have, we end up reinventing the wheel in order to generate funding. We should be supporting and nurturing centres of excellence that already exist or are close to completion, instead of further diluting precious resources. As academics, our institutions require us to show scholarship. Instead of recreating education and other programs, we should put our efforts towards improving and spreading existing ones and leveraging them for further innovations.

In Hamilton, we were not able to mobilize our paramedic services to provide emergent palliative care in homes during the pandemic. Lack of funding and a decision not to use an existing flexible, low-cost, Canadian-made paramedic palliative care training program, which is already in use across many parts of the province and the country, contributed to this. In the Niagara region next door, they had already trained the paramedics last year. They were able to mobilize.

There is good news. I can also provide many examples where patients and residents have received excellent palliative care—

The Chair (Ms. Goldie Ghamari): One minute left.

Dr. José Pereira: —because their family health teams and nursing agencies had trained their staff. Hospitals and emergency departments that have embraced the palliative care approach, long-term-care homes that have made palliative care part of their daily work, learners who are graduating with palliative competencies and amazing, compassionate community projects: We need to celebrate these and use them as role models. We need to spread and scale them up.

Some colleagues and I have been working on a project to identify what we think are top fixes needed to improve palliative care in the province. We found 10 provincial reports and frameworks in the last decade alone, including the 2019 Ontario Palliative Care Network Health Services Delivery Framework. There are common themes across them, including suggested fixes. Moving forward, I'm hoping that the bill not only draws on these recommendations, but that we also see real action on them.

The pandemic has exposed gaps, but also shown us that change is possible, that improvements can be made quickly and that we are resourceful. We don't have to wait for months and years. Investing in palliative care is not only the right thing for patients and families, it is the right thing—

The Chair (Ms. Goldie Ghamari): Thank you very much. My apologies, Doctor; I have to cut you off there, but I'm sure you'll have more time to continue in the comments.

At this point, I'd like to call upon Matthews House Hospice. Please state your names for the record and then you may begin. You will have seven minutes. Thank you.

Ms. Kim Woodland: Good morning. I'm Kim Woodland. I'm the chief executive officer at Matthews House Hospice in south Simcoe county.

At Matthews House, we support Bill 3. We're grateful to MPP Sam Oosterhoff and all the MPPs who have supported hospice care over the years. Bill 3, if passed, will provide a building block to facilitate access to care, support caregivers and providers, training, research and common data collection. It's a very good step forward.

Currently, without this act, the challenge is facilitating access to that care and supports, and understanding what people need and when they need it. At hospice, we provide controlled pain and symptoms so that people can physically and emotionally live their lives. We provide participation in active living, fun and friendship.

We provide participation in active living: Sometimes it's about roofs over heads and food in stomachs.

In hospice, we provide active living: learning how to feel well and be well despite a health condition or impending death. Yes, hospice also provides a way to die well, having lived well until that death. That's a conversation that we need to have more of across the province. We believe that Bill 3, if passed, will help us do that.

At hospice, we hear from people who have received hospice care, both individuals and families; children and youth; grandmothers, grandfathers; and everyone in between. These are things we hear from the people. They say, "I wish I had known"—that's a quote—"about hospice and what hospice does."

Here's another quote: "We should have started at the beginning, instead of now."

Other people say: "We don't know what to do now that this has happened." "I've had a fall. My PSW didn't turn up." "I'm having terrible symptoms, and it's the middle of the night." "I have no quality of life." This is the challenge for us in the hospice palliative care system without Bill 3.

The other challenge is what we, as hospice care providers, hear from our partners in the system—the nurses, the doctors, the home care providers. What we hear from them is almost the polar opposite, you might be surprised to know. What we hear from professionals and providers in the system is, "They are not ready yet for hospice." Our partners don't understand that hospice is about living and living well, and then dying well, if you must.

We also hear from our partners: "I can't refer because I don't have permission. It's a system thing, you see." "We can't share that information because we don't have permission. It's a system thing." "It's not time for a referral for good hospice palliative care. They're not dying yet."

Then the two heartbreaking things: "It's too late; they're too sick," and "No, they are too sick to transfer to hospice."

And the other thing, from a health executive new to hospice but not new to the system: "Hospice is like knocking on the door of Big Health, holding our clients' hands and hoping."

You can imagine that people not knowing themselves and care providers not understanding is a terrible cocktail, which we have high hopes for Bill 3 to help us solve. The passing of Bill 3 will enable Ontario Health to support every citizen—those who are in hospital, those who have Alzheimer's disease at home, the caregivers—to help every citizen be able to self-identify early that they need assistance with living and dying. That's the access part.

An emergency room for living well: That's what hospice palliative care could be.

0920

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Kim Woodland: The passing of Bill 3 will enable people to live fully in spite of a health condition, to feel well and be well until they die, to prevent seniors from failing to thrive and prevent suicide. The passing of Bill 3 will create a health service environment that enables providers and caregivers to know how and when to support people both in living and in dying.

We want to thank MPP Sam Oosterhoff and all the MPPs who will help pass this bill. It's time, for the citizens of Ontario.

The Chair (Ms. Goldie Ghamari): Thank you very much for your presentation.

At this point, we'll now turn to questions, beginning with the official opposition. MPP Glover, you may begin. You have seven and a half minutes.

Mr. Chris Glover: I want to thank José, Sarah and Kim for being here. I want to thank you also for the work that you do. I just can't imagine how difficult that work is, so thank you for that.

I'm not that familiar with this area; I'll be quite frank about it. I've read through the bill a few times. I listened in all day yesterday. I'm going to put it on the table; these are my concerns with this bill: It asks for a report to be done, completed, by a year from now. A year from now will be six months out from the next election, so we'll be in pre-election mode. My fear is that in that six months, nothing will be enacted, because that will be a very, very busy time. Then, after that it will be a change of government and this report could end up like one of the other 10 reports that you mentioned, José, from over the last 10 years.

I've seen this kind of thing before in committee over the summer. We had hearings on Tarion, which is a completely different topic. It's the mortgage insurance for homeowners. Over the last 24 years, there have been dozens of reports and nothing has really been done to fix that system.

I look at this bill and what I would like to see in this bill and what we would like to do is to propose amendments to take action now. We've got this bill. It's going to be going back to the Legislature. What are the top items that should be done now, while this report and this investigation and the framework are being developed? If you could list just a few of the top items that you would like us to put in as amendments to this bill, actions for now.

I'd like each of you to respond. I'll start with Sarah, then José, and then Kimberly. And we've got how long, Madam Chair?

The Chair (Ms. Goldie Ghamari): You have five and a half minutes.

Mr. Chris Glover: Five and a half minutes, so if you could take just under two minutes each. Sarah?

Ms. Sarah Putman: It's sort of a big question, and I'm not loving the idea of going first. Um—

Mr. Chris Glover: Okay. Do you want José to go first?

Ms. Sarah Putman: Perhaps. I'm—I think for me, the biggest piece is access, and equitable access, across all areas of life for anyone at any age, whether that is a child, an adult or a senior, and with any illness. I think there needs to be an easier access point.

I feel that from personal experience and from the information I receive from our clients on a daily basis, I have the opportunity to teach advance care planning, to have conversations about end of life with dementia. It's a very different picture than for some illnesses at the end of life. I think there's a lot of confusion around what hospice care looks like, what palliative care looks like. What does the theme of palliative care—people believe that it's just a DNR, but it's not. It's so much bigger.

So I think education, but I think access to that education and access to the system needs to be more clear for everyone.

Mr. Chris Glover: And when you say access to education about the system, are you talking about health care providers or the public in general?

Ms. Sarah Putman: To the public.

Mr. Chris Glover: Okay.

Ms. Sarah Putman: Yes. I actually think to both, because there are times when even health care providers have an unequal education around what's even available. Often there isn't a clear menu available across the province for what people can get and access for their end-of-life care, so having the opportunity to explore further what that might look like and how that access can happen and what the messaging is to both providers and the public.

Mr. Chris Glover: Thank you very much. José?

Dr. José Pereira: Thank you, sir. I think a few things. Number one is enough palliative care beds, so palliative care beds and hospice beds in the right proportion for the population. There are formulae that we can use that have been used in other parts of the country and internationally.

The right funding: It's crazy that hospice is largely funded through charity and fundraising. When someone has a heart attack, we don't tell them, "Half of your care will be funded through fundraising and charity." The AFP issue for palliative care physicians has to be sorted once and for all so that we can move on with the work of spreading palliative care. Funding is required to help us educate medical students, nurses and other health care professionals so we can scale this all up.

Mr. Chris Glover: Thank you. Do you have specifics around—you said the formula. Can you submit to us, to either my office or France Gélinas's office, specifics about the formula and what that would look like so that we can develop it into an amendment for the bill? And also the training in care—specific recommendations are what we're going to need for the amendments.

Dr. José Pereira: Certainly. Will do, sir.

Mr. Chris Glover: Okay, thank you. Kimberly?

Ms. Kim Woodland: Hi. Thank you. I would say, mirroring José's comments, that we spend in Ontario—I did the math the other day for one of our MPPs—0.0002% of the entire health care budget, what the province is paying for health care, on hospice and palliative care. That's not very much, considering the job that needs to be done.

I agree with you. We don't necessarily need another report. We need people—

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Kim Woodland: We need the government to understand that we need action on both funding and on making a community hub for hospice and palliative care. It would work very well through the OHT thing that is happening in the Ministry of Health in every community. And run all of the services for people who need hospice and palliative care out of that hub.

Mr. Chris Glover: Can you draft that up into specific recommendations and send it to my office for us? Same with Sarah and José: If you have specific recommendations that you want to be built into the amendments, please forward them to my office, and I'll forward them out to our team. Thank you very much for being here.

Those are all of my questions, Madam Chair.

The Chair (Ms. Goldie Ghamari): Thank you very much.

We'll now turn to the independent member. MPP Fraser, you have four and half minutes.

Mr. John Fraser: Thank you very much to all the presenters. To Sarah, to José, it's nice to see you again, even though we're remote. And Kimberly, thanks for your presentation.

I'm going to start with José, because some of the things you've talked about we've talked about before in terms of palliative care equity of access in all settings. There are impediments, especially in the hospital sector and the long-term-care sector. For the committee, can you go into that a bit more deeply, the kinds of things that you think, in terms of the AFP and other issues, would help to resolve that equity of access?

Dr. José Pereira: Certainly. Part of the access is that health care professionals upstream and downstream don't understand what palliative care is and keep thinking of it as being only at the very end of life and about death and dying. But it is about living, as one of my colleagues said earlier.

First of all, many of them don't have the training and don't have the confidence to implement a palliative care approach alongside giving treatments to control the diseases, be it cancer or not. So they're afraid of initiating a palliative care approach. They're not sure of what to do.

0930

In the meantime, for palliative care physicians, the fee-for-service model has worked for palliative care in some sectors, but in others—especially academic hospitals where we've got to be doing teaching, research and quality improvements—it doesn't pay for that activity. In the fee-for-service model, you tend to take over a lot of the care, because that's how we make a living. In doing so, we're actually deskilling our very colleagues that we want to build the capacity in. It's often said that every system is perfectly designed to get the results it gets, so why is it that we haven't built this, what we call the generalist palliative care approach, into the system?

There are a few other impediments, but the training and the funding model, I think, is the biggest one. Also, we should be seeing more of the professional organizations adopt and embrace palliative care and encouraging it to their members.

Mr. John Fraser: I think I remember, so maybe you can correct me if I'm wrong, that through Cancer Care Ontario at one point you had worked on a resolution to the AFP challenge. I know they're all over the place, they're all different, and what it does is it creates basic inequities right across the province, even within AFPs. So there was a solution. That stopped. Do I remember that correctly?

Dr. José Pereira: Correct. The first solution was actually submitted in 2013, when I was working at Cancer Care Ontario. Unfortunately, that solution was dropped. Then over the past few years, we brought it up several times. At Bruyère, we had a request to fix it denied.

Most recently, there have been improvements. There have been more positions added and the funding has been improved so that it's fairer. But we need to accelerate that more. As I told you, there are still some hospitals that still don't have palliative care doctors because of this issue.

Mr. John Fraser: So there is not a general approach to this. It's still kind of a one-off: "We'll add a bit more funding here; we'll add a few docs here," instead of an approach that says, "We'll do this in some relatively homogeneous kind of way that makes sure there is equity of access."

Dr. José Pereira: Correct, Mr. Fraser. Yes, it's very piecemeal.

Mr. John Fraser: It's very piecemeal. Thank you very much, again.

How much time do I have left?

The Chair (Ms. Goldie Ghamari): One minute.

Mr. John Fraser: I have one minute. That's not a lot of time. I had one other question here for you, but we probably won't have time to answer.

I'm interested in the training that you're trying to fund for your students. Maybe we can connect afterwards and if there is some way I can be helpful or add something to help you get that done.

Dr. José Pereira: Thank you.

Mr. John Fraser: It's amazing. It's not a lot of money. The hardest things to do in this field are when it's not a lot of money and it's going to do a lot of good.

Dr. José Pereira: Absolutely.

Mr. John Fraser: So thanks for all your work. I look forward to having a chance to speak with both Sarah and Kimberly.

The Chair (Ms. Goldie Ghamari): Thank you, MPP Fraser.

At this point, we'll turn to the government. MPP Oosterhoff, you have seven and a half minutes.

Mr. Sam Oosterhoff: Thank you so much to those who have presented today. I really appreciate all your work within the space and your advocacy for those who are positively impacted by all of your work.

I have a number of different questions, so I'm going to hop right into it, perhaps starting with Dr. Pereira. Thank you for your advocacy and your leadership on this file.

I do want to just very briefly engage with a couple of previous comments. One of the ones that I think is key in this discussion—and I recognize the need for more funding in this space. I recognize the need for increased allocation and have been advocating for that both internally and publicly for some time, recognizing that with a private member's bill, I can't force government expenditures. Any private member's bill is unable to, essentially, force the government to allocate funds. That's the discretion of government legislation. So just with that caveat, perhaps, to some of those pieces, there are some limits around what we can do within the legislation.

But addressing something that you touched upon earlier, Dr. Pereira, you spoke about the Netherlands and about the UK as being more advanced. I understand that Canada is the birthplace of palliative care, or at least as a descriptor, and so that's disconcerting to hear. What have they done well that we should be echoing?

Dr. José Pereira: Thank you, Mr. Oosterhoff. Hospice palliative care started in the UK; we termed the term "palliative care" in Canada.

Where I think they're doing well is this notion of primary level or generalist level palliative care. In other words, palliative care being provided by all health care professionals across all sectors of care who care for patients with serious illnesses—not palliative care specialists, but the family doctors, the oncologists, the cardiologists, the home care nurses, the nurses in the nephrology units etc.

What they've done very well in the UK, and in the Netherlands and in Australia, I think speaks to a very strong primary care foundation in their health care system. There's an expectation that the family physicians do provide palliative care, for example, and that palliative care is being done in the different sectors. But they support them; they incentivize that work and they support it.

In Ontario, we haven't done that. We focus too much on a fee-for-service model, for example. We haven't looked at clinics that have done this, where family doctors are doing it, where hospitals are doing it—the William Osler centre, Lakeridge Health—so we can do a better job in that area, building that palliative care capacity, that primary capacity.

Mr. Sam Oosterhoff: Thank you very much. As the members opposite will know as well, both opposition and the third party, I think one of the key things in any government, but especially in governments that have a lot of different things on their plate, is keeping the profile of particular areas. Of course, you know health care is a very broad sector. So wanting to make sure, through the use of this committee and the reports, the regular reporting and the consultation involved in this, that we are raising this profile both within the government and more broadly across the province—that there is more awareness about this. It's an interesting thing where people value palliative care—they do their hikes for hospice, they do their bike-a-thons and everything else—but then they don't really want to talk about it too much because it makes people uncomfortable. So hopefully even some of the conversations will happen as a result of this.

But I wanted to touch on something else you talked about, which is burnout among staff and a feeling of underappreciation, perhaps. Or perhaps it's not even that; it's just a lack of resourcing.

Yesterday, we were talking about this with someone from RNAO with regard to how we call them heroes, we call them health care champions and all these sorts of things, but at the end of the day, you, on the front line, you're also workers, and we need to make sure that you're supported and have mental health supports and have those support networks in place within the structures. Can you talk a little bit about what we could be doing better to ensure that that support exists? And then if you can please touch on the importance of Ontario health teams and if this could fit within that model?

Dr. José Pereira: Certainly. In terms of exhaustion and burnout, a lot of it obviously has been exacerbated by the pandemic and things like visitation restrictions—which I totally agree with, by the way. I think that's how we have to protect very, very vulnerable and frail patients. But it does take its toll. Nurses and social workers and physicians now are not only professionals, but they're also companions for people who cannot get visitors.

But I think part of it is also lack of action. I've worked on the 2011 framework. I was part of three or four of those other frameworks, and we keep saying the same thing over and over again—at some point, we think it's been a bit of a waste of time, almost. But we know that that's not true. We've got to keep doing this. This is why what you're doing here is so important, because it keeps moving things forward.

The funding also is demoralizing. On a Thursday morning, I go into the hospital and, for the first 15 to 20 minutes, I work with a whole team—doctors, nurses, social workers—to do quality improvement on our palliative care unit. And then I go and sit for an hour and we review all 60 patients. I cannot get remunerated for that one and a half hour of work at all—it's done for free—because the billing codes don't allow me to do that. So at some point, we start saying, where is the value of the work that we do and the importance of the work that we do? They're just some examples.

There need to be opportunities for grief work, for self-care work as well within the sector. I think there are programs that do really well, but we could do much better in this area as well.

Mr. Sam Oosterhoff: Thank you so much, Dr. Pereira.

Sarah and Kim, I want to thank you as well for coming and presenting. Very quickly, I know I don't have that much time left—

The Chair (Ms. Goldie Ghamari): One minute.

Mr. Sam Oosterhoff: Sarah, could you speak a little bit about what you've heard from family members? Because we can be talking about numbers, we can be talking about strategies and frameworks and formulas and all this sort of stuff—it's all good—but at the end of the day, it's about people. I'm wondering if you could talk a little bit about what you've heard from people at the Alzheimer Society in Niagara.

Also, Kim, if you could hop in very quickly as well in a 10-second pitch on what the major need is.

0940

Ms. Sarah Putman: I think the base need for people is that they need to be supported at the end of their life, but also on the journey towards the end of their life. As Kim and José have both said, there is a lot of living well in between the diagnosis of any terminal illness and the end of life. Conversations about death and dying, palliative care and hospices need to happen along the continuation of that journey.

What we hear so often when people come to us for advance care planning or end-of-life conversations is that they have never had that opportunity to talk about those items, that it's the first time it's been brought up. I think what people really need is—

The Chair (Ms. Goldie Ghamari): Thank you. That's all the time we have for this round.

At this point, we'll now turn to the official opposition for seven and a half minutes. MPP Gélinas.

M^{me} France Gélinas: I would like to thank all three presenters: Ms. Putman from the Alzheimer's society, Dr. Pereira, as well as Mrs. Woodland from Matthews House Hospice.

I have questions for all three of you. The first one is to you, Mrs. Putman. I was really surprised when you said that people with Alzheimer's and different dementias were denied access to palliative care. You went through a series of reasons why: don't know the time of death, different approach etc. Do you know of other jurisdictions or other provinces that do that better than Ontario and that we could learn from?

Ms. Sarah Putman: It's a good question. I think it's less about palliative care and more about dementia in this case. There are a lot of myths and misconceptions about dementia itself. Persons who live with dementia have a hard time expressing their own needs. Family members, at this point in the journey of dementia, are a lot more stressed and burnt out and don't know to ask for help. They also experience, at end of life, things like really extreme responsive behaviours, agitation, things that can make it hard for them to access certain services and some of the other pieces in moving to hospice care. Receiving hospice outside their home can be more difficult for someone living with dementia.

I'm not familiar with what other jurisdictions are doing with regard to hospice care. I don't know if Kim might be able to answer.

M^{me} France Gélinas: Okay.

To you, Dr. Pereira: Do you know if physicians have tools to assess people with dementia and Alzheimer's to know if they would benefit from palliative care, or is this an area that still needs to be developed?

Dr. José Pereira: That's an excellent question. There are tools to identify palliative care needs earlier in the illness, not just in the terminal phases. Part of that is actually training the health care professionals to be able to incorporate this approach alongside treatments to treat any of the other complications of the disease.

So there are tools, there are approaches, there are training programs that are ready to go and that we can apply. Part of the challenge is this notion, the belief, that palliative care is only for the last days of life, and therein lies the big challenge. We miss opportunities when patients still have mild to moderate dementia where they can still participate in expressing what their wishes are and what's important for them. We miss those opportunities earlier in the illness. We miss the opportunities to assess what their symptoms are. There are tools that we can leverage.

M^me^ France Gélinas: Okay.

To you, Mrs. Woodland, from Matthews House Hospice: Could you share with me how much is your budget? How much of it comes from the provincial government and how much of it do you have to raise for yourself?

Ms. Kim Woodland: Matthews House Hospice is—I'm going to call it a full-service hospice. Our budget is about $3.2 million annually at the moment. We have a 10-bed residential hospice unit which we receive provincial funding for, around $1.1 million for the nursing and personal support work that is provided. We receive about $80,000 for our community programs. We serve about 200 people a year in the residential unit, and we serve about 3,000 people through both our day programs and our community outreach programs. We receive about $80,000 from the province to provide the visiting hospice program, which is a volunteer program, so that covers the cost of a volunteer coordinator.

All of the mental health counselling for grief and bereavement, all of the nursing and personal support work that is provided on an outreach basis for people dying at home and all of the supports for active living, including wellness programs and so on, are covered by the donations to our hospice and our community, to the tune of about $2 million a year. So the community hospice programs, which serve most of the people, are funded at about the rate of 9% by the province.

M^me^ France Gélinas: It's 9%, so—

Ms. Kim Woodland: We raise $2 million a year to operate, yes.

M^me^ France Gélinas: Oh, wow. Okay.

Ms. Kim Woodland: Yes. You can imagine, in a COVID-19 world, that that fundraising situation is dire. Matthews House is blessed by a very supportive community, but that could end at any moment, and then it would be a very bad situation for the municipalities in our region.

M^me^ France Gélinas: What happened when you asked for more funding? I'm assuming you've asked the government for more funding.

The Chair (Ms. Goldie Ghamari): One minute left.

M^me^ France Gélinas: What kind of responses do you get? How come you don't get funding?

Ms. Kim Woodland: It's a bit complicated. Many hospices in the province, like Matthews House, have someone else who is their transfer payment agency. Hospice is not a well-understood nor well-funded thing in any community across the province. Our association does submit regular funding requests, and then after that, it's with the government to decide. What happens are other urgencies at a government level, I would say.

M^me^ France Gélinas: You say that you see about 200 people in your 10 beds. Do you turn people away?

Ms. Kim Woodland: We do.

M^me^ France Gélinas: Would you know how many?

Ms. Kim Woodland: Off the top of my head, I would say that at least 10 people—

The Chair (Ms. Goldie Ghamari): Sorry, that's the time at this point. We'll now turn to MPP Fraser.

Just for the MPPs who are in the room and in the Zoom chat, there is a vote that's happening, but we do have enough time to finish this round before we go to the vote. If you are in the committee on Zoom and you don't think you can make it in time, then I suggest you leave and go to the chamber. But for us here, we're going to finish off in the room first.

MPP Fraser.

Mr. John Fraser: Is it 10 a month or 10 a year? That was to Kimberly.

Ms. Kim Woodland: It's 10 a month.

Mr. John Fraser: It's 10 a month; okay. Thank you very much for that.

Kimberly, I'll start with you. I haven't had a chance to go out to see your new hospice, but I've seen pictures, and it looks great. Thanks for all the work that you're doing out there. In terms of your community program, just to follow on, you fund it through government funding. How else do you support that? Do you have other partners in that, or is that through your specific partners, like a Rotary?

Ms. Kim Woodland: There are a number of businesses and organizations in our local region who support us through sponsorships of events and so on. We have direct mail campaigns. There's one going on right now. Usually, at this time of year, individuals donate; third parties, like churches and so on, donate money. We also seek out opportunities through grants with both the federal and provincial governments—the Trillium Foundation, as an example. And other foundations provide help and support.

0950

Mr. John Fraser: What we're hearing in the committee is the bill here is sort of giving structure to how we can report back and what we need to get in there. It's what's important to report back to politicians so they understand what needs to be done.

I think one of the things we understand needs to be done right now is to move the level of support for palliative care. If you look at hospices, it's to get up to the full clinical costs.

Ms. Kim Woodland: Yes.

Mr. John Fraser: It's important that there are community components; I believe that. But there's too much pressure, and it's that governments need to actually increase those supports so you get a better balance.

I want to thank you for all your work.

I do want to raise one other thing with Sarah, and thank you very much for your presentation and sharing your story. Stories are really important as we're thinking about palliative care because it impacts everybody's family, but not everybody talks about their experiences. Advance care planning is a critical piece of actually creating a context for everybody to understand the importance of palliative care.

The thing that always baffles me is the entry points into palliative care are not clear or intuitive, even for people who work in health care. Can you talk a bit about advance care planning and the need to make sure that people have a very clear understanding and clear pathways?

Ms. Sarah Putman: I think any time someone is diagnosed with a change in their health care, this should be a conversation that starts to happen. I don't think it should just be, "You have cancer; you should talk about end of life," or "You have dementia; you should talk about end of life." I think it should be related to health care along the continuum of your life. We're all dying at some point, so I think it's important for everyone to have a conversation about—

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Sarah Putman: Sorry.

Mr. John Fraser: No, finish. Go ahead.

Ms. Sarah Putman: —what your wishes and needs are, whether we are an adult or a senior, and getting the word out about that. I think that needs to come right from the ground up at primary care. It should be happening in the primary care offices. It should be happening across the spectrum of community service agencies. It should be happening at all the different health care points. It should be a best practice happening across the spectrum of health care, and it's not.

I think it's a hard conversation. People avoid the conversation about death and dying, but as Kimberly and José have both said, it's not just about death and dying; it's about your quality of life. I think we need to make sure that the framework is there for people to feel comfortable, for agencies—

The Chair (Ms. Goldie Ghamari): Thank you very much. That concludes this round of questions.

We'll now turn to the government. MPP Oosterhoff, would you like to—

Mr. Sam Oosterhoff: It's MPP Fee, I believe.

The Chair (Ms. Goldie Ghamari): MPP Fee, my apologies. You have seven and a half minutes. You may begin.

Ms. Amy Fee: Thank you. Good morning, everyone. I want to say, first off, an incredibly huge thank you for all the work that you do, because I really emotionally don't know how you handle supporting people in these incredibly difficult times and the challenges that they're going through. I think it's that piece of care for yourselves especially, Kim and Dr. Pereira, working in the field, constantly being around people that you're trying to support to have the best final days that they can of their life; and for you, Sarah, just working with families as they go through Alzheimer's, trying to get the supports and having to see families who are struggling to support their loved ones.

I watched it with my mom with her mom and dad—a lot of struggle around her mom. Her mom had Alzheimer's and mini-strokes. Really, we tried to give her as much wraparound family care as we could. The emotional drain that I watched it take, especially on my mom, was unbearable at times. And you see that every day.

Where I wanted to go—we talked earlier with MPP Oosterhoff about the burnout that's there because there's just not enough people to do the work, there's not enough funding for more positions. But what about for the people who are there, the burnout when we have more people—how do we ensure that we have those mental health supports for people who are working in this type of care? Because you face traumas, and you face that every day. There are times when you might carry on and it doesn't affect you, but there will be a time where maybe something will bubble up to the surface, the same way first responders suffer from PTSD. How do we ensure that people who are working in this field know that they can access mental health supports? And how do we make sure that they're there for them to work through this?

Maybe, Dr. Pereira, if you could start on what you think is needed to make sure that people who are working in this field have what they need from us, so that way they can provide the care that we're asking for.

Dr. José Pereira: Certainly, and thank you for highlighting that. So, two areas: One is those of us who work in palliative and hospice care, and then those who don't work in hospice palliative care but provide a lot of care. We haven't spoken a lot about the long-term-care sector, so I want to start there.

I think it starts by being prepared and by having those basic skill sets and also by having the permission to be able to talk about what is happening and the difficult journeys. We've neglected that field.

Since 2014, 2015, I've been working with colleagues from across the whole country to develop one of the Pallium courses called LEAP Long-Term Care. In that training, we actually train different staff, so PSWs, nurses, doctors, to come together so they can talk about these experiences and share these experiences, so they start learning from each other that there's a common experience here and that it is important to talk about it and to be prepared to care for it, because without preparation, it's a recipe for absolute burnout.

In the palliative care world—you touched upon the importance of ensuring adequate number of staffing. The one doctor and one nurse in the big hospital having to deal with all of this is just unacceptable in this day and age. There are some fantastic support programs out there that we can leverage—they're ready to go—that we can bring in.

Sometimes, it's a ritual. Sometimes, for example, it is when someone dies on a unit, a surgical unit or a medical unit or a palliative care unit, or in a hospice, that we acknowledge that. There's an honour parade, for example. Some hospices and palliative care units do that. Those little rituals are extremely important because they acknowledge the passing of someone that we've gotten to know and acknowledge the suffering that family members are also experiencing.

Ms. Amy Fee: Kim, I don't know if you have anything to add to that, or Sarah?

Ms. Kim Woodland: Absolutely. I mentioned earlier about creating a hub or a centre of excellence in every community, related to the development of Ontario health teams in the province. One of the roles of that function, as an example—it doesn't happen everywhere, but here, Matthews House acts as a place for providers to call when they need help. As an example, there's a big COVID-19 problem happening, as everyone knows, and our local long-term-care home staff can call Matthews House any day and one of our counsellors will have a talk with them and help and support.

In addition to the things that Dr. Pereira mentioned, there's a very specific set of ways to help health professionals deal with the day in and day out, which hospice providers know all about. So the hospices all over the province, the community ones, could be providing support to long-term care, to their hospital partners, to those individuals, because it's a very specific day-in, day-out kind of experience that causes burnout. Hospices and hubs that are built in each community could help by providing supports to the providers themselves too.

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Amy Fee: And just to Sarah quickly: obviously your workers as well. Because you're getting phone calls from very stressed-out families who don't understand how to navigate the system, are struggling in trying to support their loved ones as much as they can, and obviously a whole lot of fear—and from patients themselves. I'm just wondering if there are supports and how your staff access those supports. And what more do you think is needed there?

Ms. Sarah Putman: There's grief in dying, and then there's the latent grief that comes from a prolonged illness, that you have to deal with all the losses along the way. We support our families through our counselling team at our society, but our staff is supported by each other and by services like our local hospice and bringing in care specialists to debrief and do that—

The Chair (Ms. Goldie Ghamari): Thank you very much. That concludes this round of questions.

For our presenters, I just wanted to thank all three of you for being with us here this morning and sharing your time. It was very informative, and I know that the committee appreciated your feedback. At this point, you may step down, you're released, and committee is currently recessed until 3 p.m. Thank you, everyone.

The committee recessed from 1001 to 1500.

The Vice-Chair (Mr. Mike Schreiner): Good afternoon, everyone. The Standing Committee on General Government will now come to order. We are here to resume public hearings on Bill 3, An Act providing for the development of a provincial framework on hospice palliative care.

Before we begin, I'd like to ask MPP Harris: Can you confirm that you are present, that you are MPP Harris and that you're currently in Ontario?

Mr. Mike Harris: I am MPP Harris and I am here in Toronto.

The Vice-Chair (Mr. Mike Schreiner): I also need to confirm, MPP Wai, that you are present, you are MPP Wai and you are currently in Ontario.

Mrs. Daisy Wai: I am MPP Daisy Wai. I am here in Ontario.

The Vice-Chair (Mr. Mike Schreiner): Great. Thank you.

MR. JOHN FRASER
DR. WILLIAM SPLINTER
MCMASTER CHILDREN'S HOSPITAL

The Vice-Chair (Mr. Mike Schreiner): Now I believe we'll begin with our first presenter. I will call on John Fraser, MPP. You will have seven minutes for your presentation. Please state your name for Hansard, and you may begin.

Mr. John Fraser: Thank you, Chair. I'm John Fraser. I'm the MPP for Ottawa South. I appreciate having this opportunity to present to committee.

I want to start by thanking the member from Niagara West, Sam Oosterhoff, for bringing this bill forward. It's an important bill. I also want to thank my colleague the member from Guelph, Mike Schreiner, leader of the Green Party, for sharing his committee time with me during these hearings and allowing me to participate, and also for working with me on some of the things in the bill that we think would be helpful. It's really an example of how we should be able to work together in this Legislature, and I think this bill is an opportunity for all of us to do that.

I care very deeply about palliative and end-of-life care. For over 20 years I've been involved as a volunteer, a family caregiver and as a member of this Legislature. Each one of them has been a rewarding experience and they have all taught me a great deal.

Access to quality palliative and end-of-life care is a right of every Ontarian, and that's a very important point for us to start at. This bill is an important step as it will require a report back to the Legislature and to the representatives of the people on what progress has been made. The bill needs to recognize all settings of hospice, palliative and end-of-life care so that all of the partners can see themselves in this legislation. Pediatrics, vulnerable communities, homeless, Indigenous peoples—we need to recognize everyone so they can see themselves. This includes providers in different settings.

The bill, most importantly, needs to measure outcomes, access and quality. It also needs to recognize the importance of advance care planning. It's not my favourite term; it's cumbersome. What it really means is thinking about the inevitable and thinking about what is really important to each of us in life, and then letting your loved ones know that. It's not always easy. One of the things I've learned from my experiences is that the things that are most important at the end of life are not cars or houses or even vacations a lot of the time. They're small everyday things. Sometimes they're a bit bigger, like resolutions to things. Family is important. All of those things aren't always easy, but they're usually things that we need to address in life every day. It's a deeply personal and very important task, and we need to encourage all Ontarians to try to do that, because it's going to help with all aspects. It will help people be ready and prepared, and it will be able to help us improve outcomes. It will help us create the kind of pressure we need to make change.

I think the bill also needs to shorten the timelines to report back. I think it should be inside a government's mandate. We need to measure progress more frequently, not less.

What this bill cannot address is the financial supports that hospice, palliative and end-of-life care need to ensure that everyone has access to quality services. Private members' bills can't do that. There is no question that we need to support clinical services and hospices. The funding to hospices over the years has been incremental and often episodic, so instead of being indexed, it will move every three or four years and will jump up. I can remember being part of that on at least two occasions. I would encourage all members to support hospices in this request and also their request for visiting home hospice and bereavement.

If anything, COVID-19 has shown us that there's a great need for that in our community. COVID-19 is the great revealer, and that's one of the things that it has revealed. To make progress, we must continue to invest, and invest in all settings. We heard this morning from Dr. José Pereira about the need to invest in palliative care beds in hospitals, in training, in education. We need to invest in compassionate communities, a movement that's across Ontario.

One thing about hospice palliative care and death and dying is that it needs a community. I'll tell you a story that will underscore that. I followed my dad on a palliative journey. I won't go into the really good things and the really bad things that happened, but when my father passed away, he was at the May Court Hospice in Ottawa. My sisters and I had a very good experience spending a lot of time with him there. We always spent a lot of time together, but I'll never forget it. It was very important for our family. But it was a bumpy road to get there. Some people have heard me talk about it before. It was a bumpy road.

Nine months to the day that my dad died, our first grandson was born. I was thinking, because I was thinking about my dad, and I said, "You know what? Vaughan has arrived, and we're all ready. We're all ready for him to be there." The family. There were going to be schools ready. The health care system was ready.

The Vice-Chair (Mr. Mike Schreiner): One minute.

Mr. John Fraser: Everybody was ready in that expectation. Well, birth and life, they're opposite ends of the same string. I thought of my dad, and I thought, "Not so much."

That's our job in this bill, is to make sure that we give the same kind of attention to people when they're going out of this world as we do to when they're coming in. I'll finish at that. Thank you, Chair.

The Vice-Chair (Mr. Mike Schreiner): Thank you.

I will now call on William Splinter. You will have seven minutes for your presentation. Please state your name for Hansard, and you may begin.

Dr. William Splinter: William Splinter. Thanks to the committee for agreeing to let me speak and present to you today. I'll talk in a couple of minutes about actually who I am.

Palliative care is, to the best of my knowledge, the only part of health care that reduces cost, improves the quality of life and improves your lifespan so you live longer, better and for less. This is a well-documented medical fact. Ontario obviously needs standards for palliative care, and anything that will bring us there must be supported. Bill 3, the Compassionate Care Act, will help, but frankly, it's quite late in coming. We're about 25 years behind other jurisdictions, but it will be most welcome.

So, who am I? Well, I have extensive clinical and non-clinical experience in health care. I was the medical director at Roger's House and for pediatric palliative care at CHEO, with founding roles in both. I've been a member of boards of more than one health care institution of one form or another. I have formal training as an anesthesiologist. I'm a physician. I also did extra training in anesthesia and pediatric critical care. I did informal training, more like an apprenticeship model, for my palliative care.

I've known people, either directly or indirectly, who are main parts or foundational for palliative care: Balfour Mount, John Scott. At one time, there were only four palliative care physicians in the world. Two of them are from Canada—those two gentlemen—so they're founders in our field. The first palliative care physician in Kingston, practising in the early 1980s, Dr. Boston was someone who trained me at times during my career.

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I tend to go to international meetings, not to Canadian meetings, because, frankly, they're ahead of us. We need to learn from them. The UK and Australia in particular are far ahead of us, and we need to learn and we need to find out what they're doing and how well it's working to improve our health care system overall.

So what do we do? I just want to give you a bit of an example, and I think it will be easy to see this. Think on our improvement on the quality of care that's provided, as well as how it reduces costs. I was involved in the care—this is not exact, because obviously I need to protect people's privacy. It's a bit of a blend of more than one story. But there was a four-year-old girl who died, and I got called one night to go visit her.

About two and a half years before that, this poor family found out that their child had a progressive neurologic problem and that, over the next two years, their child was going to develop something very similar to Alzheimer's disease and so was going to waste away in front of them and die. We got involved in her care early on then—many calls, many visits at home and at the hospital. Eventually, unfortunately, she progressed and she died.

I got called early in the evening in the spring, got in my car, drove, started on the eight-lane highway as I leave Ottawa, four-lane highway, paved county road, gravel county road. This was the first time I was visiting this particular home for the family because it was Grandma's home, and the child was at Grandma's home because

Grandfather had just died a few months before. So I was really thinking, "What am I going to be saying to help this family through this?" And we did, we had a lovely visit. We talked about all the joyful things their child had brought into their life and how much it had impacted on the family.

Are you okay there? Sorry. It was a dramatic story. We helped them throughout this afterwards, because we actually, even at our hospice, have a grandparents' program, so we were able to help the grandmother as well as the parents and the sibling throughout their story.

I just want to, again, in conclusion, say palliative care has far-reaching benefits today and tomorrow. Please help us bring a good ending to a good story. Thank you.

The Vice-Chair (Mr. Mike Schreiner): Thank you for your presentation.

I will now call on McMaster Children's Hospital. You will have seven minutes for your presentation. Please state your name for Hansard, and you may begin.

Mr. Bruce Squires: Bruce Squires, president of McMaster Children's Hospital.

Thank you, Chair, for the opportunity to present today. I'm going to provide some very brief remarks before turning the mike over first to Mr. Graeme Howieson. Graeme is a family adviser at McMaster Children's Hospital, and we're so pleased that he's able to join us today to share his family's lived experience with pediatric palliative care. Graeme will then be followed by Dr. Dave Lysecki. Dave is an international, national, provincial and regional leader in pediatric palliative care.

I mentioned that I'm president of McMaster Children's Hospital, but I'm also the incoming chair of the board of directors of Children's Healthcare Canada. In both of those roles, I'm focused in particular on how we can ensure that the health and health care system that serves our children, youth and families meets their needs.

Children and youth are not tiny adults. Their health needs and how we can serve them often differ significantly from those of adults, and so they can suffer significantly in the short term and in the long term if we don't recognize those differences. Palliative care is actually a prime example of where we need to specifically recognize, understand and then accommodate or address those differences. So that is our key message for today, in support of this bill and how it can be improved.

With that point, I'm pleased to turn it over to Graeme Howieson.

Mr. Graeme Howieson: My name is Graeme Howieson. I apologize because in a matter of moments—

Interruption.

Mr. Graeme Howieson: —you're going to hear that. I'm a teacher with the District School Board of Niagara, and the timing is the end of the day so the bell for the end of the day just went.

I appreciate and I'm honoured to speak to the committee today. Just a little introduction of who I am: As I just said, I'm a teacher at the District School Board of Niagara. I'm a member of the provincial pediatric palliative care committee. I am a family adviser for Hamilton Health Sciences, and I am on the Hamilton Health Sciences palliative care council as well.

Unfortunately, I am well versed in palliative care with a focus on pediatrics. My wife and I, unfortunately, lost our seven-month-old daughter, Lidia, in April 2018. She was born with an extremely rare genetic condition, pontocerebellar hypoplasia type 7—only one of 12 known cases in the world.

Early on in her life there was a need for palliative care. We had the unfortunate but positive experience with palliative care throughout much of her life. We could not have made the decisions we had to make as a family, my wife and I, or have gotten through the most difficult part of our lives without the support of our pediatric palliative care team.

We first found out early on in her life that there was a need, as I said, for palliative care both from the hospital and the community. I live in Niagara, so access to Hamilton and McMaster, where most of her care would take place, was difficult at some point, so we needed to make sure that we had the supports not only at the hospital but in our community here in Niagara as well.

Lidia had multiple life-saving surgeries and multiple needs, which needed support from different departments throughout the hospital and community organizations. This was a lot for us to set up on our own, and as I said, we couldn't have done it all without the support of that palliative care network that we connected to. We were so fortunate with the care that we were able to receive from our palliative care team and, in turn, our end-of-life team for Lidia.

We ended up making the decision to have her end of life happen within the hospital at McMaster just because of the supports that we didn't have in Niagara and we were most comfortable in the hospital as a family. The hospital was able to give us 24-hour-a-day support which brought us a lot of comfort. We knew that Lidia was going to be the most comfortable and, as a family, we knew we were going to be the most comfortable with end-of-life care within the hospital.

I probably could share a whole lot more, but I kept it brief today just to share with you all my lived experience, as Bruce had mentioned, and the importance of palliative care and the role that it played in our daughter's life.

I'm going to turn it over to Dr. Lysecki now.

Dr. Dave Lysecki: Thank you, Graeme.

I'm very proud of the work we were able to do for Lidia and of the incredible impact Graeme continues to have on our hospital infant system. I think some things that I'm really proud of in the way Graeme tells his story are the words "team" and "network," because pediatric palliative care does require a community around a child, a networking of supports. When we actually look at, when Lidia was in our care, what our palliative care specialist team looked like at that point, it was half a physician and nothing else, whereas in other places in the province, Graeme and his family would have had access to large, interdisciplinary teams, extensive community outreach, psychosocial support—

The Vice-Chair (Mr. Mike Schreiner): One minute.

Dr. Dave Lysecki: —respite admissions, an alternative location for end-of-life care, parent support groups, bereavement support groups.

I'm very happy Graeme was able to speak positively of the experience, but I live with the knowledge that we are not able to deliver the care to the families of our community the way I know they deserve to be cared for.

And why this bill becomes important to that is that the current systems, as they exist, of palliative care in pediatrics do not sufficiently address the needs of pediatric palliative care. Children are about 1% of all palliative care and children's palliative needs are about 1% or less of all pediatric care. With that small proportion, they don't reach enough significance to make a major impact at any given table. It needs to be identified independently and given the appropriate attention, oversight and administration to develop outcome metrics and system accountability to ensure that children and families like Graeme's—

The Vice-Chair (Mr. Mike Schreiner): Sorry to interrupt, but that's all the time we have for your presentation. So thank you for your presentation.

Before we begin questions, I'd like to ask MPP Ghamari: Can you confirm that you are present, that you are MPP Ghamari and confirm that you're currently in Ontario?

Okay, maybe you're not on the line at the moment.

1520

We'll move to questions, beginning with the government side. You will have seven and a half minutes. I recognize MPP Kusendova.

Ms. Natalia Kusendova: Thank you to all of our presenters. I'd like to express my condolences to everyone who has lost a loved one. And thank you for your courage in sharing your stories with us. It certainly helps to inform our policy. But especially through listening to lived experiences, I think I speak for all of us here that we're deeply touched. We listened to a lot of stories yesterday as well, and even on my way home, I was sitting and reflecting about the trauma and the pain that many of these families have suffered. It certainly helps to guide our policy moving forward.

My first question today will be to my colleague MPP Fraser. It's great to see you. Thank you so much, also, for wearing your Franco-Ontarian flag.

Mr. John Fraser: Merci.

Ms. Natalia Kusendova: De rien.

As far as I understand it, from June 2014 to June 2018, you were the PA to the Minister of Health and Long-Term Care. It's great that you decided to champion this issue of palliative care. It is the elephant in the room, and I did bring my elephant today. End of life is not an easy topic to discuss—

Interruption.

The Vice-Chair (Mr. Mike Schreiner): I know we have some feedback. Broadcast services is trying to see if they can address it. Hopefully, we can work our way through it. I apologize.

Ms. Natalia Kusendova: Excellent. I understand that there was a report that was tabled specifically on palliative care. For the benefit of this committee, can you outline a little bit of what was in that report?

Mr. John Fraser: We tabled a report. I think we had 16 round tables. We talked to providers, caregivers and families. The critical thing was access. Not everybody has access to quality palliative care. There are a number of systemic issues, depending on where you are. So a lot of the emphasis was on trying to improve it in all settings, and there was a commitment for 200 hospice beds. I'm glad the government has continued on that and added some more. There's still a lot of work to be done in every setting. I think one of the things we have to remember is that most people will die either in long-term care or in hospital, and so palliative care is there as well.

The access piece, from my own personal experience, and I heard this again and again—I've worked around health care a lot. That's why I'm here. My dad was palliative, was told he had an inoperable oral cancer. Someone told him, "Next Friday, you'll have an appointment for palliative radiation." By that Friday, nobody had called. By the Friday after, nobody had called to tell my dad he was scheduled. He was lost.

So that got scheduled. When he got out of that—in that time, trying to find an entry point was hard. Then, when the call was made after that to say, "My dad is palliative now; he's got six months to live, four months to live," the voice on the end of the line said, "You'll have a new caseworker in January." This was three weeks before Christmas.

All of those things got straightened out. They got straightened out because I know how to straighten them out and my sister knows how to straighten them out. It was a lot of work. So in my head, I think, "What happens to families?" And health—I know you're a registered nurse. I met registered nurses who said, "My mom became palliative, and I couldn't figure out how to get there."

The report was a starting point for really talking about access to quality palliative and end-of-life care, making sure people had pathways. It's a lot of work to get this right. I don't want to say the work will never be done. There are a lot of really great people out there, like the people we've heard from today. I know Dr. Splinter. I'm from Ottawa too, so we've met. We need to support the work of those people, and I know that we all want to do it.

So with that report, I would say the most important thing was access, and that's the thing we need to focus on still.

Ms. Natalia Kusendova: Thank you. In December 2017, the federal Parliament passed Bill C-277, which is a very similar piece of legislation at the federal level. Why do you think it's important that we develop our own provincial framework?

Mr. John Fraser: Well, look, we deliver the services. We pay for the services. The organizations that work in Ontario are the ones who know what we need to do. I think we should measure things ourselves. I think we should report more quickly than the Parliament does. The federal government sets broad policies. What we need is, "What are the measurable outcomes in all settings for quality palliative care?" Every Ontarian has a right to quality palliative, hospice palliative and end-of-life care. That's what we have to start with.

Because we deliver it, because we are responsible for it as a government, I think we should dictate how we're going to report back, what we're going to do and what the priorities are, working with the community to do that. That's what the report was all about. There's a lot of work to be done, and there's a real community around hospice palliative care.

Ms. Natalia Kusendova: Thank you. Now that you've had—

Mr. John Fraser: Sorry if they're the wrong answers.

Ms. Natalia Kusendova: No, no. Now that you've had two years to reflect on your time in government—for myself, I've been in government for two years—is there anything that you wish you would have advocated for more strongly or done differently, especially in your role as the PA on this topic of palliative care?

Mr. John Fraser: I wasn't satisfied; there's no question. I was really happy with the progress that we made in hospice and that we made in other areas like visiting home hospice, but I think the two things that really stick with me the most—a lot still do.

Long-term care: I had a plan to try to address palliative care in long-term care—

The Vice-Chair (Mr. Mike Schreiner): One minute.

Mr. John Fraser: —so that was one that I wanted to see move forward more quickly, with training and education, supporting more hours, backfill. Then I think there's more work to be done on the hospice end of things.

But I look at the hospital situation and AFPs, alternative funding for physicians, and the way the payment works, and I know we're not doing the right thing to make sure that we build that community up to provide the support that's needed across the board. I think that's a really tough one to fix, because there are more players than just government and the ministry. I think that's one that we should really work hard to fix. It's not the only thing, but it will help a lot in ensuring that we have people trained across the board.

Ms. Natalia Kusendova: Thank you very much.

The Vice-Chair (Mr. Mike Schreiner): Okay, thank you. That's all the time we have for this round of questioning.

We'll now go to the official opposition. You'll have seven and half minutes.

Ms. Sandy Shaw: Thank you. I'd like to start by saying I just couldn't be more grateful to have McMaster Children's Hospital in my riding. I also would like to thank Mr. Howieson for sharing your story about Lidia. And I specifically would just like to thank Dr. Lysecki and Dr. Mikrogianakis, who provided me such guidance and such support when we developed the Nancy Rose Act, which, as you know, is a bill that would provide for the provincial government to create a pediatric palliative care strategy in Ontario.

Dr. Lysecki, you've said it here and I've heard you say it before that, mercifully, the numbers of children and families that require pediatric palliative care are small, but the impacts for families, when families hear the unimaginable, the worst news that they're ever going hear in their lives—the impacts are so great, not just for the families but for the community around them.

We talked a lot yesterday about people falling through the cracks, in particular pediatrics falling through the cracks. Can you talk just a little bit more about your work and how you would like to see a strategy to deal explicitly with pediatrics?

Dr. Dave Lysecki: Thank you. I'd like to first go back to the issue of numbers and proportions. When I talk about 1% of all palliative care, that has to do with population mortality rates. But if you look at the way children die and the way adults die and the palliative care or support around that time that is required, that 1% takes up more than their worth of resources and attention, because that is always needing significant medical and psychosocial support. There are not children in our areas of Ontario who are peacefully going out into the good night after a life long lived. These are very difficult situations, very difficult decisions that need to be made, very difficult conditions that require a lot of care. So, yes, numerically, it's a small portion, but I don't want anyone to leave this meeting thinking that the work that needs to be done is low.

1530

The children who require palliative care are a very different population than adults who require palliative care, not only because of age and size and physiology and that children are not small adults, but in terms of diagnosis and care required—it's night and day. The children are often born with a condition that they ultimately succumb to, and so they live their whole lives with palliative needs, often diagnosed prenatally.

So palliative care—for me, if I were in that situation, it would be me living a healthy life and getting a diagnosis and things changing and eventually needing increased supports around my quality of life. The children we serve have those needs from the day they're born. Their parents have them often from before they're born. That life may be days or that life may be decades, and it requires significant expertise, support and attention to provide the children with the quality of life that they deserve during that time and the families with the ability to support their children and provide that care on a 24/7 basis, with all of the grief and emotional turmoil that goes with it over the course of often years or, in Graeme's case, months.

Ms. Sandy Shaw: Thank you, Dr. Lysecki. Further to that, a lot of people have said that this bill needs to reference specific actions and it needs to be broader and more defined in terms of not just including pediatrics as a distinct need with a distinct oversight body, but the other thing that's missing is reference to some of the things that are missing—you mentioned psychosocial supports, not just for the children who may start young and not be able to express their fears or their concerns or their wishes, but as they grow, they have significant needs for support. And parents need bereavement support and respite support. It's not mentioned in this bill. Can you talk a little bit about that for us as well, please?

Dr. Dave Lysecki: What I would add briefly is that the psychosocial support is inextricable from the medical care. When we talk about cost-effectiveness—palliative care is cost-effective—a significant portion of that is accomplished by aligning the care we provide to children and their families with the care that is medically necessary and within their goals of care. That requires a lot of deep digging into what life means for this child, what joy means, what suffering means, what their experience of life is, what things are going to add quality to their life and extra meaning, and what things or treatments may provide increased length to their life but may not, and may not actually enhance their life or, in some situations, may add suffering to their life. The default of health care is to prolong life, to save lives, to do, to do, to do. That is not necessarily always what's best for these children.

It isn't having the medical expertise there of someone saying, "Hey, you don't need to do that," that solves that problem or that leads to different outcomes. It is the rich discussion that is spiritual, that is emotional, that is psychological with families, where we can actually accomplish the work that needs to be done to understand their child's life and to provide that child and that family with the care they need. That is only done through the partnerships of medical care with psychosocial care, with emotional care, with grief care before and after the death of children, and of spiritual care. I would say you can't separate the two. When I hear the words "palliative care," that, to me, is incumbent in the term.

Ms. Sandy Shaw: Thank you. I'd just like to share something that Dr. Greenberg said to both of us: Grief never ends; it goes on forever, and the need for parents to have supports goes on forever. I thank you for that.

The Vice-Chair (Mr. Mike Schreiner): One minute.

Ms. Sandy Shaw: I just want to also now say that this bill talks about a framework for delivery. The Ontario Palliative Care Network has said they have a framework for delivery. I know that the provincial pediatric palliative care steering committee also has a framework with plans for delivery. My sense is this bill could leapfrog over just developing a framework, with all the heavy lifting that you folks have done. Can you comment on that, please?

Dr. Dave Lysecki: Just to say that the OPCN—many of their frameworks, specifically their health services delivery frameworks, explicitly exclude children from the model. In addition, many of the metrics that they have developed don't actually apply to children because of different diagnostic codes, because of different ways the hospitals work, because of different tools that are developed. The caregiver voice tool, which I think some people may have heard of on this committee—but that surveys families afterwards. It was not developed to survey parents after the loss of their child. It was developed to survey spouses or children after the loss of their—

The Vice-Chair (Mr. Mike Schreiner): Sorry, that's all the time we have for questions during this round.

Ms. Sandy Shaw: Thank you very much.

The Vice-Chair (Mr. Mike Schreiner): Before we go to the next round of questions, I'd like to confirm that MPP Oosterhoff has joined us. MPP Oosterhoff, can you confirm that you are present, you are MPP Oosterhoff and that you are currently in Ontario?

Mr. Sam Oosterhoff: Yes, this is MPP Oosterhoff. I am in Toronto.

The Vice-Chair (Mr. Mike Schreiner): Thank you for that.

MPP Ghamari, you've joined us online. Can you confirm that you are present, that you are MPP Ghamari and that you are currently in Ontario? So, no. Okay.

Now we'll go to the government for the next round of questions. You'll have seven and a half minutes. I recognize MPP Bailey.

MPP Bailey, I think you'll need to unmute yourself.

Mr. Robert Bailey: There, I think I'm unmuted. Thank you.

Thank you to all of our presenters that are here with us this afternoon. It's been a very interesting couple of days, and we've got a couple more days. I've got to be honest; I've learned a lot about palliative care and hospice care that I wasn't aware of, to be honest, before this.

I'm very fortunate. I represent Sarnia–Lambton, and I have St. Joe's hospice, led by Dr. Glen Maddison. I'm sure a number of you here probably know Dr. Maddison. He has a great reputation in palliative care in Ontario and across North America. So I'm fortunate. I'm one of the few MPPs who do have, and it's been there—I think I turned the sod when I first got elected, and I really had no idea what we were doing at the time. I'm glad I had that opportunity.

As you all know, I'm sure, Ontario is in the process at this time of transitioning to a new model of care through our Ontario health teams. In fact, mine just got announced last week for my area, the Sarnia–Lambton health team. They're expected to deliver more integrated care, including palliative care.

I don't know who would like to speak to this—maybe all four of you. If someone would like to speak to: Do you have any idea on how we can better connect hospice palliative care resources to other parts of the health care system as we adjust today as part of this transition? Whoever would like to speak to that—or all of you, if there's time.

The Vice-Chair (Mr. Mike Schreiner): Is there anyone you want to direct that to, or does anyone want to—

Mr. Robert Bailey: Well, Dr. Splinter; I don't think he's had a chance to speak.

The Vice-Chair (Mr. Mike Schreiner): Dr. Splinter? Yes, please.

Mr. Robert Bailey: He hasn't said anything yet maybe. He's still muted.

Dr. William Splinter: Okay, now you can hear me; I just got unmuted.

Thanks for the question. Actually, Dave Lysecki referred a bit to that, to the development of the OPCN and health service delivery framework. There was a very hot discussion at the OMA level when that was being developed.

This is constantly changing throughout the world. The most developed parts of the world, again, going back to what I said earlier, the UK and Australia—Australia shares a lot of what we have. They have an Indigenous population. They have people way out, frankly, in the boondocks. They have very rural populations they have to deal with, and they try to deal with everything and everybody as fairly as possible. They have well-developed metrics with the tiered support groups. Their system for most of this is very public-health-oriented, although they have much greater private health in their system than we do. So it's a good model to go with.

Personally, I'm biased towards that. It's not always popular with my medical colleagues, because everybody likes to want to run their own show. I'm just being straightforward and honest with you.

But I do share a lot of what Dr. Lysecki was mentioning about the importance of having pediatrics at times separate, still working within the system but often the province will need to be divided up with areas that are covered by our specialty.

1540

What we do on the pediatrics side is different than what we do on the adult side. I do both, but the pediatrics side is distinctly different. As Dave said, it should be separate. It needs a lot of special support. If you do it right, it has a lot of major long-term benefits, frankly, anything from decreasing death—because, unfortunately, we've locally had a suicide, for example, because things were not done well. This needs to be done well to minimize the grief and maximize the celebration of the life.

Mr. Robert Bailey: Thank you.

The Vice-Chair (Mr. Mike Schreiner): MPP Bailey, I think McMaster Children's Hospital would like to answer. Could we unmute them?

Mr. Bruce Squires: Thank you. It's Bruce Squires. If I could just supplement Dr. Splinter's comments. Really, as has been highlighted, the volume and the nature of palliative care needs for the majority of the population are such that it does fit very well with the notion of Ontario health teams, the planning for those services, greater coordination and seamless delivery.

But when you think about 30 to 50 Ontario health teams and you think about the very, very small numbers, as Dr. Lysecki has highlighted, and the highly specialized and really distributed nature of pediatric palliative care and pediatric hospice-based palliative care, it's pretty clear that there's a requirement for a more specific regime and a framework, including the establishment of those core components to account for those differences in pediatric palliative care. That's one of the areas where we think there might be some opportunity to enhance the bill, to set out more clearly the regime that will note and provide for those differences.

Mr. Robert Bailey: Thank you. If no one else wants to comment, I've got another question I'd like to put out to the floor here.

As Ontario deserves to have a strategy that's not a patchwork system for end of life, which is what we seem to have heard for the last two days and again today, but more of an integrated approach to improve the quality of life: In one or all of your views, what are some elements that would be necessary in a palliative care strategy to reach that goal? If you can share that with the committee so that we can make sure—

The Vice-Chair (Mr. Mike Schreiner): One minute.

Mr. Robert Bailey: Okay. Somebody? Dr. Lysecki?

Dr. Dave Lysecki: Very briefly, in 45 seconds, I would encourage you to read my letter in the submission which talks about some of the ways palliative care is different from typical health care and the barriers that creates, one of which is that as care gets more complex in typical health, you move from location to location along a conveyor belt of intensity. We need to be able to take specialist care into the home in palliative care. It requires thinking about health care in a totally different way, thinking about accessing specialist resources in a different way.

There are a number of those things written in my letter. I don't think I have time to go in deeper, but I hope you get a chance to read that, because we need to think very differently about our metrics of palliative care and our operations of palliative care to make what you're describing feasible and achievable.

The Vice-Chair (Mr. Mike Schreiner): Thank you. We only have five seconds, so I think we'll move to the official opposition now. I'll recognize MPP Gélinas.

M^{me} France Gélinas: First, I would like to thank MPP Fraser for being here, Dr. Splinter, the team at McMaster and Mr. Graeme Howieson. Thank you so much for sharing what you've done, taking your grief and turning it into helping other families—very thoughtful. Thank you for doing this.

My first questions will be to the McMaster Children's Hospital team, and you can decide who wants to answer. If you had the magic wand, if you could control everything, what would a strong, robust, quality-based palliative care network look like? Knowing that I come from northern Ontario—we do not have a children's hospital, so I would appreciate if I'm part of whatever plan you put forward. What would it look like?

Dr. Dave Lysecki: I can start. Thank you for the question and recognizing the north, which I think is an important population. Because of the specialist nature of care that many of these children, even outside of palliative care, are dependent on—they're dependent on their oncologist, who is centred out of the five pediatric academic centres. They're centred on their neurologist. They're centred on their metabolic specialist.

For pediatrics, tertiary care needs to happen and community and home care needs to happen because that's where our patients live and that's where their loved ones and network and connections are. So we need to find ways to integrate.

A hospices hub model is a fantastic way to create networks and integrate care that crosses specialist centres and community support. That can be inclusive of the north. I want to use England as an example. In Canada, we have eight children's hospices right now for a population of about 37 million, 39 million, or wherever we are now. In the UK, they have 55 children's hospices for about double that population—less than double: 66 million. A children's hospice is the community's way of caring for families and children who are living with palliative illnesses.

That is something that doesn't exclude a place like the north. I think a model where children's hospices were centred in affiliation with the tertiary pediatric hospitals would make a lot of sense. I think a sixth centre in the north could be supported by specialist resources in the tertiary centre through virtual care, which we're doing ad nauseam these days, and I think it could deliver high-quality, excellent care to patients in the north.

Realistically, we would love to be able to offer every child and family the opportunity to have end-of-life care at home, if that's what they wanted. There are some situations where the care that is required to meet the goals of a family's care is simply too sophisticated and too complex to be done in the home environment. Without a secondary location like a hospice, that care is going to be done in hospitals. We've seen that. If you look nationally across Canada at the data of where children experience end-of-life care in centres that have pediatric hospice and those that don't, it's pretty consistent that children dying at home is about 25% and that without a hospice, all of the additional ones fall into the hospital. But if you add a hospice in, it takes about 30% to 40% of that end-of-life care into a home-like environment, like a hospice, and it takes that out of the hospital. It does not take that out of the home environment. If the family's goal is to be at home, we would always seek to make that happen.

I would love to see a hospices hub model located at all of the five tertiary pediatric centres and a sixth in the north. I think the hospices hub model allows centralization of resources, including bereavement resources and psychosocial support. And I would love to see those networks be accountable to a higher provincial body, such as a provincial steering committee, that has outcomes and metrics and is looking at accessibility in ensuring that every child in Ontario does not have to face additional barriers on top of those that are already created by their medical condition to have a good life.

That's what this is about. It is about not just giving people quality of life at the end of their lives but, for many of these children, for the duration of their lives. This is the only life they will know: a life with medical complexity. We want to make that medical complexity as small a part of that story as possible, and the memories, the joy, the family, the love as much a part of that story as possible.

M^me^ France Gélinas: So what you just explained to me seems pretty simple and seems pretty straightforward. We already do this. I live in northern Ontario; we already send our kids to you guys or to SickKids. It exists on the medical side, but what you're saying is that to get the psychosocial, to get the grieving, to get the spiritual, to get the emotional, to get the family support, we need to be out of the hospital and into a hospice care model. Am I understanding this right?

Dr. Dave Lysecki: In the description of my best magic-wand vision, I think that's a great way to centralize and specialize your resources so that they have the experience and expertise in providing that care, because if you are X social worker in small-community northern Ontario, you may only experience the death of a child once every four or five years in a practice that advertises that you're open to that—otherwise, never. By having identified and centralized resources, you can put through the relatively small volumes to a relatively small number of practitioners, who gain the expertise and can provide that care effectively.

1550

The Vice-Chair (Mr. Mike Schreiner): One minute.

Dr. Dave Lysecki: But I wouldn't say that's the only way to do it, because we don't have that model and we continue to be able to strive to provide models otherwise that meet that care.

Right now, I think outreach psychosocial support into the north, partnering with communities, whether they're in the north or other places that are rural—I think we can form partnerships and we can support families, but it does involve envisioning resources that cross boundaries. Right now, health care budgets are very jurisdictional and boundary-based.

M^me^ France Gélinas: I agree.

Dr. Splinter, I realize you haven't got much time, but what do you think of this model, or what was your vision?

Dr. William Splinter: I believe initially, when we first established our program, we actually covered children dying up in nursing stations in Nunavut. We've helped children dying in Sudbury, Sault Ste. Marie. I have personally done a home visit to North Bay—

The Vice-Chair (Mr. Mike Schreiner): Sorry, that's unfortunately all the time we have for this round of questioning. Thank you to all the presenters for joining us today.

So we may have a vote; we may not have a vote. We're a little ahead of schedule, but I know some of the next presenters are here, so we're going to carry on. But, to let people know, we may be interrupted for a vote.

ONTARIO MEDICAL ASSOCIATION, SECTION ON PALLIATIVE CARE

DR. LINDA TENHUNEN

MAISON MCCULLOCH HOSPICE

The Vice-Chair (Mr. Mike Schreiner): The next presenter I will call on is the Ontario Medical Association, palliative care. You will have seven minutes for your presentation. Please state your name for Hansard, and you may begin.

Dr. Samantha Hill: Thank you. My name is Dr. Samantha Hill. I'm a cardiac surgeon and I'm the president of the Ontario Medical Association. I represent 32,500 practising physicians. I'd like to start by thanking you for the opportunity to share our support for the Compassionate Care Act, 2020.

More than 100,000 people died in Ontario in 2017-18. The percentage receiving palliative care climbs every year, with it being 60% most recently. Ontario's health care system provides amazing care, starting months before the moment a person draws their first breath, and Ontario's doctors believe the same quality of care should continue until one's last breath. We think voters expect it. If passed, Bill 3 will be a part of us honouring our lifelong commitment to Ontarians.

You are truly fortunate to hear from Dr. Pamela Liao. In addition to being a widely cited expert in palliative care, her credentials include being an assistant professor in palliative medicine at the University of Toronto, where she imparts that expertise to the next generation, and the chair of the OMA's section on palliative medicine, which gives her a unique lens to the experiences and challenges of palliative care patients and physicians across Ontario. Dr. Liao will provide important and timely recommendations to strengthen access to hospice care for Ontarians, after which I'll make some closing remarks.

Dr. Pamela Liao: Thank you, Dr. Hill. My name is Dr. Pamela Liao. I represent the section of palliative medicine at the OMA. Before I present to you under that title, I would like to start by speaking as an individual. Two weeks ago, I was bereaved by someone very close to me. I wanted to dedicate the comments that I make today to them, but also to everyone this past year who has lost someone, because this has been quite a formidable year. When someone leaves us, there is a gap, there is a space, an emptiness that doesn't quite go away. But they live on through our memories. And so thank you for the opportunity to speak.

I'd like to begin by defining palliative care, because so often I find people think that what I do is really sad and depressing, but quite honestly, I think it's quite fulfilling. Most people believe that palliative care is about the end of life, the final hours or days, but actually, it's about living. The modern definition of palliative care means that that should be accessible from the time of diagnosis and continue throughout the trajectory with treatment. Palliative care includes a number of different approaches to care, including advance care planning, talking about future beliefs, goals and wishes and all aligned with the [*inaudible*]. It includes things like pain and symptom management, as well as psychosocial support for patients as well as their families and caregivers.

We believe that any effort to improve palliative care using the definition I have just described is the right decision for Ontarians. Bill 3 is a tremendous first step, and we are encouraged that this important issue has all-party support in the Legislature.

Hospice is a wonderful place and an alternative to hospital-based care. It's a comfortable, home-like environment for patients who are nearing the end of their lives. To strengthen the positive impact of Bill 3, if passed, today we are making three recommendations to enhance hospice care across Ontario.

Our first recommendation is for the government to consider additional funding to rebuild our hospice system after the detrimental effects we've seen from the COVID-19 pandemic. Hospices have consistently struggled with funding, and COVID-19 has exacerbated these vulnerabilities. In mid-March, hospices unfortunately began to suspend face-to-face client support except in residential hospice care for dying patients, and that support in the community is tremendous. Hospices have also incurred significant expenses related to the purchase of PPE, staffing, cleaning supplies and developing virtual care programs overnight.

Hospices rely on volunteers heavily. Those are often people who have been bereaved themselves and belong to high-risk groups, such as those who are elderly and who are no longer able to volunteer in the same way.

In addition, over 60% of hospice funding comes from fundraising, and the pandemic has led to a number of cancellations of typical fundraising events. Immediate funding is needed to sustain these organizations to provide the critical services they do to our citizens. In return, hospices would be well-positioned to help alleviate pandemic-related health system pressures.

Our second recommendation is to consider the equity issues around hospice palliative care, including regional equity. Currently, one's postal code determines what palliative care services are available. Those who work on the front lines know this all too well. We know that the majority of Ontarians would rather die in their homes, surrounded by loved ones. I hear this every day from my patients. Unfortunately, this is not always possible because of resources and barriers to access in terms of home care supports. Others simply do not have secure housing. It doesn't have to be this way.

A wonderful example is the inner-city program in Toronto called PEACH, Palliative Education and Care for the Homeless, and its three-bed hospice program called Journey Home. This program provides palliative care for the homeless and other marginalized groups. Without it, these individuals often have no option but to die in hospital. Programs like this one need to become the standard province-wide, regardless of where you live, to ensure everyone has access to hospice care.

Our final recommendation is to consider the cost-efficacy of providing palliative care in the home or hospice environment.

The Vice-Chair (Mr. Mike Schreiner): One minute.

Dr. Pamela Liao: Caring for the terminally ill in acute care costs approximately 40% more than providing palliative care in the hospital, more than double the cost of providing care in a hospice bed. Hospice is the best and most dignified place of care for the patients if dying at home is not possible.

Thank you for the opportunity to share our views with you today. It is a privilege to speak to you about an issue that is important to all Ontarians. Dr. Hill will now make some concluding remarks.

Dr. Samantha Hill: In light of time, I'll keep them very short.

Echoing Dr. Liao's remarks, I want to urge the government to strengthen hospice care now. This would help ease the burden on our strained health care system from both a financial and a capacity perspective. We're urging you to consider these recommendations that will truly achieve compassionate care intended by the passage of Bill 3.

I'll leave you with one parting thought: There are many ways to die, and COVID-19 has certainly highlighted some of them. On behalf of Ontario's doctors—

The Vice-Chair (Mr. Mike Schreiner): I'm sorry. Unfortunately, that's all the time we have for your presentation. Thank you for your presentation.

Our second presenter is not present, so I will now call on Linda Tenhunen. You will have seven minutes for your presentation. Please state your name for Hansard, and you may begin.

I think she needs to be unmuted. Can you unmute yourself?

1600

Dr. Linda Tenhunen: There. Can you hear me?

The Vice-Chair (Mr. Mike Schreiner): Great, we can hear you. Thank you. You may begin.

Dr. Linda Tenhunen: Good afternoon. My name is Dr. Linda Tenhunen, and I practise and live in greater Sudbury. I'd like to start by thanking the members of the standing committee for this opportunity to speak to this bill, the Compassionate Care Act, 2020, which I think is a tremendous step forward, if it's put in place, for palliative care within our province.

By way of introduction, I'd like to share a little bit of my background with the members. I'm a family physician by training, but like many physicians, I came to palliative care by a circuitous route. I've been practising palliative care in Sudbury now for 20 years. I began as a GPO, which is a general practitioner in oncology, at the cancer centre, caring for in-patient radiation patients who were dying. From there, I moved to the hospitalist system and broadened my view of palliative care, looking after patients who were dying in the ICU or patients dying of chronic diseases, such as COPD, or acute causes, such as stroke.

I went back to the cancer centre and was involved in the development of our palliative symptom management clinic, which is currently responsible for looking after ambulatory palliative patients who are receiving care at the cancer centre, as well as looking after the in-patient population who are cancer patients at the cancer centre. Currently, I practise at the Maison McCulloch Hospice in the community palliative care system, as well as looking after home patients whose preference is to die at home.

Those are my professional qualifications. Additionally, I have personal experience in providing terminal palliative care in the home setting. My family and I were able to provide care for my husband, who died of a primary brain malignancy three years ago. The experience of being able to provide care for him at home and allowing him to die at home, as was his wish, gave me a deeper insight into the unique challenges that face patients and families who wish to receive care in their final days at home.

My combined experience as a palliative physician and my personal experience with meeting this challenge has led to my personal palliative wish list. What's on this list? Firstly, we need more support for home palliative services. We know that, given a choice, most people prefer to die at home, and we know that providing care in the home in the last weeks of life is much more economical than providing care in hospitals. Having cared for my husband at home until the time of his death, I experienced the gaps in our system that add to the challenge of delivering palliative care at home.

I'm a palliative physician. I have a daughter who is an RN who practises palliative care at the hospital and a daughter-in-law who is an RN as well. We had access to the advice from the out-patient palliative care, along with numerous colleagues, and it was still incredibly challenging.

One of the clear deficits was the limitation of manpower. The RNs and the physician who were involved in my husband's care at home were wonderful, and they were experienced, but they were incredibly busy. Our family was experienced in the management of palliative symptoms, but we still required support, encouragement and education in order to ensure that my husband was kept comfortable. The time required to support patients and families undertaking palliative care in the home is considerable, and we have very limited manpower in our region.

Another challenge was the availability of experienced PSW support. PSWs are the backbone of quality home palliative care. While caring for my husband at home, unfortunately, we never saw the same PSW twice. Each time a PSW came in, we had to teach that PSW and train them to understand my husband's unique needs. Ultimately, we decided to do our own care and discharged all the PSWs, but this obviously added to the burden of care, which is already a marathon for families who are caring for patients at home until the time of death.

What other challenges did we face when my husband became ill? As an experienced palliative physician who used to work in radiation oncology, I understood my husband's diagnosis and I understood that it was a terminal diagnosis. In the course of his illness, no one approached me or my husband to talk about the nature of his illness or his life-limiting prognosis. The focus of each visit with our oncology team was treatment-oriented. In the end, I was the one who had to tell my husband that he was dying. The unfortunate truth is that if I had not been the person that I was, with my experience, we would have missed our final family cruise together because my husband would have been in the hospital receiving futile palliative-intent chemotherapy. We would have not had the celebration—

The Vice-Chair (Mr. Mike Schreiner): One minute.

Dr. Linda Tenhunen: I'm sorry?

The Vice-Chair (Mr. Mike Schreiner): Oh, no, you're fine. Just a one-minute warning; that's all.

Dr. Linda Tenhunen: Okay.

We would not have had the opportunity to have a celebration of life at home, with my husband playing his harmonica and surrounded by our loved ones.

We are missing a key piece of this picture, because we have not been teaching our medical students, our residents, our PSWs and our nurses about palliative care. Too many of our educational resources are directed to those already involved in palliative care, and we are preaching to the choir. We need a conversation with a wider audience of health care providers. We need to earmark funding for PSWs who are specifically trained in delivering palliative care and to remunerate these individuals for doing this important work.

Over the years, I've been involved with too many patients and families who have been robbed of the opportunity that I had to remember and reminisce—

The Vice-Chair (Mr. Mike Schreiner): I'm sorry, that's all the time we have. Thank you so much for your presentation.

I will now call on the Maison McCulloch Hospice. You will have seven minutes for your presentation. Please state your name for Hansard, and you may begin.

Ms. Trish Lafantaisie: My name is Trish Lafantaisie. Can everyone hear me okay?

The Vice-Chair (Mr. Mike Schreiner): Yes.

Ms. Trish Lafantaisie: I'm speaking to Bill 3, which enacts the Compassionate Care Act, 2020. I've worked in palliative care for 26 years, starting at the Toronto Grace hospital palliative care unit. Since my return to the north, I worked as a palliative care coordinator, then assisted with the development of the palliative NP program in the northeast. I started working at Maison McCulloch Hospice providing bedside nursing and telephone nursing with the community hospice palliative care team. I'm now the manager of clinical services here at the hospice.

Prior to 2008, when the local hospice was built, resources were very limited and there was only one program that provided palliative care services in the community, that being Dr. Linda Tenhunen. There was only a handful of palliative care nurses and very few care coordinators.

In 2014, several organizations pooled resources and a collaboration was formed between Maison McCulloch Hospice, home and community care, and the Northeast Cancer Centre palliative symptom management clinic. We became the community Hospice Palliative Care Team, a team that provided 24/7 care to patients in the community. This was done at a minimal cost to the Ministry of Health, initially, until more resources were required as the program grew and more nursing and support staff were needed to meet the demands of an increased number of patients that we serve.

This program provides home visits for patients requiring palliative and end-of-life care, and has been very successful in keeping patients at home to die or transferring to hospice when they choose not to die at home. This is being done by the care of the physicians and the nurse practitioners who collaborate with the hospice. As Dr. Tenhunen mentioned, there is an extreme shortage of bodies experienced in palliative care.

Some of the challenges that we face are late referrals. We do receive late referrals all the time. The conversations are not happening. I just wanted to share a quick story about a recent patient who had been referred to hospice. Diagnosed with a life-limiting illness a year and a half ago, the patient was not referred for end-of-life palliative care, but referred to admission for a hospice bed on the day that he died. So the patient was picked up by an ambulance and he died en route on a 25-minute drive from his home to hospice. The family members were devastated, because they were ill-prepared for his death.

People are not talking about end of life. Early referral to palliative care programs provide better outcomes for patients and families at end of life. These discussions aren't happening.

1610

Another challenge is allowing oncologists to bill for palliative care when they are not doing palliative care.

Another challenge: after-hours nursing and telephone support. We are only able to support community clients that are followed by our team currently, and that's about 70 clients. After-hours calls are currently being managed by nurses who are caring for our patients who are admitted to hospice beds, to the residential hospice. This limits the number of patients who have access to after-hours coverage. The community nursing service provider on-call nurse may not necessarily be experienced. There is one nurse; they may not necessarily have palliative care experience for after-hours. And if there are several calls, there is a chance that some of those concerns are not met.

There is a lack of resources to manage these patients in the last year of life who have non-cancer diagnoses, who are difficult to prognosticate, who may be housebound. More funding for community palliative physicians, nurse practitioners, palliative and primary care to manage these patients and more funding for after-hours community physicians or on-call coverage for palliative care are also required to keep these patients at home.

There are challenges due to COVID-19. Our team specifically is one of the only community teams that are seeing patients face to face, so we are being overwhelmed with referrals that are long-term palliative: have a life-limiting illness but are not imminently dying. As many physicians are still doing virtual telephone visits, these patients have minimal coverage at home.

Another challenge: funding for equipment, such as a portable ultrasound, to provide treatments in the home that NPs and physicians are already trained to do, such as paracentesis or drainage of abdominal ascites. This can be safely done in some cases at a fraction of the cost of what this procedure would cost to have done at a hospital. Just yesterday, one of our community patients had to wait a month and a half to have his non-functioning tube changed because the hospital could not provide a tube for this gentleman, and going to the emergency department for somebody who is in his last month of life is not ideal.

The Sudbury hospice will soon partake in a gradual opening of 10 additional beds: three end-of-life, six symptom management and one transitional bed. At this time, our team completes suitability assessments for patients to fill these beds. With the addition of setting up COVID swabbing and the education with the family regarding visitation, filling the beds has become a full-time position. A solution to this would be the addition of a bed coordinator or a navigator who also would be responsible for admissions, discharge planning education for families and community providers.

We've been doing some strategic planning ourselves for better management for those requiring a palliative approach to care, especially during the pandemic. Our hospice did apply for a grant to improve the ability to reach more patients virtually during the pandemic—

The Vice-Chair (Mr. Mike Schreiner): You have one minute.

Ms. Trish Lafantaisie: —and to provide more support to families after their loved ones have died. We are awaiting the response from our local Ontario health team to see if this has been approved.

One significant point to be mindful of when planning compassionate community care: Ontario Health is responsible for the health care services for more than 565,000 people in northeastern Ontario across 400,000 square kilometres. Time and weather must be taken into account when planning the number of patients who can be seen in a day in their home.

To address the education piece: Again, utilizing the resources that already exist, educate those community providers, nurses and PSWs, rotating them through hospice, scheduling them to do placements at a hospice or, better yet, have hospice be a service provider organization to manage and schedule all staff and work palliative care in the community. This will provide this staff with increased awareness of how the system works, how to refer and how to have the knowledge and skills to identify and recognize when someone has symptoms—

The Vice-Chair (Mr. Mike Schreiner): I'm sorry, that's all the time we have for your presentation. Thank you for your presentation.

We'll now begin the rounds of questioning. The first round will be with the official opposition. You will have 7.5 minutes. I recognize MPP Gélinas.

M^me^ France Gélinas: I'd like to start by thanking Dr. Hill and Dr. Liao from the OMA, Trish from the Maison McCulloch Hospice, and Dr. Tenhunen for your presentations. They're very much appreciated.

I would start with questions for you, Dr. Tenhunen. You walked us through—and I thank you for sharing the very personal experience you've had with your family and your husband. That was three years ago. Would you say that things have changed in those three years? Do you think that people facing trying to keep their loved ones at home have the support that is needed in order to provide quality care in end-of-life care?

Dr. Linda Tenhunen: My feeling is that over the last three years, very little has changed in terms of the ability of our team to care for people in their homes. COVID has certainly exacerbated that problem because of limitations on the PSW support and the limitations on our end. Visits, quite often, are more extended, visiting for our doctors and our NPs, just because the scheduling and the PPE, the donning and doffing, have made the visits even longer.

I've been doing this, unfortunately, for many years in the Sudbury region, and I feel like I'm hammering my head against the wall in terms of getting my colleagues to understand that palliative care doesn't belong in the end of life. Palliative care has to begin sometimes a year or even two years before a patient dies in order to allow time for families to understand and accept and follow that journey. I've experienced that both from the personal side and from the professional side. The message is not getting through, and I find it very frustrating.

We still get far too many referrals in the last hours or the last couple of days of life. These families are being robbed of the opportunity to talk, mend fences, forgive, celebrate and reminisce because the message is not getting through.

M^me^ France Gélinas: Thank you. Trish, you talked about needing a piece of equipment. I think you mentioned an ultrasound that you would need to care for people at home. Where does the funding for this type of equipment come from?

Just a minute, we can't hear you, but I see people—

Ms. Trish Lafantaisie: Okay. Can you hear me now?

M^me^ France Gélinas: Yes, we can.

Ms. Trish Lafantaisie: Because hospices are only funded—I think 67% of the funding comes from the Ministry of Health, and we have to fundraise. It's often not an easy task to obtain equipment like this, so we depend on fundraising, if we even have surplus funds in order to afford this type of equipment. I really couldn't tell you where the funding would come from.

M^me^ France Gélinas: Right now, you do have a number of fundraisers happening at Maison McCulloch Hospice. Can you explain a little bit what kind of fundraising you guys have to do?

Ms. Trish Lafantaisie: I believe it's $65,000 a month we have to raise in order to stay operational. The funding that we receive from the Ministry of Health only covers the nursing and the PSW support. So any admin staff, groceries, to heat the place—all of that is something that we have to fundraise for. There is rarely surplus funding. Right now with COVID-19, the pandemic has really been impacting our ability to fundraise as we were once able to. We couldn't do our hike this year. We couldn't do our gala this year. We're really scrambling to find ways to raise funds to keep us afloat, so to speak.

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M^me^ France Gélinas: You both practise in Sudbury. You know northern Ontario well. Would you know of a model that would help people in further remote communities? If you start to think about Cartier and Gogama and Mattagami and farther and farther from Sudbury, are there models that exist so that we can support people needing palliative care who are not close to Sudbury?

Ms. Trish Lafantaisie: Dr. T, do you want to take this one?

M^me^ France Gélinas: Oh, you're muted, Dr. T.

Dr. Linda Tenhunen: There, okay. We have actually had some success with OTNs and doing virtual visits, punctuated by intermittent in-person visits. I looked after a patient who lived two and a half hours outside of Toronto for about four years—

The Chair (Ms. Goldie Ghamari): One minute left.

Dr. Linda Tenhunen: —and it was supported quite well virtually, with putting aside one day twice a year and actually going out and doing an in-person visit. Ultimately, when the patient finally deteriorated, the patient was admitted to hospice. That worked reasonably well, but it needed the support of the community nurse who lived in that area.

I think those nurses certainly require a lot more support, because their visits are so extended; they're so far along. If you have a volume of patients—say you have to see four patients or five patients a day—and one of your patients is an hour out, then the incentive to be able to go see that—

The Chair (Ms. Goldie Ghamari): Thank you very much. I'm sorry, that concludes this round of questioning.

We'll now turn to the independent member for four and a half minutes. You may begin.

Mr. John Fraser: Thank you very much. I actually just want to begin by completing my answer to MPP Kusendova because I left something out, and of course I thought of it afterward. We're always more acutely aware of the things that we still have to get done than of the things that we've done. And the last piece is compassionate communities. There was a fund to support compassionate communities across Ontario, and the money didn't flow and it got stuck in transition, as it does normally. I really regret that happening, and I hope that money will flow at some point. I think it's an important piece. So that's the other thing. I didn't want to forget that.

I want to thank all the presenters today for being here and for all the work that you do and all the advocacy that you do on behalf of the people that you serve, because it's not just enough that you have to help people at a very vulnerable time in their lives, but then you've got to advocate so that you can do that better. It's a lot of work, and people have been doing it for a very long time, and I appreciate it.

I only have four and a half minutes, so I'll try to do this as quickly as I can. Dr. Hill and Dr. Liao, it's nice to see you again. Thank you very much for your support of hospice. It's very clear, I think, that we need to fund clinical services. As I said, it has been incremental and episodic the way we've done things over the years, and I've been part of that. I think that it's time and it's reasonable, and the pandemic has shown us this. I think that's really important, to have your support and endorsement for that.

One of the things that I do want to bring up, and it was actually in my answer to MPP Kusendova, is it has come to my mind in terms of the payment models for palliative care physicians and AFPs—I've known about this for a long time and it's a bit of a nest; I'll put it that way. Is there any light towards that getting resolved, in your estimation? I'll direct that towards both of you, and maybe leave me a little time for the folks at Maison McCulloch.

Dr. Pamela Liao: Thank you for an excellent question. I spend a lot of time thinking about this. You're right, there are a number of different models. Unfortunately, what we've seen in the past year is the dearth of support for after-hours care. That was really the message we came forward with this cycle, and I think that extends into hospice. Hospices can't be successful unless teams are available after hours, because emergencies don't happen from 9 to 5. Family doctors' offices are open then. It's after hours and who is supporting that—so many of the members of our section work, without any additional compensation, after hours to do this. How long can we ask them to do that for?

Furthermore, we have struggled because virtual care funding hasn't been accessible for palliative care services the way it has been for other specialist-level care. Again, why are we doing this at a time when palliative care is so critical? It's really unfortunate. It really dishonours and discredits the work that's being done. Members feel insulted and are really struggling, yet they continue on. Money is not everything, but people are getting burnt-out. The least we can do is pay them their fair share.

I'm really glad you mentioned this. CPOC is a program that has been frozen for years, and it's meant to support after-hours palliative care in groups—

The Chair (Ms. Goldie Ghamari): One minute left.

Dr. Pamela Liao: —but also for fee-for-service and APP, those in groups and those who work in solo practices. We really need to focus on this if we want to grow and sustain palliative care in this province. Thank you for that question.

Mr. John Fraser: Yes, I think it's very important. It's not an easy solution, but it's one that we have to get to.

I won't have time for the folks at Maison McCulloch, but thank you for all the work that you do. I'm so glad to hear that you're expanding even further. I just really appreciate all the work that you do. I have to cede my time now, I think—

The Chair (Ms. Goldie Ghamari): You have 20 seconds.

Mr. John Fraser: I have 20 seconds. The member from Guelph will be asking the next round. If there's anything I can do to help you at any point, as in the past, please feel free to contact my office—all of the presenters. Thanks very much again for your work.

The Chair (Ms. Goldie Ghamari): Thank you very much.

At this point, we'll now turn to the government. MPP Oosterhoff, I believe you have some questions. You may begin. You will have seven and a half minutes.

Mr. Sam Oosterhoff: I want to thank all the presenters for appearing before the committee. I'm wondering if they could speak, specifically Dr. Liao, about the educational piece, where some of the gaps are in that and how we can use this framework to advance that education piece in the broader health care system as it pertains to palliative care.

Dr. Pamela Liao: Thank you. That's an excellent question. I think we have a lot of knowledge and expertise. The challenge is how to both inform and educate our colleagues within our profession but then, beyond that, nurses and even PSWs, because every member of the team is so important. The word "palliative" gets thrown around a lot and has different meanings to different people. I think that's a real challenge.

I think the opportunities are for universities to have academic departments of palliative medicine, because not all of them do at this time. You really benefit from that kind of centre of excellence to serve the community.

In terms of allied teams—nursing, occupational therapy, PSWs etc.—I think that's an important piece of this as well. One really wonderful resource is the LEAP program, Learning Essential Approaches to Palliative Care. There are different opportunities. There's a program for physicians and nurses, but there's also a specific program for LEAP long-term care, because palliative medicine looks different there, as well as for PSWs and bringing teams together to learn in an interprofessional way. If I could advocate for that to be made available to more and more service providers, I think it could do a world of good. Thank you.

Mr. Sam Oosterhoff: Linda, could you speak about some of the needs in the north? That's an area that is often overlooked, and it has a lot in common with rural areas, in some ways. What would be some of the important things to think about as we think about the north and rural areas?

Ms. Linda Tenhunen: From my perspective, the most pressing need would be experienced palliative care PSWs, who are educated in palliative care and are available so that they can actually have the same client that they look after for the duration—rather than for 20 minutes, and then on to the next house, and being rotated to a different patient.

My experience, both professionally and personally, is that the PSWs are not trained in palliative care and they have variable degrees of comfort with it. I would think that would be one of the most pressing needs, along with more NPs and doctors who are willing to do this work. That comes with the educational piece that Dr. Liao talked about.

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Mr. Sam Oosterhoff: Thank you. Trish, could you speak a bit about where the sweet spot is when it comes to improved access, not just to care but to supports? What sort of operating costs should be covered that are not currently covered, and what would that look like?

Ms. Trish Lafantaisie: Things need to be better coordinated. People need to join forces, so to speak, to cover the holes or fill the gaps. I have some personal ideas, but that would be more geared to our scenario, and each geography is so different. But in the north and in our area, I think that education is key, like everyone else has been suggesting, and working together with your other agencies in order to try to fill those gaps by educating people with the current resources that already exist.

Mr. Sam Oosterhoff: Thank you. Would there be any communities that you believe we should definitely ensure are consulted as we build this framework, that might typically be overlooked?

Ms. Trish Lafantaisie: In northern Ontario?

Mr. Sam Oosterhoff: In northern Ontario, but just communities across the province.

Ms. Trish Lafantaisie: Any of these smaller, little communities, even the ones that have the hospice suites, like throughout northeastern Ontario. I think it was a year ago or two years ago where they introduced hospice suites in the small hospitals and the small areas. It's a single room, and apparently there are staff that are rotated. Everyone needs to be educated about palliative care. For those hospice suites to function truly like a hospice palliative care bed, that education needs to happen.

I can think of some local towns around us that are lacking and are still trying to build programs to meet the needs of their community, one being Espanola, but I can't think of anything else. Nothing else comes to mind.

Mr. Sam Oosterhoff: I was kind of thinking around marginalized populations, Indigenous populations and other groups that perhaps don't always have access to the palliative care that more privileged groups might, and if you think there is a need there to address some of those inequities and what that should look like?

Ms. Trish Lafantaisie: Oh, definitely. Definitely I believe that there is. I know that a lot of the reserves have their own health care centres, but we recently paired Atikameksheng reserve with our manager of supportive care, and he did some train-the-trainers sessions with staff there who deal with loss and grieving and death and dying. That went really well. And like I said in my presentation, we did apply for some funding to do some virtual care, but also virtual education, for those smaller communities.

Mr. Sam Oosterhoff: Thank you so much.

Dr. Liao, from your membership, what is the top concern as it pertains to palliative care that you regularly hear?

The Chair (Ms. Goldie Ghamari): One minute left.

Dr. Pamela Liao: I think if I had to boil it down in under a minute, it would be the challenges in accessing community supports, support for after-hours care and just getting equitable funding for the work that we're doing virtually right now, because it's a real disparity. Thank you.

Mr. Sam Oosterhoff: Thank you all so much for all your time today.

The Chair (Ms. Goldie Ghamari): We'll now turn to the official opposition for the second round of questioning. Who would like to begin? MPP Gélinas, you have seven and a half minutes.

M^me^ France Gélinas: Thank you. My first question is going to be for you, Dr. Liao, and it's about pediatric palliative care. We've had a few deputations that looked at it and would like the pediatric system to be separated from the adult system for a multitude of reasons. Is this something that you support?

Dr. Pamela Liao: Sorry, could you clarify what you mean when you say "system"?

M^me^ France Gélinas: They would like hospices for pediatric clients. They would like the support system and the team that works with children to be solely working with children. They talk about a hub-and-spoke model to make sure that you cover the geography of the province, but basically having palliative children's services independent and separate from the adult palliative services.

She's muted.

Dr. Pamela Liao: Thank you.

I'll be very honest; I'm an adult palliative care physician, and my first response would be to defer to my past chair, Bill Splinter, who you've spoken with. Generally, though, I would say in terms of members, there aren't groups that do combined adult and pediatric care at this time. It's a world unto itself. I don't think we should be picking and choosing; we should have excellent palliative care across the age spectrum.

Just speaking to my own experience, we know that in the geriatric versus adult populations, there are discrepancies that also need to be addressed. But I think it's absolutely vital the pediatric palliative care gets the attention and support that it deserves.

M^me^ France Gélinas: Thank you.

Back to Trish: Could you explain to us a little bit as to the services that are presently available at the Maison McCulloch Hospice, how the new beds are going to be used, and what kinds of services those new beds will bring to the community?

Ms. Trish Lafantaisie: As I mentioned in my presentation, we will be gradually opening 10 additional beds, three being end-of-life beds. A lot of our patients who require a palliative approach to care who are in the community end up in crisis and in emerg. These six additional beds will be symptom management beds, so somehow coordinating that those patients come to hospice into a symptom management bed, as opposed to going to the emerg department, if the exacerbation or the symptoms can be managed. We're hoping to be open, I think, by the summer—all 10 beds.

I'm sorry, I think I missed part of your question. I'm not sure if I answered it completely, France.

M^me^ France Gélinas: You talked about the three end-of-life, the six crisis and symptom management. And the 10th one?

Ms. Trish Lafantaisie: It's a transitional bed. Sometimes you have patients who come to you and you're not sure if their prognosis is a little bit longer and may end up requiring long-term care as opposed to being end of life, if they improve in hospice. Then we would transition them to either long-term care or to an end-of-life bed.

M^me^ France Gélinas: All right. And can you explain the existing services at the Maison McCulloch Hospice?

Ms. Trish Lafantaisie: We currently have 10 end-of-life beds. All 10 beds are open and full at this time. We also have grief and supportive services. We have the volunteer visiting services, which are currently not functional because of COVID-19, and most of our volunteers are over the age of 65. And we have our hospice palliative care team. We have a collaboration with the North East LHIN, home and community care; two nurse practitioners who specialize in palliative care; two hospice physicians, Dr. Tenhunen and Dr. Walton; and two staff members from the hospital, Dr. Pun and Barbara Ballantyne, who is a clinical nurse specialist. We provide services out in the community, face-to-face visits for those patients who choose to die at home.

M^me^ France Gélinas: Thank you. When you say that your 10 beds are full, do you have to refuse clients, turn them away?

Ms. Trish Lafantaisie: When they're full, yes, we do, unfortunately. We try to do the best we can, work with what we've got. They either end up in hospital, unfortunately, or if they didn't have the knowledge, skill and the motivation, we may get them involved in the team and have the care coordinator or the nurse practitioner provide some education and try to support them to stay at home.

1640

M^me^ France Gélinas: How many clients like this would you say get a referral to Maison McCulloch at a time where you cannot accept anymore?

Ms. Trish Lafantaisie: It varies. We can have anywhere from 10 clients on a wait-list to two. We take our community patients into hospice first. We do often get requests from hospital as well, and more so due to COVID, because they're not allowing—the visitor restrictions. So we are getting a number of requests from hospital patients wanting to come to hospice because it's easier to manage, with 10 beds, to control the visitation and the screening of the visitors for patients.

M^me^ France Gélinas: Thank you.

The Chair (Ms. Goldie Ghamari): One minute left.

M^me^ France Gélinas: Just very quickly, Ontario Medical Association, you told us increased resources for the increased expenses; equity, and when we talk of equity, regional, not based on postal code, but also homeless and marginalized. And you talked about cost efficacy of home-delivered and hospice-delivered versus hospital-delivered palliative care. Is there anything else that you wanted our group to know as a priority?

Dr. Pamela Liao: I think doing everything up until the time hospice admission is needed, so keeping people in the community by supporting after-hours care, supporting virtual care and home care—meaning PSWs etc. who are trained and skilled in palliative care—would be so valuable.

M^me^ France Gélinas: Thank you.

The Chair (Ms. Goldie Ghamari): Thank you very much.

At this point, we'll now turn to the independent—no? All right. We'll turn to the government for seven and a half minutes. You may begin.

Ms. Natalia Kusendova: Good afternoon, everyone. Thank you for your presentation.

Before I begin my questions, I just want to give a shout-out to my local hospice, which is Heart House Hospice, and Theresa Greer and her entire team with whom we've worked very closely. Unfortunately, they're unable to come and present, but I do have a very quick quote of support to read here.

This is from Theresa Greer from Heart House Hospice: "Everyone should have access to quality hospice palliative care. Death, dying, grief and loss impacts everyone at some point and is not limited to the aged. COVID has driven home the need for families to be together when someone is dying. The trauma experienced will impact those left behind for the rest of their lives. Bill 3 is a step forward to addressing the needs of individuals who are palliative and their families and caregivers who love and care for them."

I just want to give them a big shout-out on their HUUG program. HUUG stands for Help Us Understand Grief, which is a bereavement program aimed at children, because as people are dying and we are losing our loved ones, there are families that are left behind. Often, there could also be children, and they need specialized supports as they go through grief and bereavement. So a huge shout-out to my local hospice, Heart House Hospice, for the incredible work that they do in our community.

My question today will be addressed to Trish from the Maison McCulloch Hospice. I'm really glad that you brought up nurse practitioners, because I'm a registered nurse and an aspiring nurse practitioner—hopefully, one day—and I think that, going forward, nurse practitioners will be transformative in helping us build capacity within our health care system.

I note that we do have a community-based nurse practitioner program which is funding about 70 palliative nurse practitioners across this province, and it does involve 24/7 coverage for palliative clients. Can you talk a little bit about what role you think nurse practitioners can play in helping to fill some of the gaps, especially in some of the more rural and remote areas, to help improve access to palliative care 24/7 for patients in need of it?

Ms. Trish Lafantaisie: If you're speaking about the nurse practitioners that are funded through the LHINs or Ontario Health currently, to my knowledge, in this city, they don't have 24/7 support. Those nurse practitioners are responsible for their patients 24/7, but they're off the clock at 4:30.

We're fortunate. We kind of did a homegrown type of program here where we, out of the hospice, and our generalist palliative team, out of the hospital, support those nurse practitioners. Our nurse practitioners are amazing, and as long as they take that additional education in order to have no restrictions on their practice, then they make a world of difference in the community. They can address every need in the home for patients. One of our nurse practitioners actually goes out with an ultrasound and can do a paracentesis in the home, and she's very good at it.

We really can make a difference in palliative care in the community with more nurse practitioners—and more physicians, of course.

Ms. Natalia Kusendova: Thank you so much.

My next question is to the Ontario Medical Association. As far as I understand, there are only about 270 palliative care physicians in our province. My question to you is, why is that? What can we do to encourage more physicians to pick this specialty and really grow this field?

Dr. Pamela Liao: Thank you. It's an excellent question and one I reflect on often.

Our section represents specialists, generally, who are doing specialist-level care. Part of the discussion here today is that our population is aging and getting increasingly frail, and so it can't be that all comfort care or palliative care is done by specialists. It needs to be an inclusive strategy that includes primary care, that includes specialists, that includes oncologists working together.

Absolutely, though, there needs to be health human resource planning around the future, because the need for palliative care is only going to grow exponentially. I think this means making palliative medicine an attractive area of medicine to work in. It means increasing the number of training spots.

There has been an expansion in our profession now, because you can transfer from both family medicine and there's a new Royal College program which is five years. Increasing those will help to develop the capacity over time. However, in the meantime, we need to start doing education for those in practice to at least pick up some primary-care-level palliative care. It can't all be done by specialists.

Ms. Natalia Kusendova: Thank you. I think that's a point that came across multiple times—

Interjection.

Ms. Natalia Kusendova: Did you want to add something in? Go ahead.

Dr. Samantha Hill: I did. Thank you. Just to add to the excellent comment by Dr. Liao, I'd say that part of the issue with having palliative doctors is that we frankly don't have enough doctors across Ontario. If you look at us per capita compared to the rest of the country or compared to other similarly rich countries, we are very much at the bottom end. That is a problem that we see repeating throughout each of the fields, so that's an issue here as well.

Ms. Natalia Kusendova: Thank you. I don't know how much time I have left—

The Chair (Ms. Goldie Ghamari): A minute and 30 seconds.

Ms. Natalia Kusendova: Thank you. I will ask a quick question to our doctors present today.

We have a lot of doctors who are educated outside of Canada. My family actually went through this. My father is a doctor. We came to Canada on a points system. We immigrated because he was a doctor, and yet when we got here, he was unable to practise as one. The bar to get your qualifications nostrified in order to be able to practise as a physician is extremely high. As a result, my father left and is now a practising physician in France.

I think we already have a lot of physicians here in Canada who could help us with some of the challenges we're facing. What can we do to try to tap into that potential?

To any of the doctors present.

Dr. Pamela Liao: I think Dr. Hill wanted to make some comments.

Dr. Samantha Hill: Thanks. I was trying to. The host and I were arguing over whether I was muted or unmuted.

Simply, I would say that from the OMA's perspective, that's really a Royal College question that needs to be answered. The government of Ontario and the people of

Canada do insist that all physicians are held to an equally high standard, but there are certainly some foreign graduates who could meet those standards. It is up to the Royal College to ascertain which physicians those are.

Ms. Natalia Kusendova: Thank you very much.

The Chair (Ms. Goldie Ghamari): Thank you very much. At this point, I'd like to thank our presenters for their informative presentations today. You may step down. I want to thank the committee as well.

CANAGE

DR. HSIEN SEOW

The Chair (Ms. Goldie Ghamari): We'll now turn to our last set of presenters. For now, we have CanAge present. You will have seven minutes for your presentation. Please state your names for the record, and then you may begin. Thank you.

Ms. Diana Cable: I'm sorry. That was us?

The Chair (Ms. Goldie Ghamari): Yes, your time is gone—no, I'm joking. All right. I'd like you to state your name for the record, and then you may begin. You will have seven minutes.

1650

Ms. Diana Cable: Hi, I'm Diana Cable. I'm the director of policy and advocacy at CanAge. Our CEO was supposed to be doing this presentation, but she is just finishing another presentation, so I will take over.

May I share my screen?

The Chair (Ms. Goldie Ghamari): Yes, you may.

Ms. Diana Cable: This presentation that I'm going to share was made for Laura to be presenting, so if you will excuse the very directed-to-Laura presentation. I am new in my role, so I am—ah, there we go. Okay.

Thank you very much for allowing CanAge to speak to you today. CanAge is Canada's national seniors' advocacy organization. Our CEO's work has focused on aging, inclusion, consumer rights and social justice. I won't go through all of her qualifications, given that we have a short period of time. We're a national non-profit that educates, empowers and mobilizes people on the issues that matter most to Canadians. We are clean-handed, we are non-partisan and we are pan-Canadian. We like to problem-solve and make real change happen.

I understand today we are talking about Ontario specifically. We partner with a wide variety of organizations, as you can see, all across the country, from Age-Well to the NIA to Canadian Centre for Elder Law. We have international issues, and we are municipal as well. We created a document called Voices of Canada's Seniors: A Roadmap to an Age-Inclusive Canada, and I will be speaking about some specific issues that are in this document.

We have six compass points in the road map: violence and abuse prevention; optimal health and wellness; infection prevention and disaster response; caregiving, long-term care, home care and housing resources; economic security; and social inclusion. Some of what I'll be talking about today is from specific sections of these, but that is the overview.

Where we would like to focus on—you'll be able to see it under "optimal health and wellness." We believe that these are cornerstones of active and positive aging in Canada. Canadian seniors deserve equitable access to health care, regardless of their locale and income, and our health system must invest in preventive care and well-being, including initiatives that include nutrition, movement, mental health and social activity, in addition to the acute and chronic care services.

Issue number 14 is our hospice, palliative and end-of-life issue. Hospice, palliative and end-of-life care, or HPE, is not adequately accessible or culturally appropriate for the large majority of Canadian seniors—we can just replace that with "Ontario seniors." This is particularly true for seniors with dementia and seniors who live in long-term care, congregate care or hospital care settings. The recommendations that we have for this are regarding dementia: Work with stakeholders, such as Alzheimer societies and health care providers, to integrate HPE care into all dementia supports.

Another recommendation for dying at home: Expand HPE care into home settings. Government and stakeholders in the sector should work with home care providers and families to increase education and training for this.

We'd like to talk about advance care planning. Integrate legal education on substitute and supported decision-making rights and power-of-attorney representation agreements into health and social care training as a required component of the licensing. Support health care training to support conversations around the importance and benefits associated with advance care planning.

Regarding medical assistance in dying, ensure equitable and accessible access to appropriate medical assistance in dying. Develop resources to support the education of the patients and health care professionals about disability rights and supports, HPE care and medical assistance in dying. As qualifications develop and modernize, make sure that expanded access and knowledge tools are made available to individuals, caregivers and health care professionals.

The remainder of our recommendations are under C, for caregiving, long-term care, home care and housing resources. Caregivers are an integral part of our health and social care of older Canadians, or older Ontarians, and we simply do not have enough of them. With the age demographic shift, we are likely to have significantly fewer going forward. We need to significantly advance our policies to create new paid professional caregiving staff, while also addressing the needed workplace flexibility and government support for people taking care of loved ones without pay.

This comes with our issue 26: Seniors do not have adequate publicly funded home care allowing them to age in place affordably, or at all.

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Diana Cable: Home care must be reformed. Our recommendations here, we have three of them. Transform the current home care worker model with an integrated, multidisciplinary team model of care at home. Increase quantity, quality and types of care at home. And our last one under here—this one is in our document, but it's not directly relevant—is directed federal funding transfers tied to specific outcomes.

If you want to see any further about where it's come from, you can review our document at CanAge.ca/voices. Thank you for your time and attention.

The Chair (Ms. Goldie Ghamari): Thank you very much.

At this point, we'll now turn to our second presenter, Dr. Seow. Please state your name for the record, and then you may begin. You will have seven minutes.

Dr. Hsien Seow: Good evening, everyone. Thank you so much. I'm Dr. Hsien Seow. I did not prepare slides, so I'll just speak a little bit.

Thank you for inviting me. I am an associate professor at McMaster University, and I've spent 20 years trying to improve the experience of patients and families facing serious illness. As a PhD researcher, I have looked at data, trying to look at Ontario's home care system. I have talked to hundreds of patients, families, clinicians of all stripes and interprofessional workers—social workers, nurses, pharmacists—trying to figure out how we can improve the care for patients facing serious illness. I've been involved in helping evaluate the end-of-life care strategy in Ontario. I've worked with the LHINs, and ministries across Canada and other places around the world, to think of ways that we can make this a better experience.

I'm very happy to speak to you and answer any of your questions. As you know, this bill is one of the things that affects all of us. It's one of the few opportunities where we can talk about a topic and advance a plan that is completely apolitical. It is something that affects all of us, either as individuals who will develop a serious illness, which most of us will, or who care for and love others who will have a serious illness.

For me, personally, over 30 years ago my mother died from breast cancer. She had cancer for four years, getting treatment that whole time, and never once did they ever use the words "palliative care." I can tell you, 30 years later, I still hear stories—I often hear stories—from patients and families telling me, "I don't know what that is," "I asked about it, and I was told it's not time yet," "I was not able to get it," or "They don't have it where I live." So this is an incredibly important bill that will bring attention to this, but also take concrete steps to make it better.

And two things that I just want mention in my very short time is: Parts of the bill are about measures for access and supporting providers and common data elements. I can tell you, as a researcher, there has been tons of experience doing good measurement around the world that we can benefit from and implement. If you don't measure something, you cannot improve it. Our measurement is about how well our system is, what's working well, but also, where we can improve.

This is already happening through leadership from many of the people on the call. I see MPP Oosterhoff, who sponsored this, and others you've been listening to, who have created the Ontario Palliative Care Network, which is across the entire province. It was a huge amount of work. It took eight years to get the network. But they have already been building a framework. They have already been doing some measurement, but if we do not codify it into a bill and into law, this will continue to be something that is at the side of their desk just at risk of falling off, being the flavour of the month.

Palliative care and caring for people who have a serious illness is not something that we can think of as a trend or a topic. It has to be embedded into how we can make our health system better. We know if we do good palliative care, it improves patient and family experience, but it also saves the system money because it avoids unnecessary hospitalizations, unwanted surgeries and using services and things they don't need.

1700

The second really important part of the bill is the emphasis on palliative care training and education of health care providers and caregivers. This is very innovative, because it talks about how health care providers—not just doctors, but all the professional people who care for others—have a role in understanding what palliative care is. The ABCs of palliative care are everybody's business. It's not just patients; families and caregivers play such a huge, important role, an essential role, in providing the experience. Outside of hospitals, 85% of the care is provided by families. They absolutely need support, training and education.

The thing that I wanted to emphasize here is, yes, we need training and education, but palliative care is not about death and dying. This is not about having more conversations about death and dying and accepting the death that's happening. It is about doing it much earlier so it's not about end of life and it's talking about information on what the journey is going to look like and how it will unfold. When we can prepare people for what the future is going to look like and potentially some of the possibilities that will happen, they can be more prepared, more proactive and have more choices and control about their experience. I can tell you, their experience is better. But also for the families and caregivers, they don't have as much regret and they don't have as much anxiety and pain and all those things.

This education and training is critical for all members in society, because this is a universal experience: to love other people and to care for them when they're ill. A serious illness—some of them may be cured, but for many of them it will be life-limiting and progressive. There will be a road of death. That's the difference, that this bill is not talking about end of life: It's not a better death bill; it's a compassionate care bill that can apply to everybody with a serious illness. It can be done right from the beginning of diagnosis and it can help us understand what's ahead much earlier than the last two weeks of life, which is when the majority of people get palliative care.

Thank you very much. I'm happy to answer any questions about the research, the evidence or the science about why this is critical. I know you've heard a lot in the past several days.

The Chair (Ms. Goldie Ghamari): Thank you very much, Dr. Seow. I appreciate your presentation.

At this point, we'll now turn to the independent member for a round of questioning. You have four and a half minutes. You may begin.

Mr. Mike Schreiner: I want to thank both presenters for coming today. I want to direct my first question to CanAge. Laura, if you want to expand a bit, since you weren't here to give the presentation, you're more than welcome to do that with my time.

I wanted to ask you to talk about how palliative care is not accessible, particularly when it comes to culturally appropriate care. Can you expand on some ways in which we can make sure palliative care is accessible to everyone in the most appropriate way?

Ms. Laura Tamblyn Watts: Thank you so much. My name is Laura Tamblyn Watts, and I'm the CEO of CanAge. Thank you for the question.

Hospice palliative care is challenged by not only resourcing and its lack of prioritization in government, but also by the challenges that we have with ethnocultural diversity and making sure that we're providing end-of-life and hospice palliative care in a compassionate and culturally appropriate way.

Let me tell you a small story that may illuminate this. I was working with a patient and that patient wanted to be able to express end-of-life wishes and concerns, but he said that in the culture that he came from, which was an Asian culture, he actually could not speak of that. He also wanted to speak of broader concerns with his family. Because they were not in an environment that was culturally appropriate, those conversations couldn't exist.

We know how to provide excellent end-of-life, compassionate hospice palliative care in a wide diversity of ethnocultural and appropriate mechanisms, but unless we have the prioritization and focus to do that—and this bill would, I think, allow some of those opportunities to happen—many, many families are left behind. We see not only the challenges to a good life, but we see an end is not a good death in these circumstances.

Resources and supports can be made available. We believe that this bill would help provide those supports.

Mr. Mike Schreiner: And when you talk about the need for additional resources and supports, what would be some of those additional resources and supports you'd recommend?

Ms. Laura Tamblyn Watts: We believe that trained supports within, particularly, the social work profession who work in ethnoculturally diverse communities, whether they be in long-term-care homes or providing the care at home, are available to support conversations, not just about advance care planning, although that is important, but also what death and dying can look like and what options are available. When we're talking about supports, they're not enormous, structural, bricks-and-mortar types of supports; they're modest budgets for additional people to help engage in conversations.

Mr. Mike Schreiner: Do you feel like palliative care has enough funding from government to be able to provide the care that people need?

Ms. Laura Tamblyn Watts: No. Palliative care has been one of the areas that has been left behind in the past 20 years. It is routinely an afterthought. When we're thinking about where budget goes to—

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Laura Tamblyn Watts: —we're very focused on supporting acute care and not on palliative care. Acute care is very fast; palliative care can be much longer. Targeted resources and supports on an increased basis would make a huge difference to the lives of people.

Mr. Mike Schreiner: You probably have about 20 seconds here: I think we're all supportive of this bill. Do you have any recommendations on how we could improve it?

Ms. Laura Tamblyn Watts: Palliative care resources should be embedded in all care centres, with specialized training for people there so that there are on-hand resources in acute, long-term care and community-based settings.

Mr. Mike Schreiner: Great. Thank you.

The Chair (Ms. Goldie Ghamari): Thank you very much.

We'll now turn to the government. MPP Wai, you have seven and a half minutes. You may begin.

Mrs. Daisy Wai: Thank you to both of the presenters. You hit on the right place, that we have a growing number of seniors, and it's only growing faster in the next few years because of the baby boomer situation. What have you done extra to help this situation? Because there will be more of a need for palliative care down the road.

Perhaps either one of you or both of you can respond to it.

Dr. Hsien Seow: We've talked a little bit about the need for education and training across all professions—so not just medical schools, but nursing, social work, pharmacy—and the attention of a palliative care rotation is critical to building the capacity to do this. Again, I think it's really important that we think of palliative care not as only symptom management at end of life, but about skills in conversations to bridge how we understand what we're facing today and the uncertainty of tomorrow and that whole path. People with Alzheimer's, dementia, that could be a 10-year journey, or for many cancers, it is a five-year journey. It's critical, that education and training.

Again, how do we create change? We have to do research and we need to measure what's happening and where we can improve. Yes, location of death is important, but so too are resources, PSW retention and front-line worker burnout. These are all critical to being able to have the skills and comfort to just have conversations about where you think you're at, what you hope to achieve and what is important to you in this time.

Mrs. Daisy Wai: Thank you. I agree totally with you about education and training. I'm the parliamentary assistant for the ministry for seniors, and I can see the need of not only training the caregivers, but also family members as well as the patient when they're close to the time when they need palliative care, for them to understand it ahead of time.

What have we done and where are we at? What state are we at, at this point?

1710

Ms. Laura Tamblyn Watts: Thank you so much for the question. What I would offer is there is a huge amount of stigma and barriers—in many cases, a cultural barrier—about talking about end of life as well as death and dying. When my colleague was speaking about the importance of integrated modules for training, we would emphasize that we believe there should be mandatory rotations in the helping and health professions. So we absolutely agree, and that's part of our platform.

In terms of the question about family caregivers, we really believe that there's an opportunity to work with the Ontario Caregiver Organization to support an additional set of resources around palliative care. Why we suggest our colleague organization is because many people need to be met where they're at. They may not reach out for end-of-life resources because they're not thinking about end of life. They're scared. They're thinking about caregiving. We believe that working with sector organizations in the aging space—CanAge is one of those organizations—and other colleague-based organizations on an upstream effect, we'll be able to provide information tools and supports to upskill family caregivers, which, as you know, is about two thirds of who is providing care.

So we do feel that a multi-sectoral approach is important with embedded professionalism, but also to work on the family caregiver piece as well.

Mrs. Daisy Wai: On a scale of five, where would you say that we are at right now in the training and preparing, whether it's hospitals or whether it's the PSWs or whether it's patients or family caregivers? Where are we at right now in terms of training?

Ms. Laura Tamblyn Watts: One.

Dr. Hsien Seow: We're at a one. PSWs and home care workers don't get any mandatory training in palliative care. They have to choose this as a specialty. The key things that we're missing are good mentors and coaches for physicians. If they're lucky enough to learn palliative care, they learn it in a hospital. We're talking about care in the community and all the caregivers, where they need support.

We need alternate funding plans or incentives for others to train others, and that's just clinicians or physicians. Think of your home care nurses and your PSWs who are going to spend the majority of their time providing this care. I think this is what can be done: having very clear training opportunities, but the mentorship and the coaching and the funding that goes along with the ability to do that.

Mrs. Daisy Wai: One quick last question on the process of Ontario hospitals being in transition to a new model of care: How does that affect palliative services? Is it better? What do you think?

Ms. Laura Tamblyn Watts: I think it will be left behind, unless it's very specifically targeted as a key requirement and a mandatory competency.

Dr. Hsien Seow: If you ask clinicians today, "What is palliative care?", they're going to say it's about end of life. This is why this bill, the Compassionate Care Act, on palliative care needs to be about serious illness. Right from the beginning, you can have a palliative approach, right from diagnosis. It is not about end of life. If we continue to plan about it only at end of life, we'd all have to die on time to get it, and none of us do.

Mrs. Daisy Wai: Definitely. [*Inaudible*].

Do I still have extra time?

The Chair (Ms. Goldie Ghamari): You have one minute and 20 seconds.

Mrs. Daisy Wai: Oh, that's good. With this bill, how can we improve on what we have at this point?

Dr. Hsien Seow: I would say the two things that we could call out are primary care's role in this and community support home care's role, and also community support services. Calling that out specifically with what you just talked about, with the hospitals and the Ontario health teams being in charge, is really important, because it's kind of coming out into—we need to make those partners very clear that they have a critical role in the integration of an integrated team.

Mrs. Daisy Wai: Perfect. Laura or Diana?

Ms. Laura Tamblyn Watts: We would agree that those are the critical pieces. I can't emphasize enough the importance of care at home when we're talking about palliative care. I would also make those strong linkages between other types of care being provided at home. This is especially true in the time of COVID-19, where people are not actually going to third settings, but are increasingly needing to get that support for care at home.

Mrs. Daisy Wai: Thank you very much. Thank you, Madam Chair.

The Chair (Ms. Goldie Ghamari): Thank you very much.

At this point, we'll turn to the official opposition. MPP Glover, you have seven and a half minutes. You may begin.

Mr. Chris Glover: I want to thank all of you for being here and speaking today. I'll be quite frank: Palliative care is not an area I'm that familiar with, but I've learned a lot from listening over the last couple of days.

I just want to provide—I said this to some deputants this morning—some political context for this bill. My big concern with this bill is that it asks for a report to be presented a year from now, and a year from now, we're going to be in a pre-election period. We'll be just six months out from the next election. Pre-election periods are not a time to get things done, especially to start new initiatives. And then there will be a new government, and where this will fall in that priority is a concern.

So my concern about this bill as it is, and the timing of it, is that we're going to get a report—and we had a deputant this morning who is very familiar with this and has been advocating for decades on it. He said there have been 10 reports over the last 10 years. So if we want to take action, if we want to see action, we need to make some amendments to this bill. That's the next step in this process, that we get to propose some amendments—actions that we can take right now that we don't need a big study or another study to do.

My question to you is, what are your top items? What should we be proposing in amendments? I'll start with Hsien and then go to Diana. I want everybody to have an opportunity.

Dr. Hsien Seow: First of all, I think the report can be—the Ontario Palliative Care Network has been working with every LHIN and OHT and partner across the province to be measuring this with Health Quality Ontario. So we are doing some measurement. There are just no teeth to that network because it's not a bill and it's not something that must be reported. But the things that they are focused on are community-based access to home care providers, home visits with a palliative care intent, and physician visits.

So if we wanted to add things, we would think of ways that we could support that. If we believe that most people want to be cared for at home and if we want to provide this palliative approach to slow medicine outside of hospitals, we need to find ways to do that. We can support training for or more budget for home care providers and services.

The training of them: There has been a lot of work in alternate funding plans for physicians or for palliative care specialist physicians who work in the community to not just see patients but to train other family doctors to be able to have these conversations. These are all things that could be called out specifically if you wanted to improve the bill.

Mr. Chris Glover: I want Diana and Laura to respond as well, but what I'll ask is if you could send our offices—so Sandy Shaw, France Gélinas or I—what your top recommendations are. We're working on amendments right now. Diana and Laura?

Ms. Laura Tamblyn Watts: Thanks very much. I strongly agree with my colleague's organizational key priorities. Those are the issues.

When it comes to the many, many reports we have, it is indicative not of the scope of the problem but the lack of action. That is fundamentally the piece. It also, I think, indicates the stigma associated with palliative care that has permeated through the system. So one of the reasons we don't do enough about palliative care is because it falls into a less pressing issue than perhaps acute care areas would be. We would strongly recommend that there be encouragement for competency-based modules and training across all of the health and housing continuum.

We also are in support of a reporting process. I certainly hear your comments about the report and whether we need another report. What I would offer is: If we could change the reporting process into regularly tracked key performance indicators and tether that to funding, I think you would find much more investment done by new Ontario health teams than if it is untethered to outcomes and funding.

Mr. Chris Glover: I want to pass it over to one of my colleagues because they have questions as well. But thank you so much for being here. And if you could send your recommendations to us, we'll work them into the amendments that we're making. Thank you.

The Chair (Ms. Goldie Ghamari): Madame Gélinas. Two and a half minutes.

M^{me} France Gélinas: Okay.

I, too, want to thank CanAge, as well as Dr. Seow, for your talk this afternoon. I was interested when you talked about the Ontario Palliative Care Network that has put a framework together, that has collected data. Are there options for moving things forward right now, especially when it comes to primary care, home care and community care? Are there action items that we could take now if the political will and the money are there?

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Ms. Laura Tamblyn Watts: There are. There are some that, yes, are ready to go. I would offer that some of our recommendations are very specifically built out so that they could be used and actioned right away.

There is not a lack of maturity of thought and there is not a lack of data. What there has been is a lack of action and funding.

M^{me} France Gélinas: Agreed.

Mr. Seow—I'm sorry if I don't pronounce your name properly—you talked about the Ontario Palliative Care Network. Are there action items from the framework that they have put together already?

Dr. Hsien Seow: Yes. We could fund more palliative care specialists within the community. We could change the way we incentivize people—

The Chair (Ms. Goldie Ghamari): One minute.

Dr. Hsien Seow: —so that they are not just trying to see as many patients, but spend time training them. So there's an alternate funding plan, and the government has a CPOC—it's called the Community Palliative On-Call practice. That has been one of the levers, but there aren't enough of them.

This idea of 24/7 care or community-based care, I think, is something that has been well thought of; it just never had the trigger to go forward. You most certainly could, if there was more funding to support more community-based care writ large, but also those who provide specialist training. We have pain and symptom management consultants and nurse practitioners who are specialized in palliative care. We don't have enough of those. There are, I think, four in every LHIN, so that's 40 in the province. That's not enough for the kind of capacity that we want. That could go ahead right now.

The other thing that we're doing with the measurement is they do have indicators that they track, but one of the things is it's devoid of patient experience. They had a survey that—

The Chair (Ms. Goldie Ghamari): I'm sorry, Dr. Seow, for interrupting you. That concludes this round.

We'll now turn to the independent for four and a half minutes. You may begin.

Mr. Mike Schreiner: Dr. Seow, I wanted to ask you: In response to an earlier question, you ranked training on a scale of one to five, and you ranked it as a one. I'm just wondering why we're at a one and how we can get it to a five.

Dr. Hsien Seow: Why we're at a one is because too few of us are taking it. It's not mandatory. When we are exposed to it, it is often in an acute care setting like a hospital, so a palliative care unit in a hospital, and that isn't the only place that palliative care can be provided. It can be provided in hospice, as we know, but mostly in the community.

So the reason why the training is not so great is we're teaching palliative care as end of life and complex symptom management, and palliative care is so much broader. If we really thought about it as information and helping people prepare for the illness journey and what's ahead, it would be so much broader.

That stigma that my colleagues talk about—you're right, people don't want to plan for their deaths. But they do want to prepare for their future, so if we frame it—that is why palliative care is so much broader than a death and dying well bill, for example. That's the gap that we have for all health care providers, frankly. Caregivers, community providers, churches: Everyone has a role in helping the community to prepare and support each other.

Mr. Mike Schreiner: I'm going to ask you the next question, then I'm going to ask Laura to answer it as well.

Both of you have said that our biggest challenge is lack of action and lack of funding. I can't tell you how many groups I've met with prior to and during these hearings that have all said that palliative care provides better care and saves money. I just can't understand why we don't have more funding for something that provides better care and saves us money. I'm wondering if you have some thoughts, given your experience.

Dr. Hsien Seow: We don't have a mechanism to train more, say, physicians to work in the community, because they're mostly working in hospitals if they do palliative care. We don't have the support in home care providers to provide this care without burning out. PSWs provide a lot of this, but they don't have specific training in this.

You're absolutely right that this is one of those opportunities that if we called it out, we could improve experience and save money. But there are incentives to make it siloed, to be like, "It's only about end of life, and only palliative care specialists can provide it." That is not true.

Mr. Mike Schreiner: Laura, would you like to answer?

Ms. Laura Tamblyn Watts: I completely agree. I would offer that it comes, I think, in three areas. The first is, typically, it's older people—not only, but it's often older people—and we have stark ageism in our system. We're seeing that never before as much as we've seen in the time of COVID-19.

We have an additional layer of stigma. It has to do with an illness journey which people feel uncomfortable with, and we don't do chronic and ongoing care well. If you break your arm, we can fix your arm. If you need ongoing health and supports for rehabilitation, maybe we're a little bit better at that. But if you're going to die because of something, that's where we stop integrated training and integrated funding and integrated supports. We do silo out how we provide medical supports. It's where we fall down.

The last piece of it, and this is a harsh thing to say, but eventually the issue—

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Laura Tamblyn Watts: —[*inaudible*]. At the end of each health care journey, it ends, and so we're starting this conversation over and over again. This is an area we can solve. This is an area where we just need to scale up, not solve anew.

Mr. Mike Schreiner: Great. Thank you. I probably have so little time left that I will yield the rest of my time.

The Chair (Ms. Goldie Ghamari): Thirty seconds. All right. Thank you very much.

We'll now turn to the government. MPP Kusendova, you have seven and a half minutes.

Ms. Natalia Kusendova: Thank you to our presenters today.

First of all, I disagree with my esteemed colleague MPP Glover to say that there is no political will, because, as my esteemed colleagues know, less than 5% of private members' bills actually pass and come to committee. The fact that we are here and we are having this very important discussion—and mostly we are on the same page, so this is a non-partisan issue. I think there is great political will to develop this framework.

I'm glad that the discussion today was centred a lot on the topic of education and that it shouldn't only be palliative care specialists delivering the service, and it should be, in fact, embedded in all health care curricula. I spoke to my experience as a registered nurse and in my nursing studies that I have in fact not learned about palliative care. It was not part of my training.

I'm happy to point out that in subsection 1(1)(b), this is one of the goals of this bill: "identifies the hospice palliative care training and education needs of health care providers as well as other caregivers." This is something that we are considering and it is included in this bill.

But my question right now—I would like to direct it to Laura. You spoke a lot about competency-based modules and key performance indicators. You may be interested to know that our ministries of education and training and colleges were thinking of putting forward a proposal on micro-credentials. Perhaps we could use this avenue of micro-credentials for existing practitioners, such as myself, as a registered nurse to take up a module on palliative care as a micro-credential to add it into my competency as a nurse.

Can you talk a little bit more about what these competency-based modules could look like? Then, also, on the topic of key performance indicators, what would those look like?

Ms. Laura Tamblyn Watts: Thank you so much. I'll just share that I teach in the faculty of social work, and the micro-credentialing opportunity is an important and real one. In my graduate master's programs I teach, it's really an elective and it is a rare elective to be able to take a palliative care course. I do feel that micro-credentialing will be a useful way of considering—not the only way, but one useful way of building in competency.

The good news is this: We actually have modules that are built into this area. What we have not done is provided the opportunity for them to be dropped in or to cover the cost of training and upskilling existing health care providers and health service providers. By that, I'm including social workers and social service workers, audiologists, speech pathologists, chiropodists and other allied health professionals, all of whom are engaged in the care journey. We have the modules. If we could get credentialing and training and support, that would help enormously.

The other piece that I would offer, while you're thinking about incentive-based, what we do know is if you're going to be able to provide some additional resources for people to train in an area, they will train in that area. We are in an opportunity right now, with the rise of COVID-19, to add more people into an area of interest. So if there are scholarships, grants and loans, incentive-based programming, to provide for people to go into palliative care, we know that people will follow. This is really an important opportunity.

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Ms. Natalia Kusendova: Thank you. Dr. Seow, did you want to add anything to that point?

Dr. Hsien Seow: I would just say that when you talk about key performance indicators, we are already measuring where people die, the access to home care and physician visits. I think the credentialing in our population—who's getting that would be an important measure, but so too would the patient and family experience, because that gives us so much information about the quality of the care.

It also is a win for both sides. We're getting information about what worked well, but it can also reward those who are doing a good job, because so much of this is the value, is avoiding the burnout, and the reward of why people do this in the first place. It's not for the financial incentive. If they can be recognized as part of our measurement of these are the places that are doing a great job, that is the carrot, and we don't always have to use the stick.

Ms. Natalia Kusendova: Thank you. I'd like to pass it on to MPP Bailey.

The Chair (Ms. Goldie Ghamari): MPP Bailey? You need to unmute your mike, MPP Bailey. We can't hear you, MPP Bailey. I'm just going to pause the time here until we get this technical issue fixed.

Interjection.

The Chair (Ms. Goldie Ghamari): No, we cannot hear you. Is there maybe an audio setting on your laptop? Nope.

Ms. Natalia Kusendova: If not MPP Bailey, I believe MPP Oosterhoff might have some final comments.

The Chair (Ms. Goldie Ghamari): All right. MPP Oosterhoff, do you have any questions?

Mr. Sam Oosterhoff: Yes, thank you so much.

The Chair (Ms. Goldie Ghamari): Okay. You have two minutes and 45 seconds left.

Mr. Sam Oosterhoff: My thanks to all the presenters for appearing before the committee, and just so much gratitude for the work that you've all done tirelessly. We've heard so many presentations over the last couple of days from people like yourselves who have fantastic ideas.

I want to go back to something I think is really key to this and my colleague MPP Glover also talked about: The report is going to be making sure that we have updates so that as things are implemented, as we see that funding allocated, as we see increased attention in this space—and that's really what I'm hoping this bill also does, is to create more attention for this space and create more awareness, even among members. I think of many colleagues on all sides of the aisle who, when I first arrived here, had very little idea about what palliative care meant beyond just a hospice bed. I think that's something you've touched on which is so vital, and we need to keep those conversations going.

I'm just wondering if you can talk a little bit about what you see the future looking like without improvements in palliative care. We've talked about what improvements should be made, but let's present a stark picture to my colleagues and those who are going to have to vote on this bill at third reading. I hope it will pass, but if we didn't take action, if we didn't see an impetus towards creating a better system, what would be the reality for people on the ground?

Ms. Laura Tamblyn Watts: I think I'll paint you a little picture, and then I'll ask my colleague to speak to the clinical picture. Perhaps we'll divide it in community and health care.

What you will see is many more people with long chronic care journeys, with unmet needs, with increased acute care admissions on top of palliative illness journeys—

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Laura Tamblyn Watts: —because people get unwell from secondary effects. So you're going to see an increased set of acute care concerns. You're going to see people dropping out of the field, without supports, because the burnout rate in palliative care is quite significant. We already don't have enough people on the hands-on supports.

You're also going to see increased numbers of particularly older people who will end up either in hospitals—the "bed blocker" syndrome—or be waiting in long-term-care facilities with unmet social and physical needs who do not need to be there, who could be treated in a loving centre in their home with a little bit of support.

It's difficult for the community. It's an unpleasant and miserable journey for the person themselves. And for the system, you will find it expensive and difficult to navigate.

The Chair (Ms. Goldie Ghamari): Thank you very much. That concludes this round of questioning.

Mr. Sam Oosterhoff: Thank you.

The Chair (Ms. Goldie Ghamari): We'll now turn to the official opposition for seven and a half minutes. MPP Shaw, you may begin.

Ms. Sandy Shaw: Thank you for your presentations this afternoon. We've heard presentations for two days, and we have had all kinds of expertise and answers and seen the work that has already happened in the field.

Laura, I liked that you said it's not the scope of the problem but the lack of action. When we talk about action, we're talking about resources. You've just described a system that is not only cost-effective, but it is compassionate.

We know we have an underfunded long-term-care system. Home care and community care have been underfunded, understaffed. We are right now debating a budget bill that provided no additional funding for PSWs, long-term care or community care. It seems like rather than scaling up, which we talked about, that we're going backwards. For me, I'm wondering what kind of hope this holds out for the ability to fund an additional palliative care system, and I'm wondering what you would feel about that as well.

Ms. Laura Tamblyn Watts: I'll speak for CanAge. We were very concerned to see that the promised four hours of care were not measured out in the budget. We can only hold hope that that speaks to an agreement between the federal and the provincial governments to do tethered funding, but we were very concerned to see that the budget has not been explicit.

We believe that if passage of this bill moves forward, that we can actually have something to tether additional funding onto—and I apologize for not speaking about KPIs prior. What I meant to say was we're really concerned that it not be so much a report as it is a scorecard, and that scorecards on individual indicators should be tethered to funding. My colleague probably has other aspects that he'd like to add to that.

Dr. Hsien Seow: I was going to say of course everybody wants more money, and more money helps. But what I have learned from training clinicians in this is we are not asking them to do more; we're asking them to do things that they already do. By understanding that palliative care is not about death and dying and it isn't only about complex symptom management—it's about conversations and inviting patients and families to understand and to know what lies ahead. It may take a little bit more time initially, but it saves so much time down the road. They have these skills. They have this compassion. It is about knowing how to use it and to build it into the system of what they're already doing.

We're not asking them to build a whole new system. We're asking them to embed the principles of palliative care into what they're already doing, so every single provider should have elements of palliative care at their fingertips when they need it. That is where we, with some training and education or even just some good mentorship, could do much better without any additional dollars—not that additional dollars would not help.

Ms. Sandy Shaw: Thank you. I really will take the opportunity with my last words of this committee to say what you have talked about is the same for pediatric palliative care. I do have a bill called the Nancy Rose Act, which calls for a provincial strategy for pediatric palliative care. The same problems exist. There are all kinds of people who have done all kinds of work, done the heavy lifting. There is a framework for delivery. It just needs to be implemented, backed with resources.

Having said that, I'm going to pass the remainder of my time to my colleague MPP Gélinas.

M^me^ France Gélinas: Thank you. Continuing on the conversation you were having, do you know of any other jurisdiction that has done this well; that has taken the existing care providers they have and made them realize that they all have a role to play in palliative care, that palliative care is not about the last two weeks, that you have to change the way you provide the care to people who are severely ill? Does anybody do that well, and how did they get there?

Dr. Hsien Seow: I was going to say the places that do it well are places like Kaiser Permanente in the US. It's because the financial incentives are aligned for them to not be siloed, so that I'm a specialist and you come to me for my specialty, and then when it's palliative care, I refer you to another specialist.

When they are incentivized to provide good continuity of care focused around patient needs and preventing these exacerbations or crises management, then you take the time to explain to people: What are the things that you need so we can prevent you running to the emergency department or being hospitalized for breathlessness that could have been prevented if we had just put something in place, like a fan in your room?

When we are incentivized to prevent unnecessary use and bad experiences, we integrate palliative care much better. It is hard to find that because of the way that medicine is taught, frankly, but it can be done. There are very clear steps to get there, so it isn't an insurmountable problem.

M^me^ France Gélinas: What do those incentives look like?

Dr. Hsien Seow: I think we are moving towards that when we have some of these Ontario health teams, where they are an integrated team, in theory. In practice, the devil's in the details.

But conceptually, when we are paying in bundles or when we are having specialists work with primary care and they're embedded together and can share patients much more easily, that helps. The electronic medical records, where we can see the flow of information, that helps. When community care is embedded, not just with doctors leading the charge but nurses coming together, that helps.

When they are thought of as an integrated team along the continuum, that is the key to having good palliative care but also a good experience along the journey.

M^me^ France Gélinas: Okay. I come from northern Ontario, and bundled payment for care in northern Ontario means that the easy cases get really good care and all the hard ones get nothing. It's hard to get me excited when you start to talk about bundled care payments, because where I come from, if you don't speak the language, if you come from a First Nation, if you are at a distance from the point of care, they will be too busy and they're not going to take you on. Then you're left with nothing.

Dr. Hsien Seow: Certainly, bundled payments are not the only way, but the idea is to incentivize good experience. This is why I talked about the missing KPI about patient experience, because if you are getting paid or part of your payment is linked to experience, then this is where we'll get feedback of providing services in the French language and for First Nations and treating people with respect and getting rid of the ageism.

The Chair (Ms. Goldie Ghamari): One minute left.

Dr. Hsien Seow: These are all the things that people experience and know, but we have no way to filter it back. All we measure are hospital days and ALC days and money, money, money. I think if we can provide the experience piece and link that to funding or some kind of quality measure, that's how we can also incorporate some of that.

M^{me} France Gélinas: Do we do this in any part of our health care system: incorporate the quality measure into a payment system?

Dr. Hsien Seow: Home care, several years ago, was doing a patient experience survey that covered multiple settings, including hospital, but there was no financial lever or accountability to do it. So our only measure is to see if anybody is using any kind of patient measure. But we have a validated tool that works across all settings for Ontario; it is just not mandated for use and there's no accountability to what they should be reaching for.

The Chair (Ms. Goldie Ghamari): Thank you very much. That concludes the round of presentations. I'd like to thank both of our presenters for joining us today. It's been very informative. I'd also like the thank the committee for everything they've done. At this point, the presenters may step down. Enjoy the rest of your evenings.

Just to everyone on the committee, that concludes our business for today. As a reminder, the deadline to send in written submissions is 7 p.m. today, Tuesday, November 24, 2020, and the deadline for filing amendments is 5 p.m. on Wednesday, November 25, 2020.

The committee is now adjourned until 9 a.m. on Thursday, November 26, 2020.

The committee adjourned at 1743.

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