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Chair

Mr. Bill Casey

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● (1105)

[*English*]

The Chair (Mr. Bill Casey (Cumberland—Colchester, Lib.)): Colleagues, I call the meeting to order.

We welcome our presenter.

We look forward to your presentation on palliative care. We appreciate your interest in this issue, because many of us are interested as well. We look forward to this study and all of the presentations, starting with yours. You have 10 minutes. Then we'll go to questions; they'll be brutal.

Voices: Oh, oh!

Ms. Marilyn Gladu (Sarnia—Lambton, CPC): That's excellent.

Thank you and good morning.

I thank the committee for the opportunity to appear today and for the unanimous support the bill received at second reading.

I think this bill is timely. Our population is aging and only 30% of Canadians currently have access to any type of palliative care service. The special committee that studied the Carter decision on assisted dying stated that without quality palliative care, a true choice was not possible.

I was surprised to find out that not every location in Canada has the benefits of the integrated palliative care that is offered in my home riding of Sarnia—Lambton, where we have more than five palliative care specialists, palliative beds in hospital and in hospice, and an excellent network of home care, counselling, and crisis response services.

I began to ask about this. I found that an all-parliamentary committee in the 2011 session had studied palliative care and brought forward a report with recommendations. Although a motion was made, not much further action occurred.

With an aging population, the implementation of Bill C-14, and the desire to innovate and to get more out of the health care dollars that we invest in our system, we can see that the time is right for this bill,

Bill C-277 proposes a framework for palliative care in Canada, including a definition of the services to be covered, a definition of the training required at the different levels of service provision, care for those giving palliative care services, collection of appropriate data, and the development of a plan to get consistent access to palliative care for all Canadians.

During debate, amendments were suggested to add first nations to those covered by this framework and to ensure that the language of the bill reflects the proper balance of provincial and federal jurisdictions. I'm very happy to work with the committee should they choose to adopt these or any other changes.

My theme today will be to explain the sections of the bill and recommend to the committee how I see the framework proceeding.

I'll start with services to be covered.

Palliative care can begin more than a year before end-of-life care, and end-of-life care is defined as the last two weeks of life. Pain control, including the cost of the drugs, along with spiritual and emotional counselling, home care, hospice care, and home crisis intervention are the basic services that I would like to see covered. Today some of these are covered in part, and only in some provinces. Others are not covered at all. It's important to note that the costs associated with palliative care in hospital can be $1,200 a day, versus $400 a day in hospice and $200 a day, on average, in home care.

[*Translation*]

As compared to intensive care, palliative care in a hospital could save our health system between $7,000 and $8,000 per patient. Recent data suggests that, in Ontario, transferring just 10% of end-of-life patients from intensive care to home care could yield $9 million in savings annually. That is a better use of health care dollars in order to get better results for Canadians.

● (1110)

[*English*]

The second part is with regard to training. Different levels of training are required for the various types of care providers. There is currently a shortage of palliative care specialists in Canada. We have 200, versus a need for at least 600.

General practitioners receive two months of palliative care training as part of their medical degree. Registered nurses may not receive any palliative care training at all, but they should take training as offered today by organizations like Pallium Canada or equivalent.

Home care providers and personal support workers, when trained, would provide a cost-savings delivery model that would be effective, especially in remote regions where innovative solutions to delivering service will be needed. More registered nurses, RPNs, and personal support workers will be needed with our aging demographic. As the provinces are introducing training, it would be wise to set a standard terminology, set the training requirements, and have interprovincial recognition of those standards.

We also need measures to support those who are giving palliative care services. As you can appreciate, watching people die and seeing the emotional and physical agony they are in can bring symptoms similar to PTSD, and there is some need to provide support in the care system for those people, as well as for care providers who may be needing respite and rest. It's important to consider them.

[*Translation*]

Moreover, the lack of data on the need for palliative care, the total average cost, and the breakdown of services should be addressed by collecting data in order to standardize and monitor the provision of palliative care services.

I encourage you to consult the Minister of Health, who already has some ideas on what she would like to see in this regard.

[*English*]

With respect to research data, there's not really even a baseline of how many people are in need of palliative care or how much palliative care can be expected to cost per person. These are the kinds of numbers we would like to benchmark and monitor.

We also need a plan to develop consistent access for all Canadians. This is one of the most important parts of this framework.

The plan should have several pillars. We've already talked about the trained resources that will be needed. Second, infrastructure will be needed to achieve consistent access for all. There's an opportunity for the government to put money into building hospices and palliative care centres. Canada has about 30 hospices compared to the United States, which has 1,300. Building this infrastructure will create jobs and will address a need.

Finally, in order to service rural and remote communities in Canada, use of innovative ideas will be needed. One such idea is the virtual palliative care centre in Winnipeg, where home care nurses or doctors can call in on a 24-7 basis and get access to palliative care specialists who can guide remote treatment. Web and Skype consults will rely on the government's current infrastructure plan to address Internet in the rural and remote north. Training paramedics, nurses, and home care workers in palliative care and combining this with the fly-in crisis response teams has been shown to work effectively in other parts of Canada, and doing so should be levered as part of the overall plan.

[*Translation*]

Choosing the mechanism to implement this framework is also important. There are various options. One of them is to add palliative care to the services covered by the Canada Health Act. Another option would be to include palliative care in the new health accord. A final possibility would be to create a government palliative care program to fund the infrastructure, establish training standards, and work with the provinces to implement best practices.

I think any one of these options could work. There are probably other mechanisms I have not thought of, but it is up to the government to provide direction on implementation through the budget.

The $3 billion that is currently promised in the 2016 budget is a good start and I hope to see more in the 2017 budget.

● (1115)

[*English*]

The government should leverage the many national organizations that have supported this bill, each of which has solutions to help deliver the services. These organizations include the Canadian Medical Association, the Canadian Cancer Society, the Canadian Nurses Association, the Canadian Society of Palliative Care Physicians, Pallium Canada, ARPA, the Canadian Hospice Palliative Care Association, and many other member hospices, such as Bruyère Continuing Care, St. Joseph's Hospice, West Island Palliative Care Residence, the Heart and Stroke Foundation, the Kidney Foundation, the ALS Society, and the Canadian Association of Occupational Therapists, as well as the more than 50 member organizations of the Quality End-of-Life Care Coalition of Canada and the many faith organizations across the country, including the Canadian Conference of Catholic Bishops.

In addition, coming up with a standard definition of services to be covered and of the training requirements will be a priority, as provinces are already progressing in their offerings in different ways. Now is the time to act to address this important issue so that Canadians can choose to live as well as they can for as long as they can.

I appreciate your time. I'd be happy to answer any of your questions, and I look forward to our discussion.

Thank you.

The Chair: You have 16 seconds left.

Moving to our questions, we're going to start our seven-minute round with Mr. Kang.

Fire away.

Mr. Darshan Singh Kang (Calgary Skyview, Lib.): Thank you, Mr. Chair.

Thanks, honourable member.

Before you brought Bill C-277, did you do any consultation or did any stakeholders you consulted raise any concerns with respect to the structure or the contents of the bill?

Ms. Marilyn Gladu: That's an excellent question. Actually, when we first started discussing this, it was during the time Bill C-14 came forward. I was made aware of the 2011 committee, the all-parliamentary committee that studied it. I was able to consult with them on the work they had done and their recommendations, and then they put me in touch with people across the country who are working in palliative care, working in a similar way to try to get a consistent service across the country.

I had the opportunity to sit with members of various hospices and talk to palliative care specialists, nurses, people who receive the palliative care, and home care workers to understand what they saw as the biggest need and how—if the federal government was going to act—they'd prefer to see that.

Then when I drafted the bill, I was able to review it with all the various stakeholders so they could see the language in the bill and be able to support it.

Mr. Darshan Singh Kang: Some of the patients are in the hospital. They don't put them in the hospice, but in the hospital, and literally they are getting the palliative care in the hospital. This is costing us lots of money.

Do you have any studies on how much it's going to save our health care system if we have palliative care? In Alberta, they were calling them bed-blockers.

Ms. Marilyn Gladu: Yes.

Mr. Darshan Singh Kang: In the hospital because—

Ms. Marilyn Gladu: It's a real problem. The cost is about $1,200 a day for palliative care in the hospital. Most hospitals are very limited in the number of beds they have. There's a real logjam, and trying to even get a bed is problematic.

The cost depends on when the palliative care begins; it can begin even a year or two in advance of the end of life. The only studies that have been done came out of Ontario, saying that in hospital you could be spending $200,000 to $300,000 on a patient, whereas you could reduce that cost by 80% or 90% by providing home care or hospice care if it was available.

● (1120)

Mr. Darshan Singh Kang: Every time we study something new, we talk about cost savings. Whenever we implement the program, we don't see any cost savings. You're saying it costs $200,000 or $300,000 per patient. If you could put the number on the patients, we'd be talking about lots of money.

Ms. Marilyn Gladu: We have to talk about the money, especially when you consider the population is aging. Right now one in six are seniors, and soon we will have one in four.

While I think doing palliative care in one way or another is less expensive and there are cost savings to be had, I wouldn't want you to get the impression that it would be cheap. This is going to be a huge need. The government will have to decide how to pace that effort, especially when you consider the $3 billion originally pledged by the health minister. She sees that home care is a way you can easily start spending that money without having any infrastructure in place. Infrastructure might be the next logical step, and then we'd be branching out from there.

Mr. Darshan Singh Kang: That's what I was coming at—how much it's going to cost us for the infrastructure. In the end, will we be saving money by instituting a palliative care framework?

Paragraph 2(1)(f) of Bill C-277 requires that the proposed palliative care framework include an evaluation of the advisability of amending the Canada Health Act to include palliative care services provided through home care, long-term care facilities, and residential hospices. Has this possibility been raised with the provinces? If so, did they raise any concerns with respect to amending the Canada Health Act in this manner?

Ms. Marilyn Gladu: Certainly this is one of the most controversial parts of this bill. There are those who believe the simplest way to get the provinces to deliver palliative care is to make it clear in the Canada Health Act that it's an included service. There are those who are reluctant to open up the Canada Health Act, because of the many other changes that would be desirable there.

The Minister of Health is leaning towards incorporating this in the health accord because the negotiations with the provinces have indicated the provinces are already starting to move in this direction, and they're obviously looking for governmental support on it. That's a possibility.

When it comes to how best to implement it, there are different parts of the strategy. The government may choose to put a specific palliative care program in place that could be a multi-year program that gets training resources, gets infrastructure in place, starts to work with the provinces to determine what services need to be put in place, and does the rural Internet that will be required as a basis for the north.

Mr. Darshan Singh Kang: Under BillC-277, who would be responsible for funding the additional resources required to give Canadians access to palliative care?

Ms. Marilyn Gladu: Today a combination of people are paying.

If you're talking about the hospital, palliative care is already covered in the hospital. You also talked about hospice care; well, in most cases hospices are covered provincially for some of the services that they offer in terms of the pain control meds, but it's only about 43% of their budgets. The rest they are currently raising from charity. Many of the home care organizations, such as the Victorian Order of Nurses, are getting half of their money from charity as well, so I would imagine that in the future as well it won't be just one pot of money. It's not just for the federal government to contribute; it's to encourage the organizations that exist today to continue growing their services through charitable donations and through co-operation with municipalities and the provinces.

● (1125)

The Chair: The time is up.

Just as a little plug, my daughter is a VON nurse. She spends an awful lot of her time with people in palliative care situations, even though it isn't a palliative facility.

Dr. Carrie, you're up.

Mr. Colin Carrie (Oshawa, CPC): Thank you very much, Mr. Chair.

I want to take this opportunity, MP Gladu, to congratulate you on the great work you've done on this bill and the collaborative approach you've taken. To get all these stakeholders on board was really quite a feat. I've tried this in the past, and to see you succeed in that is wonderful.

Ms. Marilyn Gladu: Thank you.

Mr. Colin Carrie: I've been hearing concerns about getting the money flowing. The Prime Minister campaigned on an immediate investment of $3 billion directly into palliative care. Disappointedly, 18 months later we're not seeing that promise being executed. One of the concerns I've heard is that that the Prime Minister or the health minister seem to be using palliative home care as a bargaining tool in the health accord, and again, the two most-populated provinces, Ontario and Quebec, still haven't signed on. We're seeing delay after delay. They were supposed to be using the collaborative approach, and we're seeing more of an adversarial thing.

My question is simple. What are your thoughts on the immediate $3 billion investment into palliative care that's no longer on the table, while instead, the government has announced, I believe, an investment of $5 billion over 10 years into home care?

Ms. Marilyn Gladu: To start out with, the Minister of Health was clear that there was $3 billion set aside in budget 2016 for home and palliative care. She made that comment at least five times in the House of Commons and certainly many times in the public sphere. While I didn't see a specific line item in the budget that talked about that, I don't know that it's off the table. I think the $5 billion that's being talked about is a combination of home care and some of the other services that the provinces are looking at. The negotiation of the health accord needs to have palliative care if that's the mechanism—which I believe it is—that the health minister favours.

I would say we need to see more action. Certainly if there is work going on, I'm not aware of what it is. That's part of the reason for my bringing the bill forward: to try to actually come with a plan and start moving down the path. You can't press a button and instantly have consistent access to palliative care everywhere in Canada, because it's a huge feat, but taking action and starting with that $3 billion would be great.

Mr. Colin Carrie: That is the comment: it takes time. I know the budget's coming up and I'm really interested to see what is in there. Your bill specifically requires the Minister of Health to develop and implement the palliative care access framework, but the government is now using different language. Language is extremely important. I remember the issues when we were looking at Bill C-14, and the language. There was more "palliative". It was the same during the election. Now we're hearing different language, and they seem to be referring to it as "home care".

I was wondering if you could explain your interpretation or the difference, if any, between palliative care and home care, and what your concerns would be, if any, about the new terms being used by the government instead of the specific term that they were using before.

Ms. Marilyn Gladu: Home care is a subset of palliative care. It's one of the many things that are involved in delivering it. Not everybody wants to be at home. Some people need to be in the hospital because they are in such an acute situation. Some people don't really want to be at home; they prefer to be in hospice. There's a continuum of palliative care services, and home care is just one part of that.

In terms of the government coming forward with a framework quickly, there has been a lot of work done by numerous organizations. There was a paper put forward in 2015 by the quality coalition, these 50 organizations that are doing palliative care in Canada. It was called "The Way Forward", and it recommends a framework. That was done with government support and funding, I believe. In terms of a framework, there are a number of examples out there, and the government may decide to adopt them, which will then really hurry along the beginning of the implementation of those plans.

Mr. Colin Carrie: You mentioned how important innovation will be because of the demographic wave that's moving into this area. Palliative care and home care will be required. You mentioned the Internet, Skype, and things along these lines. Have you talked to any stakeholders who are worried about red-tape obstacles for that type of innovation? I've heard, for example, that if a doctor does a Skype interview in certain provinces, or people provide different consultations, it even gets down to the billing. How do people bill for that type of thing?

As well, has any work been done on that for rural and remote areas? If a Canadian is a Canadian is a Canadian, what about first nations, indigenous communities, and remote and northern communities in terms of how this will work?

● (1130)

Ms. Marilyn Gladu: I think while there's always an opportunity for bureaucracy to creep into everything, if you look at the places today that have no palliative care services and are in desperate circumstances, you see that these are the locations that have come up with innovations. In some places they only had paramedics, so they had their paramedics trained in palliative care so that they could start to deliver that and were phone-calling into the Winnipeg centre. There are fly-in resource teams for some of these very remote communities, where they can do crisis intervention. There's training the only nurse on the reservation or the only nurse in a northern community in palliative care to be able to provide it and to be able to call a palliative care specialist to walk her through what needs to be done to administer it. In an area where there is nothing else and they are without palliative care, people will hugely suffer.

Mr. Colin Carrie: I have one more question. You and all members around the table will remember all the work that was done on Bill C-14. We had a lot of concerns from people around the country. There were concerns about lack of palliative care and end-of-life options. There was a lot of deliberation on the fact that if you have an efficient palliative care program, many people don't choose to go into assisted suicide or take options along that line.

Do you think the government should have made an investment into palliative care and home care in conjunction with or prior to Bill C-14? Do you think we're being tardy here?

Ms. Marilyn Gladu: Well, certainly the special committee that studied the Carter decision did recommend that you needed to have palliative care in order to have a choice. I can't speculate, but Bill C-14 was a criminal bill, so it may be that the government preferred not to muddy the waters and put health things into the criminal bill. That's why this bill is such a great idea for the government. It will be able to do palliative care, which was clearly a recommended outcome from the special committee.

Mr. Colin Carrie: Thank you.

The Chair: Thanks very much.

Mr. Davies, you have seven minutes.

Mr. Don Davies (Vancouver Kingsway, NDP): Thank you, Mr. Chair.

Ms. Gladu, thank you for your work on this issue. I think it's a very important issue, and I applaud you for bringing it before our Parliament.

I want to start with the education of physicians. I read a couple of quotes in preparing for this meeting. One of them was from Dr. David Henderson from the Canadian Society of Palliative Care Physicians. He said, “When we plotted out people who had received their palliative care competencies, there was one physician in all of northern Canada.”

Dr. Robin Fainsinger, a professor in the division of palliative care medicine at the University of Alberta, said, “Every primary care physician should be able to do palliative care, have an understanding of the basics of care provision and access to palliative care specialist services.”

Finally, Dr. Stephen Singh, a co-chair with the Canadian Society of Palliative Care Physicians, said, “There are huge gaps in terms of the education family physicians are currently receiving...versus their own comfort level when they get out in practice. We’d like to see that everyone graduating from any residency has the basics.”

I wonder if you have any comment on whether we should be addressing this issue of physician competency in palliative care.

Ms. Marilyn Gladu: Yes. I've met with a number of the people you cited, including Dr. Henderson, who gave me the evolution of what general practitioners used to receive. Keep in mind that palliative care is evolving. They're learning more and more about different cocktails for pain control and different methods to bring comfort to people.

I do think there's an opportunity to revisit this issue. The Canadian Medical Association is willing to continually update the curriculum that the doctors are going into. They should receive palliative care... because when you think about the shortage we have of palliative care specialists—we're short 400 specialists—you realize it's not a “press a button” thing.

What can we do with our existing resources, just by training our existing GPs who are out there today? There are training programs available through Pallium Canada and through universities across the country. You could increase exponentially the amount of palliative care that's delivered.

Mr. Don Davies: Would you like to see every physician graduating from medical school have some basic training in palliative care?

● (1135)

Ms. Marilyn Gladu: I would, because I think that will provide care, especially in these remote areas where they may have a GP but they have nothing else that would be useful in providing the resource.

Mr. Don Davies: Thank you.

Your bill calls for a number of things, including a definition of palliative care. I'm curious why you would like to see a definition when we know that the WHO and other organizations have definitions. What are some of the definitional issues or cleavages that you've identified in your research?

Ms. Marilyn Gladu: You're correct. The World Health Organization has a definition of palliative care. The Canadian Palliative Care Association has a definition of palliative care. Those two are not quite the same, although they're similar.

The problematic point in the definition is that some people only want to look at end-of-life care. They only want to look at those last two weeks, when really palliative care can begin one or two years earlier. That's one point of contention.

Another point has to do with long-term care. Some people see long-term care as more of a seniors health care issue as opposed to a palliative care issue and would like to separate those two.

Mr. Don Davies: Thank you.

We have International Women's Day coming up this week, so I'm going to ask a question on gender. My understanding, Ms. Gladu, is that currently family caregivers provide more than 80% of care needed by individuals with long-term conditions, whether at home, in long-term facilities, or even in the hospital sometimes.

Also, according to I think a pretty broad consensus in the literature, palliative family caregiving for older adults is gendered. Essentially, the responsibility to provide end-of-life care predominantly and disproportionately falls on women and is predominantly unpaid. I'm wondering if you have any comments, as we face International Women's Day, about how we can address this imbalance in the way this care is being delivered now.

Ms. Marilyn Gladu: Absolutely. What you are saying is true.

As the chair of Status of Women, I know we are currently studying the economic status of women, and one of the testimonies we've heard several times is about how more than 80% of care is given by women, causing them to lose the opportunity to work, etc.

In addition to that, I would say that we've heard testimony about the emotional strain this takes. Consider women who are working. They're also providing care to their children, plus caring for a dying or palliative-state parent or relative. This is where some of the caring for caregivers part of this bill comes forward. Today what's covered in some of the provinces is four hours of respite every week, which may be insufficient, especially if you live far away from a grocery store. If you have to go get groceries and come back home, that could take the whole four hours of your break, so it's definitely of concern.

Mr. Don Davies: I think Mr. Kang touched on this, and I want to follow up with this question.

Many people want to provide care for their family members, and that's a good thing, and perhaps it's also an intimate thing at the end of life. Obviously, if we're going to provide more palliative care professionally in Canada, that's going to cost some money, particularly if we transfer some of this unpaid care by women onto more professional paid workers. Do you have any idea how much money that would cost or what we should be allocating as a country to increase palliative care services?

Ms. Marilyn Gladu: I think those are harder numbers to know. It's easier to know how much for the infrastructure. It's easier to know how much for the average population to get home care. Those are easier numbers.

Today, because we don't know how many people are doing unpaid care and there's no set wage equivalent for that, it would be a hard number to calculate. I would say that in the beginning, one way of providing the resources that are needed for palliative care is potentially to provide families with a mechanism to encourage them to care for their own relatives who are in the palliative state through tax incentives or other government mechanisms. That's beyond the scope of my bill, obviously.

The Chair: Your time is up, but thank you very much.

Mr. Ayoub is next.

Mr. Ramez Ayoub (Thérèse-De Blainville, Lib.): Thank you, Mr. Chair.

[*Translation*]

Thank you, Ms. Gladu, for this excellent bill, which focuses on the patient and not the administrative aspects. It is important, however, for me to properly understand the definitions. You were talking about that earlier with Mr. Davies. In the case of a number of definitions, they pull in opposite directions and ultimately cast a very wide net.

In terms of palliative care, it involves addressing something. For example, there could be a patient who does not require care or daily monitoring for their quality of life. The term “palliative care” often refers to end-of-life care. Its purpose is to improve a patient's quality of life at the end of their life when they are suffering from a serious illness that is difficult to control or whose outcome is known.

That is why this is naturally, although not systematically, related to Bill C-14, which pertains to medically-assisted dying. I would like to hear your understanding of the term. Care for the elderly is one thing, but palliative care is something else, and end-of-life care is something else again.

What is your understanding of it?

● (1140)

Ms. Marilyn Gladu: Thank you.

[*English*]

In terms of the definition of the services to be covered, it's for the government to choose. I'm recommending something that's beyond just the end-of-life care. I'm saying we should have pain control from even one to two years before, and I think we want to have hospital care for palliative services, hospice care, and home care as covered services. I'd like to see these fully covered.

I also believe we need to cover spiritual and emotional counselling, which is something that is a little controversial as well, but to me very important. If I look at the model in Sarnia—Lambton, we have palliative care specialists who are working out of the hospice with a crisis response team, with spiritual and emotional counselling integrated into a home network. This is the same model that's in the West Island hospice in Montreal and in a number of what I would consider the leading-edge hospices.

Those are the services that I believe should be defined.

[*Translation*]

Mr. Ramez Ayoub: Thank you.

We are talking about home care. This is important and will obviously be important in the years to come. The population is aging and people with chronic illnesses want to be treated at home, whenever possible. This is especially true in the case of grave illnesses that can be treated at home.

The report provided to us summarizes the bill. It says that family physicians are the primarily care providers. I would like to talk about the first responders because I have some questions in this regard. I understand the idea about family physicians, but at a centre, there is a whole range of health professionals, including nurse clinicians, who are involved in palliative care. Even in family medicine, there are occupational therapists and other kinds of professionals.

I would like to know why we should train all these physicians when the range of services offered—not only by doctors—includes specialized care.

[*English*]

Ms. Marilyn Gladu: It's very true that the service is not just provided by doctors. In fact, I would argue it should not just be provided by doctors, because it is extremely expensive.

In order to innovate in the health care dollars and optimize the spending, you should have people do the most that they can with their training level. If personal support workers have palliative care training, they may be able to administer pain control drugs and work in that area. It's the same thing for nurses. Nurses, especially in remote areas, can rise to the occasion and be walked through how to administer palliative care from a palliative care specialist, and then physicians could take over. The gap today with palliative care specialists is so great that it will not be closed for some years.

● (1145)

[*Translation*]

Mr. Ramez Ayoub: Thank you. We touched on provincial jurisdiction for health. Federal jurisdiction is also important.

What role do you see for the federal government in areas of provincial jurisdiction that are not dealt with the same way across the country?

A Canadian is a Canadian, but right now, there are inequalities among the provinces.

Should the federal government step in and impose an approach so that palliative care patients receive balanced treatment from one province to the next, right across the country?

[*English*]

Ms. Marilyn Gladu: I think it's clear from a jurisdictional point of view that the province will execute whatever the federal government decides is the service they're going to provide transfer payments for. That said, I do think the federal government has a role in ensuring standardization. Think about skilled trades areas: welders can weld in Ontario, but they can't weld in Alberta because the standards of training have been prescribed differently and they're not recognized across provinces.

Right now we have provinces starting to train in palliative care and starting to determine and develop jargon. The federal government has a role in ensuring that there is a standardization across the country so that there's a common understanding of terminology, a common set of requirements as we move forward. It is for the provinces to execute those. I'm certain that the provinces would be looking for government assistance if the dollar value of delivering those services increases.

[*Translation*]

Mr. Ramez Ayoub: Thank you.

[*English*]

The Chair: Thank you very much.

You mentioned basic training in palliative care for a physician. How many hours of basic training would it take to give a family physician some level of confidence?

Ms. Marilyn Gladu: The family physicians are usually getting two months of training now as part of their medical degree. Because of the evolution in palliative care, there are week-long seminars offered at McGill University, for example, through Pallium Canada, through the Center to Advance Palliative Care.

I would say it would take a week, plus access to web-based materials that allow them to up their game on palliative care.

The Chair: That's not a lot.

Ms. Marilyn Gladu: It's not a lot.

The Chair: Thank you.

Go ahead, Mr. Webber.

Mr. Len Webber (Calgary Confederation, CPC): Thank you, Mr. Chair.

Thank you, Ms. Gladu, for the work that you do here and for your constituents. They must be proud of the work you're doing on this palliative care issue.

I have two hospices in my riding of Calgary Confederation: the Rosedale Hospice and the Agapé Hospice. They are wonderful facilities that do great work. The Rosedale Hospice opened about 20 years ago. My family and I were quite involved in starting up that hospice. There was a lot of volunteer work done there. Also, my constituency assistant right now was the executive director of the Rosedale Hospice for many years, and then she came to work with me in my office. We're quite proud of the work we have done in Calgary with the hospices.

One struggle that Rosedale Hospice has always had was funding, and they continually had fundraisers and such. It seemed the director was more involved in trying to raise money than in providing care to the patients there. It was quite a struggle, and I'd love to see more funding come from the government for these private hospices.

The other hospice we have is the Agapé Hospice. I know that hospice very intimately. My wife, at 37 years of age, was diagnosed with stage 4 breast cancer and went through a long struggle with the disease, and there was wonderful home care provided to us. Donna Dryer, a lovely, wonderful registered nurse came to our home daily to care for my wife, and she was a godsend. I would love to see more focus on home care in the country here. My wife Heather spent three days in the hospice. We kept her at home as long as we could, and that's where she wanted to be. Where most people want to be is at home. Again, I can't say enough about how important it is to have a good home care system throughout the country.

Ms. Gladu, I find that Rosedale and Agapé are incredible care facilities. They would be wonderful for best practices around the country. Have you looked into federal best practices, whether here in Canada or internationally? Do you know of other countries that are doing a better job at this? If so, who are they, and what can we learn from them?

● (1150)

Ms. Marilyn Gladu: Yes, certainly. There certainly are very many.

First I want to thank you for sharing the story of your wife. My father-in-law died in a hospice, and that was my first exposure to seeing the excellence of their multi-faceted care. My daughter is now a home care nurse providing palliative care, so I'm seeing this from all angles.

In terms of people who do it well in the world, if they have implemented assistance in dying, they have typically put palliative care in place to provide a choice, so many of the countries, like Belgium and the Netherlands, are very far down the way in terms of palliative care. I think you're going to have testimony from Dr. David Henderson. He keeps an eye on who's doing it well in the world, and what to leverage. The quality coalition organization, which brought forward "The Way Forward" palliative care framework, has had a lot of hospice members as part of its organization, and so they share best practices. I think in the future that's exactly what should happen, because many provinces are starting to implement things that are working very well, so having conversations with the provinces and providing some standardization across the country would be a great direction for the government to go.

Mr. Len Webber: With regard to jurisdiction within the provinces and territories, then, do you see an issue there? I know we had that issue with pharmacare in the past, and also with organ donation registries and programs. Do you see some issues with regard to palliative care?

Ms. Marilyn Gladu: There's always a fine balance between what's provincial and what's federal, but the provinces are clearly the ones to execute the care. I don't think we're in a situation of the provinces not wanting to implement palliative care. I think the provinces do want to implement palliative care, and they're struggling with resources and an overall plan of how to get there. I believe that's what they would look to the federal government to provide, a plan, and then to determine how long that is going to take. As I said, this is a hugely expensive thing that you cannot do instantaneously, and the $3 billion that's been announced is a great place to start.

The Chair: Thanks very much. Your time is up.

Go ahead, Ms. Sidhu.

Ms. Sonia Sidhu (Brampton South, Lib.): Thank you, Ms. Gladu. We worked in the past on the pay equity committee. This is a very important issue. Thank you for raising this issue.

If we see that in the background—the issue of pay and gender equality when we were working together—what's your thought about gender equality? It also raises the question from the perspective of the varying types of work, varying hours, varying lifestyles. How might a national strategy on palliative care reflect on the needs of the people who are providing the care to the loved ones?

Ms. Marilyn Gladu: This is a very interesting question, because if you think about the resources that are needed to get more palliative care, you're talking about a lot of nurses, a lot of personal care workers, and an increase in physicians, and these are areas where women are predominant in the workforce. This measure would create well-paying jobs for women. I think that would be a step forward, certainly.

In terms of whether women are more affected than men in the need for palliative care, I have not seen any statistics on that. I would be interested to take a look at some of the things, such as ovarian cancer and breast cancer, that seem to be very prevalent with women and typically can lead to the need for palliative care.

Ms. Sonia Sidhu: You talked about $1,200 in expenses in the hospital and $200 in home care. Is this new research? Is there any data like that?

● (1155)

Ms. Marilyn Gladu: An economic report that just came out has studied this aspect. I could provide it to the clerk, if you like. A previous study that was done by the Canadian Medical Association looked at the average figures for a palliative care bill in hospital versus hospice versus home care.

Ms. Sonia Sidhu: When you talked about standardization of training for the PSW, I wanted to raise the question of the language barrier. Canada is a diverse country. People are from different areas. Do you have any strategy for the language barrier for people in palliative care?

Ms. Marilyn Gladu: Well, I think there is an opportunity. Palliative care training is offered in English and French in the programs that exist today, but as you move into some of the remote communities where first nations languages may be the language of choice, or into other communities, then there would have to be an effort, I guess, to move into other languages. One way of addressing that is to hire people who are from that area and who speak that language; then that is an immediate overcoming of that barrier.

Ms. Sonia Sidhu: Do you foresee any other challenges or any other barriers to the implementation of a national strategy of this kind?

Ms. Marilyn Gladu: No, I think the time is right. I sense that across all parties and across both provincial and federal governments, people are ready to start doing palliative care. I think there is a question of how fast we could implement it and what should come first.

There are things that are easier to do. Putting money into home care is easier than building infrastructure, for example. Addressing the rural and remote communities is the most complicated, because in many cases they are without Internet and without any transportation or fly-in crisis response service.

I would say there is an order of operations, and that should be part of the plan that is recommended in this framework.

Ms. Sonia Sidhu: You also mentioned the palliative home care and virtual home care in Winnipeg. Can you elaborate a little bit more?

Ms. Marilyn Gladu: Yes, this is amazing. I had them come and show me what they were doing there. They have a 24-7 staff of palliative care specialists. You can call in there—nurses and home care workers from anywhere—and receive a walk-through of what to do to the patient in terms of administering pain control, crisis intervention, and all of these different things. This makes the service, first of all, economically great to deliver, but also just think about having access to that service. If you're nowhere with your resources and all of a sudden you have access to seasoned palliative care specialists who really know what they're doing and can give specific instructions and are experienced in doing that, I think that is an innovation we should definitely leverage across the country.

Ms. Sonia Sidhu: Okay. Thank you.

The Chair: Go ahead, Ms. Harder.

Ms. Rachael Harder (Lethbridge, CPC): Thank you.

Thank you so much for taking time to be with us today and to answer questions with regard to your bill. I think this is a cause that is certainly worth fighting for, so thank you for taking the initiative.

As we're all aware, Bill C-24 came to fruition in June, and with that, of course, we have now given Canadians the opportunity to choose physician assistance in dying.

Ms. Marilyn Gladu: It was Bill C-14.

Ms. Rachael Harder: I'm sorry; I meant Bill C-14.

With that, we have given people the option to choose physician assistance in dying. At the same time, however, we have not given them the option to choose access to palliative care should they choose to die without medical assistance and simply want to be pain-free in an environment of comfort when they do die.

In my estimation, then, I would say that our present legislation and of course our lack of palliative care are creating a problem in Canada, and that problem is a lack of choice. I wonder if you can comment on that further.

Ms. Marilyn Gladu: Certainly the special committee that studied the Carter decision said that without good palliative care, you don't really have a choice. You can appreciate how somebody who would be suffering agonizing pain day after day after day, with no hope of any intervention, would choose assisted dying. That certainly was the pattern in countries that began to implement assisted dying without any palliative care to come alongside. However, countries that have put good quality palliative care in place find that 95% of people choose to live as well as they can for as long as they can, so I think we do have a responsibility to Canadians to give them a choice, and the 70% of Canadians who have no access to palliative care today really don't have a choice. That's why we need to move quickly to address the need.

● (1200)

Ms. Rachael Harder: Thank you.

In your overview, you briefly mentioned research and data collection. Can you comment further on how we currently do that, and whether there are changes needed so that we can have better delivery when it comes to palliative care?

Ms. Marilyn Gladu: I had great conversations with the Minister of Health on this one, because apparently there is a vacuum of data. There is really no information about how many people need palliative care or how many people are being given palliative care because it's being administered in so many different places and in so many different ways, and some of them are tracked and some of them are not.

This is the data we really need to understand: what is the need, what is the cost, and how are we making progress over time? I'm certain that the information could be collected in any number of ways. It could be through Health Canada; it could be through Statistics Canada; and there is the Canadian Health Information Management Association, which collects a lot of health information. I think it's for the government to determine what is best, but definitely you measure, and then you do. I think that would be good.

Ms. Rachael Harder: Thank you.

As the next question, we come up with a national palliative care strategy, but that has to be built into legislation. You commented on that briefly, but I'm wondering if you could expand on that aspect a bit more. In your estimation, should we have this as part of our health act going forward? Should we renegotiate that?

Ms. Marilyn Gladu: Well, it's a balance of what else people will want to put into the Canada Health Act. I'm an engineer, so I'm very pragmatic, and I'd just open it up. Originally when we first did the draft of the bill, we said we'll just amend the Canada Health Act and stick in palliative care, including end-of-life care, as a covered service, and we'll be away, but there are a huge number of people who want to add many other things to the Canada Health Act, so I think there is an inherent fear of opening that can of worms.

Right now we're negotiating a health accord with the provinces, so there's an opportunity. Provinces want to be offering the service and they're already starting to move in that way, and the federal government is in discussion with them, so there's an opportunity naturally at this time there.

That may take a long time to put in place, so in the interest of trying to get things happening in a hurry, that's where government programs can come into play. We've seen infrastructure announced of $186 billion over the next 10 years. Why couldn't some of that be for establishing a palliative care infrastructure in co-operation with municipalities? Why couldn't that be used to provide some training resources to upgrade doctors, nurses, and home-care providers and paramedics?

The third mechanism I described is my idea of how to get there fast while you figure out what the other long-term mechanism is to make sure it's clear what is federal jurisdiction and what is provincial.

Ms. Rachael Harder: Awesome. Thank you.

The Chair: Thanks very much.

Mr. Oliver is next.

Mr. John Oliver (Oakville, Lib.): Thank you very much.

Thanks for bringing this forward. I think it's a really important piece of legislation to be considering, particularly, in my view, against the medical assistance in death. To have that coming forward and not to have appropriate palliative care choices or to have anybody opting for some of the provisions under MAID because they don't feel there are adequate palliative care services for them makes me think it's morally imperative that we have appropriate palliative care programs.

I totally support what you're doing and also your comments about whether people are getting care in the right place. I think the Canadian Hospice Palliative Care Association said the majority of Canadians wish to die at home, but 75% of deaths are occurring in hospitals and long-term care facilities, so we really do need to change our understanding of where and how a well-managed death can occur.

My questions are a bit more detailed, then, within the bill itself. There's been some discussion here about federal versus provincial jurisdictions. In subclause 2(1), where you talk about the Minister of Health, in consultation with the provinces and territories and private care providers, developing and implementing a framework, I'm just wondering about your choice of the word “implement”. Clearly the delivery of these services and the implementation of palliative care programs will, under our model, belong with the provinces and territories, not the federal government, so what was your view of the word “implement” there?

Ms. Marilyn Gladu: My view is let's do something. The comment I heard during the debate was that this was one area where they would like to modify the words. Although it says that it's the Minister of Health in consultation with the provinces, it's clear that the provinces have the responsibility to implement whatever it is that's determined, so I'm happy to see an amendment there to reflect that point.

● (1205)

Mr. John Oliver: Okay.

Under “Review and report”, you have to report back, within five years of the tabling of the report, on the effectiveness of the framework and implementation of it, but then you're proposing every five years after that. I have a concern with legislation that never ends, and I'm not quite sure what you gain in year 10, year 15, from these reports. I was wondering about your thoughts there.

Ms. Marilyn Gladu: Well, I would say that being new at this private member's bill business, I took what was typically recommended in other similar bills.

That said, the idea is that you're going to start down a path of implementing palliative care and you need to check back every so often. Does the mechanism have to be legislative? No, it doesn't, but if it's not, sometimes governments come and go and they slash Statistics Canada or whoever is collecting the information, and then you lose information and you lose your benchmark. It was an attempt to see that this is in place.

As with everything, I think it's important to move forward, so I'm flexible to change if there's a different suggestion.

Mr. John Oliver: On that one, after five years, assuming we have a successful take-up by the provinces and territories, the federal leadership is done at that point, and it's really going to be the provinces and territories that will have to be executing and delivering the palliative care models. That's why I thought that at a federal level to have a report 10 years after it starts.... I just wasn't quite sure. Thank you, Ms. Gladu, for that.

Ms. Marilyn Gladu: Sure. I'm open to wording to say that it would be succeeded by provincial reporting or whatever. Somebody needs to be tracking it and looking at it.

Mr. John Oliver: On education, then, I think the Department of Justice talked about palliative care when they had their consultation on physician-assisted dying in January 2016. They said that out of 77,000 physicians, 51 are palliative care specialists and 123 family practitioners have that focus. Out of 77,000, fewer than 200 are equipped to medically provide supervision. Out of 360,000 RNs, 1,348 have a certificate in palliative care.

There's clearly going to be a need to focus on education to make sure there's appropriate training. You were kind of silent on that, I guess. You identified palliative care training and the educational needs of palliative health care providers, but we're really looking at generic positions and having them with some degree of specialty versus.... Or were you picturing a whole new type of provider who is focusing on palliative care?

Ms. Marilyn Gladu: No. There are providers today who are offering palliative care training, and I think we need to take advantage of it at the different levels to start expanding the amount of service that can be provided.

For example, think about RNs. There's a course they can take with Pallium Canada. It's available today. It's available in multiple provinces. There are also other courses. I don't want to pick only one, because we have to be non-commercial here. In universities and in a number of places, levels of training are available for doctors, nurses, home care providers, and paramedics. It's available for different levels of service providers.

With regard to the numbers you're talking about, certainly those programs would grow over time, but even with the existing programs, I think moving down that road and getting people trained is what's required.

Mr. John Oliver: You talked about the educational needs of palliative health care providers. I want to be very clear about it. My view is that we provide some additional training in palliation to doctors and nurses who already have broad skills. You're not looking at a new type of health care provider, then?

Ms. Marilyn Gladu: No, but I'm looking at using some of the less traditionally used health care individuals, such as paramedics and home care providers, especially when you start to think about what the plan is for rural and remote areas. They don't always have a palliative care specialist, that's for sure, and sometimes not even a doctor. They might have a nurse, but they might just have people providing home care or people coming by occasionally, so what can you do? There are examples of people who have trained the paramedics to understand palliative care and to be able to administer it. I think that's a great innovation.

Mr. John Oliver: Thank you.

The Chair: Thanks very much. Your time is up.

Mr. Davies is next.

Mr. Don Davies: Thank you.

Dr. Carrie asked some questions about the current health accord. Do you feel that there is enough money in the current new offer by the federal government to the provinces to adequately allow the provinces to deliver the palliative care services that you believe are necessary?

● (1210)

Ms. Marilyn Gladu: Well, I don't think there's enough that has been put forward, but that said, I think there's enough to start. I haven't seen what's been done with the $3 billion that was already proposed, but in terms of some of the things that could begin, between that and the $186 billion over 10 years in infrastructure that's been announced, I think there's an opportunity to double, triple, or quadruple the amount of palliative care that's available. That's the direction we need to move in.

Mr. Don Davies: You believe that in terms of whatever infrastructure funds for capital projects may be allocated over the next 10 years, at least some of that should be allocated to publicly built palliative care facilities. Is that right?

Ms. Marilyn Gladu: I believe the federal government should be putting in that money, to be matched by individual providers, municipalities, or charitable organizations, to build the hospices we need, for example, or to build the kind of virtual palliative care centre that's available in Winnipeg. I think these are things that the government should do.

Mr. Don Davies: Certainly, you wouldn't, I take it, support those public funds going to private sector for-profit facilities. Are you calling for that kind of public subsidy to private providers, or are you talking just about—

Ms. Marilyn Gladu: No. This is part of the standard health care provision under provincial health care.

Mr. Don Davies: Okay. Of course, you come before us as a Conservative in opposition. Ms. Gladu, you know that under the previous Harper government there was an imposed health accord in 2014 for 10 years that had no money for palliative care. There was no $3 billion allocated for any kind of home care palliative care.

Would you agree with me that this was an accord concept that would not be able to fund the kind of palliative care you think is necessary?

Ms. Marilyn Gladu: I would say that I can do zero about fixing the past. I can only fix the path forward. I think it's clear from the unanimous support the bill got that people are ready to implement palliative care. It is going to take some money, and the government has to determine the rate at which to pace that. It's not something that you can bankrupt yourself today on, but it's something you need to invest in and you need to figure out how to get the best bang for the buck.

Mr. Don Davies: For sure. Ms. Gladu, as my late father used to say, wisdom comes so seldom that we shouldn't reject it because it comes late. I agree.

The health accord is live before us, so I'm trying to find out what your policy would be, what recommendations you would make to this government about how much they should spend on palliative care and home care, given that we had 10 years of government that really didn't allocate anything.

As a matter of fact, from 2001 to 2006 the federal government funded the Secretariat on Palliative and End-of-Life Care, giving them $1 million to $1.5 million a year. One of the first acts of the Harper government in 2006 was to cut that. That basically took about $10 million to $12 million out of a federal government entity that was charged with creating an end-of-life strategy. Would you like to see that money restored?

Ms. Marilyn Gladu: Certainly I would like to see that Canadians actually have the choice now that we have assisted dying in place, and there will be money required to spend to get that to happen.

I'm a fan of doing that. As I said, I was not here during the Harper regime, so I can't fix the past. I can only improve the future.

The Chair: Thank you very much for your contribution and presentation, and your motion. I hope we weren't too hard on you.

Ms. Marilyn Gladu: No. This group is great, and I thank you again for the ability to come and testify to you and for your interest. I can tell that you have been looking into this issue and have been studying it, and you're ready to see what we could do together.

Thank you.

The Chair: It sounds like everybody is going in the same direction.

Thanks very much again. We're going to take a little break while we change witnesses. We'll resume in two or three minutes.

● (1210)

(Pause)

● (1215)

The Chair: We'll reconvene now.

We would like to welcome our witness. We had two witnesses for this panel. Dr. David Henderson was scheduled to be here from the Canadian Society of Palliative Care Physicians, but his plane is stuck in Halifax.

We're now going to devote all our time to Dr. José Pereira. He has a very interesting background. He is the co-founder and scientific officer for Pallium Canada. He is also the director of research for the College of Family Physicians of Canada and has many other positions and appointments. He has appointments at the University of Ottawa and at McMaster.

Dr. Pereira, would you take it away and tell us about Pallium? Then we'll ask questions. You have 10 minutes.

Dr. José Pereira (Chief Scientific Officer, Pallium Canada): Thank you very much, Mr. Chair and honourable members of the committee. Thank you so much for this opportunity to present today.

[*Translation*]

I think palliative and end-of-life care are very important to Canadians.

Thank you very much.

[*English*]

Today I'm here to speak on behalf of Pallium Canada and to share with you some personal reflections based on my 22 years as a palliative care physician, researcher, educator, and leader.

I and Pallium Canada recommend acceptance of this draft bill. I wish to share with you the main reasons we endorse this bill, and I'd also like to share with you some additional considerations and recommendations for a pan-Canadian palliative care framework.

I want to start with a story that changed my career completely and has inspired me and hundreds of people across the country to provide palliative care. The story goes back to the early 1990s. I was working as a family physician in a small rural community in southwestern Manitoba. One particular day a patient came to see me. His name was George. He asked me for help. Through that experience I learned the importance of palliative care and how we can make a difference when there is palliative care.

While things have improved much over the last two decades—and I've been privy to that, and I've worked alongside amazing colleagues across the country to do that—there are still significant gaps across the country, and these gaps do need to be addressed. However, there are wonderful centres of excellence, and we need to look at them as role models and try to scale them up and spread them.

George was in his early fifties. He was accompanied by his wife when he first came to see me. He said he had seen other doctors but none had been able to help him. He went on to say that he had advanced cancer and knew that he probably only had a few months to live. However, he was experiencing severe pain and could not spend the rest of his life in such suffering. I vividly remember feeling helpless. I can just imagine how he and his wife were feeling at the time.

Like many other colleagues and peers in those years—and unfortunately, still today—I had not received any palliative care training. He told me he was on a very small dose of morphine, a dose that I found out only later was woefully inadequate. Not knowing any better, I told him I could do nothing because he'd become addicted if I increased his morphine. I was not sure how to deal with the other symptoms and fears he was experiencing.

He got up, took his wife's hand, and started walking out of my office. I'll never forget the next moment, because he stopped, turned around, and said, “I hope that one day doctors like you are able to look after people like me.” I felt embarrassed that I could do no better. George and his wife were devastated.

The experience prompted me to look for some training in palliative care. To be quite honest, in those days I had never even heard the words “palliative care”. I found the course because the subtitle said “Caring for the terminally ill”, but I now know it's not just about caring for the terminally ill; it begins much earlier in the illness.

Palliative care courses for physicians and other health care professionals were very scarce. The only course I could find was in Hamilton, and at the time that course was held only once a year. A few weeks later, I flew to Hamilton to participate, and over the course of five days I came to learn a lot more about palliative care.

Equipped with this new knowledge and skills, I returned to Manitoba and called George. I told him I was sorry, that I had made a mistake, but now I knew better. I'd got some training. He very graciously accepted me to look after him, so I did, and I cared for him until his death a few months later.

This experience taught me several things. I learned that people like George experience many needs that we should be able to address, no matter where in Canada one lives. I learned that with a little training, a health care professional like me can make all the difference. I learned that it is not only patients who suffer but also their families.

I decided to pursue a career as a family physician working in palliative care. A year later, I was accepted into a clinical research fellowship at the University of Alberta to undertake further specialist-level training in palliative care, which I completed in 1995. I've worked in palliative care since then.

● (1220)

George inspired the creation of Pallium Canada in 2001 by his words, “I hope one day doctors and health care professionals like you can look after people like me.”

Pallium Canada is a non-profit pan-Canadian organization whose mission is to educate and support all health care professionals who are not palliative care specialists and other caregivers across Canada to provide a palliative care approach, those basic, essential skills that I learned and was able to apply in the case of George. Over the years, mainly with funding from Health Canada, we've been able to grow and reach out to more health care professionals across the country.

It is estimated that overall only between 15% and 30% of Canadians have access to palliative care services. These numbers vary considerably across the country, and there are regions with much higher numbers. As I said earlier, these are role models that we should try to emulate across the country.

However, those numbers may also reflect an overdependency on specialist-level palliative care services. While there are significant gaps in many such services, gaps that require more palliative care providers and services across many parts of the country—and I can give you examples of how, over the years, I've tried to get more of those resources in place in different provinces—another part of the solution involves making palliative care everyone's business.

There are, for example, tens of thousands of health care professionals who are not specialists in palliative care but who are involved in the care of patients with progressive incurable illnesses. They are at the forefront of diagnosing these illnesses, treating them, and providing care across the illness journeys. They include many professions, from doctors and nurses to pharmacists, social workers, therapists, personal support workers, chaplains, physiotherapists, and occupational therapists, etc., working in areas such as family medicine, primary care, internal medicine, oncology, nephrology, pulmonology, and geriatrics, and I could go on and on. They are committed professionals who want the best for their patients and, in many cases, acknowledge their need to upgrade their skills to be able to provide the care that George received.

There is significant evidence that the lack of palliative care-related training and services results in needless suffering, inappropriate use of health services, and often treatments that hardly provide any benefits. In fact, I can provide examples of treatments that do more harm than good.

Pallium Canada, through our modules and one- or two-day courses called “learning essential approaches to palliative care”, or LEAP, as well as other products such as our pocketbooks and app, is building system capacity to provide palliative care. Our LEAP courses bring together professionals from different professions, disciplines, and settings to learn together, allowing them also to work better together, transition between different settings of care, and help patients transition through those different settings. Our courses cover settings that range from homes and long-term care to outpatient clinics, hospitals, cancer centres, and emergency services. Our community consists of 540 trained and certified facilitators and organizers across the country, and that's our sustainability model. It's not us doing it from a small office in Ottawa; it's a whole community doing it across the country.

We are proud of the return on investment and value added that we have achieved. From 2001 to 2003, over the course of two years, we delivered 47 courses. In this past year, we delivered almost 210 courses across the country, with over 8,000 professionals. We've trained paramedics in Nova Scotia and P.E.I. We've trained nephrology teams all over Ontario. We've trained long-term care facilities with LEAP in British Columbia, Ontario, and other provinces, Nova Scotia included.

While these successes are very encouraging and our model is proving successful, we still have a very long way to go. There are still tens of thousands of health care professionals to be trained. There are still thousands of hospitals, long-term care facilities, family medicine clinics, heart institutes, etc., that need to get their staff trained and oriented toward the palliative care approach, thereby building system capacity.

One of the greatest challenges that I and Pallium have experienced over the years is that funding for the program, while precious and very much appreciated, has generally been piecemeal, temporary, and often not sufficient, given the scope of the challenge and the work at hand. We've had to spend a considerable amount of time and energy searching for sustained funding instead of actually doing the work at hand, at times. With adequate, sustained core funding, Pallium Canada would be able to further mobilize and grow our diverse network of committed palliative care professionals, providers, and volunteers and increase palliative care education in all regions of the country, be they urban, rural, remote, English, or French.

● (1225)

We would be able to spread to other provinces and territories successful programs such as LEAP paramedic, LEAP long-term care, and LEAP renal. We would be able to build upon our earlier work to ensure that the voices and wisdom of aboriginal peoples are included in palliative and end-of-life care education in the country.

This experience of piecemeal and non-sustained funding is a challenge faced by other organizations, not just Pallium, that are making a difference at the front lines of care, organizations such as the Canadian Society of Palliative Care Physicians, the Canadian Virtual Hospice, the Canadian Hospice Palliative Care Association, the Canadian Nurses Association, etc., all of which are trying to make a difference in their spheres of influence.

This brings me to my first recommendation for a Canadian framework: the framework should harness our existing strengths in these organizations and provide us with the capacity to scale up and spread our work by way of sustained and adequate core funding for these initiatives. Opportunities for renewal should be available if there is evidence of success and impact.

My experiences working in education—including co-chairing the education working group for the Secretariat on Palliative and End-of-Life Care from 2003 to 2005; developing a regional palliative care program, the first in Ontario, in the Ottawa area; developing education materials and curricula in universities; and trying to develop programs that are rural and programs that are urban—have brought me to the following recommendations.

The framework should include the development of standards on what constitutes key palliative care services for every region in the country. It should also include standards on how these services should be resourced. I would argue that it is no longer acceptable to have hospitals or community support teams without adequate staffing or resources. It is unacceptable in 2017 to have teaching hospitals such as a large hospital in Windsor without a proper palliative care team, a city such as Hamilton without a palliative care unit, a region such as Brampton without a hospice and with inadequate and inappropriate funding for palliative care physicians and teams. It's inappropriate and inadequate to have rural or urban regions without palliative care support teams to help patients with complex situations. It is no longer acceptable to have little or no palliative care education in the curricula of medical and nursing students and students in other care fields and residents across different specialty areas.

● (1230)

The Chair: Doctor, I have to cut you off. I'm sorry.

Dr. José Pereira: Thank you.

The Chair: I hate to do it, but I have to cut you off.

We want to get to questions, and we're going to start with Dr. Eyolfson.

Mr. Doug Eyolfson (Charleswood—St. James—Assiniboia—Headingley, Lib.): Thank you, Dr. Pereira, for coming.

This is a topic that is near and dear to my heart. I am an emergency physician. I practised in Winnipeg for almost 20 years.

One of the challenges in palliative care is in addition to what we've talked about so far, such the lack of services. As you probably know from practising medicine, very often the court of last appeal for a patient in the extreme is the emergency department. One of the challenges we find is with pain control. You know this, practising in Manitoba. Not everyone on the board might know that. You're familiar with the triplicate prescription program.

Dr. José Pereira: Yes, absolutely.

Mr. Doug Eyolfson: Anyone who wants to prescribe a medication stronger than Tylenol 3, such as Percocet or morphine, needs this special triplicate prescription that you apply to have. There are many physicians in primary care, either in walk-in clinics or some family doctors' offices, who are concerned about addiction issues in the community. They've chosen not to have triplicate prescriptions. There are clinics that actually have signs on their door saying, “We do not prescribe narcotics”.

What happens is that some palliative care patients who are on large doses of painkillers run out of them at inconvenient hours. Walk-in clinics are open or their family doctor's offices are open, but they say, “I don't have the triplicate prescription. Go to emergency.”

They might wait eight hours in our waiting room just so that we can write a prescription for Percocet because their doctors refuse to provide this service.

We've talked to our college in Manitoba, and I think other colleges feel the same: that there's no precedent for mandating that everyone in primary care has to be able to provide that service. Would you support mandating in all provinces that if you are providing primary care to patients, you at the very least be able to give adequate analgesia for patients in your care?

Dr. José Pereira: I've heard another question that I think is extremely important, and that is the one about the use of emergency rooms to address palliative care needs. I believe that within systems we can do a much better job further upstream of preventing those sort of visits by being proactive.

I worked for three years as the palliative care lead for Cancer Care Ontario. We found some evidence that if you address symptoms beforehand, manage them, and are proactive in having goals of care discussions and advanced care planning, you actually start to reduce the number of visits to emergency rooms. When you train paramedics, you start reducing them, so I think it's important that there be strategies upstream to prevent those visits.

With respect to the issue of comprehensive care, I also work as research director for the College of Family Physicians of Canada, and we're very proud that we are really promoting the concept, through the “patient medical home”, of comprehensiveness and continuity of care. You will see with time those concepts moving much more to the forefront and becoming integrated as well in the training of family medicine residents. Comprehensive care will become integrated as well in what's expected of family physicians, so I think those sorts of programs need boosting and need encouragement, and it's not just the family physicians: it is all other physicians as well—oncologists, cardiologists, etc., who, with some basic training, can actually be part of the solution.

● (1235)

Mr. Doug Eyolfson: Yes, and I couldn't agree more. Thank you.

Again, because these problems come down in the emergency department, we're often left knowing what this patient needs, but it's often hard to find the right thing, and it defaults to calling internal medicine to admit the patient.

You actually touched on the next question I was going to ask. One of the hats I wore during my career was provincial medical director of the land ambulance program for Manitoba. We were starting to make explorations into community-based paramedic care. There's a very good program in Winnipeg whereby paramedics go out and regularly assess high users of the emergency department to prevent emergency department admissions. For other areas that are very underserviced, paramedics can go out into the community and perform certain tasks, such as some home care tasks, immunizations, and medications. In the isolated, northern, and remote areas, do you see a role for an organized community-based paramedic strategy in the care of these patients in palliative care?

Dr. José Pereira: I really believe that we should harness whatever resources we have, and if it is everyone's business, then absolutely, a PSW or a paramedic can play a critical role in helping out. In fact, we're seeing this happening in Nova Scotia and P.E.I., where we went out and developed a LEAP paramedics course. It's a one-day course that trains paramedics. They do some online learning beforehand and then they come together in a classroom.

We're beginning to see some of those early successes in reduced admissions or transfers to the emergency room. Why? Well, it's for two reasons. First of all, the paramedics are now equipped with some of that knowledge and the skill sets, and they are more comfortable addressing a situation, including undertaking some discussions about goals of care and even advanced care planning.

Second, it's part of a whole system. If we also train the emergency staff so that they often phone with the basic essential skills of palliative care, then everyone's talking the same language and everyone's on the same page, and you start seeing things changing. Instead of saying, “Bring the patient over”, it becomes, “Okay, let's look at this. What's the situation? Let's try to care for the person at home and let's put in resources that are available in the home.”

Mr. Doug Eyolfson: Thank you very much. I have so much more to ask, but I think I only have about 15 seconds left, so thank you very much for coming.

The Chair: It was 14 seconds.

Go ahead, Ms. Harder.

Ms. Rachael Harder: Thank you very much.

Thank you, José, for taking time to be here with us today. We certainly appreciate your comments.

I am going to split my time with my colleague over here, Mr. Webber, so I'm going to try to be quick.

You said that we often think of palliative care being necessary at a specialist level—that was your term—but you said this isn't always the case, that perhaps we should think beyond this idea. I'm wondering if you could expand on that thought for me.

Dr. José Pereira: Sure.

It is well known that in any health care system we need a strong primary level base, and then a secondary and a tertiary level of care. The tertiary is the highly specialized care that a much smaller proportion of the population requires. You see that in the care of patients with hypertension, for example. Not all patients with hypertension need to go to a cardiologist; a lot of it can be really well controlled at a primary level.

It's the same thing for palliative care. If we provide what I say are the “generalists” with those basic competencies from a palliative care perspective—how to assess symptoms; how to start managing them; how to ask about the understanding of the illness; what the psychological, social, or spiritual needs are; and how one can help—then we start implementing that palliative care approach.

If we start equipping those professionals who are not palliative care specialists with those basic skill sets, they can start initiating a palliative care approach much earlier, which means the much smaller group of specialists can then focus on doing certain things, such as caring for patients and families with complex needs; leading education; leading quality improvement in hospitals, in long-term care, and at home to improve palliative care; and doing research.

Unfortunately, at the moment, in some provinces that triangle with primary care is upside down. Ontario is an example. In a study I published with some colleagues about a year and a half ago, we discovered that most of the palliative care, including primary level palliative care, was being done by a very small group of palliative care specialists. There are only about 260 palliative care specialists in this province to do all the care for cancer patients, heart patients, nephrology patients, and geriatric patients, etc.

First of all, there is a significant lack of those specialists' services in many parts of the country. We need them. Second, there are problems with funding mechanisms. In Ontario, for example, much of the funding of palliative care specialists is by a fee-for-service model, so it drives the specialists to take over palliative care, to do the clinical work only, but it doesn't pay the specialist to teach and build capacity. That needs to be changed to models using existing funding that can build capacity, rather than undermining that primary level that is so critical.

● (1240)

Ms. Rachael Harder: Thank you very much.

Bill C-14 came into effect in June. Of course, it allows for medical assistance in dying, but it doesn't protect a person's choice of palliative care when only 15% to 30% of Canadians have access. Can you comment on how this bill will take care of people's right to choose?

Dr. José Pereira: I can spend the rest of the day providing examples of cases of a palliative care intervention saving someone from saying they wanted to end their life earlier.

I worked for a few years in Switzerland, and one particular case comes to mind. A young man with advanced lung cancer came into the hospital in Lausanne saying that he couldn't live like this, that he wanted to end his life, and that he had the right of access to assisted suicide. We got the palliative team involved, controlled all his symptoms, and a few days later he went home again. He published a story in the newspaper saying that it helped him, because he could now spend quality time with his family.

I totally agree with your saying that if there is no palliative care, then there isn't any choice. Palliative care does make a difference for the overwhelming majority of people.

Ms. Rachael Harder: Thank you.

I'm going to hand it over to Mr. Webber.

Mr. Colin Carrie: Mr. Webber said I could ask one really quick question, so I know I don't have a lot of time.

First, Dr. Pereira, I want to thank you for your compassion and commitment, because this is something Canadians are going to be dealing with. I think we're at a crossroads here, so it's a very timely bill and it's very timely for you to be here.

I know Bill C-14 concerned a lot of Canadians, and my colleague brought up the question about choice. Just so that moving forward we're doing the right thing, could you outline some of the current barriers to accessing palliative care services that Canadians face?

Dr. José Pereira: I think there are many barriers, but let's not forget as well the examples of excellence across the country where they are able to overcome those barriers. We are known across the world as innovators. The problem is that we innovate a lot of pilot projects, and we need to scale them up.

In terms of barriers, there are numerous barriers. One of them, though, and an important one, and almost the elephant in the room, is a culture that refuses to talk about end-of-life care issues, a culture that unfortunately equates palliative care only with death and dying and does not see it as about living and improving quality of life, and a culture as well that is overreliant on the health care sector to come up with solutions. I firmly believe that it's time we started looking at other sectors, such as education, the financial sector, and social services. Can you imagine, for example, if our children, finishing K-to-12 school, ready to go into the world, are equipped with those life skills that allow them to have frank discussions about this, to talk about advance care planning, and importantly, to be able to care for their grandparents—even perhaps their parents, perhaps even friends, as my children have experienced—and able to have those skills to sit at the bedside of someone who's frail and elderly and listen to their stories and hear from them? We'd start getting this cultural shift occurring.

Imagine if companies were able to have programs in place so that they were aware that a staff member or family member had an advanced progressive disease and were able to put measures in place to help them out. I think there's a lot we can do as well from a non-health care sector.

If we look at the health care sector, there are a lot of resources we already have. It's a matter of reformulating and readjusting them. I gave the example earlier of the fee for service. If the ministries in those provinces, including Ontario, were to say, “Okay, we're already paying these doctors; let's pay them in a different way that helps them build capacity”, I think we might start seeing more capacity being built.

● (1245)

The Chair: Thanks very much. The time is up.

Mr. Davies is next.

Mr. Don Davies: Thank you, Mr. Chair.

Thank you for being with us today.

I have a two-part question about the national Secretariat on Palliative and End-of-Life Care that operated between 2001 and 2006. My dual question is, did that secretariat do productive work, in your view, in advancing palliative care in Canada, and if so, would you recommend that the government re-establish that secretariat?

Dr. José Pereira: As with any new program, some fantastic work was done, and there were also some failures. We need to learn from those failures.

I'll give you an example of what I think was fantastic work.

I happened to be co-chairing the education working group. There were five working groups in total, and I chaired the education one. The work we did as an interprofessional team went to the implementation of a project called Educating Future Physicians in Palliative and End-of-Life Care, or EFPPEC. With the funding we received from that, we were able to put teams in place across all the 17 medical schools to start mapping out the curricula and start implementing palliative care in the curricula. Some of those schools now are amongst world leaders, the University of Ottawa being one of them, in palliative care-related education.

There were examples of successes. We tried to do same EFPPEC type of project for nursing, and unfortunately by the time we got to that, there was no further funding, which is again an example of not having the sustained funding that we needed.

There was another working group that I was very disappointed did not continue. It was one that was looking at measures, performance indicators, and standards. I believe that had that work been funded properly and moved forward, today we would have had much richer data on this topic to inform us and guide us in terms of planning the health care services at regional and provincial levels, and also at the federal level.

Mr. Don Davies: I'm not sure that I got an answer to my second question. I think the secretariat cost about $1 million to $1.5 million a year. Would you recommend that we re-establish that secretariat?

Dr. José Pereira: I would strongly recommend that we re-establish a secretariat or office or framework—

Mr. Don Davies: Something.

Dr. José Pereira: —building on the successes that we had earlier on—

Mr. Don Davies: Thank you.

Dr. José Pereira: —but adding much more to that.

Mr. Don Davies: Part of the proposed palliative framework involved in this bill involves collecting research and data on palliative care. I think you've well covered that there's some exciting and very valuable work being done in the area. I wonder, Mr. Pereira, if you could advise us if there are any specific gaps or really critical areas that you would like to see research dollars or efforts directed at that would be helpful.

Dr. José Pereira: Certainly. There are two or three. One of them relates to identifying the patients who need palliative care going forward and tracking them on a large scale across a whole region to see where they are going, what services they are using, and what the impact is of different models .

I've been having meetings, for example, in the Durham region. If we implement these things throughout the region and do the work to see the impact and how we can learn from that.... The whole concept of using models, studying models, and the impact of different models and different decisions on large-scale deployment is an important area.

One of the challenges we face is that in the data that we have—large databases across the provinces—it is difficult to identify who is a palliative patient. We don't have very robust data.

I've been meeting, for example, with colleagues at the Canadian Institute for Health Information, CIHI, and there are gaps there that we need to address. If organizations like that were given additional resources, they would be able to start studying in more detail the palliative care needs across the country and how services are being used.

● (1250)

Mr. Don Davies: Thank you.

I'm not sure if you know the answer to this or not, or if you could get it for us, but I am interested in where Canada is situated internationally in terms of our allocation of public funding to palliative care. Do you know where Canada ranks?

Dr. José Pereira: It's variable. Canada has many different health care systems provincially, so it varies a lot within Canada. There are different organizations that have looked at and tried to rank Canada according to different parameters. We rate sort of in the middle of the field in terms of the top 12 or 14 OECD countries, but in some areas it is much lower and in some areas it is higher. By and large, I think that we have a lot of catching up to do with some of the leaders in the world, such as Australia and the United Kingdom.

Mr. Don Davies: How am I doing for time, Mr. Chair?

The Chair: You have one minute and 49 seconds.

Mr. Don Davies: Thank you.

I think the whole doctor-assisted, physician-assisted death debate offered an opportunity for us in Parliament and all Canadians to consider some of the very profoundly difficult questions that surround end-of-life care. Of course, we had the Supreme Court of Canada decision that required us to come up with a framework of some type.

Mr. Pereira, I think that you have indicated some concerns about assisted suicide. I note that in a 2011 *National Post* article, you are quoted as saying:

> Legalizing euthanasia and assisted suicide places people at risk, affects the values of society over time and does not provide controls and safeguards....
>
> What we really need is good palliative care that addresses the issues, suffering and fears that surround terminal disease.
>
> I think death has become something that is very alien to our culture.... We seem to have forgotten that it is a normal, natural process and we have projected our fears onto it.

I think that sums up some of the essential issues involved in this difficult discussion. Are you suggesting that palliative care and physician-assisted dying are mutually exclusive approaches, or can they co-exist as part of a comprehensive end-of-life care strategy?

Dr. José Pereira: As a citizen with my own views on it, I will share my view that it's not right to legalize euthanasia and assisted suicide, but I also live in a democratic country and I respect the democratic processes. I, personally, will not do it.

I want to focus on all the other work that I've been doing in terms of addressing the palliative care needs. That is my focus today, and it's my focus in the work that I do now with palliative care. How can we improve palliative care to make sure that every Canadian has access to it when he or she needs it?

Mr. Don Davies: I think that we all share that. I think everybody agrees that having top-notch palliative care that all Canadians can access is a sound policy that we all want.

The Chair: Thanks very much.

Mr. Kang, you are going to share your time with Dr. Eyolfson.

Mr. Darshan Singh Kang: Thank you, Mr. Chair.

Mr. Pereira, there was a big debate in Alberta about the patients who were in need of, say, acute care or palliative care and were in the hospitals. The argument was that if those people, those patients, were moved out of the hospitals, it would cost us a lot less, and the emergency wait times.... Because they were holding those beds in the hospital, it would really streamline our system.

In your view, what kind of difference will it make if we invest more money into palliative care? Do you think that in the long run it's going to save us money and improve our health care?

● (1255)

Dr. José Pereira: That is a fantastic question, and I think it speaks in a very poignant way to what we're talking about here. We often hear that the majority of Canadians, over 75%, want to die at home. It is true that we can improve the number of home deaths, given resources and processes that we can put in place, but we cannot forget the other components of the health care system.

I always use the analogy of a car. If we go into a dealership and we say we want a car with a fantastic right front tire and forget about the other tires, that car is not going to go anywhere. It's the same thing with the health care system. We know that patients experience different palliative care needs across the illness trajectory, from diagnosis to the very end. Sometimes they are basic needs that can be addressed by a generalist, and sometimes their needs are very complex. We do know that we can't just focus on home care. We need to improve home care, but there are some patients who don't want to die at home, and there are other patients who can't die at home. There are patients who find themselves in hospital.

In Edmonton there was some wonderful work done when I was working there in the first regional palliative care program in Canada at the time. We were making sure we put in place the different components in the right proportions. We improved home care services significantly. We made sure there were enough beds in the palliative care unit, so that those patients across the illness trajectory with very complex needs could get the best care possible by highly trained specialists. We made sure there were enough hospice beds. In fact, we used the formula that's known quite well across the world, which is that for every 100,000 population, we need two or three palliative care unit beds and about six or seven hospice beds. We put all of that in place. Within a few years, we showed not only improved care of patients but also a significant lowering of cost to the health care system.

There was a very well-known paper published in 2005 by researchers in Edmonton and Calgary, who showed that putting in all the components in the right proportion, not neglecting one or the other, helped patients and saved the system lots of dollars.

So yes, we can do a better job in improving home care and palliative home care, but we cannot neglect the other components of the system.

Mr. Darshan Singh Kang: In your opinion, is the health care system working in silos, then?

Dr. José Pereira: That is one of the problems, health care professionals working in silos. We have to break those silos.

With our palliative course, for example, we bring people together from different professions and different settings to start speaking to each other and working with each other so we can start breaking those silos.

Mr. Darshan Singh Kang: Thank you, Chair. I'll pass it on.

The Chair: Thank you. Go ahead, Dr. Eyolfson.

Mr. Doug Eyolfson: Thank you.

We talked about the regional disparities across Canada and mentioned that there are some centres of excellence. In your view, in which centres do we find these centres of excellence and the best palliative care?

Dr. José Pereira: I believe if we were to look at it from a regional perspective, from a large population basis, I would argue that some of those are in Edmonton, Calgary, and Fraser Health, and some in Nova Scotia.

If we look at specific components of excellence—for example, community-based palliative care specialist teams who are supporting family doctors, etc., hospices, palliative care units, and even things like palliative rehabilitation programs—we would see that they are spread in different places in different parts of the country. I think we need to look for those and scale up the successes and implement them more widely.

Mr. Doug Eyolfson: All right.

Regarding the framework that we talk about and what we implement, are there existing frameworks that you'd say we should expand, or do we need a new framework?

Dr. José Pereira: I think it's always good to learn from what has been there before and what is currently in place elsewhere. There are frameworks under development, for example, in Scotland, the United Kingdom, Australia, and France. There are other countries that have some of these frameworks. It might be useful to learn from what is working there to see if any of it is adaptable.

I think we also have created some fantastic learning within our own country, such as the secretariat. Across the provinces, some of the provinces are doing some really innovative work, at large population levels, that we can learn from and scale better.

● (1300)

Mr. Doug Eyolfson: All right. Thank you.

I have no further questions.

The Chair: That winds us up for the day.

I want to thank you, Dr. Pereira, for your great contribution to our study and also to health care. I think you've made quite a difference to health care in Canada. We want to thank you for that.

With that, we're going to wind up. We just have a little bit of committee business. I want to update the committee on a few things.

We met with the PBO this morning. They are not able to have the report done within the time we wanted. They won't have all the information until the end of March, and then at the end of March they'll start their study. We gave them a 40-day working window, and it's not enough. They're thinking that it will be shortly after the summer before they're ready to make a statement.

It's a very complicated thing. The tonnes of data they deal with, they're telling us, are mountainous. The 40 working days just aren't enough. That's where we are with that. If you have any comments or anything, I welcome them.

At the last meeting Mr. Oliver asked for a letter to go to the Department of Health to find out how many thalidomide cases there were in Canada, how many were turned down, how many were appealed, and how many of those were turned down. We've prepared that letter, and it will go out right away. We've asked for a response by April 10.

Mr. John Oliver: There's a second element to that as well.

The Chair: I'm sorry; the second element is the background on how the program was established and the reasoning behind it. Is that okay with everybody? All right.

Mr. Len Webber: Mr. Chair, I have a very quick question with regard to our study on palliative care and the witnesses who are coming forward. Today we didn't get to hear from David Henderson. Will he be coming back?

The Chair: He'll be here on Thursday.

Mr. Len Webber: Okay. We have submitted a list of 10 individuals from the Conservative side. Who has chosen these witnesses to come forward in the future?

The Chair: The clerk has the list.

Mr. Len Webber: Are you working on that right now?

The Chair: We're inviting everyone. Some can't come and some won't come.

Mr. Len Webber: Thank you.

The Chair: Thank you very much. The meeting is adjourned.

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