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—
Co-Chairs

**The Honourable Kelvin Kenneth Ogilvie
Mr. Robert Oliphant**

Special Joint Committee on Physician-Assisted Dying

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• (1635)

[English]

The Joint Chair (Hon. Kelvin Kenneth Ogilvie (Senator, Nova Scotia (Annapolis Valley - Hants), C)): Colleagues, we have quorum. I'm calling the meeting to order.

[Translation]

I want to welcome you to the ninth meeting of the Special Joint Committee on Physician-Assisted Dying.

[English]

I'm Kelvin Ogilvie, a senator from Nova Scotia, and co-chair of this committee along with my co-chair, Mr. Robert Oliphant, the member of Parliament for Don Valley West.

In today's session we have two panels. We have the Canadian Cancer Society, represented by Gabriel Miller and Kelly Masotti. Appearing by video conference from the First Nations University of Canada, we have Carrie Bourassa, who is a professor in indigenous health studies.

Because of technology, I always invite the video conference contributor to go first.

I would remind you, Ms. Bourassa, that you will have 10 minutes.

Mr. Miller and Ms. Masotti, you have a total of 10 minutes together for your presentation.

With that, Ms. Bourassa, I invite you to make your presentation.

Prof. Carrie Bourassa (Professor, Indigenous Health Studies, First Nations University of Canada): *Meegwetch.* Thank you very much.

I don't have a very long presentation. I doubt that it will take 10 minutes. I want to thank you for this opportunity to present. I'm sorry that I couldn't be there in person today.

I want to start out with a few points, mainly around the health and history of indigenous people. I'm sure these are things you already know, but I want to state them for the record.

For indigenous people, given our history and the range of health and socio-economic issues and our age, our vulnerabilities are broad. Indigenous people have the highest suicide rates in Canada, with indigenous young women having the highest suicide rates in Canada, at nearly eight times the national average.

Compared to the general Canadian population, first nations people continue to suffer from high rates of chronic and infectious disease

and higher mortality and infant mortality rates. Cardiovascular disease, diabetes, obesity, cancer, stroke, suicide, motor vehicle accidents, and homicide are the major causes of death among indigenous populations.

Preventable deaths due to circulatory diseases account for 23% of all deaths. Injuries account for 22% of all deaths. That is almost 50% of all deaths in our population.

For first nations aged 1 to 44, the most common cause of death was injury and poisoning. The primary cause of death for children less than 10 years old was classified as "unintentional"—or accidents. The potential years of life lost from injury alone were more than for all other causes of death and almost three and a half times that of the general Canadian population.

Consultations with indigenous communities across Canada need to take place with regard to physician-assisted dying. While I have engaged and worked with several different indigenous communities and I myself am indigenous, I cannot speak for them. Further, taking a pan-indigenous approach to policy is not a good idea, given the sensitive nature of this subject and the diversity of indigenous people and belief systems.

The issue of physician-assisted dying is not one that is taking place in communities. As noted, true engagement and communication surrounding this sensitive issue is necessary, and any legislation or policy implemented that affects indigenous people must not only include us but be appropriately communicated to us.

Health care practitioners have an obligation to provide culturally safe care to indigenous people, and that includes physician-assisted dying and understanding all sensitivities surrounding this issue. While strides are being made in palliative end-of-life care, there is still much work to be done, particularly in physician-assisted dying, as this is a very new area for indigenous people, and in my opinion, will require additional training.

That's really all I wanted to say. As I said before, I spent an hour with the committee that went across Canada, speaking about spirituality and belief systems. This is really so very new. Communities have not really had a chance to engage and discuss. There is no policy around this at any of the national levels—the AFN, the MNC, or the ITK. I think there are many sensitivities around this issue, so while I'm honoured to be here to perhaps provide some perspective, I certainly cannot speak for communities. From speaking with some of the community members who I've worked with and with some indigenous physicians, I know that certainly the greatest need is probably community engagement.

I will leave it at that.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you very much.

I will now turn to the Canadian Cancer Society.

Please begin your presentation.

Mr. Gabriel Miller (Director, Public Issues, Canadian Cancer Society): Thank you very much, Mr. Chair.

[*Translation*]

I am very happy to be here today.

[*English*]

My name is Gabriel Miller. I'm the director of public issues for the Canadian Cancer Society here in Ottawa. I'm joined today by my colleague and our assistant director, Kelly Masotti. I'll be delivering our opening comments, but Kelly will be here to help me answer any questions people may have for us.

It's a privilege to be here on behalf of the Canadian Cancer Society, which is Canada's largest national health charity. Canada faces no greater health challenge than cancer. Two in five Canadians can expect to develop the disease during their lifetimes. One out of every four of us can expect to die from cancer, making it our number one cause of death.

I want to thank you for inviting us today, and most importantly, thank you for dedicating your time and attention to this important issue. You're wrestling with some of the most difficult questions any parliamentarian could ever confront, questions about who should be able to seek assistance in dying and who should be able to provide it.

These are important and urgent questions; however, we're not here to help you answer them. We have neither the expertise nor the authority.

We are here to advise you on a related issue, and that issue is palliative care—care designed to protect the quality of life of critically ill patients and their families. Any serious conversation about the needs of severely ill Canadians must include palliative care, and any responsible policy on assisted dying must guarantee access to quality palliative care for all Canadians.

Three weeks ago, we released a new report entitled “Right to Care: Palliative care for all Canadians”. The report found that due to serious gaps in palliative care across the country, thousands of critically ill Canadians are not receiving proper care. That's hurting patients and families, and it's increasing health care costs.

In the absence of clear national standards and accountabilities, individual provinces and territories and health regions are left to develop their own policies, programs, and guidelines, which is resulting in inconsistent and inadequate palliative care in many parts of the country. In Ontario, 40% of cancer patients do not receive a palliative care assessment in their last year of life. In some regions of Atlantic and western Canada, less than half of the people who die in hospital receive palliative care.

Often, palliative care can be provided most effectively and affordably outside of hospitals, yet one of every two Canadian cancer deaths occurs in acute care hospitals, despite the preference of

most patients to die at home. By global standards, Canada does a poor job of providing affordable end-of-life care, ranking 27th in a recent comparison of 40 countries. By expanding home care and improving support for caregivers, Canada can reduce hospital costs while protecting families from the potentially crippling financial burden of a critical illness.

A costly and confusing system that is failing too many patients, that's what our report found. But you don't need to take our word for it. This is an area where parliamentarians have done some outstanding work over the years. As the federal panel on assisted dying pointed out in their report, the Senate published studies on palliative care in 1995, 2000, 2005, and 2010. In addition, there are the findings of the federal and provincial panels. Also, the issue of palliative care and end-of-life care was touched on, importantly, in the Romanow report on health care.

Going back to 2000, the report led by Senator Sharon Carstairs found that palliative care was often based on the luck of the draw rather than being a basic entitlement of Canadians. It found that palliative care was provided in hospitals, long-term care facilities, and hospices, as well as through home care, and that when it was provided in hospital it was fully publicly covered, but when it was provided at home, only some services and some drugs were covered, depending on the territory, province, or region.

● (1640)

The Romanow report found that there were considerable disparities in access to palliative care across the country, and that these services had been developed on an ad hoc basis and were limited by the financial capability of communities and charitable organizations. Consequently, many Canadians did not have access to palliative care.

The root of this issue is that only medically necessary hospital services are currently insured under the Canada Health Act, with additional care and services paid for through provincial programs and private insurers, and by patients and families themselves. This complex and piecemeal funding is particularly problematic for palliative care, which often can and should be delivered outside of the hospital setting.

Other contributing factors include a lack of national standards and data collection, insufficient training for health care providers, insufficient information and support for patients, and inadequate investment in palliative care services.

How do we fix this?

We need to begin by making palliative care a top priority for federal and provincial governments as they craft a new health accord over the coming year. Specifically, we are calling on both federal and provincial governments to enact new legislation guaranteeing universal access to palliative care; to expand palliative care generally and home-based services in particular; to increase support for patients and family caregivers; to develop and implement national palliative care standards; and to increase training for health care providers in palliative care.

Palliative care doesn't have the same complexity as assisted dying. It is simply the notion that people should be well cared for—as people—to minimize their suffering and maximize their enjoyment of life. The only enduring mystery is how Canada has failed for so long to fix its broken palliative care system.

Canadians believe in the right of all people to access reliable, affordable, high-quality medical care. Palliative care is necessary, and the need will only grow more urgent as our older population grows. It's time to recognize the right to palliative care and to build a health system that delivers it.

[Translation]

Thank you very much.

• (1645)

[English]

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you.

We'll now turn to questions.

For the benefit of the witnesses, I'll note that each member of the committee has five minutes. That includes the time for the question and the response. Because we have a video conference, I would ask members of the committee to make sure they direct their questions and identify the individual they want the question to go to.

Mr. Aldag.

Mr. John Aldag (Cloverdale—Langley City, Lib.): Thank you.

I'm going to start with some questions for you, Professor Bourassa. That's where I'm going to aim the first bit of questioning.

I fully appreciate your comments about not being able to speak for the diversity of communities that we find within the indigenous populations of Canada. They are extremely diverse. I realize that one person simply can't represent them, but I would like your thoughts, if you can direct us, on pitfalls to avoid, perhaps, or on the types of discussions we should be having.

With that in mind, I've had the chance to live in a number of rural and remote areas, including eight years north of 60, and many indigenous communities are underserved medically. Part of the Carter decision talks about access. As we look at accessibility to physician-assisted dying for those who choose to participate, I'm wondering if you have any thoughts related to that question of access from what you know of the diversity of indigenous communities across a range of options in Canada. Are there any thoughts you can share on how we can consider the question of access?

Prof. Carrie Bourassa: That's a great question. As the previous speaker was speaking, I was agreeing—I apologize, but I've forgotten his name—because everything he was saying applies to indigenous people as well. If you think just about access to end-of-life and palliative care for indigenous people, it's even worse, particularly in northern and remote communities, so if you're talking about physician-assisted dying, I think that is one of the main issues.

You can't account for the diverse beliefs around whether or not physician-assisted dying will be accepted. I think it's something that will be the same in indigenous communities as it will be in broader communities. Some people are going to be accepting of it, and some people will not be. But when it comes to access, there are going to be

issues that are similar to those right now about appropriate services. It's not only about appropriate services. It's about culturally appropriate end-of-life and palliative care services.

Right now, for indigenous people, it's not only about access to end-of-life care services. It's about culturally appropriate end-of-life care services. When I was referring to training for physician-assisted dying, that's what I was referring to. How are you thinking about the service itself and the training of the physicians? People are going to be seeking out culturally safe services. What will that look like? If we're just getting there for end-of-life and palliative care, what is it going to look like for physician-assisted dying?

It's about access, but it's also about access around culturally appropriate and culturally safe care and what that means in those communities. It might look different from community to community or region to region. Certainly, in end-of-life and palliative care, that's what we're talking about now: what culturally safe services would look like.

Mr. John Aldag: In your comments, you also talked about vulnerabilities, and I'd like to explore a bit of that. We'll be looking at culturally sensitive discussions on physician-assisted dying and looking at both on-reserve and off-reserve populations and trying to understand what additional vulnerabilities there are. You talked about some of the absolutely horrific statistics that the indigenous populations already are faced with concerning life and death in Canada.

One of the reports I read was a summary about people who have already had access to physician-assisted dying in other jurisdictions. In a lot of cases, they were talking about how it's almost a service that I interpreted to be for the elite. You have a lot of white men with a university education and with above average incomes who are accepting or taking advantage of physician-assisted dying. I'm really concerned. Given some of the vulnerabilities of the population, if we want this to be universally accessible, would you say that's a concern we should be looking at?

• (1650)

Prof. Carrie Bourassa: Yes, I spoke about this, of course, in the first consultation. It is a concern. The reason it's a concern is that in our population, end-of-life palliative care isn't necessarily for an elderly population. We have multiple deaths in our communities. We have multiple suicides. We have young people who are dying. It's a real issue in our communities that we have a lot of people dying in the younger populations.

When you think about physician-assisted dying, you think about what message that might send in a community where you've just had a number of youths who may have committed suicide or who have been in motor vehicle accidents. It might not be as accepted. It might not be something that is welcomed. That's why I was speaking to really communicating what physician-assisted dying could mean in communities and to really engaging communities around this. If you want it to be accessible, it's going to have to be well communicated.

You talked about access. Who would access it? Where might it make sense to have access to it? I can see it being used in cases where you have.... We talk about this concept of not wanting someone to “die hard”. If you have a terminally ill patient who is suffering, I could see a family wanting to access a physician-assisted death, but it would be in a very particular circumstance, because we don't want someone to suffer and die hard, if you see what I mean.

There are circumstances where I could see that access being welcomed, and then there are some circumstances where, if a community has just had some very tragic losses, I could see them not wanting anything to do with physician-assisted death. It's really about context, understanding the community, and understanding where it would be something that's acceptable and where it would not be acceptable.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you.

Mr. Warawa.

Mr. Mark Warawa (Langley—Aldergrove, CPC): Thank you, Mr. Chair. I will split my time with Mr. Deltell.

Thank you to the witnesses.

First, to the Canadian Cancer Society, thank you for your highlights on the importance of palliative care. You've shared the importance of palliative care and you've also highlighted the fact that in Canada right now palliative care is not readily available for a large percentage of the population. We were told by Health Canada that 70% of Canadians do not have access to quality health care.

The Supreme Court, on the other hand, has said that by June 6 we need to provide legislation that permits physician-assisted dying. Let's say palliative care were to be a component, one of the safeguards, to ensure that people were giving informed consent. In terms of some of the issues causing people to consider hastening their death, would you think palliative care would be a very important component to ensure that there is truly informed consent?

The second part of that question is this. Should the decision by the previous Parliament to ensure that we have a national strategy on palliative care, that we have this change of culture in Canada, start with, within this legislative requirement, palliative care being offered to people—anyone? We're not talking a large number, but it would be required to be offered to people who are considering hastening their death.

Mr. Gabriel Miller: Based on everything I've read about this, I think it makes a great deal of sense to say that palliative care needs to be available and that it needs to be an option in any scenario where assisted death is made available.

I would only go a step further to say that we need to think of palliative care as something that is provided to every Canadian who is dealing with a life-threatening illness and is part of their treatment. Managing their pain, dealing with their emotional and psychological needs, helping them to receive care in the best place possible—those will all be part of their treatment right through, with particular emphasis, of course, when people face end-of-life issues and also when they're confronting the kinds of choices you describe.

• (1655)

Mr. Mark Warawa: Thank you.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Mr. Deltell.

Mr. Gérard Deltell (Louis-Saint-Laurent, CPC): Thank you, Mr. Chairman.

Thank you, Mr. Warawa.

[*Translation*]

Ladies and gentlemen, welcome to your Parliament.

[*English*]

I will continue in English, because my question will be short.

We're not here to say whether physician-assisted dying is good or not. The main issue we're talking about today is “how”. The main question we're asking is this. Do you think the federal government should clearly indicate to the provincial legislatures how to deal with that, or do you think the federal government should let the provincial legislatures have their own definitions of how to help people at the end of their lives?

Mr. Gabriel Miller: I think I can speak on behalf of the organization on this point and say that we need national guarantees in terms of what Canadians can expect to receive in end-of-life care and a common set of standards and definitions around the terms we're using, so that there is a comparable experience for Canadians. As well, as I think Canadians expect, universal access to equal services and support will be guaranteed across the country.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you.

Mr. Rankin, I understand you're sharing your time with Madam Sansoucy?

Mr. Murray Rankin (Victoria, NDP): No, not necessarily. She's been generous....

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Pardon me.

Mr. Murray Rankin: First of all, to Professor Bourassa from the First Nations University, thank you very much for your presentation.

You talked about the fact that there was no specific policy from leading indigenous organizations, the AFN and the like, yet you stressed the need for culturally adopted services in this field and in others. From your experience, do you see a role for traditional indigenous healers in this exercise of physician-assisted dying and constitutional rights? We've heard testimony that nurse practitioners in remote communities may well be able to play a role here. I'm wondering if you can envisage a role for traditional indigenous healers.

Prof. Carrie Bourassa: That would definitely be great.

The thing is, this is already happening. Maybe it's not with physician-assisted dying, but it's already happening in health care in general in New Zealand. They're recognized. They work alongside physicians and nurse practitioners, and they are as recognized as any other medical professional. I think Canada really needs to consider this.

In this particular instance, with this very sensitive issue, I think they would be most welcome. I think they would definitely enhance any kind of experience by indigenous people. Right now, even in end-of-life palliative care, we're getting to the point where most hospitals will at least allow an elder or a traditional healer to come in at end of life. It's not happening in every hospital, but it's happening in most. We're starting to get to that point where maybe they're not working alongside physicians but they're being recognized. I think we have to get to that point and that doing so would be highly recommended..

Mr. Murray Rankin: Thank you.

My next question is to the Canadian Cancer Society.

You talked very passionately about the need for improved palliative care in Canada. Given the requirement under the Canada Health Act for comprehensiveness and accessibility, and given the fact that those are just not there, I would like your reaction to having the federal government withhold funds, under the Canada health transfer, from those provinces that simply do not step up and provide funding for palliative care. Is that something you might be prepared to endorse?

• (1700)

Mr. Gabriel Miller: I heard a similar question put to the minister by the media. I thought she did a pretty good job of handling the question, so I'll borrow from her. I don't think anyone would want the conversation to begin with ultimatums being issued by one order of government to another on this. Hopefully, there's going to be enough of a sense of a common mission, partly as a result of the need to respond to the Supreme Court but also out of recognition of the need to address this issue, that the provinces and the federal government can come together and agree that, as part of the tens of billions that are spent on health care, Canadians deserve a guarantee that they'll receive access to palliative care.

I do think that, as part of an accountability framework for a new health accord, there need to be targets for palliative care, and home care in particular. Canadians need to see, in exchange for the money that goes out across the country for health care, the kinds of results being achieved in their communities compared to those in the rest of the country.

Mr. Murray Rankin: I know you've been reluctant to jump into the physician-assisted dying part of the equation, but I'm going to push it anyway, if I may. This is a requirement of the Constitution. As my colleague said, we're here to figure out how to implement the court's decision.

Given the experience the Canadian Cancer Society has with people suffering, I would presume that you take the position that we ought to be moving forward with doctors, perhaps with a conscientious right not to proceed, but that generally this service ought to be available at the end of life. I see you nodding.

In that case, do you agree that publicly funded health care institutions like hospitals and hospices should be required to provide physician-assisted dying on their premises?

Mr. Gabriel Miller: I won't speak to the question of where, because I wouldn't be speaking for anyone except for me, and that's of no use to you whatsoever, I promise you.

Our view is that end-of-life care needs to be considered to be medically necessary care. We have a principle in this country that, just by virtue of being Canadian, people deserve access to that, regardless of their ability to pay. It seems, certainly, that as a result of the court's decision, this will now be part of the spectrum of care available to Canadians. Access to that care should not depend on people's pocketbooks.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you.

Senator Seidman.

Hon. Judith G. Seidman (Senator, Quebec (De la Durantaye), C): Thank you, Chair.

Thank you very much for your testimony.

If I might, I will say to Mr. Miller and Ms. Masotti that likely every single one of us around this table would agree with you that palliative care is a pretty important aspect of health care in this country, and that there is a continuum in end-of-life care that includes palliative care as well as physician-assisted dying now that the Supreme Court has made this ruling.

There are those who would suggest that parliamentarians—and I have heard this—should consider a separate piece of legislation around a national palliative care strategy and program, but I would like to ask you about and push you into physician-assisted dying, if I might.

We know that Bill 52 in Quebec has already begun. There was much conversation about it. It's been in effect since December. I'd like to know if the cancer society in Quebec has had any kind of feedback or if your national organization has something to say about how things are proceeding in Quebec.

Mr. Gabriel Miller: I have an answer to your question. I'm not sure it's going to satisfy you, but we'll find out.

The cancer society in Quebec has had quite a bit to say about the process there. The organization has been very involved in these discussions right along and has expressed strong support for where that process came out, most importantly because part of what the province did was enact end-of-life legislation that included a right to palliative care.

That was always the number one priority for our organization on the issue. Certainly, I think they felt that they were actively engaged and that a broader view of the needs of Canadians as they approach their end of life was seen by the government. Not only has that right been recognized in legislation, but the Province of Quebec has now started identifying some investments to help make the transition to a more home-based and community-based approach to palliative care.

• (1705)

Hon. Judith G. Seidman: You talked about the conflicts in terminology and the misunderstandings about the terminology, about definitions and things like that. I know that I've often heard the confusion about what palliative care does, compared to physician-assisted dying. From the point of view of Canadians, there is a good deal of confusion. I wonder how you would respond to that and what you would recommend in terms of education.

Mr. Gabriel Miller: Thanks for that question.

I hadn't even considered the confusion between palliative care and assisted dying. We have confusion within the country just on competing definitions of palliative care.

This is tremendously important, because of course if we're talking about rights and we're in the process of defining what all Canadians have a right to in terms of assistance in hastening death and we also decide to say that palliative care needs to be in place, then we need to have a common definition of what palliative care is across this country.

Education is a big part of this. In our report, I think we identified it in a few places. I would defer to any medical professionals in the room who could correct me, but certainly the latest information is that these issues are still simply not a big enough part of the education and training of our medical professionals. For physicians, taking into account and learning how to meet people's palliative care needs is a very small part of their overall medical training.

There are some astounding figures in this report by the federal panel about the number of palliative care specialists in Canada. According to this, the situation is even more challenging than we have found. We need to train more people. We need to have more specialists in palliative care, but we also need to train people as members of teams to be more familiar with how to deal with palliative care needs as part of their specialty, whether they're a nurse, a psychotherapist, an oncologist, or whoever. That's part one.

Then, obviously, Canadians need to be better educated. There's a variety of ways in which we can do that, but one thing we need to do is get advance care planning dramatically increased in this country. In Canada, less than half of the people who die from cancer have an advance care plan.

Having an advance care plan is not just about under what circumstances you should be revived or resuscitated; it's about really looking forward at the potential progression of your disease and the types of choices that you and your family may face. I think it's our best insurance for people making clear and informed decisions and also then maximizing the quality of life they have for however much longer they're going to live.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Senator Joyal.

Hon. Serge Joyal (Senator, Quebec (Kennebec), Lib.): Thank you, Mr. Chair. I will start with Professor Bourassa and then Mr. Miller.

Professor Bourassa, in the section on health in the Truth and Reconciliation Commission report, there are specific recommendations that address the responsibility to train doctors and nurses who provide services to aboriginal people regarding the special realities of aboriginal life conditions and the particular description that you have outlined in your presentation.

What would be your recommendation, in relation to physician-assisted death, in the context of those two sections of the report? I'm thinking of sections 23 and 24 of the report. I bet you know the report. I should have asked you, not put you in an uncomfortable position.

Prof. Carrie Bourassa: No, it's good. I'm glad you're familiar with it.

Hon. Serge Joyal: It's not an exam.

Prof. Carrie Bourassa: It's refreshing.

I was just looking at it the other day. I actually have a grant related to aging and dementia, and in the areas of aging, dementia, and end-of-life care, we are sorely lacking in training, especially with regard to indigenous people. I sit on the Royal College of Physicians and Surgeons of Canada, and end-of-life care and palliative care are, in general, areas where we're lacking in training.

I think these have to be priorities, particularly around indigenous people. Cultural safety in general is such an area. There is a high need for all of these things, so for the TRC to make the recommendations and to have those recommendations in hand, we not only need to train more indigenous people but we also need to have more indigenous physicians. We also really have to train the physicians we have so they will understand the reality in indigenous communities.

It's really twofold. We have a lot of work ahead of us on both sides, if that makes sense.

• (1710)

Hon. Serge Joyal: Thank you.

Mr. Miller, do I understand that since you have no position on physician-assisted dying, you did not intervene in any of the cases that went to the Canadian court and raised the issue of physician-assisted death?

Mr. Gabriel Miller: That's correct.

Hon. Serge Joyal: That's correct.

Can I give you my candid appreciation of that?

Mr. Gabriel Miller: Of course.

Hon. Serge Joyal: I'm surprised that a society as important as the Canadian Cancer Society—which I would think all of us around the table have supported at some point in time through a fundraising drive or a benefit auction or whatnot, as well as through the sale of all kinds of goodies that you put forward on the market—has no position on that, since cancer is the first cause of death in Canada and one can presume that those who will have recourse to physician-assisted death will be Canadians suffering from cancer. I find it strange.

Could you explain to me the rationale behind that? Is it the fact that you don't want to scare Canadians—or donors—with physician-assisted death?

Mr. Gabriel Miller: I can only make some observations based on.... I've been there only a little while, so I'll play that card to protect myself a little bit on this question.

Hon. Serge Joyal: Be candid, like me, you know.

Mr. Gabriel Miller: I'll wait until I'm a senator.

Voices: Oh, oh!

Mr. Gabriel Miller: I have to be honest with you. My best guess, from what I've seen, is that there was a lot of concern about the potential for the issue to divide people. Obviously, when you count on donations, you worry about how your supporters will feel. However, I think there's also genuine ambivalence within the organization.

I have to say that as someone who's fairly new to being immersed in this issue, I've been struck by how it feels as though the country's opinions on it have come around pretty quickly. The conversations I'm hearing in the city now about this are very much focused on "how". I think five or six years ago, they were more about "if".

To be honest, the Canadian Cancer Society has been going through what a lot of Canadians have been going through, which is to make its peace and to address the questions and misgivings that it had about this.

I should also say that one thing I've told people is that defeating cancer is enough of a day job. We don't have to solve all of the mortal questions of the universe, and we have to leave some stuff for other people to figure out.

Hon. Serge Joyal: Thank you very much for the frankness of your answers.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Ms. Dabrusin.

Ms. Julie Dabrusin (Toronto—Danforth, Lib.): Thank you.

I would like to direct my question to Professor Bourassa, if I may.

One of the discussion topics that we've heard a lot about is the question of what is an adult and what is a mature minor. There are differences across our provinces and different frameworks for that. From your research with indigenous health issues, what do you know about how "adult" might be interpreted in different indigenous groups across Canada? Are different ages used?

Prof. Carrie Bourassa: Oh, yes. Sometimes an adult is 18, sometimes an adult is 21, and sometimes it's 26. It really depends on the region. Sometimes we say you're still a youth when you're 26. That seems crazy to some people. How could you still be a youth when you're 26? But I was a youth for a long time, and I was sad when I wasn't a youth anymore. Clearly I haven't been a youth for a long time.

It really depends. It's different in different regions, different territories. It really varies.

• (1715)

Ms. Julie Dabrusin: Is there a concept beyond numerical age? Is there a concept of when a person reaches...? We've been using the term "mature minor", but it's the age when a person is assumed to have reached a certain maturity in being able to make decisions. Is there that kind of concept in the different cultures you've investigated?

Prof. Carrie Bourassa: In the Anishinabe culture, which I'm familiar with as a Anishinabe Métis, we go through rites of passage. For my daughter, when she had her first moon time, she was age 12. At around age 12 or 13, when they are going through their rites of passage, that's when you say they are starting to make their mature decisions.

Now, they're still youths. They still need the love and support of their parents and their community and their *kokums* and *mushums*, their grandmothers and grandfathers. But that's when they're starting to go into, as we say, the rapids of life. Those are their tough years, their teenage years. That's when they have to start making their decisions and learning from their mistakes. You give them in their younger years what you hope will be their values. We call them the seven sacred stones. You hope that they will make those decisions. It is up to us now to stand on the riverbank and yell words of encouragement. We don't get in the river with them but just let them make their way. That's really when they start to mature and learn. You have to let them make their mistakes, if that makes sense.

So it's usually around those rites of passage.

Ms. Julie Dabrusin: Is there a point in time when that starts applying to health care decisions? You've been talking about 26 years of age, and 23, and also first moon time around 12.

Prof. Carrie Bourassa: Yes, it would be around then, because you have to start taking care of your body. As a young woman, now it's your first menstruation, and now you have to start taking care of your body. Now you have to start making those decisions about your body. As a sacred young woman, or as a young man, you have to start making those decisions. Now you're of child-bearing age. That's when you have to start making those decisions around your body, your health.

It varies, obviously, from community to community and nation to nation, but those are the teachings that I was given. It doesn't mean that I'm completely void as a mother, that I don't have input, but you want your children to start making those decisions now. They're maturing, and they have to start to listen to themselves and make those decisions as a young woman or a young man.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Mr. Cooper.

Mr. Michael Cooper (St. Albert—Edmonton, CPC): Thank you, Mr. Chair. I'll be sharing my time with my colleague Ms. Harder.

Professor Bourassa, in your presentation you referred to the need for provision of "culturally appropriate" and "culturally safe" services. That's how you characterized it. I'm wondering if you might be able to elaborate on exactly what that means in the context of euthanasia and assisted suicide.

Prof. Carrie Bourassa: I think it's going to depend on communities, to be honest with you, but I think the first thing would be for physicians and clinicians to really understand about power and the systemic issues. We have a lot of systemic issues that I think people don't want to acknowledge. Really, cultural safety is about acknowledging power systems and understanding the ongoing impacts of colonization. Knowing that and understanding it means that then you learn about how to engage with communities.

Then, when you can engage with communities, that's when you can open up those lines of communication in order to understand what the needs of the community will be around physician-assisted death. If you can't do that, it's not going to be a success. You're not going to know what those needs are. The needs are going to be very different. It's not going to be much different from end-of-life and palliative care issues. In fact, I think it will be more sensitive.

If physicians are trained around understanding those root-cause issues, those deep-seated systemic issues, they're going to be able to open up those lines of communication. The number one problem we've had—and nurses have said this to us—is that they don't know how to start discussions. They're worried about offending the people they're working with. They don't know enough about them. They don't understand the spiritual needs and aspects. They don't know why they have to smudge. There are all these kinds of things.

If they can understand those things going in, that is going to make those lines of communication open. It's going to create that environment of safety for the first nations people, Métis people, or Inuit people they're working with, and it's going to make their jobs a heck of a lot easier.

• (1720)

Mr. Michael Cooper: Thank you.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Ms. Harder.

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

Thank you very much for coming out today and being with us.

My question for you, Mr. Miller, is about how as an organization you've clearly taken a very strong stance with regard to palliative care. You've been great advocates on that front. I'm wondering if you can explain to me the impact that a lack of palliative care might have on a patient's decision to opt for physician-assisted suicide.

Mr. Gabriel Miller: Why don't I speak first about the impact of a lack of palliative care on any patient? Then we can talk a bit more about how it might affect someone facing that issue.

Palliative care is care that's designed to protect the quality of life of the patient and their family. It's easy to forget, I think, how much our system is built around delivering services in hospitals that are typically about fighting a particular disease or treating a particular ailment.

That system, left to its own devices, can leave people in a place where their pain is not effectively managed; where their symptoms, from dehydration to nausea to dementia, can become a greater and greater drag on their quality of life and their ability to think clearly; and where their despair, their anxiety, and their fear in confronting their own mortality or confronting the pain of dealing with severe illness can have a profound effect on their outlook. Also, of course, there's the factor of whether they're able to receive care surrounded by loved ones and be in a community setting, versus sometimes being in an emergency room or in an intensive care unit, where they can be really removed from the people they need around them.

I think it's intuitive for all of us to see how much those factors can affect someone's well-being and their mindset. Also, there's evidence that it actually affects their medical outcomes. The people who receive effective palliative care, especially early palliative care, do better. I think we can all understand how having a positive and healthy outlook, and not dealing with depression and anxiety, can make it easier to combat a physical challenge.

I don't have research or expertise in terms of the connection between that and assisted dying, but I think of what was said in the consultation piece that was done by the panel. In fact, these are quotes from *Dying with Dignity*, "Nobody should have to choose an

assisted death because the medical system has failed to give them other options", and, "Canadians do not want assisted death to become the preferred option simply because other options, such as high-quality palliative care, are not accessible."

I think we need to see that one of the unifying principles in all of this is that we would like as much as possible to help people overcome their suffering and meet their challenges through care and support. If anyone chooses death because those things aren't available, that would be a tragedy.

• (1725)

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you.

Senator Nancy Ruth.

Hon. Nancy Ruth (Senator, Ontario (Cluny), C): Thank you, Chair.

I would like to know, what is "palliative care"? The reason I'm asking is that I heard recently of a friend whose husband had colon cancer and was in palliative care. He was effectively starved and not given fluids. His muscles contracted, and it seemed that he was in more pain. It was an extraordinary story. The whole family suffered—the child, the wife, and so on.

Could you tell me what it is you mean by palliative care?

Mr. Gabriel Miller: Sure. The professor may have more to add, or corrections to make, to my response.

We take a broader view of palliative care in that we really believe it needs to begin as soon as someone is diagnosed with a critical illness. Palliative care is the care that's focused on and preoccupied with the patient's quality of life, and quality-of-life issues emerge the moment someone is diagnosed with a critical illness. From that moment, they have to start dealing with a great deal of uncertainty. They need to be engaged in planning their treatment. There may well be symptoms to manage as a result of early treatment. Of course, these issues become more pressing the closer you come to end of life, because the time that you have is sacred and those challenges are pressing in on you.

More specifically, palliative care is delivered by a team. It is not delivered by a single specialist. That team could include a palliative care specialist. It potentially could include a family physician, a psychologist, a nurse, a support care worker. All of these people need to be working from the same playbook in terms of the choices the patient has made in terms of their care planning.

The team really focuses on three things. The first is pain and symptom management, which gets very complex, as people know, with a variety of medications and treatments going on. The second is psychological and emotional support. We all know, with the mental health awareness week that's just happened, what an interaction there is between mental and physical health. The final piece that we like to emphasize is engagement of the patient in key decisions, including the location of care. That means patients having the option to receive care in the community or at home when that's medically feasible, which is also usually more affordable for the system.

Hon. Nancy Ruth: Were you surprised by the story I just told you, that this happened to this particular man in palliative care?

Mr. Gabriel Miller: Yes.

Hon. Nancy Ruth: All right.

You've given all these criteria. When my own mother was 90 and was told it wasn't worth pumping out her lungs and doing heart work, she was given three choices on how to die. She chose one and that was it. She was put on a morphine drip and out she went. There was no food and there was no water.

Is that unusual, in your experience?

Mr. Gabriel Miller: Senator, I really need to be careful, because I'm not a physician.

Hon. Nancy Ruth: Okay. Thank you.

Mr. Gabriel Miller: Thank you.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Senator Cowan.

Hon. James S. Cowan (Senator, Nova Scotia, Lib.): At the risk of appearing to be sort of ganging up, I wanted to follow up on some points that Senator Joyal made earlier. All of us are aware of the statistics on the availability of palliative care and the need for better palliative care more widely distributed across the country, but that's not the issue we are here to deal with. You have asked to come tonight to help us deal with a very specific issue, which is how we should advise the government to respond to a decision of the Supreme Court of Canada.

This has to do with assisted dying, not with the availability of other things. None of us see physician-assisted dying to be an alternative to palliative care. None of us see that.

However, if we look at the international experience with physician-assisted dying, I don't have the numbers in front of me, but it seems to me that in every country where they track the numbers and the reports over the years, patients suffering from various kinds of cancers are the highest users of this option. If that's the case, it really surprises me that the Canadian Cancer Society, which has done so much good work in this area, is not prepared to come and give us some assistance in the task that we have before us.

I think particularly of advance consent and directives. I know from my experience as a lawyer the number of advance directives that I've drafted for clients who have cancer and who are concerned about the prognosis.

The Canadian Cancer Society must have thought about this. Is there no advice you can give us on the specific issues that are before us today? All of us would, I'm sure, support greater availability of palliative care, but that's not doable. We have to report to the government by the end of this month on some very specific issues. I was hoping you might be prepared to provide us with some assistance on those issues tonight.

• (1730)

Mr. Gabriel Miller: I appreciate what you're saying, and I think that as this issue moves on, there's no question that there's probably some more thinking that we have to do and we'll have to be part of some of those decisions. Certainly we recognize that the country's moving forward in this area and that there's a discussion to be had.

To be honest, I think, having reviewed the consultations that have been had, there's some very good feedback being provided to the committee.

I can appreciate your frustration with our not engaging on that question. I would only say—and I hope you'll take this in the spirit in which it's provided and I don't mean in any way to insult you—that I think the greatest risk in this situation is that the country will go through this situation and say, “Oh yes, of course everyone can agree with palliative care but we really need to take care of this assisted-dying piece.”

I go back to what's listed here in reports from 1995, 2000, and 2010. Mr. Albrecht—

Hon. James S. Cowan: Excuse me. I don't mean to cut you short, but I'm going to get short here in a minute.

Isn't it exactly that? This committee has been charged with a responsibility. The government has said that it will act in response to a specific time frame that's been set forth by the Supreme Court of Canada. Even if we wanted to say all right, let's set this issue aside and solve the palliative-care issue and then we'll get back to this, we don't have that luxury.

Mr. Gabriel Miller: Senator, if I, in any way, have left that impression, I want to correct it. We completely understand that direction has been provided by the court, that there's work to do on assisted dying, and that a response has to be provided on that. Frankly, we accept that this is now a right that's going to be recognized in Canada and that there are questions about how it's going to be exercised. This is not a question of “wait until”.

My concern, frankly, is that we will deal only with assisted dying. I think what we would say is that we should deal with assisted dying—and I'm happy to go back to our society and say that these people need some more feedback from us—but it will be a failure and a most dangerous failure if we don't also fix palliative care at this moment.

Hon. James S. Cowan: I would agree with you absolutely. Thank you.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Mr. Arseneault.

[*Translation*]

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

My question is for Mr. Miller, who represents the Canadian Cancer Society.

Mr. Miller, I don't want to repeat what senators Cowan and Joyal just said candidly, but you started off by announcing that you were not here to help the committee find a solution in relation to its mandate concerning the Carter decision. To be frank, and perhaps not candid, I must say that I am very disappointed in the Canadian Cancer Society, since many Canadians die from cancer.

Are you the spokesperson for the Canadian Cancer Society? Was your mandate to come here....

[*English*]

Mr. Mark Warawa: I have a point of order, Mr. Chair.

•(1735)

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Yes, Mr. Warawa.

Mr. Mark Warawa: Thank you.

We've invited witnesses and I'm concerned that we are now criticizing one of the witnesses because they don't have a position. They've shared their position and now to bait them and insult them, saying that we're very disappointed with this organization, which is respected around the country, I think that's inappropriate and it is carrying this too far.

They're here to witness and I encourage us not to put words in the mouths of any witnesses, and that we respect the witnesses and we show respect. I'm concerned that we're going too far when we start criticizing them and saying we're disappointed that they don't have this or that position.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Your point is well-taken. We are here to get advice with regard to advising the government on the legislation and I would urge us all to stick to that objective.

[Translation]

Mr. René Arseneault: Mr. Chair, I wanted to point out that we do not know what the Canadian Cancer Society's position is regarding the Carter decision. My intention was not to insult anyone. If that is how you understood what I said, Mr. Miller, I apologize.

You said a few times that thousands of Canadians had no access to palliative care. I even read that about 70% of Canadians had no access to such care. Is that indeed how you see the situation in Canada?

Mr. Gabriel Miller: Thank you very much for the question.

I will answer in English.

[English]

I have to be honest with you, I've heard several different figures. That's the figure that's in the panel's report. Our report has different figures from across the country. I've heard figures as low as 15%, and to be honest that illustrates the problem.

Mr. René Arseneault: Pardon me, what would be 15%?

Mr. Gabriel Miller: That's 15% of Canadians have access to palliative care.

Mr. René Arseneault: Only...?

Mr. Gabriel Miller: The fact that in public circulation there are estimates as low as 15% and up to 50% to 60% is a pretty clear indication that we don't have a good handle in this country on how well palliative care is being provided, or at what level in different parts of the country. In fact we don't even have a common definition.

[Translation]

Mr. René Arseneault: Mr. Miller, let's talk about statistics when it comes to access to palliative care.

Like me, you said that you have heard some things on the issue. Has the Canadian Cancer Society conducted studies to obtain accurate statistics on the accessibility of palliative care across Canada?

[English]

Mr. Gabriel Miller: Our report is based on a complete review of all the most recent literature across the country. In terms of the statistics that we cite in ours, because palliative care isn't measured or defined in the same way across the country, you have to gauge access through other indicators. One of the best indicators is how many people are dying in hospital instead of at home. Almost one in two cancer patients are dying in hospital, which is an indication that they aren't getting palliative care early enough and not getting the chance to choose where they receive care.

We don't have an estimate that we've generated ourselves of how many Canadians have access to palliative care. It would take considerable resources to generate such an estimate, because first you would need to define it for the whole country and then you would have to go out and collect data. That's not being done in the same way in different parts of this country right now, by anybody.

Mr. René Arseneault: Thank you.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): This brings us to the end of this session. We've let it go a little bit longer because of the absence of the third panel we had hoped for.

I do want to thank our guests today.

Before I officially close the meeting, I have a couple of notes for committee members.

I can advise you that tomorrow's meeting is expected to be as scheduled, from 5:30 until 8:30. It is expected to go as per the schedule. However, for Wednesday and Thursday there may be votes, so we will try to adjust the schedule as required. We will let everyone know as soon as we have confirmation of the vote issue. In doing so, we will try to start the meetings earlier, as opposed to going later. With regard to Friday, I want to remind us that we have two meetings in camera, one from 9 to 11, and a second one from 12:30 to 2:30.

That is the schedule, with certain certainties now, and certain uncertainties. The uncertainty will be as to when the meetings start on Wednesday and Thursday. That's it.

With that, I declare the meeting adjourned.

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