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Chair

Ms. Hélène LeBlanc

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● (1530)

[*Translation*]

The Chair (Ms. Hélène LeBlanc (LaSalle—Émard, NDP)): Hello and welcome to the tenth meeting of the Standing Committee on the Status of Women.

First, I would like to tell you that this week, 2 to 8 February, is Eating Disorders Awareness Week. I believe that it is entirely appropriate for our committee to recognize this national week, and that it is particularly timely for us to lead this study, which is related to that subject.

I would also like to let you know that one of the witnesses who was scheduled to appear between 3:30 p.m. and 4:30 p.m. is unfortunately not able to make it because of weather conditions around London, Ontario. We are trying to see if it will be possible to meet with this person later.

We have with us, byvideoonference, Ms. Merryl Bear.

[*English*]

who is the director of the National Eating Disorder Information Centre. She comes to us by video conference from Toronto.

Welcome, Mrs. Bear.

I would like to let you know that you will have 10 minutes for your presentation, followed by questions.

I invite you to start your presentation.

Ms. Merryl Bear (Director, National Eating Disorder Information Centre): Madam Chair and members of the committee, thank you for helping to raise awareness of Eating Disorder Awareness Week. I know that some of you have been on social media, and we very much appreciate that.

Eating disorders are complex conditions with no one cause. Biological, psychological, and societal influences contribute to their development. With the right kind of intervention, eating disorders may be prevented, the course of the illness shortened, and full recovery achieved.

Dr. Woodside has provided this committee with information on the extent, severity, and impact of eating disorders and inadequate treatment options across the country.

In Canada, like other western nations, we have a particular cultural idea of the ideal body, which includes notions of healthy eating, healthy weights and appearance. We also share similar views towards mental health challenges. The impacts of these beliefs on eating disorders are experienced in myths, stigma, and social and economic hardships, which perpetuate the problems of prevention, identification, and treatment.

I represent the National Eating Disorder Information Centre, as was mentioned, and since I have limited time I'll refer to the organization by its acronym, NEDIC. This socio-cultural space is where we at NEDIC do our work, and through NEDIC, the situation across Canada can be explored.

NEDIC was begun in 1985 and is unique in Canada in a number of ways. We're the only community organization focused on eating disorders and related issues that works nationally. We have a national helpline and database of approximately 800 service providers for eating disorders. The vast majority of these are fee for service, and about 80% of our callers can't afford this and are looking for services that are covered by provincial health insurance.

Difficult as it is to find services in urban and peri-urban areas, remote and rural services are largely non-existent.

NEDIC provides information, support, and resources to individuals with eating disorders, family members and friends, health and education professionals, the media, and students. We are often the first port of call for frightened parents, a confused spouse, or an individual wanting reassurance with regard to her thoughts and behaviours.

To lower barriers to information and services, most of our assets are web enabled. One of the most important aspects of our work is to increase understanding among the public, professionals in health and education, and the media of what eating disorders are, who gets them, what influences their development, and what help is available.

We work hard to build partnerships. We believe in collaboration to maximize resources and impacts. For example, we create curricula for educators and youth-serving organizations to support and build critical thinking and emotional resilience in children and youth, which will help to prevent eating disorders. Examples are our “Love Yourself” badge for the Girl Guides of Canada, a fact sheet for the Canadian Centre on Substance Abuse, and our work with the Elementary Teachers' Federation of Ontario. We have developed a critical media literacy curriculum for grades 4 to 8, which fills a national gap and meets ministry expectations in all provinces and territories.

To disseminate the latest information, NEDIC is partnered with groups such as the Canadian Women's Health Network, formerly funded by the now defunct women's health contribution program. Already challenging, it's getting increasingly difficult for small organizations like NEDIC, focused on more intangible goals, such as increasing understanding, education, and prevention, to actually find partners with the capacity to support our common interests and without commercial interests. This situation leads to a lack of accessible evidence-based information on eating disorders and related issues.

NEDIC's limited budget means that we rely on pro bono services and are not able to saturate markets as needed for real traction. No other organization in Canada does this educational work. Nationally, community-focused eating disorder organizations working in education, prevention, and support come and go because of limited and insecure funding.

● (1535)

Individuals who have recovered from an eating disorder or parents begin many of these organizations, such as, Sheena's Place in Toronto, Hopewell in Ottawa, and the National Initiative for Eating Disorders. They are heroic in their efforts to improve access to information and treatment. For most, it's not a sustainable model.

To effect change in belief, attitudes, or behaviour, there has to be a strategic, multi-platform, sustained approach which is appropriately funded. Without this, our attempts to raise awareness of eating disorders are like whistling in the wind. We must get our message to a critical mass or to a tipping point. There is too much competing noise in the culture from the diet and appearance industries and much misinformation about healthy bodies and healthy minds.

Some public health messaging, particularly that which bleeds through from the U.S., contributes to weight stigma and body shame, and can influence the development of food and weight preoccupation in general and eating disorders in particular. Research shows that girls with poor body image are less likely to engage in academic, social, and economic opportunities, and are less likely to voice an opinion.

The stigmatization of an eating disorder is complex. The common face of an eating disorder is that of an emaciated young woman, usually white skinned. Common beliefs about individuals with eating disorders are that it's self-inflicted, it's just a phase, they should just eat and get over it, and it's just an attention grab. Research shows that both the general public and health professionals hold these myths. The fact is that one cannot tell the health of an individual based on their physical size and weight, including whether they have an eating disorder.

The actual face of an eating disorder is heterogeneous: mostly female, but also male; individuals who identify with their assigned sex and gender, and those who don't; racialized individuals; newcomers to Canada and established Canadians; individuals with physical disabilities; individuals with concurrent medical or psychological disorders, such as, diabetes, substance abuse, depression, PTSD, and so on. Individuals from all socio-economic walks of life have eating disorders.

Eating disorders have the highest mortality rate of all psychiatric illnesses and are the third most common illness among adolescent girls.

The consequence of these mythologies about eating disorders is that shame creates silence that can be deadly. Individuals ashamed of what they are going through are less likely to seek the help that they need. We need to amplify the conversation about eating disorders in Canada, mindfully, fully, respectfully.

There is simply no financial support by any level of government for an appropriately resourced, sustainable organization focused on increasing understanding of what eating disorders are, how they develop, what maintains them, what kinds of treatment are available and how to access it.

NEDIC, for example, has 2.5 permanent staff members and our sole source of annualized funding is a small budget from the Ontario Ministry of Health and Long-Term Care. The majority of our work is done by cobbling together student, volunteer, and project funding.

Working upstream, in education, mental health promotion, and prevention of eating disorders is of critical importance. Awareness and education campaigns are important because they can lead to better population health and fewer subclinical eating disorders. They can relieve shame, denial, and decrease stigmatization and discrimination against individuals with eating disorders. Education campaigns can lead to better early identification of individuals at risk. They can lead to earlier treatment which is known to have better outcomes. Earlier treatment for less entrenched eating disorders will relieve the pressure on already inadequate services for the severely ill.

● (1540)

Clearly, appropriate prevention, early intervention, and early identification and treatment will have social and economic benefits that are largely unquantifiable. Parents of individuals with eating disorders will not be taking time off work to care for critically ill children. Youth will remain in school, socially engaged, and will contribute more to society, enriching all of us.

There are enormous gaps across Canada in the continuum of care that should exist for eating disorders. They run the gamut from research and health promotion to prevention and treatment. Canada desperately needs a coherent national eating disorders strategy. I believe that it's critically important to invest in education at the population level as well as within segmented audiences.

Thank you for this opportunity to appear in front of you today. I'm happy to answer questions.

The Chair: Thank you very much for this very good testimony.

I will ask Ms. Truppe to start the first round of questions.

Mrs. Susan Truppe (London North Centre, CPC): Thank you for appearing today, Ms. Bear, and for your presentation. I know that you have over 20 years of experience in the area of eating disorders, so we're pleased to have you here, to learn from your extensive experience.

I understand the goal of the National Eating Disorder Information Centre is to raise awareness and promote understanding of eating disorders. What would you say is lacking, whether it be in our health system or socially that makes this awareness necessary?

Ms. Merryl Bear: Perhaps I could have another 10 minutes, please.

Our health system is embedded in our socio-cultural and economic context so it's very difficult to separate them out. Certainly the mythologies that exist in our culture carry through into our health system, so the values and perspectives of what is seen as important and what gets funded arise out of our cultural and economic context.

● (1545)

Mrs. Susan Truppe: You mentioned we must get the message to the critical mass. What do you think is the best way of getting the message about awareness to the critical mass?

Ms. Merryl Bear: It needs to be a sustained effort and it needs to be multipronged. In my opinion, it would be important to provide education to the general population and to target within the population particular influences, such as institutions of the media, health, education, and justice.

Mrs. Susan Truppe: Thank you.

Ms. Merryl Bear: Sorry. I guess I'm trying to keep it short with shorthand, so if you'd like me to elaborate, please let me know.

Mrs. Susan Truppe: Thank you.

You taught and counselled at schools, colleges and universities. How did you bring awareness when you were teaching and speaking to the students?

Ms. Merryl Bear: By raising it at every opportunity within the curriculum, and also in conversation.

Because a lot of the underpinnings of eating disorders lie in cultural messaging and some of the treatment strategies are counterculture, we have to create opportunities for conversation which allow individuals to have a different perspective and to test that perspective against what they already know.

Mrs. Susan Truppe: Thank you.

I'd venture to say there's certainly a lot more awareness now about eating disorders than there was probably 20 years ago when you began, but why does it continue to be under-reported and understudied? In other words, why does your organization still need to continue to exist?

Ms. Merryl Bear: Well, 20 years ago I had hoped that I would work myself out of a job. The reason it hasn't happened, I believe, is that few resources have been put into this area. It has been made a problem by a media and a culture that glamorizes some of the behaviours that are symptoms of an eating disorder: overly restrained eating; excessive physical activity; guilt around eating; shame around one's physical appearance; and the mistaken belief that having a thin body is going to provide access to all the good things in life, such as health, wealth, happiness, etc.

Mrs. Susan Truppe: I'm interested in the network that you must have as a national organization. How do you connect with colleagues in your field? Do you share best practices?

● (1550)

Ms. Merryl Bear: As much as we can. The limitation is that we are extremely small, and we have a very small budget. The other organizations working in this area, particularly in the areas of education, awareness, and prevention are also very small and have limited budgets. Therefore, when one has to choose between helping the individual who's sitting across the table from you to find help and support, and spending time on the phone with a colleague, it's often the person in front of you who's going to be privileged, and we all understand that.

It's very difficult for the local community organizations to actually find the time and the resources to break out of the silos created by the pressure of the work that we face.

NEDIC has a website that includes an events site where any individual or organization who has an event or has an education opportunity can list with us. We try to support other organizations where we can. We are in very close contact with the other six community-focused organizations in Ontario. We support those that are in B.C., Quebec, and Newfoundland.

Mrs. Susan Truppe: Very quickly, because I probably don't have a lot of time left, what would you say is the best practice that you've heard? What is the best practice that you would like to share in regard to bringing awareness to eating disorders?

Ms. Merryl Bear: I think it's in terms of focusing on children and adolescents to not focus on eating disorders and to build critical thinking skills and emotional and psychological resilience.

The Chair: Thank you very much.

Mrs. Hughes, for seven minutes.

Mrs. Carol Hughes (Algoma—Manitoulin—Kapuskasing, NDP): I really appreciate your taking the time to be part of this study.

You've talked about a strategic, multipronged approach. You also talked about the coherent national eating strategy that is needed.

When we look at this we know that the impact is not only on the person affected, but as well you mentioned the family, and then there's the community, and then there's the health care system. There's a big ripple effect. I want to address the gaps in treatment that you have encountered along the way.

Eating disorders afflict people from all communities and backgrounds. That we know. Can you speak to the fact that minority communities may have a harder time accessing services and culturally appropriate information? Is that a factual statement? I'm also wondering what the impact is on first nations people as well, and those who are not financially well off.

Ms. Merryl Bear: The impact is devastating. There is a lack of resources for all individuals with eating disorders.

For those who fall outside what we commonly call the main stream, there are huge barriers to accessing appropriate education, support, and treatment. All I can say is that it doesn't exist. A treatment strategy for individuals from minority communities, as far as I'm aware, does not exist. There are valiant efforts by health care providers in communities to do what they can. However, if the priorities are focused elsewhere, whether it's diabetes or other health issues, then eating disorders are going to remain under-identified and under-treated.

Mrs. Carol Hughes: I want you to know that I think you have a lot to contribute, so if you want to contribute a little bit more, and you feel you're taking too much time, don't worry about it. It's my time, and I'll allow you to do it.

Ms. Merryl Bear: Thank you.

Mrs. Carol Hughes: You talked about the funding aspect as well. You said that there's not enough financing. I see that the provincial government puts a little bit in, and you're in Ontario, of course, and there's nothing from the federal government. Is that correct?

Ms. Merryl Bear: Correct.

Mrs. Carol Hughes: How would you see this be properly resourced?

You talked about the need to be properly resourced. I'm wondering, given the fact that the federal government.... If the federal government was to undertake a national awareness campaign, how might such a campaign address marginalized communities? On the aspect of the funding as well, how much do you think you would need to get that off the ground at this point?

I know that the government would probably say that this is a time of financial constraints, but I'm saying we have to put financial constraint aside for a second and think of the lives of people, and the impact this is having on the health care system itself.

Ms. Merryl Bear: With regard to engaging the needs of marginalized communities, it's my opinion that the best way to do that is to actually collaborate with them. They will be the individuals who will be able to provide the most appropriate entrees into their communities with the support of experts in eating disorders.

In terms of funding for a national awareness campaign or strategy, I would prefer to see a strategy rather than a campaign being funded. It might be semantics, but I think of a campaign as a one-off project, whereas I see a strategy as being mindful and focused on the multiple levels of society that need to be engaged in a conversation about eating disorders and food and weight preoccupation in general. That would be at multiple levels of society.

● (1555)

Mrs. Carol Hughes: When you're talking about a national strategy, how would you view that outreach? There are communities that are a little bit more difficult to get to, and Canada is actually quite vast. Are you talking about putting something on the Internet or are you talking about bringing in the school systems, the school boards? I'm trying to get some sense on that as well. You've talked about the education piece, the health piece, and the justice piece, but I'm just trying to see how we actually put this all together.

Ms. Merryl Bear: All of those are useful aspects of a national strategy. There are huge opportunities to use new technology and media to engage with individuals. Developing a website is not, in my opinion, useful unless one knows about it and has access to it.

NEDIC, for example, is a very well-kept secret in Canada because we don't have the resources to raise our profile. I wouldn't want to replicate or duplicate things that already exist. I would want to see a strategy where there's an environmental scan of what does exist in the country, pull together what actually is working and what is good, and amplify it. We don't need to start from the beginning.

Many of the local community organizations have made very good inroads into the local communities, and we can capitalize on that. They have the trust of their communities. They're working in the institutions, not just the schools, but the health care system and other institutions as well. A strong collaborative strategy is what I think is sustainable.

The Chair: Thank you very much.

[*Translation*]

Ms. O'Neill Gordon, you have the floor for seven minutes.

[*English*]

Mrs. Tilly O'Neill Gordon (Miramichi, CPC): Thank you for being with us. Certainly, this is a very important topic to all of us, and with your years of experience—you sure have a lot of experience—you can provide us with a lot of information.

As we look over and listen to your presentation, we are speaking here about treatments, and a lot of what your organization talks about is prevention and awareness. How have you found that this preventive approach is working so far?

Ms. Merryl Bear: This is an area that is also underfunded, so it's very difficult to implement evidence-based prevention strategies, especially as a national strategy.

As much as there is a need for increased funding and kinds of treatment for eating disorders, so too there is a need to step back and look at what evidence-based prevention programs exist—there are some—and to see how they can be integrated into curricula, whether it's in the schools, at primary and secondary levels, or in professional training.

● (1600)

Mrs. Tilly O'Neill Gordon: What can we learn from this about new potential practices?

Ms. Merryl Bear: I'm sorry, could you repeat the question?

Mrs. Tilly O'Neill Gordon: What can we learn from this about new potential practices, practices that we'll promote later that perhaps would be even more helpful than this? Are there any other means that we can use?

Ms. Merryl Bear: I'm sorry, I don't understand the question. Are you asking me to comment on additional strategies?

Mrs. Tilly O'Neill Gordon: Yes.

Ms. Merryl Bear: Additional to school-based strategies?

Mrs. Tilly O'Neill Gordon: Yes.

Ms. Merryl Bear: Okay.

It's a big challenge, because many of the attitudes and beliefs that underpin eating disorders are endorsed by our culture. We need to create a cognitive dissonance. We need to have a conversation that starts to enable individuals to begin to challenge the understanding of what is health, what is a healthy body, and what is a healthy mind.

Mrs. Tilly O'Neill Gordon: Okay.

I know a family with a daughter who had an eating disorder. She received a lot of help, and went off to a facility where she was given the help she needed. Today she is a nurse and is doing very well. However, her parents and her other siblings had to deal with this, and they certainly had a very tough time handling it.

I'm just wondering if you can elaborate on what help is out there for parents and other siblings.

Ms. Merryl Bear: There's very little, actually. There are the local community organizations—I've referenced some of them—which do have groups to support family members and significant others of an individual with an eating disorder.

For those individuals who don't have access to that, if they can call NEDIC, then we do provide them with information about the Canadian Mental Health Association local branches or other opportunities in their community where they might be able to get some support.

It's spotty, and many of the individuals who staff mental health organizations don't have training or education in eating disorders. It can be frustrating for family members and significant others to get support in their local community.

Mrs. Tilly O'Neill Gordon: Would you say this is probably one of the most difficult tasks you have to deal with in this area?

Ms. Merryl Bear: Yes. One of the most difficult tasks we have is that when we pick up the phone, we ask how we can help the caller at the other end and there is absolutely no service to which we can refer them. We cannot fabricate or make treatments and support services available. It's a very difficult conversation to have.

Mrs. Tilly O'Neill Gordon: As a great friend of the mother and father, I know it was very difficult just to talk to them about this. As is always the case, they were always just hoping that she'd get over it and that it wasn't anything really serious. It wasn't until she was finally diagnosed with this that they began to realize it and to then look for help for her and for them.

It was difficult, as a great friend, to know where to turn; that's what I'm saying.

Ms. Merryl Bear: Yes.

Mrs. Tilly O'Neill Gordon: We spoke last year to a doctor who was vocal about the effect of the media and its representation of women. For young women, young people, this sends certainly a message about beauty.

Could you tell us more about your campaign “Cast Responsibly, Retouch Minimally”, which is aimed at fashion?

Ms. Merryl Bear: It was a pro bono campaign that we developed with an advertising agency. We were focusing on raising awareness both in the public domain and in industry about the unattainable beauty ideals that are in the fashion industry, in fact, in marketing. It's not just the fashion and beauty industries. If you want to look at what kinds of bodies are used to sell cars or tires or whatever it is, it is across all the marketing of consumer goods.

What we wanted to do was raise awareness of the damage that it does when we hold onto a very narrow idea of what is beauty and what that ideal beauty can bring the individual.

● (1605)

The Chair: Thank you.

Ms. Merryl Bear: We were very successful among industry in raising awareness. We got a lot of media in the advertising and marketing publications.

The Chair: That's good news. It's good to hear the campaign was good.

Thank you very much.

Now we go to Ms. Duncan for seven minutes please.

Ms. Kirsty Duncan (Etobicoke North, Lib.): Thank you, Madam Chair, and thank you to NEDIC for the tremendous work you do.

Before I start with the witness, I did ask for some very specific information to be tabled on December 10 and I have yet to receive it, so I hope that's forthcoming.

Dr. Bear, you said there are 800 service providers in the country. Do you have an exact number for what percentage of those are fee based, and if not, could you table it with the committee later?

Ms. Merryl Bear: I'd like to clarify that we hold a database of approximately 800 service providers. It is by no means exhaustive, because not everyone who practises in the field necessarily lists with us. We often have to go out and find individuals who are providing services.

In terms of a fee base, I can certainly get that information to the committee.

Ms. Kirsty Duncan: I'd appreciate that. Thank you.

Some people will require day treatment, some will be hospitalized, sadly, and some people will require long-term treatment. How many long-term treatment centres are there in Canada?

Ms. Merryl Bear: There are far too few.

I would also like to draw the attention of the committee to another area of treatment that hasn't been addressed. Before individuals get into hospital-based treatment, whether it is a day hospital, out-patient, or in-patient treatment, there are a range of other options that should be explored and that should be a part of every individual with an eating disorder's options, because that is often a less traumatic, less intense, and less invasive option for help in recovery.

Ms. Kirsty Duncan: Yes, we would like to catch it early, but if we don't, do you know exactly how many long-term treatment centres exist in Canada?

Ms. Merryl Bear: May I send that information to the committee? I can also break it down by child, adolescents, and adults. Would that be helpful?

Ms. Kirsty Duncan: It would be extremely helpful.

If people require long-term treatment, and this may be something you want to table with the committee as well, what is the average wait time if they require that long-term treatment?

Ms. Merryl Bear: I think that Dr. Woodside spoke to the wait times for the Toronto General program. We are not always privy to how long the wait lists are in institutions across the country, and that does change depending on what resources they have at any one time.

Ms. Kirsty Duncan: If people can't wait and they require that long-term treatment, I understand they have to leave the country. Do we know what percentage of them are having to leave the country?

Ms. Merryl Bear: I don't have that information. That information is quite probably available from each of the provinces, because they're the ones paying for that treatment.

However, there is a vast number of individuals whose parents are mortgaging their houses in order to send their children to out-of-country programs, and those programs are generally not long term in the way that many of the in-patient programs in Canada are. They're potentially a month long.

● (1610)

Ms. Kirsty Duncan: I know that many people are asking for a national strategy. Some of the stakeholders I have talked to would like to see treatment as part of that.

I know there's a federal-provincial issue here. If you could make a recommendation regarding the various types of treatment, if you could have your wish list, what would you like to see in this report?

Ms. Merryl Bear: From my perspective, I'd like to see enough.

In terms of actually articulating the kinds of treatment and how they are best delivered, that is definitely not NEDIC's domain. I would refer you to the clinicians.

Ms. Kirsty Duncan: Okay, that's fine.

You talked a bit about funding. You said that you used to be funded by the WHN, if I remember correctly, the Women's Health Network.

Ms. Merryl Bear: No. We partnered with them. They were funded by the women's health contribution program. They provided the initial women's health portal on Health Canada's Canadian health network, which was as well a valuable source of information, credible and timely information, for women and individuals with a food and weight preoccupation.

Ms. Kirsty Duncan: Again, if you could have your wish list for the recommendation that you would like to see in this report regarding funding, what would it be? Would it be funding for awareness and education or something else? Could you break it down into exactly what you'd like to see?

Ms. Merryl Bear: I would like to see funding for health promotion which is population based. I would like to see funding for prevention. I would like to see funding for education in all of the institutions. That would be throughout the system of education, from prenatal education, quite frankly, all the way through to education for professionals who will go into education, health, justice, and the media.

I would like to see treatment options that include.... Well, I would like to see strategies for early identification of eating disorders and a streamed process for supporting those individuals to recover.

The Chair: Thank you very much.

I will let you just finish your thought and then we'll move on. Did you have something else?

Ms. Merryl Bear: Yes. It's intensive treatment, and it's not just to focus on the individuals who are severely ill, but also to focus downstream, so that individuals don't have to get severely ill in order to get treatment and help.

The Chair: Thank you very much again.

[*Translation*]

We will now start the second round of questions.

Ms. Ambler, you have five minutes.

[*English*]

Mrs. Stella Ambler (Mississauga South, CPC): Thank you very much for being here, Ms. Bear. We really appreciate someone with your number of years in the field coming to spend an hour with us this afternoon.

Over the holidays I read an article in *Canadian Living* magazine, one of my favourite magazines, about a teenage boy with anorexia, from the point of view of his mother. Did you see that? She blamed herself. Once the disease was diagnosed, she thought back to all of those times when she used to tell him that he shouldn't eat that plate of pasta because it was fattening, because she'd had weight troubles all her life and she felt she had passed that along. It made me think of something Dr. Woodside said, which is that families get a bad rap with this disease, and that it's not caused by dysfunctional families.

Would you consider that to be part of the awareness piece? Is that a valuable exercise, educating family members? As a mother I would want to be reassured that this is a disease like any other, and we tend to be hearing that.

Would you agree with that?

● (1615)

Ms. Merryl Bear: It's not a disease like any other. It has a cultural component that is challenging to address, and it is absolutely critical not to blame parents when their child develops an eating disorder. There is no one cause of an eating disorder. If every parent who made a comment about their child's weight, shape, or eating had a child who then developed an eating disorder, then we'd recognize that maybe that's.... It's just much more complicated than that.

I'm sorry, could you please repeat your question?

Mrs. Stella Ambler: Do you think that should be part of the awareness when we're reaching out, to make sure Canadians know that this isn't caused by something that parents do or don't do, or say or don't say?

Ms. Merryl Bear: Parents are perceived, both by most health practitioners and definitely by their child, even though they may be reluctant, as the biggest and most important support in the recovery process. It's critical for any awareness campaign to recognize the multi-determined nature of eating disorders, that not one thing causes an eating disorder.

Mrs. Stella Ambler: Earlier this week I met with representatives of the National Initiative for Eating Disorders, who were on the Hill this week. I know many other members of Parliament have been doing that as well. Again, on the awareness piece, they talked about the fact that when parents are given their child's diagnosis of an eating disorder, they're often relieved because they think, “Oh, thank goodness it's not cancer, or something worse.” Meanwhile they are completely unaware that the mortality rates for anorexia are actually twice as high as for many forms of, say, leukemia, which is not something I would have known either, until they told me.

Again, in terms of the awareness that you talked about earlier, do you think that should be a part? This is something that I think is valuable to tell Canadians. Do you agree?

Ms. Merryl Bear: Yes, I think it is important to put eating disorders into the context of other issues, but not to minimize those other issues. Eating disorders are deadly, and they need to addressed.

The Chair: Thank you.

[*Translation*]

Mr. Harris, you have the floor.

[*English*]

Mr. Dan Harris (Scarborough Southwest, NDP): Thank you very much, Ms. Bear, for being here today.

On Mrs. Truppe's very first question, your first answer was to ask for 10 more minutes on the answer. One of our best-kept secrets in committees is that when witnesses come to testify before the committee, they never get to say everything they want to say. If there's anything you feel that's important to share with the committee, you can certainly contact the clerk and send an email, document, or brief to elaborate further on some of the things you might not get the chance to get into today.

I would certainly encourage as a follow-up when you're asked about best practices, if you know of a list of best practices or somewhere we could go for that, that would be particularly relevant for the committee and its work.

I also appreciate your not wanting to reinvent the wheel, and instead build on the work that has come before. As such, I did want to ask, if we members of Parliament wanted to share with our constituents some of the issues and concerns and information about this disorder, because as you said, a lot of it is about networking and making sure people know, would we be able to go to the website and get a kit or a package or something to share with our constituents? Would there be a leaflet we could print off to put in our offices? Is that information available?

● (1620)

Ms. Merryl Bear: Yes, in fact, we are actually launching a new website, hopefully later today, and all of our material is printable. There is a lot of information. I certainly encourage anyone who finds a gap in our information to please let us know, because we will do our best to fill that gap.

Mr. Dan Harris: Excellent.

You mentioned that you partner with many different organizations. Would we, or I personally, be able to get in touch with you later, about getting a list of groups and organizations in my area, that we could work with in helping to inform people about the issue?

Ms. Merryl Bear: We would certainly be very happy to help you.

Mr. Dan Harris: Thank you very much.

You also spoke briefly about the fact that eating disorder patients may suffer from other illnesses or disorders. My partner is a social worker at the Centre for Addiction and Mental Health in Toronto and works with many clients who have concurrent disorders. Could you elaborate a little bit on what some of the additional challenges are to dealing with something like eating disorders when someone is facing multiple challenges at the same time?

Ms. Merryl Bear: Probably the biggest challenge is that very few treatment facilities will actually work with both of the concurrent issues. If someone, for instance, turns up at a substance abuse treatment program with an eating disorder, the person might be told that they will deal with the substance issue, but for the eating disorder the person will have to go somewhere else. Or if the eating disorder is particularly loud or negatively impacting the person's capacity to work on the substance issue, the person might be told that they're not going to actually treat the person at all, that the person will have to go deal with that first.

It's like a roundabout. It's a revolving door where individuals who are ready for help actually find it exceptionally difficult to get in a door where they are going to be accepted as they are, as whole human beings with multiple difficulties.

Mr. Dan Harris: Thank you very much.

Are there other models in other provinces or countries—this would fit into the best practices—that are leaders in tackling anorexia or other eating disorders that you'd be able to share with the committee, that we could reference and learn from?

Ms. Merryl Bear: Certainly the United Kingdom at the government level has done some really interesting work. They currently have a committee looking at best practices around, I think, education and awareness. They also have a best practices treatment schedule, I'd guess you'd call it.

Mr. Dan Harris: Thank you.

[*Translation*]

The Chair: Thank you very much.

Mr. Young, you have the floor for five minutes.

[*English*]

Mr. Terence Young (Oakville, CPC): Ms. Bear, thank you very much for sharing your time with us today.

If you wanted to find out how many patients had died due to an eating disorder, where would you go? I mean within Canada.

Ms. Merryl Bear: I would send people to Statistics Canada for those statistics.

● (1625)

Mr. Terence Young: Are they available? Have you tried to find that out?

Ms. Merryl Bear: No. I don't believe it's captured. I also think it is complicated by the fact that many individuals with eating disorders die of medical complications that are documented as the cause of death. Also, many individuals with eating disorders commit suicide.

Mr. Terence Young: If Canada had a death registry where you could go to find that information, would that be useful?

Ms. Merryl Bear: I'm one of those people who think the more information we have, the better equipped we are to tackle the issue at hand.

Mr. Terence Young: What do you think should be the minimum standard of care for girls and women with eating disorders? You can take the rest of my time, which is probably three minutes.

Ms. Merryl Bear: I think there needs to be timely, early identification of an eating disorder. It needs to be done in a respectful and collaborative way with the individual and the family members involved in her or his care.

It needs to take into account the complexity of the individual's position in—I want to use the jargon—“social location”, so their socio-economic status and the experience of living in their shoes in Canada. It needs to take into consideration the multiple challenges they might face and to accommodate them. Treatments need to really meet the person where they are and move them forward.

Mr. Terence Young: Because I sprang that question on you, I'd like to ask you if you would consider adding to that list that there should be family-based treatments to assist the family as well and treatment options, because not every treatment works for every patient. Would that make sense to add to the list?

Ms. Merryl Bear: Actually, yes, I'd support that.

Mr. Terence Young: Do hospitals address these various components now?

Ms. Merryl Bear: Some do. Family-based treatment is the basic model for a hospital such as Southlake in Ontario. The Hospital for Sick Children has family-based treatment. It's currently the model of choice for many hospitals.

Mr. Terence Young: What happens to girls and women who drop out of the in-hospital programs? I assume they don't all stay until the end of the program and get cured. What happens to the ones who drop out? Are they offered options? Do they slip back into their own patterns and symptoms of eating and purging?

Ms. Merryl Bear: In the discharge process, I believe every individual would be provided with some alternatives she could follow up. The nature of the illness is such that many individuals with eating disorders don't have the capacity to advocate for themselves and may fall through the cracks.

For young individuals, or those who are closely connected to their families, the outcomes are probably much better, and opportunities to improve quality of life if not to recover fully from the eating disorder are largely enhanced.

Mr. Terence Young: Thank you.

The Chair: Thank you very much. I think your testimony was very much appreciated by all members of the committee. I want to convey my heartfelt thanks for your time, Mrs. Bear. It was very informative.

We will suspend for a few minutes, so we can arrange for the next video conference.

●

_____ (Pause) _____

●

● (1630)

[*Translation*]

The Chair: We are resuming the meeting. We will hear from two people who will testify by videoconference.

[*English*]

We have Dr. April Elliott, who is a pediatrician and the chief of adolescent medicine at Alberta Children's Hospital. Thank you very much for being with us.

We also have Dr. Debra Katzman, a professor of pediatrics in the division of adolescent medicine in the department of pediatrics at the University of Toronto.

Welcome to you both. You each have 10 minutes. We'll start with Dr. Elliott.

● (1635)

Dr. April S. Elliott (Paediatrician, Chief of Adolescent Medicine, Alberta Children's Hospital, Calgary Eating Disorder Program): I'd like to thank the committee for conducting its study of eating disorders among girls and women and viewing this as an important health concern in Canada. I'd like to add that eating disorders also affect males, albeit in smaller numbers. Currently, I'm actively seeing four young men struggling with both the disease and a system that they don't fit into.

I'm a pediatrician with a fellowship in adolescent medicine. I've worked in the area of eating disorders for about 14 years. I see patient population generally between the ages of 11 and 23, but unfortunately, I have seen several young people more recently as young as 7.

I reviewed the transcripts of Dr. Blake Woodside. I'm aware he reviewed extensively the epidemiology, including the incidence, prevalence, and characteristics of eating disorders, as well as the statistics of those who die from eating disorders, so I won't repeat this information today.

I want to re-emphasize, though, that the cause of eating disorders is not fully understood. However, for many years socio-cultural influences and environmental risk factors have been thought to be important.

As the research on this subject has progressed, there are now indications that the development of an eating disorder is multi-factorial, with socio-cultural, biologic, and genetic influences. Research in the neurobiology of eating disorders has revealed genetic links. Overall, anorexia nervosa and bulimia nervosa appear to be far more common among the biological relatives of anorexic and bulimic probands than in the general population. Eating disorders can be pathological solutions to a developmental challenge, especially in children. Research also suggests that an obsessional, perfectionistic, and anxious personality style may be premorbid traits that contribute to the development of eating disorders.

I ask, then, what are we doing in our schools and early intervention prevention programs to help children learn to self-regulate and learn mindfulness techniques to counter these traits and pressures? The severity of a medical problem associated with eating disorders is significant and should not be underestimated however the patient appears outwardly.

Mortality in anorexia nervosa is the highest of any psychiatric illness. It is the third most common chronic illness among adolescent girls. The medical complications of both bulimia nervosa and anorexia nervosa are multi-system and can have both acute life-threatening and long-term sequelae.

It is again important to note that individuals at normal or above normal body weight who lose an excessive amount of weight may show similar changes in medical status as the individual who starts at a normal body weight. I bring this up as a story related to me by patients many times who are suffering with bulimia nervosa. Their general practitioner looks at them and says they don't look like they have an eating disorder, while potentially these average or possibly overweight individuals may have a serious electrolyte issue that is caused by repetitive bingeing and purging activity.

The primary pathophysiologic response to extensive weight loss is one of metabolism reduction as a physiological adaptation, as we have seen in a very classic study done in...[*Technical difficulty—Editor*]...Minnesota experiment.

I am a medical consultant at the Calgary Eating Disorder Program. The Calgary Eating Disorder Program uses a multimodal, inter-disciplinary team approach to provide service across a continuum of care. We believe it is imperative to work collaboratively as a team and include the patient and the family in this process. In this respect, we strive to have the patient and family in control of their own treatment and give choices and options within the boundaries of responsible care. We utilize a biopsychosocial approach to treatment, including all the necessary team members, to meet the needs of the patient and family. We also work very hard to build community capacity.

I will give you some statistics of our program.

Since 2009 we have gone from 276 referrals a year to, presently, in the 2012-13 fiscal year, 437.

Our diagnoses tend to be divided...[*Technical difficulty—Editor*]... eating disorder not otherwise specified at about 42%, anorexia nervosa at about 29.4%, and bulimia nervosa at about 22%. A very small percentage is very young patients with an early onset eating disorder.

● (1640)

The age range over the last five years has stayed consistent between the majority being between 18 and 24 years of age and the next large age group being between 14 to 17 years of age.

Our program is a tertiary centre, but I recognize that family physicians are the cornerstone of health care. Their knowledge and ability to screen, support and refer these individuals is essential.

I've always endeavoured to provide continuing medical education for family physicians as this is where we make the most difference in screening, prevention, and promotion. Without a bold standard approach, these physicians often feel at a loss.

There is very little funding to support these types of educational presentations outside of a formal conference. I suggest funding to create a web-based CME program with formal credits, and increasing curriculum in medical schools.

Even in the last 15 years I've watched eating disorder treatment in Calgary go from an orphaned, non-humanistic approach if no one was trained or willing to treat the eating disorders, to some very organized and evidence-based programs.

Generally, I feel we have excellent resources in Alberta, with the exception of a few critical aspects that could both decrease morbidity and mortality. This may be generalized across Canada, but again, there is such a variation in funding and programs.

Number one, there are no specific in-patient eating disorder units for under 14-year-olds or other long-term intensive care. Often, there is nowhere to admit if they are already medically stable, but underweight and failing to thrive. This has significant impact on future growth and development, and other psychiatric comorbidities and chronicity of the illness.

We do not have adequate spaced, very well organized, multi-disciplinary in-patients units. The conditions are very concerning. We have six patients in a four-bed room at the Foothills hospital. Often, additional patients are placed in rooms with elderly sick medical patients, often with dementia, and the space for the critical meal support and therapy is a mere 150 square feet. Patients sometimes leave against medical advice because the conditions are so bad and they are ambivalent about getting better.

I will close with a relevant example of a patient I just saw on Monday, ironically, just after I received the invitation to give my testimony.

This is a 19-year-old woman with anorexia nervosa and a BMI of 16, which is far below the third percentile for someone her age. She's medically unstable with a low resting heart rate and dehydration, and she's becoming more cognitively impaired every day. She requires hospitalization, but our allotted beds are over capacity, eight people for an allotted six. The room in which they participate, as I mentioned, is a mere 150 square feet.

I have nowhere to admit this patient who, by the way, wants to be admitted and supported. Therefore, I continue to do intensive out-patient clinic visits biweekly and prepare her for our day program that is more resourced, but is not the best option for her medically at this time.

Her mother's response, through tears, during the appointment, “I'm at a loss of what to do. My daughter has lost so much weight and now hasn't eaten for four days. She is my only priority, and to the program and to the medical resources just a number; hopefully, not a statistic of mortality to be looked upon in 10 years.”

I obviously comforted her and reassured her that she wasn't a number to me and that I would do everything in my advocacy powers to get her the treatment she needed. Unfortunately, this is not a unique presentation in the over-18 population. Hopefully, we can continue to examine the roadblocks and allocation of resources to assure these young women and men, with so much potential, get the adequate care they need to achieve optimum health and well-being.

Thank you.

● (1645)

The Chair: Dr. Elliott, thank you very much for this very good testimony. It was also very touching.

Mrs. Katzman, for 10 minutes.

Dr. Debra Katzman (Professor of Paediatrics, Division of Adolescent Medicine, Department of Paediatrics, University of Toronto): Good afternoon. I would like to thank the members of the House of Commons Standing Committee on the Status of Women for inviting me to speak with you today about girls and women with eating disorders.

My name is Dr. Debra Katzman. I am a professor of pediatrics and an adolescent medicine specialist at the Hospital for Sick Children, University of Toronto. I have worked in the field of eating disorders for the past 28 years. I founded the pediatric eating disorder program at the Hospital for Sick Children and was the medical director for 22 years. My research has focused on young girls with eating disorders, specifically the medical complications of these devastating disorders. I have also been involved in research on early diagnosis in children and adolescents and treatment of these life-threatening disorders.

I have played an educational and advocacy role in eating disorders on a national and international level as a member of the steering committee of the Ontario Community Outreach Program for Eating Disorders, the past president of an international organization, the Academy for Eating Disorders, and now as the current president of the Society for Adolescent Health and Medicine. As you can see, I am passionate about pediatric eating disorders and what we, as health professionals, researchers, and Canadian citizens can do to prevent, identify, and treat these disorders.

I have the daily privilege of working with and caring for very, very sick children and adolescents, and their families, who suffer from the severest forms of eating disorders. Eating disorders, as Dr. Elliott so eloquently said, are biologically based, serious, life-threatening mental illnesses. These disorders warrant the same level of breadth of awareness, identification, treatment, prevention, and research funding as other illnesses. Let me explain to you what I mean by this.

Since I started my medical career some 30 years ago, biomedical research has had an impact on pediatric illnesses and has made some incredible advances on the outcomes of many serious diseases. When I was a medical student, acute lymphoblastic leukemia, the most common cancer of childhood, had a mortality rate of 95%. Today the mortality rate has been reduced by 85%. Six thousand children each year who would have previously died of this disease are now cured.

Another example of important scientific advances is the HIV/AIDS story. For example, a 17-year-old infected boy with HIV 20 years ago would have lived months, only months, and now can live up to 60 or 70 years.

These remarkable changes are due to funded scientific research that has focused on understanding these very tragic major killers. Unfortunately, these types of success stories are not the same when we're talking about eating disorders.

Over the past 20 years we have indeed made some headway with eating disorders, but not to the same extent as what we've seen with cancer, heart disease, or AIDS. Let me share with you, however, what we do know about eating disorders.

Eating disorders are a huge public health issue. Eating disorders are on the rise in children. We've done a study here at Sick Kids, in collaboration with the Canadian pediatric surveillance program, and showed that young people as young as five years of age develop eating disorders. Eating disorders have a relatively high prevalence rate. Approximately 1.5% of women between the ages of 15 to 24 years old suffer from an eating disorder. That means an estimated 525,000 Canadian women will suffer from these disorders. Compare this to 10,000 children and youth living with cancer or 25,000 living with type 1 and type 2 diabetes. Yet, eating disorders do not get the same research funding, nor do they get the same general attention.

Eating disorders start early in life. There are two peak ages of onset, one at 14 years of age and one at 18 years of age. This is very different from other illnesses, such as heart disease and hypertension, that start in adulthood. Most children and adults with eating disorders are girls and women.

● (1650)

Anorexia nervosa is the third most common chronic illness affecting adolescent females. Eating disorders know no bounds when it comes to race, colour, gender, and socio-economic status. No one is immune to an eating disorder.

The cause of eating disorders is, as Dr. Elliott has said, multifactorial, and includes a combination of genetic, biological, and temperamental vulnerabilities that interact with a very toxic environment.

Eating disorders are associated with impairment in emotional and cognitive functioning. We know that girls and women with eating disorders exhibit difficulties with cognitive functioning, specifically, difficulties in their ability to judge things and difficulties with their memory, decision-making ability, and sort of getting the gist of the bigger picture of things.

Studies from our group here at SickKids have shown that young women have pronounced cognitive deficits during the acute phase of the illness that significantly interfere with their cognitive abilities and their ability to make relationships. This type of cognitive impairment is thought to compromise a young woman's ability to engage in psychological treatment, making treatment much less effective. Further, it is unclear whether these cognitive deficits actually return to normal.

We also know that girls and young women have significant comorbid psychiatric problems. The most common comorbid psychiatric conditions in anorexia nervosa include major depression and anxiety disorders. Commonly, comorbid conditions in bulimia nervosa include anxiety disorders, major depression, and substance use disorders. Approximately 80% of individuals with anorexia nervosa and bulimia nervosa are diagnosed with another psychiatric disorder at some time in their life.

Eating disorders limit the life activities of young girls and women suffering from these conditions. Individuals with anorexia and bulimia nervosa rate their quality of life as very low. Social adjustments tend to be impaired; social communication skills are poor; and social networks tend to be very small.

Vocational and educational functioning in individuals with eating disorders is below that expected, with absences from work and from school. In one study, it was shown that girls who suffer from eating disorders spend approximately five and a half months per year in school over a two-year period.

Eating disorders are life-threatening illnesses and are associated with numerous medical complications. Eating disorders have the highest rate of medical complications of any psychiatric disorder.

Eating disorders affect every system in the body. The medical complications represent significant forms of disability. Medical complications include: significant impairment of normal adolescent physical, social, and psychological growth and development; cardiac abnormalities; gastrointestinal problems; and osteoporosis. In fact, our group did the first study in this area and found that young people with anorexia nervosa who only had the illness for three months developed brittle bones, or osteoporosis. In addition to this, these young people also, as I've mentioned, have cognitive impairment. We have shown in studies that they also have changes in the structure of their brain.

These are but a few of the medical complications. Also, from the research we have done, it is not clear that these long-term medical complications are reversible.

These medical complications can and do lead to death in some cases. Death rates for anorexia nervosa are the highest of any psychiatric disorder and are 12 times higher than the annual death rate from all causes in females between the ages of 15 and 24 years. Children with the disorder are 10 times more likely to die than their healthy peers. This inexcusable increased risk of death in eating disorders is frequently due to the numerous medical complications and also to suicide.

Overall, eating disorders are associated with some of the highest levels of medical and social disability of any psychiatric disorder. These conditions carry significant costs to the individuals, to their families, and to society at large.

● (1655)

There is a large cost to eating disorders in young women who suffer from them. Girls and women with anorexia nervosa have higher rates of pregnancy complications than women without eating disorders; they have higher rates of infertility and of spontaneous abortions; and their children seem to have a higher prevalence of emotional and nutritional problems. Parents and carers of individuals with anorexia nervosa and bulimia nervosa have high levels of psychological distress.

Finally, eating disorders result in a significant economic burden and health service use. A recent study on hospital admissions from adult psychiatric illness in England found that eating disorders contributed the highest proportion of admissions of all psychiatric disorders. Most child and adolescent psychiatric beds are occupied by young people with eating disorders, more than any other diagnostic group. In the U.S., individuals with eating disorders have a higher health care utilization rate than individuals with other forms of mental illness.

We have just completed a study—

The Chair: Dr. Katzman, we'd like to start the questions from the members. Maybe you could complete your statement afterwards in an answer.

Dr. Debra Katzman: Certainly.

The Chair: Thank you very much for your testimony, Dr. Katzman.

We start with Ms. Crockatt, for seven minutes.

Ms. Joan Crockatt (Calgary Centre, CPC): Thank you both for being here.

Hi, April. This is Joan Crockatt. How are you?

Dr. April S. Elliott: Hi. I'm good. How are you?

Ms. Joan Crockatt: I have to say that I know Dr. Elliott from Calgary and have been familiar with her work for quite some time.

Hello, Dr. Katzman. Thanks for being here.

Dr. Debra Katzman: It's a pleasure.

Ms. Joan Crockatt: Dr. Elliott, let me start with you.

First of all, I want to thank you very much for the testimony. It's obvious that you've taken a very forward-thinking, solution-oriented approach. I believe you have pioneered the program for eating disorders at the children's hospital in Calgary.

Could you start by telling us how you designed that program from the beginning? Did you have to reinvent the wheel? Is there a bit of a centre of excellence developing, and at what point is it right now?

Dr. April S. Elliott: We started out under the department of psychiatry. They came, when I was doing my fellowship with Dr. Katzman at SickKids, to view various programs to determine the best model.

The uniqueness of the Calgary eating disorder program is that we see all ages, and so we had to develop a program that went initially all the way from as young as seven years old, unfortunately, to 24 years of age. Over the last eight years, we've been seeing all ages. You can imagine the complexity of trying to have a program that reaches all ages.

As a pediatrician joining the team about two months into the initial program while it was continuing to develop, I had a concern around the developmental appropriateness of mixing all ages. They then decided to have the programming for those ages 14 and up. What then happened was that we missed the under-14 population for intense programming.

It took a lot of years and a lot of showing of the evidence base for family-based treatment, as well as other approaches, such as the multi-family from Eisler in England, to convince them that it was really important to have specialized programming for the under-14 group and for many of the adolescents.

It has been a work in progress. There has been an amazing partnership and collaboration between the department of psychiatry and the department of pediatrics. Now that we have the evidence for some of the family-based programs we do for the younger groups and also for some of the other work that we're doing with adults, I think we are developing a centre of excellence.

● (1700)

Ms. Joan Crockatt: Forgive me if I go into more depth with this. We've had a good overview from some of our witnesses, and now I'd like to move into this area of best practices so that we can capture what your and Dr. Katzman's experience has been in that regard.

If you can start from the top, what would you say are the top things you have observed over your 14 years that you feel are best practices we should definitely be capturing in this study in order to move forward?

Dr. April S. Elliott: With regard to the under-18 population, and Dr. Katzman can comment on this as well, I believe that Lock and Le Grange have done some amazing work in their manualization of family-based treatments. The evidence is there that they're effective. We're trying to use that, as well as some of the multi-family groups that also have evidence of efficacy. That's in the younger population.

In the older population, as you've seen in our study that we did looking at Canadian eating disorder programs, there's such a variation, but the evidence points more to.... In our program we're using both a motivational...moving more to dialectical behaviour therapy, because we do see a large proportion of population having problems with borderline personality and some of these other things. That's where we're moving in our program.

The new director of our program is Dr. Monique Jericho. She has been excellent in getting the program very evidence based. Those are some of the examples we're using.

Ms. Joan Crockatt: I'll ask you the same question in just one moment, Dr. Katzman, but I wanted to bring up something that Dr. Woodside raised with us. I'm wondering if you have seen the same thing or something different. He said that 60% of the cases he dealt with were PTSD, most revolving around some kind of sexual abuse. I'm wondering if that's unique to his program or if that's something that you're seeing.

I know you mentioned genetics as part of causality, but are you also seeing some sort of trauma in that regard as being a cause?

First Dr. Elliott, and then Dr. Katzman. Thanks.

Dr. April S. Elliott: I don't know whether it's as high as 60%. I know that in the under-18s it's in a much smaller proportion. In the older population we see a lot of comorbid history of abuse and post-traumatic stress. A lot of our patients really benefit from dialectical behavioural therapy, as well as a unique treatment that some of our therapists use, EMDR, which is very effective in post-traumatic stress.

I don't know the exact percentage in our program, but I would say it was probably at least 40% to 50%.

Ms. Joan Crockatt: Dr. Katzman, perhaps you could go back to the best practices, either what are best practices that you want to highlight here, or how we make sure that we share them, given that health care is a provincial responsibility, either of those two areas that you want to address.

Dr. Debra Katzman: There are a number of best practices that I would really like to highlight. The first is that we need to educate pediatricians, family physicians, and those on the ground running who see young people, young children, adolescents, and women to identify these illnesses as soon as possible.

Part of good practice in the primary care setting is to make sure that you screen for these illnesses, and for children and adolescents, to make sure that pediatricians and family physicians alike are keeping growth curves so that they can identify young people when they fall off those growth curves. I would say that is a best practice.

The other thing I would add to what April said is that family-based therapy is really the first-line therapy for adolescents and children with eating disorders. This is an out-patient therapy. Although we have in-patient wards, and we need in-patient wards for the sickest of the sick, the goal would be to admit kids, get them medically stable, and then discharge them from hospital as soon as we possibly can and begin to engage them in the only evidence-based treatment we have, and that is the Maudsley or family-based therapy.

We know that these treatments are good, and I say “good” because they're not excellent. They're good. We know that 75% of young people recover using this treatment, but there is 25% of young people who do not recover as a result of this kind of treatment and need something more and different.

● (1705)

The Chair: I'm sorry to interrupt, but we have more to come.

Thank you very much, Dr. Katzman.

Ms. Joan Crockatt: Thank you so much for your testimony.

The Chair: Mrs. Hughes, for seven minutes.

Mrs. Carol Hughes: Dr. Elliott and Dr. Katzman, thank you very much for your presentations.

The question that I had drafted basically talked about research. I know you've indicated there was a need for funding for research, and there was a need for increasing the curriculum in medical school. Both of you have touched on that.

I'm going to be sharing my time with Mr. Harris.

[*Translation*]

Can you hear the simultaneous interpretation?

[*English*]

Dr. April S. Elliott: Yes.

Dr. Debra Katzman: Yes.

[*Translation*]

Mrs. Carol Hughes: My questions are as follows. Are there existing models that we should consider? Are some governments investing significant sums of money in awareness or treatment programs? And are there studies or reports that the committee should look at during its work?

I would also like to know how much Canada has invested in research on this subject compared to the United States or the United Kingdom. I have heard that the United Kingdom is one of the leaders in this area.

[*English*]

Dr. Debra Katzman: I'll deal with the research question first.

There are examples that you should be referring to. I would refer you to the National Institutes of Health. Tom Insel has taken eating disorders as a really important research agenda for the U.S. It would be really important for you to look at some of his thoughts about this. The U.K. has also done a significant amount of work looking at the issue of eating disorders, treatment guidelines for disorders, and in their health care system how to divide up...or look at how to create a country that delivers health care with respect to eating disorders. I would say that the U.S. and the U.K. are nowhere near developing the optimal or gold standards. I think people are working towards that.

When we're looking at eating disorder funding, I think in Canada our eating disorder funding is significantly less—I want to underscore that—than in the United States. However, the United States has very, very low funding earmarked for eating disorders.

As a researcher, a lot of my funding has been through the National Institutes of Health, because they do have earmarked funds for eating disorders. Here in Canada there are no such earmarked funds for eating disorders, and neither are there other special foundations where you can go to for funding for eating disorders.

There's a lot of room for the development of a research agenda, and there's a lot of room for increased research funding.

● (1710)

Mrs. Carol Hughes: Mr. Harris.

Mr. Dan Harris: The last part of that answer was actually a little surprising, that you're getting funding and support from the U.S. government, through the NIH, and yet we don't really have federal funding here in Canada.

Is that something you'd like to see changed?

Dr. Debra Katzman: Absolutely.

The studies that I do are really on the medical complications of eating disorders. We have a huge NIH study looking at the treatment of osteoporosis in young adolescents with eating disorders. That's been funded by the National Institutes of Health for seven or eight years now. It would be great to have funding for these types of things for eating disorders. I could list a whole agenda for you of needed research, and of the funding that needs to be pointed at it.

I might add to underscore this that across Canada there are very skilled clinicians in eating disorders and there are very skilled researchers in eating disorders. We in fact could, together as a country, as a collaboration across Canada, really develop some very important research initiatives.

Mr. Dan Harris: Yes. Thank you very much.

Certainly anything that's going to help to improve health—in particular when we're talking about prevention, an ounce of prevention is worth a pound of cure—will save the health care system money, which will in turn give us more money to allocate into resources.

It was interesting to hear, I think it was Dr. Elliott who said this, that among the programming, there is a 75% success rate, which means there's still 25% that isn't successful.

We have now heard from the previous witness and also here now about good programming in the U.K. Do either of you know what percentage of success they have achieved in the U.K.?

Dr. Debra Katzman: The studies I quoted you were studies that were done in combination in the U.S. and the U.K. Together there may be now about 15 to 20 studies looking at family-based treatment, and if you look at those studies, depending on how long you follow out the patients in those studies, we would say on average 75% of them recover. That's both U.S. and U.K. data.

Mr. Dan Harris: Do we have Canadian data for the programs we've engaged in? Are we near there for a success rate?

Dr. Debra Katzman: I think we probably are near there for a success rate at least in our program. I'm sure April can speak to her program as well.

Dr. April S. Elliott: One of the things I'd like to say is I'm not sure about The Hospital for Sick Children, but at our program we actually have an analyst. I think we're so lucky to have a specific person. We do measures at the beginning and end of every segment of our programming, and we have an analyst to look at it, and look at our numbers.

I think we're one of very few programs that have that luxury, so it's definitely something we need. We need the measures to make the changes and that doesn't exist everywhere.

The Chair: Thank you very much.

Now we go to Mrs. Young for seven minutes, please.

Ms. Wai Young (Vancouver South, CPC): I'd like to thank you both for your presentations, which were extremely comprehensive.

I guess the reason we're doing this study is we have learned we have this incredible population who are suffering from this illness who are needing support and help. It's 1.5% of the female population, some 525,000, I think is the figure both of you mentioned.

I guess there are positive outcomes here in the sense that obviously you have worked very hard in Calgary for 14 years, and Dr. Katzman for 28 years in Canada and in Toronto, on crafting effective programs. We're hearing a success rate of 75%.

My question, being a sociologist, is how can.... You have obviously worked very hard and very long on crafting the programs you have crafted within the provincial health care systems you work within. As you know, in Canada the health care delivery system is actually provincial. Can you share with us how you're able to craft your programs, and how is it that other provinces, cities, or jurisdictions can therefore craft theirs for as high as a 75% success rate such as yours?

Perhaps we'll start with Dr. Katzman this time.

● (1715)

Dr. Debra Katzman: I think the way we did it at Sick Kids is there were champions for eating disorders when we came in. We fought long and hard within our hospital to make sure this was an important issue that needed to be attended to, because there were no other resources in the province of Ontario when I came in that tended to children and adolescents. Now, however, there are. We're really thrilled there are these other programs in the province of Ontario.

As a result of that, we created the Ontario Community Outreach Program for Eating Disorders. This is a network that really delivers education and provides support to primary care physicians, secondary care physicians, and centres. The tertiary care centres, like CHEO and like us, are really the hub.

When physicians in the community or physicians in secondary care institutions have patients with eating disorders, they can call where they get support from the hub. There are educational programs that happen once or twice a year. The Ontario Community Outreach Program for Eating Disorders provides education and support to people who are interested in caring for eating disorders.

I think having that system in place has really helped, encouraged, and empowered people to take care of patients with eating disorders. They can be very sick and it can be very time consuming, but knowing you have backup at the tertiary care centre can be very helpful.

Ms. Wai Young: I'm just asking a supplementary question here because I think this is the nub of the issue.

Your group has been valiant and obviously successful, and kudos to you for fighting hard to ensure this happens and that these services and programs are in place.

What more needs to be done? How hard do we need to fight to raise this as an issue so that we don't just have a 75% success rate, but we reach 100%?

Dr. Debra Katzman: Do you want to speak?

Go ahead.

Dr. April S. Elliott: I just want to say that if you look at a province, and I'll use the example of Saskatchewan, you will see there are pediatricians and psychiatrists there who are very competent and could do this work and build a program—having had residents who came out of Calgary and so eagerly went back to Saskatchewan and wanted to build a program—yet there aren't the resources laid out for them. They may not be in a place in their life to actually put in the fight that we did in our time. There just isn't the infrastructure.

I think the important thing is you not only need the resources, but you also need those champions and a strategic plan. When you look across Canada, there are programs that are going for that gold standard of care. It's about getting those programs together, looking at that template and having that strategic plan, so that we can then help other provinces do that. I think that each individual fight was fine, but as a nation we have to give those other provinces the support so they don't have to start from the bottom.

● (1720)

Dr. Debra Katzman: The only thing I would add, Ms. Young, is that there are provinces that have eating disorder programs. Some of them have eating disorder programs for adults, some of them have them for children and adolescents, and some have both. There are provinces that do not have these services yet, so we're not there yet.

The other thing I would say to you is that as a pediatrician who goes for a 100% cure rate, 75% is not good enough. We are just at the very beginning. We have one treatment for anorexia nervosa, and that's family-based therapy. If that doesn't work, then we're sort of piecing together various treatments that have not been evidence based and have not been studied. We have a long way to go.

Ms. Wai Young: I absolutely agree with you. That's why I was asking the question of how we reach 100%.

To divert a little bit, 25 years ago we were the first country in the world to say that smoking is bad, so we implemented legislation, etc., and now smoking is at its lowest levels ever in Canada. Given that this is very much societal and cultural, as we heard earlier from Ms. Bear at NEDIC, what recommendations can you give us to get to that broader messaging or that broader education?

The Chair: You have one minute.

Dr. April S. Elliott: I think both Dr. Katzman and I have emphasized over and over again that this is a lethal illness, and it's the number one psychiatric illness that kills young women. I think that people are unaware. I think that a lot of physicians even think that this is a choice, that it's a life way. It's not a choice. It's a mental illness that has severe, short-term, life-threatening as well as long-term consequences. We need to get that message out.

Dr. Debra Katzman: We have the advantage now of social networking and other means which we can use to get this message out. Public health announcements are really important. Working with people who have had the disorder, who are in some way visible to the public and are known to the public and are speaking out about this disorder is really important. You hear lots of people, famous people, speaking out about having depression. It's very rare that you see somebody who speaks out about having an eating disorder and what it's done to their life.

The Chair: Thank you very much.

Mrs. Duncan for maybe seven minutes.

Ms. Kirsty Duncan: Welcome to you both, and thank you for your excellent comprehensive testimony.

I'm going to focus on recommendations, and what you would like to see in this report in order to better serve the families you treat.

What I'm hearing from Canadians living with eating disorders, from their families, from the research community, and the various stakeholders is they would like to see a national strategy for eating disorders.

Dr. Katzman, I'm looking for a yes or a no answer, and then if you are interested in a national strategy, I'm going to drill down. Would you like to see a national strategy on eating disorders?

Dr. Debra Katzman: Yes.

Ms. Kirsty Duncan: Thank you.

Dr. Elliott.

Dr. April S. Elliott: Oh, definitely.

Ms. Kirsty Duncan: That's terrific.

In drilling down, I'd like to look at the various pieces. Do you need a registry? What are the best practices? What do we need in terms of treatment, the range of treatment? I know long-term treatment is a real issue in this country and families are forced out of the country. The last piece would be research funding.

I'm just going to let you talk. Be as specific as you can. Say, ”Recommendation one, this is what we want: the registry, best practices, treatment, and research funding”.

Dr. Debra Katzman: The final part of my discussion listed what we need to do. If it's okay with you, I'm going to read my points. I have seven bullet points that I think we need to do.

We need to improve early identification of young people with eating disorders. That means comprehensive education and training of health professionals.

We need more effective treatment modalities. As I said, we have some and they're okay, but that's not good enough. That's where the clinicians and the researchers need to work together to find those modalities.

We need to make sure evidence-based treatment programs are available in every province so individuals will have equal and immediate—immediate—access to these programs. The spectrum of treatment settings that need to be available in Canada and to Canadian citizens include in-patient facilities, out-patient programs, treatment programs, and residential programs. Right now in Ontario we do not have a residential treatment program and kids who need that need to go south of the border. We, our health care system, is paying for that, when we have fantastic and skilled clinicians here in Ontario who could easily treat these kids in the right setting.

We need to ensure immediate access to programming because there's very good evidence to show that early diagnosis and aggressive evidence-based treatments do make a difference in their recovery.

We need to increase awareness of these disorders to the general population, as we just said, especially for those who work with children and young women.

We also need to work on prevention. We need effective eating disorder prevention, and that starts with all of us. We need to address prevention at multiple levels to ensure consistent messaging, and we need to collaborate with and across sectors of health, education, and sport.

Finally, we need to conduct state-of-the-art research and provide excellence in clinical care. We need a research agenda and we need research funds. If you go to any international meeting, Canada has the people there who are doing the research, but we just can't find the funds. There are really skilled people here right across the country, especially working with children and adolescents and young adults.

● (1725)

Ms. Kirsty Duncan: Dr. Katzman, I really appreciate that. You've given us seven very strong recommendations. I'm going to go through some of these and ask if you could table them with the committee.

You mentioned early identification and comprehensive training. Could you table exactly what you would like to see? I know Ontario has a great model for training physicians.

You talked about more effective treatment modalities. I'm wondering if you could table how we get to those more effective treatment modalities, which I assume requires more research.

You also mentioned we need these programs in every province. Could you table which provinces have them and where we are lacking? We really need that information.

You talked about the range of treatments that are available, and that in Ontario we are paying when families are forced out of the province. Can you table what that is costing?

Very quickly, because I'm running out of time, what would you like to see that research agenda look like? The more specific you are, the better it will help our report.

Dr. Debra Katzman: How much time do we have? I'm happy to put this in a report for you.

Ms. Kirsty Duncan: A report would be great. If you could table that with the committee, I'd be extremely grateful.

Dr. Debra Katzman: Do you want me to talk to this, then?

The Chair: You have a minute. Again, I am the minute person.

[*Translation*]

I am sorry.

[*English*]

Dr. Debra Katzman: I'm not sure I could do this justice in a minute. There were so many things that were tabled.

Let me see, what did we talk about?

The Chair: Dr. Katzman, I think what Ms. Duncan is asking for is to have more detail on the point that you stated so well. Maybe the clerk will communicate with you. When we have the blues, we will be able to send out what is really required. I think that will help the committee very much, because what you have stated with your seven points was really helpful.

Dr. Debra Katzman: I'm happy to do that.

The Chair: Ms. Duncan, I ate into your time, though.

● (1730)

Ms. Kirsty Duncan: No, that was terrific. We can table that.

The Chair: That was fine? Okay.

I want to thank you, Dr. Elliott and Dr. Katzman, for your patience with me, your passion, and your dedication. Your testimony is very helpful to the committee.

I will invite the members of the committee who may not have had a chance to ask questions to these witnesses to please forward them to the clerk, and then we will forward them to the witnesses and they can answer them in writing.

Again, I thank you very much for your time.

Dr. Debra Katzman: Madam Chair, you've done a great job. Thank you so much.

Dr. April S. Elliott: Thank you. Merci.

The Chair: Thank you.

We'll see each other next week, on Monday.

The meeting is adjourned.

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