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Chair

Ms. Hélène LeBlanc

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● (1530)

[*English*]

The Vice-Chair (Mrs. Tilly O'Neill Gordon (Miramichi, CPC)): Good afternoon, everyone. It's 3:30 so I will call the meeting to order.

First of all, I have a few housekeeping things I need to take care of.

As for the update on witnesses, Health Canada was asked and declined the invitation, but will be available at a later date. The topic for Health Canada will be healthy eating initiatives. The topic for Canadian Institutes of Health Research will be research funding. The Public Health Agency of Canada would be interested in talking about mental wellness promotion. Status of Women have declined. Other witnesses were also invited, but were unable to appear before Christmas because of time constraints.

We're happy to have Dr. Blake Woodside with us today. Welcome, Dr. Woodside. Thank you for taking the time to be with us. We will begin with your statement. You have 10 minutes.

Dr. Blake Woodside (Medical Director, Program for Eating Disorders, Toronto General Hospital): Thank you very much, Madam Chair, and members of the committee.

I'm most pleased that the committee has chosen this topic to investigate. It's very important, and I hope that your work goes well.

You may have my bio, but just to remind you, I'm Dr. Blake Woodside, and I'm medical director for the program for eating disorders at Toronto General Hospital. It's the largest program in the country. I'm a psychiatrist and a full professor in the department of psychiatry at Toronto General Hospital. I've been here 27 years. This is all I do, so without seeming to blow my horn, I would say I would be described as an expert in the treatment of eating disorders, especially the more severe forms of anorexia nervosa, which is all I've been doing for the last 20 years. I run the in-patient service here.

Let me talk to you a little bit about the overall situation first. I'm going to talk about two very serious eating disorders, anorexia nervosa and bulimia nervosa. Anorexia nervosa is a severe medical illness characterized by significant weight loss, denial of the severity of the condition, and serious medical complications that can lead to death. Bulimia nervosa is a syndrome of binge eating, usually associated with dietary restriction, and sometimes with behaviours to undo the episodes of the binge eating, like vomiting or taking laxatives or diuretics.

These are serious medical illnesses. Anorexia occurs in about 0.5% of the population, so there are about 150,000 people across the country who have or have had this condition. Bulimia nervosa is a bit more common. It affects nearly 1% of the population, so there are about 300,000 people with bulimia nervosa across the country. That's nearly half a million people. About 80% of the sufferers are women, and almost everybody in our treatment system is female.

These are lethal disorders. The mortality rate for anorexia nervosa is 10% to 15%. What that means is that of the 150,000 people who are currently affected, between 15,000 and 23,000 will die from their illness. The rates per year are difficult to determine, because very often mental health causes are not listed on death certificates for a variety of reasons. Probably between 500 and 1,000 people die from this condition every year in Canada.

Bulimia nervosa is a bit less lethal with a death rate of about 5%. That still amounts to about 15,000 deaths per year in Canada caused by bulimia nervosa. Again, probably 500 to 700 people a year die from bulimia.

The cumulative death rate from these two conditions would be on the order of 1,000 to 1,500 people per year. To put that into context, and I'm going to come back to this a bit later, prostate cancer in Canada kills between 3,500 and 4,000 people per year, so it's a bit less than that, but we're in the same ballpark, for sure.

In addition to the mortality rate, about 15% to 20% of people with anorexia nervosa will develop a chronic form of the illness. Of the current population of people affected, that's another 23,000 to 30,000 people. For these two illnesses, we have on the order of 50,000 to 60,000 people dead over the chronic form of the illness that is normally not responsive to treatment.

Anorexia is probably the most lethal psychiatric illness in terms of gross mortality rates. That's something people find difficult to believe when they're first told about it, but it is the case. The people who have this illness, while sometimes not aware of the severity of the condition, are extremely unhappy. These are not people who are pleased with their situation. When you assess people's happiness with their life with paper and pencil measures, women with anorexia and bulimia score worse than women who have chronic schizophrenia. Women with chronic schizophrenia are an unhappy lot, by and large, and people with anorexia and bulimia are even more unhappy than them.

These are complex illnesses and they're a complex mix of hereditable genetic factors, subtle abnormalities in brain circuitry responsible for regulation of emotions, and so on. The societal focus on objectification of women which leads to unrealistic goals for weight and shape results in a society focused on dieting and weight loss. While dieting does not cause a condition per se, it can unlock or activate the underlying vulnerability factors and cause the illness to occur. There are risk factors that exist in people which get activated in a variety of ways. One way to activate those risk factors is to become a chronic dieter.

This is why the illnesses are more prevalent at present, but they are ancient illnesses. The first English-language report of anorexia nervosa was in 1693. Bulimia nervosa is reported in the Jewish holy book, the Talmud, which takes it back 5,000 years.

● (1535)

I was meeting with a patient earlier this afternoon who is about 40, who mentioned on her way out the door that her grandmother, who died at 98, had bulimia her entire life.

Despite the severity of these conditions, especially anorexia nervosa, there is a pervasive discriminatory and stigmatizing attitude towards these illnesses. Nothing could be further from the truth than phrases like, “Why won't she just eat?”, “She's just looking for attention”, “It's all her mother's fault”, or “These are just spoiled rich girls”.

The best example of the egregious discrimination suffered by these individuals is access to treatment. For anorexia nervosa, one of the most lethal psychiatric conditions, wait times from referral to admission to a bed in an expert treatment setting run from four to six months. The average weight of my patients who wait this length of time is 80 pounds, with a body mass index of 14, for a woman who is five feet, four inches tall. That woman will wait four to six months from referral to admission to my program.

In my province, and I can speak a little bit to the rest of the country, there are only two other facilities with in-patient beds, each of which has a similar waiting list. It is much worse in other provinces, many of which have no intensive services available at all.

If there were waits like this of four to six months for prostate cancer treatment, there would be a national outcry. There would be marches in the streets. The marches would be attended by middle-age men like me, but of course prostate cancer is a disease of middle-age men just like me, and older, so there is a clinic for prostate cancer in every hospital in this country. Compare that with the situation for anorexia nervosa where, in the province of Ontario, one of the wealthiest provinces in the country, there are only three treatment centres that have in-patient beds for a population of 12 million. If this isn't discrimination, I don't know what is. There is just no other word for it.

On top of that, we spend millions and millions of dollars sending these patients to the United States when they have waited so long for treatment in Canada that they're going to die. It costs two to three times the daily rate to send them to the United States, and the treatment results are awful. We waste tens of millions of dollars when we could invest this money in Canada to provide treatment for people in their own country.

The good news is that treatment does help the majority of those suffering; 65% to 70% of those with anorexia nervosa will eventually recover, and 70% to 80% of those with bulimia nervosa will also eventually recover.

Early treatment is associated with better outcomes, so it's important to identify these patients in the early stage of their illness and get them to treatment right away. Prompt treatment is associated with better outcomes. Expert treatment is also associated with better outcomes.

To treat one of these people in my program, they'll be attached to us, living in the hospital or coming in during the day for six months. There are about 35 members of the multidisciplinary team who treat them. The interventions are complex, far more complex, for example, than a kidney transplant or even a heart transplant, which are very expensive procedures but relatively straightforward. Yet you hear all the time that these people with anorexia should be treated in general psychiatric units by people with no experience or expertise, and that is difficult.

The expert treatment isn't cheap, but the cost is trivial compared with the rest of the hospital system.

My own program, which is the largest in Canada, provides intensive treatment to about 200 patients per year at a cost of about $2.5 million. That's $10,000 per case. That's the cost of maybe 10 heart transplants, and my hospital does 75 of those a year.

We're further hampered in our ability to do adequate research into new treatments. I'm a career researcher with millions of dollars of research money in my research portfolio. We're engaged in cutting-edge research in neurostimulation on anorexia nervosa. We are the world's leading centre in novel treatments: deep brain stimulation and transcranial magnetic stimulation for eating disorders. Every last penny of my research money, aside from donations from generous individuals, comes from the United States, either from granting agencies or from private foundations.

The most recent large study I was involved in cost $8 million. The entire budget for the Institute of Neurosciences, Mental Health and Addiction, INMHA, is on the order of $13 million to $15 million per year. It is simply impossible in this country to do meaningful research on illnesses like anorexia or bulimia, given the amount of research money that's available. That $13 million to $15 million has to cover addictions and neuroscience as well as mental health.

There is no point in—

● (1540)

The Vice-Chair (Mrs. Tilly O'Neill Gordon): Excuse me, you are on your last minute.

Dr. Blake Woodside: Thank you, I'm almost done.

As I was saying, there is no point in even trying.

What do we need? First, we need more attention paid to this situation. The work of the committee will help with that.

We need to set some standards for appropriate clinical care for these patients, the type of treatment that works, appropriate wait times, and appropriate levels of access. We need national standards that can be applied across the country. Setting national standards is in the purview of the federal government and Health Canada. You can't force the provincial governments to do it because they control health care, but you can set the national standards.

We need examinations of the priorities and policies of CIHI and INMHA to allow us to develop a national plan for research into novel treatments for these deadly conditions.

Finally, you need to know that the work of the committee is very important in a whole other arena, in that it offers hope to both those who suffer and their families, hope that change can occur in our system of care, hope that the discrimination and stigmatizing attitudes can be reduced, and hope that the suffering associated with these conditions can be eliminated.

I thank you very much for your attention, and I am very happy to take questions.

The Vice-Chair (Mrs. Tilly O'Neill Gordon): Thank you very much for this very worthwhile and important information. We certainly appreciate your time.

We will now turn it over to Madam Susan Truppe to start the questioning.

Mrs. Susan Truppe (London North Centre, CPC): Thank you, Madam Chair.

Thank you, Dr. Woodside, for being here today and sharing your expertise with us. You're our first witness. We're quite happy to listen to your findings.

Seeing that this is the status of women committee, we decided collectively that we would like to see how we might help women and girls with this very dangerous disease.

You mentioned a couple of things. You mentioned that the diseases remain hidden for some time when one isn't aware of the warning signs. You mentioned that early detection is important with eating disorders.

How can we work to reach out to people, to parents, teachers, coaches, other stakeholders, who are with these young girls, and educate them about what to look for or where to go for help if they suspect that someone important in their life is suffering from this?

Dr. Blake Woodside: Public awareness is very important.

First of all, these are serious medical conditions. They shouldn't be ignored. They don't generally go away on their own. They're not phases or bad behaviour.

I think you're going to have testimony later from Dr. Gail McVey, who is in charge of the Ontario Community Outreach Program for Eating Disorders. She's devoted her life to raising awareness in Ontario and can provide you with insight into how she does that and the extent to which it is effective.

I think it is a model for the rest of the country. It's primarily raising awareness, both among young people—children, adolescents, young adults—and their families, teachers, health care practitioners, and so on.

● (1545)

Mrs. Susan Truppe: You also mentioned some of the comments that people make about spoiled rich girls. Do you think attitudes have changed over time?

I did volunteer work a long time ago in a psychiatric hospital, and I remember this one girl who had anorexia. Those were the comments back then, but I'm talking about 30 years ago.

Have the attitudes changed more now than way back then, and if so, how?

Dr. Blake Woodside: I don't think so.

These illnesses continue to be viewed as kind of pseudo-illnesses, that they're not real conditions, in spite of their enormous mortality rates and the rates of suffering that these people endure.

The illnesses occur right across the board. The patient we admitted yesterday is homeless and in a shelter. That's where she is, and she has wicked anorexia nervosa. The notion that these illnesses are confined to higher socio-economic groups is absolutely untrue. That's an outdated theory that goes back 50 years and has been disproved over and over again.

The notion that families or mothers cause this illness has been disproved endlessly. My master's degree research was in family functioning and eating disorders. The family functioning improves when you treat the eating disorder. The theory at the time was that it would get worse as you took away the eating symptoms and uncovered the family pathology. Families still get a bad rap for this, unfortunately. There's absolutely no evidence to support that's the case.

We keep working away at it. I will go to talk to anybody, at any time, about this, but I'm afraid that these discriminatory attitudes continue to persist.

Mrs. Susan Truppe: Yes. Thank you.

Why do you think it affects more girls than boys?

Dr. Blake Woodside: That's an excellent question.

In community studies, it's about one in five, for men; in the clinic, it's about one in 30. The answer is that we don't really know. One of the theories is that its genetic, related to something on the X chromosome. Women have two; men have one. Other theories relate to patterns of brain development. There are clear abnormalities in neural circuit function in anorexia nervosa that probably pre-exists the illness. Some of those may be more common in women than in men.

It's really unknown at the present time. Certainly one of the important triggering factors, which is dieting, is much more prevalent in women than in men, although there is the computer geek thin for men as well, and many men who start weightlifting end up pursuing weight loss rather than getting bigger.

The actual answer is that we don't know.

Mrs. Susan Truppe: Thank you.

For my own curiosity, what is the youngest girl you've seen with one of these diseases?

Dr. Blake Woodside: I'm an adult psychiatrist. I believe you'll also hear testimony from some of the child psychiatric experts in this area.

One who I believe is going to be invited is Dr. Leora Pinhas from Toronto, who sees patients as young as seven and eight, with what she is pretty convinced is full syndrome anorexia nervosa. She tells me that she thinks the age of onset is getting earlier and earlier. When she started in this 10 or 15 years ago, it would have been unusual for her to see a child before the age of puberty, and at this point, it's relatively common.

Mrs. Susan Truppe: That's very young. That's very disturbing.

I'm assuming that treatment differs for women and girls with eating disorders depending on which disorder they have. How do they differ? We're brand new at this, so how do they differ?

Dr. Blake Woodside: The treatments actually are somewhat similar.

I'll start with bulimia nervosa, which is easier to treat than anorexia nervosa.

The binge eating of bulimia nervosa is not food addiction. It's actually a response to starvation in the same way that if you held your breath for a minute or two you would gasp for air because you were starved for oxygen. A certain percentage of the population, about 5%, will respond to hunger with these episodes of binge eating. That makes them different from everybody else.

To treat bulimia you have to feed people. In our day hospital we feed them lunch, afternoon snack, and dinner, and teach them strategies to resist urges to binge and to purge, because these things get tangled up into stressors and stuff like that. The fundamental treatment is to feed people. You eat your way out of bulimia, oddly enough. People in our day hospital service will stop bingeing in a week or two if they are able to do what we ask them to do.

The treatment for anorexia nervosa is similar in some ways. Although most people with bulimia don't like binge eating, and they'll do whatever they need to do to get rid of it, for anorexia nervosa, the decisional balance is often much more finely balanced, because the illness has advantages to the person as well as disadvantages. The fundamental thing you have to do is help people to eat and gain weight. That's the behavioural change that has to occur first.

Then people have to address the underlying cognitive set, the way people think about weight, shape, food, and eating, which has to happen with bulimia as well. Then people have to deal with their other psychological problems that underlie or are associated with the illness. Depending on what those are, that could be the work of many years.

About 60% of my patients have chronic complex post-traumatic stress disorder. They've been sexually or physically abused. They will work for eight or ten years to recover from that, although we have some novel treatments for PTSD that we're working on right now that are looking to be very promising.

● (1550)

Mrs. Susan Truppe: Thank you. My time's up.

The Vice-Chair (Mrs. Tilly O'Neill Gordon): Thank you.

We'll move now to Niki Ashton.

Ms. Niki Ashton (Churchill, NDP): Thank you very much, Dr. Woodside, for joining us today.

I wonder in your work if you've encountered any federally led programs or campaigns that you believe meet the needs of those suffering from eating disorders.

Dr. Blake Woodside: No.

Ms. Niki Ashton: That was a pretty quick answer.

Dr. Blake Woodside: It's the truth, unfortunately. There has been no federal attention to this ever in the last 27 years I've been involved in the field.

Ms. Niki Ashton: You did mention research. That is an area in which the federal government is directly involved, funding for research. In that area has there been some interest, or did you see perhaps a trend or interest before that doesn't exist any more?

Dr. Blake Woodside: Typically, I submit a grant application to CIHR. I've been involved in two or three grants recently. One was a grant looking at the health costs associated with eating disorders. It was a moderately complex study where data from a variety of sources was going to be obtained, and we were going to look at the lifetime health costs, or the 10-year health costs associated with these conditions, which is something that had never been done before. That grant application was sent to a committee of dieticians at CIHR, who said they could not review it because it was outside their area of expertise, so it was rejected. That's the type of thing that typically happens to grant applications that we write to go to CIHR.

We're very successful at NIMH, the National Institute of Mental Health, and in other countries' granting agencies. We're very successful with private foundations, but there seems to be a lack of interest at the INMHA level, the Institute of Neurosciences, Mental Health and Addiction. There seems to be a lack of interest and a lack of ability to appropriately review grant applications that go in.

Plus, frankly, the amount of money that they have to spend is trivial compared to what we need. We're submitting two grant proposals in February to a private foundation. We've been invited to resubmit because they currently fund our research. The total amount of those two grants would be $800,000 over two years. We could not hope to get that sort of money out of CIHR, regardless of our reputation or experience in the area of mental health. An amount of $800,000 would be most of their new grants for the whole year.

Ms. Niki Ashton: Dr. Woodside, you also mentioned societal factors at play. In particular, you pointed to the objectification of women, whether it's cyberbullying or the kind of messages we're seeing in all kinds of media, the pressures that young women are facing in different ways. I wonder if you are seeing a trend in that sense when we're talking about societal factors with the patients that you work with.

Dr. Blake Woodside: First of all, the way to think about the societal piece, especially when you think about the genetics of these illnesses, is that anorexia nervosa is one of the most heritable psychiatric conditions. The heritability is about is about 75%. The heritability of schizophrenia, for example, is about 50%. The heritability of sugar diabetes is about 70%. It's a highly genetically determined disease. Genetics loads the gun, and environment pulls the trigger.

Since the early 1960s the ideal for female beauty has been an unrealistically thin ideal. There's a bellwether; that's a sociological term for a single person who resets a societal trend. This person was Twiggy in the early 1960s, who literally overnight reset the expectation for what a woman should look like, as compared to someone like Marilyn Monroe, five or six years previously, who at five feet six inches weighed 135 pounds and everyone thought that was fine, thank you very much.

By the time you get to the early 1980s, if you can think of that Jane Fonda 20-minute workout image—everybody knows that image—she's five feet seven inches and weighs 115 pounds, which meets a diagnostic criteria for anorexia nervosa, by the way, and she did have anorexia for many years. She's fessed up about that.

There was this massive sudden change. I've been watching this, obviously because of what I do for a living, for 25 or 30 years.

In the 1990s we thought we were getting out of it because there was a brief interest in muscularity and strength for women. That went on for about five years, from 1990 to 1995. The AIDS epidemic starting in the late 1980s certainly made it not particularly attractive for men to diet and lose weight, because if you lost weight everyone thought you had AIDS. That resolved itself after about 10 years. The female muscularity thing very rapidly turned into leanness and muscle definition and went straight back to calorie-reduced dieting.

I wish I could say that this is changing, and sooner or later it will change, because a preference for body weight and shape is like hemlines or hair length: it is a fashion statement. It keeps getting gussied up as a health issue, but it's not. It will eventually change. It's relatively recent in our history, only about 50 years, but there's very little evidence that it's changing right now.

Education about attitudes to weight acceptance and so on is very important, but they are being plowed under right now by a belief that we have an epidemic of obesity, especially in children, which frankly isn't true. It's very complex.

● (1555)

Ms. Niki Ashton: Thank you.

I'm wondering how much time I have left.

The Vice-Chair (Mrs. Tilly O'Neill Gordon): A minute and twenty eight seconds.

Ms. Niki Ashton: I have a quick question.

I came across an article by Karen E. Faith entitled, “Addressing Issues of Autonomy and Beneficence in the Treatment of Eating Disorders”. She talks about the tension between intervening against the will of patients and their ability to choose in terms of treatment. Obviously, this is an area which for women in general, whether we're talking about history of psychiatric treatments or forced sterilizations, has some pretty negative connotations. I'm wondering how you manage that tension and how you and your colleagues treat your patients.

The Vice-Chair (Mrs. Tilly O'Neill Gordon): You have 50 seconds.

Dr. Blake Woodside: My treatment program is voluntary, and that goes for people who have a body mass index of 10. Nobody is forced to come to my treatment program. Nobody is forced to stay; people can exit any time.

The program has in it elements that we think are evidence-based and supported by the scientific literature, so we believe we're practising in an evidence-based way. We also innovate in our treatment. We're one of the world leaders in developing better and newer treatments for anorexia nervosa, but it's voluntary. For most of what you would call the treatment programs in Canada, the treatment is voluntary.

Then on the other hand, there are people who are going to die right now, who are unwilling to come to treatment, and a decision is then made about whether to salvage them or not.

I'll give you two examples. We have a woman who is 23, who happens to be a medical student, who was going to die right away. She was on death's door in the emergency department, had been offered treatment repeatedly for months, would not consent to come to treatment, and a decision was made to partially weight restore her against her will to save her life for the moment. Another patient, 53, with 35 years' duration of illness, was in another local hospital in Toronto. I believe the decision there was made to let nature take its course.

The only circumstances under which people are treated against their will at this point for adults are where the person is going to die right away unless a medical intervention is made and a decision is made that the patient is too young and has not been sick long enough to simply let them die, but otherwise, the treatment is voluntary. It doesn't mean the patients like all of it. There are lots of anorexic patients in Toronto who will tell you that I am the devil on earth because of how my treatment program is structured, but it is voluntary.

There are limited choices for patients, very limited choices.

I think you're out of time and I've got to stop, but there are very limited choices and that's the big problem.

The Vice-Chair (Mrs. Tilly O'Neill Gordon): Thank you.

Next is Terence Young.

Mr. Terence Young (Oakville, CPC): Thank you.

Thank you very much for your time today, Dr. Woodside.

I wanted to ask you about family physicians, because I've had family physicians tell me that they often don't know what to do with the patients when they come into their offices. Because of the complexity of the disease and the comorbidities, the patients are difficult to diagnose. Once they are diagnosed, or once the physicians think they have them diagnosed, they just don't know how to treat them.

How big a problem is that?

Dr. Blake Woodside: The illnesses are relatively straightforward to diagnose, especially anorexia nervosa. There aren't that many reasons for an 18-year-old to be at a body mass index of 14. That one's pretty obvious. Bulimia is more difficult because it's an invisible condition.

Part of the problem is the total lack of exposure to these conditions in medical school curricula and residency training programs. In Toronto we have the largest residency training program, I think, in North America. We have 128 residents in the program. We have the largest program for eating disorders in the country. The total exposure to eating disorders that psychiatric residents—those are people who have graduated from medical school and are going to be psychiatrists—get in five years of training is two one-and-a-half hour lectures, and that's it. The situation for family practice residencies is even worse.

There's virtually no attention paid to this in medical school, so physicians graduate from medical school with no information available to them, no training, and no ability to do anything useful with these patients once they're identified. There's some room here for recommendations about curriculum in medical school, family practice residency programs, and frankly, psychiatry residency programs as well, because those institutions do an atrociously bad job of preparing their trainees to deal with this. Bulimia nervosa, in the core business group which is women ages 15 to 40, is nearly 3% of women ages 15 to 40. The percentage of bulimia in unhappy young women is very, very high.

I have a colleague who's an outpatient psychiatrist. Many, many years ago when we graduated, he went into private practice. As a favour to me, he added a couple of questions to his psychiatric review systems: have you ever been underweight; have you ever had binge eating; and, have you ever had vomiting? In his first 100 consultations, three people were referred for a clear eating disorder. He discovered 30 additional cases, mostly bulimia.

These are extremely common illnesses in family doctors' offices and in psychiatrists' offices, because these people are unhappy, so they're seeing their doctor or they're seeing a psychiatrist, and there is almost no training in these illnesses in medical school or residency.

● (1600)

Mr. Terence Young: Thank you. That's very helpful.

When I first became knowledgeable about these issues, that is, when I first began to learn about them, as I wouldn't say I'm knowledgeable, I discovered that for patients who require service quickly because their body mass is so low, it is often recommended that they go to clinics in the United States, and OHIP won't cover them. Then I found that if an MPP letter went out, OHIP would approve to cover them.

The girls were not getting good service. In fact, because of the delay in getting beds.... If your beds were full at TGH and Homewood was full, they'd be waiting, as you said, for up to six months. That could take them from being in a risky position to quite a dangerous position.

Do you have any familiarity with the rejection of services by OHIP to pay for out-of-country service when there's a great need?

Dr. Blake Woodside: Sure. I'm involved in reviewing almost all the cases in Ontario. There's a panel of us who have a look at the cases.

The most common situation for people applying for out-of-country treatment is that they have never been assessed by an expert in anorexia or bulimia and have never even been offered treatment in Ontario. That's the most common situation.

I refer very few people to the States. I'll refer one or two people a year, people with extraordinarily complex situations, and there are one or two places in the States that have special expertise that can help out. But by and large, referral to the States is not necessary, and the outcomes are awful, partly because patients are not held there long enough. They need to be held there eight or nine months, and they're held there two or three months. Patients come back partially treated; they don't want any more treatment, and they get sick again right away.

Because the access is very quick, if it's granted, you get this subset of people who kind of get hooked on the quick access to ineffective treatment and stay ghettoized into repeated efforts of going into the States. They have a belief that the treatment system in Ontario is bad, and they won't come for treatment when OHIP finally cuts them off. This is actually doing people a disservice, by and large. There are very, very few good outcomes from treatment in the States, because OHIP won't send them there for long enough, and OHIP is confused about what the purpose of this program is. Most people in the treatment programs in the States would stay there 12 to 18 months at varying levels of care. Two to three months is just getting started.

Mr. Terence Young: Okay, thank you.

Can you please comment, Dr. Woodside, on the nature of secrecy in families for the girls who suffer from these...or think they might have a problem or are trying to hide a problem? How does it remain hidden in the family? Even sometimes when the parents become aware, due to privacy reasons, the disease remains hidden. How does that prevent diagnosis and treatment?

Dr. Blake Woodside: There is widespread fear among the general public that if a member of the family is diagnosed with a mental illness they will encounter overt discriminatory attitudes or stigmatizing attitudes. I prefer the word “discrimination” to “stigma” because I think this is discrimination, and you can do something about discrimination. Stigma is much harder to deal with, but discriminatory attitudes can be changed by policy, for example.

People are afraid to come forward because they don't want to be identified as having a mentally ill family member. That's true for eating disorders, depression, schizophrenia, bipolar disease, anything. I used to be president of the Canadian Psychiatric Association and then chairman of the board for many years. I've testified at many of these panels before. I'm very close to pressing my mental health advocacy button, but I'll resist the temptation to press it.

For the individual, these are shameful illnesses, by and large. Again, this is more of a problem with bulimia than anorexia. Most families will notice if somebody's anorexic because of the weight loss and the amenorrhea, but bulimia is quiet and patients with bulimia are ashamed. They don't like it. They're not proud of it. It's not socially acceptable to be bingeing and vomiting, so they don't say anything until maybe they have a bit of a bleed when they vomit and they get terrified and say something, or maybe their dentists say something.

I give lectures to dental students about this, because they're often the front-line practitioners who identify this. But bulimia is invisible. It can go on forever until someone just drops dead from an electrolyte disturbance.

● (1605)

The Vice-Chair (Mrs. Tilly O'Neill Gordon): Thank you.

We'll move right along to Ms. Jones.

Ms. Yvonne Jones (Labrador, Lib.): Dr. Woodside, I'm from Newfoundland and Labrador. I wanted to outline that, because you'll know that eating disorders became a very public issue in our province. Families came forward looking for help for their children who were suffering from eating disorders, and unfortunately, in some of those cases, they were too late and the children died.

As a result of this, we've seen some movement on eating disorders and a lot of it has been through tremendous advocacy work in the community, committees being established, work being done on trying to find treatments and reducing wait lists. I guess because of these people, the issue became more known to the public.

What work is being done today in the country to make people aware of the seriousness of eating disorders? What work is being done in our schools, in our colleges and universities, to help young men and women self-diagnose that they may have a problem like this and seek help? I'm wondering what your knowledge is of those kinds of preventive measures.

Dr. Blake Woodside: A very exciting event occurred a month or so ago in Toronto when representatives from advocacy groups from across the country got together with the intention of forming and launching a national advocacy group for eating disorders. It may well be that you will invite some of those principals to come and testify before the committee a bit later on as well.

That, in my 30 years, is the first time that's happened in Canada. Local groups tend to bloom and then wither and die, depending on the energy and efforts of the people involved. Creating a national advocacy body is very important, because then you have lots of self-support among the people who are doing the work. There is endless opportunity for that to occur and for that to be supported even at a federal level perhaps.

These are mostly parents of very ill or deceased people. They're passionate about this and they deserve everybody's support. That's really important, because at the end of the day, a family member who's willing to get up and say, “This is my story. My daughter died from this” or “My daughter has been sick for 30 years from this”, is much more powerful than anything I can possibly say, although I'll still get up and keep saying it. However, it's much more powerful for people who are directly affected to speak. Those people need to be supported. I hope this initiative is successful and I will support it as much as I possibly can.

It varies from province to province. You in Newfoundland are very active and I've met some of the principals from Newfoundland. There's a very active foundation in British Columbia, the Looking Glass Foundation, which has raised several million dollars and actually started a treatment centre on one of the Gulf Islands. In Ontario we have the outreach program that does public awareness and teaching in the schools.

I'm not as familiar with what's available in the other provinces, but I think when you do some digging, what you'll find is that there isn't all that much, to be honest, and there's lots and lots of room for that activity to be encouraged and expanded.

Ms. Yvonne Jones: Your response leads me into my next question. In your opinion, what other treatments are offered in the country that are working that we need to be duplicating more?

Dr. Blake Woodside: There are good international standards for treating anorexia and bulimia, and those treatments have reasonable success rates. As I quoted earlier, it's 60% to 65% for anorexia and 75% to 85% for bulimia. These are evidence-based treatments, as much as we can tell. They're described well in the literature, and there are both American and British guidelines to support their use. They simply aren't available in most parts of the country, or at least they're not covered.

The gold standard outpatient treatment for bulimia nervosa is cognitive behavioural therapy. It's virtually impossible to find a physician to deliver that because physicians are not trained to do it. It's provided by psychologists, who are not covered by provincial health care plans. It costs $180 to $200 an hour. A course of treatment costs about $5,000. People won't pay that.

People with more than trivial illness with anorexia need to be in hospital. They need to be in a day hospital program. It's not that we don't know what to do; those services simply aren't available. Again, we know what to do about prostate cancer, but there were only three clinics in Ontario for all the guys with prostate cancer. We knew what the treatment was, but there were no services.

We need to develop new treatments. We're at the forefront of developing new treatments in neurostimulation here in Toronto, and there is urgent need to work on those new treatments. But for your garden variety anorexia or bulimia, we know what to do; it just isn't available.

● (1610)

Ms. Yvonne Jones: In your opening comments you ended by making a couple of recommendations. One of them was asking the Government of Canada to get involved with setting national standards around eating disorders. If you were to outline to us today what two or three of those particular standards need to be, standards that we could negotiate with provinces in the country to meet, whether they be standards or benchmarks around treatments for eating disorders or whatever the case may be, what are the key things you would want to see included?

Dr. Blake Woodside: I'll just pick two or three out of the air as examples. One would be to recognize that appropriate treatment for anorexia nervosa of even moderate severity involves an intensive treatment program that starts with hospitalization and needs to be delivered by experts who are trained in the field. In the same way that you can't expect a general surgeon to do a heart transplant or a kidney transplant—those are specialized areas of practice—you cannot expect a general hospital or a general psychiatrist to deliver these treatments. The first would be that that's the appropriate treatment for anorexia nervosa.

Another would be to recommend that there be covered availability of cognitive behavioural therapy for bulimia nervosa, which is the gold standard, evidence-based treatment, and that it be readily available in communities all across the country.

Those are two just off the top of my head.

The Vice-Chair (Mrs. Tilly O'Neill Gordon): You have 20 seconds left.

Ms. Yvonne Jones: That's fine.

Thank you very much for your time today.

The Vice-Chair (Mrs. Tilly O'Neill Gordon): Moving right along, we will have a second round beginning with Ms. Ambler, for five minutes.

Mrs. Stella Ambler (Mississauga South, CPC): Thank you, Madam Chair.

Thank you, Dr. Woodside, for bringing us your expertise today and for your time. We really do appreciate it very much.

I was wondering about those lifelong skills you mentioned that you teach or provide in your program. What skills does someone who is recovering need in order to leave your program and begin to deal with this on their own? How do you teach them what to do when they leave the clinic? What are the skills you're trying to teach them?

Dr. Blake Woodside: There are eating disorder-specific skills, and then there are other skills that will differ depending on a person's precise situation.

Just to be clear, somebody who comes in with a BMI of 14 would be attached to our in-patient service for about five or five and a half months, and would then transfer to our day hospital service for two months. Then we'd meet with them individually for four to six months to do follow-up treatment to prevent relapse. Someone like that will have contact with our clinic for nearly a year, during which time they will repeatedly practise, with less and less supervision and containment, skills related to eating normally in a healthy, balanced way, and eventually, if they have anorexia, eating enough to maintain their weight.

Those are the core eating disorder skills that we have to teach people. It takes people about a year's practice to really get those nailed down and generate a robust behavioural recovery.

There is cognitive and psychological recovery as well which takes longer. We have to teach people skills to look at their thinking, cognitive therapy skills to identify streams of thought that are related to the eating disorder, and teach them how to deal with those types of thinking.

Then there is what's eating the person, and that varies wildly from person to person. Some people, as I said, have PTSD. They have to be taught mindfulness skills, affect tolerance skills, and do that work. Some people have other psychiatric comorbidity that has to be treated. That third part is a wide array, a vast array of different things that people might have to learn.

● (1615)

Mrs. Stella Ambler: For the cognitive recovery skills, that's not treatment that needs to be administered by someone like you, an expert in the treatment of eating disorders. It could be another mental health professional with that expertise. You're saying there needs to be a team of doctors and health professionals.

Dr. Blake Woodside: Absolutely. We work in multidisciplinary teams. We have many disciplines on my team.

I would probably challenge what you said. This sort of work is equivalent to what happens, let's say, in an organ transplant unit where people are monitored for many years regarding rejection levels of their organs. The family doctor doesn't do that. You need people who are expert and trained in transplantation to actually understand the results.

While you can train a wide variety of people, it's not the purview of physicians, God forbid, to do the cognitive work that's required. People have to have the training. Without the training, they won't function effectively. This is specialized work. This is not general work that anybody can do. You have to be carefully trained in order to do it.

Mrs. Stella Ambler: Would you say that in the mental health profession there's support for the concept you just described? You mentioned that eating disorders are not covered in medical school curricula. Would you say that overall in the medical profession there's support and understanding for this kind of treatment within health care, or are you fighting that discrimination even within the medical profession? I guess I'm asking if they take it seriously.

Dr. Blake Woodside: I think there's primarily ignorance in the health care profession. In my experience, the average family doctor, in their entire career, may see only two or three patients who are very sick with anorexia. They get very interested when they have such a person. They call me on the phone and they want to learn all about it. They're more frightened than anything else.

By and large, it's simply ignorance and lack of knowledge. There is a certain amount of discriminatory attitude present even in the medical field, but it's mostly that they just don't know. They've had no exposure. They don't know anything about it, and when they see a patient, they don't have the first idea of what to do next.

Mrs. Stella Ambler: That's because—

Dr. Blake Woodside: I'm not sure if that answers your question.

Mrs. Stella Ambler: Yes, sort of.

The Vice-Chair (Mrs. Tilly O'Neill Gordon): You have 20 seconds left.

Mrs. Stella Ambler: I'm just wondering how it can become part of the curriculum in medical schools, so students will spend more time learning about it.

Dr. Blake Woodside: That's public awareness and lobbying, right? That's why, for example, this national public advocacy group will be so important, if it's established and sustained. I think the federal government has a role to play as well in terms of public information.

The Vice-Chair (Mrs. Tilly O'Neill Gordon): Thank you.

Ms. Sellah, go ahead for five minutes.

[*Translation*]

Mrs. Djaouida Sellah (Saint-Bruno—Saint-Hubert, NDP): Thank you, Madam Chair.

Dr. Woodside, thank you for being here and for providing clarifications concerning this very serious medical condition, which is increasingly prevalent in our society.

I was happy to hear you speak about factors that predispose people to this disease. As you said, it is a disease. It is thus a medical issue, without going into the societal factors that trigger it. I am happy that you said so.

I am myself a health professional, a general practitioner by training. For this reason I know that the DSM-V, like the previous DSM-IV, are included in the books that medical students study. They take psychiatry courses. They are acquainted with these eating disorders, whether we are talking about anorexia nervosa or bulimia. As you said earlier, it is true that people have a tendency to dismiss this. We know that there are specialties. I agree with you that specialists should be handling these cases.

All of that said, I am concerned, since this is a health care issue. I know that you head up one of the best eating disorders programs in the country. However, I wonder how accessible these programs are to people who live in rural areas, for instance. That is my first question.

● (1620)

[*English*]

Dr. Blake Woodside: For people who live in rural areas who need intensive treatment, they have to travel. My catchment area in Ontario covers, for example, most of northern Ontario. People come from many hundreds of miles away to attend my program. That is not ideal. It would be better if they could be treated closer to home. Dealing with remote and rural populations is complicated because the volumes are low in such locations. There aren't a lot of patients. The patients there are just as sick as anyone else, but there aren't a lot of patients, so it can be hard to justify setting up proper clinics for those people.

Having said that, setting up clinics where you teach somebody to do cognitive behavioural therapy for bulimia in a micro-agency with two or three employees, that's dead simple. You can train someone to do CBT very easily. There should be CBT in every community in the country, or available in every community in the country.

Training people in diagnosis in small clinics, that's fairly straightforward. You should be able to do that. I think enhanced awareness of this among family doctors and pediatricians is very important, to at least identify patients and then refer them to the nearest treatment program.

I agree with you that there's a serious problem in terms of access to care for remote and rural communities for all aspects of medicine, not just this.

[*Translation*]

Mrs. Djaouida Sellah: Yes, that is precisely the issue. You recommend that there be experts in all fields.

I am from the province of Quebec, and I know that service delivery is a matter of provincial jurisdiction, and not a federal one. Has there been any contact or communication with other provinces to discuss this issue?

[*English*]

Dr. Blake Woodside: In any province where there is an advocacy group, those groups have made representations to the provincial government. Most of those groups have professionals as advisory panels, so they will help out. Usually it's family members who are doing the advocacy. That's where it comes from right now. If there's a national advocacy group, they will work on things like recommended standards, and so on.

I'm aware that the federal government has a limited role in terms of health care provision. My own view is where the federal government has an important role is by setting standards and raising awareness, and saying, “Look, this is important. Here's an area that's been neglected, and where care is probably not being delivered appropriately, and here are some ideas about how the health of these citizens could be improved.”

The Vice-Chair (Mrs. Tilly O'Neill Gordon): We'll move right along to Madam Crockatt for five minutes.

Ms. Joan Crockatt (Calgary Centre, CPC): Dr. Woodside, we're really pleased to have you here. I think we recognize there is not enough information out there and that we could advance the knowledge by having this study. It's great that you are able to be here. One of our Conservative members brought it to our attention.

I'm happy to be able to follow it through, too, because I have had quite a bit of association with Dr. April Elliott, whom you might know. She is the chief of adolescent medicine at Alberta Children's Hospital and deals with bulimia and anorexia.

I think you're in the process of trying to break down some of the myths here, and there appear to be a great many of them. I think that the public has no knowledge of the degree to which people are dying from anorexia. They do believe that it is a controllable urge. I think you've already started to change minds today by bringing some of this information forward.

I was interested in a couple of things that you said. One of them that just struck me is how we have a view in society that children's obesity is at some kind of crisis level, and you said that it isn't true. I wonder if you could explain why that is. Perhaps that's another of our issues.

● (1625)

Dr. Blake Woodside: I hope you invite Dr. Leora Pinhas to address your committee. She'll explain it to you in great detail. She is a biostatistician. In brief, and you'll get her to explain it in more detail, her read on the epidemiology is that rates of disordered eating among children are twice as high as rates of obesity, and obesity is the epidemic and disordered eating is ignored. That's the short version of what she would say.

Ms. Joan Crockatt: Oh, wow.

Dr. Blake Woodside: I'm not pro-obesity; don't get me wrong. I am anti-dieting, because I don't think dieting helps anything, not even obesity for that matter.

There is a risk for things like programs in the school, where kids' BMIs are measured and they have fingers wagged at them if they're too heavy. That's like giving people a pill that will make them anorexic. There has to be some balance here. You don't want to stigmatize eight-year-old kids because their BMI rating is two points higher than somebody thinks it should be.

Ms. Joan Crockatt: Absolutely.

You mentioned some new treatments that are coming forward, and you spoke about some neurological-based treatments.

Can you tell us what novel treatments need more research and study right now?

Dr. Blake Woodside: Sure. We are doing two things. We are world leaders in this. We're doing something called deep brain stimulation for chronic, severe, intractable anorexia, for people who are going to die. We've done 14 cases and we have six people lined up.

It's the same type of treatment done for Parkinson's disease, where electrodes are implanted in the brain and hooked up to a stimulator that is turned on permanently. It's showing good promise. Just as a sidebar comment, people will often look at these chronically ill patients and say they don't want to get better. Often what they are pessimistic about is routine treatment. These are 20 women of varying ages who have lined up for brain surgery in the hope that we will improve their condition and that they will have a chance at a recovery. These are people who are very willing to engage in even extreme treatments. We're getting some good results with that.

We're also investigating the use of something called transcranial magnetic stimulation, both for treatment of bulimia nervosa and also for treatment of important areas of comorbidity and anorexia nervosa, and particularly of obsessive-compulsive disorder and post-traumatic stress disorder, which can impair people's ability to respond to treatment.

I am proud to say we're also partnering with the Canadian Forces in piloting this treatment for post-traumatic stress disorder for combat veterans, and we're having good results there as well.

Those are two neurostimulator treatments we're working on right now.

Ms. Joan Crockatt: Is brain retraining one of those treatments?

Dr. Blake Woodside: Transcranial magnetic stimulation alters the function of specific brain circuits, mostly brain circuits related to the regulation of emotion. People who get a good response say that they feel more normal inside, that they feel like they have a better, more consistent experience of their internal emotional life. They don't need to do things like binge and purge anymore, or if they have PTSD, they don't get so activated and cut themselves and stuff like that.

I wouldn't exactly call it retraining. It's more like restoring normal function to brain circuits that have been demonstrated to be not functioning normally. It's the same for deep brain stimulation.

The Vice-Chair (Mrs. Tilly O'Neill Gordon): You have 15 seconds.

Ms. Joan Crockatt: Did I hear you correctly, that 60% of your patients have sexual or physical abuse issues?

Dr. Blake Woodside: Yes, in my population, I treat the sickest of the sick with anorexia nervosa on the in-patient service. Sixty per cent of my patients have a history of physical or sexual abuse.

The Vice-Chair (Mrs. Tilly O'Neill Gordon): Thank you, Dr. Woodside. This brings our hour to a close.

We want to thank you very much for your valuable information and the great insights you have given us into this topic, and for taking time from your busy schedule.

Dr. Blake Woodside: Thank you, Madam Chair.

I wish you the best of luck with your study.

The Vice-Chair (Mrs. Tilly O'Neill Gordon): Thank you so much.

There being no further business, I remind you that our next meeting is Tuesday, December 3.

The meeting is adjourned.

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