Speaker 1: The Cancer Assist Show, hosted by Dr. Bill Evans and brought to you by The Cancer Assistance Program, help when you really need it.

Dr. Bill Evans: Well, welcome to The Cancer Assist Show with Dr. Bill Evans. That's me. And we're doing this on behalf of The Cancer Assistance Program here in Hamilton, Ontario, Canada. Cancer Assistance Program offers a variety of free services to cancer patients in this Hamilton area. So, if you're a first-time listener, welcome. I hope you enjoy this show. And if you've listened before, welcome back.

Today's show is going to be a little different. We've done a lot of talking in prior shows about COVID-19, about supportive care, about palliative care, and in the more distant past we've talked about a variety of different cancers, like lung cancer, breast cancer, colon cancer, so on. But today we're going to talk about the cost of cancer care, something that's not maybe talked about enough, and I have a very special guest with me here to talk about that who's knowledgeable about costs and particularly the cost to the individual cancer patient, the out of pockets costs that they can incur. And I don't think we often think about those costs very much. Certainly as a physician, I've probably never considered it. I have to be honest. But the truth is, there are significant costs and now people are starting to shine a light on that fact and give it some consideration. So, I want to welcome Dr. Chris Longo to the show today. He's an associate professor in health services management at the DeGroote School of Business at McMaster University and a member of the Center for Health Economics and Policy Analysis. Welcome, Chris.

Dr. Chris Longo: Thanks, Bill. I'm happy to be here.

Dr. Bill Evans: Well, Chris, I like to always start with my guests and sort of figure out how they got to where they are today, you know, what's been their career path. How did you end up being a health economist and after that, how did you end up being interested in the costs of cancer care and out of pockets costs in particular?

Dr. Chris Longo: Well Bill, the first question is how much time do I have?

Dr. Bill Evans: Well, not all day.

Dr. Chris Longo: So, for me, I think my career path's an unusual one and I basically... I did my undergraduate degree initially starting out in physics, believe it or not, and first year of physics wasn't fun for me mainly because the teacher could barely speak English. So, I decided I couldn't spend four years doing that and I switched over to economics. I worked for a few years then went back and did a master's in physiology at Western then worked for about another 10 years and then did a Ph.D. in health policy. But I'd spent a lot of time doing the economic work when I worked in the pharmaceutical industry, which I did for about 16 years.

So in 2005, I moved over to academia. My list of careers is much longer than that, but I don't think we have the time. So, that brought me to McMaster in 2005. Of course, my work for my Ph.D. was looking at cancer patients' out of pocket costs and I will tell you, part of the reason for me that that was an interest was because I grew up in a low socioeconomic status sort of environment, two parents who never finished grade school. My dad was a laborer. Five... Five of us, five kids, not a lot of money. So, I really identified with people at the lower end of society who suffer through some of these challenges.

Dr. Bill Evans: Yes.

Dr. Chris Longo: And as much as we have a publicly-funded health care system, it's not perfect. It's miles better than the United States, but it's not without its problems. So, I think part of it came...

Dr. Bill Evans: And apologies to our U.S. listeners listening by podcast, but...

Dr. Chris Longo: Yes. But I think it's... It's well-known, to be honest.

Dr. Bill Evans: Yes.

Dr. Chris Longo: That the U.S. numbers are much more grave for patients who don't have the means to pay for a lot of care.

Dr. Bill Evans: Oh, absolutely. And we now talk about financial toxicity, and in addition to the toxicities of treatment, one of them is financial toxicity, including being made bankrupt.

Dr. Chris Longo: And it's interesting, you know, because that term came up when I was at a conference recently and one of the clinicians said, "You know, I don't think you should use the term financial toxicity." And I said, "Well, in a way, I think it is a good term because a clinician understands toxicity and so when we say financial toxicity, I think from a clinical point of view, it just makes a bit more intuitive sense." Really what we mean when we talk financial toxicity is situations where people have to make very important financial decisions in order to get care. And I think it's a fair description. I mean, historically, we use terms like financial burden, but I think in a way, financial toxicity is a better description.

Dr. Bill Evans: Yeah. The older term sort of obfuscates the real harms to people, doesn't it?

Dr. Chris Longo: Right. Exactly.

Dr. Bill Evans: Now, I think some people in Canada probably have a misconception about cost because there is sort of this idea that it's universal health care that's commonly referred to as such. And in fact, it's not universal in the sense of coverage. It's... There's universality in the sense that every Canadian's covered to the same degree. [inaudible 00:05:05] actually in the Canada Health Act. And it's probably useful to remember that you go back before 1957, you paid for everything out of pocket or through private insurance. There wasn't a public coverage for hospitals, for doctors, and so on. And it's been sort of incremental in Canada since 1957 when hospital services and diagnostic tests were covered and then 1966 when the Medicare Act... Medical Care Act came in, which covered physician fees, not without controversy amongst physicians, too. I sort of was just getting closer to being in medical school around that time and was aware of the controversy. And then finally, in 1984, the Canada Health Act, which did speak to universality, comprehensiveness, accessibility, portability and public administration.

And so, I think a lot of people think that everything's covered.

Dr. Chris Longo: Right.

Dr. Bill Evans: When the reality is, it's 70% of health care costs are covered and principally it's the hospital costs, the physician fees and medications that are delivered in hospital and, to some extent, outside of hospital as well, although there's variability in Canada. So, about 30% of costs are covered privately and that can mean out of pocket costs if you don't have private insurance, right?

Dr. Chris Longo: Yeah. And so, of course, this is work that I've been doing for... Looking at this more closely, work that I've been doing for almost 20 years now. The first piece of work I did was in 2001 and 2003 and there's several publications looking at Ontario specifically. And I think one of the points you're making is really important, that each province makes its own decision. So, the Canada Health Act is very specific about doctors and about hospitals and about diagnostics, but nothing else.

Dr. Bill Evans: Right.

Dr. Chris Longo: So that means pharmaceuticals, each province can make it their own decision. It means home care, each province can make its own decision. It means... You know, do you cover for transportation costs? Each province makes it own decision. So, all those things mean that there's quite a bit of variability between provinces, as you alluded to. But in addition to that, in one province, the cost might be quite high for a particular patient. In another province, it could be quite a bit lower.

And so, the work I initially did was in Ontario, but the more recent work, which was just recently accepted and will be published in the Journal of Supportive Care and Cancer probably within a week or so of today's date, looked actually at all of Canada. And so, I ended up collecting data on about 900 patients, looking predominantly at British Columbia, Alberta, Manitoba and Ontario. I did capture data from the other provinces, but not large enough to analyze separately.

And a couple of things we saw. So essentially, this work looked at out of pockets costs, so... As you mentioned earlier... So, out of pocket costs are typically things like co-pays for medicines or co-pays for devices, those sorts of things, or any kind of co-pay associated with home care. We also looked at travel costs. We also looked at the type of insurance coverage they had to cover some of those things. And then, we also looked at lost time from work for both patients and for caregivers.

Dr. Bill Evans: Right.

Dr. Chris Longo: And the variability there was interesting. So, couple of things to say about that. Firstly, looking at Ontario specifically. When I did that work and I collected data between 2001 and 2003, the average out of pocket cost was $213.

Dr. Bill Evans: Per?

Dr. Chris Longo: Per month.

Dr. Bill Evans: Per month.

Dr. Chris Longo: Yeah. Thanks for that clarification. Today that number is 518.

Dr. Bill Evans: Oh, wow. [inaudible 00:08:51].

Dr. Chris Longo: So, that's more than doubled over about a... [inaudible 00:08:56] look at the collection time period, over about 16 years. So, that's well beyond inflation. But when you start looking at other categories like the impact on lost time from work for patients and caregivers, that cost averaged out to about $1,000 a month and now it's closer to $3,000.

Dr. Bill Evans: [inaudible 00:09:16]

Dr. Chris Longo: Now, there's a couple of reasons for that, I think, and part of it has to do with decisions by governments to roll back some of the supports that were in place as the number of patients grows and the budgets aren't growing quite as fast, and that's partly a governmental issue, I think, that more and more of the care, for instance, has fallen to caregivers. So, when I look specifically at the numbers, and I know we don't want to get into the numbers specifically so I won't go too deep into them. But when I look at the numbers and I compare between patients and caregivers, the bigger increase is in caregivers and that's because as the supports disappear, then what happens as a consequence is more caregivers are forced to take on those tasks.

Dr. Bill Evans: Right. Right.

Dr. Chris Longo: That historically might have been provided by home care. So, that's been quite evident. There have been some differences across provinces. That hasn't been published yet because when I initially wrote this paper, I tried to cover everything in one paper and the reviewer said, "Too much data. Too much data. Take some of it away."

Dr. Bill Evans: [crosstalk 00:10:20]

Dr. Chris Longo: So, that paper's to follow, where I look more deeply at how the provinces differ and other factors, like how income impacts this and how gender impacts this and all those sorts of factors.

Dr. Bill Evans: So, what are the big differences, let's say, between... You mentioned British Columbia and Alberta, and say, and Ontario, in terms of out of pocket costs? Or maybe differences in how drugs are funded, like oral drugs? Because we do have differences in who gets coverage in Ontario versus [inaudible 00:10:54]. If you're under 65 and have cancer and the best treatment for you might be some molecular targeted drug that's taken by mouth, then it falls on you to pay for that, right? In Ontario.

Dr. Chris Longo: Right.

Dr. Bill Evans: [crosstalk 00:11:09]

Dr. Chris Longo: So, before I get into the provincial differences, I think one point you just raised there is a really important one, is the difference between if you're under or over 65. So, in a lot of provinces, not every province, there is a very clear distinction that once you turn 65, there are a number of programs that kick in that weren't available before 65. So, when we look at the data and we compare those under 65 versus over 65, the out of pocket cost is larger. And in addition, the lost income is larger because they're more likely to be working and taking time away from work as opposed to taking time away from leisure, which of course, we can value, but generally not at the same rate as when you're in full employment.

So, as a consequence, what we see is much larger impact on those under 65. And so, one of the differences that we see between provinces is what they decide to cover for those under 65. So, we might see more comprehensive coverage in some provinces, and Manitoba's a really good example of this. Manitoba's numbers were significantly lower, partly because they don't make the distinction between 65, so across the board, the coverage is more or less the same. But when you start looking at Alberta and BC and Ontario, they have that more distinct line at 65, that you see the difference between goes under and over.

So, when I looked at the entire population, which includes both under and over 65, in Manitoba, the number's lower because they don't make the distinction about age, whereas the other provinces, they do.

Dr. Bill Evans: Sort of calls in question the universality of the Canada Health Act, doesn't it? Are there... Are there other important differences that you've seen in the out of pocket costs? I imagine one would be travel, just depends where you live. If you live in an urban setting and you've got a cancer center literally blocks away versus living, say, in the northern reaches of a province and you have to come in by plane or a long drive and so on, the cost would be markedly different.

Dr. Chris Longo: Yeah. So, what's interesting here is in Ontario, when I compare the work I did in 2001 to 2003 versus the more recent data, which was basically 2017 to '19, in fact the cost of travel went down. It's the one category where it went down.

Dr. Bill Evans: Hmm. Why would that be?

Dr. Chris Longo: And that... Initially, I looked at that and thought that was odd and then I realized that in 2003, there were six cancer centers in Ontario and now there are... With satellite centers, I think it's 18 to 20.

Dr. Bill Evans: Oh, at least. I think Sudbury and Thunder Bay in this province, our two northern centers, each have 13 to 15 satellites. So, yeah. [crosstalk 00:13:44].

Dr. Chris Longo: So, this is really... If there's one piece of good news in this research, it's that those satellite centers have really had a significantly positive outcome for patients and their travel.

Dr. Bill Evans: That's really important to know. And even, though... You don't have to even look at the far north. You know, we have centers in Barrie and Newmarket and Durham and so on. And formerly, people would have had to come in to Toronto for the care. Instead, they can have their care in Newmarket and have high quality care. So, that's a great difference.

Dr. Chris Longo: Yeah.

Dr. Bill Evans: But now, I'm imaging that they're also probably differences depending on the type of cancer you have, because some cancers require, shall we say, short, sharp treatments and others are sort of ongoing for multiple years, characterized by being chronic illnesses and have to keep showing up to the cancer center to be assessed, perhaps re-staged. At least see their physician to determine their status and [inaudible 00:14:43] further treatments necessary. So, did the research shine a light on some of those differences?

Dr. Chris Longo: So, surprisingly, and I haven't done deeper analysis into this yet... I've done some very superficial analysis to this point. The differences between tumor types were not that large. Now, these patients, on average, were just a little under a year on treatment, so some of them less, some of them more. But an average just under a year, about 318 days on average. So, 11 months, 10 and a half months, something like that. There didn't... There wasn't any... The distribution was different in terms of where the costs were, but they weren't that different, and I was a bit surprised by that. Now, I just looked at the four primary tumors, right?

Dr. Bill Evans: Right.

Dr. Chris Longo: So, I looked at breast, colorectal, lung and prostate. I have other work where I'm looking at other cancers. That work is in progress in head and neck cancer and AYA and a few other cancers. Those work are occurring in Canada, in the U.S., in some work I'm doing in Australia. So, that work is probably four or five years out by the time I'm writing papers and talking about it on radio shows. But...

Dr. Bill Evans: Getting the word out.

Dr. Chris Longo: Yeah. Getting the word out. Yeah.

Dr. Bill Evans: So, you mentioned the beginning and maybe this [inaudible 00:16:02] some of the motivation for your research, that coming from a family that wasn't well off, the impacts of some of these out of pocket costs would be profound, really, and the average cost if you were to take all in from your research is what? How much a month did you say?

Dr. Chris Longo: So, when you add it all up, it's... It's... And you take account of all of the factors, so that's the out of pocket costs, the parking, the travel. And I want to be clear about travel. Travel's imputed, right? So, I'm looking at how far they travel. There are some cases where people are spending for a cab or for a taxi, but most times, it's... They're traveling and so we use the... Basically the CRA rate to say, "Here is the amount you're paying per kilometer for the wear and tear on your car."

Dr. Bill Evans: Yeah.

Dr. Chris Longo: So, adding that in, which is, by the way, not a huge amount of money. On average, it's about $200. And the lost income, which is the biggest chunk of the pie. It's about $2,500 a month.

Dr. Bill Evans: $2,500 a month.

Dr. Chris Longo: Yeah.

Dr. Bill Evans: I think that would shock most people [crosstalk 00:17:04].

Dr. Chris Longo: Right.

Dr. Bill Evans: When they think about our publicly-funded health care system that, in addition, after you get a diagnosis of cancer, your costs, including the loss of income from not being able to work, would be $2,500 a month. That's amazing.

Dr. Chris Longo: What's real worrying, to be honest, is... Of course, we have information on the income of these families, so we measured it at the family level, not at the individual level.

Dr. Bill Evans: Yeah.

Dr. Chris Longo: Is that in those people... We asked a question, specific question, about the financial burden and we gave them a category that went from not a burden at all to the worst possible burden. And for those who claimed the worst possible burden, in many cases, they were spending... The mean was 50% of their monthly income on their cancer treatment. And the median value was 21%. So, that's a really high percentage of their net income for the month spent on cancer care. Now, this is just a month. It's just a snapshot. But the fact that 21% is the median, where they're spending close to a quarter of their income on care in a month, is concerning.

Dr. Bill Evans: It's a huge impact.

Dr. Chris Longo: Again, it's not the U.S.

Dr. Bill Evans: No.

Dr. Chris Longo: And I'm happy about that. But...

Dr. Bill Evans: Yeah. So, we're far better off, but still it's an impact and the impact's not small and it probably changes some of the behaviors. We know in the U.S. and hate to keep referencing the U.S. as a bad player in this, but people do become bankrupt as a result of getting a diagnosis of cancer and your kids don't get to go to college because there's no money because Mom got leukemia or something [inaudible 00:18:50]. So, those awful circumstances do arise. But I'm sure... I'm sure that in Canada, that that financial burden must sometimes interfere with the cancer treatment itself, making choices about whether to continue a treatment or not or whether to pay for those pills and take them or maybe take them alternate days instead of every day.

Dr. Chris Longo: Exactly.

Dr. Bill Evans: These sorts of things would be kinds of decisions that might start to be raised because when 21% of your income's taken away suddenly, that might be the difference between whether you feed your kids or have a lunch for them to go school with. [crosstalk 00:19:30].

Dr. Chris Longo: Right. So, this is a really important question you're asking and interestingly enough, when I did my work back in 2001 and 2003, I didn't ask that question and I realized that that was a mistake. There has been some work done out of the U.S. by Dr. Kent, who's looked at this and found that a good percentage of people do make decisions to forgo care. So, I added that question into this most recent analysis and I looked at everything from drugs to devices to home care to complementary and alternative medicine and all of those sorts of categories. And what I found was, surprisingly, on a national level, that depending on how you look at it... For instance, if you look at the under 65, that close to 50% of the population made decisions to forgo care. Now, the decisions to forgo care may just be as simple as what you've described. They may be, they've given me the pills, I'm going to try to make them stretch for two months as opposed to, "I'm not getting the care at all."

But it was shocking to me because these numbers were quite similar to the U.S. numbers. Now again, I don't think it's as extreme. I think in terms of the number of individuals making decisions to forgo care, this is a fairly serious issue in Canada. But it's not, "I'm not getting treatment at all." Because a lot of it is covered. I think it's the discretionary stuff. Am I getting pain meds that are over the counter and I can't quite afford them so I'm taking lower doses and putting up with the pain or something along that line? I think that is actually quite common.

Dr. Bill Evans: Or to be more functional in your home, to have a roll aid or a wheelchair or these things, so if you go out and price them, they're astronomical. We had an occupational therapist on in a recent show, Sarah Shallwani, and she was saying a wheelchair costs you $1,000. So, if you're already low in income and then 20% of its out of pocket stuff for various and sundry things, it's a pretty easy decision not to get the wheelchair.

Dr. Chris Longo: Mm-hmm (affirmative)-

Dr. Bill Evans: You can get it from a public provider for a month and then you have to either rent it or buy it. So, these costs could be prohibitive. And I guess I... At a place where I can make a plug for the Cancer Assistance Program because providing that access to equipment loans for as long as you need is a great benefit to individuals who particularly just don't have the income to get these aids that would help them have quality of life while they're going through their cancer journey, so...

Dr. Chris Longo: And I think the one thing that you're saying there that's really important is in a way, as the costs for care go up and governments are struggling with their budgets... COVID is certainly not going to help. Increasing them slowly, not enough to keep pace. It's actually putting more pressure on these charitable organizations to sort of fill the gaps and those charitable organizations only have so much capacity, so they can help those most destitute, those most in trouble, but there's a lot of them they can't. I mean, they just don't have the resources to do it and there probably aren't enough of them.

So, I think my efforts have been really clearly focused on government and looking at different ways that they can maybe improve, closing some of those gaps where they're most concerning, and that's sort of my mission, to be honest. Part of the reason why I agreed to speak today was because I think awareness about this is important. I think there are decisions that governments can make that are a little bit different. They won't make this problem go away completely. I'm not expecting that. But I think there are some things that government can do that can mitigate that, and part of the reason for looking at different provinces is some of them have done a better job.

Dr. Bill Evans: It's really important to shine a light on it and to show the differences and what are the best practices that are going on in the country and in maybe other provinces, because they all look over each other's shoulders to see what is happening and by shining a light on this particular issue, maybe some policy changes could come about. I'd particularly like to see some harmony between the provinces around access to oral drugs and not have an arbitrary age level for it. It just seems ridiculous that at the Ontario/Manitoba border, it suddenly changes from requiring you to be over 65 or on social assistance to anybody can have the drug at any age.

Dr. Chris Longo: Right.

Dr. Bill Evans: It just doesn't seem equitable to me as a Canadian and that's a policy issue I'd love to see addressed in due course, and I know there's been folks down in Nova Scotia who have been leading the charge of trying to shine a light on it, but I'm not sure that has gained enough momentum to get into the consciousness of our political leaders, especially at a time of COVID. We may just have to wait for that to be brought under control.

Well, I think it's a really important issue and I'm delighted that you're continuing to work on it and expand it and dig deeper into it. I want to just switch to talk a little bit about drug approvals in Canada because we've talked... We've mentioned already that drug costs are a big part of the total costs of treating a patient with cancer. And there's a good news part of it, that is, we have many more effective drugs as a result of research and development, and virtually all of them come out of the pharmaceutical industry, so we have to say a big thank you to industry for creating these products. But they come with an enormous price and it seems it's only escalating over time.

And in the past, individual provinces would have to negotiate with each manufacturer over their drugs and I'm sure they tried to kind of whipsaw the provinces to get top dollar. I think it's a great step forward in Canada. We have a body that reviews the drugs after Health Canada has approved their marketing and that body was called the Pan-Canadian Oncology Drug Review, or pCODR. It's now brought under the umbrella of another acronym, CADTH, C-A-D-T-H, which stands for the Canadian Agency for Drugs and Therapeutics in Health. And CADTH, pCODR, review cancer drugs, and we talked about that on a previous show with the executive director of the day and people could go to the cancerassist.ca website and find that show and listen to that conversation to hear again about how drugs are reviewed.

Importantly, obviously, we review the clinical benefit. That's absolutely important, that there's a net clinical benefit when one weighs how much improvement in survival, quality of life versus maybe the attack toxicities of the therapy. And then there's important patient input given and there's patients at the table as part of the decision-making process. There's also patient input and caregiver input through advocacy groups, which is really given a lot of attention at that... As drugs are reviewed. But then there's an economic aspect of it and we're looking at the cost, cost effectiveness and so on. And as a health economist, you're around that table and you receive inputs from external health economists who've reviewed the file and have come up with an estimate of the cost per quality adjusted life year.

And then... So, what do you do when you sit at that table and review the file and receive this information from external health economists?

Dr. Chris Longo: So, I... You know, I feel really fortunate and privileged to have an opportunity to input on those processes and I've had two opportunities to do that, one with the Ontario Steering Committee for Cancer Drugs between 2013 and 2016. And there actually, I got the files directly and I actually reviewed the economic documents directly, manipulated the models, tested some of the sensitivity, et cetera, to determine whether or not it was a well-built model. And then, from 2018 to present, and my contract's been renewed until 2023, I'm now doing that with pCODR, our basically expert review committee. There actually, I'm sort of one step removed in that there is a team that actually does the analysis. They do the sensitivity analysis and then they hand me their analysis.

Dr. Bill Evans: Now, let's back this up just a little bit because I'm sure there's a lot of listeners who are wondering what you talking... Models and sensitivity analysis. So, when you're talking about an economic model, we're looking at the benefits of... That have come out of the clinical trial. And typically, it's, what we say, a randomized controlled trial. So, there'd be an arm with a new drug and an arm with the current standard and if the drug is effective, there'd be a difference, right? But typically, when this information's presented to reviewers like yourself, the data is relatively immature. You don't know if the person's going to live for two years, five years, 10 years. And so, what has to happen is you take some of the early data that's coming out of the trial and you model what the results will be over time.

Dr. Chris Longo: It's like a forecast.

Dr. Bill Evans: A forecast. That's a good expression that people can understand, because we're forecasting the weather all the time. And you know, the weather forecasts are sometimes wrong and they can be... Economic analysis can be wrong, too. And in fact, that's part of the challenge, isn't it, because...

Dr. Chris Longo: Absolutely.

Dr. Bill Evans: Because the company will model it in a certain way and they may do it very well, but they're obviously interested in seeing that the drug has the best benefit or a large benefit, so they may choose some of the modeling parameters to kind of make it look even better. And part of your job, I think, is to critique that. Does it make sense? Does it...? Is it clinically sensible? Is it the right choice of parameters to use in the model? Correct?

Dr. Chris Longo: Yeah, that's... I mean, that's absolutely correct, and I think one of the real challenges for us is the measurement of what we describe as uncertainty. So, when you do a forecast for the weather and you say, "What's the weather going to be tomorrow?," you're fairly confident and you can look. You can talk to someone 200 and... 300 miles away and say, "Hey, what's going on there today?". And tomorrow that weather's going to be here. But you ask somebody for the weather report for a week from now, you have a lot less certainty about whether or not that's truly going to be the weather. If you're going to book your tee time to play golf, you book it a week in advance. It looks like it's going to be a sunny day. There's a really good chance by the time you get there, it's not a sunny day.

Dr. Bill Evans: Mm-hmm (affirmative)-

Dr. Chris Longo: The same is true, really, when you talk about the outcomes from a clinical trial. They don't measure the patients, generally, until they die. A terminal cancer, you would. But curative cancer, not necessarily. So, in those cases, we have two years' worth of data, maybe three years' worth of data. But we're projecting out 10 years or 15 years or even 20 years.

Dr. Bill Evans: Yeah.

Dr. Chris Longo: And so, the further out we're projecting, the more uncertainty there is about whether what we're seeing is a true reflection of what's really going to happen, and when we're investing large sums of money, we're worried about making those investments with that level of uncertainty. And so, these committees deliberate. We spend a long time after everybody presents their data deliberating on the strengths and weaknesses of the data. Do they pose risks for patients? Is it possible there's no benefit at all? These are important things. I mean, one of the things economists talk about is opportunity costs. So, if we're going to invest in a technology, by definition, that means that money is no longer available to invest somewhere else.

So, we really don't want to invest in a new technology if we're highly uncertain about whether the benefit's going to be seen, because we'd rather spend that same amount of money on a cancer drug where our confidence that the benefits are real are going to be realized.

Dr. Bill Evans: Right.

Dr. Chris Longo: And so, that's part of the exercise for us. And everybody at the table takes it very seriously. It's not a... It's not a trivial exercise, and we spend more time deliberating than we do presenting the data, and I think that's appropriate.

Dr. Bill Evans: Well, it is and I think it's good for our listeners to know that this... There are these processes going on behind the scenes, so to speak, to try and ensure that the drugs that are going into people are actually... Have been well-studied, that there's a confidence level that it's truly beneficial from a clinical point of view and it's of good value to society as a whole, right? Because as you say, there's opportunity costs. If we're spending it on a drug that doesn't work very well, maybe we don't have the money to spend it on something that really does work well [crosstalk 00:32:32].

Dr. Chris Longo: Right. And it's coming maybe five months down the road.

Dr. Bill Evans: Exactly.

Dr. Chris Longo: And the other piece here that you mentioned briefly is the patient perspective, and I think for me, that has been a real learning, to see what matters to patients and what matters to clinicians are not always exactly the same, and getting the patient perspective in there. There have been a couple of cases, and I can't talk about specifics, where the patient perspective completely changed our conclusions. And it doesn't always happen that way. But I guess the point is sometimes you need to look at these things from how the patients are experiencing them, and I think adding that in... And I think that's happening in a lot of jurisdictions outside of Canada as well. I think it's a really important step forward.

Dr. Bill Evans: Well, I agree entirely. At an earlier time... We didn't overlap, but I also served on the expert review committee and I... I really became very impressed by the inputs from the patient groups and it opened my eyes because as a clinician who had seen patients over many, many years, you see them relatively briefly in the clinic room. You don't really know what living with the disease is like. You don't know what it's like to be a caregiver, providing support to someone with advanced cancer. And it really and truly changed my perspective on what's important and how we value these new therapies.

Now, so... It's really, I think, a very amazing process that's been put in place and I think Canadians should know about it. I'd like them to know about it and I'd like them to feel that there's... There's people there who are working very hard to ensure that the very best and most useful therapies are available and that we're getting them in Canada at a reasonable price. I think it's well known that the prices of drugs in the United States are extremely high and much higher than they are in Canada. And part of what you do in terms of looking at those economic models and looking at the numbers, at so many dollars per quality adjusted life year, that information's used in the determination of price, isn't it?

Dr. Chris Longo: Absolutely. I mean, I think it becomes, in many ways, a negotiating chip. You use that to say, "It's not that we don't believe in the clinical value of this drug. It's that we as a government can't afford to spend this amount of money. We need you to see if you can sharpen your pencil a little bit and do something a little better on the price point so that we can make this available to a broader... You know, broader population, essentially."

And I will say the one thing I have really appreciated about CADTH is that they've really done an excellent job of being as transparent as possible. Their conclusions are published. You can go online. You can read about them. They have a sort of front section, which is a bit more layperson term, and then they have the deeper dive in the body of the document that goes into much more detail. I would say [inaudible 00:35:29] going to depend on the reader, how far along they want to go into that document. But the fact is every single drug reviewed, whether it's approved or not approved, that data's available, and I think that's tremendous.

Dr. Bill Evans: And there's opportunity for input from groups, aren't there? So, if initial recommendation comes out, perhaps not supportive a new drug, and clinicians really think that it has value, there's an opportunity for input. If the industry says, "Well, you didn't get it right. You didn't understand our presentation well enough," or so on, there's an opportunity to challenge, shall we say, and reconsider the decision. And the same for the patient advocacy groups. So, there is an [inaudible 00:36:16] process here.

Dr. Chris Longo: And in addition to that... That's true, 100%. But in addition to that, in some cases, the decision, a negative decision, could be that the data's not mature enough. You mentioned that earlier. And so, we'll encourage the pharmaceutical company to submit again with more mature data. It goes back to that same issue I mentioned earlier about the level of uncertainty and making a decision when you feel like I don't quite have enough information to make a decision with confidence. Help me here. Give me some more data.

And so, there are lots of cases where they do come back. Maybe it's six months, maybe it's a year. Maybe there was an interim analysis that was due six months from now. They know that new data's coming and we say, "You know, send it to us again." It's not that we're trying to be anything but careful.

Dr. Bill Evans: And one of the problems is when you only have data from what we call a single arm trial, like a phase... We call them phase two study, a study that's done in a cohort of patients but without a comparison to people getting a standard of care. So, how do you know that just that cohort is truly benefiting or maybe they were just selected to have a better survival? Decisions when you're faced with that are difficult and it's become a more common problem because as we understand the molecular drivers of cancer, what were common diseases, say like, lung cancer, are becoming somewhat rare diseases because they're defined by a specific genetic abnormality and it's rare, and so you can't find a lot of these people, so the industry comes with 30 patients with this, collected over two years, who got a treatment and they seemed to do very well. But is that what's going to happen in the real world? Or can we do a randomized trial to really define that this new treatment works?

So, there... There are real challenges in evaluating drugs and I thank you for your commitment to being at the table there and the work you're doing in evaluating the economic side of it. I know from my past experience, it's challenging, but also very rewarding.

So, as we sort of wrap up here, what messages would you like to leave our listeners with about costs of cancer care?

Dr. Chris Longo: You know, it's interesting. I think... I know I've had some opportunity to do some qualitative work in this space as well, where I've sat down and interviewed patients and talked to them about their cancer journey. And one of the things that's surprising to me is a number of these patients who are really in a tough position are just unprepared for a financial challenge of any kind. And so, one of the things I've discovered is financial literacy is a really, really big problem, and I think in our culture in general, not specifically about cancer. But when you have someone who doesn't really understand their finances very well, isn't really planning ahead, doesn't have a little nest egg somewhere... My experience from this work is that we're talking about the average family being impacted for somewhere between 25 and $50,000. And that's a combination of lost income and additional expenses. So, whatever their budget was, they're going to need an extra $50,000.

So, my comment to you is... My comment to the readers, I guess, or listeners, is that in the Canadian system, you should be prepared for that. I mean, you'd like to think that everything is covered, but the data doesn't suggest that's true. And so, that's a bit of a wake-up call. You know, somebody making $100,000 a year probably isn't the person you're worried about. The person you're worried about is someone in that average income, family income of $50,000. Losing $50,000 for those people is really significant.

Dr. Bill Evans: Huge.

Dr. Chris Longo: So, I think it's a bit of a wake-up call, unfortunately, to say, as good as our system is, there are gaps and if you think you're going to go through a cancer diagnosis and not have to worry about finances, I think for a lot of people, they need to think twice. And one of the pieces to that that's really interesting is when they interview people, the social workers interview people, they ask them, "Are you okay financially?" And they say, "Yeah. Yeah. I'm fine." The problem is they ask them at the beginning, before they realize all the things that are coming.

Dr. Bill Evans: Right.

Dr. Chris Longo: And there are resources at a lot of cancer centers. You know, some of them are like wheel trans type things that get people to appointments to save them on travel costs. People don't necessarily ask for those things because they think they're fine and then three months in, they realize, "Oh my God. No, I'm not fine. I had no idea I was going to have to pay for this or this or this or that." And so, I guess the other message to cancer patients would be take the help. Ask for the help and don't assume because you have 5,000 or $10,000 in your bank account, you're fine. You're probably not fine and you should take the help if you can get it.

Dr. Bill Evans: That's a really important message and I'm glad that you're able to deliver it for us because the whole purpose of these podcasts is to make people aware of the challenges of facing cancer, also the hopeful aspects of it, the better therapies that we have. But just being aware that there are going to be costs is important, and also that there are resources. You mentioned one and the cancer center has a social worker. I think physicians need to be aware, too, that as treatment progresses, that this may be having a financial impact. And there are guidelines from the American Society of Clinical Oncology that physicians should be having conversations with their patients about treatment costs. We don't, I think, do that hardly at all in Canada and I think physicians need a bit of a wake-up call as well to raise this topic and... Because then they can be directing their patients to other resources that might help them out.

Dr. Chris Longo: Mm-hmm (affirmative)-

Dr. Bill Evans: Certainly the Cancer Assistance Program, which is responsible for these podcasts, is filling some of those gaps, at least in the Hamilton area, by providing free transportation to the cancer center. That's been limited a bit by a virtue of the COVID pandemic. We're back and doing that in a lesser degree just at the moment, but as the pandemic passes, we'll be back and providing free rides to cancer patients. In the interim, we've been providing some food support to people who have need of that and also helps them stay at home and not go out and mix and place themselves at risk.

But we have an important program in lending equipment that could help people get by better in their homes, so whether it's a wheelchair or a roll aid or things to help you with your toiletries and so on. There's a lot of equipment that we loan free of charge. We provide some nutritional supports and continence supplies. So, there's a number of things that we're trying to help with in this community. Of course, they all cost money. Back to cost. Nothing's for free, so those of you who are listening, if you have means and a willingness to be a supporter, if you could donate to the Cancer Assistance Program, you can go on their website at cancerassist.ca or put a check in the mail to Cancer Assistance Program at 555 Concession Street, Hamilton, Ontario, L8V 1A8. They'd be grateful to receive donations.

So, this has been a bit of a different show, as I said at the beginning. Instead of talking about cancer, we're talking about one of the impacts, so I think has been a really, really valuable conversation that we've had and opening people's eyes about the potential impacts financially of a diagnosis of cancer and how you need to prepare for it. You've got some idea of the magnitude of those impacts. And so, we hope you've enjoyed this podcast and look forward to you joining us in another month. And again, thank you very much to our guest, Dr. Chris Longo. It's been great to have you.

Dr. Chris Longo: Thanks, Bill. I really enjoyed it. Thanks for giving me a voice.

Speaker 1: This has been the Cancer Assist Show, brought to you by The Cancer Assistance Program.