

**Season 1 – Episode 3 – Dr. Camilla Zimmermann  
Transcript**

**BTB**

This is Behind the Breakthrough, the podcast all about groundbreaking medical research and the people behind it at Toronto's University Health Network, Canada's largest research and teaching hospital. I'm your host Christian Cote and our guest on the podcast today is Dr. Camilla Zimmermann, head of UHN's division of palliative care and an award-winning scientist at the Princess Margaret Cancer Centre. Dr. Zimmermann is a palliative care pioneer in Canada helping to transform the field in practice and education. She joins us in a minute. But first, here's the backstory on Dr. Camilla Zimmerman.

When she suffered a cut or bumps and bruises growing up in Vancouver, Camilla says treatment was never a problem. She'd just head to her parent's office. Both were general practitioners who shared a practice. She and her brother spent a lot of time there after school, even going on house calls. Camilla was particularly drawn to her mom's whole person approach to care providing psychological and social support as well as tending to her patients' physical needs.

Another profound influence was the early death of her parents — her father when she was just age 13 and her mom when Camilla was 18. She says her mom's death from cancer hit hard, in part because she didn't get the palliative care she should have. But the practice was barely known at the time and there was no education program in Canada. It was at this point Camilla embarked on a quest — including several degrees and a PhD — to become a leading researcher, advocate, and educator in the practice of palliative care.

Dr. Camilla Zimmerman, senior scientist at UHN's Princess Margaret Cancer Center, welcome to Behind the Breakthrough.

**DR. CAMILLA ZIMMERMANN**

Thank you. Happy to be here.

**BTB**

Let's start with what is palliative care?

**DR. CAMILLA ZIMMERMANN**

Yeah. So that's a trickier question than one would necessarily think because everyone thinks they know what palliative care is and I think we'll talk maybe about more, more about that later. But what we define palliative care is as palliative care physicians or practitioners in palliative care is just care that improves quality of life throughout the course of a life-threatening illness. And it's care not only for the patient but also for the family. And we focus on symptoms such as pain and other symptoms but also importantly on psychosocial aspects and on spiritual aspects of care.

**BTB**

Ok, so what's your take then on how well it's understood in the health care community?

**DR. CAMILLA ZIMMERMANN**

In the health care community, it's variably understood, I'd say. So it's getting to be better understood partly through our research and also research of others. It's become sort of a hot topic in health care which is wonderful. But much of the health care system still defines or perceives palliative to be care at the very end of life when there's no other treatments that can help to prolong life. And I think that's part of what we're trying to change with the research that I'm doing.

**BTB**

Where are we at right now today in terms of its acceptance as a full member in the continuum of care?

**DR. CAMILLA ZIMMERMANN**

I think we've made great strides in the last 10 years but we've got a long ways to go I'd say as well. I think in tertiary care centres — especially in cancer centres — it is being understood now more as care that begins early and includes prevention as well as treatment of symptoms and is becoming more sort of woven into the fabric of care at cancer centres. But there's still a lot of health care workers, including also oncologists and other health care professionals, who still see palliative care as being really only appropriate at the very end of life.

**BTB**

So this is a perfect segue into your work. Let's begin with your 2014 paper, the first clinical study of its kind if I'm not mistaken? Tell us what you set out to do and what you discovered?

**DR. CAMILLA ZIMMERMANN**

Palliative care has been defined really by the World Health Organization since 2002 as care that improves quality of life. But prior to our study, and some other studies that came out around the same time, really that hadn't been proven. It had been very hard to show that palliative care improves quality of life and that was mainly because these studies were conducted at the very end of life. And it's not that palliative care can't improve quality of life at the very end of life, it's more that it's hard to study patients at the very end of life because in our field quality of life is measured by what's called patient-reported outcome measures. So it's the patient who's actually reporting the outcome.

So rather than for example us looking at a CT scan and seeing if the tumour's grown or not, the patient has to be able to complete the measure. So if you're looking at patients at the very end of life it's hard for them to complete measures. And also they tend to get what's called co-intervention. So if you do a palliative care study to have a palliative care team provide care versus not provide care and you're doing that in patients at the very end of life, pretty much everyone thinks palliative care should be given at the end of life.

So you get co-intervention in that the patients and the control group who are not supposed to be getting palliative care get palliative care as well. So what we did was we brought the whole study up about a year or two. So we have patients who have a long prognosis. That's why we called it early palliative care, because palliative care is usually given in the last few weeks of life.

**BTB**

When you say you brought it up, you introduced palliative care much earlier?

**DR. CAMILLA ZIMMERMANN**

We brought the whole study up earlier. Yeah. And the intervention — which was palliative care in an outpatient setting. So most studies had been done with palliative care in an inpatient setting at the end of life. What we were doing is, we had a palliative care clinic where we had a team, mostly of doctors and nurses, who were delivering care for the patient and their family in the outpatient setting when patients are still getting chemotherapy and other cancer treatment. They're still ambulatory. In other words, they're coming back-and-forth to the hospital, seeing their oncologist, seeing their other doctors. And we were sort of an extra layer of support for the patient and family. So when they come to see their oncologist, they also come to see the palliative care team.

So that was the intervention — is that patients who have a prognosis of approximately a year, in addition to seeing their oncologist — their goal is still to prolong their life, they're still getting active treatment — but they're also seeing a palliative care team for those extra things, like their symptom control, like caring for their family, psychological support while they're — for anyone with advanced cancer, that's going to be hard to deal with, emotionally. And not only for the patient, but also for the family who's caring for them and living through this with them. So we were this extra layer of support for them. So that's that was the early palliative care intervention.

And then the other half there was actually, we randomized clinics — so oncology clinics. And 12 clinics were randomized to early palliative care. Twelve to standard oncology care. They still got all the care that they usually get. And in fact, they could be referred to the controlled arm, the arm that wasn't getting any early palliative care. They could be referred to palliative care whenever the oncologist wanted to, or whenever the patient wanted to. That was the control arm. And there was 461 patients in all. And what we found after four months (they were seeing the palliative care team (the intervention group) every month for four months), and the control group, about 9% of them eventually got palliative care during those four months as well. So there was some what we call co-intervention, but only for about 9% of the patients.

And what we found at the end of the four months was that the patients in the intervention group — the group that got early palliative care — had better quality of life, better symptom control and also better satisfaction with care.

**BTB**

So what did these results tell you?

**DR. CAMILLA ZIMMERMANN**

These results tell us that with routine involvement of a palliative care team in the outpatient setting, patients with advanced cancer will have, after four months, better quality of life, better symptom control, and greater satisfaction with care.

**BTB**

I'm curious what kind of reaction you got in the world of health care?

**DR. CAMILLA ZIMMERMANN**

It was a strong reaction and it's still reverberating.

**BTB**

Because this is only five years ago.

**DR. CAMILLA ZIMMERMANN**

I'm still being invited to speak places because of this study and I'm pursuing more research in this area as well. But it was a big, big finding. And as well, I think research in this area is difficult to conduct as I've mentioned earlier, just because the patients and even patients in this setting who are a bit more well than patients at the very end of life. But it is harder to recruit patients who are ill with advanced cancer and also harder to retain them to have them continue in the study when they're not feeling so well. So it's many thanks to the patients who actually participated in this study.

**BTB**

From those results did you feel compelled that that is evidence that you could start to apply in practice?

**DR. CAMILLA ZIMMERMANN**

Oh absolutely. And we have been applying that in practice. So we've had this clinic, actually, for...well, when I started at the cancer centre, I started the clinic just by myself. And that was 17 years ago, so 2002. So we've had the clinic in some form since 2002, it's just much bigger now.

Now we've got nine physicians instead of just me and we've got four nurses. And it's a much bigger deal but we have been doing this. The difference was when the patients were getting referred. And that's really been an issue across the world, is that patients tend to get referred, even to these outpatient palliative care clinics, really quite late in the course of illness. So, with about six weeks to live kind of thing, on average.

The frustrating part of that is that the patients come to see us and say 'Gosh, you know I wish I'd come to see you earlier, because I've really been suffering with this pain for about six months now.' And it's really sad to see because we could have made a big difference in this person's life in terms of their quality of life if they'd been referred earlier.

**BTB**

What's been the ripple effect in terms of then this first study of yours?

**DR. CAMILLA ZIMMERMANN**

So, we have groups from all over the world who visit our cancer centre. We have another group coming shortly, actually, from a cancer centre — a big cancer centre in the U.S. to see what we're doing here, and to try to emulate it in their cancer centre. And that's partly why I am being invited to

speaking as well at different cancer centres around the world. So there has been a ripple effect. And there've been other studies.

Ours isn't the only study. It was one of the first studies but there have now been several studies and there's even systematic reviews and meta-analyses putting all these studies together and showing the combined effects of these studies, showing that early palliative care does indeed improve quality of life. But you would think it would, right? If you have a specialized team that focuses really on quality of life and on the different aspects of quality of life, you would hope that at the end of all that, after several months of interacting with that team, that your quality of life would actually be improved.

But now we have definitive evidence — research evidence — to show that that's indeed the case. And ASCO, the American Society of Clinical Oncology, has actually come out with a guideline saying that every patient advanced cancer should have access to early palliative care. So that was a huge step.

**BTB**

When is early?

**DR. CAMILLA ZIMMERMANN**

Well that's a really good question actually. And that's partly the next step in my research is who should actually be getting early palliative care? And we don't really know that. So far what the studies have done and the statements that I can make definitively have to come from research evidence. So, so far what we know from the studies is that if you intervene early and early was defined as, in some studies as 'at the diagnosis of advanced cancer' and the studies that did that were mainly cancers that have a poor prognosis right from the outset.

For example non-small cell lung cancer. Though the prognosis is improving through recent treatments for that but still a pretty poor prognosis if you're diagnosed with Stage 4 – so metastatic non-small cell lung cancer. That group was defined at diagnosis. For our group, because we had a wide range of different cancers all with different prognoses, we just asked the oncologist to specify that the prognosis had to be, according to the oncologist that the patient was estimated to live anywhere from six months to two years. So, that's why I say approximately a year. So on average it was about a year or a little over a year actually. But the range was between six months and two years.

**BTB**

How do you determine which patients will accept or want early palliative care?

**DR. CAMILLA ZIMMERMANN**

If patients don't know what early palliative care is, then it's hard for them to want it, right?

**BTB**

Because we associate palliative care with "I'm dying"?

**DR. CAMILLA ZIMMERMANN**

Because we associate palliative care with dying. I mean, we've done just a big survey of the Canadian population of 1,500 people, of the general public, And people do associate palliative care with the end of life and with death and dying. And so if you ask patients 'would you like to see the death and dying team early' they're all going to say 'well, no, thank you, I'm just fine, I'm not ready to die quite yet.'

But if you ask people 'Would you like help with managing your pain, with managing your shortness of breath, with managing your own nausea, with managing the emotional strain that you're feeling, and the anxiety that you're feeling about your illness, would you like help with home care, with organizing care at home for your family with helping your spouse deal with the cancer.' They're usually they say 'oh yes actually I could use help with that.'

So it depends very much on how you're defining palliative care and how people see palliative care defined. So I think part of my mission is to get the word out there that palliative care is — sure, it's end of life care — but it's much more than that and it can start early as an extra layer of support to help people through what's a very difficult time both physically and emotionally, and often spiritually as well.

**BTB**

I'm curious, as a layperson, our perception of when we go into a hospital or go into care is [that] all of the things you've just mentioned would just come naturally.

**DR. CAMILLA ZIMMERMANN**

You would hope so but that's actually not the case. And palliative care was set up very much in reaction to the fact that, as a society in general, we tend to focus on curing illness. And particularly with cancer, all the ads for cancer centres are all centred around curing the cancer and getting rid of the cancer and diagnosing the cancer but not necessarily on caring with the person with the cancer. So that's where palliative care is different. And you would think — or you would hope — that really that should be a central focus of all medicine is caring for the people rather than for the disease.

But the person tends to — and I think anybody who's been through cancer care would probably say that — that the person can get lost in all the technology that we have now. On high-precision diagnosis of disease and then also on high-tech treatment of the disease. And it's becoming more and more complicated in terms of personalized cancer medicine and genetics, etc, and identifying which treatment to give a patient and then getting the whole protocol organized, that it tends to be that the cancer visits that the patient experiences are very much focused on the cancer treatment and not a lot on what you're actually feeling and experiencing while going through that treatment.

So that's where we're able to sort of be this extra layer of support as I've called it. And also step back a bit and say 'Ok, how are you doing as a person and what are the things that we can do to help with that?' And most patients are very receptive to that. Some people are doing just fine and are able to get that kind of support or they don't have any pain and symptoms which are the people that I don't think probably need early palliative care or a specialized early palliative care. But a lot of people do have a

whole list of issues or problems that it would help to just go through with an experienced professional, or a professional team, which is what we can provide.

**BTB**

That study, the 2014 study, I'm curious to know, in terms of the results, you talk about people by and large appreciate early palliative care, and that for many of those people, their optimism and even hope, rose as a result of that early intervention. What to your mind would explain that?

**DR. CAMILLA ZIMMERMANN**

I think it's the focus. So it's true that a lot of patients when we ask them – we actually ask them at the end of the study what they thought palliative care meant – and a lot of them actually associated with hopelessness. That there was no hope left. But they were sort of pleasantly surprised that a lot of the meetings with the palliative care team were very hopeful. And I think the difference is what we're actually hoping for.

So we're helping patients do the things that they want to do with the rest of their lives and that's a very hopeful kind of a thing. Like, what do you what do you actually want to do with the rest of your life? You know? If you had the choice, would you go traveling? Would you go and visit a lot of people from different countries, want to visit family and wherever they're from — from the Bahamas or something? So we make that possible for them.

**BTB**

How do you mean?

**DR. CAMILLA ZIMMERMANN**

Well, we work with them and with their cancer team to say 'Ok, if you do want to do that, probably right now is a good time to do that. You're still feeling pretty well, so let's try to take that trip that you want to take and fit it in between your cancer treatments and let's make sure that your symptoms are controlled so that you're actually able to get on the plane and get over there and make sure that you understand what the implications are for insurance, because it's hard to get covered — or hard or impossible to get covered. So have your bases covered and go at a time where you feel particularly well. Or do you want that family member to come from Greece, or wherever, to come in and visit you?

So, you know, people are happier when they're able to talk openly about the fact that, sure, yes, I have a serious illness but what can I do with my life right now? And that's a hopeful experience. Also it's easier to have hope when you're not struggling with terrible pain that you haven't been mentioning because, you know, you didn't think it was important to mention. So we specifically... people don't necessarily tell you how much they're suffering. They think, 'Well this just sort of comes with the diagnosis and here I am with my pain, but you know I'm not going to mention it because of course I have pain, I have cancer. Everyone with cancer has pain.' So they don't understand that you can actually prevent the pain. And that requires special discussion and also knowledge of how to treat pain. So, we're able to do that for people.

**BTB**

Since your 2014 study, where has your research taken you?

**DR. CAMILLA ZIMMERMANN**

So, in a number of different directions. One is this whole idea of stigma in palliative care. So we did another study in 2016 that actually arose out of that study, where we asked patients what they thought palliative care meant. And the patients and their families, Almost all of them thought that it meant end of life care, given up hope, lying in bed unable to do anything for myself. It was a very negative perception of palliative care. And we found that during the course of the study, the patients who received the intervention actually had an enlightened view of palliative care that you know that they now realize that palliative care meant early involvement, meant improving quality of life. And were tremendously grateful for the care that they received.

But they still felt that there was a stigma associated with the name palliative care and the concept of palliative care. So they weren't easily able to speak to their family members or their friends about the fact that they were going to a palliative care clinic because they were afraid of being stigmatized. 'Oh that must mean you're dying.' So I think that's the next thing that we have to work on. I think as a society is getting the word out there that palliative care is more than end-of-life care. So my next step was doing a larger survey, as I mentioned earlier, of the general public and asking them about perceptions of palliative care.

And the step after that is going to be trying in some way through social media or other to change the perception of palliative care. I think, you know, we've redefined palliative care, way back when in 2002 the WHO redefined what palliative care is. Before then, it was end-of-life care.

So, it's not that people got this conception that it's end-of-life care out of nowhere. It is actually where palliative care was born and started, was at the bedside of terminally ill patients in the 60s with the hospice movement. But it's gradually changed and there's not many definitions of things that change over time. So, the health care profession isn't quite ready yet, as I've mentioned earlier. And patients and the public are even less ready, I think. Because, you know, they don't read the World Health Organization definition. They just see the care they get and the care that they're getting tends to be, still, in many cases, end-of-life care for various reasons.

**BTB**

In addition to your research you run a clinic. You see patients.

**DR. CAMILLA ZIMMERMANN**

Yes. Oh, absolutely, yeah.

**BTB**

Does that inform your research at all?



**DR. CAMILLA ZIMMERMANN**

The interaction with patients and with their families informs my research and my research informs our practice as well. As does the research of others in our group and around the world. So, what we're doing is evidence-based medicine. So, with every bit of research we do, we're able to improve our practice. And of course, the patients we see also inform the kind of research questions that we're posing.

**BTB**

As that — I'll call it a relationship — unfolds with your patient, part of the approach I understand is to help them with trapped emotions. What is that?

**DR. CAMILLA ZIMMERMANN**

It's more than trapped emotions. It's trapped feelings in that a lot of patients don't tend to say exactly what's on their mind just because they don't know that they're allowed to. A lot of time.

**BTB**

Even at this point in life?

**DR. CAMILLA ZIMMERMANN**

Even at this point in life because a lot of people still have this impression that, 'well, I'm here to receive my cancer treatment and I just better grin and bear it because the idea is to improve my survival. And if that's going to cause discomfort then that sort of comes with the baggage.'

And they try to put on a good face for their doctor when they come to see us. So, you really have to dig deep. Even doing this Edmonton Symptom Assessment Scale, which is just nine to eleven different symptoms on a scale from zero with no pain at all for example and 10 the worst pain you can imagine — if you don't ask people that, a lot of people won't mention it at all. And they've done actually studies showing that use of a standardized tool like that — which is just a simple paper and pencil tool — vastly improves symptom control for patients and quality of life for patients because you just bring out things that people didn't think were important to mention. Like, you know, the constipation for example. 'I didn't know you could do anything about that. You know, I just thought I had to live with that.' Or even pain. I just I didn't I thought I had to live with the pain. I was on a pain medication. I thought that this is a pain medication. So, I didn't know that there could be a better pain medication that could make me a lot more comfortable.'

And with depression and anxiety it's even worse, just because there is — just like there's a stigma with palliative care — there's also a stigma with having depression, or having anxiety, and people just don't mention it, until you specifically ask. You know, 'are you depressed, are you feeling sad, how are you coping?' So when you ask that, people actually tell you, surprisingly. And you're able to help them with that. Even though they felt kind of uncomfortable bringing it up in the first place, when they do talk about it then they feel a lot better because then you can actually do something about it.

And it's not just the patients it's also the caregiver who's often the sort of silent partner in the room who's you know dealing with the whole load of things and often working at the same time and also

trying to be a supportive spouse sometimes they're suffering as well and no one's addressing that either.

**BTB**

It sounds like your biggest issue is almost a messaging issue of you need to get the word out there.

**DR. CAMILLA ZIMMERMANN**

There's several issues. So yes, one issue is a messaging issue that we need to get the word out there. The other components to that are educating health care providers so that they're actually able to provide the care that we're advertising. So you know it's all very well if we say that palliative care is early involvement and improving quality of life, but then if what we're providing is end-of-life care, then those two messages don't jive. So... and that needs to be not just specialists but also family physicians also oncologists because we can't we really can't as specialized palliative care providers provide care for absolutely everybody. Because it's not just cancer, it's really any life-threatening illness that has symptom burden, that has emotional symptoms associated with it. It's a huge number of patients that we're talking about.

So we need to have a whole different approach to how we're dealing with these patients in a team-based way so that primary issues — so simple pain and symptom issues we need basic training at the medical school level or at the residency level to make sure that everybody is trained in pain and symptom management, everybody is trained in communication because like I said it is an art but it's also a science. There's certain things that you should just do that many people don't think of doing unless they're, you know, specifically trained to do that. And then we do need higher level specialized palliative care specialists who are able to both nurses and physicians and other interdisciplinary team members, who are able to jump in when things get really complicated. So we don't have that kind of a system set up yet in Canada or really anywhere else. And that's where I think we need to move towards.

**BTB**

You're listening to Behind the Breakthrough, a podcast about groundbreaking medical research and the people behind it at the University Health Network in Toronto, Canada's largest teaching and research hospital. I'm your host Christian Cote. We're speaking today with Dr. Camilla Zimmerman, an award-winning senior scientist at the Princess Margaret Cancer Centre who is pioneering the practice of palliative care in this country.

Camilla, I want to talk about your career path. I read where you describe your decision back in the mid-90s to be a palliative care physician as "coming out of the closet." What is it, or what was it, about that admission that was such a challenge for you?

**DR. CAMILLA ZIMMERMANN**

Well, I think palliative care has evolved — thankfully so — over time. But when I was going through my training, it was still perceived as being kind of airy fairy I guess. As being not really a serious academic discipline. And I did, I was a very academic person and I wanted to work in a research centre and an academic hospital. And people would say things like, 'well, why would you choose that? Well, you're so

smart.’ Like why wouldn't you go into something that's a bit more serious? Or, ‘isn't that just about people who are dying? don't you just give them morphine?’ You know.

**BTB**

It sounds like you were well warranted not to admit this to everyone.

**DR. CAMILLA ZIMMERMANN**

So I soon thought that you know it's probably better if I just keep it to myself. And I won't admit to people that really what I want to do is palliative care because I did want to be taken seriously by my colleagues. I didn't appreciate necessarily their comments or their input. There were certain people, obviously, that I would confide in but it wasn't just anybody.

**BTB**

So what's your sense of how those attitudes and that almost — it's like a denigrating attitude— towards palliative care, has that shifted? Have you seen it?

**DR. CAMILLA ZIMMERMANN**

It has. I mean, it still exists to some extent. I don't think palliative care is taken as seriously as an academic discipline. But it's changing hugely and with large strides. First of all, we have a Royal College specialty now in palliative care, which is a huge step. The UK has had that since the 1980s by the way. We're sort of a bit behind other countries, I would say. Even the US has had it for more than a decade. But we're getting there and I think we'll only get more recognized over time. I mean we need to develop more research, I would say. And a lot of what we're doing right now is still doesn't have an adequate evidence base, I would say, just because the research hasn't been done. So there's a huge amount of research for anybody who's out there who's thinking of a field to go into. It's really, I would say, ripe for further investigation and research in this area because it's vastly under-developed.

**BTB**

I can't imagine a more daunting career though. I was wondering what's it like to attract students?

**DR. CAMILLA ZIMMERMANN**

It doesn't attract every student and it's not meant to. We are a special breed of people. Not everybody feels comfortable dealing with seriously ill patients and not everybody feels comfortable with a focus that's on quality of life and care for the family rather than on curing disease and not everybody is comfortable with the communications skills that you need to develop to do this work. So it's a different focus and it requires a different sort of a person. There's issues of spirituality that come up as well. I mean, you need to be comfortable with serious conversations with people.

**BTB**

I read that a key mentor of yours, back a med school at McGill, Dr Balfour Mount — who I understand is the man who coined the phrase “palliative care” — part of his message was we live in a death-denying society. What have you learned about why we are death-denying?

**DR. CAMILLA ZIMMERMANN**

I don't like the term death-denying very much and I wouldn't necessarily say we're death-denying. I mean, when you think about it, the fear of death that people have isn't because they're denying that they're dying. It's because they know very well that they're dying and they just don't want to deal with that. So it's more avoiding than denying I would say. But what I've learned is that if you don't focus on that, you know, you must accept that you're dying is I think the wrong message. The message is meeting people where they are and asking them what their goals are and what they want to accomplish. And for some people, they're focused very much still on curing their disease and that's even if a cure is really, you know, foreseeably impossible, but they're very much focused on treating their cancer. Which is absolutely fine. But then you have to sort of say, 'OK but wouldn't you like to feel a little bit better while you're pursuing that goal and isn't there other things that you'd like to be doing other than only coming back-and-forth to-and-from the hospital focused on curing the cancer? You know, what about some of your other goals in life that you'd like to achieve?'

So we try to make the focus a little bit broader than only the disease and only the cancer.

**BTB**

What have you learned from patients about facing death?

**DR. CAMILLA ZIMMERMANN**

I have learned a tremendous amount from patients over the years and what I've learned is that every patient has their own way of dealing with their situation and that you can't really change that. And mostly it sort of is the kind of person that they were before they got ill, right? Some people who are just tremendously practical people, and you know, they come in and say 'I want an end-of-life plan and I know I've already chosen my, you know, my coffin at my burial site, and I've made my will, and you know, here's my power of attorney.' And they've done all this planning and they need to do that because they're just people who need to be organised and plan for their death. There are other people who just don't even want to talk about that.

So you have to sort of, as I said, meet people where they are in their illness and try to help them in the way that they want to be helped. Like, no one wants to come to a doctor's office, especially not to a palliative care clinic, because they won't come back if you're telling them what to do. You need to ask them what they want to do and then help them achieve that. That's the way I see it.

**BTB**

There is only one outcome in your work. So, as a medical professional how do you approach that inevitability?

**DR. CAMILLA ZIMMERMANN**

Well I don't know if there's only one outcome. There's many different outcomes. We do know that ultimately, all our patients are going to die. But you know, ultimately all of us are going to die. So we all have one ultimate outcome. The focus isn't on, you know, 'here I am, preparing you for your death.' The focus is on, how do you want to live? And how am I going to help you live the way you want to live from day-to-day, or from month-to-month, or, for many patients, it's from year-to-year. There's

patients that... we just did a study and we were looking at how long we've seen people. There's patients who've had 36 visits over five years to our clinic. These are people who are coming back because their focus is on their quality of life. They want to make sure that their pain, all their symptoms, are controlled.

And over the course of time, sure, we do talk, ultimately, about the end of life and preparing and making sure you have a power of attorney. At the very least, someone who knows what kind of plans you would like to put into place.

But, honestly, everyone should have that. I have that. I don't have a terminal illness that I know of. But I have a will. I have a power of attorney and that's what I tell my patients as well. I have three kids. They're grown up kids by now. But I want to make sure that they're cared for so I've written a will. I think everyone should have a will.

So, it's not about, you know, death preparation. It's more about improving quality of life. And ultimately all of us are marching slowly towards dying and need to deal with that eventually. And some people want to hold off that dealing with the actual reality of dying longer than others and that's just fine.

**BTB**

You once said that you began dealing with death quite early on because of the death of your parents and you had to accept death. So you've been at this a long time.

**DR. CAMILLA ZIMMERMANN**

I have.

**BTB**

Do you grow weary at all?

**DR. CAMILLA ZIMMERMANN**

Yes. I had my parents both died when I was in my teens and I have for that reason probably dealt with dying a lot longer than other people. But everyone deals with it slightly, or very, differently, as I've said. And we can't, I think as palliative care specialists we're all very comfortable talking about death and dying. Well, we better be. That's our specialty. Right? But we have to understand that not everybody else is like that and we can't expect them to be.

So I've learned over the years that I had my own experience and that's not going to be anyone else's experience. And it's the same thing for all the other people who are going through this.

For every single patient, it's a unique experience that they're going through with their unique family. And we need to make sure that we're dealing with their unique needs. And that's what's special about palliative care is that we don't start from a protocol or a template. Is this what you do in this stage of disease and this is the protocol we have for dealing with your kind of cancer? We start from, where your needs and what do you want to achieve and what are your goals? So it's very different focus.

**BTB**

I imagine though you have to be vigilant about your own self-care to avoid burnout?

**DR. CAMILLA ZIMMERMANN**

Yes. Now that's true for all of us and perhaps especially in palliative care. But I would say that we are especially good because of, you know the inherent, I guess danger, of getting burned out right from the beginning. Like I'd say right from the 60s when palliative care started there's been a huge focus on self-care. And there still is.

So, firstly we're a network. We work in teams. So that helps hugely. So none of us are ever alone in dealing with a patient's situation. We're always working with an interdisciplinary team of, first of all, other doctors that we can run things by and we certainly do. But also, nurses, social workers, spiritual care workers, occupational therapists, physical therapists, pharmacists. It's all a team that's working together so we're never alone in what we're doing and if we need an extra hand or layer of support it's there for us as well. So that's the first thing. And the other thing is that we have, even in our Palliative Care Program, our specialty program, we have special wellness sessions. So there is a focus on trainees as well, for wellness.

And then we have our own ways of dealing with wellness as well. We have retreats. I run every day, so that's my outlet, I guess. I have a dog. I run with the dog. Music is an outlet as well. Reading. So we all have things that we do too. And my family, I think, as well. They are tremendously supportive to me as well.

**BTB**

In a sense, you are showing people they matter right to the last minute of their lives. Is there anything they say to you about what you are doing for them?

**DR. CAMILLA ZIMMERMANN**

Well, all our patients are tremendously grateful, I would say, for what we do for them and their families are as well. Because we accompany them. So I think that's the main thing that we do is they're on a difficult journey and we're walking with them through that journey. And people appreciate that, that there's an extra person there who's walking the journey with them and that we're available.

And that's the neat thing about outpatient palliative care is we're not, you know, visiting them every day as an inpatient but we're always there. We have a 24-hour telephone line. So if they're ever in need, they have someone they can call. That's what they mention as well. You know, whenever there was any question about, you know, should I be going to the emergency department. What do I need to do here, the pain is a bit worse? There's a number you can call and there's someone at the other end who knows you and who's been following you and is able to give tailored advice to your problem.

So, yes, they're tremendously grateful. And so are we, for having the honour to accompany them on this really important journey.

**BTB**

I need to ask you because they had such a profound effect on your career path, the choice you made. Your parents — what would they think of what you're doing?

**DR. CAMILLA ZIMMERMANN**

I think they'd be very proud. Yeah. I would hope so. Yeah, yeah. I don't really think about that much. But yeah, I think they would be very proud of what I do. My mother especially. She was someone who really embodied person-centred care.

**BTB**

What should we look for next from you, Camilla Zimmerman?

**DR. CAMILLA ZIMMERMANN**

Well, the next study is this study of tailored palliative care according to symptom control. So we're launching that now. It's funded by the Canadian Institutes for Health Research and we've just started recruiting. We're hoping to recruit more than 500 people. And it's a joint study that we're doing together with Kingston General Hospital so it's going to be at two different sites and it's quite a complex intervention. So we're all very excited. We've literally started, I think, last week or the week before, and recruited our first few patients. So that's the next new step. And also, as I said, trying to get the word out there that palliative care is more than end of life.

**BTB**

Well Dr. Camilla Zimmermann, award-winning scientist at Princess Margaret Cancer Centre, thanks for speaking with us and continued success.

**DR. CAMILLA ZIMMERMANN**

Thank you.

**BTB**

For more on the podcast go to our website, [www.behindthebreakthrough.ca](http://www.behindthebreakthrough.ca), and let us know what you think. That's a wrap for this episode of Behind the Breakthrough, the podcast all about groundbreaking medical research and the people behind it University Health Network in Toronto, Canada's largest teaching and research hospital. I'm your host Christian Cote. Thanks for listening.