University of Manitoba: "What's the Big Idea?"
Series 3, Episode 5: HARVEY CHOCHINOV

TITLE
Get Dying Right: Why Dignity in Care Matters with Dr. Harvey Chochinov

INTRODUCTORY MONTAGE:

HARVEY CHOCHINOV
Nobody wants to be seen as just a patient. They want to be seen and understood in terms of what ails them, but not at the expense of who they are.

And I can tell you that the responses to the question, so what do I need to know about you as a person, are nothing short of profound. And they change the outlook of the healthcare provider indelibly**.**

We need to get dying right. I mean, it only happens once for each person. We need to get it right. But as well, it has ripple effects that are felt by everyone who will survive that death.

INTRO MUSIC FADES IN

INTRODUCTION:

MICHAEL:
Welcome to What's the Big Idea? I'm your host, Michael Benarroch, President and Vice-Chancellor of the University of Manitoba. Today, I'm joined by Dr. Harvey Chochinov, a Canada Research Chair in Palliative Care and a Distinguished Professor at the University of Manitoba, his alma mater. Dr. Chochinov is an Officer of the Order of Canada and member of the Canadian Medical Hall of Fame. He is also the co-founder of the Virtual Hospice, the world's largest repository of information and support for patients, their families, and care providers. With over 350 publications and a lifetime of accolades, he joins me to share his big and profound ideas on how we must approach end of life care.

MAIN INTERVIEW

MICHAEL: Welcome, it's great to have you here today. I just wanted to start, What's Your Big Idea? And it turns out to be one of the titles of your book, *Dignity and Care*. Tell us a little bit more about this idea and maybe what it looks like in practice.

HARVEY CHOCHINOV: Sure. You know, a number of years ago, I published an article that was called, *The Secret is Out, Patients are People with Feelings that Matter*. And when I think about dignity in care, in some respects, that, really, in a rather sort of cryptic, pithy way, addresses the big idea that patients are people with feelings that matter. And to kind of dig down a bit deeper, in contemporary medicine, we tend to think of it just in terms of transactional issues, things that we do to patients, you know, drugs, we give them surgeries we give them, radiations we administer and so on. The things we do to. But what we really don't pay much attention to is the relational, the interactional. And as it turns out, certainly in the

kinds of work that I'm doing and others have looked at, if you fail to provide the relational, along with the transactional, then patients suffer. There's more discordance around goals of care. People are less trusting. Organizations lose reputational capital. And even health care providers who become disconnected from the human drama, the pathos of what happens in clinical medicine, become more vulnerable to burnout. So, I would say that that is a big idea of dignity in care.

MICHAEL: Now, just think about your career. Was there aha moment somewhere, where you kind of thought, wait a minute, it's not just about being transactional. There's so much more to this.

HARVEY CHOCHINOV: My background is in psychiatry, and I've also been a researcher, in palliative care, for many years. And at least at the outset of our work, we were looking at fairly kind of traditional psychiatric issues like depression, anxiety, hope, desire for death. But we then discovered that the issue of dignity was highly salient to patients near end of life because again, looking at data that was coming out of the Benelux countries, it turned out that loss of dignity was the most highly cited reason as to why patients were seeking out a hastened death. So, we began doing a series of studies on dignity. These were really the first, the only empirical studies that had been done on the issue of dignity.

And the aha moment came as a result of one of the findings in the study. So, we asked patients to rate their sense of dignity along with other things that might correlate with their sense of dignity, pain, anxiety, a whole variety of experiences. The thing that turned out to be the single most ardent predictor of sense of dignity was how patients perceive themselves to be seen. In other words, even though this is driven by data, metaphorically, the thing that is most important for patients is that they see, in the reflection, in the eye of the healthcare provider, an affirmation of self. They see the entirety of who they are. So, if they just simply see reflected, in the eye of the healthcare provider, a problem checklist, a differential diagnosis, then, they feel that personhood has been eclipsed by patient hood. But on the other hand, if they can see the entirety of who they are, you know, that there's recognition that I'm not only the illness I have, but I continue to be the person that I've always been, then dignity, personhood is intact. So, that was the aha moment, which led to also the realization, by the way, that how health care providers see their patients, this perception, becomes a very important parameter, a very important dimension of what we need to understand, if we're going to deliver good quality palliative care. And I would say if we're going to deliver good medicine.

MICHAEL: Right. And so, in the definition of dignity is really being seen.

HARVEY CHOCHINOV: Very much so. This idea of affirmation. Now, we've done other studies on dignity that have looked at qualitative work and what you find out, and we've published an empirical model of dignity in the terminally ill, is that there are multiple variables that can influence sense of dignity from the physical to the social, the external, environmental, supportive, to the psychological and spiritual wiring. So, the model has been helpful for us because it really provides healthcare providers out there a way of, in some ways kind of like having a therapeutic map. You know, how do we know how to support patient dignity? We can give that lip service, but in the absence of knowing elements of what that constitutes, we're just kind of working in the dark.

MICHAEL: And that helps me so much better understand when you came up with the idea of the

platinum rule, which is doing unto patients as they would want done unto themselves.

HARVEY CHOCHINOV: Well, exactly. I mean, if we're going to consider the importance of the health care provider gaze, then we need to really seriously consider, well, what has shaped our lens? And the reality is that whether we're conscious of it or not, we have a particular outlook. I mean, we grow up in a way in which certain things are given value and other things may be given less value. Which then intuitively, as a first go when we try and gauge what might a patient need, we think about the golden rule. If this was me, if this was somebody that I loved and cared about, what would I want done? Well, I mean, that's an important moral adage in religious traditions across millennia. But it does impose this external standard. It says, I am going to be the gauge of what I think is going to serve you best.

Now, if your lived experience happens to overlap with that person relatively well, then you might get it right or may often get it right. But there are many instances where we can't intuit what the patient would want, what the patient would see as being in their best interest, what values they would have informed the way they are cared for. So, the platinum rule then says, well, the important perspective is the patient's, doing unto patients as they would want done unto themselves. There are many applications. I mean, I think just in terms of the whole conversation that we have these days about EDI, equity, diversity, inclusiveness, it seems to me that you can't have that conversation in the absence of really acknowledging that we all have a perspective. What I say to, learners is that, at the bedside, if you're with somebody who can no longer speak for themselves, the correct question to ask is not, what would you want done for your father or your mother or your brother, sister, partner, in this instance, if they can no longer speak on their behalf. If we could bring them back into this room the way they were a week ago or a month ago, what is it that they would want? And to me, that's a platinum standard, and that's raising the bar on person-centered care.

MICHAEL: That’s really fascinating. I've had two parents who have passed away in the last eight years. One who, end of life happened primarily at home, except for maybe the last three or four days. And another who had dementia and had to move into a home. I thought back, after all of that, and reading some of your work too, what would it have meant to ask that question and to think about that? It does mean, and then this is just a sample of two, but it happens over and over, it wouldn't be the same care for each person.

HARVEY CHOCHINOV: Well, absolutely not. And this is the thing. The same is what we think about when we're, you know, referencing patients, because patient is a generic designation. A patient with dementia, a cardiac patient, a renal patient. I had a woman working in nephrology who said to me, with no joy in her heart as she shared this, she said, you know, after so many years working with kidney patients, patients begin to look like kidneys on legs. And essentially what she was saying is, at some point, you know, you see patients or you're at risk of seeing patients in this kind of generic, dispassionate, objective way. And that's not good for healthcare providers. I mean, it places them at higher risk for burnout, but it's not good for patients or families because no one, and, this is the irony, we train our entire lives to look after patients. Nobody wants to be seen as just a patient. They want to be seen and understood in terms of what ails them, but not at the expense of who they are. So, we have introduced something very simple and that we call the patient dignity question. What should I know about you as a person, in order

to take the best care of you possible**.** And that's meant to be the stem of a brief conversation, 5, 10, 15 minutes, at most. We summarize the conversation into a couple of paragraphs, and we bring it back to read to the patient, give them an opportunity to share any editorial changes and the litmus test, do you want this placed on your chart? Without exception, in every instance, patients want it placed on their chart. We've done this in palliative care. We've done this in intensive care, with family members whose loved ones are either unconscious or on ventilators. There have now been studies at, in fact, at Memorial Sloan Kettering where I did my fellowship. There have been studies of thousands of patients who have participated in this. It is a quick and simple way of making sure that healthcare providers remind themselves that besides asking about the vitals, that personhood is vital.

MICHAEL: And so, I look at healthcare. It's in many ways very different than what you're describing. And it shouldn't just be at the point of palliative care, right? I mean what you're describing is really about a way of caring that puts the person at the centre.

HARVEY CHOCHINOV: Yes, and that's applicable across all of medicine.

MICHAEL: And you can imagine, even if your doctor had a 10-minute conversation with you about that, at your first appointment, you would feel that this doctor cares about you, as more than just a patient. And I'd used the word patient, and you correctly said, it's not about that, it's more than that. But that seems like the status quo. So, I mean, a lot would have to change from where we are now.

HARVEY CHOCHINOV: Well, it's a question of mindfulness. It's a question of appreciating what is at risk if we don't do this. Some people say, well, you know, is there really enough time and is this kind of touchy-feely? And would it make that much of a difference? You know, there was a study, of young patients with advanced malignancies, and they were looking at correlates of suicidality in this cohort of young people with advanced cancers. The most ardent predictor of suicidality was the solidity of the relationship between the patient and healthcare provider**.** Even more so than psychotropic medication. So, if we're saying, well, is it that important? Do we really have the time to do this? Can we afford to do this? I say, well, you know, if this is a matter of life and death, can we afford not to do it? We also, by the way, besides the fact that this is the nice thing to do, the good thing to do, it is the humane thing to do, from the perspective of patients and families. The stick is, if you don't do this, organizations risk reputational capital. I mean, the reason that a health care provider or organization is likely to be litigated is not because of medical misadventure. It's because people just didn't feel treated right. They didn't feel treated well. And, as I point out, we have data that has shown that if health care providers avail themselves of this information around personhood, they actually report increased job satisfaction. So, this kind of marriage, between the transactional and relational, actually is a way of not only safeguarding reputational capital, but as well, safeguarding the well-being of our healthcare teams.

MICHAEL: And are we teaching this in medical schools?

HARVEY CHOCHINOV: We're certainly trying. I was asked this past year to give the White Coat Ceremony speech by the Dean of Medicine, and every student was gifted a copy of my book, *Dignity and Care: The Human Side of Medicine*. So, I look at that and say, you know, we're making a start. The other thing that you point out, by the way, is clearly this isn't just about palliative care. One of the messages I gave the

students is that patients won't care what you know until they know that you care**.** And subsequent to that, I was also asked by the faculty of dentistry to do a half day seminar for 100 dentists and people in the dental sciences from across the province. So, this applies to anybody in health care who has contact with patients.

MICHAEL: And I was at that white coat ceremony. I heard you address the incoming class, and I spoke to some of the students afterwards. It was certainly important for them to hear it and what I saw in them is a real openness to want to be that kind of physician.

HARVEY CHOCHINOV: And now the challenge is finding a way of somehow sustaining that, of reinforcing it. You know, it has to be a message that is repeated. And as well, it has to be something that is modeled by, their mentors, because that has a profound influence on the way people see the world and the way they practice medicine.

MICHAEL: You've written that, an element of dignity in care is dignity therapy. Tell us a bit more about that.

HARVEY CHOCHINOV: So, when we developed the model, the empirical model of dignity in the terminally ill, it gave us, for the first time, this kind of scientifically validated or objective map of how do you, in fact, uphold the dignity of patients with life limiting and life threatening conditions. I mean, up until then it's something people gave can give lip service to or you can say, well, I kind of think I'll know it when I see it. But the map, the model says these are the constituents of dignity conserving care. And one of the elements of that model was something called generativity. Generativity is a term that comes from the developmental psychologist, Eric Erickson, this idea that we reach a point in life where we begin to look at our influence on the next generation. So, what ripple effect will we have had, as a result of having been on this Earth? So, the insight then from that was, well, if we're going to do something that would be therapeutic and we coined the term dignity therapy, could we create a psychotherapy that would also address generativity needs of people approaching end of life? And so, dignity therapy is, at this point, the most studied psychological intervention in palliative care in the world. There are over a hundred papers in the medical literature, over a dozen systematic reviews of dignity therapy. We have been training therapists from around the world, for the last couple decades.

To do this, they need to understand and learn how to elicit a dialogue that is really focused on legacy. So, some elements are biographical, some have to do with wisdom that they have learned, some have to do with specific things and messages that they would want to pass along to the people who will soon be bereft. Those conversations are recorded, transcribed, and a return to that individual, as part of their legacy to share with whomever they feel would feel comforted, by virtue of the fact that they can carry their words with them, forward in time. And as I say, this is now being done in healthcare facilities and palliative care programs, worldwide.

MICHAEL: And is that found to give people greater hope at end of life?

HARVEY CHOCHINOV: There have been, now, multiple trials. And so, depending on the cohort that is used and the outcome measures that are also used, dignity therapy has been found to lessen depression, decrease anxiety, heighten quality of life, increase sense of spirituality or spiritual comfort,

and enhance meaning and hope towards end of life. The other thing that's interesting, is because dignity therapy was initially meant to try and help elicit personhood in people near end of life, over the last couple of decades, it has developed legs, meaning that it's found its way into other areas in life where personhood is under assault. So, for example, mental illness. There have now been trials of dignity therapy amongst people who are experiencing serious mental illness. Dementia, you know, cognitive deterioration, a whole earlier diagnosis. People who are in, what I would say is, a state of existential readiness, in order to begin a process of, kind of, looking back, reviewing, pulling together the threads of their life, and weaving it into a legacy document.

MICHAEL: And it seems to me the connection between all of this is affirming that the person matters.

HARVEY CHOCHINOV: They matter because they are who they are. And as I say, dignity therapy, it requires a certain amount of time and resources, and it's not a panacea. It's not that everybody needs dignity therapy in order to have a good death. But every human being who has a health care encounter does need some affirmation of personhood. None of us like to be seen just on the basis of what we have. We want to be seen on the basis of who we are. And I can tell you that the responses to the question, so what do I need to know about you as a person? The responses to the questions are nothing short of profound. And they change the outlook of the healthcare provider indelibly.

And we have data that shows that even this brief intervention enhances sense of connectedness, respect, empathy. So, although we tend to think of those things as immovable objects, the reality is that when you open someone's eyes to who this individual is, it forever changes their perception. And again, that's why the whole issue of the healthcare provider lens is one that we have thought important to look at and examine.

MICHAEL: But does that not make it harder for the healthcare provider, when the person passes, when they lose a patient? Because you've made the personal connection. I mean, they have to go through this every time. Or am I missing something?

HARVEY CHOCHINOV: No, no, you're not missing something at all. In fact, it’s a very obvious question, a question that many people have asked me and asked themselves. I mean, how much information do I avail myself of? How close do I allow myself to become, in the context of providing care. My dear colleague, Mike Harlos, used to be the head of palliative care. He said, you know, you're going to work in the kitchen, you have to be close enough to the ovens where you can feel the heat. But on the other hand, you don't want to be so close where you feel like you're going to be burned and singed. What that means is, you need to know something about who they are, but you can't own their suffering, because when you own their suffering, it makes you ineffectual. Let me give you an example. I always refer to a woman, not too long ago, as tragic a case as you can imagine. A young woman in her early 30s, young marriage, young child, and now is dying of disseminated, you know, stage four breast cancer. So, you think, oh my God, you know like, how can you not feel, kind of, overwhelmed and almost paralyzed by the sadness? If you allow yourself to go there, then you are not helpful.

On the other hand, she came to me because she knew that she would not live long enough for her daughter to remember who she was. Dignity therapy, in her mind, was the perfect solution. It was extraordinary. We sat down and she told me about who she was, the formative experiences in her life

that she would want her daughter to take forward in her own life, the important lessons and principles and values that she thought were meaningful to her, thanked her parents, thanked her friends, thanked her husband, gave her husband permission to find a new love partner, understanding that whoever he chose would have to love his daughter or her daughter the way that a mother is meant to love a daughter. I did not feel overwhelmed and impotent. I felt this was a profound thing that she and I were able to do together. So, if you can negotiate, that ideal, empathic distance, it allows you to do things with patients that are really quite profound and meaningful, without feeling overwhelmed with a sense of kind of therapeutic nihilism.

MICHAEL: I mean, I have to wipe the tear from my eye on that one, cause what you just described is really powerful. I'm thinking then, kind of next step, what happens and where does medical assistance in dying fit into this kind of work that you've been doing?

HARVEY CHOCHINOV: Well, that's really interesting. Medical assistance in dying has sort of been a dynamic or an issue that has been a part of my career almost from the outset, decades before Carter versus Canada. We published one of the largest studies on desire for death in the terminally ill that had ever entered into the literature. I think data out of the Benelux countries showing the association between a wish to die and more a sense of dignity was very formative in our work. And in their studies, they went back to the death record, they identified the physician of record and then said, well, why do you think your patient sought this? And indeed, it was because they reported, their sense was a lost sense of dignity, which no one had ever studied.

I have a doctoral student now who's doing a study on medical assistance in dying, primarily to try and find out, do a deep dive with people, to find out what motivates you to make this decision. I mean, how have you arrived at this place? You know, we're not doing it with any political axe to grind. It's just very much interested in how do you arrive at this decision? And there's one interview that I remember we did recently, and I was with a gentleman who, this man has been, he's got, you know, a bad disease and he's been approved for MAID. And he says, I am not going to die the way my grandmother died. Because he had this memory of her having died a terrible death and it was bad and he's just not going to go that way.

And so, I said, well, tell me, how long ago did your grandmother die? He said, well, 30 years ago. 30 years! For three decades, he has carried around this memory of what did or did not happen at the bedside of his grandmother. So, we need to get dying right. I mean, it only happens once for each person. We need to get it right. But as well, it has ripple effects that are felt by everyone who will survive that death and even shape the way that they too will then approach their own death.

Assistance in dying, it's informed my work, but it is, in my estimation, it is one very narrow approach to trying to address the issue of suffering. I'm interested in the much broader spectrum of suffering. You know, what is it, how can we understand suffering? And much of our work, in some ways, is consistent with findings of earlier American investigators, people like Eric Kassell, who reported that suffering was something that happened when people felt that personhood was under assault or threat of disintegration. So, that is the way in which issues around medical assistance and dying have continued to kind of inform and be a part of my work, but not, certainly, being the focus of my work.

MICHAEL: I like the way you said that. It's a small part of that and it's focused on dignity. And dignity has been a big part of the conversation we've been having and you're working on a different stream of that.

HARVEY CHOCHINOV: Well, and unfortunately, the hasten death organizations have kind of hijacked the term dignity and I hope in some ways that some of the work that I'm doing, and others, has at least tried to reclaim that term to say that, I mean, the way to preserve dignity is not exclusively by having access to a mechanism that can result in your death and choose the timing and circumstances of your death. That dignity is a much broader, a much more complex issue than that. And we went into this thinking, if we can understand why somebody doesn't want to be alive, if we can get a better handle on that, it ought to give us more insights, a wider breadth of insight about how to deliver better care. And I think, you know, over the decades that's been born out.

MICHAEL: And I hope we've made some gains though. And we've advanced. I mean I certainly saw it in the care of my mother. And just to give one example, at the care home she was at, here in Winnipeg, after she passed. They used to take the patients out the back, and now they decided to take them out the front. And all the staff and other people in the home lined the hall, as they moved the casket down the hall. And you just felt that she was seen as a person who lived in this home. And it made such a difference, at that last moment.

HARVEY CHOCHINOV: Now I'm the one who has to wipe the tears. It is a wonderful and profound story. And it affirms everything we've said because it says that while she was alive, she mattered. In her moment of death, she mattered. And immediately after her death, as they removed her from the care home, she mattered. And her connections with people mattered. And to have taken her out the back door would have ignored all of that. So, it is a profound example, and poignant and meaningful.

And one of the very famous adages of Dame Saunders, the founder of the modern hospice movement, that has really become a kind of a philosophical primary tenet of palliative care, is you matter because you are you, and you matter to the end of your life.

MICHAEL: So, on that. Last question: You've been studying this your whole career, and I wonder how it's impacted you and how your view of death and suffering have changed through your career.

HARVEY CHOCHINOV: So you're wondering if I've gotten good at dying. I haven't died yet, not even once. You know, it's interesting. I mean, has the work changed me or have I chosen the work because of the way, kind of, I've been shaped, in my own life?

I mean, my mother died a couple of years ago. Her last year of life was not easy. And um, the variability in care was profound from the extraordinary to the outright horrific, outright horrific, where I was sitting down having to go toe to toe with, I remember one nurse in particular, who, do you understand that what you said to my mother this morning made her wish that she were dead? And she said, oh, do you think I should apologize? And I said, I think that would be a good start. I was seething. So, it's not like doing this work, you know, kind of makes you immune from the fact that this stuff happens and it's unacceptable. We need it. We need to try and change it. So, I'm doing my little bit to try and change it.

I see opportunities to present and to engage in these kinds of conversations, as a time-limited opportunity to make these things well known until I no longer have a voice to be able to do so.

MICHAEL: Harvey, thank you so much for this. It's fascinating conversation. And as we say, I mean, everyone's going to deal with this. And I hope our listeners really have learned about some of the options that are available and how to approach it and how to think about it, either for themselves or loved ones that are coming to end of life. Thank you so much.

HARVEY CHOCHINOV: My pleasure.

OUTRO MUSIC FADES IN

MICHAEL: I hope you enjoyed this episode of What's the Big Idea? Please consider sharing this important conversation with your friends and family. Join me, next time, for another great conversation, and until then, keep thinking big.