

BCHPCA FORUM | 2014

FRIDAY AFTERNOON SESSION MAY 9, 2014 2:30-3:30

Planning Conversations to inform and educate people about personal advance care planning and to encourage them in documenting their plans.

ROUNDTABLE ①

Family Physician Perspectives

MODERATOR: MEG MILNER, BCHPCA President [Outgoing]; Vice President, Quality Assurance, Park Place Seniors Living

INVITED EXPERTS

- DR. GAREY MAZOWITA, President-Elect and Chair of the Board, The College of Family Physicians of Canada; Chair, Community and Family Medicine, Providence Health Care; Clinical Professor, Family Practice, UBC Medicine
- DR. CATHERINE CLELLAND, representing General Practice Services Committee; Member, Advance Care Planning Project Group, Council on Health Economics and Policy, Doctors of BC; Former President and Executive Director, Society of General Practitioners of BC; Former Executive Director, BC Medical Association
- DR. TREVOR JANZ, Family and Emergency Physician; Regional Medical Director, Residential Care Interior Health East, Nelson BC

QUESTIONS

BCHPCA invites you to share your perspectives on the following questions. BCHPCA welcomes your personal experience in this discussion.

- the current nature of public conversations on death, dying and planning for care and the paths to opening these conversations
- the current and potential role family practice professionals have in engaging and educating the public about death and dying, and advance care planning
- the potential for family practice organizations to partner with hospice palliative care organizations to promote public and personal conversations on death, dying and advance care planning
- the potential for family practice organizations to partner with hospice palliative care organizations to advocate for hospice palliative care in British Columbia

MEG MILNER: So if it's alright with everyone as you come in and help yourself to a chair, I think that we'll start, just because we're ... So having such fulsome conversations today, we're running late on time a bit. This session and dialogue is with the physicians, the planning conversation with family physicians and from the family physicians' perspective. The planning conversations are literally, we went from starting the conversations to now we're planning the conversation, so we're progressing through the day to move forward.

I'm Meg Milner, BCHPCA President. Well you know that from the other conversations we've had. And I'm very pleased to welcome Dr. Garey Mazowita and Dr. Mazowita is President-Elect and Chair of the Board for the College of Family Physicians of Canada. He's Chair, Community and Family Medicine, Providence Health Care and a Clinical Professor of Family Practice at UBC Medicine. Dr. Cathy Clelland. Cathy is representing General Practice Services Committee member, Advance Care Planning Project Group, Council on Health Economics and Policy, Doctors of BC; former President and Executive Director of the Society of General Practitioners of BC. Welcome Cathy.

GAREY MAZOWITA: And an all-round good person.

CATHY CLELLAND: And a midwife.

MEG MILNER: Welcome Cathy. And Dr. Trevor Janz is a family yes of course, you don't want me to say it again. [Dr. Janz was a keynote speaker in the previous session]. So we're going to have conversations about planning conversations. And these are with the focus of informing and educating people about person advance care planning and to encourage the documentation of those plans. So I have a few questions – same format as the other conversations. And we'll start with hearing from the physicians around the table and then what I find works best is when someone has something they'd like to ask and/or say or share, that we kind of don't wait until the end, we just kind of have a conversation across the whole room.

TREVOR JANZ: Meg, could you read us the three questions right at the start just so I know the shape of the conversations, so we'll know where things belong? Just to give me an idea of what we're going to do.

MEG MILNER: I will do that. So BCHPCA invites you to share your perspective on the following questions. We want to hear about personal experiences in this discussion. The first question is: What is the current nature of death, dying and [planning] for care and the paths for opening these conversations? The second question is: What is the current and potential role of family practice professionals in engaging and educating the public about death and dying, and advance care planning? The third question: The potential for family practice organizations to partner with hospice palliative care organizations to promote public and personal conversations on death, dying and advance care planning. And the final question is: The potential for family practice organizations – I would say family practice physicians – to partner with hospice palliative care organizations to advocate for hospice palliative care in BC? That's more the political picture. Okay?

So to start with, in your opinion, what is the current nature of public conversations on death, dying and planning for care and the paths to opening these conversations?

CATHY CLELLAND: Who wants to start?

MEG MILNER: Whoever just opened their mouth has started. [laughter]

CATHY CLELLAND: Garey knows me. My name growing up was “Chatty Cathy”. I had a Chatty Cathy doll; I had a Chatty Katie daughter so, and I have a Chatty Roger husband so we're a really good family. There's a lot of things that are changing right now. As you mentioned in the talk earlier, physicians are trained to treat, to cure. That's always been our goal. And we're, things are ... the shift, there's a big shift in our understanding and our comfort level that has to occur for us to start to talk about dying well. Because I think we've not ... we've avoided that conversation for a number of reasons.

And we're starting to do some of that work in BC in particular. So I'm going to put a bit of a shameless plug in here for the Practice Support End-of-Life Program. And I wasn't sure who all was at this session so I thought I'd bring some information. The Practice Support Program is developed through/by GP [General Practice] Services Committee, which is a joint committee of the [BC] Ministry of Health and the Doctors of BC. And we develop a number of programs. And we developed, I was the Chair of the working group that developed the End-of-Life Program whereby we were trying to encourage family doctors to a) utilize the “My Voice” as a tool for having conversations with their patients. But also looking at their practice in a broader sense going, “How should I start having this conversation? Who should I start having the conversation with?” And part of the module was to develop an initial registry.

Some of the physicians who participated decided they'd look at everyone over a certain age. Others looked at people with multiple co-morbidity. So that means more than one medical condition. So everybody had a little bit different way that they decided they would look at their own practice. But then they'd start to have conversations with their patients. As of the end of April [2014], we have had 1,000 family doctors either who have graduated from the Practice Support Program or who are currently taking it. Pretty good numbers eh?

GAREY MAZOWITA: That's wonderful numbers.

CATHY CLELLAND: So a 1,000 family doctors. So that's out of, we figure there's probably about 4,200 family doctors in BC who are actually practicing longitudinal care. So your traditional cradle to grave type of family practice. Only about 15% of us do deliveries but that's another issue. And so that's not bad. We're roughly 20-25% of the family doctors have either completed or are currently undertaking the End-of-Life module and I think it's about "What are you doing in your own practice?"

But the other bigger piece that we've brought about this is "How are you going to influence change in your community? How will you help to set up, and what are the needs within your communities, how can you help to set up the supportive team around supporting your patients and their families, particularly if they're wanting to die at home?" Because there's a lot more supports for us available when they are in hospitals. It's not as nice a place to die because it's very clinical and it's very cold. Hospices are lovely.

When it comes to trying to organize it in the home, you need to have a lot more pieces in place. So part of it was also developing that team by community so that, for example, maybe a community like Salmon Arm might decide to take on the End-of-Life module and maybe there's five of the family docs there and they'll connect with their local organizations. So it's both looking at your own practice and your own patient population, but also looking outward to your actual community. And so that's sort of, I guess, touches a little bit on a few of the different pieces that you've got within some of your questions.

GAREY MAZOWITA: Sure. I'll perhaps add a few things to that from the perspective of the College of Family Physicians which is the training and accrediting body of family practice. So the standards, if you will, for family practice, the competencies are set by the College of Family Physicians which is an organization, which now is over 30,000 family physicians [in Canada]. So in Canada, any new family physician who is trained in Canada must go through that training program. And that training program certainly emphasizes all the principles that we heard Trevor talk about in the earlier session and many of the things that Cathy referred to.

The ... it's interesting ... I think like so many things in our health care system which is changing so rapidly, the answers to the questions that are posed are complex and they involve more than one partner. And the dialogue that's going on between family practice and communities and community groups and NGOs [non-governmental organizations] now through the Divisions of Family Practice is an important piece of the puzzle. The administrators are an important piece of the puzzle. The public is an important piece of the puzzle. The politicians and policy makers are important pieces of the puzzle.

I can remember, in fact I kind of look back with some amusement ... about 20-25 years ago, I was practicing in Winnipeg at that time and I suggested to our community hospital that we should try to normalize advance care planning. And that when the patient comes in to register with the registration clerk, that's where the questions should start. And when the patient gets transferred to the ward, there should be another conversation: "Do you have an advance care plan? If not, would you like to talk to somebody about it?" On discharge, again.

And it was interesting to me. The resistance wasn't with the physicians. And the patients at that time of course weren't even asked, but it was with the administrators who thought, "This is territory that might have some liabilities and we shouldn't be treading there. And I think even to some extent, not so much recently, I think even for the politicians, I think there's a worry that advance care planning for some citizens of the province will be code for cost cutting. "Let's talk about what we're not going to do because we can't afford it."

The reality is we all have a stake to play in this, whether it's a training body, whether you're in administration, whether you're a policy maker, and certainly, the dialogue with the public, particularly I think in the light of what a sustainable health care system means. And what role we all ... what personal responsibility and what family responsibility we all ought to consider taking.

I've been on call all this week. I work on a geriatrics ward, so we see a lot of death on our ward. And our average age now on our ward is actually now 85. And we're a rehab ward, so we don't admit somebody unless we think they're well enough that they can go back into the community. So these are relatively well elderly people. But bad things happen to them, just by virtue of the age and the co-morbidities.

And yesterday I spent over three hours talking to two families about dying issues. It was just one of those days. I/we had someone who had an acute subdural bleed after a fall. The family completely unprepared about death dialogue. And another family, of course with a relative from California who'd flown up. A 93 year old lady who hadn't been eating for almost a month had been otherwise healthy and had come in to try and uncover why is she not eating. And we had ended up, as it turned out, doing some, doing a CT scan and it showed that she had enlarged lymph nodes in her chest, in her abdomen, in her pelvis. So it was some sort of malignancy at play there.

And this was one of the most difficult conversations we'd had. And at the end of the day, the family ... the wishes of the family were "We have to do everything". And I'm not saying this to say it was the right or the wrong decision. It was their decision.

Unfortunately the woman was profoundly deaf. She could articulate her views; she could not hear. She could not read. Even with amplifiers, she couldn't hear us. So she could tell us when she was in pain. We didn't, we weren't able to communicate with her to the point where we could ask her wishes. And it had never been discussed with the family. So this 93 year old is going to go through on Monday, a bone marrow biopsy, a gastroscopy, and I think with very little hope of a positive outcome here. And as much as we had a conversation with the family about really trying to separate the family's needs from their mother's needs, that was where it was left.

And I completely agree with Trevor's comment. In fact, it was interesting, you framed it as "The difficult conversations are often when there's family dysfunction." And I had always framed it, because when I had my family practice in Winnipeg, there were a lot of middle aged people and it was around death of a spouse and I would see the partner. And for me it was a flag of a dysfunctional relationship if the surviving partner was still grieving after six months. And psychiatrists like to tell us there's nothing so difficult than to separate from an ambivalent relationship. And that's often what we're dealing with.

There are these ambivalent relationships where the communication has never been quite robust enough. The feelings have never been discussed. The conversations have never been comfortable. And often there is a cultural or an ethnic overlay to this as well. And so these are incredibly ... I guess what I'm trying to say is sometimes it's not just the doctor that doesn't want

to have these conversations. [laughter] But it's also a whole lot of other factors that are coming to bear that, as Trevor said, so often have to do with unresolved issues, whether it's in a couple or in the family or with the individual.

It's interesting, before I came ... its' about ten year ago, before I came to Vancouver here, I actually co-authored the advance care planning strategy for the Winnipeg Regional Health Authority. And so this is not a new conversation. This is absolutely not a new conversation. We've been doing this ... certainly I started practice about thirty-five years ago and in a sense we're kind of coming full circle. Because at that time, there was enough freedom for family doctors, enough ability, and in fact it was actually a task to actually build a practice. You'd leave university and you had to build a practice. So I can remember having a lot of one hour appointments with new patients where you could get to know them and you could talk to them and really understand the family, the values, and it made things so much better when death came along. The trust, the continuity of care, the comfort levels.

Now we're in a system where those things are far more difficult. The challenge of continuities are difficult. And we're trying to fix those things. Cathy alluded to that. We really are trying I think to move in a direction where we are enabling physicians to carve out more time for those kinds of discussions. But we've got this big wave of frail elderly that are coming through with some manpower challenges that I think are confounding this whole issue. So perhaps I'll stop there.

MEG MILNER: So what I've heard so far is that physicians are making sure that physicians have the background information and resources to be able to start these conversations with their patients. And we're looking at a quarter of the physicians who are the family physicians approximately so far already having this support, this resource support.

And also I've heard, which I absolutely ... it has been my experience too, coming from a nursing background but I've heard, and also long-term care, I work in long-term care with a couple of other people and consistently it is the dysfunctional families where we end up really in trouble. Even if we have it – an advance care plan – for someone who has been able to express while they're still cognitively clear, their wishes, here comes that other family member who is embedded in guilt, grief, confused, and ending up with a very expensive plan. And I'm not meaning just money and resources. Emotionally expensive, pain expensive for the elder who's having to go through this. And so, in two words, it's complicated. Yeah. And I don't think that's a surprise for anybody.

COMMENTOR 1 [Dr. Lyne Filiatrault, Vancouver General Hospital]: In emerg we call it the "seagull effect". The distant relative who flies in and shits over the entire plan. [laughter]

GAREY MAZOWITA: And it's fascinating because it's almost as if they bring with them the sort of guilt of being away. And they suddenly have to make up for perhaps ten years of absence or of only calling by phone or I ... who knows? But it's amazing what a common pattern that is.

COMMENTOR 1 [Dr. Lyne Filiatrault]: But I think we're also guilty of not involving them. So the conversation, it's always the person that always comes to the appointment and you don't ask, "Well, how many other siblings is there that we should be involving?" Because you've got this volunteer who's coming with the elderly parent, who's always there. So I think making an effort to say, "Is everybody on board here?"

COMMENTOR 2: I have to say that within thirty years, I think I can deal with it. And I've been working for many doctors in those thirty years in family practice plus being involved in hospice, I've noticed amazing changes. And I'm really pleased to see that residents that come now are trained in palliative care and they're really good with palliative care as well. And when this

advance care directive came on Vancouver Island, the Federation [Vancouver Island Federation of Hospices] and VIHA [Vancouver Island Health Authority] has said the hospices are the ones responsible for educating and doing the conversation, I went to the medical rounds of the doctors on the Island – I'm on Salt Spring [Island] which happens to be the highest percentage of over 50s and going on – it's a bit scary – but I went to the doctors in medical rounds. And we worked out a system because what I see, the doctors don't have time to have a really quality conversation with the family and deal with all the nitty gritty.

So we evolved and said, "Okay. If you refer the patient to hospice, volunteers can sit down and help facilitate the conversation with the family, get everything sorted out so they've got it in their mind. They've got what they want written down." They can then go to the physician and say, "This is what I want. Is this viable? What do you think?" and sign on the dotted line. And the doctors actually felt very responsive to that. It's now just educating the patient to come to the hospice and talk to us.

CATHY CLELLAND: I think one of the challenges we've had though is we talk a lot about advance care planning as though it's only at end of life and only about end of life. And Trevor had raised an issue in his presentation that it isn't just about the end of life regardless of your age or your underlying conditions. It's something that we need to normalize much earlier on.

And so one of the things when we we're doing the train the trainer part, so we've trained family doctors and we've trained specialists to be the facilitators for our practice support module. And when we did the train the trainer process, I remember sitting ... I got to be in a room with about thirty specialists. I'm a family doctor. I've been in BC since 1986, so I've got a fair number of years under my belt. Most of the specialists in that room know my personality and know that I tend to call a spade a shovel when I need to. And we were talking about one of the tools that we're teaching family doctors to use, to figure out who to initially start the conversation with, because it is to a degree, it's easier when someone is sort of more towards that, facing that end of life, because there's a much more urgently looming possibility.

We're using the surprise question: "Would you be surprised if this patient were to be, to die within the next six to twelve months?" And that's what we're trying to teach the family doctors, to go "You know what? With all the things going on, they may not. But I wouldn't be surprised if they did. Therefore I need to start having that conversation." They may not be acutely ill. But when they've got COPD and heart failure and diabetes and hypertension and all of these other pieces going on, you know that it doesn't take much for something to happen that's going to trigger them from being stable to being unstable.

So I'm in this room about this size with all of these specialists and I said, "Specialty medicine can also apply the surprise question within your practice. Many of these patients you're seeing over a course of time. Not doing the same continuity that the family doc is. But you're still seeing them over and over and over again. So when you first of all see your patient" and I said, "I'm going to pick on cardiologists because some of my best friends are cardiologists. So if as a cardiologist you're seeing this patient who you've built a relationship over time. Maybe you saw them at the hospital for their heart attack five years ago and they've recovered from that, first of all ask that surprise question from the focus of their cardiac problems. Would you be surprised if they were to die from their cardiac conditions in the next six to twelve months? And if you said 'Oh they're really stable. I'd be shocked if they died.' No problem. If you say 'It wouldn't surprise me' then use that knowledge in the recommendations that you send back to the family doctor."

"But if you would be surprised that they would be to die, take a step back. Be the general internist that you were all actually trained to be first and looking at all the comorbidities, all of those medical conditions that the patient has, not just their heart but at all of the other pieces. And would you be surprised if they were to die in the next six to twelve months of some

combination or complication of any of those? And if your answer to yourself was ‘Nah. I wouldn’t be surprised if they were to die in the next six to twelve months, their heart’s stable but the rest of them isn’t as stable’ then again, turn that around and use it in your recommendations back to the family doctor.”

Because as a family doctor there’s nothing worse than sitting down with your patient and their family, having maybe talked to the respiratory doctor about their COPD that “You know what, they are ... we need to look at taking a palliative approach.” Because they’re starting that slippery slope down. And the patient and their family are on board with maybe not doing quite as aggressive treatment. And then having the cardiologist turn around and send you the most aggressive recommendations back and the patient’s going “But the cardiologist said ...” And that makes it really tough for us as the family medicine generalist who’s looking after the patient and all of their complications and their families and everything else that’s going on in their life to find that balance and to redirect that conversation again.

A personal story ... my grandmother. My father was an only child and when my grandfather passed away at age 78, he’d been out in Edmonton helping my dad shovel snow on a November day. Got a bit of chest pain. So my dad said “Get out of here.” So they went in the house because they lived side by side, and he passed away in his sleep that night. And my grandma phoned my dad the next morning and said “I think your dad might be dead.” Because they’d slept in separate bedrooms forever. But my grandfather would every morning get up and turn the furnace up and would start the coffee. The house was cold and there was no coffee. My grandma was afraid to go and check. So she got my dad to come over. And my dad checked and sure enough, he had passed away.

Now interestingly that summer, like three, four months before, we had this really interesting conversation. I lived in BC. My family is there and I’d been going back maybe every six months or so, and my grandpa said, “Bob. When I die I want to be cremated.” Now they’d had a plot at the local family cemetery for a long time. They were going to be buried in caskets, just the two of them. And there’s my grandfather saying, “You can fit six of us in there if we’re cremated.” [laughter] But that opened his conversation to what he did and didn’t want if something were to happen to him. So he passed away.

Well my grandmother didn’t pass away until she was almost, until she was actually just past her 91st birthday. But my father being an only child didn’t want to talk to my grandma about what her wishes would be. I being the oldest grandchild, and being the doctor of the family got to be the one who facilitated all this. I knew what my grandmother wanted because she and I had some really good conversations.

Two weeks before she died, I get the phone call from my parents “Grandma wants all the grandkids home. She’s in hospital at the University Hospital with some GI bleeding. Her time is coming.” So I go back and I’m in there talking to my grandmother. My sister is there, my brother is there. The doctor of the week, which is kind of like a hospitalist type of setting, comes in and says to my grandmother, “Your hemoglobin is 58. We’re going to give you blood.” Now my grandmother’s hard of hearing and her bureaus heard really well because that’s where her hearing aids always were, and he’s standing at the end of the bed. I’m sitting on the bed, three feet from her, and she looks at me – “What did he say?” I said, “This is what he said. Your hemoglobin is 58, which is very low grandma. Here’s what normal is but you know you’ve been bleeding and this has been something going on for a couple of years now. And he says he wants to give you blood.”

And she looks at me and she goes, “Well if he thinks ...” And I said “Grandma, it’s not what he thinks. What do you want? We’ve had this conversation. What do you want? If you want the blood, it may make you feel less short of breath, but you’re in bed.” And Grandma looked at me, she looked at the doctor and she said, “Give the blood to someone where it will make a difference.”

It wasn't a pleasant situation because he really felt I was blocking his barrier and the fellow who came on the following week was much better and understood that we'd had these conversations. It wasn't in writing but we had these conversations. And he took the time to sit on the bed three feet from my grandmother so she could partially read his lips instead of standing at the end of the bed with a clip board and all the nurses behind him, and actually had that conversation with her and confirmed she didn't want any of the aggressive treatment.

She knew she was going to die. Her birthday was the following week and she was going to be 91. Her goal at that time was to see her 91st birthday. And my daughter and I came back to visit that weekend, celebrated her birthday. My daughter did her hair, did Grandma's hair. And then her goal was not to die on Christmas Day. [laughter] Because my grandma's birthday was the fifteenth of December and she didn't want to die on Christmas Day. And that was coming too close. She didn't want to die before Christmas. So her next goal was to make it until after Christmas.

So she'd seen my daughter – her only great grand-daughter. She'd seen my brother's, my sister's boys – two of her great-grandsons. My brother had not yet brought his great-grandsons, his three boys up, and they were the oldest of all the great grandkids. He brought them up on Christmas Eve day finally. He was really – my brother I have to say was the one who was the most resistant even though his kids were the oldest of them all. She saw the great-grandsons there. She'd seen all of her great-grandchildren, she'd seen all of her grandchildren, and my father's the only child. They spent Christmas Day with her, they went and spend Boxing Day with her and she died on the 27th. She went to sleep and went peacefully. But her goals, like I said, were to reach her 91st birthday and then not to die on Christmas Day or before Christmas because she just didn't want us as a family to have to deal with her death around Christmas.

GAREY MAZOWITA: It was for her kids.

COMMENTOR 3 [Jo-Ann Turner-Crean, BC Bereavement Helpline]: How long ago was this Cathy?

CATHY CLELLAND: Let's see. Well it would have been nine years ago.

COMMENTOR 3 [Jo-Ann Turner-Crean]: So you're still telling a beautiful story. What a loss. And I'm sure each time you tell it, it really makes you feel good. You're sharing. We appreciate hearing those wonderful stories about you. And I don't ... I think that when we are in grief, six months is not a lot for grieving. Up to two to five years is more than normal. As long as you're telling your story. Tears should turn to laughter eventually and smiles which were on your face. Stories of grief and loss are beautiful to share with others and we find healing and sharing so thank you for sharing that story with us all.

CATHY CLELLAND: And the tears, quite frankly, the tears were because I was so angry with the doctor that first doctor. For completely ignoring my grandmother's wishes. And for treating me like I was a leper because I was advocating for my grandmother. As professionals, as physicians, we have got to stop that. This paternalistic "I know best because I'm the doctor. And your hemoglobin's 53 therefore I must give you blood." No, that's not what the conversation needs to be.

GAREY MAZOWITA: And you know, Cathy, I like to think that where you do have a longitudinal relationship, that you don't get that. In fact, as a family doctor, I'm sort of taken aback now because I'm working in a much more episodic setting. And I had a situation about a year ago that I haven't encountered in so long. And we had a 95 year old. A woman who'd actually emigrated to Canada, she didn't speak English and I was communicating through an interpreter. And we had uncovered just in the course of some routine investigations, she had come in because she had a bit of a functional decline at home. And we

weren't sure what the cause was. And she'd been doing quite well living independently prior to that. And we had uncovered a new cancer diagnosis.

And so I had gone with the interpreter and asked the interpreter to say to her, we have some new results that I'd like to discuss with her so we could understand what her wishes would be. And what came back to me through the interpreter was, and I quote verbatim, "I am an uneducated peasant woman. The doctor should decide." And I haven't heard that in years and years and years. And what was sort of fascinating was this sort of realization that I had, how much this complicated my life in terms of treating her. Because I had no idea what her values were, what the wishes were, how the family felt. And so I ... so suddenly I had all this work I had to do to uncover something that really should be part of a normalized conversation. I, for me that's the key. It's the normalization of this I think that we haven't accomplished.

And about a week ago I heard on the news that one of the Maritime provinces was about to vote on legislation to make the default position for organ donation, if you didn't sign that you didn't want it, it would happen. On your driver's license. And you know what, so this is kind of a related issue right?

CATHY CLELLAND: Negative option billing.

GAREY MAZOWITA: Yeah, this is kind of a related issue that gets people thinking, about gee whiz, how can you not think of death with something like this? And I think we don't take enough advantage of those kinds of opportunities to almost bring in sideways the normalization of these kinds of conversations. I think, I really applauded what they were doing because you know what? I betcha it's got people talking in ... I think it was Nova Scotia or New Brunswick that they were going to be doing this.

MEG MILNER: You were going to speak?

COMMENTER 4 [Dr. Parin Dossa, Simon Fraser University]: I do not underestimate the complexity involved in advance planning. But BC is a multicultural society and my, I have two intertwined questions: first, do you address cultural diversity in your practice and second, do you not think that when we do want to have a conversation, should not we change the language through which this conversation occurs? And what I mean by language is the biomedical language. How can one have a conversation with a patient who may not be familiar with the kind of language, vocabulary that is used in your field? And so I think that it is important that this fundamental issue is addressed. Because what happens is that the patients are often rendered very passive in front of a physician because they think the physicians have the knowledge and we do not.

GAREY MAZOWITA: Excellent points. And I don't want to pretend that we're skilled at this but I think we're getting better at it. I think we're extremely sensitive to it. In fact, Providence Health where I work puts out a wonderful manual on diversity that speaks to the language that's acceptable, the distance you are from the patient that's acceptable, boundary issues, cultural taboos and norms. And I do like to think particularly, the hospital where I work, we have interpreters around almost all the time because we have so many patients who come from different countries and different cultures. And I really do think we try to keep the language as non-medical and as simple as possible and to make sure the conversation is with the individual.

It's not always easy. We still I think have lots of learning to do about this. It's imperative for a province like BC where there's such a diversity of population. And I think both parties learn. I've learned an awful lot about cultural expectations around death that quite frankly when I first came here were foreign to me. And we absolutely have to respect them. And often it's a mutual learning kind of dance that we have to do. And so your point is very well taken.

CATHY CLELLAND: I think the original “My Voice” that was developed by Fraser Health was available in Punjabi and Cantonese as well as in English. I’m not sure if when they adapted it to be the provincial document, whether the Ministry of Health has it all languages yet or not. But I know it was originally. So at least that’s a tool to help.

And I think the other important thing around that – that’s why it’s so important to have families there. Because you really can’t as an outsider, just ... you can try to do all the reading you want and take all the classes you want to try and help you understand what might be some of the sensitivities. But if the family aren’t there to help be that cultural interpreter for you, it makes it even tougher. So that’s one of the reasons why with the module, we’re trying so much to involve families within communities as well.

So the modules aren’t just about family doctors, their MOAs [medical office assistants] and specialists. It’s also about your community organizations, it’s about the patients within your community. And I look at some of the communities in particular where they’ve gone. They have really reached out to their communities to bring in that family and cultural sensitivity and to how they’ve worked out the program within their community, how they’ve approached the module within their own communities. So absolutely we’re trying. Personally I’m not in practice any more other than doing obstetrics so I’m at the other end of life. But at times even there, when you have a patient that comes in and in fully active labour and is fully dilated at twenty-one weeks gestation, that baby is not going to survive. And you have to have that same conversation at the beginning of the end of that life.

COMMENTOR 4 [Dr. Parin Dossa]: So a question I have is, I know in the plenary Dr. Janz brought this up a little bit but what is your thirty second opener to start having this conversation with your patients? And I’m thinking much more before it comes to a point where you’re talking palliative. But when you ask yourself the question, “Would I be surprised?”, how do you start that conversation so that perhaps I could take components of that to have conversations with the people in my life who are afraid of talking about it even with me?

GAREY MAZOWITA: I must admit, I do ... almost verbatim what Dr. Janz did. And it’s easy because I can say to people, “You’re new to me. You’re new to our hospital. This is something we discuss with every new patient who’s admitted to our ward. And it’s not because we’re necessarily expecting something bad to happen. But you’re at a stage of life where we just don’t know.” So and then I launch into the same kind of questioning. In fact what’s fascinating is there’s never any, rarely are there concerns or issues expressed by patients when I do it that way. But I can tell you, if I come in after three day that they’ve been on the ward and try to have that conversation, it’s “What are you not telling me? What have you uncovered that you’re not telling me.” [laughter]

CATHY CLELLAND: So some of things we’re starting, we’re trying to do and I think it’s ... we’re starting to change some of the culture back in medical school and the hard part there is you have to change the approach of the people who are teaching in medical school to include the fact that illness doesn’t just, isn’t just about the active management phase. And I’m just going to show you a little picture, it’s hard to see here, but in our module, we use this, it’s really tiny and I’ll leave it up here for you to look at, but this is called an algorithm, this is our end-of-life algorithm. And part of our, in our program, what this does is, it looks through the different transitions in life.

So we start with transition 1 which is really when a diagnosis is first made. You could be 32 years old with diabetes. We already need to start talking about the fact that “At this point in time, here are the things we’re going to recommend you do – diet, exercise, medication – to hopefully delay or prevent complications x, y and z. But the reality is that things are going to

happen in your life that wouldn't happen in someone that doesn't have diabetes. So we need to just start talking about what those might be."

We've also, the Doctors of BC when it was still called the BCMA, I think it was just in the fall, we had an article – no, the actual, the CHEP [Council on Health Economics and Policy] program, the CHEP paper that we just released – it starts off with a conversation about a couple that are in their 30s and they'd been out hiking and one of them had fallen and had a bad injury. So it was that – absolutely no chronic conditions – but what are the conditions, what have you thought to talk about? And it's really about how you open that conversation depends on the person at the time and this is taking a lot of us, our own mindset's having to change.

So the 20 year old who's a mountain biker and likes to go and do these really crazy things off of really steep hills and stuff, well, "What would you want if your landing didn't go well and you broke your neck? Skiing. You fall, you go into a ski well and end up upside down in a ski well and nobody finds you for a while. And you've had very little oxygen. That could potentially cause damage. What kinds of things would you be considering? You like doing high risk stuff. There are potentials. You need to think about it. Have you talked with your parents about it? Have you talked with your partner about it? Have you talked with your siblings about it? Have you even ..." Even if all it is is "Have you talked with someone to be your voice if you're in a situation to not answer for yourself? That may be the first thing, is identifying that, who's going to speak for you when no one else can?" And that's something that a 20 year old needs to talk about.

Advance care planning isn't just about end of life. From the time you're 18 and an adult, or 19 in this province, whatever the Health Care Consent Act says you're old enough to speak for yourself, you need to start thinking about who might be your voice, if you aren't in a, if you're not able to do that because you've had a car accident.

I was in a very bad car accident when I was in my second year [of] medical school, or in my second year [of] family practice training. I was on my way home from a C-section and I don't remember the three minutes prior to the accident happening and I don't remember anything until eight days later. My car, it was a blizzard outside of Edmonton. I lost control. I was broadsided by another vehicle. Thank heavens the Maytag repair man, Mr. Don, was driving by and didn't have any washers to fix because he and his buddy stopped and pulled me out of my burning car. It exploded five minutes later.

I was taken back to the hospital I trained as Miss X. I was unconscious. They didn't know who I was or anything. They cleaned me up. Somebody recognized me because one of my colleagues was there. And these were people I'd been to medical school with. So they at least, then they could phone my parents. Well, 23 years of age, 24 years of age, my parents are going to say "Pull out all the stops." You do everything you can obviously in that situation. Did I see that coming? Not a chance.

Now I'm in my mid-50s. I have a 14-15, well she's almost 15, a 15 year old. My husband is nine years older than I. We have had these conversations. We both know what each other does and doesn't want. Have we put it in writing? No we haven't yet. That's our own lapse and that's something we need to deal with. But at each stage of life, the start of the conversation is different. So I don't really have any quick and easy ways to do it.

But look at something about that person's life that might be an entry point into that. Whether it's "You've just had a diagnosis of this condition. We're not talking that you're going to die right now. But there are things, bumps along the way. How would you want them handled? Who's going to talk for you if you can't." So those are, you find those little, something about that individual's circumstances, their history, their life history, that might open that door a bit.

MEG MILNER: We've talked about physicians becoming more prepared, about a whole shift in the medical profession focusing on end of life and the advance care planning. We've had some samples of starting the conversation. A question that we're asked to look at is, is there potential of having physicians work with hospice societies and volunteers and organizations in the community that are focusing on this work right now, and starting to take it on. Because there's such a gap, it needs to come from all sorts of providers.

CATHY CLELLAND: Absolutely. And I can give you a real life example. In Salmon Arm, they underwent our End-of-Life module. They did a community survey. They took on the Division of Family Practice. So the Divisions of Family Practice were developed by the GPSC. As you probably know, a lot of family doctors, particularly in urban centres, have left the hospitals. And they end up in these little isolated pockets. And they don't even talk to each other, let alone the health authority and the hospital. So we developed these Divisions of Family Practice to reconnect family doctors with each other with a goal of looking at the health and needs of the community. And so within a lot of these Divisions of Family Practice, they are identifying that as a gap.

So Salmon Arm, Similkameen-North Okanagan covers Vernon, Salmon Arm and a number of other ... But in Salmon Arm, this was one of the areas that they wanted to tackle as a group of family doctors. And they reached out to the community and their health authority and they developed a program. And now they brought in a bit of hospice in the home. They're doing some outreach so that the palliative docs that are not there, because it's a smaller community, they have the Telehealth ability, they have ability to conference with them. And absolutely, I think that the Divisions of Family Practice and we now have some rural ones that are more of an umbrella group to look, to help those communities that maybe only have five to ten doctors but they have some of the, they have the same supports and access. I think absolutely. This is going to be a huge way to help identify gaps in communities and really be at the forefront to advocate for closing those gaps and being directly personally involved in closing those gaps.

GAREY MAZOWITA: And I absolutely agree with Cathy. And I can say from the perspective of the College of Family Physicians of Canada, they now have a series of programs, one of which is palliative care. And they would be delighted to engage with agencies such as yours to also look at opportunities to move this forward.

COMMENTOR 5 [Leslie Rogers, Fraser Northwest Division of Family Practice]: I can hardly stand it. I'm so excited to say something. I'm from the Fraser Northwest Division of Family Practice. Hello. We're going to be having dinner soon. And like the North Okanagan-Similkameen Division, the family practitioners in our area which is New West[minster] and the Tri-Cities [Coquitlam, Port Coquitlam, Port Moody] have identified advance care planning as a chief priority. So we're really attacking it from a very strategic sense.

We began by bringing together multiple specialists, hospitalists and family practitioners to develop a vision for advance care planning. That's, it's way out there. It's managed, a utopia – what would it look like fifty years from now if everyone had an advance care plan? So it's a very forward looking, well it's actually an image – a four foot by twelve foot image that's been drawn by an artist and we roll that out at all of our discussions to lift up the vision so it's not a “Gee, where are we stuck now? And what happened in the past?” This is what we're going toward. And so what do we need to put in place to plug the, to bridge from where we are now to where we want to be?

So certainly, since we're approaching this from a community-based level, we're looking to achieve very concrete things. So this isn't policy development. That's being done very well at other levels. But how can we pull together in partnerships with Doctors of BC, BC Hospice Palliative Care [Association]... How can we work together to do something that may be easier to

accomplish because it's at a smaller level. But by pulling together all of the existing resources and partnerships and all the smarts and the can do that is out there, we can use this as a bit of a crucible, a micro-model in the community, that we hope after a couple of years of working through our priorities, that we can have something that we can provide as a basis for models for other communities. So that is advance care planning and hospice and palliative care are not the sole responsibility of anyone. It's not something that's just got to be directed at the federal or the provincial level or health care systems or individuals or societies or Divisions of Family Practice. We all have a part to play. We're all a piece of the puzzle. So a chance to try this out and try and put a lasso, cast a net around what we can do at a community level is quite exciting because it's more tangible. I think it's more something we can get a grip on. So, thank you

MEG MILNER: Thank you.

GAREY MAZOWITA: Well said.

MEG MILNER: Maybe one more because we're overtime. Sorry. We are. How time flies.

COMMENTOR 6 [Ruth Edwards, BCHPCA Regional Director – Interior, Incoming; North Okanagan Hospice Society]: I'm wondering if the College of Registered Nurses has been included in some of these discussions going forward about advance care planning and whether the curriculum in the registered nursing program has been altered or adjusted to accommodate advance care planning.

GAREY MAZOWITA: That's a great question and I can tell you that we did get some push back from the nurses when we tried to build it into part of the nursing intake. Because we thought when we did some of the design at least in Vancouver Coastal [Health], the more opportunities there were to raise it, to talk about it, the better it was. And there was a bit of push back from the nurses about adding that to their plate. And I think some of the reasons that were given were hard for some of us to wrap our minds around. I think we've made some progress in that regard. And so now, at least in Vancouver Coastal, any licensed provider can have the discussion. But it's not quite as normalized in the nursing process as I think we would have like to have seen it.

CATHY CLELLAND: It will take time. Just like it's taken time to ... are we there yet in medicine? Not a chance. But we're ... at least we've taken a couple of steps on the way. And I know that there has been outreach to try and include the other organizations as well. Because we all need to be ... it's like the yellow brick road. Going down this together holding hands.

MEG MILNER: So I can see from the number of participants and the eagerness to have the conversation today that this has been, this is just the beginning of a conversation. But I hugely appreciate ... thank you very much the three of you for being a part of this and ...

CATHY CLELLAND: Sorry we monopolized the conversation there, Trevor.

MEG MILNER: I think that he's ...

TREVOR JANZ: I did lots of talking. I spoke for an hour non-stop. I think I'm done.

GAREY MAZOWITA: And we have to stay tuned for Cathy Clelland, the Movie. [laughter]

MEG MILNER: So thanks everyone.

REFERENCES

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