BCHPCA FORUM | 2014

FRIDAY MORNING SESSION MAY 9, 2014 9:30-10:30

Opening Conversations to engage, inform and educate the public on death and dying, and to initiate discussion on future care for themselves and their loved ones.

ROUNDTABLE ❸

Cultural Conversations: First Nations

MODERATOR: LYNN TURNER, BCHPCA Regional Director – Vancouver Island [Outgoing]

INVITED EXPERTS

- DR. EVELYN VOYAGEUR [Kingcome Inlet (Tsawataineuk) Band, Kwakwaka'wakw Nation] Past-President, Aboriginal Nurses Association of Canada; Elder in Residence, North Island College
- LESLIE VARLEY [Nisga'a Nation], Director, Aboriginal Health, Provincial Health Services Authority
- DR. SHANNON WATERS [Stzuminus (Chemainus) Nation] Chief Medical Officer, First Nations Health Authority
- DR. MELISSA GIESBRECHT, Research Associate, Health Geography Group, SFU Geography

QUESTIONS

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

- the nature of conversations in First Nations cultures and spiritual traditions about death, dying, and planning for care and the paths to opening these conversations
- the current and potential role of First Nations in public education about death and dying, and advance care planning
- the role of hospice palliative care organizations to support First Nations persons and communities in death, dying and advance care planning
- the potential for First Nations organizations to partner with hospice palliative care organizations to advocate for hospice palliative care in British Columbia

LYNN TURNER: Okay. I have 9:23 [a.m.] and I think we should get going because I think conversation is going to really develop and move on and take advantage of every minute that we can. So good morning and welcome. My name is Lynn Turner and for today, I'm the [BCHPCA] Vancouver Island regional representative and tomorrow I'm stepping down and Gretchen Hartley from Cowichan Valley is going to be in that role. It's been a great opportunity for me. Challenging times but exciting times and this Forum is about initiating the conversation as we move forward as an organization and to support the work of hospice all across our province. So I'm really excited that you're here today.

Our expert panel at the roundtable, we're going to give some discussion items and they're going to speak to that and at the end of that then we'll open it up for questions. And just again, we are recording. It's going to be transcribed, summarized and posted on the website. So that should be up within a couple of weeks. So somebody said, "Well everybody's going to be quiet now" so hopefully we'll forget all about that part and just let conversation flow.

So right now I'd like to introduce our panel. And starting here it's Melissa, Dr. Melissa Giesbrecht, you're a Research Associate, Health Geography Group, SFU Geography. So I understand you did surveying?

MELISSA GIESBRECHT: Yes. I've done interviews and various different types of research methods.

LYNN TURNER: Okay, so we have some really great perspectives on our panel today. And Dr. Shannon Waters with Chemainus Nation; Chief Medical Officer, First Nations Health Authority. Leslie Varley, Nisga'a Nation; Director, Aboriginal Health, Provincial Health Services Authority. And Dr. Evelyn Voyageur and you were very kind to forgive for not to be able to try and pronounce the name of the Nation and be able to say Kingcome Inlet Band; Past-President, Aboriginal Nurses Association of Canada; Elder in Residence, North Island College. Right? So welcome and thank you for participating with us.

So we have the session or the opening of starting the conversation. Now we're opening the conversation. And this session is Cultural Conversations: First Nations. And the purpose is to engage, inform and educate the public on death and dying, and to initiate discussion on future care for ourselves and for our loved ones. So we'll start with, and this is exciting to me because I love learning about different traditions: the nature of conversations in First Nations cultures and the spiritual traditions about death, dying and planning for care and the paths to opening these conversations. So I'll just leave that open and anyone who would like start.

MELISSA GIESBRECHT: I defer to Dr. Voyageur.

EVELYN VOYAGEUR: It was very emotional when I got the e-mail to come and be a part of the panel because my younger sister was just diagnosed with esophageal cancer. And I'm keeping this here because today we find out what her prognosis is. She just had her biopsy a couple of days ago so today the doctors will let us know. But it seems ironic because one of the things that we were asked to talk about was how do we initiate conversation with the dying. She, they often initiate, the one who is sick. And my sister came to my house and moved to Victoria and she said to me, "Evelyn, everything is all set. Everything is all prepared. I don't mind going home." And my people didn't say "die". They always refer to "going home". So I thought, wow, she's given me the answers to the question that I've been asked to address, "How do you initiate?"

As far as I, and I thought back to all the people that have been sick in my life lately, how they … they're the ones that initiate it. They're the ones that are prepared to tell us they are ready. My nephew who was 33 [years of age] got really sick and I saw him get so sick in front of me and I said to his Dad, my brother, "Take him to the hospital". But before he got up to go to the hospital he said, "Auntie, I've arranged with …" He gave me the name of the person that he had talked to that if he didn't make it. He had already felt sick, so he was preparing. He said "It's all ready."

So it seems like the people in my life that have prepared to go, prepared and talked to us about it. And I try to think back to all the others that have died. Did I ever initiate? I don't think I have. They always do it. They always seem to be prepared to go. In my teaching – I'm from the Kwakwaka'wakw Nation and my tribe is the Tsawataineuk of Kingcome Inlet. Kwakwaka'wakw just refers to all of us who speak Kwakwaka'wakw that's part of the mainland and Vancouver Island. In my culture, we were … we've always been taught that death is not bad, that death is not an enemy, that to die was to go home to a better place.

But the thing that's changed is that yes, people in my world are dying younger, very much younger than when I was young. It seemed like everybody that died was of old age. My Dad died at a 104; my Mother died at 99 and I had a maternal grandmother who was 118. So they were very open, so they accepted death. You welcomed it when they got too old. But to this day, they're younger because of the lifestyle, because of colonization, residential school … all the pain my people are gathering and more. They're dying younger because of the pain they carry.

So death was always openly discussed. I know it's not so in other worlds but in my world it was always. My Dad always told us they need to know how to deal with it when you lose a loved one, they need to know how to accept death. So he always said, "Don't keep your children from the dying. Don't keep them. They need to accept death." Because we're all here to die and

we've seen that on the board today. That was the teaching. That's what we're born for. "We're going to all die." That is what he used to say. Then he used to joke to us. He says "I'm really lonely for my Mom and Dad now." He used to say that. So anyone else?

LESLIE VARLEY: I'll go next if that's okay. I'm Nisga'a from northern British Columbia just below the Alaska panhandle. And we actually have a lot of similarities in our culture in terms of how we speak about death. And we understand that this is a process of life. In my culture, we have a very strong belief in reincarnation so death isn't such a fearful thing if you know that you're going to come back or you might return. And I think the only … and I really don't have anything to add. We have a very similar culture except that in our culture, historically we didn't engage children with the funeral process.

We … I remember when my great grandfather died, and he was very old as well – he was over a 100 – children weren't allowed to go to the funerals. We did go to the … we have a celebration feast afterwards and we thank everybody for supporting us in our time of sorrows. It's really a celebration feast but we do all get together and support each other. And it's a very strong supportive process. The death process or the mourning process is very ritualized so that you're expected, all your job is if you're lost a loved one, all your job is is to mourn. You're not supposed think about the eulogy or the clothes that they're going to dress the loved one in, or the, any of that. It's not your job. Your job is just to mourn and people make sure that you do that. And so they look after all of the details that are required to help somebody when they have passed on.

And so at the end of it, you have a feast. And a year later, your family who has lost the loved one has another … we call it a headstone moving feast. I think it's very similar in most cultures on the West Coast. And that's our family thanking everybody who's helped us through our year of sorrow.

So there's a lot of ritual around it and I think it makes it acceptable when you're constantly revisiting and engaging. And it's not you put them in the ground and they're gone and you forget about them – constantly revisiting. And we, I know that your, more so than ours, have memorial feasts. And so I think death is so much more integrated in our lives in that sense. That's all I want to say for that.

SHANNON WATERS: I'll say … start off by saying the two people that spoke this morning – Roberta Price she's saying she was from Cowichan which is near Nanaimo. I'm from, my Mom's side is Cowichan and Stzuminus and my Dad was Swedish. And my Mom was adopted out like Roberta had been talking about. She was born in 1955, so right around the time of Section 88 in the Indian Act. And she married my father. He was posted to a military base on the Island. So she had been largely removed from her culture.

And when I got older I asked a lot about it and so kind of reconnected myself. And worked as a family doctor on Duncan on Vancouver Island and reconnected with my family who knew who my Mom was but kind of knew she wasn't wanting to go to the place of reconnecting. And thought for many reasons why I was doing that. And when I went back to do further training in public health, which I'm in a public health position now, my Mom died at the age of 52 very suddenly of a heart attack. And so we never talked about it because she was young.

But what saved me at that point when I was still going through my training was I had that connection with my culture and there was things that needed to be done and I didn't have to take care of it. So there as the whole cultural … that surrounded me and helped to take care of me and my brother during that time.

Eight months after that, my father passed away suddenly. And so that was a really hard point for me, where just thinking whether I am going to continue with my training, listening to Renu talk about, she just left work. I was seriously thinking about that type of thing but through things such as, when someone goes to the other side, I think we call it more in Cowichan "going to the other side" and likewise it's going to a better place. I was very shocked at how suddenly my loved ones had gone. But people were "That's harder on you here, but they've gone to a better place."

And another thing that we talk about – the teaching is what people can leave when their work is done. So my mother and father's work was done and I had to accept the fact that I felt that was much earlier than I thought I would lose my parents. But that was … the work was done.

And so another … but also because they left quite suddenly, so there was never any of these discussions and I was … they were living in Alberta, both of them at the time they died so I didn't get the chance to talk to them. But we did have spiritual practices, things such as burnings or what have you, where I was still, I'm still able to connect with them and get some other of their guidance. And that, so it wasn't also like they were gone completely. I still have my ways for them to have influence in my life and to provide me guidance through cultural ceremony. So that was also a very good ending for me.

And the last thing I'll just say is I now work at the First Nations Health Authority and one reason I'm so, it's a challenge because it's new. What do you do and what is this Health Authority? But we really have the opportunity, well we have the opportunity and our population has told us that they want to look at health holistically. And so mental, emotional and very much spiritual health are part of that. And that I don't think spiritual health is something often the healthcare system really talks about. So/but we are talking about that because it is part of all of the aspects of our health. So I think opportunities for how we deal with death and dying and having an open conversation around it for First Nations here in BC is something that hopefully can happen more.

MELISSA GEISBRECHT: Hi. I would just like to say that I sit here today very humbly. I just completed my PhD. I myself am not from First Nations. I'm Danish, German and Croatian actually. And/but I have a background in health geography, which is a very different perspective than all of this. But what I look at is the importance and significance of place, particularly in end-of-life care. And this tends to really relate a lot of First Nations cultures with place in itself is very important.

And so my research, I've actually been interviewing caregivers including some Aboriginal/First Nations from across Canada, in rural Canada. So I'm not specialized in BC at all either. I'm really gathering different perspectives and trying to see themes in that.

What comes across is very much that with First Nations and everyone is each death is unique. We are all aware of that. But the, in terms of speaking about death and dying, I've found language is very important. The, a lot of the people, I've spoken to nurses as well, so I have really both sides, and this idea that the importance of language and how we speak about these things is going to be very different for each culture, each person. And that seems to be a real challenge that I've, that people are coming across, very especially for the non-aboriginal care providers. And so I know that there's definitely a desire to learn more on their side.

In terms of place and home, I know that, for, there's been many examples where I have spoken to some aboriginal family caregivers where they were, had to leave their home reserve, travel for example two hours, three hours away to be in a hospital institutional setting, which hasn't always been the best experience for them. And so I'm really looking at ways to

improve the cultural and physical spaces of care for aboriginal people. But I'm not an expert in this at all. So I'm just coming here today really to learn as well. So …

LYNN TURNER: Thank you. And I think that's what we're all doing is learning from each other and we're just so grateful that you're here to share experiences and your heart and your life and death with us. So we will have an opportunity at the end to have questions and revisit some of this. So the next item is "the current and potential role of First Nations in public education about death and dying and advance care planning. And again if you want to just speak as you …

EVELYN VOYAGEUR: I've been working with North Island College for nine years. In 1999 I retired from active nursing and have worked with the residential school for four years and I went on to North Island College. I was asked to come aboard to help with the nursing program because North Island College was changing its curriculum to be inclusive of cultural teachings. And to this day I can honestly say that North Island College is the best school of nursing across Canada. And I've been across Canada because I was the President of the ANAC [Aboriginal Nurses Association of Canada] at one time. And that is part of what they're teaching. They're doing a lot of teaching from the First Nations perspective or other cultures.

I always say when I became a nurse, I was taught only one way – how to look after the dominant society – as a lot of us were. We never even touched the other cultures. We never even heard about the other cultures. And so we were meeting the needs of the others through the lens of the Western way, which did not meet their needs.

So I can honestly say I'm really happy to be a part of North Island College School of Nursing because we do that. We teach all about culture. And we even take them to a village to be … we go to one village one year, and we go to another village the next year. We use two remote villages. And in fact yesterday we had a meeting because these people, these students that have gone to experience. I have nothing against research but a lot of it is not experiential. It's … you read it, you don't get it as much.

But these students – and we've taken faculty. Faculty have taken the course. And they say they've transformed. They don't know what happened to them. These are their words. How they learned. They lived with the First Nations for a whole week. They do everything the First Nations people do. They live with a family, they go berry-picking, they go herbal picking … whatever they do in that village. And we hold our classes in a, in their ceremonial big houses. That's where we hold our classes. And the whole community … it's open to the whole community, to come and share their stories, their teachings.

So I really believe, just by seeing the changes in these people that are doing it, just hearing them … how they've changed their own attitude. One teacher said "I'm a better teacher now and look at the students as people. And then if they're having problems, what is, how can I best help them?" I really believe that's the way to do a teaching.

And not … it isn't about First Nations. It's about you. How well are you comfortable with your own self and your own culture? So if you're not comfortable with yourself and your culture, then you're not going to be comfortable working anywhere. I believe experiential is the way to go and I've said that to the powers that be when I was asked to critique the cultural safety online. I said, "Yeah, the content is good, but it's a process that's very, very important. They need to experience what they're learning. They need to see it and don't bring the Western way."

There was a young woman that died in my village about three years ago. And I usually take over for the nurses that work there – both Rivers Inlet and Kingcome. I, whenever, they don't, short of nurses … I still go and take over. And when I got there in Kingcome, they were … they asked me to fill out, tick out this form, how she was. I said "I'm not doing that. You can, you know

by interacting with her. You don't need to tick out how you know she's doing ." "This is not our way" I said to the nurse that was there. So that's another … don't bring what doesn't work when you're with First Nations. So I'll say it again – experiential is the best way.

LESLIE VARLEY: I'm sorry. Can you just repeat the question again? I lost my trail [of thought].

LYNN TURNER: Sure. The current and potential role of First Nations in public education about death and dying, and advance care planning.

LESLIE VARLEY: The current and potential role, okay, in education. Okay, so for at PHSA [Provincial Health Services Authority], we work closely, Provincial Health Services works closely with all the regional health authorities and the First Nations Health Authority. And we do an introductory online training for, they call it cultural competency. But really, it's anti-racism training. It's asking people to look at who they are and reflect on what our biases, our racial biases are, and to think about what we bring into every care relationship.

And so we have 100,000 health care workers in BC that work for health authorities. So although we would all love them to go to Evelyn's course and have the one week of experiential [learning], financially it's impossible to do.

Also, the thing that we do is in our training is we don't talk about nation-specific training. It's not our role. It is the role of the First Nations individual communities to determine what they want people to know about themselves. So we don't go there at all. But we do an introductory type of training. It's very foundational. And we talk in very general senses about some cultural norms among First Nations that we all generally have. So that's an important foundational piece of training.

And then I would … what we try to do is encourage the regional health authorities and the First Nations to develop their follow up repertory. So that's the place where you would go for any specific information. For example if you're going to Cowichan tribes and you want to know, because when we're talking about birth and death, the processes are very, very important and very unique for each culture. So we could never cover that in a training. And it would never be our place within a bureaucracy to do that kind of training. So that's what we offer. We offer the indigenous cultural competency. It is online. It takes about 8 hours to do and/but we don't get into any cultural specific types of training.

SHANNON WATERS: I guess I'll speak from two perspectives: one being in a role as a family physician at one point and one from a First Nations Health Authority perspective. In medical school – I went at UBC – we didn't really get a lot of adequate training around death and dying. And for me, when I went back home to work as a family doctor, I purposely made the choice of working three days a week which wasn't popular amongst the local physicians.

But I knew that I wanted to connect with home and my culture and that I needed to have that experiential of learning and going to ceremonies and to the big house and being part of funerals which is unfortunate in a way because you bring up birth and in a lot of our communities birth isn't really there anymore. Women have to leave to give birth. And sometimes death is the only thing that's still in our communities even though sometimes people can't die in their communities either. But especially if it's sudden, they still do. And that needs to be balanced, a lot of people had said the birth and the death – the cycle of life.

But that … so there was nothing about my medical school training or being a physician that helped me with when I had my own patients who were facing end-of-life decisions or even worse, or when I faced the very difficult decisions of when my

Mother and Father both passed away very suddenly, very close together. And so I think the cultural competency course is an opening for a lot of our health care workers to kind of start thinking about some of these issues. But really to have it be something that they can really offer to someone in a good way, people have to be curious and engage kind of in a different way.

Now around the role in public education, I think physicians are trying to be more, kind of interfacing with the public more and bringing up specific issues. I was on the BCMA or Doctors of BC "Walk with Your Doctor" last week. And we're, physicians are trying to talk with their patients more generally. But that, walking with your doctor, I think is a far cry from talking about death and dying. Maybe some people talked about that but probably not very likely. But I do feel that now in my role as a public health physician at the First Nations Health Authority, because we're looking at health very holistically and that spiritual health is part of that, and death and dying is part of life, that these types of conversations are coming up more now.

And even I'll just say, one specific example, some communities have issues that come up around autopsies and our cultural practices around funerals. And nations are different around the province but in my community, we have four days of [ceremonies] leading up to the funeral. And we of course want to know if there's foul play, or something like that, like what happened to our loved one. But we are looking after their spiritual health and the rest of the community's spiritual health in our ceremonial practices that a number of days go by and then you have your private burial or what not on the fourth day. And the health care system maybe doesn't recognize that. We want to go through, investigate all these things, often which there's no final answer from, especially for babies, for sudden infant death.

So it's opening up that conversation to say actually the spiritual health of that person who's on the other side now, or on their journey to the other side and the spiritual health of their loved ones who are here needs to be taken into consideration with things such as the physical aspect of an autopsy on what might have been the cause of death. So yeah …

LYNN TURNER: Thank you. Melissa?

MELISSA GEISBRECHT: Again I speak from my perspective of being non-aboriginal. But I had the valuable opportunity to, I've been connected with the Chehailus Band in Agassiz, near Chilliwack. I'm from Chilliwack originally and just recently moved back home there. And what they do for public education I found very empowering and was very useful, I know, to many of the hospice workers in Chilliwack, for example.

What happened with them is they had a member who had died – there was an incident – and they kept the body at the coroner's for past the four days. And they finally said, "Enough is enough. We need to start educating the people here of our ways." And so what they hold is a death protocol day. I think they hold it annually. And it's, they hold it on their land and everyone is welcome. And it's a day where they actually explain their protocols, the things that are necessary, what they need.

It was an excellent way for that conversation to happen. There were people from border control, there were … the audience, it was filled with people. And it was just the most fulfilling day. I learned so much that day as well. And I thought that that was a really excellent way to go about making sure that their voices are heard and that there's a respect there for, to make changes, to ensure that things are done in line with their culture, cultural and spiritual needs.

So I think that that's a really great model. I know that not all communities are organized and strong enough to be able to organize such an event. But at any level, I think any sort conversation in that way, to be able really to have their voices heard. And I think that that's something that's really important. It was just an example of an event that I went to.

LYNN TURNER: Great. Thank you. And that's a good lead in to the next discussion item. So asking your perspective on the role of hospice palliative care organizations to support First Nations persons and communities in death, dying and advance care planning.

EVELYN VOYAGEUR: I live in Comox. And I think it was about five years ago. I don't know very much about the hospice, the palliative care in Courtenay/Comox. But we had a family member die and we were constantly there. The family was sitting with him. And I don't know if she was very new, the person that came, but she went right up to the patient. He was quite unconscious, he wasn't aware at all. She said hello to us and I'm from the hospice. But she went right up to him and spoke to him and said "I'm from the hospice society", I think she said. I don't really remember their correct words.

I thought that was not acceptable. That she should have asked us, his daughter and me who were sitting with him, "Was he conscious [etc.]?" And I think his daughter got kind of upset that, because she went right up to him and he wasn't aware. He was, we were just taking turns sitting with him because we knew it was going to be a matter of time, it was anytime. And his daughter said to her, "We know all about it. We don't need you," she said. So I think that was not a good experience.

But I think that they have their place. As I said I'm not sure. I've never really had encounters with them. But I had a niece who died in Nanaimo in palliative care. They were very good. They were very, they weren't strict in allowing us to be there. We stayed there all night and day and supportive of whatever we did but/and they didn't interfere with what we were doing. So I don't really have an experience with them coming to the houses. So I can't really say what they've done and what they haven't done.

LESLIE VARLEY: Yes, I don't have very much experience either. But I agree with what you're saying is what, we have a, we in many ways in terms of death and dying rituals, where we become very … it's a time when our culture really strengthens. And we are, as Dr. Voyageur said, we're trained from a fairly young age to know the process, to know what's going on. So we tend to kind of insulate ourselves and I don't think we make room for external people who are very well intentioned.

But I don't think we generally make very much room for that because we do have … this is a very, very common complaint that hospitals have about First Nations is that when somebody goes to hospital and all the extended family shows up. And we do and that's our role. And some of us play the role that in other cultures there are sort of paid members of society who play those roles. In our culture, we all try to play, we all try to be involved and do what we can, if nothing else, sit there quietly and show support.

So I think that there tends to be a little bit of a rub there sometimes. And it's, I don't think it's intentional, I think it's just two cultures trying to figure out how to help and support each other in a really difficult time. So as I say, I've seen them, the work being offered. I … unless it's a First Nations person who doesn't have any family or supports around, who, maybe they're here in Vancouver and this person is from New Brunswick and you don't know who the family is for example. Then I think it's really appropriate. But if there's family there, like Evelyn said, it's always best to approach the family first rather than to go to the individual. I don't know if that's helpful.

LYNN TURNER: It's valid.

SHANNON WATERS: Yeah. Likewise I don't have very much experience with hospice. Where I'm from, back home, Cowichan, in Duncan, we have a Cowichan District Hospital. So often when people who are on their way out, they're at the hospital. And

likewise, it's a lot of people showing up at the hospital trying to show their support in and around the time, which I think is … it's allowed in the hospital, whether and how long it's accepted in the hospital I don't know. I think it's now kind of an unwritten policy in the hospital that that's allowed. But there's always new turnover of workers who are uncomfortable with it because I think they might more come from a culture where you might, where you are a bit more close knit, small, you don't invite big groups or big groups of people don't come when someone's passing away. So it's okay where we're at. I think it's better than where we were ten, fifteen years ago.

I did have a physician that I worked with that was very well integrated within the community who I worked with when I was there and I did some training with him. And he was very trusted by the community because he took the time to get know a bit more about the culture. And he did help a number of people die in their homes. And really, his role there was pain control. And I think that was the thing. He just came very humbly saying "I can offer some pain control". And knowing that everything else was taken care of.

And so I think sometimes that's one of the parts I guess I could see when some of those people, like people from my family, we were all very grateful that we didn't have to worry about that part. And we could just concentrate on everything else.

But that's in a somewhat more urban place. I do know, and in my role now even as recently as yesterday, I was on a teleconference from/with a chief and a nurse and health director from one of our communities in the Interior where they're not that far from a major center, Williams Lake. But people want to die at home and they don't have, they have a nurse that comes three days a week. And so when it does get to the point where someone might need something like some shots of morphine or something like that due to extreme pain from cancer or what have you, the way things are set up is it just can't happen.

And how can we address that? And it's looking at what kind of care is provided. I don't think that, well I can say for sure, palliative care wasn't considered in what the services and funding the community received for what they would be able to provide to their members. And they're saying "Well people want to die at home. We want to work through ways to do this." So, and I don't know, if there's very many hospice connections in some of those smaller communities. So/but I don't think it's something that comes up, that community members know very much is a resource for them.

MELISSA GIESBRECHT: Yes, so again, building off of what you were speaking about as well, of the places. That's really what I look at. And that is one of the main challenges that I see coming up over and over again is when someone from an Aboriginal community does reach a point where they would, they're unable to or afraid to do at home [care] they move to the hospital setting. In some places, the hospitals, it's so rural, the hospital, everyone knows everyone anyways. It's not like in Vancouver, you go to the hospital.

But the physical space is just not set up for a First Nation to have … all the family comes from all over and the rooms are just too small for the ceremonies. Smudging – these sorts of things – often is not allowed in the hospital setting as well. Some cultures with the window, require with the window to be open and not all rooms have that either. So it's really about considering these cultures and building facilities that really incorporate these spiritual and cultural meanings into these physical spaces. It's very important.

Also in terms, I've also heard in terms of people who do live far from hospital settings or very remote fly-in communities, the need there for hospice organizations perhaps to go to those communities and train community members there in how to nurse and what to do with pain management and these sorts of things, as well as trying to create some sort of network where

they can share medical equipment, hospital beds, these sorts of things because the resources often in these communities are very low. So to be able to bring those sorts of equipment, like a rental, bring it in, sharing this equipment among the communities would also be valuable. That was mentioned in Prince George.

So there's lot of different ways that I think the hospice could work with First Nations communities. It's just … our West[ern], the way that our, the hospitals are, these spaces, I think, it's just still not there yet. We have a long ways to go.

EVELYN VOYAGEUR: Okay. I'm just going to share. I'm involved with planning of the new hospitals on the Island [Vancouver Island]. And they have included the First Nations in the planning. And they will build those such rooms that's needed to accommodate the First Nations needs that they're dying in the hospital. So that's something that we're working on.

MELISSA GIESBRECHT: That's great.

EVELYN VOYAGEUR: Whether it's going to come or not, we're hoping it will, being there. Because it is much needed. Because a lot of our people live off reserve. They don't go home because there's not enough housing and not enough jobs. And some of our people are too colonized. Some of our younger people have not found their ways back home. So they want to live here. They still need that care. So that we're really looking forward to this new, two new hospitals – Campbell River and Courtenay/Comox. They are including us in their planning.

MELISSA GIESBRECHT: Excellent.

LYNN TURNER: Thank you. So the last item of discussion before we open it up for questions: In your view, the potential for First Nations organizations to partner with hospice palliative care organizations to advocate for hospice palliative care in British Columbia.

EVELYN VOYAGEUR: Well I do think we do need, all need to work together. And I'm sure that we can learn from each other how things are done. Because for so long the non-natives have come into our communities and told us what to do, whether it worked or not. So I think that there is a place for us to work together to listen to each other and learn from the other. And as I said before, it is not all just about First Nations. It's about working with the different, the multiculturalism that we live in today. And it has never ever been addressed before until lately. Now all of a sudden it's cultural competency, cultural safety and all those things. And that kind of worries me because people are just reading about it.

In my job in North Island College, I do a lot of things. Even the people who are studying for their Masters are having me read their papers. And I read one lady's Master's paper and she said you have to have the skills and she named all the skills to have cultural competency. And I made a remark there. They may have the skills but are they doing it mechanically? And just doing it because it's a job. That's what bothers me when we do all this cultural competency training. Is it really coming from their hearts? And that's what I hear about North Island College nurses.

I was on a ferry coming from a small village where there was just a potlatch[1] and there were some visitors that came from Chilliwack and [inaudible]. And I had introduced all the nurses that went with me to this little village. And I got them up and introduced them. And as we were leaving the village, this lady said, "Tell me about your program?" So I was telling her about what we did and why we take the nursing students there. And there was another native lady sitting in a lower seat. And she turned around and said "We have two North Island College graduates working and they are the best nurses we've ever come across."

They're not there because it's just a job; they're there because they love it, they like the job. And they're just part of the community. They're included in everything that's going on. I'd like to see that all across Canada in schools of nursing. Not only nursing but doctors and everybody else who works with people.

LESLIE VARLEY: I think it's important for hospice workers and First Nations to work collaboratively together because there's always somebody that needs help and assistance. And I think the important thing is to learn how to approach and be with First Nations people. And if I could make some really broad cultural generalizations, which I don't like to do, one of the things that I think First Nations are very, very good at is listening and being quiet, hearing. And that's one of the things we find other cultures aren't as good at. And it feels, I think it creates anxiety or something in us when we're the only ones listening.

So if I could give you one piece of take away advice, that might be it. It's just learn to be still and when you're with First Nations people, to listen, to try to engage in some deep listening. And even if that means no conversation at all, I think that you're still deeply connecting with somebody. And I think that's the … when we find non-Aboriginal people who are able to give us that, we cling onto it. So then your skills would be so valuable to us, so …

SHANNON WATERS: Yeah. I think it's a place that it's important to work together, between First Nations and people who provide hospice type care. In the broader scheme of things, one of the things that we're trying to do in First Nations Health Authority is really incorporate traditional and spiritual healing more into the programs and services that First Nations people have across the province.

And someone described it as there's kind of three ways that that can happen. One is well, that it's not happening. Things are very siloed and that's where things are at in a lot of cases. There might be a whole traditional and spiritual healing system in a community. Maybe it's not integrated with what's provided there in Western medicine terms. And maybe there's very good reasons for that. People are not, scared that it wouldn't be received well or what have you.

Then there's systems where there's kind of a hierarchy and that the traditional or spiritual healer would be kind of referring to the higher power of a physician or a nurse of whatever. The physician or nurse, once they realize they're not helping the person, might at that point, probably after quite some time, refer to a traditional or spiritual healer. So there's some integration there but it's very much from a one is better than the other type place.

Then there's one where it's kind of like a new paradigm where both are working together to create something new and better. And that I think that's, like Evelyn was saying, learning from each other like that. We as First Nations people, we talk about death and dying. We have lots of spiritual practices around that even though we've been trying to be quelched for decades, centuries. And there's a lot to learn from us. But we can't do it all. We know, like we're right now, a lot of our people aren't able to die at home if they want or things like that. So I think just coming from a very humble place as someone who can look at providing hospice care and knowing there is stuff that can be given and received in exchange, so …

LYNN TURNER: Thank you.

MELLISA GIESBRECHT: I'm not sure I have much more to add. Only to reiterate what all of you have already said and … This needs to go, there needs to be this recognition of the history, respect for non-Aboriginal people, and to listen and to learn. And the conversations that go on, they need to occur in this sort of environment. And I think if people can get there, then

there's the potential to actually be able to work together and maybe advocate for better hospice care across BC for everyone. So I don't really have much more to add.

LYNN TURNER: Right. Thank you. So at this time, if you have questions for our panel, I'll come around with the microphone. We have I think about ten minutes. So …

COMMENTOR 1 [Mike Hickey, Prince George Hospice Society]: If you don't mind, I'd like to touch on a topic that you brought up Dr. Voyageur earlier on and that is, I find it hard enough to deal with death and dying issues in everybody, but I don't find it anywhere near as difficult, and maybe that's just personal, if you've have some who's led a really full life and is dying at an old age. We're ready for that. The hard moments for sure. But I find it way more challenging to assist anybody or understand what's going on or come to grips with somebody who is dying when nobody's ready. They're not, we're not. They're in an accident, they're murdered maybe even or they have an illness that just takes them away very quickly. Is there a differentiation on this one or are there things in particular that Aboriginal cultures do different or find work particularly well or it's the same issue everywhere?

EVELYN VOYAGEUR: I/we, when anybody dies we treat them the same regardless of whether they got cancer, yeah as I said it it is very difficult when they're young. But we go on treating the dead with respect. Their families. Be there for their families. It's not easy because as I said we all die whether they're young or older, old – it is hard, it's very hard. We have to be there to support them.

I'll give you an example of – I worked in Bella Bella as a community health nurse and there was a doctor, because there were suicides, there was a doctor that wanted them to stop having big funerals. He said "They're envying each other." That's what he told us. That … I was floored. He certainly didn't understand the history of why my people are committing suicide. The deep pain that they're walking around with that [inaudible] isn't any good. But we bury them the same, no different. It is hard.

SHANNON WATERS: I'll just add a little bit more, just around the topic of suicide because that is especially hard. And I just think even then, we're still open, we're still talking about, it's not, it's devastating but we face it and we know it's going on. And I think in some other cultures [inaudible] it might not be addressed face on where we do. And we know it's an issue and we have to tackle it.

And I'll just give an example of a very difficult situation where a non First Nations person had happened to find someone in the community where it happened. And I think it was so interesting because I went to that funeral and that person and their partner were invited to the funeral and everyone was surrounding them saying "We know this was a difficult thing for you" to find him. They got healing just like everyone else did. And it was such a painful sad time but I was, wow, here we are embracing this person who had this very difficult thing and they were just driving down the road. But let's … they were integrated into part of the funeral ceremony. So I think, just always not being afraid [and] in a very humble way to say "What's going on here?" or what have you, just starting that conversation.

COMMENTOR 2 [Joyce Kuhn, Comox valley Hospice Society]: Hi. I'm Joyce and I'm a hospice volunteer in Comox. And the reality for some of our communities is there is no hospice facility. So we do have certainly people dying at home more than some of the bigger centres would. And where hospice comes in, certainly where we come in before the person actually dies, more to touch on what you touched on. Certainly being a good listener, approaching the family as opposed to the client themselves is very important in the First Nations culture. And these kinds of tips, with more focus on tips for us, like how can we be helpful - tips like that when we go into the home when the person is still with us, before the actual death. Because

that's what we do in Comox at this point. That's very valuable information for us. If anybody has any more tips like that to add, it's very helpful.

COMMENTOR 3: [Shelley Stickel-Miles, BCHPCA President-Elect [Incoming]] What experience have people had with asking the question about organ donation? It's a difficult question anywhere.

LESLIE VARLEY: That part of the health care system is part of Provincial Health Services [Authority]. And we know that there's a lower – aboriginal people tend not to be organ donors. And it seems that the more deeply ingrained you are in your culture, the less likely you are. And I think, I was trying to explain it to somebody and this is a … when my late mother passed away, aside from her lung cancer she was very healthy. And I talked to my siblings and our family, her sisters about whether we would do any organ donation. And my family, my aunts were just "No, absolutely not. We're sending this person off into the next world with all their parts intact." And if possible, there was an option to do an autopsy.

And if the option is to decline it, then it needs to be declined. So that's just my culture and my family and part of our belief system. And to add a little bit of humour to that, my mother was a … we used to tease her and call her "Imelda" because she had so many shoes. And so I wanted to really send her off. And even though my family, our role was to mourn, we didn't want to do – we were told not to do anything – I knew my Mom really well and I wanted to send her off in great style with a great outfit and a fabulous pair of shoes. She used to totter around – a tiny little women – totter around in these high heels and so I thought "Oh. I'm going to get her these amazing high heels."

Well in our confusion and all the emotions and stuff, the shoes got forgotten. And I'm still really troubled by this. I need to do a burning and send her off with a pair of shoes. But I don't know what shoes she ended up in because that got sort of taken away from us when we brought her home. And then when I finally got back to Vancouver, I was "Oh no. There's this expensive pair of size 5 shoes here that are my Mom's and what am I going to do?" And so I made a donation. I just donated them.

But the whole thing on organs is something we're talking about at … because we have a lot of transplant needs too, right? There's a lot of diabetes and livers, lots of kidney transplants, that kind of thing. And I was talking to the head of BC Renal Agency and she says on the one hand that the palliative, it's not, you generally don't get people who are volunteering to. But anytime there's a family issue and somebody needs a kidney, she said the entire family is stepping up trying to offer a kidney. So I guess it's different. We'll offer our organs while we're alive but maybe not at the palliative state.

So it is a tough question to ask and one of the things we're thinking about doing is doing a very First Nations specific campaign so that … If I was in your position, I wouldn't want to ask the question either. But maybe we can ask the question broadly to a First Nations audience in some sort of campaign that's directed towards us. Sorry if that's kind of weaselling out of your question.

COMMENTOR 3 [Shelley Stickel-Miles]: As a hospice worker, I haven't asked that question. But I think it's an awkward question for anybody.

EVELYN VOYAGEUR: It's something very new to the First Nations. You have to remember we didn't have donations, body donations and things like that. I know I worked with the One Stem, and the One Stem is having a hard time getting donors for the people who need the stem cell donor. They're having a hard time getting First Nations to do it and I do talks on that because I, it's something that they didn't know about, that they never heard about. So these are all new so we need to educate our people about them.

COMMENTOR 3: It comes from a Western medical place? So lots of people are going "What?"

LYNN TURNER: Okay. We've reached the end of our time.

COMMENTOR 4: One question. Lesley, you spoke of the importance of sitting in silence. And is it better to sit in silence for a long space than respectfully after a period, a comfortable period of silence to say "In what ways might we help you?" Which is better?

LESLEY VARLEY: I guess I would just put that back to you. You're sitting there and you're feeling comfortable. If you feel that it's a good time to ask the question, I would certainly ask the question. I was thinking that myself, after I said that, sitting in silence. But you also want to be able to communicate and to ask how to help so.

And I sit with, because I work at BC Women's [Hospital] we have a lot of people coming down. And I have a huge extended family, I do a lot of that – sitting with people who are terminally ill with cancer. And sometimes I ask the question and sometimes I don't. Sometimes I don't have the courage to ask. And I accept that. Sometimes I just feel like it's "Is this the right time?" And then I realize that I've just got a lot of anxiety in my own head and I try to calm down and just to be there for them.

And often times when people just ask for what they want. And sometimes it's something really, really small and simple. And sometimes they're asking me for a really big thing. So I don't know if I have, I don't think that's a very good answer but it's … try to connect with them and try to feel when it's comfortable to ask.

COMMENTOR 5: I don't need the mic, forget the mic. One thing I remember that a person spoke to us a couple of years ago who was from the First Nations and the question was asked, "What can hospice people do to help in the days following a death?" And she said, "Stay away." And that was to a room full of hospice workers. But I respect that. She said "There's enough going on in the family" and as you've just said, they'll ask you. You'll be sought out and in fact, that is what happened to me when I was involved with one too. I was sought out, so that respect I think is what she was underlining.

EVELYN VOYAGEUR: Be good.[laughter]

COMMENTOR 5: Stay away. I thought I would just help you out.

LYNN TURNER: Thank you. Thank you experts for opening the conversation for us on First Nations culture. I learned a lot. I have lots of learning to do and I'm sure we're all feeling that way. So at this time we're going to have a break and thank you all for coming and attending, and hopefully this conversation will go on in your community and hospice if you're with a hospice. And so on behalf of BCHPCA, thank you, and we have a small token of appreciation for each one. Thank you.

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