

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 ③

Spiritual Care Perspectives

MODERATOR: REV. SHELLEY STICKEL-MILES, BCHPCA President-Elect [Incoming]; Minister, Trinity United Church, Creston 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 spiritual care professionals have in engaging and educating the public about death and dying, and advance care planning
- the potential for your professional community to partner with hospice palliative care organizations to promote public conversations on death, dying and advance care planning
- the potential for your professional community to partner with hospice palliative care organizations to advocate for hospice palliative care in British Columbia

SHELLEY STICKEL-MILES: So Welcome. Welcome everyone and especially welcome to Chris Bernard and Rev. Doug Longstaffe and Rev. Viktor Gundel. So Viktor is from the Royal Inland Hospital, Interior Health Authority and Chair of the BC Chapter of the Canadian Association for Spiritual Care. And Doug Longstaffe is Profession Leader – Spiritual Care and Multifaith Services, Vancouver Acute Care, Vancouver Coastal Health. And Chris Bernard, Practice Lead, Spiritual Health in Providence Health. And I'm Shelley Stickel-Miles. So I'm incoming [BCHPCA] President-Elect so gently being warmed to this group.

And so this is a conversation which will begin with these folks talking about how they/their work inter-relates with hospice. It's to inform and educate people about personal advance care planning and how to encourage them in documenting their plans.

We're going to, we have a recording device going and it works from the table here fine. But when we get to questions, we're going to use this mic which is just a recording mic. And it's not so that we can put you on the radio but simply to type up what's ... the information that's said and it can go on the website after this so it will be available for everyone.

INVITED EXPERTS

- REV. VIKTOR GUNDEL, Royal Inland Hospital, Interior Health Authority; Chair, BC Chapter, Canadian Association for Spiritual Care
- REV. DOUG LONGSTAFFE, Profession Leader - Spiritual Care and Multifaith Services, Vancouver Acute Care, Vancouver Coastal Health
- CHRIS BERNARD, Practice Lead, Spiritual Health, Providence Health

So welcome all and how about we start with a little five minutes or so on the current nature of public conversations on death and dying and planning care and what might be paths that your organization takes to get that conversation going. And Chris, are you okay to start?

CHRIS BERNARD: Sure. I could just say a few things. In Providence Health Care, and if we're talking about advance care planning and end of life, I do know that we've been entrusted to implement that in acute care in St. Paul's Hospital with our renal program, so those who are on dialysis. Pastoral care is actually, the spiritual health practitioner is the point person. He has been appointed part of the interdisciplinary team to have, to start these conversations going about discontinuing dialysis for example, and starting that conversation.

I personally work in residential care, extended care facility in south Vancouver – St. Vincent's Langara. And we're at a point now where a lot of our residents who come in you would say are actually palliative, if they're coming from home or coming through acute care. And we're starting to have this conversation ... our disciplinary team with other professionals, especially those who work in the palliative field, around how we can actually start that conversation right from the word "go", right from admission with families and with residents, see what their care is. A lot of our residents within the first week we might assess them as being, yes, they are palliative. And yet, everything is set up for long-term stay so very often we do not have the resources to deal with that. I think we're at a bit of a crisis right now.

Roughly about a half of our residents – we have 205 residents in our facility – half of them die every year, and within the first three months. So we are turning into, this facility and a number of our other long-term care facilities – we are turning into large hospices. I'm not sure if, maybe this is something you talked about today – the changing nature of extended care.

The other, I think the other conversation we're having as an interdisciplinary team and amongst our nurses and care aids is around how we can companion with our dying residents, and what are some of the issues around companioning for the dying. So ... In long-term care we, you're familiar with the "options for care" that are presented to the residents or the family members that represent them? I guess you might call that our advance directives if you like. So/but we usually go over that within the first two weeks with the resident or their families. But we really want to start those conversations right at admission. I think that's our goal right now: end-of-life planning, end-of-life care. And right now we're not doing that satisfactorily so that's sort of the state where we're at. So pastoral care, spiritual health is part of that interdisciplinary team who has those conversations in residential care.

SHELLEY STICKEL-MILES: [inaudible]

DOUG LONGSTAFFE: Sure. Well we're certainly having lots of ongoing conversations in Vancouver Coastal Health and Vancouver General Hospital regarding advance care planning and as you probably know it's becoming a large priority for the government so the health care authorities are having to embrace it. It's a personal passion of mine, so I'm very happy to be here today because I think there's a lot of suffering that every chaplain or spiritual care practitioner across the country has seen with families experiencing not knowing what to do. And you've already got mom on life supports or dad on life supports or some other person on life supports, and we are there literally holding the hand, trying to help the person make the decision with regard to removing life support. So this is a long history for me in terms of my involvement and how it grew into a passion for me in terms of advocacy and advocating for a more intentional approach, intelligent approach to advance care planning both in the community as well as in the residential care and also in acute care.

But let me just say in terms of the topic here that it quite correctly frames the larger discussion as being questions of death and dying in society and I think this is where spiritual care can play a role to try to help people understand that we can talk about death, we can talk about dying. Somebody from Vancouver actually was saying – Chris on the way over here – that wrote a Pulitzer prize winning book, *The Denial of Death* [by] Ernest Becker. Some of you may have read the book some years ago. And it's on that level of conversation that I think we really need to go to some extent.

There's all the practical issues about advance care planning that I'm very dedicated to but I really agree with starting it with that bigger picture because society has a big problem talking about death. Various different subcultures have an even larger problem talking about death. I teach something called Clinical Pastoral Education and I have students from literally all over the world at times and it's very interesting to see the cultural differences that exist.

And then within health care we have a lot of health care workers, including physicians too, who have a hard time talking about death, some of them. And so I think this is a very big issue. It's one of the largest issues facing society right now. I know Dr. Edmunds from the North Shore gives some very interesting talks on the statistics related to some of this in terms of who wants the care, who is getting the appropriate care, what should the goals of care be, etcetera. And I think it's really just starting. And I'm pleased to see that the Canadian Medical Association teamed up with McLean's magazine not long ago. Some of you may have been at that public hearing I was at downtown. That was a great example of getting the discussion started, some of the discussion started. I think that hopefully we can be part of moving this forward because we spend so much time in end-of-life issues.

We also spend a lot of time in other parts of the hospital where people are not dying. The number one reason we're called is actually anxiety. But there's a lot around death and dying issues. And it's, from my own tradition, I come from the United Church of Canada, the Christian tradition broadly, if you're from the Christian church, Jesus talked more about financial issues, economics, than any other single thing. If you check it out, you'll find it to be true. There's an economic side to this.

If we're providing care to people who do not want the care – we're not talking about euthanasia – we're talking about giving care to people who do not want it and torturing them in some ways, in some respects, we need to stop. It's a moral issue and it involves squandering resources that could be used to give somebody who wants that care, that care, regardless of their age. But could be given to somebody else if we weren't wasting it on somebody who does not want it and torturing them and putting the families through kind of a living hell, really to use spiritual language, of having to decide what to do with mom because we never asked mom before. So I guess that's just how I'd just open it up that way.

SHELLEY STICKEL-MILES: Let's bring in ... And Viktor.

VIKTOR GUNDEL: I'm Viktor Gundel and I originally come from Prague and I was raised in my 20s and early 30s in California where I did my training in spiritual health and worked in a UCLA cancer hospital there. And literally every hospital patient who went through emergency had advance directives. And those conversations just took place right at the door. And this is about seventeen years ago. When I moved to BC and Canada, I remember bringing into Royal Inland Hospital and I remember the chief of medical staff back then which I highly respect say "It's going to take about fifteen years before we can even start touching those issues here in Canada." And I said, "I just don't understand." And I can resonate with my colleagues. My perspective will be again unique from where I work which is a trauma centre. And most of my work is spent around MVA [motor vehicle accidents] and trauma, oncology, palliative care within the acute system and ICU, so death around children and lots of times spent in ICU.

The nature of palliation and those conversations I see ... the, when I started at the hospital fifteen years ago, we had an acute palliative care team within the hospital. With a shift of the culture and I see going through the different names and titles here, what I have seen: the palliative aspect of care has been taken out of the acute system and has moved into the community. So for instance, we have phenomenal hospice in Kamloops which is free-standing. What happened in the process is that it fragmented the continuity of care. And so we have this acute critical culture within the acute system. And we have the palliative culture in the community or in the hospice. And I don't see often the bridge being made.

So in a full circle after all these years, we're coming back to realize people will die because of dialysis, people will die because of MVA, because people will die in ICU because there's nothing else the medicine can do for people. People die from cancer in the hospital before they transfer. And then the health care plan in those courageous conversations, advance planning needs to take place in the acute system because this is often where the moral and the ethical, the courageous conversations have to begin before we can even start moving and making and building the bridges with the community and the palliative care. And so what I've seen often is that our conversations which may take place are often reactive or sometimes they won't take place. They happen in a sort of a critical, linear way of communication. And often it doesn't start early enough.

And I think what Doug was saying – what I think is now coming through – and infiltrating the system, that it's the families and it's the – I would say visible minorities, it's the Aboriginal culture, it's the Sikh culture, it's the people are coming with a very clear set of beliefs and culture who are very clear saying about what we want and what we need and what we would like to do. And they're challenging the medical system in terms of bringing this to the front of their planning. And so it's the Anglo-Saxon white culture sometimes that's been very shy around conversing on the subject matter. It's actually making the professionals to think. And I think in my region it's the Aboriginal culture and the families are very cohesive and very holistic in their way of understanding. And they want to have those conversations and say "Where are you going with this? How far are we going to take our Mom with ventilation?" Can we discuss about what is their plan? What is the purpose and meaning? What is the outcome? What is the quality of life?" Because they see the quality of life not in terms of how far we can go with that person but what is their whole life before and after?

SHELLEY STICKEL-MILES: Alright. So now it might be that you work from suggestions that you have for hospice but also as spiritual care professionals, your ideas about engaging and educating the public about both death and dying but also advance care. Where do you see that possibility? And Chris, we'll start with you.

CHRIS BERNARD: Educating the public? Well I work within a health care system so I'm very intent on educating even my colleagues in the interdisciplinary team, definitely with families. We have a wonderful booklet – I use this even now in pastoral care. You've probably seen this, "Preparing for the Death of a Loved One" put out by [Vancouver] Coastal [Health Authority]. But this is very, very helpful I find around the time of death or end of life to explain to families exactly what's happening. It sort of normalizes and describes the dying process. The pastoral care is with the families, with the resident who is dying – supporting but also informing. Nursing does this also. I think anyone on the interdisciplinary team can do this. I think our ministry, at least in spiritual care, is one of presence and also maybe, "Where do I see this going?" Teaching our colleagues we are working with, even nursing, how to be present with the dying.

There's a lot of doing, there's a lot of busyness, there's a lot of care going on. But how do you feel comfortable in your own skin being with somebody who is dying? And very often that comes back to our own inner process about how do we deal with death? How do we deal with our own dying, our own fragility, our own mortality? And I know I've been talking with a lot of staff around that, about their own perceptions of death. I've had a nurse come to me and say "I just can't take another death. It's

just too much.” So I mean their own sense of burnout and not processing dying. So I think we can educate in that way: supporting the staff but also leading them to be better presences for the dying. Sometimes family members come into residential care with expectations of their loved one getting better or having a vibrant active life in extended care and that is actually not the projection. That is not the prognosis. So we often have to educate the family members. We say, “Well, the diagnosis is not good. Your loved one is dying.”

SHELLEY STICKEL-MILES: Thanks. And Doug?

DOUG LONGSTAFFE: Sure. Well I agree with everything that Chris has said. A different level of that would be education with respect to the community in a more direct way. And not that we have any time to spend on this but it would be useful to have folks like ourselves interfacing with the faith communities more on this matter. So there could be a real role for conferences or for educational workshops of some kind with clergy in particular or the leaders often in the various different faith communities of all stripes. Because the clergy are the people who know the folks in their congregations the best. Much better than we do. And we know the hospital. And so we can be a bridge I think to the faith communities to have discussions about how a person coming in from faith tradition “x”, what they can expect in interfacing with the hospital system in terms of advance care planning, advance care directives, how that works in terms of a complex medical system and what their particular needs are in relationship to that.

Often, even when there’s an advance care plan or directive, there’s a lot of interpretation required – especially if they’re not written very well. And as you know, you can overwrite them or underwrite them. No puns intended. [laughter] And if that interpretation is not done correctly, there can be a lot of problems. So I think just educating people about that and helping them to understand a little bit about how the hospital will look at this and some of the concerns the hospital has will be very useful and vice-versa. You know one of the concerns in the faith community, we’re often bringing that to the hospital and helping them to understand. And the better those linkages are, the smoother things go.

We have excellent representation at Vancouver General, for example, from the Jehovah’s Witnesses. And as probably all of you are aware, there’s some pretty particular unique interests of the Jehovah’s Witnesses have regarding blood transfusions etcetera. So it’s very important that we have them there, that they can network with the physicians when necessary with the patients and understand one another so that we don’t have an abrasive moment, shall we say, or misunderstandings that cause lots of problems. And it’s true for every tradition. Even in the mainline Protestant denominations which you often think might not have a lot of difficulties, there are unique things that come up from every denominational perspective.

I mentioned economics. I mean my own faith tradition, the United Church, is very mindful of social justice. And so questions of resource usage actually are pretty prominent for some of our United Church folk who come into the hospital and they want to know about whether or not they will be utilizing their fair share or whether there really should be looking at things from a more economic perspective. And you’ve got to look at that and say, “Look, when you’re looking at this, it’s wonderful that you look at it in that way. But you also have to let the physicians be the physicians and make decisions in conjunction with you based upon what they think is appropriate rather than you becoming overly concerned about whether you’re having your share or not.” Which is kind of the opposite situation from some others folks who come in with a very different position. So that’s one angle that we can be helpful with too.

SHELLEY STICKEL-MILES: Great. And Viktor, your thoughts?

VIKTOR GUNDEL: My gosh. It’s always a disadvantage to go third because you’re [laughter]

DOUG LONGSTAFFE: You're the brilliant one. That's why you're third. [laughter]

VIKTOR GUNDEL: "This is what I was going to say." It's all gone now. My gosh, it's hard to add to my colleagues comments. I think, as I started out the conversation, I think there has to be more continuity between the acute, community, palliative care, hospice.

What Chris was saying about, I see a big theme in the culture of death where providers and practitioners in whichever practice they do – medicine, nursing, physiotherapy, speech pathology, name it – it's hard to have conversations around end of life or even having the [lenses?] where people don't even begin to touch their own mortality or their vulnerability. Or people go into all the different misdirected outlets because they have the burn out, because of fear of touching something which is very painful. There has to be systemic education where people know that it's okay to feel pain, that there is a dimension, there is a room and space beyond our pain. That it doesn't have to go into doing more and providing more or testing more or over medicating more.

I think that, as Doug said, that the connection with good religion and bad religion and whether people in a crisis time, in a crisis mode, they tap into their spirituality or religiousness as a way of trying to figure out and find some kind of a purpose and meaning, with/as an existential. They often have religious beliefs which may be elementary because that's where they did, let's say, Sunday school training or whatever they may be, it becomes really a collapse of the belief system because it makes no sense in the realm of what they are dealing with. So there has to be interpretation of a positive spirituality which is not going into some sort of either denial or nihilism or escapism, whatever it may be transcendentally.

I've seen lots of people in my experience using their religious expressions as a way of being antagonistic or distrustful when it comes to interaction with the medical system. And I think that's a major piece of, we need to have a collective from the perspective of spiritual health, a collective knowledge of some sort on a certain level, to know, to create or even establish a therapeutic relationship. To understand the client-based, patient-centered care, and understand where people are coming from and know how to tap into interdisciplinary resources. Bring people in.

And lastly, there is I think, the role of the leadership and the government to create and shape a culture that dying is just part of living. And I think that we have some ways to go. Those are just a few comments off the top of my head.

SHELLEY STICKEL-MILES: Yes. So the next two questions, I'm going to kind of put them together and just aim where you like. So what potential within your professional community is there to partner with hospice to promote these conversations or also to advocate for hospice palliative care, whichever way you feel is where your organization can help.

CHRIS BERNARD: When you talk about a professional organization, you're talking about our profession of spiritual health or the places where we work, the larger team?

SHELLEY STICKEL-MILES: I think probably that larger team.

DOUG LONGSTAFFE: Go with both.

SHELLEY STICKEL-MILES: Yeah.

CHRIS BERNARD: Okay. From my point of view,

DOUG LONGSTAFFE: No, no. Let Viktor go first. You were always complaining! [laughter; multiple comments]

CHRIS BERNARD: Oh, I'm sorry. You're not happy one way; you're not happy the other way. [laughter]

VIKTOR GUNDEL: One the one hand or the other hand. I'm half Jewish so it's the way it is. You go ...

DOUG LONGSTAFFE: You see where I'm put.

CHRIS BERNARD: Okay. I'm going to go first.

DOUG LONGSTAFFE: Okay. Well I have to say something because I have chaired the Advocacy Committee for my professional association [Canadian Association for Spiritual Care] for the last three years, so I think in terms of advocacy, as contrasted with education, although I think there are opportunities for both, there's a real need for all of the groups to talk to one another and present a united voice wherever we can. Because one of the things I've learned about advocating for various different causes over the years in more than one province is that the government does not want to be involved in backing anything that has any, even the slight association with "splinter, splintering." So if you're coming to the government and you can say "All of these groups are in agreement and there's nobody really that we see who's not on the same page with us" that speaks very loudly to them because they're trying to protect themselves from getting slammed from the side. Nobody likes to get whacked from the side when you're not expecting it, or from the back. So I think the more we can talk with one another, first of all, it may seem fundamental but it's a very important point, the more we can talk and get on the same page and even form coalitions, that this would be very important in advocating for faster change with the government.

Now the government as Viktor will probably mention has already actually, is on side, is on board with this. When I moved from Manitoba, actually from Ontario to here, I was very impressed with the fact the British Columbia government had bit the bullet and tried to do something with this, with the "My Voice" program etcetera. They're actually interested in moving ahead. This is great because years ago I had a conversation with the health minister in Manitoba. He was a great guy – Dave Chomiak, a long standing health minister in Canada at the time – and he said "This is wonderful. I'm very interested in doing something with Manitoba Interfaith Council to do something with advance health care directives. But do you know what you're asking me to do?" What he meant was "I'm scared of this, because how is it going to be perceived by the public?"

Now the faith communities are with you. I don't think you need to be so frightened. But here, the BC government has gone out on a limb really and started to do something already on their own. So I guess my message would be the time is ripe right now. The government is open to this. They're pushing this. It's one of their three pillars as I understand it right now. So if we can partner, we're going to make their job a lot easier. They're not the enemy on this. Nobody's really the enemy here. But we need to get together and see what is the problem? So the problem is really the enemy, no person, no group. The problem I would suggest is that we don't know how to talk about this for one thing. So let's get together and see what we can do as a group en masse. The government will likely say "That's wonderful. You're on board with us. Let's push this." I think there's actually money for this right now. I think they will go for it for a number of different reasons. So that's what I've got to say.

CHRIS BERNARD: I come at this from a little bit of a different perspective. In Providence Health Care [Vancouver] we have a palliative care outreach team. And they've asked us basically to travel around to all our different facilities, residential facilities, through referrals. And I think it's one approach by which all the disciplines can actually work with this team to

provide the best care in situations which are less than ideal. So as I said before, I think our residential care programs are becoming more and more palliative. And as the need for palliative care becomes more and more pronounced within residential care itself, I think what we're heading towards is a fuller continuum of care, right from admission right up until to the point of death. And I don't think we have that now. We have these disjunctures like acute care, and then a hospice way over there.

I think what we're talking about is continuum of care in future. I'm not sure if any of you have been talking about that. It's so crucial. And in our facilities I think we're just waking up to the fact now that our extended care facilities, extended care itself is becoming, it's becoming a palliative approach basically. That's what we're calling it. We're calling our type of care now the palliative approach. We're transitioning but we don't have the resources. So now we're starting to advocate for the resources in our ... I think that's going to go a long way to get the money, the resources we need from the Ministry of Health – more resources and appropriate resources for end of life. That's just sort of a little bit different bit of a perspective. But I'm really advocating, at least in our organization, for a continuum of care in complex care.

SHELLEY STICKEL-MILES: It's interesting.

COMMENTOR 1 [Gretchen Hartley, BCHPCA Regional Director – Vancouver Island, Incoming; Cowichan Valley Hospice Society]: As you're talking about ... may I ask a question?

VIKTOR GUNDEL: Yeah, absolutely.

COMMENTOR 1 [Gretchen Hartley]: As you're talking about barriers, I'm hearing that fear is there on both personal and institutional levels. And I'm just interested in what you'd have to say about that from a spiritual care perspective. How do you respond to that? How do you push back fear, engage with fear?

CHRIS BERNARD: Are we talking about denial?

COMMENTOR 1 [Gretchen Hartley]: We're talking about fear which can cause various things that can result in denial or ...

CHRIS BERNARD: Denial and fear.

DOUG LONGSTAFFE: Fear of ... you say fear of what?

COMMENTOR 1 [Gretchen Hartley]: Fear of death. You're talking about death. I mean both on an institutional level and one a personal level.

DOUG LONGSTAFFE: Yeah, okay. I think there is a fear of talking about death with patients lots of times. I also there's fear inside health care providers of their own death so they have a hard time talking to patients about it because of that. I also think what, I think Viktor brought it up, is what's really important too is this culture that we have in acute care of wanting to, which is understandable, wanting to save everyone. But none of us lives forever.

And you're correct about continuum of care. Its goals of care is a similar kind of way of talking about it. What is the goal of care here? What is appropriate for this person at this particular time because there are physicians who would say that we are treating about 50% of the population in acute care – and I'm not a physician so I'm just quoting what I've heard. They're, they

would say we are treating 50% and with the wrong goals of care. That based upon their diagnosis, we are attempting interventions that make no sense. So that's got to do with fear, I think in a sense, that "If I'm not saving them then what am I? Who am I? I'm a doctor. I've got a scalpel. That means I'm supposed to cut."

The whole system is predicated upon taking certain actions that we've been doing for so long in a certain way. There's also financial interest connected to this – large drug companies etcetera. Everybody in this room is probably very aware of that. So I mean when you talk about fear, I think it's at many different levels. Sometimes it's just sort of an unknown anxiety that's sort of floating around there that we really don't know what this will look like. There's fears to establishing new patterns of doing this, to being more intentional, being more focused in our approach, being more assertive in our approach. There's all sorts of fears about that too. So it's a big question that you're raising. It's just my little piece to respond to you.

SHELLEY STICKEL-MILES: Did you have a comment on that Viktor?

VIKTOR GUNDEL: I remember in Kamloops. I'm an Anglican priest by background and I remember Bishop Snowden who happened to be an Anglican priest, a bishop in Kamloops, and his wife. They had this big dream to establish hospice in Kamloops and it took a number of years. But it started out of the Church of England and the Anglican movement for hospice to, that drove the spirit of that. So nowadays, Mrs. Snowden's hospice, which is free standing in Kamloops and does a phenomenal job, is bearing the name of the bishop and his wife.

So/and everyone who lands there and who dies there – and I go there three or four times a week – not just part of my job but because I feel that I fail people morally if I don't follow up because they have been discharged. Or they get, they just disappear. Because I'm trying to get to an experience, is this: we created beautiful places for people to die with respect and humanity and dignity and honour. But at the same time, we create a void in the acute system. And I'm just witnessing the same thing over and over again. And not just physical because there's a desire to push and bring people from procedures and for surgeries and for ICU beds. It's a competition for acute beds, all over the province.

But in the culture of that, we've created a void. And not just the void in an attempt to bring and appropriate acute beds etcetera etcetera and all the different pressures that come with it. We also generated a new culture of professionals who are not present to understand and detect where people are saying "No" to things. And it perpetuates this whole problem of denial, if you want to call it so, delayed conversations, and perpetuates the problem itself.

And so back to your question about what to do, I think it's just we need to start from the education. We need to go back and have conversations with all the professionals and the front line staff and nurses so there's no "The people are the wonderful palliative care nurses, they're the wonderful spiritual health professionals and the wonderful palliative care doctors." And yet you go to a different building and people are just so preoccupied on fixing people [while] missing the bigger picture.

And I've seen the same with what Doug was talking about, our participation and piece of how we can help is we ... for instance, liaison with forty different faith groups in the community. About 170 people who somehow have comings and goings through the hospital and hospice at any given time. And I've seen where there's a dialogue and proper conversations with the faith groups and leadership, how that translates when we talked about the nursing staff, how that culture translates into all these different faith communities.

This, it's quite naïve of many people in the larger society that every clergy and every faith leader is an expert in death and dying and people are theologically trained and they can do this sort of a intercultural and interfaith communications with

people etcetera etcetera. And I first experienced, people are as scared as any other profession. They are not trained in death and dying. Often people are hiding behind rituals and sacraments and putting things on God etcetera etcetera.

So our participation is being the culture broker, being the mediator, being the communicator. So we don't have people coming and ready to either say to their people "Don't trust the medical staff" or "Trust too much" or "Let's make the hospital liable because they didn't give the blood transfusion." So there's a number of levels of conversations we all can do professionally to improve.

SHELLEY STICKEL-MILES: Are there some other questions?

COMMENTOR 2: Maria Kliavhoff. I'm from the Hospice Society of the Columbia Valley. So I'm Interior [Health Region] in the East Kootenays. And I'm just curious. So this looks like a fabulous document from [Vancouver] Coastal Health [Authority]. Does Interior Health have the matching document? Is there shared between the different areas of health, the documentation? Because it seems to me that's part of the conversation.

VIKTOR GUNDEL: I've seen ... no, in simple terms, no. I have seen pilot projects around dialysis for instance or we do that as a part of the planning in ICU. But I haven't seen anything that has a purposeful vision of this nature. Thank you for the comment.

COMMENTOR 2 [Maria Kliavhoff]: I just want to follow up with that by saying I think that may be a starting place, is that we have it in the province but we don't have equality across the province. In Interior, we know that our numbers are going to be higher whereas provincially it's going to be one in three or one in four, in Invermere, it's going to be one in three by 2034 that is 65 [years of age] and older. So we already have it in the province, right?

CHRIS BERNARD: But if you're talking about the stock, you can get it from [Vancouver] Coastal [Health Authority]. Providence Health Care – we get this from Coastal.

DOUG LONGSTAFFE: We're very evangelistic about it. [laughter]

CHRIS BERNARD: We do have the information. The health authorities do speak to each other.

VIKTOR GUNDEL: But it's the ownership right? You don't have ownership of that.

COMMENTOR 3: I'm Don Morris from Victoria. I started the Death Café movement in Canada just by being the first one. But I was looking and waiting and looking for something and it came along. But what I'd like to know and first of all, the three of you are top-notch guys. We're so privileged, fortunate to have you in your positions. I'm just wondering if any one of you would care to imagine what the future could be like as far as end-of-life care and your positions. What's the best scenario? What would you like to see?

DOUG LONGSTAFFE: Sure. I love questions like that. I get to imagine. Well, I mean first of all, my mind gravitates immediately first of all to advance care planning and advance health care directives. Simply to first of all to end at least a significant amount of suffering that's unnecessary. And what that would look like from my vantage point would be for the hospitals and acute care hospitals across Canada, BC – whatever we're talking about – to address the issues as to who has the information and the competencies needed to address certain aspects of care related to that.

So for example, if we're looking at a representation agreement, it may be that the social workers have a particular expertise in working with that because they work with a lot of legal related type things and so maybe we should be involving them in an intentional way with that. If we look at the medical side of the equation, I think the physicians need to become increasingly involved with this because they have medical expertise. Nobody else has it quite like a physician does and it gets complex sometimes.

With respect to the initial conversations, I think we also need to identify who has the skills to be able to work with the values and those kinds of questions that come up of a more intimate nature. And I would see a big role for my profession in that, our profession in that, with respect to – we have a dialogical practice that is not based in a mental health model like the diagnostic and statistical manual that the psychologists have. We're used to having conversations with people on a very intense, very deep level that is not pathology based. And so I'd like to see the system take a look at how they can utilize our profession in that process. I have some very specific suggestions on that that I have itemized. And I think the same thing with social workers and with nurses and with physicians. How can we work together in a way that assigns responsibilities.

Because one of the things I've seen in many different centres across the different provinces is, goes back to something my Dad said when I was younger, "Everybody's business is nobody's business son." So in health care I think we're very good usually at assigning tasks: "You will prep the patient. You will do this and then we'll have follow up" etcetera etcetera.

When it comes to advance care planning, it's like everybody's got a piece of it so nobody has a piece of it. And I'm just not competent to discuss medical realities with a patient. I'm very good at initiating conversations and discussing how their values relate to what they should be talking about with their physician and networking with the families to help them come to a common agreement. That's my training. So my wish would be around that first of all and I'll let my colleagues jump in now. But that would be the beginning of my wish list, would be that we would be intentionally focused in doing some things that make sense rather than sort of going around in circles which I think we're doing that in many places, many, many different places.

COMMENTOR 3 [Don Morris]: Might there be an office of advance care planning?

DOUG LONGSTAFFE: I think that's actually a good idea. Look, Gunderson Lutheran Hospital in Wisconsin has a 99% success rate with establishing advance health care directives with their patients. Looks like you're already aware of that. They have a 98% follow through rate too. These statistics I've never heard of anything in health care ever in my life. So that to me says we should be doing what Gunderson is doing. Gunderson is doing exactly what I just mentioned but they use similar principles and established allocations for different things. So I think that this is doable. We should be able to do this. We shouldn't take forever to do it.

VIKTOR GUNDEL: When we were, it was eight or more like ten years ago now, in addition to what Doug said, we actually created this virtual reality for the future which never happened. But we had a pain management of course on board and physiotherapy and a respiratory therapist. And really I think it covered all of the aspects of people living and dying with dignity. And we basically worked like a team. It was phenomenal how we interfaced, how we interacted, how we were integrative together. Because we had a very similar vision.

I would just like to formalize or actualize and formalize what I think each of us do every day. I do know what I do. I mean I can conceptualize it. I can go down the points. But I know what happens when internal medicine or a brain surgeon or internal

surgeon comes and says, “Viktor, I don’t know whatever you’ve done in the conference with the family in ICU, but all of a sudden they’re so at peace. They’re not angry. They’re not ready to sue the hospital. They are cooperative and they know that what I could not explain they just get it and they feel at peace with it. Whatever white magic you’ve done (it’s nothing black magic) – but white magic you’ve done, it happened.”

And I said, “Yeah. Because somebody talked the language of humanism. Somebody talked the language of existentialism with them and helped them to find whatever that it was within themselves and give them their own language to it.” And that’s the magic and the art that happens in those conversations. And unless we engage the proper people in the mix, we’re just going to just keep beating around the bushes.

SHELLEY STICKEL-MILES: A tiny last word – Chris.

CHRIS BERNARD: Okay. My wish list, I think in the area I work in extended care is definitely the conversations right from admission. And pastoral care will be part of a team that will actually maybe with the medical coordinator, could be with the RNs or even one of the palliative care nurses who rove around our facilities, have that conversation right from the word “go”. Right now it’s probably within the first weeks to a month. It just stops a lot of expectations from family members which causes [inaudible] sometimes. They have expectations of something else [inaudible] threat. But they maybe on the palliative route already when they come in and that’s what we’re having more ...

The second thing I would like to see is more education of the staff around death and dying. And I think palliative care, pastoral care, spiritual health is very well placed to be part of that type of education. And to teach staff – not so much to teach but to model that dying is not a failure of the medical profession, of the caregivers. It is a normal part of life. Can we accept that? Can we deal with the dying in a very natural way? Can we journey with them? And I’d say all the health care professionals from dietician to social worker, pastoral care, we can accompany them on it in our own capacities. And it’s with the families. So we go from that model of death as a huge failure – “We’ve all failed. It’s terrible.” – to “This is a normal part of living.” And as [Elizabeth] Kubler-Ross used to say, “It’s the final stage of growth” for the dying and for those who accompany them.

That’s, and as I said before, I want to see the continuum of care. And from where I work, that may, I think the day is coming when we will have one of our wings, one of our neighbourhoods, will become a palliative wing. We already have – it’s been like pulling teeth to actually just get palliative rooms. We only have two palliative rooms for 205 residents. But we are going to have whole wings that are palliative. That is what I wished to say.

COMMENTOR 4 [Sandra Castle, Langley Hospice Society]: Just a small comment. I’m Sandra with the Langley Hospice Society. So I see hospice societies playing a huge role in advance care planning. We’re in the community already. We have the relationships formed with seniors centres, extended care facilities. We do a lot of education and I really see, I’m pretty excited about going back into my community and being able to advocate for this. And I did, through Fraser Health [Authority], I did take training in advance care planning. They brought in people from – it was probably from the States I know for sure, there were experts and I think the place that you quoted [Gunderson Health Systems, LaCrosse WI]. I think they did training. Yes. And Fraser Health brought them in and trained a lot of the executive directors and educators and hospice care facilities and ... but it didn’t go anywhere. Sort of everybody was trained and then it was just left. And it was actually quite a simple version compared to with what the provincial government put out. And anyways, I’m excited to go back into my community and to really, really grab a hold of this and from all aspects in the community with relationships that we already have.

VIKTOR GUNDEL: Sandra, Fraser Health was actually for a number of years has been a model on this initiative, right? And it would be so wonderful to see it continue because you've been role models to other authorities. And so thank you. I want to commend you to continue in that because ...

COMMENTOR 4 [Sandra Castle]: Yes. We have an excellent relationship with Fraser Health. All the hospice societies in the Fraser [Health] Region.

DOUG LONGSTAFFE: I think as Sandra was also saying they did a great job in the education and it didn't really go anywhere.

COMMENTOR 4 [Sandra Castle]: No it didn't.

VIKTOR GUNDEL: But I didn't want to pick up on that piece. [laughter]

COMMENTOR 4 [Sandra Castle]: I didn't want to admit it because I was one of the ones that took the training.

DOUG LONGSTAFFE: That's the thing. You have to then assign the roles or it's not going to happen. You have to accountability.

SHELLEY STICKEL-MILES: So I would invite you to have conversations with these people. They're motivated, they're inspired and available at the moment. So thank you very much Chris Bernard and Doug Longstaffe and Viktor Gundel. [applause]

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