

BCHPCA FORUM | 2014

FRIDAY AFTERNOON SESSION MAY 9, 2014 4:00-5:00

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

ROUNDTABLE ③

Conversations in the Life Span: Children, Youth and Seniors

MODERATOR: JAN MOREAU, BCHPCA Regional Director – Provincial Health; Discharge Planning and Family Education Coordinator, Neo-Natal Intensive Care Unit, BC Women's Hospital

INVITED EXPERTS

- DR. GLORIA GUTMAN, OBC; Founder and Professor Emerita, SFU Gerontology Program and Gerontology Research Centre.
- DR. JANET KUSHNER KOW, Program Director, Subspecialty Training in Geriatric Medicine, UBC Medicine; Chair, Continuing Education Committee, Canadian Geriatrics Society; Director, S.U.C.C.E.S.S.
- LILIAN HUNG, Clinical Nurse Specialist; Chair, Education Committee, Gerontological Nurses Association of BC
- CAMARA VAN BREEMEN, Nurse Practitioner, Canuck Place and BC Children's Hospital; Affiliate, iPanel
- KERRY KEATS, Social Worker/Coordinator, Bereavement Program and Counselling, Canuck Place Children's Hospice

QUESTIONS

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

- the current challenges pediatric and geriatric specialists have in opening conversations about death and dying, and planning for care with patients and their loved ones - families of children and youth or seniors and their loved ones
- the current and potential role pediatric and geriatric specialists have in engaging and educating families of healthy or children and youth, or healthy seniors and their loved ones about death, dying and advance care planning
- the potential for pediatric and geriatric specialty practice organizations to partner with hospice palliative care organizations to promote public conversations on death, dying and advance care planning
- the potential for pediatric and geriatric specialty practice organizations to partner with hospice palliative care organizations to advocate for hospice palliative care in British Columbia

JAN MOREAU: I think we'll get started. It's five [minutes] after 4:00 [p.m.] and we are expecting a couple of more speakers. But we've ... I think we should get going for the interests of time. So in continuing planning conversations around advance care planning, this session is Conversations Across the Life Span. So we have a group here from pediatrics and a group here from gerontology. And so on my right, I would like to introduce Dr. Gloria Gutman, and she is the founder and professor emerita for Gerontology at SFU [Simon Fraser University]. And then Camara Van Breeman who is a nurse practitioner at Canuck Place Children's Hospice. And Kerry Keats who is a social worker and counsellor at Canuck Place Children's Hospice and also runs the bereavement program. And Lilian Hung who is a clinical nurse specialist in gerontology for, I'm sorry I can't read the writing on. You're with which group?

LILIAN HUNG: Oh with Vancouver Coastal ... I'm with Gerontological Nursing in BC, GNABC [Gerontological Nurses Association of BC].

JAN MOREAU: So what we're going to do is, we've got a ... and I guess I should introduce myself. My name is Jan and I'm the PHSA [Provincial Health Services Authority] Regional Director for BC Hospice Palliative Care Association. This is my second

term. And I have also been a neonatal and pediatric nurse for about thirty years. So the part on gerontology will be quite interesting for me and I have a personal interest as well. So from your specialties, from pediatrics and geriatrics, what are your current challenges and ways of being in opening the conversation with patients and families around death and dying and advance care planning?

LILIAN HUNG: I'll start in gerontology. It's a big taboo. And still there's anxiety on talking about death and choosing ... often nurses are not sure if patients are ready to have that conversation, patients and the family, and oh, I'm sorry. [request to speak louder] Is this better? I often, it depends on the setting. I work in gerontology so the hospital often people come in ... I face a lot of patients and families that they have dementia or they came in not aware that even people with very advanced states of dementia, that conversation doesn't happen about "This is end of life." People would be very surprised that their loved one are dying. So you are not aware of where they are at. That's one of the challenge[s]. And conditions are often, nurses are not, there's still a lot of discomfort about the topic and I think that's probably the biggest challenge.

GLORIA GUTMAN: Well, I'm a researcher so I don't do direct work with clients in the same way that Lilian does. But I hear a lot about the issues and about advance directives and the need for people to get involved in doing, making wishes known so that when the time comes, there isn't a huge amount of stress and additional stress put on for the person and their family. But what I was just telling Ross [Waddell, BCHPCA advisor] is that I'm as a researcher getting involved with a number of different topics.

And very recently the one that we've just been funded to do is with advance care planning in the LGBT community. Because as it's turned out, people are living with AIDS, HIV/AIDS longer than they ever did before. Half of the men – the gay men – are HIV positive. But the fact that people are now living means that when they get to the point they they need palliative care or they need just long-term care, some of them have had to go back into the closet because either the other residents and/or the staff really do not accept them or do not understand what their special needs are.

So this is the group that has all of the things that any of us who are growing older would experience. So could have dementia, could have various chronic illnesses. Plus on top of that, the experiences that they've lived through and the stigma. So I was asking Ross if your organization has done anything in the area of working with the gay community and if not, then this is a time to raise awareness and that's part of our project is that we will be going across the country doing focus groups with clients and service providers doing public affairs.

COMMENT: You don't mean affairs. [laughter]

GLORIA GUTMAN: Town hall meetings. That's the correct word. Town hall meetings. And then with the objective of trying to find what are the right documents that will apply and so that, and also, to bring people together. Because what they, my co-PI [Primary Investigator] on this project has found is that when people start talking to each other, communities get built and people start to help each other. The questions that he asked are "Who drives you to the doctor?" or "Who helps you in your later age?" And amongst this particular community group, they have fewer children to rely on. So the good news is you won't be fighting with your kids. [laughter] The bad news is you don't have your kids to help you as you require assistance.

JAN MOREAU: I just actually wanted to pick up on your piece about partnership. And this past year, BC Hospice Palliative Care Association worked very hard on our strategic planning. And one of our next steps and goals for next year is forging partnerships. And so that's timely. And Dr. Janet ...

JANET KUSHNER-KOW: Kushner-Kow. Hi.

JAN MOREAU: Has just come into the room and she is the Program Director in sub-specialty training in Geriatric Medicine at UBC [The University of British Columbia]. And so the question I actually asked is in your given specialty in geriatrics, what challenges do you face or how do you go about opening up the conversation with your patients and families around death and dying and advance care planning? So we may as well stay on the geriatrics stream and move over to the [pediatrics] ...

COMMENTOR: Can we ask you to just speak up a little bit? I'm having a hard time hearing with the HVAC system there. It's very difficult to hear your voices.

JANET KUSHNER-KOW: I'm Janet Kushner-Kow. I'm a geriatrician in Vancouver. I work at Vancouver General, Mount St. Joseph's and St. Paul's [Hospitals] doing in patients, out patients. I also work in the community to a different extent. Do home visits, work with Evergreen Health Unit. The two, I was thinking the two biggest themes of concern I have on top of those questions is firstly, we deal with a lot of non-cancer people who are struggling with chronic disease and they're end-stage dementia, COPD [chronic obstructive pulmonary disorder], CHF [congestive heart failure]. And that is a really ... I find that very, very challenging because there's not the understanding that these diseases are likely the way that you will pass away.

And so having that discussion about "Well, now you've got stage IV heart failure. We're going to have to talk about your last few years, maybe months of your life." And it's challenging because you've got this whole system that says, "Okay. Now let's change your beta blocker." It's "Add this and that. And let's take you to the clinic and let's do another test. And maybe you can get a valve replacement." And it goes on and on. And there's this sort of "Well I'm not going to talk about advance care because I've got a valve replacement coming up next week so why would I talk about that?" So it's very challenging with the non-cancer. There's an understanding [with cancer] even there's still treatment but "Oh this cancer's bad." That's hard enough for some patients to realize this is metastatic cancer and "This is going to take my life." It's even harder with the non-cancer diagnoses. So that's the one thing.

And then the transition from hospital to community, back again from the [BC] Cancer Agency to the acute care to the health unit. Part of it's information management and part of it's just lack of coordination and the patients and families feeling completely at a loss to figure out what's going on. Especially even if they're quite ready to say "Palliative care is definitely ... I'm very interested in that." But there's a feeling that they don't really know how it fits into everything. So those are the challenges we see every day where I work.

COMMENTOR 1 [Lynn Wood, Oceanside Hospice Society]: I'm wondering if the three geriatric experts could address dementia in some way because in hospice, when we get a palliative diagnosed client coming to us, it's usually because of a physical ailment or a chronic ailment, but dementia is not part of it. So if the person has Alzheimer's [disease], the doctor doesn't diagnose them, very seldom diagnoses them as being palliative. And yet that person is likely going to die. It's just a longer trajectory of the illness. So I'd like to hear from you on that if that's possible.

COMMENTOR 2 [Donald Carson, BCHPCA President, Incoming; Prince George Hospice Society]: Can I just add something to what she said? I work in a ten bed hospice house, free standing. And we've had a heck of a time over the years to get between ourselves and physicians, figure out who is suitable to come with dementia and who isn't. Because we've often got people referred to us, they become long-term care. We spend a full year trying to find them another bed somewhere. And our hospice staff cannot cope with what, they can't provide the care that the dementia person requires in changing the environment and making it comfortable and safe for them to be functioning in that environment, especially if they're ambulatory.

LILIAN HUNG: I'd like to speak to that. Well I think there's a lot of complexity. People with advanced dementia, it doesn't mean that they won't have CHF or COPD. And often they have a lot of co-morbidities as well. And it also depends on the setting: if they're in an acute hospital or they're in care facilities. A lot of people die in care, residential care facilities with dementia. It's actually I think a large percentage of the residents in long-term care do, they have dementia and they die there. And the length of stay for about a year.

GLORIA GUTMAN: About 90%.

LILIAN HUNG: Yeah. Residential care is hospice. It's palliative. And there's, I think, it adds to the complexity is if a person who is cognitively intact likely, if they're that sick in that stage, do they know that they have CHF, they've been sick for a while, they realize the symptoms that they have and they're probably thinking about they're dying. Even if family and friends, they're not talking about it. But the patient, the person themselves will think they're dying. They won't ... it might be easier to have that conversation. But if the person with dementia, they don't have that capacity to initiate the conversation to talk about that kind of things so/and family often have their limited understanding about how, dementia care it's palliative care. It's a progressive disease. A person is going to die with the dementia.

But when we see in acute hospital, when we see people with dementia, they could be in a moderate, in the middle stage and with acute illness that then they die from or in advance stage and they die from complications from dementia, patients and family often they have no idea that they are dying. Even if there are very obvious symptoms that tell you that the person is dying, actively dying. Often the person themselves, family, or even the conditions around, no one is having any conversation about the person's dying. And when the person actively dies, often it's within the last few hours or a day or two, then people start thinking about "Oh, we need to do terminal care" and stuff like that. So there's very little preparation. The window it's very, very narrow. If you have family around, then they come and maybe they can do a little bit of work around their end-of-life, terminal care. If the family's away, then they have to travel.

GLORIA GUTMAN: But the huge issue is that case that came to light recently of the woman who was a nurse [Margot Bentley] and who had what she thought written down, an advance directive and then there was not agreement with the care facility and they kept her alive. And her kids were begging for her to be allowed to die with dignity. So there are a lot of issues. And I've asked the question a number of times about whether or not, and how people with dementia are cared for in palliative care units. So what I'm saying is what I've been hearing that in fact it's very difficult. And you have staff who are not trained for that kind of care.

[BCHPCA NOTE: Margot Bentley wrote and signed a "living will" before the Legislature of British Columbia amendments to the Health Care (Consent) and Care Facility (Admission) Act, [RSBC 1996] Chapter 181 came into effect on September 1, 2011. The living will was not recognized under this amended legislation.]

COMMENTOR 2 [Donalda Carson]: It's just if they're mobile. If they're mobile, it creates all sorts of problems because they can be wandering into other rooms where you have families sitting in the last hours or even moments with someone. Plus we don't have the systems they have in long-term care to alert staff that someone's gone out the door or this type of thing, so ... But we do take people with dementia provided they're at that stage where they're not able to be up and around on their own. Because we want to take them.

GLORIA GUTMAN: But it's safety and security.

JAN MOREAU: So I think we'll move to the pediatric perspective and then you can talk about how you begin to engage families in the conversation.

CAMARA VAN BREEMAN: Well actually there's a lot of similarities in what we're talking about in terms of engaging families in ... "Children don't die" is sort of our society's perspective. But that isn't true. And I think when we have children that actually have a diagnosis like cancer, there's again, there's a division of saying "There's no more treatment." And as palliative care people, we know we can enter into those conversations. It's difficult but we can sort of offer something in terms of pain and symptom management.

Most of the pediatric population that we see in palliative care however have progressive illness over years and years and years. And so actually very similar to some of the population concerns that you guys deal with in geriatrics. And what I think is, I think from what we've learned in pediatric care that's been really helpful is how do you build relationship and provide something to these families that makes sense for them so you can enter into those conversations. Because it isn't about just decline all the time [for the patient]. It's sometimes decline and then a little bit of wellness and then some more decline.

Pediatrics has some very complex differences in that they're not, they're developing, they have different age ranges. We see kids that are progressing and they're having delay but they're growing up and they need different equipment because they've grown two feet and need a different chair. So there's some things like that.

But one of the terms we use a lot in pediatric care is "Hoping for the best; planning for the worst." And so entering into those conversations with families to say "You know last year you were in hospital six times in ICU [intensive care unit] with your child. And I know you're hoping to get to this next thing but what is it, how's your quality of life? How's this like? And how do we help plan for the next thing? Do we do IV [intravenous] antibiotics the next time or do we not? Do we add in morphine because we see that they're struggling breathing and their lungs aren't as good or do we wait? What are the other things we can add in?" And so how do you build that relationship so that you can come and talk about those planning opportunities?

KERRY KEATS: We're very fortunate I think. Often it's a bit of a holistic approach that in entering into the conversation just doesn't start with advance directive discussions. And we use what is called the PEST model which is an acronym for we talk about the physical [P], emotional [E], spiritual, social [S] and trajectory [T]. And when you couch it in a holistic way, it takes some of the burden away in that our practice is that when we meet with families, we always suggest that we'll bring up trajectory as part of the discussion, just as we would talk about anything else. Even if it just means to see "Where are you? How do you feel about that? Have you noticed any changes?"

And part of it is introducing the topic so the parents, if they end up in emerg, someone has already talked about something with them, even if it's a bit ... They don't have to have the answer, but we're willing to ask a question that they can think about. And I think that helps to educate even it's ... It can be uncomfortable for the most part if it's put in the context of a holistic approach, they can then know that. And if they have any questions if they end up in emerg, they know they can call so it won't be such a frightening ... those words are scary and what does that mean. So we've been very lucky in being able to talk to families about that.

JAN MOREAU: In your current roles, in the current and potential roles of pediatric and geriatric specialists, how do you see the role of engaging and educating families of healthy children and healthy adults and their loved ones about death and dying? I know we have a lot of challenges with people who are ill.

JANET KUSHNER-KOW: I think our feeling is that the family physician is key to starting that conversation. We've, there's been some efforts to talk to people like for instance, the nephrologists in the kidney clinic or the COPD clinic in getting the social workers and clinicians there to talk about advance care planning. That's certainly part of it. But if we don't get the GP's [general practitioners] who know these people the best engaged and give them the skills to talk about this, I don't think we're going to get too far. It needs to happen fairly early. By the time they show up in the hospital with their delirium and the dementia's progressed so far, it's really hard. You feel like you're just pushing that huge rock up the hill, trying to get everyone on the same page. That's my impression.

LILIAN HUNG: I agree. And I see there's a huge gap. In Providence [Health Care], the palliative team does a lot of education work. And there's an app that they developed. And they do lots of different type education to help physicians, clinicians in our discipline to help families. They have little cards or an app that helps people how to have those conversations with a family member to do advance care planning.

But I see a huge gap in residential care. Because in residential care, there's ... they don't have the same kind of resources. There's no clinical nurse educator there to help. They don't even know there's the website, the VirtualHospice. And they wouldn't know there's an app. There's no connection to those educations and there's no resources to support. We have a large number of people that they die in residential care. But these are the people that they, the nurses ... we have a lot of LPNs [licenced practical nurses] and the training that they have working in residential care, it's limited in hospice palliative care, end-of-life care. So I see that's a really big need for support, in having tools and resources to help.

JANET KUSHNER-KOW: We do have that really good book. That "My Voice" talks about agreements and that sort of thing. It's not getting out to enough people, I think. And there's online versions. We just need to keep spreading the word.

KERRY KEATS: I've often thought that the campaign for organ donation is such an opportunity. Because essentially, if someone makes a decision to donate their organs, they're talking about their end of life. And that campaign has been so successful in opening a discussion that I think in some ways if there can be something shouldering that. Because that's with the healthy population. It's something people can relate to. It's what they put on their driver's licence. It's what they say. And I think there's missed opportunities in partnering with other ways of framing what that means, thinking about what your end of life is. And looking at it from a healthy person, how can we engage people in a way that hits a population. And I think organ donation has been successful, so what model did they use and how can you put forth things like that? Anyways, that's ...

COMMENTOR 1 [Lynn Wood, Oceanside Hospice Society]: I think that's a really good idea. I just wanted to let this group know, because we just discussed it in the last group, that on Vancouver Island, the Federation of Vancouver Island Hospices have taken on a contract with the health authority to disseminate information around advance care planning. And how we do that is different for/from each hospice to hospice. But we have a website – advancecareplanning.vi I think it is. And it's out of the Comox Hospice. Each of the websites for each of the hospices has links to that.

And we also, many of us have speakers bureaus or volunteers who go out and talk to groups such as chambers of commerce, school boards, younger groups so that we can get them before they actually have the health need. And talk to them about the need at that point. And it's an introduction to hospice so it serves two purposes for us.

And I'd just like to ask Gloria again about the LGBT piece of it because I work in a very senior community in Parksville | Qualicum. And I know that there's probably a lot of gay people in the community who would like to come out to an

information forum. And how do you engage them if they're uncomfortable about making it known in small communities. I'd like to learn more about that.

GLORIA GUTMAN: Well that's our view that there are some who will come out. And CBC [Vancouver] just did the "Gay and Grey" thing.

COMMENTOR 1 [Lynn Wood]: Gay and Gray?" That's cool.

GLORIA GUTMAN: "Gay and Grey" And they had it at the Fountainhead Pub on [Davie Street] downtown [in Vancouver]. And it was a huge turnout. And I was amazed at how many people actually stood up and talked about their concerns about late life issues. So obviously it's penetrating the psyche of that community. And I think that there are others who are not wishing to be quite a public but that's the whole purpose. Our project will end up with a secure website where people can chat with each other and form community.

And so the question we were asked by people who don't know that community, sort of said, well most old, when you're talking about old people, you're talking about a group that are the fastest-growing users of the Internet but still there's lots of them that don't. Well as my friend Brian said to me [Brian DeVries, Co-Primary Investigator], he says "Well one of the things the gay community are good at is using the Internet." But he says "Gay men." We don't know about lesbians or trans, whether they have the same skills in accessing. So when you talk about opening conversations and about websites and our government is in the Ministry of Health in the Seniors Division putting a lot of money and effort into websites. But you have to remember that not everybody is computer literate. And so your point is well taken. How do we reach those who aren't and/or how do you reach the ethnic community?

COMMENTOR 1 [Lynn Wood]: So would your project come out to a small community such as where I live and do a forum or something? Is that within the scope of what you're doing?

GLORIA GUTMAN: Well, what we can do is invite your people to come. Because the forum will probably be in downtown Vancouver. But we are, we have been alerted – several people have said to us "What about those who are on the Gulf Islands or on the Islands?" So that would probably be stage two of the project. But let's keep in touch on that.

COMMENTOR 1 [Lynn Wood]: Okay. That sounds good.

JANET KUSHNER-KOW: I think the demographic shift is really going to be very interesting. The first Baby Boomers are hitting 70 [years of age]. It's a huge bulge of people we're going to have. And they're a totally different generation than the generation that are 70 to 90 [years of age] at the present time. And another point is that dementias and cognitive impairment hit older people almost very markedly. So you've got this whole bulge of people who we've never dealt with, these types of folks. Their skills, their attitudes are different. How their family structures are different. Their children, their whatever. And then they are going to have cognitive impairment and all these chronic diseases and end-of-life issues. And there's a lot of them. And we don't, we're not very well prepared. Canada's not very forward thinking in this sort of thing. I think we're a bit behind other Western countries unfortunately.

So I think we're all learning how we're going to adapt to this Baby Boom – the Grey Tsunami if that's not too offensive.

COMMENTOR 3 [Don Morris, Death Café Victoria]: Not prepared in what way?

JANET KUSHNER-KOW: We, because what we do right now in seniors care is, I see a lot of gaps. And we often end up with Cadillac services for certain people and not addressing some of the fundamental determinants of health in older people. Because we sort of take, oh there's a family, there's an older person. Let's address their needs. We'll put a whole bunch of services in. Maybe this, maybe that. That's paid for, that's not paid for. The family can take care of the rest. That works okay on a small scale. But then when you've got millions and millions of people with the same issues, then things start to fall apart very quickly. And what are we going to pay for? We can't pay for Cadillac service for everyone. Not everyone can die in a hospice. And how about palliative care at home? How are we actually going to make that fiscally practical for most people?

LILIAN HUNG: And I think engagement is another big piece. And compared to the UK, the UK they do a lot of work in engaging people with dementia to try to understand their needs. And they will have different projects. And here, it's not so much, in here in Canada and BC. Maybe in Toronto they're starting to do a little bit, but we certainly are behind.

COMMENTOR: Manpower for one.

JAN MOREAU: Well segue a little bit into the next topic. And it's, I think I'll combine the last two questions so we can open it up a bit more for discussion. But to share your perspective on the potential for both geriatric interest groups and pediatric specialties to partner with hospice palliative care organizations to promote advocacy and to promote public conversations around death, dying and advance care planning. Do you want to start?

CAMARA VAN BREEMAN: I was just going to say that I think one of the frustrations we have within our system is how we define palliative care and who fits in it and when do you get services and when you don't. And I know with the fact that we actually are helping children with chronic difficult diseases last longer, live longer with more and more technology and then they graduate from our system at 19 [years of age] and go into the adult system. What families talk about is there's just absolutely this dropping off point where there's no service. And we've had, depending on which health authority they're in, even a child who has muscular dystrophy that has a very poor prognosis – trach[etomy] and vented – will not fit our services, will not receive palliative care.

And so this message to families around, this is what you get if you have this condition and this is what you don't get if you have this, is really, really difficult. And I think the conversation and the partnering has to open up. And I know it's a resource issue. But how do we actually provide care – better care – across the spectrum of illness, a progressive illness, and help families find their way in making decisions that make the best sense for their quality of life where they're living and ... They're difficult choices but journeying with them.

And one of the things we often will say is well the family needs to self-identify almost when they need service. But we know that families don't want to think about their child's dying or their own dying. And so how do you actually, how does that work then? If we don't have health providers journeying with them, to then say this is, these are some choices and here are some services that might help, families can't necessarily do that on their own. So those partnerships I think are really, really important. And it's not just about "I know a kid and can you see them?" It's a system. We need to build a system that makes sense for, as we said, this increasing need in all age groups.

COMMENTOR 1 [Lynn Wood, Oceanside Hospice Society]: And that's where hospice can come in. Do a sales pitch but you're talking about how expensive the system is, we can be part of the team. We bring volunteers and value-added to the health

care system, so we don't do all of the piece. We don't do the clinical piece or the medical piece of it. But we can do the psycho-social piece of it. [I was finished.] That's where hospice can come in. The psychosocial piece in support of the team.

COMMENTOR 4 [Louisa Sanchez, Prince Rupert and District Hospice Society: I'm just wondering. In terms of, and this is a question, do you meet with the people that are giving, the [government] ministries? Do you meet with them quite often? Or especially the MLAs [Members of the Legislative Assembly] or something like that to talk about the deficiencies that are here in BC? Do you at any time?

CAMARA VAN BREEMAN: Well for pediatrics, it's difficult, especially in that transition phase. Because they go from Ministry of Children and Families to Ministry of Health. And I find those two ministries don't talk to each other at all. And so it is ...

COMMENTOR 4 [Louisa Sanchez]: A problem.

CAMARA VAN BREEMAN: Yeah. And I don't know how to answer that. I think clinicians are typically fairly separated from the political decision makers. And that is a, that's not a skill clinicians usually come with. We're not trained to do that work. And it's not – we probably should be. And where we get to the table, I don't know the answer to that.

KERRY KEATS: I think part of my observation in pediatrics, and like Camara was saying, is the idea that we actually have a lot in common with the adult community is that in the future is that shared common language. The idea that the adult model of what hospice is and the pediatric model of being different, really ultimately at the end of the day should be the same. Because whether you're switching health authority or the Ministry of Health or the Ministry of Children, part of the disservice we're doing to families is not having the same definition. And you can't then fundamentally create an infrastructure if it's not the same. And so I think, in the future my hope would be is that collectively, as community organizations come together, that one unified definition would then help drive some of the funding differently. That's ...

COMMENTOR 4 [Louisa Sanchez]: The thing that's a problem – we're working in silos.

KERRY KEATS: Yeah.

COMMENTOR 4 [Louisa Sanchez]: The same thing I education. I think that ... I'm in education. So I understand when ... but what's happening not only in education and obviously in health, there are siloes. The right hand doesn't know what the left hand is doing. And until we come to have a system that's working and working together as a team, it's not going to happen. I'm so frustrated when it comes to things like this because ... I know you all mean well. But sometimes I don't think the people at the top understand what's going on. The system sucks.

COMMENTOR: They're here tomorrow morning [politicians] if you look at your schedule. [laughter]

COMMENTOR 5 [Christy Linder, Comox Valley Hospice Society]: So just what was being said right now in terms of the splintering, what happens using pediatrics as an example but we certainly see it in terms of what's going on with seniors as well as switching ministries and the ministries that don't talk to each other. There was something created many years ago when it was dealing with injuries and injury prevention. And it was all siloed in all the various different ministries for many, many years.

And probably about fifteen years ago or now, or so now, they, what was developed was something called the Office of Injury Prevention. And it allowed for groups and organizations and ministries and what not to be talking laterally and working together in that way. And it was the way in which they were able to start looking at addressing injury prevention from all the different aspects.

And I'm, knowing what was said a little bit earlier about the provincial government and coming together as a group rather than being splintered and what not, if we were to take a look at the idea of creating something like that as well, asking for something like that that allowed for the speaking across ministries and with the different organizations that there might be a way. And all of us are all part of organizations that do cross the spectrum. And so is there a way that we could actually advocate for something like that and then have something that did cross ministries and certainly did address the issues on the continuum of the life span?

JANET KUSHNER-KOW: I think if we don't collaborate we're not going to get anywhere. We work for a group – although there's going to be a lot of seniors, the ones that are frail are really struggling. They don't, they can't advocate for themselves very effectively. They're struggling with their day to day lives. Their families are struggling with supporting them. We don't see that same political push from them because they're so caught up in their issues.

So, and then there's not a lot of us out there working on, and we're all in this sort of long-term care, community services, end of life, hospice palliative care, geriatrics. So we've, and there's not many of us. There's twenty-five geriatricians in the whole province, which everyone's shocked about. These sort of things. And we're busy with our clinical practice.

But if we don't get all of these people that are basically talking about different parts of the elephant, if we don't get them in the same room and talking to the government, no one else is going to be able to advocate for these people. Because by the time they get to that, where the system sucks, they're just, they're just struggling to keep their heads above water and we have to be saying, "These people are struggling, struggling, struggling." So yes, we need to find some way of talking across our siloes, we really do.

JAN MOREAU: Now I, recently on the news there was something on a national strategy for patients with Alzheimer's. They're actually – I pricked up when I heard it – and it makes me think we could look at a similar approach. And it's a shared issue. So if they're looking at a national strategy for Alzheimer's, we could look at dovetailing or combining or collaborating in regards to advance care planning.

JANET KUSHNER-KOW: And maybe shifting their focus because a lot of what came out of that was, "Well, we're going to cure Alzheimer's disease" which I thought was the, was really the wrong way to go about it.

JAN MOREAU: And maybe not picking one disease but looking at the person more holistically.

JANET KUSHNER-KOW: Yeah. It's a lot more complex than just curing Alzheimer's disease.

COMMENTOR 1 [Lynn Turner, Oceanside Hospice Society]: It's the fight again. It's the fight against the disease. The medical model.

GLORIA GUTMAN: It's interesting that I was just at a meeting of the Advisory Committee for the Institute on Aging. The CIHR [Canadian Institutes of Health Research] Institute. And what we're seeing more and more, the Institutes are starting to come together and to partner. And so that's a group that we want to be involved with and to get some words to.

There's also what's known as TVN which stands for Technology Evaluation of the Elderly but in fact is a group. It's a National Centre of Excellence that focuses on end-of-life issues. [Former Senator] Sharon Carstairs was the champion. She had just stepped down as of yesterday morning. But that group is quite interested in end-of-life issues and that's one, another one to sort of watch and to partner with.

But more than anything, we've got umpteen organizations. We've got the Gerontological Society, we've got the geriatrics, we've got various disease groups. And whether it's arthritis or Alzheimer's or whatever, the odds are the clients are going to be older people. And so we need to get them together because at the moment we're all competing against each other for public attention and for public dollars.

COMMENTOR 1 [Lynn Wood, Oceanside Hospice Society]: And public funds.

GLORIA GUTMAN: Yeah. And the thing is that numerically if you come together, you're very powerful. But if you're fighting each other, we're never going to get anywhere. And the Alzheimer's Society were very clever because in fact with the "Rising Tide" strategy and so on, they have managed to paint the blackest possible picture which does capture attention. And I spent half my life talking about the fact that it is not a tsunami, that in actual fact we can afford to give quality care because not everybody's going to get sick at the same time. And they're not all going to die at the same time. So the numbers are manageable if we use our brains.

And in terms of projecting how many beds we're going to need for hospice, you want to think about the fact that you're going to have "x" percent of people who will know that they're going to die. There are others who are going to die suddenly. So they're not all going to end up in your beds. So you have to think about, sometimes you want to paint the picture that yes, they are all going to end up, or you'd like them to all end up in your beds, but other times that's not the reality.

JAN MOREAU: Any other comments or questions?

COMMENTOR 6 [Karen MacKay, Central Okanagan Hospice Society]: This is directed at the two representatives from Canuck Place. One of the conversations that comes up in the Okanagan a fair bit is this desire for a children's hospice and the need for a children's hospice and the heart that goes into it. And so the question that I have for you is how much of what you do is with more, because you've been speaking a lot of the longer term degenerative illnesses that affect children that really are quite similar to aging where you don't know how long it's going to be and so you need to provide care for quite some time. And how much of it is more of what really we deem to be more the hospice side of it which is the "We know what's going on and we have a fairly good idea of how long it is." I'd just like to know that for personal interest.

CAMARA VAN BREEMAN: So the philosophy which we follow has actually come from the UK and the idea of hospice palliative care, the tenets around it are that it is end-of-life care. It is about providing respite to families and that families require short breaks and breaks from the caregiving role. And that it is a holistic total approach to care around family. And so in building Canuck Place, it very much is about having that opportunity to get to know families through respite, giving them a break.

When we actually looked at how we booked our respite, I think it was in 2010, although we said 50% of our beds were filled with respite, when we actually looked back on it, there was, those, only 10% were pure respite meaning it was a break. The other majority of the time was pain and symptom management. So I think we sometimes say, “Oh it’s hospice care and that’s the end of life.” And these kids are living a long time and they have progressive and neurologically, neurological changes. Pain syndromes. A whole bunch of things that actually require a clinical team that can do all of those things. So the admissions to hospice are pain and symptom management, end-of-life care and respite.

I think the other thing that we’ve seen in the last ten years and Kerry can add to this is that we really do a lot of outpatient support for families because we are such a small specialty and there isn’t a lot of kids on our program compared to adult care, that being able to be available to providers anywhere they are – in the Okanagan, wherever. So providers – and to families and provide that consultative service has really been such a growing need. We would like to keep people in their communities. I don’t know if you need a hospice to do that. It’s very expensive care – hospice in terms of how pediatrics defines it – it’s very expensive care. It’s ... families do need respite. They do need respite. They do need breaks and they need access to a consultative team. I would say that would be really the, for BC and for our population.

COMMENTOR 6: Okay. Thank you.

KERRY KEATS: I moved from California and I was working in pediatric hospice and palliative care. The definitions were slightly different in that hospice there didn’t mean a free-standing building. We provided care in families’ homes as the model. We were an umbrella under an adult hospice and we had a 150 mile radius. Provided consultation. And so I have to say coming from both models now that it is possibly to certainly provide services within the realm of peoples’ communities. It’s just finding the clinicians who would like to do that kind of work and be there. Because I think also the reality is that once you’re exposed in the community from the hospitals and build relationships, we get referrals a bit earlier. Before children might have come into the hospice and died rather quickly which is what some of you guys see with a later referral. But we do, through the relationships over many, many years people have built, you do get referrals earlier than have been before we do have the opportunity sometimes. So/but we do find that we do extubations and more acute care too, so ...

CAMARA VAN BREEMAN: I think the idea of, like Kerry said, it’s not the building. It is the approach to care and we need to really, I think, expand that idea of it isn’t a place. It is a perspective of care and we all as providers need to do that. The cardiac, I think one of the things we’ve done is work with cardiology and oncology saying “You can still have a palliative approach to care and offer a surgery. But we need to look at what is the quality of life for this child from this point to this point. Are we still going to do that?” And so that’s our biggest challenge actually is to infuse that palliative approach across settings so that families, we’re speaking the same language. We’re giving families opportunity to reflect on what are important for them and their child.

KERRY KEATS: It’s a philosophy of care, not an option of care. So it is true, what she’s saying that.

COMMENTOR 1 [Lynn Wood, Oceanside Hospice Society]: I’m really glad you said that because that’s what my next comment was going to be that we have a hospice on the Island [Vancouver Island] that’s of an outreach nature. We don’t actually have beds in our hospice so we encourage people not to think of hospice as a place where you go but rather, we’ll come out to you in the community. And perhaps our first point of contact will be [an] equipment loan for activities of daily living to remain the same, or a hospital bed or something. Perhaps it will be a contact with the family or the respite. But it’s certainly not about the building or the place.

JAN MOREAU: Do people want to add anything else? Otherwise I want to thank everyone for participating and I'd like to thank very much our panel of experts in sharing different ways and opening the conversation and being with families. And I think there was some good information here about strengthening ourselves and "My Voice" through collaborating and maybe even in integrating having partnerships with many different organizations. Thank you. [applause]

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