

BCHPCA FORUM | 2014

FRIDAY MORNING SESSION MAY 9, 2014 11:00-12:00

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

ROUNDTABLE ④

Cultural Conversations: East Asian

MODERATOR: DR. BARBARA PESUT, Canada Research Chair Tier 2 in Health, Ethics and Diversity; Assistant Professor, UBC Nursing; Member, Advisory Committee, Institute for Healthy Living and Chronic Disease Prevention, UBC Okanagan

QUESTIONS

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

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

BARB PESUT: I'm Barb Pesut. I'm from UBC Okanagan. [I'm] delighted to be here today and moderate this conversation on East Asian cultural conversations. And I'm just delighted to have our speakers here today. So I'll tell you who they are and their background and where they come from. And I'll let them tell you a little bit about their connection to this topic.

So right here we have Dr. Li. He's an Associate Professor in Communication and Culture from Royal Roads University. And here we have Dr. Baker. He's a Professor, UBC Asian Studies Centre for Korean Research and the UBC Institute of Asian Research. Delighted to have you. And here we have Dr. Karen Kobayashi. She is an Associate Professor in the Uvic Sociology Program and she is a Research Affiliate with the Uvic Centre on Aging. And we have Dr. Jessica Main. Now I am not going to pronounce this well so I'm going to let you do that.

JESSICA MAIN: It's the Tung Lin Kok Yuen Canada Foundation. They established a program and a chair in Buddhism in Contemporary Society.

INVITED EXPERTS

- DR. JESSICA MAIN, Tung Lin Kok Yuen Canada Foundation Chair on Buddhism and Contemporary Society, UBC Institute of Asian Research
- DR. ZHENYI LI, Associate Professor, Communication and Culture, Royal Roads University
- DR. KAREN KOBAYASHI, Associate Professor, Uvic Sociology; Research Affiliate, Uvic Centre on Aging
- DR. DONALD BAKER, Professor, UBC Asian Studies; Centre for Korean Research, UBC Institute of Asian Research

BARB PESUT: Thank you. That's wonderful. So I'm going to actually let them start right away. And we kind of have a bit of an agenda here but we're certainly willing to flex. I'm going to ask each of them one of four different questions and as they tackle that question, we're going to go down the group. And then we'll save our questions and our more general conversation after they've had a chance to kind of present the topic from their perspective first, if that's okay with you. Good. Okay. So the first question I'm going to ask you to address is the nature of conversations in East Asian cultures as it relates to traditions around death and dying, planning for care and pathways to opening these conversations.

KAREN KOBAYASHI and JESSICA MAIN: And you want us to give a self-introduction as well?

BARB PESUT: Yes, so do you want to do that first quickly or before you actually answer that first question?

JESSICA MAIN: Actually, why don't we make that our first question?

BARB PESUT: Okay, that's great. Good. You get to start.

JESSICA MAIN: As I was kindly introduced, my name is Jessica Main. My connection with the topic of hospice and palliative care comes from my research on Japanese Buddhism. So that's my speciality and I'm particularly interested in the way that Buddhist institutions and professionals go into society in order to perform tasks that are considered morally good, that they feel is their calling: the relief of suffering, the relief of poverty, dealing with the problem of suicide in Japan, dealing with the problem of social discrimination, women's rights etcetera. So palliative care and caring for children, the elderly and end-of-life care, grief care, counselling – these are all part of a research program which I have a great deal of interest in. It's a pleasure to be here.

KAREN KOBAYASHI: As a social gerontologist and a Research Affiliate at the Centre on Aging at the University of Victoria, end-of-life care is central to the work that I do. And I will just say, I'm just going to mention it in the context of a project that I'm just finishing up with the Fraser Health Authority. So right now my team is evaluating the residential program care delivery model in Fraser Health and we have three sites and we're just concluding a three year study. Palliative and hospice ... let's [?] hospice here ... but palliative care has been an issue that has emerged time and time again. We're interviewing staff, we're interviewing residents, we are interviewing family members.

We are also looking at across the board, at objective indicators of quality of care. The MDS-RAI indicators [Resident Assessment Instrument – Minimum Data Set] for those of you who are nurses by training. And we recognize that the objective indicators don't tell the whole story of quality of care. So what we are doing is, we did a 160 interviews across two years with nurses, with residents and their families. And the executive summary for this report is just coming out. I'm happy to share that with you at some point down the road after it goes to Fraser Health. But to say that palliative care certainly has been a significant, a key issue that we have responded to in our report and in the summary of that report.

And I'm also the theme team leader for ethnicity and aging for the National Initiative on Care for the Elderly and I chair a committee for the Canadian Institutes of Health Research on the social dimensions of aging [Peer Review Committee, Social Dimensions in Aging]. And palliative care is certainly, it's an issue that doesn't come up a lot in the research that's been proposed at the federal level, at the national level – not to our committee. Now Kelli's work [Dr. Kelli Stajduhar, University of Victoria] with Barb [Dr. Pesut] certainly it goes to different committees. But we haven't seen a lot ... and I just literally came back from Ottawa last night ... we had no applications in this area. So I would like to see this certainly change over the next few years. Thanks.

DONALD BAKER: I probably have the least professional expertise in this area. I'm an historian of Korea, a cultural historian. But I've been living off and on in Korea since 1971. So obviously I've seen people have to deal with issues of end-of-life care and so on. I can talk about that. And also I know my specialty is Korea's beliefs and values so I know what Koreans feel about death and I also know how different Korea is from Japan and China including ... And I also know the community here pretty well, the Korean Canadian community. I watched it grow. I knew almost every one of them when I first came here. Now that there are 70,000 of them, and so I'm really drawn, not through professional research but through my own personal experience.

ZHENYI LI: Well my major is intercultural communication and I [am] specializing in intercultural health communication. I've been doing research also with Fraser Health Authority for quite a long time, at least six years I think. And our focus is on, to put it simple, is on protecting, preparing and protecting health care professionals because we believe that they come across with different cultures, different needs every day. But the patients from different cultures, they, families, they don't have to visit cultures or care about the other cultures every day. So we found that for example Fraser Health has a diversity strategy as these plans but how to implement that and how to prepare and protect the vulnerable group – the professional health care providers – is a very important issue.

And we will elaborate current research. We started ... I have a couple of researchers. One is doing the out rescue concept which is closer to this conference and doing another research – medicine acculturation – which refers to how, let's put it simple, how long does it take for an immigrant, wherever they are from, to Canada, to start to adapt to Canadian medicine instead of pack[ing] their medicine in their luggage and smuggling it into Canada. And it's more difficult than to adapt to a different food. Because medicine, you put that into your body, is more relevant ... instead of knowledge ... it's more relevant to their values, beliefs and attitudes. I can talk on this but let's ...

BARB PESUT: Okay. Great. So the first question is of course about the nature of conversations in East Asian and Canadian cultures about death, dying, planning for care and the paths to opening these conversations. And so I'm going to ask you to limit your comments to about four minutes if possible and that will give us enough chance to address all of them. So Dr. Main would you like to begin.

JESSICA MAIN: I will begin. My speciality is East Asia so what I'll do is I'll talk very briefly about Japan and then move across to talk about diaspora groups in East Asian Canadians. My first general comment is that religious traditions tend to provide both the most difficult and the most obstructive beliefs when it comes to end-of-life care as well as some of the most helpful and motivating. So it's a paradox. So I'd encourage you to think about religious traditions as having a paradoxical relationship with end-of-life care. One example would be beliefs about impurity associated with illness and death which are contained within religious traditions. And another positive example is views of compassion and active relief of suffering which are also contained within religious traditions. So the tradition that I focus on, Japanese Buddhism, both deals with views of death and dying that stigmatize it and which has developed practices and institutions and virtues that look at addressing end-of-life care as positive.

Moving to the East Asian Canadian community, I would say that across the board, religious groups are supportive of end-of-life care especially because religious institutions in diaspora cultures are the centres of communities. So when you have linguistic barriers that separate that community from surrounding groups, the church or the temple ends up becoming a place where many of their needs are met including ageing, end of life, terminal illness and so forth. In the Japanese Canadian community, for example, you have Japanese Canadian specialty elder homes and you have a class of Buddhist priests and

Christian ministers and priests who deal with Christians and Buddhists from the Japanese Canadian community as they're approaching the end of their lives. So I would say that religion in terms of its values has a paradoxical relationship with death and dying, but that religious communities as they exist in Canada today are going to be supportive.

KAREN KOBAYASHI: Okay. I'm going to speak a little bit to the changing nature of communities, I think, in Canada, of ethnocultural minority immigrant communities in Canada. But first of all I do want to say a little bit about the legal aspects of this around advance care directives and capacity etcetera, because our team has been working very closely with the Canadian Elder Law Foundation [Canadian Centre for Elder Law?] for a while now and so, I thought I'll provide a little bit of that background in a very short period of time. But I think what I wanted to say at the outset was to call attention to the heterogeneity or, the very, the heterogeneous nature of what we call East Asian culture. And we have to be careful of course not to lump all cultures into one particular, under one particular category.

You know, it's interesting because my feeling is there is a general sense that there's a difference between what we call Western legal norms and Eastern cultural norms, which can lead to confusion and clash. And this is that idea that I was thinking on the plane last night from Ottawa, thinking about this tension between Western individualistic, kind of autonomous neo-liberal ideas of decision making versus this collectivist model that's always, that's sort of seen as the model that East Asian communities subscribe to and which can lead to, as I was saying earlier, confusion.

In Canadian laws generally, I think consent for health or personal care treatment is given by a capable adult and this is the idea of capacity again, so I want to say something about that a little later on, by a capable adult to the person who needs a decision made. And it is a binary so sure, the capable adult may get all the input that they want or find appropriate but in the end it is one capable adult providing consent for a specific decision to one other person such as a doctor or a health care provider.

It sounds quite simple but underneath this legal structure is a norm of individual liberal autonomy. And so that our understandings of freedom and rights and independence stem from, are rooted in, each capable adult's ability, I think, to make their own decisions about the course of their lives, their treatments and even their deaths.

To a certain degree the debate is still out – and this is something that we've been talking with at the Canadian Elder Law Foundation – it's still out on some of the right to die issues but you can certainly refuse treatment, even if it will cause death if you are capable of making that decision. And that's something that I think just, having that connection with this Foundation has really helped us to understand this issue much better.

Our legal system for consent certainly which includes the ability to do advance care planning, make decisions about hospice and palliative care, other decisions on the health and housing continuum, they look like ... sorry, I was at this as part of a PowerPoint presentation and I realize we're not going to have ... It's looks like this [shows graphic]. So there's, this is what we call the nexus of capability which is often a grey zone around changing capability. And I'm happy to share these with you by the way. So if you leave e-mail addresses, whatever.

The last thing I want to say is that the capable adult which is this top left corner piece, this top left corner box, is mentally able to understand and appreciate the decision which needs to be made as such the capable adult thus makes the decision. And so how does this capable, you decide, incapable, someone else decides this. As when we talk about this and a substitute decision maker, is then, a substitute decision maker then enters the picture. So it looks, in truth or reality, it's not likely a binary decision. It's for many in East Asian communities, it's indeed likely to look more like this. Capacity versus

incapacity. And I think it's more likely to look more and more, as you start to, I think, understand the heterogeneity or the differences within these communities, like a Venn diagram or a context capacity, continuity and culture are all overlapping in this particular context.

There is an excellent study on racial and ethnic differences in advance care planning from the U.S. and it's written by Deborah Carr and I have the resource for that, I have the reference for that. [http://www.rci.rutgers.edu/~carrds/carr_jah2012.pdf] And there's an excellent study on end-of-life and palliative racial, care for racial/ethnic groups in the UK which came out in 2013 which I have. So I have a lot of references for people as well because that's what we've been doing is compiling a list of resources in this area. I'll stop there. Sorry. I think I went over my four minutes.

DONALD BAKER: Okay. I'll just talk about the Koreans. There's a lot of diversity in the East Asian community. There's also a lot of diversity within the Korean community. Korea has changed so quickly that you'll find pretty different reactions to end of life among the older generations and among the younger generation. Let me give you an example from my personal experience back in Korea. My brother-in-law died in 1979 of cancer. He died at home and we were not allowed to say to him we knew he was dying. Everybody knew but we couldn't say that. My father-in-law died in 1999. He was told he had cancer. He moved to a hospice. That's a twenty year difference.

And so you'll find the older generation of Korean-Canadian immigrants who still have ... when people immigrate they're frozen in that time in their country. And they'll still have those kind of expectations. You don't mention death. The younger generation are more comfortable with it. Well my father-in-law wasn't younger but he was that era, they're more comfortable. Now hospice started being built in Korea in the 1980s. The government finally recognized them about twelve years ago. So it's a relatively new thing.

One more thing that makes the Koreans a little bit different from other East Asians. In Vancouver, 50% of Korean Canadians are going to be Protestant Christian and 15 to 20% are Roman Catholic. It's not the case in Korea. It's 20% Protestant in Korea itself and 10% Catholic. But they [Korean Canadians] are overwhelmingly Christian and most of the hospices, two thirds of the hospices in Korea itself are run by Christian groups. There are even hospice ministries. In fact they call themselves proselytizing hospice ministries. So that makes Koreans stand out from the other East Asian communities in Canada – how strongly Christian they are and obviously that's going to be involved in conversations about end of life. They'll want to have a pastor there.

ZHENYI LI: Point to note. When we do our research, we also find the Chinese in Canada – let's focus on the Lower Mainland, for example – they're also very much diverse and some, we call some of them, they're much Westernized and some of them still ... It really depends [on] their choice and their time of immigration and the outside impact. Some of them they choose to segment from the mainstream, some of them they choose to integrate as much as possible. So it's also a kind of a matrix, very simple ... We asked two questions: "Do you agree with the host culture?" or "Are you proud of your heritage culture?" The double "yes" is integration, the double "no" is "No way. I'm nobody." So many of them, they choose separation, like the typical Chinatown phenomena and also we are seeing in Richmond a new Chinatown for example. And then, they are also, some people it's kind of based on forced immigration. They actually choose to be more proud of their heritage culture. So that's the basic diversity here.

And then when they make decisions, and their family makes decisions, we told the healthcare professionals you need to figure out if that's cultural or legal. And so, make sure there's an equivalent conversation or dialogue on that. Otherwise we say it's a mismatch, the dialogue. "This part, yes, sign the consent form because we are legally binding, you have to do so."

But then they say “No, in our culture we don’t have to do so.” But in other parts like their traditional ways of all what they’ve adapted here like the Christianity, they pray all these things because they feel they’re obliged to do so but it’s not legally they have to do so.

So what we have been doing is prepare the nurses, physicians by hosting these, facilitating those workshops we discussed. And we, particularly East Asian, why we picked that population because (a) of course it’s bigger, visible and pretty much distant from Western culture; on the other side the diversity within that population is so valuable. Once you crack that, break, it’s easier because we cannot say Africa as one continent or Middle East. But once you crack that one, it’s easier to [inaudible]. So I think I’ll stop here.

BARB PESUT: Thank you. Okay. So the next question I’m going to ask you about is “Can you make some comments on the current and potential role of East Asian Canadian cultural and religious/spiritual communities in public education about death and dying and advance care planning? And Karen, I’m going to just start with you this time, if that’s okay. We’ll start one over each time.

KAREN KOBAYASHI: So certainly, and I want to refer to some of the projects at the National Initiative on Care for the Elderly is working on here. Because I see this really interesting sort of connection between what is happening for example around conversations around dental health among older adults and which leads to these conversations around palliative care and end-of-life care. So communities, all communities, and what we talk about all the time within the context of this initiative, is that they need champions. And ensuring that when we talk about language appropriateness is done, is part of it. But also the method of having the conversation is also very important. We need methods, so constantly around the table we’re saying we need methods which are culturally appropriate. And this is where I’m going to talk a little bit about cultural competency models and I’m going to use those floating quotations marks there.

A close colleague of mine within the National Initiative is giving talks on dental issues to what they call it, a more closed, again more closed communities or more what they were categorizing as more delicate communities. They don’t want to talk about certain issues. But/so this colleague of mine who’s been giving this says it’s really a Trojan horse to talk about elder abuse and advance care planning for example. And so when you have a look, there’s a, the project is called “DEAR” [The Dental Elder Abuse Response Project] and it’s in Toronto [<http://www.nicenet.ca/dental-care>]. We started it in Toronto. But the question about this having the conversation about elder abuse and advance care planning, we didn’t really know that this was going to be the issue that it was until we actually started having these small focus groups and getting people together. People are willing certainly to talk about these issues. And when I say people, I mean people in East Asian cultural communities are willing to talk about these issues with the subject of their teeth but what happens is it leads to this, as rapport sort of develops over time, it leads to the bigger conversation and set of learnings that we have found over time.

And some of the key points that are coming out of those conversations are that we need real cultural competency. And what does that mean? Because cultural competency models have been around for a long time. And they were meant, they were developed to address in health care settings, to address issues mainly of language incongruence in my mind. And we know that culture is so much broader than just linguistic incongruence. So when we say real cultural competency, my colleagues and I are talking about, we want a really, a very specific model – a Canadian one to one decision making model. We need one that doesn’t ... when we talk about not discriminating or accidentally by assuming that ethnocultural heritage or background equates with a shared or collective decision making model, that’s not the case.

What we need, and that's what we were talking about, the shared, the one on one, the Canadian one on one decision making model is that we have to recognize that beyond just saying that these communities are heterogeneous, is that these families and within these communities are very heterogeneous. So that's something that we want to talk about. We need to be alive, I think, to [be] aware of group dynamics but in the end, when we talk about the law and culture, it's still the law that a health care provider or hospice care provider must get specific individual consents from one adult. So that's the other sort of piece that keeps coming up time and time again.

And this takes us to a question of ethics and there's an excellent model to describe the tension and minimum effect and so ... Mark Handleman, this is, and the ease of how we can conflate law, policy and ethics and this comes from the joint Centre on Bioethics at the University of Toronto. The law's minimum ethic, so policy about what someone else wants you to do, ethics which you ought to do, law which you are obliged to do or what you're obligated to do. And Dr. Li spoke about that and touched on that. And I just wanted to mention that if you really want to look at an example, if you look at the controversy at the UBC Endowment Lands. The predominantly Asian home owners and realtors didn't want the hospice near them. So this is the example that we use when we talk about, when the Canadian Elder Law Foundation and the National Institute get together and we do this presentation on this area. So I'm going to stop there and that brings up ... and the headline of "culture clash" – a very interesting sort of media take on this issue.

DONALD BAKER: Okay. I think if you want to educate the Korean Canadian community about end of life issues, you have to work with the pastors. Again, it's a very Christian community. There are over two hundred Korean churches in the Lower Mainland. There's one Buddhist temple that I know of. It's a big one but it's only one. And the pastor, even though there's a Korean Canadian Community Association, it's the pastors that's where, people trust their pastors, that's their real community outside of their workplace and their family. They go to church every Sunday for hours, they just don't go for an hour. It's their life and they respect the pastors. And so you get to the pastors and if [it's] the pastors who talk about this, they'll listen. And so that's really what you have to do. Just always remember when dealing with Korean Canadians, it's a safe assumption to assume they're Christian.

And I should point out, I pointed out that two-thirds of the hospices in Korea are run by Christian organizations. Actually in Korea, they're in hospitals. It's a one-stop shopping in Korea. You go to the hospital when you're sick. If they give up on you, you move down the hall to the hospice and then when you die, down the hall, the funeral is also part of the hospital, the funeral parlour. It's all in one place. About three-quarters of hospices in Korea are associated with the hospital. So Koreans would expect that also. But again, work with ... they want to see a pastor and after they see their family when they get a bad diagnosis, the first person they'll want to see is their pastor. It's very important to them, whether it's in Korea or here. So just keep that in mind.

ZHENYI LI: Well I think that both of the panelists mentioned about the cultural competency when we give training to the nurses and the physicians, social workers. We have a discussion on that because we cannot prepare them on each culture and each possible culture. Because it's not only ethnicity or language, it's also their background or whatsoever ... there's a lot. And so our approach is very much focused on culture [in] general. And so not culture specific but culture [in] general. Basically, you view a person – we don't call them patients – you view a person or group of persons as cultural beings, not only human beings. So don't view them as a physical, then I fix which part of ... [They're] cultural beings, they are [working?] to you, they represent the very complex [inaudible] combination of cultures. And of course you don't have to learn all about these cultures. You don't have time. Somebody's dying. But you have at least, we suggest, respect, and also we emphasize a lot is to let them know you are also a cultural being.

Because very often, the patients, they know their rights and privilege[s] and whatsoever, and they complain a lot because, well, emotionally sometimes. And for example, Surrey Memorial Hospital once had a very bad nickname as a “slaughter factory”. And because, once I attended another conference – the CEO of Boston Hospital – he said that’s a very bad position career he would take. Because the doctor, physician’s hospital, they all fail, finally. If you view dying as a failure. And so they would receive a lot of complaints for whatever reason. But then if you present yourself as the provider that you are also a cultural being and you share a lot at first. And also you are bounded by your culture and your professional culture. And so let them know that and let them know that you also know that they are a cultural being. So then you can start a fair dialogue and a productive one.

Because we talk about two things to measure cultural competency is appropriateness – we find that a lot of our healthcare professionals, they do so, they try, but they try their best. But you never know who’s the next person. How, let’s say strange, they will be. But that’s one thing. Second, is effectiveness. That’s what the system, the health care system focuses on. And also, that’s what we will think is important. So you cannot spend too much time with every person, every family, but you need to figure that out quickly. And the only way is to tell them you are also a human being and a cultural being and you care about them. But you are not a magician; you cannot fix everything. And, one thing, you also have parents, family, advance care plan, so we found that’s helpful.

JESSICA MAIN: Thank you Dr. Li. Thanks to all my colleagues. These are great things for me to get to go last after. It’s wonderful. One thing is this discussion of whole person care, of treating people as if they are more than just the mechanical workings of their body and I think that Dr. Li addressed that really well. Dr. Baker spoke about the role of religious institutions in the Korean community.

To give a very quick contrast, that’s not the way it works in the Japanese Canadian community. What you have are civic institutions and you should consider religious institutions as to stand equally and alongside other kinds of associations. But on the plus side, for educational purposes, there’s a very long history in Japan of civic mindedness, of going to lectures and listening to educational discourses on a wide variety of topics so that public education in terms of the Japanese community is very straightforward in that you choose people to go and deliver talks on the topic in question. And people will go and listen and ask questions and think about what is said. So there’s, in the case of Japanese Canadians, it’s not a dominant religious doorway or gateway to education but it’s a variety of civic institutions that are open to the idea of a kind of standard educational model. And I think that that’s something that anybody can take advantage of.

The idea that civic and religious institutions are going to be interested in these issues is true but I wanted to mention the idea that in line with the view of a doctor as a cultural person or a health care provider, a nurse, a chaplain as themselves a cultural being, what we see in our current medical system in palliative and hospice care is people who are strategically competent with one particular cultural background. They are aware of death aversion and fears of dying and views of death as defeat from a Judeo-Christian, modern industrialized, mobile, Western European extraction, that kind of perspective. So what we’re talking about here is trying to suggest that yes, those kinds of strategic competencies can be developed when addressing East Asian communities as well. And they’re going to be there. So just as kind of a hopeful note, that we have health care providers and team, whole-person care team providers that are competent in one or more cultures already. There’s no reason why that can’t be the case for East Asia as well.

BARB PESUT: Great. So I’m going to ask you to address the last two questions together because they’re actually quite close. The role of hospice and the potential to partner with East Asian communities. And so Dr. Baker, we’ll start with you.

DONALD BAKER: Well the Korean Canadian community is relatively recent compared to the Chinese and Japanese communities in Canada. So they don't even have, they're trying to build a retirement home for Koreans. They don't have one yet. So obviously, there's no Korean hospice yet here. But obviously Koreans coming from Korea in the last twenty years, those who immigrated in the last decade or so, are familiar with the concept of a hospice. The older generation would not be. If we ever get a hospice in Vancouver for Koreans, I suspect it will be run by a church which is the way it is again in Korea. And Koreans would, they'd accept the fact the hospice was separate from a hospital, because there are some such in Korea but they would expect it probably to be Christian. This is normally ... Korean Buddhists often by the way would feel very left out in the community. And again there is a Korean Buddhist community here but that's what I would say.

We would expect Koreans ... I think the Koreans are very much aware that their community is growing older and there's been discussion over the past five or six years about building a retirement home for Koreans. I haven't seen them [having] raised the issue yet of the need for hospice but when people are dying, they want to speak the language they grew up with and eat the food they grew up with. And one more thing, you mentioned, traditional medicine. I just finished an article on the history of traditional medicine in Korea. Koreans will often, especially if it's a long term illness, they want traditional medicine. They feel that's just better for that, especially when/if they're dying, they want to have that traditional medicine. And we have to take that into account too, so traditional medicine and most likely Christian religion is what the Koreans are looking for when they're approaching the end of life.

ZHENYI LI: I will emphasize only one point because there are a lot to discuss, these topics. One point I will emphasize is the generational difference. From what I understand, at least there are three generations of Chinese immigrants getting older, and they have different needs, different background, different family structure and they need to hopefully, I would say preferably, register into different homes. The first group came to build the railway and their offspring, and they're very much different from the second tide, I would say, they ... Hong Kong before it turned back to China. That's a second tide. The third one is the from Mainland China, skilled and business investor. Many of them, they are not too old yet. But then these three groups are very much different from each other.

And then also concentrating in different regions, like Chinatown, Richmond, and because I teach in Victoria, so I learned that Victoria Chinese Canadians are also very different, very different from the Lower Mainland. And also some of my Masters students, they told me from smaller cities like Kelowna, Kamloops, the Chinese there are different. And then if we go beyond B.C., the more diversity. So that's what I would say. Pay attention to when they arrive in Canada. And also they are those first generation, one and a half generation, second generation – they carry a Chinese name, a Chinese face but they are also different. Their values have been changed. Because they have ... we very often not only ask them when they arrived but when they, did they get to the full K-12 education in Canada or not. That's ... those years we collect cultural information year. And so it's like a disk, it's formatting an Apple or a PC. Thank you.

JESSICA MAIN: I'd like to follow up and continue with the theme of generations and generational change in East Asian communities. What we see in the case of Japanese Canadians is when the first generation came to Canada in the pre-war period and the immediate post-war period, these communities were really vibrant, financially self-sufficient to an extent which they are not today. And they were also more prominently linguistically non-English. As time passed, the language barriers broke down. The level of commitment and resources that were given to each institution, whether civic or religious, declined. And now you have declining membership capacity and financial well-being amongst many organizations. And that's normal, that's happening across the board in voluntary religious and civic organizations in North America in general.

So one thing I can say is that if a palliative care organization or group approaches one of these latter generation groups, they're going to find eager recipients. They're going to find people who don't have the capacity to care for their community members themselves because of the financial strain, the labour strain and various other things. And also, interest in connecting with the kinds of approaches, methods, systems that have already been developed in other places in Canadian society. So I think that as groups are here over time and they become less self-sufficient communities and become in some ways, performing a role that is less all-encompassing than earlier generations, they're going to be more receptive to cooperation with palliative care, if only because the linguistic boundaries are not going to be as extreme. But that's about it.

In the case of Japanese Canadians we have the most inter-married, the most fully integrated East Asian community. And they are, there are very few boundaries that exist. So it's a question of when and how can we cooperate rather than how can we get a conversation started.

KAREN KOBAYASHI: And if I were to follow up I think with what Jessica was saying, I'm third generation Japanese Canadian and I am not inter-married but no, but I am an outlier in the community. No, I'm well aware of that. The idea of integration, assimilation and forced assimilation I think in many ways is an important issue with the Japanese. And I'm working with the Nikkei Home right now in Burnaby to develop their dementia care program, for example. This has been a really fascinating experience for me – sorry I'm sort of going off on another tangent here – but I think it's certainly relevant to this discussion.

Because what we're seeing is that a larger proportion of those who are actually wanting to gain admission to assisted living and long-term care in the Japanese Canadian community are actually either first generation – what we call the post-war Isei or older Sensei or older Nisei now. Because it's who have very different sort of understandings of what care looks like, what obligation is. But and yet, there is an underlying common understanding of filial obligation, maybe not the way that it is presented all of the time, in other words, or it's enacted, but there is an interesting common understanding among my generation and those in the post-war Isei or among the foreign born Japanese.

I think if we go back and just talk about the role again – the question that you were asking in the last two questions – the role of hospice and palliative care – I think it's an opportunity for us to talk about the fact that we need to be individually focused still, even within a culturally competent system. And that's I think the point that I was wanting to make throughout: that death and dying and pain and dignity and the planning around these issues certainly, is actually a person centered and a life course question.

And culture which, and this is as seen in this kind of a Venn diagram [shows graphic], is only one important part. Of course a part that you don't want to miss. Of course not. But a person is not – you have to be careful to understand that a person is not their culture or their race or their ethnicity. And often times what we found is that people talked to us, they left their country of origin because of issues in that country of origin: they're moving away, perhaps, from a particular set of values and beliefs. And then we talked about the generational piece. So you add all the research on second and third generations into that.

And also don't forget, I think as a sociologist I'd be remiss to not mention gender, the intersection with gender. Men and women and the way they understand and take up these different norms and values. And the different sort of expectations of women versus men etcetera – and Jessica and I were having a discussion about this earlier.

I think we have an opportunity here – and this is why I was very happy to participate in this panel – I think we have an opportunity here to ensure that there are culturally and what we call ethnoculturally appropriate environments, treatments, social norms etcetera. That they are incorporated. But again, this should not be assumed just for what we would term

“obvious ethnics” and that’s a term that’s used. Rather that I think this is an issue for everyone. There’s still lots of improvement, we, I think for this.

In terms of the last question around the potential for East Asian communities to advocate? Advocacy is one thing but understanding it first is another. And I think it depends entirely on what is developed and understood as hospice palliative care. And we need to find a place where possible systems and supports can be augmented by the needs and the wants or the desires of a community. And so I think I’ll sort of leave it there.

BARB PESUT: What a helpful panel. Thank you. Now we have a few minutes for questions and comments, so I am going to pass the mic because we are tape recording. So who would like to start?

COMMENTOR 1 [Karen Mackay, Central Okanagan Hospice Association]: A comment more than a question. I really appreciated what you said about needing to be individually focused. I think that that’s something that is often misunderstood is that just because somebody appears to be a visual minority, I know many of my friends, they’re third, fourth generation and when somebody says to them, “Where are you from?” and they say “B.C.”, people go “No, but really, where are you from?” And I think that our privilege as being white skinned, really we forget the fact that we expect diversity amongst ourselves but we don’t allow that for others. So I think that that was a really great comment and something particularly in hospice palliative care is what will work for one person is not going to work for the next and so it’s a matter of asking a question of “What do you want?” and allowing that conversation to happen and not assuming anything regardless of what we see in front of us. So thank you for that.

KAREN KOBAYASHI: Thank you. Sorry, can we get the people to say where they are from? I’m just really interested

COMMENTOR 1: I’m Karen Mackay from the Central Okanagan Hospice Association.

KAREN KOBAYASHI: Thank you.

ZHENYI LI: I can quickly add on that. We have a very simple model for the nurses to check. It’s a triangle and we divide it into three pieces. The biggest part is human, human being – whatever we share. We all eat for example, we all feel hungry. And then in the middle is cultural which they share particularly with a particular group of people in whichever way, like their language, whatsoever. But then at the top, don’t forget it’s personal, so, say, it’s very much individual, so I use the example: eat is shared but then in the middle you eat with the chopstick or hand or fork and knife – it’s very much cultural. And also you cannot assume that’s a chopstick person. Just to the other people they use chopsticks. And so you have to figure out. But then with your left or right hand. That’s very often personal.

Of course some religions, they have different definitions of it. But, so you need to figure out like “Do not rescue [resuscitate]” for example. Is that a personal choice, cultural choice, or/and which part of a cultural choice? Or did they influence by the mainstream culture that they do that. And then how about the other neighbours? So trying to find simple diagrams so that they can easily be remembered, visualized and used.

COMMENTOR 2: Al Jina with Parks Place Seniors Living and I just really appreciated your comments on cultural competency models. And we own and operate a number of facilities in BC and Alberta and it’s a growing challenge. And it was a challenge particularly for my mother in law when she was in hospice. And I could sort of see the gaps. And as a practitioner in the area, you can see huge gaps. They were very readily visible from the North Shore. And we were just very, very fortunate that we

moved her to hospice at Jim Pattison Pavilion. And the director of that hospice was from the same country that she was and was from a nearby town and spoke the language and that made all the difference. It was a huge difference and it was just major. So you really, really see what a difference it can make. So your work here is just tremendously important. So thank you.

COMMENTOR 3: [Dr. Parin Dossa, Simon Fraser University] I really enjoyed the comments. Thank you. I have a question about language, not linguistic diversity but the language that we use in terms of death, dying without associating these terms with life as well. I think that it is very critical that we start a conversation on a continuum of life and then death as the end point. Otherwise, I think a lot of issues that we discussed this morning and now has to do with the fact that we tend to draw boundaries around culture, boundaries around ethical issues, legal issues. So I would be interested in your comments. Karen, you elaborated on this quite a bit, on how we go about crossing these boundaries.

JESSICA MAIN: My comments are from the point of view of tracking the way that people try to change the way they speak about things when they're trying to introduce positive change. So as you mentioned, if you talk about death as a part of life, as a natural part of something that is a continuous process, then that feels different than talking about it in a different way. And that discourse change can have radical social change as well.

In the case of Japan, cultural and religious terms that were quite negatively loaded around death have been replaced in public education and public health campaigns with terms that are much friendlier and are easier to talk about. So people talk about living with vigour, living with meaning, finding a place of calm and peace, having a chance to reflect, having a chance for the dying process to be beautiful. There's all kinds of language that gets brought in, even amongst the very frank admissions of the painfulness of it. So I think you're absolutely right. I think that the way we talk about things reflects the way we put things into boxes. And if death weren't so separated from life, we might all have an easier time dealing with it.

ZHENYI LI: I think each culture has a way to put that in a positive manner. And the only thing is, we need to figure out which way they prefer to ... language, do not translate or Google translate these things. Just say, "Okay, what is your preferred way to talk about death?" And I agree with Dr. Main that, let's just look at people living in this century, no matter how old or how young they are. My parents-in-law, they're in China and they quickly adapted the idea that they are the, not only the survivors of cancers, but they quickly adapted the idea is to co-live, co-exist with the cancer after the surgery or these things, which is not traditional Chinese culture. But it has been on the Chinese media as well and they quickly adapted to that.

And so what I found is, that's, I would say, that's human nature. So it doesn't matter if they are not religious at all. They don't have any religion but they also ... human beings, they have a drive, to find a way to handle difficulties in each stage. And so you provide them the words. It's another way. And they found, "Oh, that's something." And so "celebration of life", for example has been replaced as "funeral" in many cultures. Because people feel "Yes, that's a better way. I never know that." So don't be afraid, like all they are afraid from another culture, like "I don't want to die". You just go and introduce, "This is my way. If you like, you can try it. If you don't like it, it's okay." So let's have a dialogue. And I find, especially my father-in-law, he's now 84. He's very open, so, he has been to Canada. He's very open to different concepts.

BARB PESUT: Did you want to, either of you, want to take the language issue on?

KAREN KOBAYASHI: Go ahead Donald. I have something to say but I'll just say it at the end.

DONALD BAKER: Well, I just think when you're again talking about Koreans, again they didn't use to talk about death, their own death. But obviously death is a very important part of a Korean family because they have regular rituals in Korea, on the anniversary of the death of a parent or a grandparent. Even the Christians in Korea have adopted Confucian rituals, so they still have annual rituals. And so they are constantly reminded that they are not an isolated individual, that when they die, they become part of the ancestors. And so that's one way to and so by the way they want their family around them when they're dying, of course.

That's very important and it's very important for everybody, but specifically because they see themselves as members of families and they're constantly reminded of these rituals that there were those that proceeded them and there those that will come after them. And so you have to talk in a way that reminds them that this is the, if the family ... they will be remembered by the descendants. That's very important. They don't tend to do those rituals as much here in North America. But there's still a stronger sense I think among the Korean Canadian communities when they're not in the normal Canadian community that you're simply part of a family of several generations. And it helps to think about that when you're facing your end.

KAREN KOBAYASHI: I just quickly, I guess Parin [Dossa, Simon Fraser University], in talking to ... Parin was on my PhD dissertation committee so I have a special, and helped me to see, I think to understand culture in a different way as a cultural anthropologist in a department, in a joint Department of Sociology and Anthropology. What I've learned I think is that these boundaries, when we're talking about the porous nature of boundaries around cultural competency, I think they're just that. It's that in some communities, for example the work that's been done in Toronto around Caribbean communities, talking about death is a taboo subject. So when you go into families, into communities, families who are dealing with the issue of death and dying and grieving, there's a strong resistance to not talking about it.

The laws unfortunately are not written in that way. When we ask for substitute decision maker, we ask for if somebody is incapable, etcetera, there's a huge conflict between what is the law, and of course what is understood as important and central or salient to families as they negotiate this process. I think that in many cases at the end of the day we, when we're thinking about person centered care versus cultural competency in many of these communities, I think we should think about person centered, this person centered nature of care as trumping models, these writ large, of cultural competency.

BARB PESUT: Good. Well we're at ... would you like a quick response? Yes.

COMMENTOR 3 [Dr. Parin Dossa, Simon Fraser University]: I'm not actually responding. All I would want to say is that's why we have had an extensive discussion on culture. I think the biomedical model should take a lead in changing the language.

BARB PESUT: Yes, thank you for that comment. And I'd just like to thank you on behalf of all of the participants today for your contributions. I'm always amazed when a panel is put together, they don't plan very often and yet it's enormously complementary that each of the perspectives you brought today just fit like a jigsaw puzzle. And so thank you so much for your time and your contributions. And on behalf of BCHPCA, here are some nice little gifts for each one of you. So please join me in thanking our panel for today. [Applause]

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