

# BCHPCA FORUM | 2014

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

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

## ROUNDTABLE ④

### Cultural Conversations: South Asian

**MODERATORS:** GRETCHEN HARTLEY, BCHPCA Regional Director – Vancouver Island [Incoming]; Executive Director, Cowichan Valley Hospice Society. 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

### INVITED EXPERTS

- DR. NEELU KANG DHALIWAL, Sessional Lecturer, UBC Sociology; Associate Professor, Sociology, Punjab University, Chandigarh, India
- DR. PARIN DOSSA, Professor, SFU Anthropology and Sociology; SFU Centre for the Comparative Study of Muslim Societies and Cultures

### 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 South 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 South 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 South Asian Canadian persons and communities in death, dying and advance care planning
- the potential for South Asian Canadian organizations to partner with hospice palliative care organizations to advocate for hospice palliative care in British Columbia

GRETCHEN HARTLEY: Hi. I'm Gretchen Hartley from Cowichan Valley Hospice. And apparently our moderator perhaps missed the plane and isn't here. But I have the questions and one of the three speakers is also absent. So Dr. Neelu Kang Dhaliwal may show up. And so would you like to introduce yourself? I have a ... and then I can talk a little about the questions. So just the format, because this is our first one this morning, the format is that we have some discussion points and we were invited to ask the panel to speak to them. Please include any kind of personal reflections that come up for you and because we're such a small group, I think it got, an open conversation with the whole room is probably what's appropriate at this point. And do you think we should gather even in a smaller circle?

PARIN DOSSA: That's what I was thinking. Why don't we form a smaller circle. Did I get it right? The other two speakers will not be here?

GRETCHEN HARTLEY: One speaker we're still expecting because they came for breakfast – Dr. Dhaliwal. One will not be here. But the moderator, who was going to convene the conversation, has apparently not arrived either. So sorry about that.

PARIN DOSSA: Okay. I think I can see from the introductions that all of us have backgrounds in hospice palliative care. So I think we will have a very interesting discussion. So what I was thinking, that I have an informal presentation, because we were told to prepare some background information – those were the guidelines – so I just thought that I will just say a few words. I have a couple of case studies and this way ... So we have time limits?

GRETCHEN HARTLEY: We should have lots of time.

PARIN DOSSA: We will have. So I think if it's okay, I'll just start it on what I have. And I'm actually going to present the Islamic perspective. And to begin with, I want to state that in Islam, there is no distinction between life and death because death is perceived as being in between life in this world and life hereafter. This is not an abstract statement. It really informs the deeds and words of a Moslem. So if you engage into a conversation with a Moslem, you will find that the name of Allah is invoked in every death conversation.

That's why I would like to start this particular session by stating *Bismillah ir-Rahman ir-Rahim*. "In the name of Allah, the Most Merciful, the Most Beneficial." This is how Muslims ... so essentially ... so what the point I want to make is that the presence of Allah is mainly by fable. So when it, because it forms part of everyday life discourse, so when it comes to death and end-of-life care, there is this continuum that it would be important to keep in mind. So that is [the] number one point that I wanted to emphasize.

Second, in Islam, and I'm sure in other minority cultures and traditions, there is a greater emphasis on a sense of social self. We often in the Western world, although this may not be the reality, the norm is that of individualism. We are connected with families and we have our network of ties, but it's assumed, at least in the public sphere, that there is an individual that really counts. And that is not necessarily the case in Islam. So I think that the emphasis is on the social self and I think this is very important because when one thinks of oneself as being interconnected, then one recognizes that there is a community and from the community we can draw support. And community by nature does have all kinds of resources that can be drawn upon. So that is the aspect that I wanted to emphasize.

And a very important point I want to make is that when we talk about minority traditions and cultures, we must never consider them as a discrete entity. We must never ... my point is we must never draw boundaries around these cultures, whether they are religious or they are oriented towards heritage. How will we pursue them? Because if we start to drawing these boundaries, what will happen is that we will "other" them. "Oh, they are different from us". They come ... if they seek a hospice care, "we have to learn about their difference". And I think this would be an error because there is a lot of literature that says, that states that if we use culture in a rarified form, then we can "other" people. And "othering" them means considering them as different and then can lead to what we commonly known as racism. And discrimination.

Now what I've done is I've stated in very simple terms ... I do not want to present a theological treatise. That's not my intention. What I have done is presented Islam in a very fundamental way, being aware of the presence of Allah, that when a person is on his or her deathbed, the presence of Allah is invoked. And that one revisits one's life as one has lived it and also at that particular moment, a person may have certain wishes. They require "I didn't do this" or "I ask for forgiveness" or from this particular person. And so there are rituals connected to this. But we can talk about that later.

Now I do want to point out, and I'm glad that we are having an open conversation, I do want to point out that when it comes to palliative hospice care, it is still embedded in the biomedical model. It means that the biomedical model, there is this

element of making decisions based on pragmatic, rationalistic concerns. But when it comes to religious and cultural traditions, there may be more emphasis on affect. And I am aware of the history of the evolution of palliative and hospice care and what it comes down to is that it is actually [an] encountered image of the care that was received at the hospital. So here, the philosophy of hospice and palliative care is compassion and care. But how this compassion and care is translated into the lives of individuals is very complex.

So what I want to do, I want to leave the maximum time for discussion. So what I'm going to do is just present some case studies and then make some recommendations as to how we can move forward in terms of themes that can be put forward for discussion and then you have some things to say to [inaudible].

GRETCHEN HARTLEY: Can we put on the table the general question that we were [given]. The first question to think about as you're talking and just put that on the table.

PARIN DOSSA: Yes, you can.

BARB PESUT: I'm sorry I'm a few minutes late. Well actually I had myself down for 11:00 [a.m.] so I got my schedule mixed up. So you were moderating.

GRETCHEN HARTLEY: Well I'm just ... and I hadn't really started because happily you've launched [Dr. Dossa] into the real meat of the conversation which I appreciate. There's a ... this question of ... the first question is sort of a framework and you've been speaking to it but I'd just like to put it out for people.

BARB PESUT: Yes. So it's really the nature of conversations in South Asian Canadian cultural, religious and spiritual traditions about death, dying and planning for care and the paths to opening these conversations.

GRETCHEN HARTLEY: That's why I appreciate that you've been going there. But juts to help ...

PARIN DOSSA: So it's up to you to decide. If you want some case studies that will highlight some issues for discussion and then I have some recommendations as to how, at least in terms of themes, that we can discuss or not discuss if you do not think they are practical or important. But when I talked to Lorraine [Lorraine Gerard, Executive Director, BCHPCA] she did say, she did emphasize that presentation of case studies would be quite crucial because it provides the concrete context that we otherwise ...

BARB PESUT: So do you have a preference? We have a series of conversations around ... that was one of the questions, and then the current and potential role of South Asian Canadian cultural and religious/spiritual communities in public education about death and dying, and then a question about the role of hospice palliative care to support South Asian Canadian persons and communities in death and dying, and then about the potential for partnership with South Asian communities. So we can do one of two ways: we can kind of touch on each individually and then move to the case studies or we can go to the case studies now. Do you have a preference in how we ... I think we have a fairly generous amount of time.

MULTIPLE COMMENTORS: Well I'm really interested in the case studies. I'd really like to get some information regarding the case studies and then we could go on.

PARIN DOSSA: Well very brief because ...

BARB PESUT: And that works for you? Okay. Good.

PARIN DOSSA: Okay so the first case study I want to present is that of a person by the name of Amin. He's a South Asian Muslim. He was. And he contracted cancer. Unfortunately, it was very sad. And he was diagnosed as having terminal cancer. So his GP in fact suggested that he be placed in hospice care. But the GP, the general practitioner, did not explain what hospice care is. So not a lot of minority communities know about hospice care or if they've heard about it, they don't know much about it. So the only information they were given is that he'd be well taken care of in this particular place.

So what happened was – and this is his wife's version – that he was put on morphine. Now because it was assumed he would be in pain. But his wife thinks that he was not in a lot of pain. And that he was always averse to medication. So because they gave him morphine, she feels that when he died ... she actually had a bed placed in his room and she was to stay there 24 hours ... But she feels that when he died, she missed that moment of death because he was on morphine. And it was the nurse ... like she got up at 4:00, she touched his forehead, she went to the washroom, she came back and she started saying her prayers. And when she was saying her prayers, a nurse came in the room at 4:15 and said that he had, he was gone. She just said he has died.

And she was ... it was very hard for her to accept that. And it was at that particular moment that she started asking, "What kind of dosage were you giving him with respect to morphine?" But I was not able to verify whether he was indeed given morphine or that was her perception. So that was one aspect with this case. That's a very brief.

The second case is one of Fatimah. She is 102 years old. She lives at home and she stopped eating. So they placed her in hospice care. All the ceremonies were done in a subdued way. So some religious communities do want to pray in the context of the families, so there is some kind of rhythm and rhyme, singing ... but they were very subdued. Anyway, all the rituals were done because she was given the diagnosis that she was going to die. The family members came from England, from Toronto, from the United States and other parts of Canada. So they all gathered. And she did not die. So after a month, all the ceremonies were done and it was announced in the community, asking for forgiveness – there was a ritual – now she's still at home. So perhaps what we have to learn from here is maybe we should not associate hospice care with just, with death. That we need another term.

And the third case is also very short. Another woman by the name of Reymat, was provided home hospice care. And she had difficulties breathing and she had the diagnosis that she was going to die too. So the nurse used to come a couple of hours a day. That was the arrangement that was made. But I was really surprised. When I talked to her daughter-in-law and when I talked to the lady herself, they hardly knew the nurse. They could hardly describe what she was like because what it came down to and this is my understanding is what I call bed and body work: you give the medication, you give them food, you give them a bath, you make sure they are comfortable. But beyond that, there was not that direction. So it just shows, and she did pass away, it shows that there's a lot of work that needs to be done. I will stop. I have some recommendations but I will not go into it until there is time for that or it comes up in the conversation.

BARB PESUT: Yes. So is it your preference to discuss the case studies or to move on and come back to them?

MULTIPLE COMMENTORS: We should talk about it right now and I think we should deal with it now. Yeah, before we forget.

BARB PESUT: Yes. Do you have any comments, questions?

PARIN DOSSA: I have no problems whatever. I'm flexible.

BARB PESUT: Good. So comments, questions?

COMMENTOR 1: I just think it's difficult some times to comment on some of these case studies because there's not enough information about what really happened. In the case of the gentleman who died in hospice and was as his wife was saying, that he was being given doses of morphine and she wasn't aware what those doses were and whether or not he really required morphine. We found in hospice that a lot of people wait until their loved one leaves the room to die. They very often do that, and we're not sure why that happens. There's a lot of mysteries in life and death and it doesn't always happen but it, on many, many occasions, families have sat there for days and all of a sudden they'll decide to go down the hall and get a cup of coffee. And when they're gone, their loved one will die. So we ... that could have been a factor as well. Because I'm sensing that she was upset that she wasn't there when he died.

PARIN DOSSA: Because he had actually told her that "I want you to hold my hand when I'm dying". That was his wish. That's why she still can't get over it. So I guess what it comes down to is preference.

COMMENTOR 1: Is she feeling that the morphine killed him or that the morphine didn't allow him to communicate with her?

PARIN DOSSA: I think that the morphine rendered him very passive. She said that he hardly talked, once he was admitted to hospice. First of all, he got this message, "I'm here to die". I think we have to change his language. "I'm here to die." And second, he just became very passive. He just resigned to the fact that he was going to die. That's what it came down to.

COMMENTOR 1: It's rarely a message that we actually communicate at our hospice, that "You are here to die". More so the messages around "We are here to support you as you are living, until the time comes". So I'm just ... it's unfortunate that that's the message that he was getting. Hospice is a place where a lot of people end their lives but it's not, that's not certainly a message that we put out there.

PARIN DOSSA: But this is the silent script that you write, that the word hospice

COMMENTOR 1: So you felt there was, she felt there was little communication about what was really happening, what was really going on.

PARIN DOSSA: Yeah. And she appreciated that he was made, he was very comfortable. They took care of his needs. They ... if he asked for certain foods they made sure that he was provided. A very comfortable room. It was spacious. They brought a bed for her. But the fundamental issue of communication, I think, was lacking.

COMMENTOR 2: That seems to me also that it might be an awareness of what's really happening in hospice. Because I find in so many instances, people don't really know until you go to a meeting or something like that, or have that training. Because when I was looking at, I'm going to the home and the person hardly knew the nurse, and when you get that training in hospice, the nurses there and then that nurse goes in, but there's ... I'm also looking at the volunteers because when you get the training, the thing is there are lots of things that we cannot do. There are barriers. And it's not only that. It's for our own protection because we can be sued if we go and do something.

Because I remember I went into hospice because my mother was up at the hospital for eight years. And I used to do a whole lot of things. I used to go into the room. And there were four people in there and because there was such a shortage, I used to go and change diapers and get water and everything else. And then I got the training as hospice and “Oh, you can’t do that”. “You can’t do this”. So I’m just looking at nothing done for the person. And that might be part of it. It’s the ignorance of not knowing some of it and do we really, when we sit down ... unless it happens with the doctor ... do those people really understand or do they tell them or give them that information? And that is so important. And again we come from that silence where people don’t particularly want to talk about it. So I’m not sure.

PARIN DOSSA: I think you have made a very important observation. In one of the themes that I have identified here, is for the health professionals, the patients and the families to have a conversation outside the topic of death. Now, how would you have a conversation if you go to a Moslem family? Well, I think one of the themes that would probably in fact stimulate conversation is about nature. You know, we are all concerned about the environment. And hospice facilities are situated surrounded by nature. There are trees and ... in the case of Islam, in the Koran, there is tremendous reference, there is very prominent space given to nature: sky, light, clouds, birds, heavens, earth. And so I think that if the health professionals were trained that you could have a conversation that would recognize that we are all human, and we forget that. And the second thing is that we are all vulnerable. Being vulnerable does not mean that we are weaklings. We are all vulnerable. So I think that if there are those common themes of conversation, that will go a long way. Storytelling is another method. So ...

BARB PESUT: So storytelling on the part of the person that’s in hospice, hearing them tell their story? Or storytelling on our part as health care providers? Which is more appropriate or both.

PARIN DOSSA: I think that some professionals are reluctant to tell their own stories. But we can bring to light dignities. Stories that we know about things that have happened to other people. Like talk in more in a, not exactly abstract, but you can keep your distance because health professionals sometimes do not want to go beyond their professional boundaries. So we can bring up dignities or any kind of story that we think will recognize our common humanity.

GRETCHEN HARTLEY: So I’m just thinking again about the man who died and his wife didn’t have the chance to hold his hand. So would it have helped there for someone to be saying to her, “He’s very close. At this point we think he’s very close to death.” Would that have helped? And then even it’s framed in, as you’re saying, a story about, because sometimes people pass very surprisingly suddenly. My own father had ... my sister fed him porridge in the morning, he had a visit with the family and then in the late evening, his breathing changed and I wouldn’t have thought anything of that but the nurse said to me, “You know, we hadn’t expected this but he passed this evening”. And so I ... he chose to leave when I had just fallen asleep and the nurse came in to check on him which I think was ... he liked nurses and I think he wanted to spare his child. But just, it speaks to a few things: it speaks to, at least I somewhat expected what was going to happen and also afterwards, I didn’t feel so badly about him leaving without me there but ...

PARIN DOSSA: I think you raised a very important issue. When it comes to death, sometimes nurses can tell or doctors can tell; other times, we cannot. Nobody can. But the Islamic perspective here is that Allah chooses the moment of death. So the wife would have found it easier to be resigned to the fact that she was not holding his hand if the nurse had not broken the news to her and if she had found out herself, I think. Because she was awake. It was not that she had gone to sleep. And she would have said, “Well, this is the moment chosen by Allah”. That is the Islamic explanation.

COMMENTOR 3: Because last weekend I was in Kitimat and Mary Gavan is a storyteller and was, she was there ... an awesome lady to listen to, I don’t know if you have heard her. She is here today. She’s not giving any talks or anything but she

just told us that people choose to die at their own time and on their own way. So you can't carry that guilt with you if you're not there, so ...

COMMENTOR 4: What I think was interesting, I heard something in a webinar that we were, the other day, and it was talking about how, you're right ... people do very often ... we don't know whether they choose when they are going to die, but it is very helpful for health care professionals to be able to give a heads up. And there was a situation where a family had travelled a long distance to get to their loved one. They'd actually brought their mother up from the States and they were all there and they were very tired and they wanted to go home and have some sleep and then come back. And the nurse made a point of saying to them, the family members, "Would you please go in and tell your mother what you're doing. That you're going to go home and you're going to have a sleep and when you will be back. Even though she was not conscious, they say we often believe that hearing is the last sense to go. And so the daughter went in and she told her mother that "Mom, we're going to go have a sleep, We're going to come back. We'll be here by 8:30 tomorrow morning".

So the next morning they come back and her mother passed away about 10:30 that morning. But they ... she wanted her to, because we don't know if people choose or not. But given that information and that communication. And thank you for that. I had no idea that in the Islamic culture that it would be helpful to allow the family to be the one to discover if their loved one has passed away as opposed to being told.

PARIN DOSSA: I think that we have raised a very complex issue. Because in Islam, scientific knowledge is very much valued. And so if the doctor knows that this particular person is going to die, the family would appreciate knowing that. But at the same time, it is also recognized that science has its limits, that medical knowledge has its limits and that's where they say, okay, this is the information that we had, but this person did not die on the day that it was predicted, but the next day, that is the moment of death chosen by Allah. Because in the Koran says Allah gives life and Allah takes life.

BARB PESUT: I have ... do you ... I have a question or you. So I'm thinking about the reluctance to take morphine and I think we just probably had a conversation the other day. In Western health care, it's also very much an individualistic ethic. So we very much see our primary responsibility being to the patient. And although we include the family, it always, if there's differences between what's needed or required, we'll typically give precedence to what the patient wants. So in cultures where you describe the families being, it's a family decision, how is it that we help to navigate those waters when we're so used to going for the preferences of the individual? So if we see an individual in pain, but the family doesn't like the idea of sedation and analgesia, how might we help to bridge that a bit?

PARIN DOSSA: I think that the families that I know, they do include the patient and they do respect the patient's decision. It's only, I think the issue only arises when the patient does not express a preference. And that's when the family has to move in and then also, there are conflicting views within the family. So it's a very complex scenario and it's good to highlight these complexities, because that's what we need to do to recognize how complex the whole area of death, dying, life is.

COMMENTOR 5: It seems to be that really you have to ask people. You can't make any assumptions about what a culture does or does not want. Because each ... it might be very different depending on that family. So it sounds more like, whether it's the doctor or the nurse or the volunteer – whoever it might be – asking "What is it that you would like? How can we help you? What do you need?"

PARIN DOSSA: Yeah, you are right. Culture is not rarified, means it's not static. It just allows us to have a world view. And I think the issue here would be the kind of rapport that one has built with the doctor or the nurse. And that really helps.

Because sometimes, before the family makes a decision, they want to have a conversation. “Okay, if it’s morphine, what is going to be the side effect?” They want to weigh pros and cons and sometimes in a crisis situation we don’t have that space. So I think to have that rapport and knowing where the doctor is coming from. The doctors do have philosophies. And I think that’s what would help.

GRETCHEN HARTLEY: So if you can comfort with those kinds of advance care planning conversations that we’ve been talking about here where at any given point in somebody’s life we could be having these conversations and ... How does that fit for ...?

PARIN DOSSA: Yes, I think in Islam and South Asian culture as a whole, from what I know of it, planning is regarded as important; planning for care is regarded as important. In Islam and also in other religious traditions in South Asia, there is a fusion of medical knowledge and religious knowledge [and] cultural knowledge. I don’t think that they are broken into compartments. So planning is not ruled out. I think it’s, intellect is given emphasis.

COMMENTOR 2: I think that’s problem though, the planning. Just Renu [Bakshi, Keynote Speaker] was talking about this morning, some of us are aware of what’s happening but how many plan that whole scenario out, okay? And I guess that’s where the complexity is beginning to happen. Because we’re not aware of what’s happening. I am ... so many things that happen when somebody dies ...

I, where I live, we have 60% aboriginal clients I should say in the population and it’s entirely different. This morning when I walked in there and I realized, “My God, where are the cultural representatives? Where are they?” I was shocked. I’m one. If I could have counted ten people, that’s a lot. And I think that’s a concern, that some of us ... it’s a concern provincially, federally, that something like that should be done. Because it’s, and this to me is a thing that causes a lot of problems. If we don’t have cultural representatives to share that information that’s happening today, how are we going to know? And those scenarios that we’re talking about, I believe that if we had that conversation, if we had that information and the pre-planning, these are some of the things that wouldn’t be happening. So I think it’s important for us to get that type of information. So I’m glad that we’re having something culturally embedded in this Forum.

COMMENTOR 6 [Beth Kish, South Surrey Hospice Society]: I think it’s evolution, the evolution of our communities as well. Although I’m new to British Columbia and South Surrey and I was surprised when I became Executive Director that I learned quickly through demographics that 52% of the community was South Asian. So I said well what, where’s the literature for South Asians? There was nothing. There was no pamphlets on hospice in Punjabi or Hindi. And I’m thinking “But who are we here to serve?” We’re here to serve the community and I think that it sometimes takes fresh eyes. It was like the people the people that lived here didn’t even acknowledge that there was this huge change. And then fresh eyes, it’s obvious to me.

So myself, I’ve been going to temples on Sundays and visiting. I’ve gone to all the celebrations – Visakhi – and have bought pop-up banners made in Punjabi that state what hospice is, what service we provide. I’ve been welcomed with such open arms and conversations and kindness from that community. I’m just in awe of them. I usually leave any event with a pot full of donations. And they’re learning. But that’s what we have to do. We have to share, we have to learn. And we have to recognize that it’s part of the evolution of our communities, of our country. And that’s our responsibility. That’s why I’m so pleased with the fact that this organization has said, “Let’s start the conversation.” And that may be in a different language though.

BARB PESUT: Yes. Now I’m conscious we’re about half way through. So I’d like to turn it over to you Dr. Dhaliwal to ... Thank you very much.

NEELU KANG DHALIWAL: Thank you ... Would you like me to go through all the questions right now?

BARB PESUT: if you have prepared differently, it's up to you. I think we're just, I think it's fairly unstructured so why don't you take it with what works for you.

NEELU KANG DHALIWAL: Alright. Well thank you. First of all, in terms of talking about South Asian culture, I would like to mention what she just said ... what Beth [Kish] just mentioned, that communities are, there is evolution of communities. Similarly we can talk about [the] South Asian community. So when we say [the] South Asian community not only in South Asia. There is evolution and development taking place. But at the same time, when these communities have migrated here. So if you look at the communities say seventy years ago, fifty years ago, a hundred years ago, when they came, particularly the Sikh community, they're celebrating a hundred years of their arrival here in 2014.

So you would say, because I have my, I have seen my father in law and my father in law's father as well who died a couple of years ago. And when I hear stories from them, so there is a large gap in the sense, a difference in how people perceive and look at different things and particularly in the context of death, dying and palliative care. And then as generations move. So we see the difference in any of the communities, similarly in [the] South Asian community as well, we have second generation, third generation.

So when we come to the conversations about this particular subject, I would say first of all that we are now talking more than we ever did before. But then this is mainly among the very educated people. And it is a very small section of society. And again, when I'm going to tell you about, based on my experience and my understanding and my conversations being part of the South Asian community, then again I would urge that we, as Parin said, that we have to be careful that we don't sort of "other" them. So that is one caution that we have to ...

So when we talk of South Asian culture, I'm ... mainly we are talking about, here I would be talking mainly about Hinduism and Sikhism in terms of religion and spirituality in order for you to understand it better. So when we are talking about Sikhism of course it's only five hundred years old religion. But it was ... all Sikhs were Hindus before that. And then among Hindus whatever happened, then one person who was not very happy with some of the things that were happening and started a separate kind of a sect. And all those who followed him became Sikhs. So therefore Sikhism is in some ways distinctive. If we see the religious scripture, it is different than Hinduism. But when we see culturally, we come from that same background. And in many ways I say I am a Sikh by religion but in many ways I am Hindu basically because I follow all those, many of those things I would say.

So when we talk about religion, there is no contradiction between religion and culture. So when we look at our religion tells us time and again – looking at the religious scriptures – that death is a reality and we are being reminded every time that this, my place in this world, is temporary and this is a journey. And my final destination is after my death. So that is my real home and I'm moving towards that. And that means that my soul is immortal and when my soul in this body, when I die, so I will try my level best that after death in whatever way I can that I become one with God, I become one with the Universe. And I am free from the circle of death and birth, birth and death.

So therefore we also believe in theory of reincarnation, theory of karma, theory of action. So if I do bad deeds – this is the belief that if I do bad deeds, then after my death my soul will enter into another body – human being or animal or insect or anything. That means again, I will go through pain and suffering. And if I do good deeds, so after my death, my soul will not

enter into any body but will become one with God and I'm free from the cycle of birth and death. And that is what every one of us is supposed to achieve, that stage of [what] they call "moksha."

So that means whenever we read books, we do our prayers, at every step we are reminded of death. And we are reminded of this moment which is short. And this moment which is temporary and therefore we should be doing with ... So that means, death is not something that we don't think about. So religion, so this is the religious philosophy. So therefore, religion in a way is encouraging us to do good deeds and have charity, humanity, believe in equality, because all of these are good things if you want to become one with God and be free from death and birth. But with less pain and suffering, that is bliss. And that is peace where you want to go.

But when we say culturally, we are not ready to talk about death. Death is something, talking about death is very bad. You should not be talking about it. Because if you talk about it, you make it happen. So therefore, we're not ... if my person is sick, absolutely sick and though we know that death is coming, we don't have to tell that person "You are dying". We just tell [them], "You will be okay. You will be fine. Have trust in God. Have faith in God. You will live a hundred years. You will see the wedding of your sons and grandsons and great grandsons" like that. So that kind of thing, culturally we never talk about this. It's not ...

As I told you in the beginning, things are changing of course and we are talking. But traditionally, if you say, so this is something, and even death and dying is stigmatized. So what we in ... culturally, when we are ... we're not supposed to be talking about death. So if we are not talking about death, then how can we talk about advance care planning? Because if this topic is a taboo and we want to deny the fact that we are dying, and we don't want to tell the other person that you are dying. Even I have seen a patient who would be having a cancer and the family members don't want to tell the person that you have cancer because that means that person is close to death and it's a nasty disease and death will be coming soon, sometime in a few years or a few months, whatever, and we don't want to break this news to that person.

So now when we come to, so when this topic is a taboo and nobody likes to ... if I want to talk to my mother in law or my father in law or even my husband for that matter, in terms of I want to plan my life ... This is my second marriage to my husband. I have left India - my security, my this, my job and everything else - and I'm here. And when I feel insecure in the sense that I don't have earnings and I don't have ... and if I want to talk to him that "This is our life together and if something happens to me and you won't be financially hurt because you're all set. You're here for the past fifty years. But if something goes wrong with you and I'm here for only the past five years and, where do I go, what do I have?" Because I've signed a pre-nuptial. I've signed this and that.

And he doesn't like it and he thinks that I'm a bad wife because he says "My ex-wife" - I mean late wife - "never talked about this. She never even thought of that moment. She trusted me. She believed me." So he would say - I'm telling you because this is some place you say you can share even your stories. And this is, I'm not talking about one person but it's not his fault but the way he has been brought up and the way, what has been taught. Because if you talk about it, this would happen. So "My late wife never talked about this." So that means if you talk about this, probably you are wishing that when I get rid of him or something like that. I mean having those negative parts.

I'm telling you - this is the fact. I cannot talk to my mother about this at all. My sister who lives in Italy - Milan - so she at some point of time talked to my mother about "We should be knowing. We ... I'm there, my sister is there. There's nobody with you if you fall sick." Something like that. [My sister] she phones her every day and somewhere in some conversation, some

indirect reference to this thing is, would have come. Not exactly explicitly death, but something what will happen in a few years. And then my mother phones me and she tells me “Look, what she is talking [about]? She’s talking to me like this.”

So she thinks she [my sister] is bad and she thinks I’m good because I never talk [about] this topic [laughter] because I know that she won’t like it knowing her nature. And she said “Oh, she’s wishing, she’s thinking that when do I die and what then happens to her inheritance and ...” So she said she’s selfish and she’s this and that, whereas my sister is acting very responsibly. And she thinks that as a daughter she should know and if she’s away and something happens to her in her absence and how do we approach this? So whatever kind of ... But this is how my mother thinks. And my mother who has been born and brought up, lives in India – even she is educated. She has all her life a white collar job. And my husband who is a very high profile person – highly educated and lived all his life here – and he also thinks the same thing.

So therefore, when we talk about the palliative care, we talk about the planning, advance planning. So in the South Asian culture, the advance planning is traditionally nothing. And we need to educate the community. We need to tell them that there has to be public education.

So the first thing on advance planning is, has been traditionally having a boy. Having more children, particularly having a boy – investing in the son. Because traditionally, now we have when we get old, we have old age pension. But earlier there was not. So we need to understand that too. So that means that was their insurance policy. So that means investing in, because daughters will get married and they will go away. And these are the sons who will look after them in their old age. So investing in having sons and investing in some praying to have a son. Or praying “God blessing me with a son” was important for them because this is the son who is ... There are no old age homes. Now we do have and things are changing.

But traditionally when we say, but then when we see people move and come to say, this country, where things are different, you have counselling, you have palliative care, you have all those kinds of Western medical education and facilities and infrastructure in place, but still it is difficult for every day time for people to break away from those traditional thinkings and get into the new ones. And as I told you that people are changing but it is a very slow change. So this was traditionally, it was having a ... so that was advance care planning in my opinion and, when I look at and I understand culturally my community. So that’s ...

But then we have to leave that, and we have to come ahead and we have to think differently because things are not a similar situation or not similar ... people in agricultural society and that was the land was an asset. People are now earning their own ... so things are different when we come here. And also then, investing in property and making property is like having an asset. Investing in again a lifetime advance planning in terms of then using it as a tool to traditionally, again traditionally things are different here now. But traditionally using this asset as a tool to not only sort of control children – control in the sense that I will pass it on to you only if you look after me. And therefore making the child bound, that I have to take care of the [parent]. So they are of course changing now. Now children are not giving that much attention to it. “If you don’t give me, that’s fine. I can make my own money.” So those things are changing.

But then when I’m talking about culturally, so people, there is still in that stigma or shame attached to going to hospice and palliative care. So if I am a parent and I’m sick and I am being sent, or I choose to go, then what I will think how will my community look at this? That maybe I don’t have a good relationship with my kids. I did not bring them up well. They are not ready to, at this stage, take care of me and therefore I’m being “sent”. So I am worried about my community. How would my community react? And as a child, again I’m worried, because of the way I’ve been brought up, if I send my parents who are

old and sick and they need 24 by 7 care and it cannot be provided at home, if I .. then how is my community going to respond and respond in the sense that I have dumped my parents. This is the wording, that I have dumped my parents.

So those kinds of things are changing but it will take some time. As you know, that communities are evolving and they are getting exposure to the Western way of thinking or the Western facilities that are here and then taking advantage of those. So those are some of the cultural ... but then again as Parin mentioned – she was giving the case of Fatimah, I guess, in terms of a recommendation when I come to of course community groups, senior citizens groups, temples and religious institutions can play an important role in public education. Even media for that matter, where I know that there is one temple in Surrey where every Thursday, some speaker is invited to speak to the people who visit. So those could be a help, workers and also then having health fairs and education fairs. There's one I guess annually in Coquitlam, the one from probably ... isn't there one in ... health fair.

MULTIPLE COMMENTORS: Surrey. There's one on the Island. Well we have health fairs, yes.

NEELU KANG DHALIWAL: Okay. But then when we are talking about home care, so what happens is, now there are different things for the South Asian community. Going to a hospice and palliative care is very threatening. So that means if I'm sick and I go there, who is going to take care of [me]? Those people are not my people, in the sense that, first the language barrier. That is big. Then the culture barrier. They will not probably understand. So therefore maybe I want to be looked after at home by my own people. And my own people – my daughter-in-law, my son and they're all working full time. They are earning. They have to make their living. They cannot leave their work and ...

So maybe something like that so my daughter is ready to take care of me. And she is then being paid instead of that she takes off for one year, for six months. And she's the one who is looking [after me] ... Because she is being paid instead of she taking off for one year , six months, and she is the one looking [after me]. Because she culturally understands me too. And where she says that the nurses – Parin gives us a case study that a nurse goes to a home , so she bathes her, she gives a wash, she gives her medicine, she gives her food, but then it stops. It's full stop. There's nothing more than that. But how seniors or who are sick, they're close to death or under hospice and palliative care, what else do they want?

So there's a very good point that storytelling was made, and another very good point that what beyond medicine? But the ... so culturally speaking, South Asian people would love to have people around them and talk. So storytelling is a ... and one can, if we come to think of death, there could be various ways and methods that we can devise those stories, storytelling programs. We can have another brainstorm ... how we can do it, what would be successful. We can make a whole program of charting out the steps – one, two, three, four – and how to execute that plan. That's another exercise. But that is a very good thing. And then because they want their own people around them and talk. They like to talk and also reflect upon, seniors in retrospection, looking at their life and then sometimes giving those life-long learning lessons to their grandchildren and to ...

So something which may not be possible in that kind of scenario which is out of home, their own home, with families, or if there is some way we can treat that, but then some kind of alternative arrangement can be done where the same kind of care is being provided at home, at the same ... But I also don't want that, in my opinion, that making it fully home-limited. But similarly at the same time we can try and encourage through public education that how they themselves become willing to come or being sent there. And that this is not a bad place and that how they can be taken better care of and ...

A lot of you know what I mean to say is that public education required in this context and at the same time, whether these are health care professionals or volunteers, need to understand their limitations culturally. But then we also don't want that

these are your cultural things, but we can always and in many ways construct or reconstruct those thinkings and through public education and persuade, not persuade, convince them through public education where they become more receptive and welcoming to the hospice and palliative care. So these are some of the limitations where, as I told you, that people are changing on their own. When they look, when they face those kinds of problems and they have those challenges, when they try to solve those issues, hidden trial. They sometimes reject certain things and sometimes they start, sometimes somebody is forced to go to this kind of a place. And the person is very reluctant to go. But then they find that it was something very good that happened to him or her. So people are learning.

But I think public education via different, using different medias and making people educated about this ... Because this is a new concept for them. Planning, again, advance planning is something very new for them. It's very difficult for them to understand . So they're not used to ... this is not something they have ever heard about before. But then through public education then how important it is.

I know about when mother was about to, in a dying kind of a situation, and there was – you [Parin Dossa] were talking about the conflicting situation – so two sisters were fighting. They were [inaudible] because one sister is very emotional, the other is very rationale and she says, “No, this is the right thing that we should be doing.” At this [time]. And mother who is – she cannot make any decision at this point of time, she's very critical, terminal ill position – and the other sister who is very logical thinking and she says, “No. This is not right. This is what we will do.” But nobody knows what the mother wants. What are her wishes? What would she think that if this kind of situation this, if this kind of situation this, if ...

Many times people spend ... I may not like any kind of prayer to be done in the temple after my death perhaps, but if I don't tell this, our planning along with my family members and talk and discuss, then I would tell them that. Otherwise they would probably do fifteen days prayer in the temple and feed how many people or whatever. I might say “No. This money should go for some endowment under some charity.” Who knows? So therefore, through public education I think it is very important. And this is a new concept for them. So we tell them that how this can help – advance care planning. And then public education that death is a reality and we need to talk and everyone talks and this is a good thing for them to come out of this stigma or taboo that death is not something, a good topic to talk about. Public education can play a great role.

BARB PESUT: And that story is a very good one of the two sisters ...

COMMENTOR 6 [Beth Kish]: The volunteers are a resource that we forget. That right now we've got a huge influx of South Asian volunteers and that, they spread the word and they get into the community. Until recently we didn't have any. We didn't have a Punjabi speaking councillor and we offered grief support and didn't provide it in another language. So we're learning and changing. I think some of the best resources are right in front of us. And they spread the word and they learn to care. And when you are with somebody that's dying and you develop that talent to just open the space in the room to help them to tell their story, it's often not just a culture, it's good for anybody that would want to do that. But those volunteers are just, I'm just in awe of them, the talent they have and the care that they provide. But culturally ...

NEELU KANG DHALIWAL: So when I talk about South Asian culture, it doesn't mean that I don't know about other cultures. But it could be true of many other cultures. But in my observation, just based on, so therefore, that is why we can't just say that it is typically about this because there are certain things like when we talk about violence, that there was a lot of hue and cry [about] violence against women, and it was considered as South Asian typical. But that's not true. It cuts across all races. So similarly, therefore because I'm not aware of other cultures, so that is why.

But she has made a good point, Beth, that South Asian volunteers, when/if we have plenty of them or we can increase their number and we can encourage people to get into this field in terms of counselling because people, old people because they can't speak. I mean English, they don't understand. They would impose more trust, perhaps in them, than if it is a non-South Asian. Understood. That's right. So I would probably ... and if you have any questions, I am happy to answer.

**BARB PESUT:** Do you have questions?

**COMMENTOR 7:** I have a comment. So both Parin and you, Doctor, have done a great job outlining some of the issues, concepts, religion-wise. I really appreciated the conflict between culture and religion and often how that comes out. I think what's also important as you were saying is when thinking about the South Asian culture, even people who are Muslim are part of the South Asian culture. They've immigrated from different perspectives, from different regions. But even within the South Asian culture, there's diversity. And so often you can't really assume that one approach is going to work for all.

As part of my PhD I'm doing some data collection now. And it's very interesting because I've been talking with South Asian older adults and their family caregivers with issues around access to residential long-term care and end-of-life care. And I've had, just generally in a few interviews, a range of comments. I've had comments saying that "When it's God's wish when I die, I will die. I will worry about things when the time comes. And my children will handle whatever needs to be handled afterwards." Then ... and I had two instances of that ... and very reluctant to really talk about even residential long-term care. And thinking about that aspect of potentially if you had to move because your family couldn't provide the level of care that you needed at home, how would that work?

But what I wanted to say is I had another interview where the family caregiver who was the daughter of the senior was saying, "Well, my Mom's talked to me about everything that she wants when she dies and I really didn't want to talk about it. But because my Mom wanted to talk about it, we talked about it. And now I'm comfortable that she's content, that she's told me what she wants." So just that the diversity and the readiness, I think, to talk about these things. And in fact this woman, who was wanting to talk with her child about the things that she might want was a result of the fact that her husband passed away and they hadn't prepared or talked about anything. And so now the Mom is saying "I don't know if that's how I want it. I think I need to tell somebody something about what I want."

So the diversity within the community is important and one of the things that I've been thinking about is that regardless of culture, how to have that conversation and where might the starting point be. And perhaps the starting point might be, when somebody is beginning to be ill, when somebody has had a diagnosis – whether it's a chronic illness that could go for a long time or a terminal illness – but then the question arises, how do you have this conversation when you're not going to say death or dying. And I wonder if the conversation is really about what's important for you to have while you're being cared for. What are the things that you would, that are important for you in terms of the type of care you want, whether longevity versus quality of life, and of course not in those terms because those are medical terms that I'm using but trying to understand where are they situated in their thinking rather than using terminal illness or that "you're going to die" or ... It's trying to ascertain what's important to them. And I haven't quite figured this out because I'm just beginning to explore in my PhD how can we begin to have these conversations regardless of culture. Because I think that there are difficult conversations no matter what – moving to long term care, end of life, so I just kind of wanted to just put that there.

**NEELU KANG DHALIWAL:** I thank you for pointing out but I didn't mean that. I do recognize there's always diversity and ... But I was just speaking at general level, by and large what is, how the conversations are held or not held around this issue.

BARB PESUT: I have a question for you and it relates to ... so much of hospice is very, arose out of the idea that people, that is provided a particular service for people. And in many parts in our culture it's that people do not have people to look after them at home. So for your culture, what would be the thing that hospice would offer that would be attractive, that would offset the idea of the stigmatization of my family not looking after me. And at this point, if people are cared for in the home, how do you find the ability to deal with symptoms that arise near the end? I'm not sure if you can comment on that.

NEELU KANG DHALIWAL: Really it is hard to say but as I just said that public education can help but in terms of home care, these people would prefer to have their own family members. Because even though they're, we don't have many joint families and extended families here. But if you would see that in South Asian culture, people tend to live very nearby, like two blocks away, one block away from one another. So the sons are married and the daughters are married and besides that, there are also they, not only sons and daughters – their family – but they are very extended: my niece, cousins, wives, so and so like that. And so there are, and people are in touch with them and people know them and they phone them.

So many times those people, because my sons and my daughters are busy, they're young, they're active, but there are still some people who are old but they are fit, still to work. And they, sometimes they cannot drive. They need somebody to be dropped, or there is distance but they are ready to come and help them. In the sense they would come and many times they do come and then they would cook for them for one week because they cannot come every day.

But in some way, if something could be arranged where if they need a lot of attention and care, so somehow making use of these people who are not working and making them employed. And giving them some salary so that they get some stimulus, they get some motivation and it gives them some accountability as well that they're being paid for this and they ... Because they would just come and do it voluntarily. So instead of someone else coming. And then we do have professionals also coming, depending upon the situation, once a day for some time, once a week for some time. And then also give these relatives who can afford to come, some kind of education that if this kind of emergency arises, if this happens, this is the phone number that you need to call and this is how you let us know – something of that kind. This is what I'm thinking. Thanks.

BARB PESUT: Well it's 10:30 so unless we have other ... I just want to thank you both for coming and sharing those insights. I have to tell you I think I learned more in the last hour than I've learned over many months. So I have something for you both from BCHPCA – a little gift for your contributions – so thank you very, very much. [Applause]