

Appendix 11- A marked up interview transcript for Mrs Dolly Islam

Codes	Transcript
<p>Describing that topic is manageable to talk for her only.</p> <p>Working with Bangladeshi people as community worker.</p> <p>Describing different roles of her that suits her all.</p> <p>Describing about different views of everyone. Stating that older people are not satisfied with hospital.</p> <p>Talking about “no choice” at health services.</p> <p>Explaining that existing social structure that makes them for this situation.</p> <p>Recalling her home country culture of caring older.</p>	<p><u>Research notes:</u></p> <p>Dolly was a key activist in Kollun Bangladeshi women’s welfare centre. Kollun was a Tower Hamlet based voluntary organisation that works particularly with Bangladeshi women’s in terms of educating about social living skills.</p> <p>I met Dolly Islam while I open meeting with another community group, called Bengali International where her husband was a member. She volunteered to herself to be interviewed and also she invited me to work with their organisation.</p> <p>Thank you for accepting my invitation. Please introduce yourself and then tell me that how do you feel about talking such topics?</p> <p>Di: That’s alright for me. I have been living in Tower hamlets... for in 8 to 9 years. I have been working 33 or 34 years with Tower Hamlets Bangladeshi people as a community worker, community informer or activist... Whatever which way you think that it suits me.</p> <p>Yahh... different people have different views. (generally) People are happy not in their older days with hospital. But they have no choice... They think like that. Because our community... our social structure... like that way... in olden days... children thinks it is their responsibility to look after their parents or grand parents. It is easy in our country. Although it was a poor country but still it was easy. But here lots... lots of problems... Lots of restrictions... lots of time consuming and space extra. It is very... very hard. Although they think that they can look after their parents, but it is not possible. It is not good for the older people and also it is not good for the family who want to do that.</p>

<p>Sending her friend to Hospice as no one to care at home.</p>	<p>Hospice...St....Hospice. I visited the Hospice for couple of times and I saw her there. I felt very sorry for her... very very sorry for her.</p>
<p>Feeling sad to be admitted in Hospice.</p>	<p>She did good things for lots and lots of people. But in there... the nurse... she has language problem...language barrier. She cannot express her needs... her pain... her problems which is our people...</p>
<p>Describing about communications problems in Hospice</p>	<p>means (for) South Asian people... the another problem that is I believe 95% cannot speak their problems. Especially the medical terms... they don't know anything. The other one...one young lady...she was our treasurer. She was 32 or 33 years and suddenly she fainted. Because the Asian people... she was losing weight and they taught that she got TB and it was wrong diagnosis. Latter on... after a month... no it is not TB and gradually they said it was brain cancer. That cancer...so quickly it spreads lungs...breast.</p>
<p>Inability to express her own needs</p>	<p>After couple of months she passed. I saw her in Hospital...it was so hard that time.</p>
<p>Misinterpreting diagnosis based on ethnic origin</p>	<p>So people want at their last couple of days family friends together. Even I also expect... I will die one day and nobody cries for me... I cannot believe that... (Laughs).</p>
<p>Experiencing dying from cancer as hard time</p>	<p>KR: what is mean by nobody will cry for me? DI: Yahh... nobody will hold my hands. I can think... I will go ...nobody will see me in that time and I will not able to see other my family...my friends.</p>
<p>Expecting togetherness at end of life</p>	<p>KR: OK... so what is your expectations at end of life DI: It is very hard to tell... because it is depends. People loves to stay home...I Know that. But that time... home is not sweet home. Because other people... how they can care the patients in home. That is different... is that it? Person to person or environment to environment or patient to patient. Some patients are really they don't know like a cabbage. But still they want to stay home. But it is hard for the relatives... friends to look after that kind of patients, if the hospital is not giving that proper support like nursing or the</p>
<p>Wishing that death and crying is a expectations</p>	
<p>Not being able to die without cry: a culture of death</p>	
<p>End of life personal preferences: Holding hands while die, like to see friends and family</p>	
<p>Inability to describe expectations' since as individualised</p>	
<p>“Home is not sweet home”: preferred place of care</p>	
<p>Being cabbage but still wish to die at home</p>	
<p>Seeing as family burden for eol</p>	

<p>at home</p> <p>Expressing importance of health services support for home care.</p> <p>End of life decision making: unconscious vs. conscious at eol</p> <p>“I am on the way to go”: Thinking about family than personal choice</p> <p>Viewing Caring at end of life as emotional torture for family</p> <p>Viewing Hospital as a practice “better” place for eol. Expecting exclusive nursing homes</p> <p>Expressing notions of “ready to pay” for getting good eol.</p> <p>Expecting family not to be burdened</p> <p>Listing out home care needs for end of life: carers at home</p> <p>Stating that good communication makes meets needs of eol</p> <p>Illustrating the practical</p>	<p>trained carers for the last couple of days.</p> <p>KR: what is your opinion of end of life care wishes</p> <p>DI: If last couple of days... If that person knows ...if I know that I will not survive, I like to stay at home. But if unconscious, that time... I don't know... I am conscious or unconscious. If I am conscious, then I will see the family as well that how they coping with me. Because of myself I don't want to kill. I am on the way to go and they have quality of life. So I will not torture them. I feel the emotion... that emotion is torture for other people.</p> <p>KR: If you like to be stay at home you don't want to be burden your relatives. Then what is the solution</p> <p>DI: You know... Hospital is better. Or if suitable (nursing) home... You know sometimes older people live in (nursing) homes. But for our Asian people... I don't think so there is proper Asian people` home, where couple last days or months they can stay and family can...you know. Sometimes they are ready to pay the rent but there is not a suitable place.</p> <p>If you preferred to die at home what kind of service without burden</p> <p>DI: Then I will expect that because if the family members are working, I Will expect somebody give me right time medicines...right time food and other natural needs to fulfil like want to go toilet like that sorts of things ...somebody care for me</p> <p>KR: You mean 24hours care service</p> <p>Yes sometimes we need 24hrs carers</p> <p>KR: You said couple of incidents... what kind of services they received at their end of life?</p> <p>DI: Our treasurer went...to Hospital last year she passed away and that girl she can speak English and so there was no problem until she went to unconscious. But other lady...our user... she cannot</p>
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<p>difficulties with communication barriers</p> <p>Being away while at needy moments</p> <p>Explaining that her friend can speak but not communicate</p> <p>Illustrating benefits of ethnic exclusive eol caring environments'</p> <p>Taking back, caring and dying at home.</p> <p>Taking family decision to die at home</p> <p>Supporting death at home</p> <p>Enacting the end of life preference</p> <p>Expressing the prefers to die at home</p> <p>Home is not sweet home vs. home is not only house</p> <p>Taking decisions based on the condition</p> <p>Not taking chance of long suffering: life prolonging treatments.</p> <p>Stating that yet not think about.</p>	<p>speaking...cannot ask anything... even glass of water. So last stage really.... really painful. Two daughters were out of the country. Only before 4 or 5 days before one of her daughter came. But that's not right. Because she can speak...she can tell others. How she is suffering what she need and how she feel comfortable. If she is in her own environments, if that is Asian people care home or hospice home, then somehow she can feel that someone is with me.</p> <p>KR: she was been in the hospice and she died in the Hospice?</p> <p>DI: No last days... I think one or two days before they brought her to home.</p> <p>KR: Who took this decision?</p> <p>DI: Her daughters, son in law and husband. Hospital gives the carer and bed, because she needs a special bed. They charge 1400 pounds for that, but still they give bed.</p> <p>KR: So she died at Home</p> <p>Yes</p> <p>Who made the decision?</p> <p>Family</p> <p>Whether she wants to come home or the family ...</p> <p>I think she wants to come home.</p> <p>Is this normally happens in the local community</p> <p>I think people loves their home, because the home is home, is not only house. Is it not? so</p> <p>Well... when Doctor said for example you are going to live only couple of months or weeks or days, are you prefer some sort of life prolonging treatment?</p> <p>It is different, based on what kind of suffering I am having. Like if I am unconscious or totally I have no hope to cure, then I will not take the chance to get long suffering.</p> <p>Who will take this decision?</p> <p>I am not thinking (about that)... My son... I know that my son will not agree with me. In my case I will tell to GP and write it before</p>
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<p>Informing GP about eol wishes and document.</p>	<p>that.</p>
<p>Discussing eol at “sometimes”</p>	<p>Have you had of any kind of discussion like this with anyone?</p>
<p>Informing family about eol preferences</p>	<p>Sometimes we do. Sometimes like my husband, because he is a doctor, he doesn't like that ... if accidental death... what you called...post-mortem... he don't like that. He said that post-mortem can bring the reason, but the person will not come back. In his medical records, he wrote that not to do that. What ever happens, not to do that?</p>
<p>Documenting eol at medical records</p>	<p>What about you?</p>
<p>Expressing views of post-mortem</p>	<p>If accidental death happened to me as well, I will not prefer. Because to build up the cause may be it help the medical people, but it will not help the family.</p>
<p>Viewing about post mortem as disturbing family</p>	<p>Do you have any kind of discussions for example dying other than by accidental death?</p>
<p>Informing bad news at 2 o clock</p>	<p>Two years back, my husband went into a deep coma and after two days the medical board said he will not survive. That was two 0` clock at night. They told us that call your family and friends. He was not in that machine as well. So, My son jumped and said that no... We will not take the decision, lets god will take decision. Then anyway thanks god... after seven days, he gradually back and he is still alive.</p>
<p>Using words like “call friends and family” to break bad news</p>	<p>Great... could you explain to me bit more about that decision?</p>
<p>Viewing being on ventilators means end of life</p>	<p>Oh my god... you will not believe that. My son... I have only one son, my son continuously holding his hands and calling dad... dad... dad... Doctor testing all way. Even they put probe in feet and all way they tried. In my family and friends, there is couple of friends are doctors around us. Some doctors, like in Bedford, my nephew and his wife also doctors, they took week off to give me support and at least 6 to 7 doctors is my friends. They also took week off to keep my son support. He was holding his hand all most</p>
<p>Believing god as a decision maker Positive experience of believing god</p>	
<p>Explaining her son` dedication to care his dad.</p>	
<p>Getting support from her relatives.</p>	
<p>Not believing about death is near as not using ventilators</p>	

<p>Expecting the information's about the cause but not received</p>	<p>all 7 days. I could not believe that....</p> <p>Calling dad ...dad...Just like whispering in his ears. No... he is not dead, he is taking breath without machine. Doctors did not reveal any cause, why it is happening. It happened twice. He was sleeping on the day time. Suddenly I found that he is not moving. I gave him a tea and it is getting cold, but he is not taking. Then I was in confusion.</p>
<p>Disclosing bad news as a group</p>	<p>After 2 days whether Doctor told to you or</p> <p>We and one of friends daughter, she is local GP and my son and one of my friend was there.</p>
<p>Describing the process of breaking bad news</p>	<p>How did they break the news?</p> <p>They called us, two to three doctors who see him last 2 days. They said us that he may not comeback and if you want any electric shock or life machine, we can try. Then my son said that let me think and I will ring my cousin and I will tell. Then my nephew came from Bradford and she was counselling my son. She said that because uncle is not in good health and he has severe diabetes and some times breath was also weak, so trust Allah... if he comeback, it is our luck, if not let him go.</p>
<p>Taking collective decisions about using life prolonging treatments</p>	
<p>Getting views from relatives with experience of health care</p>	
<p>Believing god and fortune</p>	
<p>Trusting god when no choice left to fight</p>	<p>In that condition normally do you believe god rather than going ventilator?</p> <p>You know... we are human beings. We trust somehow that is the peace. When you surrender god... Allah. Or whatever God, when you have no choice to fight.</p>
<p>Viewing CPR as inappropriate: collective views and its influence.</p>	<p>When doctor giving a choice electric shock and ventilator why did you not opted</p> <p>Because it is very painful. I know that it is very painful. Sometimes my husband also discussed with us as it is a painful procedure for his age is above 70 all and also my nephew told that is very painful.</p>
<p>Influencing the end of life</p>	<p>So your relatives also involved that decision?</p> <p>You know... my relatives ...there are part of my family. So, they</p>

<p>decision by relatives.</p> <p>Withholding views and relies on her sons' decision.</p> <p>Trusting her son love and responsibility to take decisions.</p> <p>Involving decision making as a risk taking.</p> <p>Describing the reason for her son to take decisions</p> <p>Monitoring the decisions</p> <p>Making sure that her husband wishes have been fulfilled: moaning?</p> <p>Describing "time to talk" about eol</p> <p>Viewing as unpleasant despite important</p> <p>Describing after death preferences</p> <p>Informing family beforehand: only after death?</p> <p>Viewing as horrible discussion at last days</p> <p>Describing as people are strong and don't prefer to discuss.</p> <p>Needs early information to plan</p> <p>Thinking about the family than</p>	<p>help my son to take decision. I haven't told anything. I don't want to say anything. I trust Allah. I feel that he need to take decision, otherwise later once he will feel... ohh mum! If we tried that way. So he is younger than me and he is his dad. So I don't want to take that risk... So I haven't tried so...</p> <p>It is another argument because he is male, in South Asian culture you are female and mother that's why given right to your son take decision</p> <p>Not for the reason that because he is male. Because he is our child and he is quite matured as well. So if he takes responsibility, what the things I thought.... it is in my mind. If he goes wrong that no I want to do that let him get the shock, then I tell him.... may be mouning...ohh dad will get more pain and also I will remaid him that his dad did said us before that he doesn't want that since no it is more pain for him.</p> <p>What are the situations do you discuss this kind of end of life discussion death, post-mortems when it happens</p> <p>Actually in the normal time... in the good time you will not think that. For example...now... because we need to talk, we are talking. Otherwise, we don't discuss, because it is not pleasant to talk. Although it is very... very important topic and everybody needs to take some decision...is it not? For example somebody thinks that to send their ash to their country...or send body back to their country. They will tell their children beforehand like that. So that they do after that. But it is a horrible discussion to have in last couple of days and no one wanted to do that. I don't believe that people also are not that strong to discuss.</p> <p>Are you happy to be disclosed the bad news to the person or family or how we want to be disclosed?</p> <p>If we know the information beforehand, then we can choose, which way will be better for us and for whole family. Because when I go...</p>
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<p>her death.</p> <p>Uncertainty about last days.</p> <p>Prefers family discussion to inform her wishes.</p> <p>Being left into their feasibility to execute her preferences.</p> <p>Feeling pity on family if suffer</p> <p>Being lost</p> <p>Smiled and unbelieved about family decision.</p> <p>Endorsing family decision about CPR.</p> <p>Agrees with sons decision Trusting son decision making skills</p> <p>Trusting son for any decision</p> <p>Expecting early disclosure</p>	<p>I will not think about that I am going, but I think I am leaving my family with the pain. So which way is comfortable for them (they can decide). Also I don't know in last time, what I will do. But I believe that it is better that I want to discuss with my family about what I wanted and which way they feel more peaceful for them as well. Because if they see I am suffering lot...that time people are emotionally very... very low.</p> <p>This is very interesting question is after those 7 horrible days whether your husband started to talk?</p> <p>He doesn't know anything. He cannot remember not a single moment.</p> <p>Have you discussed about that moments</p> <p>Yes...he did not believe that things happened and that he doesn't believe where the 7 days last.</p> <p>Here my interesting question is after one or two month when you said about your decisions that you took around his end of life, what was his reaction?</p> <p>He smiled (she laughs)..... His eyes say I cannot believe that.</p> <p>The decisions that you made in name of Allah but it was his life because everyone what was the reaction from him?</p> <p>He said you took the right decision, because he is fine and he came back in a good condition. He said that it is a right decision and also said ohh god if you decide to give electric shock, it was a very painful and break my ribs. He is taking like a joke, but we know what we faced.</p> <p>So do you mean that after the incident he agreed with family decision?</p> <p>Yes, he agreed that was a right decision.</p> <p>So he did not say why you did not opted ventilators agreed the family decision?</p> <p>No. He has not no problem.He said that (my son nick name is Lingan...) Lingan took the right decision, because he will not let me (she laughs).</p> <p>Is it your culture?</p> <p>No ...It is love and trust.</p> <p>Ok...so I think like do you want to be disclosed about any</p>
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<p>Self decision making.</p> <p>Being lost hope after cancer diagnosis. Need for information and direction.</p> <p>Being confused about nurse presentation.</p> <p>Volunteering to talk as a role model as a cancer survivor.</p> <p>Viewing cancer also one kind of disease. Encouraging peers to use health services.</p> <p>Describing about people miss-concepts regarding cancer.</p> <p>Encouraging peer group to use services.</p> <p>Feeling strong to be disclosed</p> <p>Feeling others Describing the process of disclosing: making the situation</p>	<p>terminal illness to you...If you are in that situation?</p> <p>Yes... I will... I will...</p> <p>Or do you want disclose only to your family?</p> <p>No I will because like...I like my own decision. Because women's are women's. In my organisation, lots of women come and the women's with breast cancer or uterus cancer, they think that is their end of life. But if they get right treatment, they will not feel like that way. If we open their mind, ask them to go to doctor, get tested and get right treatment. I do such kind of counselling in hospitals sometimes.</p> <p>Ok the situation is</p> <p>I give example of my self. In one of the meeting in last year, one table of people were talking about breast cancer. There were lots of mixed cultures of women. I realised that Bengali women did not understand about what the nurse was talking about. I stopped the nurse and said I am a best example, I am living with cancer, so let me to talk with them. I told them that they diagnosed my cancer before 10 years, but still I am alive and I am working for you. It is like a slow disease like other diseases and anybody can get. It is a part of life and it is not crime. So why you are hiding and telling that you will not go to doctor. Why your husband also thinks that ohh no... it is end of the family life. No... Not like that..! Come forward and tell them about your problems and they will find if you have this problem.</p> <p>Ok in this situation doctor comes to can I say your example</p> <p>Yes you can....</p> <p>And doctor comes and tells you ok you are not going to live another three months do you want to disclose?</p> <p>I am strong enough. So I will take it easily... not very easily bur easily. Then I will plan with my son. But some people they will feel very low. They think they will live only two months like that. So how you present the word and to whom you talking that is also one factor. You can tell to the family and gradually the family will tell in right situation to the patient. So you need to make situation to tell.</p> <p>In this situation do you like to make some decisions?</p> <p>I will tell them about which way I like, then their decision. But I will be in unconscious, so they will take decisions. But I will say that I</p>
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<p>Being willing to tell about her wishes Leaving on the hands of the family Including friends in discussion</p> <p>Being advised with people with health care experience Involving doctors in the discussion</p> <p>Describing process of disclosing</p> <p>Emphasising importance of considering family while breaking news</p> <p>Leaving until last moments</p> <p>Wishing to be together Prefers to go to Hospital at last days.</p> <p>Leaving the choice on family hands. Prefers hospital as a better place.</p> <p>Explaining the benefits of place of care as hospital than home. Considering the involvement of children's at end of life.</p>	<p>like it that way, so you think about my wishes.</p> <p>Do you discuss only with family</p> <p>No. With friends also. Usually we discuss with friends</p> <p>Who do you want to included such kind of discussion about end of life</p> <p>My thing is different from others. In my surroundings, lots of doctors. So ultimately doctors will come one by one to help me (take decisions) But for other people... I think if I am in their place, I will involve my doctor.</p> <p>Ok...yes...you already said about best way of doing appropriate decision making and best way of disclosing would explain people want to be disclose</p> <p>You don't tell them the directly. You can tell the family...to the elderly one...whoever the responsible person. If you spread the news to one person, then he will choose the moment and how he will tell the family. Because not only the dying person is important, of course he is important, but the family also important for them to consider how to break the news. So if the doctor tells that ohh your mum will die within two days... That is not a nice way to tell them those sorts of whole life message.</p> <p>It is interesting now about planning about future care? Have you made any made plan</p> <p>If I know that I have only six months, within six months I will plan with my family. I will stay in home with family and friends and loved ones. In last couple of weeks, I will ask family to send me to hospital when I need more medicine and care.</p> <p>Whose choice this</p> <p>If they ask me, I will tell them what my plan. Then they will take decision.</p> <p>You mean last place of care is hospital</p> <p>I think hospital is better place.</p> <p>Why?</p> <p>Because if you need emergency then you can have immediate care. So you can not have such things in home. In home... you are not only the person to fell experience such things. There are children too and they will see that pain and they will go through the pain. So it is difficult you know.</p>
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<p>Not had any decision</p> <p>Making attempts to have discussion</p> <p>Showing resistance from the family.</p> <p>Sharing information's with her relatives</p> <p>Informing his wishes with family</p> <p>Initiating time to time discussions</p> <p>Informing while not feeling well</p> <p>Making relation between her immigration experience and death experience.</p> <p>Making her son as a responsible for eol care: "duty to care"</p> <p>Being agreed with any family decisions.</p> <p>Using hospital as an eol care place.</p> <p>Unpopular word of Hospice.</p> <p>Telling that none had experience.</p> <p>Using community groups as a messenger</p>	<p>What discussion you had about this?</p> <p>I haven't yet decided (she laughs)...</p> <p>So you haven't had any discussion with anybody?</p> <p>No...I try to talk to my son. But he does not like to discuss. He says that you are only started 60. He is soft and he is very completely different type of child. He doesn't want to discuss even to listen.</p> <p>You did initiated such discussion</p> <p>I...I try...I have nice. I talk with her sometimes like what my husband planned such things like where to bury after death.</p> <p>He discussed with you</p> <p>Ohh He discussed with me and with my son.</p> <p>When it happen?</p> <p>Time to time... he tells.</p> <p>What is time to time?</p> <p>Like... if he is not feeling well or time to time, he tell us like if I die.. You do that like that sort of instruction. But in my case, I saw the liberation war in my country. Where the people die... nobody knows. (She laughs)... so I said to my son, when I die it is your duty that what you do with me (laugh). I told my son like that. I said you are not seen the war but I seen saw freedom fighting for my country so it is your duty what you do.</p> <p>So you are happy with any decisions what ever your son takes</p> <p>Yah my family takes.</p> <p>Well what kind of services do the dying person in East London they received... from you experience?</p> <p>Most of them if they die from sudden heart attack or stroke that sort of things; usually they go to local hospital.</p> <p>You mean general hospital</p> <p>Yes. General hospital. Hospice is not any popular name for our people. Because nobody had that kind of things that.</p> <p>What is your opinion about Hospice?</p> <p>Hospice... (after silent) I think like lots of community groups we have and other people even GP also can talk about Hospice to this people. Even you can visit the case beforehand to see other people. It is true that everybody will go someday or other day. So it is</p>
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<p>Explaining the methods of making awareness.</p> <p>Expressing about lack of control over last days.</p> <p>Comparing communication facilities between hospice and hospital</p> <p>Feeling lonely while in Hospice</p> <p>Stressing the Hospital as better place.</p> <p>Making a wish to have exclusive eol unit.</p> <p>Pointing out importance of language.</p> <p>Describing the preferred last moments.</p> <p>Informing about adopting the importance through generations.</p>	<p>truth. People should realise this. Anyway there is no choice what is happened last days.</p> <p>You said you visited hospice what is your experience</p> <p>It is clean place. When I went to visit the lady, who cannot speak the language, there is communication gap between nurses. But like a child, you need some sort of comfort from closed one like that. If in Royal... hospital, lots of interpreters, lots of doctors, nurses are South Asians. Even the other people` visitors, though they may not be your visitors, still they will say hello. You will not feel that lonely.</p> <p>Do you know have any other local end of life service</p> <p>I think hospital. Although hospital is not good place...without hospital there is not place.</p> <p>You said about people not heard about hospice even you came from good health professional background how to make such end of life care service aware to the local people</p> <p>I know there is a possible. Great Britain is a big place and lots of faith things happening. In England, more than 106 languages that the people speak. So it is not possible, but if...if...I am talking if... if possible may be unit for Asian people, where we can provide more cultural religious things not only the language. Because language is important factor in last days. When someone hurt you will speak in you language is it not?</p> <p>So people in last days, they want to talk in their own language and hold own peoples hands even lots of doctors and nurses support. If they make that sort of corner for Asian people...I think gradually things will improve. Because you may be second generation and your son will be third generation and their children is forth generation like that, gradually they will know the world and the environment. Although your father or our grandparents they live in this country, but their full of mind is your country...Asia..! Is it not? They expect like that way I told... I will die... nobody cries for me. I don't like this. But in this country, people have no time to cry.</p>
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Keeping own culture still in heart.
Expecting death moaning in Asian way.

Informing about the need for information.
Pointing out that the traditional methods of information generation often fails.
Using face to face interactive methods works well.
Making them to think makes things better.

Spending lot of money on traditional methods often fails

Discussing why olden methods fail.

Conducting workshops may help to retain the information.

Cultural flexible ways of information generation
Pointing out about the misunderstandings about Hospice: Jamkar
Being shocked about the misinterpretations
Meaning of Jamkar-slating

Have you feel adequately informed about end of life care and So what kind of things you like to know about end of life care

No...Actually I think that different organisations can talk about this. Because leaflets, brochures are not enough. Lot of people cannot read that. If time to time if we do things like workshops for even if we start from 50+ and group wise to discuss about which sorts of options and facilities available, they can get ideas then thinks twice and things will improve.

Do you have any other tips?

Why I am telling this is, in here...the health authorities, they spend lots... lots of money to make brochures, leaflets and sometimes compact disc. But they never had been useful. Do we know whether man or women have access to play cd at home? Or do they know the language to read the leaflets? They take the leaflets and through away. Because I am living in this 33 years and working with them, so as I can see more.

OK...So they may not prefer leaflets?

No if you do like small... small workshops and then send the message, they will keep something... not all... still 50%. When suddenly when doctor tell those people, I am sending hospice... ohh yes I heard that word and it is not a bad place and they will give good care as well.

Other than workshops another ways

You can do general meeting tell that. Because it is very... very sensitive topics, so you need to talk to them with passion and kindly. Because you are giving message that is not about a journey we are going for holiday something is it not?

When you gave open meeting talk on that day, they women are talking about hospice as a Jamkar. I shocked when I heard that word, how they choose the word.

Jamkar?

Where the people would be slaughtered...the last place. I was looking on that that lady, because I know what they mean. Because they thought it is a last stage.

<p>Explaining about ignorance vs. views. Being first to use the word to them.</p> <p>Listing out appropriate people who can be good messengers</p> <p>Trusting religious people words than medical words.</p> <p>Being paranoid about medical opinions.</p> <p>Giving importance for religious leaders words.</p> <p>Uncertainty about end of life Prefers to be with family at end of life. Leaving in the hands of family to decide the place of care.</p> <p>Emphasising the social influence on family decision.</p> <p>Not been thinking about eol preferences. Not thinking about such discussions Importance of family than friends in decision making</p>	<p>Is that view of community about Hospice? They are not views...because they don't know the word. How they can give views. Just on that day, you break first corner of the ice... Otherwise they don't know. There was 9 to 10 women's and they haven't not heard the word before that.</p> <p>Who will be appropriate person to inform such kind of information? Community leaders, Community groups even that mosque... temples the priest kind of people. Ordinary people... like you and me; we have logic in our mind. But some other people have no logic and they fully believe each other. Particularly if the priest... Molina...mosque people tell something... ohh nice... it is alright he tells us so, it will be true. They will not count doctors words, they think that ohh... doctors have some reasons, like some avoiding things and there is selfish behind that decision. But if the mosque person tells, then they will think several times.</p> <p>What are most important things in end of life? I cannot think that way, because I don't know which way I am ending. So I cannot think. However in last days as long as I am not burden to my family, I want to stay with family. Then if I am conscious, I will ask them if you not able to cope with me send me to Hospital or whatever suitable you think. So it is their decision.</p> <p>Any other preferences at end of life care? No. Because what I feel that, because our social structure is like that... you will not take own decision, only family will take.</p> <p>But what is your preference? If it is my preferences... I haven't thought yet....(laughs).</p> <p>Have any friends discussed with you? No... No... I think our people will not thinking like that kind of discussion.</p> <p>Time to time?</p>
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We discuss...but I believe when they go home they will not tell to family. Because some point although I am friend, I am outsider. No one tell decision... you will not allow me take decision for your mum.

Thank you for your time...We are at the end of our session do you want to tell anything more

No thank for coming here