Basic Certificate in Palliative Care
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Week-12
Lecture 08: Panel Discussion

Dr. Piyush Gupta: Greetings from National Association of Palliative Care for AYUSH and Integrative Medicine, an organization in association with Department of Global Communications of United Nations. I am Dr. Piyush Gupta, Secretary of NAPCAIM as well as Secretary of Cancer Aid Society, which is having a special consultative status with United Nations Economic and Social Council. And together we have our colleagues from National Association of Palliative Care for AYUSH and Integrative Medicine, Mr. K.Radhakrishna Menon, Dr. K.L. Babu and Madam Malarvizhi. So I would request Mr. K.Radhakrishna Menon to kindly introduce himself.

Dr. K. Radhakrishna Menon: Good evening, I must first of all congratulate the students who have been in, who have enrolled for the course, for the foundation course being undertaken, taken up by the NPTEL and NAPCAIM joint venture.

This is a very good course and every student will understand the depth of, you know, depth of understanding, the learning new knowledge in the field of science and palliative care. And first of all speaking I am K. Radhakrishna Menon, National Vice-President of NAPCAIM. I had been to palliative care way back in 1997, working in different capacities in the state of Kerala.

And in Kerala as all of you may be aware, palliative care is volunteer driven and we have a very good volunteer strength and nearly 900 palliative care centers are working across the state. Thank you.

Dr. Piyush Gupta: Dr. Babu, can you introduce yourself?

Dr. K.L. Babu: Yes, I am Dr. K.L. Babu, former principal and professor, Government Homoeopathic Medical College, Kozhikode, Kerala and I am the Assistant Vice-President of NAPCAIM, that National Association of Palliative Care in AYUSH and Integrative Medicine. Actually I have 22 years of experience in palliative care and it was the home, the project director of SHORE OF SOLACE, a project on palliative care and in management with home medication. And this actually it was a project of Government of Kerala and I had 20 more than 20 years of experience still I am working with this association.

Dr. Piyush Gupta: Thank you Dr. Babu and Dr.Malar, do you, can you please introduce yourself?

Dr. Malarvizhi: Yes, thank you Dr. Piyush Gupta. I am here Malarvizhi K. Natarajan, I am the principal of the College of Nursing from Bangalore, Karnataka and I also deal with palliative care because one of my family member was affected and that has motivated me and I have joined NAPCAIM as a Vice-President, Karnataka State Branch and also I have done my doctorate in breast cancer related lymphedema, wherein I am practicing the management of lymphedema, both cancer related and non-cancer related lymphedema patients. So, that is my passion and at present I am continuing with curriculum also being in the academic side for more than 25 years. Thank you sir.

Dr. Piyush Gupta: Thank you Dr. Malar and maybe Dr. Malar, do you have a carry home message for the students?

Dr. Malarvizhi: Yes sir. As I said I was being motivated because one of my family member was affected, everyone has the same history and that motivates. If you are not having in your family, I think one of your friends or a neighbour will be motivating for you that is why you are here. If you wanted to continue with the foundation course, I think this basic course is going to help you because it has loads of loads of knowledge and practical aspects which will develop the skill what you wanted to independently and confidently take care of the patients, especially in the home care setting without any supervision where you are going to lead and be advocacy for the patients who are dependent on you.

Dr. Piyush Gupta: Thank you Dr. Malar. So, as we all know that palliative care has four major components, one is physical to address the sufferings, treat it may be using modern medicine or AYUSH.

Then we have psychological component because many of these patients are withdrawn and in severe depression. So, how to handle them again requires skills. Then comes the social component where the society's interaction with the patient and the patient's interaction with the society, again it is two way traffic and we have to again work on it to restore it because the patient is totally withdrawn and socially non interactive. So finally, the spiritual concerns are there which need to be addressed because many of these patients are going to die very soon being terminally ill and addressing those concerns again by not only improving the quality of life but also improving the quality of death, cutting down the cost of death. It is very important not only for the patient but for the entire family because right now the trend is that cost of death is increasing day by day and while the patient dies the family comes on the verge of financial breakdown.

So again Mr. Menon, do you have a carry home message to our students?

Dr. K. Radhakrishna Menon: I had a very very rare experience of interacting with a patient who had debilitating illness. She was having a kidney failure, renal failure. So, I connected her with doctors who are already in the palliative care profession and gave her medication and all that but still the pain continued. So, she asked me, sir can you kill me, can you kill me that is the you know the question she asked me. So, in palliative care we do not wish to you know kill patient, we just understand the underlying factor behind.

There may be a reason behind every you know suggestion or question that is being put forth by the patients and the family. So, I asked her why you said so, why you asked to kill, kill you. So, she said I am having a very excruciating pain. So, pain is a reason for her you know such words coming from a patient. So, I was really I was in a very very precarious condition.

I could not make a reply at that point of time. I just paused a while and asked her if that pain is a reason there are you know facilities in palliative care, your pain can be reduced to a substantial extent I will not be able to connect with the physicians who are already in the profession. So, after connecting those physicians morphine and other medicines were given to her and she consumed. After a few days I visited her and she said sir I am getting some sort of a relief. So, that is what palliative care intends to do with patients who are having a life limiting disease.

That is a very rare experience I had and I could not, even now I could not you know withstand that particular situation. I am, I pray almighty that such situation should not occur in any of the human lives. There is a message I would like to share with you.

Dr. Piyush Gupta: Thank you Mr. Menon and with you I remember a case recently which was hospitalized in one of the tertiary care hospitals. It was a liver substance patients almost 70, 80 years old and she was not responding to any of the antiemetics being given and she was also having breathing issues and she was on oxygen.

So, basically all of us had left home, but finally a few drops of homeopathic medicines made us dramatic change and almost she was discharged after a single day. So, doctor Babu my question to you is do you have anything in Ayush when we do not have a remedy for any symptom which is not working in case of the patient of modern any of the modern medicines they fail to work. So, do you have medicines in Ayush and are you really prepared to introduce Ayush medicines to the palliative care patients.

Dr. K.L. Babu: Definitely you know this my with my experience of 20 years you know have lot of come across with lot of patients you know. This pain management is also possible without this opium or this morphine derivatives and we are giving more importance to total care of the patient.

In that case you know that those who are with this dysphagia that you know that difficulty to swallow something and this there is painful swallowing or like that. We can manage the patient with the homeopathic medication and even in certain cases where the patient are coming with this ryles tube now to feed themselves and we can gradually

withdraw the ryles tube and we can put on the patient on oral feeding after medication. Like that we can improve the quality of life of the patient with homeopathic medication. Do not think that you know this palliative care is the end stage of the disease and we have to give certain relief to the patient with homeopathic medicine and there are other systems also that they can also and we can combine all these things and we can give relief to the patient. So, lot of experience I have and the patients are getting relief out of all these things.

All, the better thing is that you know we can improve the quality of life of the patient with the homeopathic medication. Because you know once the patient is under this morphine or this other sedatives they are always under sedation. They cannot communicate with society the family members. So, what we are doing you know we gradually withdraw this sedatives opium or whatever may be and gradually put out the patient under homeopathic medication. They can survive very well, they can communicate with the family, they can communicate with the society. It is a very good thing.

Dr. Piyush Gupta: Thank you doctor Babu and Mr. Menon since you are national vice president and you are involved in training and content development and other issues in palliative care. So, are you targeting only homeopathy or other AYUSH streams in palliative care?

Dr. K. Radhakrishna Menon: If some system of medicine which can give relief we always welcome. There is no point of you know a particular system of medicine alone can do palliative care is a question to be discussed among ourselves. And I am fully I strongly believe that any system or modality or healing practices which can give relief to the patient can be taken into account.

Dr. Piyush Gupta: Great. So, my question to doctor Babu is that many a times because let us say personally many people believe that homeopathy does not act fast. And whereas, the these patients are in immediate need of relief and you are giving for example, they are suffering from multiple issues whereas, we normally give only a single remedy for treating. So, what happens to other issues and can you would you like to say something

on this particular aspect? How you are going to use homeopathic medicines in palliative care and will we be addressing all the sufferings of the patients or they still have to suffer for a few days or weeks and then homeopathy medicine will start working?

Dr. K.L. Babu: You know that in palliative care we have to address the main complaint of the patient, the main symptom of the patient. So, at that stage you know we are giving certain medicines which will relieve the major important symptom of the patient or suffering of the patient. And only after that we will give medicine which will cover the old disease of the patient and the disease condition.

So, in the early stage we will address the most distressing symptom of the patient. So, for example, you know if he is having homeopathy or she is having vomiting, we will give medicines to relieve the vomiting. The only after that you know she can or he can take some food. So, after that we will give medicine to the disease proper. So, like that we can manage.

Dr. Piyush Gupta: So, that means you can give multiple medicines for multiple symptoms at a time.

Dr. K.L. Babu: Yeah, you know that we can change the medicine because you know this at one time you know the only thing may be the most distressing symptom. The next time some pain or something like that. So, we have to change the medicine.

Dr. Piyush Gupta: Okay. So, my friends you do not have to worry. Along with the allopathic treatment you can go towards AYUSH also because they are going to work together and help you in this. So, Dr. Malar would you like to add something?

Dr. Malarvizhi: Yes, you were all listening to all the experts here talking about homeopathy then how to just take the professional help as a volunteer. Now, I wanted to put forth what I am actually doing with my patients. I deal with patients who are having lymphedema.

Now, what is the role of a nurse here? She is coming across patients every now and then and me being in the teaching line, I can teach my students in preventive and management

aspect. Now, this lymphedema can be cancer related or not cancer related. Non cancer related is primary lymphedema or due to any genetic problem which we do not have a control over that. Whereas cancer related lymphedema we know that when the patient is undergoing or diagnosed with cancer he or she will be knowing that this is the stage I am in, the diagnosis time if nurses or any health care professionals who is approaching that patient or preparing for the surgery is being taught what is it they are going to expect after the surgery the removal of tumor along with that the removal of lymph nodes we can just stop the development of lymphedema. This we have trying through research and it is working out well because there are many modalities it is I do not know how to explain it.

It is the techniques what we are following one is that bandaging system, manual lymphatic drainage, skin care and exercises. These all put together as collectively along with nutrition helps the people to overcome this condition because the patients they do not know what to do pain again is due to the heaviness what they are having in their extremities and at the same time the body image is affected as Dr. Piyush rightly said that we have physical problem, we have psychological problem, we have spiritual problem, and we have social problem. Here you can see that the image, body image plays a major role especially for the females. So, we have to overcome that by supporting them in preventive aspects and also promotion and maintain them also. So I think you all if you do not know that what profession we are, but if we learn we can help our patients. I think this is the take home message I can tell the maximum knowledge we can gain and what the best we can do we can help our patients.

Dr. Piyush Gupta: Thank you doctor Malar. So now we have learnt about body image and that is something which is again very important because most of the time when we are dealing with the patients the care givers are not sensitive towards the body image or their privacy issues which affect their psychological well being. So, remember like us if the patient is not active then we have to maintain their body image, their dressing, clothing and grooming. We cannot neglect the patients and whatever their needs are, even privacy issues they are very important because normally if there are too many meetings we may put the patient in the drawing room rather than the private bedroom. So all those issues

have to be taken care of. So Mr. Menon you are a volunteer and do you have a message for the volunteer what is volunteering and how does it help in palliative care what are the national trends.

Dr. K. Radhakrishna Menon: You see palliative care is teamwork actually it is a combination of you know professionals, doctors, nurses, volunteers, social workers, carers, Chaplains and all it is a team of various you know segments of the community. The community itself should come up to take care of the patient who is on the dying side. So in that way thinking in that way I believe that it is a team work and all the professionals jointly put some effort so that the quality of life as well as the quality of death of a patient is taken into account that is one point. Another point is that even after the death of the patient we give bereavement support. We think that after the death of the patient palliative care is nowhere there but it is not.

It is also part of that, rehabilitation is a major chunk of the palliative care activities. Suppose if a patient dies all of a sudden or when we think that the patient is about to die the family members especially the children, the wife who are not bread winners and all that maybe the patient alone may be the bread winner. When he is on the lying bed you know their daily routine will be affected seriously. So the volunteers and the team as a whole will have to take the burden of taking care of the whole family.

There you know renovation or you know rehabilitation is another major component in palliative care which is easily neglected but it has to be taken into account very seriously that is one point.

Dr. Piyush Gupta: Thank you and what are the national trends in volunteerism?

Dr. K. Radhakrishna Menon: Volunteerism you know that had its roots in Kerala. I am really proud of being from that part of the country. I belong to Kerala and apart from the northern when we come to the northern side there are some palliative care in patchy areas not as a whole of the state or taken by the community at last.

But in Kerala things are entirely different. Palliative care is volunteer driven in Kerala. So we take the lead in organizing seminars, awareness programs, establishing palliative care

centers, giving training to the volunteers, nurses and doctors and all that and make them skill. It is a skill transfer is one of the major component to be taken into account. When you are taught then only you can teach others. So in that way thinking we human resource is the most important component in palliative care.

They have to be trained in such a way that it should be beneficial to the patients and the family members of the patient.

Dr. Piyush Gupta: So when we are talking about the Kerala model, so we all know that Kerala model in palliative care is famous and may be it exemplifies when we are talking about palliative care. So, doctor Babu do you have AYUSH integration in palliative care at Kerala or not?

Dr. K.L. Babu: Yeah, yeah because in Kerala this state government they are promoting this AYUSH system in this palliative care. So that every AYUSH doctor has to visit the patient once in a month. Home care is a part of their work and now they are giving training in this palliative care because you know that I am a resource person for that also.

I am going to every district and giving imparting training to the doctors about this palliative care because you know that now in Kerala each and every person is aware about this palliative care. That is why you know in every local corner we can have a palliative center also that was it is run by volunteers or some organization. So that every system that I mean Ayurveda, Allopathy and Unani, Siddha that all are going together and giving imparting this palliative care to the patient in Kerala. That is the scenario in Kerala.

Dr. Piyush Gupta: So, Mr. Menon I have come to know that palliative care is working at the level of panchayat and it is enforced by government. So, can you share the model why is this model not replicating and again to the students you are coming from various states why cannot you force your government to adapt the palliative care model in palliative care. So, can you explain a bit about those palliative care reaching out to the level of the panchayat.

Dr. K. Radhakrishna Menon: You see the story begins in 2008 and we started our work from 2006 onwards when I was the vice chairman of the Indian association of palliative care, Kerala chapter. We organized seminars in awareness programs getting feedback from the people in 14 districts in the state of Kerala.

So, every month we go to, on Sundays rather we go to a particular place in a particular district and we organize an awareness this is palliative care what else can you do. Government of Kerala is proposing to have a Kerala state palliative care policy and they wanted a draft of the declaration to be prepared by this organization. So, we drew you know feedback or you know take a message from all the people across the 14 districts and a draft of the palliative care policy was prepared and that was handed over to the chief minister and that time Shri. Achuthanandan was the chief minister he took it and declared it as such. So, the thing is that along with that you know the Panchayat Raj Act was amended in 1934. You see many times it was amended and as a result of the amendment of the Panchayat Raj Act the three tier administrative, administrative system came into being across the country and that also reflected in Kerala also.

So, the government of Kerala decided that palliative care should be introduced in all the panchayats or the in all the three tier administrative system that is primary health center in the grama panchayat, community center in the block panchayat and district level hospitals in the district administration. So, such a system came into being on 14th April, 2008. So, along with that many other you know changes took place and the NRHM national the rural health mission came into being and they also were requested to join hands with the Kerala state and you know the training of professionals like doctors, nurses and volunteers took place. And now we know the system is that suppose if the patient requires homeopathic or ayurvedic interventions in palliative care the NRHM has the resource you know provision for that. They have trained you know doctors and trained doctors in homeopathy and ayurveda and it is a government policy if a patient wants a homeopathic intervention naturally, he will be given homeopathic intervention in the state of care.

Dr. Piyush Gupta: Along with the modern medicine.

Dr. K. Radhakrishna Menon: Yeah, definitely that is a breakthrough achievement in the state of care. So, we are getting good results out of it.

Dr. Piyush Gupta: And Dr. Malar my question to you is that what makes the state government not very actively working on palliative care whereas, it can reduce the health care cost to substantial level. When we are talking at any point of time almost 50 percent of the population is suffering from pain and this pain most of the time is untreated. So, we can treat this pain, but still we are ignoring it and when we are talking about pain, now untreated pain may lead to adding on the mental pain because it is disturbing the routine, it is creating complications and family issues. So, how is it that the government why are they not that much interested in working on palliative care.

Dr. Malarvizhi: There is a gap between the professionals and the government.

Dr. K. Radhakrishna Menon: Policy makers.

Dr. Malarvizhi: Policy makers. So, that is that which is the main reason in India we are not able to achieve what we are from planning the objectives. Because they are all working independently they are not coming together that is what the gap I can see Sir. And if you just see we also should take initiative thinking that it will not happen instead of considering that what a drop I can do to make a ocean. So, we can join together like what we are all doing integrate our self and show to the government that this can happen and this is what because they are not aware about what is going on. When I was approaching the district officer for my project for Lymphedema I wanted to go and do the home care service they did not object.

In fact, they were very supportive. So, I feel that they are thinking that we are not going to them and we are thinking that they are not helping us. So, this is what the gap I feel and if we are working together I can be I think that we can make wonders for the patients.

Dr. Piyush Gupta: Rightly said and that is where the advocacy comes into picture. So, all of you you have to be apart from learning from palliative care is not going to solve the issue. You have to become the advocate, you have to propagate the message, you have to

reach the community make them aware that your sufferings can be treated your pain can be treated.

And you have to approach the government also that how this pain has to be treated by establishment of pain clinics in government hospitals by availability of oral morphine in government hospitals. It is very sad that in India in 2014 we had amended the narcotic drugs and psychotropic substances act. I was also one of the members who advocated for this amendment and we discussed in north block along with other stakeholders. The central government was good enough to amend this act, but again when it comes to state governments it is not being implemented. So, you are our representatives, you have to go to the state governments and ask them educate them about the amended NDPS act because still there is phobia.

They are because it was having harsh punishments for keeping oral morphine, the licensing process was very very difficult and there were drastic punishments also, but all that has been removed and we have a new act and which needs to be sensitized. So, availability of essential narcotic drugs is again very important. They should be made available in government hospitals. So, as to treat the pain of the patients. So, advocacy again comes into picture.

So, what you like to share your experience on the burnout Mr. Menon?

Dr. K. Radhakrishna Menon: Burnout when we teach the students we generally say that burnout should not be there in their you know in their interaction with the patient, but what happens is that in one way in one way thinking in one way we are building a rapport with the patient may be a catalyst between the patient and the carer or the family members that is a good thing, but this rapport at a time, at a different time you know will depress us because the patient will have a very good rapport interacting with you even the doctor becomes a stranger, the volunteer becomes the most important person in the day and whatever secrets or wishes of the patient that will be passed on to the patient I mean volunteer. So, the patient is always looking forward to the next visit of the volunteer rather than nurses or doctors that is what is happening the real you know scenario is there. So, the problem comes when the patient is about to die he may have last wishes for

example, which could not be fulfilled so far. So, at that point of time when he says that you have to help me out I have a wish which we may not be able to fulfill at that particular point of time.

So, the patient dies and then the distress comes to us. So, even if we teach the volunteers that there should not be a distress or a burnout. actually when comes to us you know naturally we will be forced because we are empathetic towards the situation, empathetic towards the patient and the family members. So, we even discarding our own family relations our work and all that we just give more importance to the patient. So, in that way thinking you know even though we say for you know for clarity in the training programs that there should not be a burnout, actually there is a burnout because we have already entered into a bondage or a very good relation with the patient and if you are very very close to a patient when he passes away naturally we will have burnout and we will be become sad at least for a particular duration of the time after that it will be subsided. That is the natural course of death and the bereavement.

Dr. Piyush Gupta: So, this is the magic of palliative care, a patient who is withdrawn who is not at all interacting either with his family or anyone who is not even eating properly, sleeping or doing any household course properly. Entry of palliative care teams they motivate the patient and many a times the same patient who is not interacting with their family starts discussing his issues his problems his wishes with the palliative care team. So, that is the magic of palliative care and now the problem is that an outsider knows more about the patient rather than the home.

Dr. K. Radhakrishna Menon: Family members.

Dr. Piyush Gupta: And family members. So, this is a very tricky situation because you have to take the family into confidence and many a times what happens is that when the patients all of a sudden starts improving now we may get may be false hope. So, getting false hope about the patient that the patient is recovering no, no, it is only that his temporarily he has improved and the second thing is we should not give any false hope to

the family or the patient because there may be unfinished assignments with the patient has to complete. So, that is why slowly and slowly we come to the patient and start talking about death.

So, can you throw some light on that.

Dr. Malarvizhi: Yes sir. So, many times we just meet the patients in the name of caring we should not neglect what the wishes of the patients are. I have come across patients requesting when we just take our vehicle from the hospice care, please do not bring it near to my house. I do not want the neighbors to know what I am suffering. So, that is also badly that wish we have to take and at the same time if they do not want to discuss about that give respect to that also.

Dr. K. Radhakrishna Menon: Patients autonomy is all the worry.

Dr. Malarvizhi: Important and whenever they are comfortable we have to be open to receive that and we cooperative with the family members and the patient and as a team member we also can get involved in that and help them out.

Now, how do we help them as a professional we can think about if they are having a willingness to do organ donation we can just have because that may be the will many of them are ready to do that because they wanted to see the body to be utilized for 4 or 5 people which is of going to be a big vision for the physically disabled people. And the family members also will be thinking that yes the particular loud ones organs are distributed in so many people and we can see them the lost person through them also. So, preparation need not be that you are going to die get ready no it can be the wishes and how we are going to contribute that that is also matters for the patient.

Dr. K. Radhakrishna Menon: I would like to add that particular episode. One, Tara that is the name of the patient she was 30, 35. She is no more. She had a bowel, I know pain for many years she was doing menial jobs in the nearby houses. She has her husband who is

not you know capable of doing the hard work and 2 kids and over a period of time she went to the pharmacy and asked for pain relief you know tablets for pain relief.

So, the pharmacy you know the medical shop gave her pain relief this thing, but unfortunately that did not stop. The pain is continued and the pharmacy, the shopkeeper told her you better have a clinical this thing you just check with somebody else, consult a doctor and the doctor said you will have to take so such and such what you call, Test. Test you had to undergo certain so after the test results he said that you are having some problems. Then only she was able to know that there was some cancer in the abdomen so it was too late at that time. So, what happened she was taken to one of our pharisee care centers for palliation and the doctor told her for a period of time that there are little hope for there is little hope for it to live longer this is a situation do you have any wish to be accomplished. Then she said I do not have a house of my own. I am staying in the you know the what we call tharvad of the husband he has, his father got six cents of the land and we volunteers and the team members discussed it with the father of the husband. He agreed to share three cents of the land.

So, that part was over and the nearby there was one convent. The father told us we will take care of the registration charges nearly five thousand rupees or so. So, that case was also settled and her wish was before I die I should die in my own home that was the wish, how it could be done. We mobilized the common you know the community, the local community and we designed a small house for her and we you know requested many to donate even the what you call the mason old that I will come after my doing the daily job free of cost I will do this. One quarry owner told us you know that you need give only the transportation charges we will give you the what you call this thing free of cost. Then like that you know the whole community stood for her a small house was constructed and the what you call the Grihapravesha was done fantastically and after staying there for one week she died.

This is Palliative Care. So, even after the bereavement of the I mean death of the patient also we take care of the children for the studies, even the husband who is not well you know we gave him some we help project. We give twenty five thousand rupees and you

know took the initial expenses for providing all the provisions free of charges and later they will have to do it on our schedule. So, this is not what you call stop the show we just we continue till the whole family comes back to the normal position it is very difficult task, but if the community around us cooperate it is very easy this is very easy and we enjoy doing it. We do things interestingly not out of any compulsion this is my experience I thought of sharing with you all thank you.

Dr. Piyush Gupta: Thank you mister Menon. So, I have a question which is very awkward, but again it is the reality of life. How many of you have planned your death mister Menon.

Dr. K. Radhakrishna Menon: It is very difficult to give you an answer. This planet is a very good planet to live in and it has got all the essential inner comforts and luxuries how can I go away with it.

Dr. Piyush Gupta: Yeah and that is probably with you Dr. Malar than with myself, but again death is the only reality which is going to come.

Dr. K. Radhakrishna Menon: But we do not know when.

Dr. Piyush Gupta: We are sure about it 100 percent sure, but whereas other things we are not sure about, but we are not prepared for it. So, talking about death again is very important and more soon when the patient knows that he is going to die in sometime when I am talking to the patient I simply say that I am talking to you now, but I do not know whether I will be talking to you tomorrow or not it is not certain. So, similarly you have to accept that death is going to come whether today tomorrow or any time.

Dr. K. Radhakrishna Menon: It is inevitable.

Dr. Piyush Gupta: So, why to have this crisis, we should welcome death we should finish our task day to day basis we have to assign the priorities that this has to be done in whatever time. So, that we do not have any unfinished business and this is again very important when you are talking about dying patients their unfinished businesses may be

there, their will may not be there, and again we can ask the patient to have a advance directive. That means once he is not able to take a decision that whether he should be put on ventilator or aggressive may be life saving devices. So, advance directive helps his nominee to take the decision in his absence or he can either do it write it down that I do not need any medical devices when I am dying no ventilator, no dialysis nothing or I can nominate someone to take the decisions when I am not conscious.

So, that again is very important. So, would you like to share something on that?

Dr. K.L. Babu: Yes, yes, yes you know that nowadays you know this everybody is wants to be with within the final stage also with family members and the relatives other relatives. Because you know that nowadays this death this in a single room in a ventilator or in a in an ICU. Because you know that in the last moment everyone will think that you know I want to see the face of my immediate relatives husband or wife or children or like that. So, that you know, but what is happening nowadays you know that we are in a ventilator with all these tubes in an old orifices and we cannot talk we cannot that we are many that we express every nothing and we know we cannot that at least we cannot I mean we want to see the face of our immediate relative. So, promote the final stage with along with the family members and the palliative care itself promote that type of death in the final part. So, we have to encourage that.

Dr. Piyush Gupta: So, doctor Babu is saying improve the quality of death and reduce the cost of death. Madam Malar do you have anything to say.

Dr. Malarvizhi: Yes sir. I just recently came across one of a 85 year old person who was along the, he has a 4 daughters who has been married and he lost his wife long back 35 years back. So, now he is feeling the loneliness and he is feeling who is going to take care of me, but already the 2 daughters are taking care of him, but he was not very comfortable. He wanted to go back to his native the house what he is owning because these are all something his daughters house. So, he is telling if I am going to be along with this 2 daughters, I may not reach my home.

So, he is trying to do something with the next daughter. So, he puts blame and he tells I wanted to come with you. So, the patient will have so many thinking and we should understand that and the other daughter found out that there is some reason or 15 years when that person is with 2 daughters why he wanted to come to my house. Then what happens is that family has transportation facility everything. So, he tells I wanted to go to my house.

So, he is taken there, he goes to each and every corner of the house. He tells I wanted to spend 10 minutes. I wanted to be lying down on this own my bed for some time. all these experiencing and he is very happy. Once he finishes, that satisfaction. He tells we can go. The next week, he passes out. What is that he created for the family members. Yes, everyone said that when they were they used to cry, your father is gone and what is this this this and all. The daughters were so happy they said what was there left for my father. We did what we can, we also celebrated his 85th birthday by cutting cake which he never did and we brought him when he wanted to see this house and we spent at least 3 days here.

He had a very good death he was eating and he just lost us. The final wish. This satisfaction it need not be only for the patients it is also for the family members.

Dr. Piyush Gupta: So, message to you, have you asked the patient about the final wish, has the family honored the final wish of the patient because most of the time the family calls the shot, they do not listen to the patient and that leaves a disgraceful dying. We increase the cost of death and the patient is dissatisfied. Is that the type of death which we are looking for?, certainly not. The parental home and the family members are the best companion and it is the best place to die not an ICU where you have machines and machines and people do not know even the last time of breath. So, when we are talking about chronically ill patients, remember they have not to be they are not to be taken to ICU's, emergencies you have to be prepared to face the death.

So, Mr. Menon, facing the death the final moment comes how many people or families they prepare for the death of the patient is it being done or not.

Dr. K. Radhakrishna Menon: I have my personal experience. My 95 year old mother our mother died peacefully. She had some you know aging problem, some mental issues were there, but remember we are 7 in number and I am the only main member in the family all the other female members are above. So, since I happen to be in palliative care, I know what would be almost the last breath of a patient and all that. So, during that particular period I visited my mother you know very often. Just to ensure that she dies peaceful. She was taken to the nearby palliative care center for the last you know 2,3 days and one of our physicians is very close to me and he said Radhakrishnan you better come tomorrow it is almost time for her to pass. So, what I did instead of putting her in a ventilator on ICU I asked the requested all my you know sisters to come to that and we spent the last hours with her in the palliative care center. There was a hall meant for them and she breathed her last.

Dr. Piyush Gupta: So, that is the death which we expect with our family and that is the most satisfying death. Again all the religions they have some protocol for the dying people, but are we fine with those protocols, certainly not. We start those protocols after death of the patient, why not if it can be done before the death. So, doctor Babu can you.

Dr. K.L. Babu: Yeah, that is the problem when we put the patient in this intensive care unit or ICU or in this ventilator you know.

Actually these are only hours or even after this you know the doctors will declare that in the patient dying. So, we cannot perform the final rites, rituals. So, if we are sure that you know that is the final time and the last breath he is going to take. You know ask the, put him in his around surrounding with his family members. He can look into the eyes of his immediate relatives, that is the first thing we can give to that particular patient or that person.

Dr. Malarvizhi: Saying goodbye in a better way.

Dr. K.L. Babu: Yeah. So, I.

Dr. Piyush Gupta: Can you add on.

Dr. Malarvizhi: Yes sir. So, I also had a personal experience when one of my family member was in the death bed. I got a call whether I have to take the person to the hospital. I said because I was one of the in charge person for that patient.

I said please do not disturb him. Because you know he was suffering for so long. Why you wanted to again put a burden on him? Let him be where he wanted to be and we will send off in a nice way. Instead of putting him into the ICU or wherever it is, regaining his life and then again going on for suffering. I do not think so. If we are having that advocacy for the patient, we can decide and say a very good nice way of bidding goodbye to him.

Dr. Piyush Gupta: Bidding, again is very important and I recollect my grandfather in 90s, when he may be in last one week he stopped eating, he was semi-conscious.

So, we got drip at our home itself. We called all the relatives they were there for last 4, 5 days and finally, we as per the rituals which were to be done for a dying patient we were ready with everything the Ganga jal, then tulsi, then gold and what not and as soon as he died all the rituals were completed. But I am not seeing those rituals coming right now and may be people are not aware of that. So, as per your religion you learn about how to face the death, be prepared and again do not take the patient in ICU, do not panic it is going to come, you know it that it is going to come in next few days, be prepared and face the death. Say adieu to the patient.

So, that you have wonderful memories and you do not feel that I could have done something better to the patient. So, that is my message and let us not hesitate from discussing or talking about death because that will always leave unfinished businesses which will be most distasteful at the last minute. Any one of you if you have anything in mind to share again.

So, you can just share in case if you want to say something. So, that means we have a take home message to you, palliative care is not only improving the quality of life of the patient.

But again it should improve the quality of death. The death which is peaceful at home with the relatives and with whatever the last desire of the patient is, it should be followed and it should be not very costly also. So, with this we are winding up this interview all the best and best of luck to all of you. Thank you.