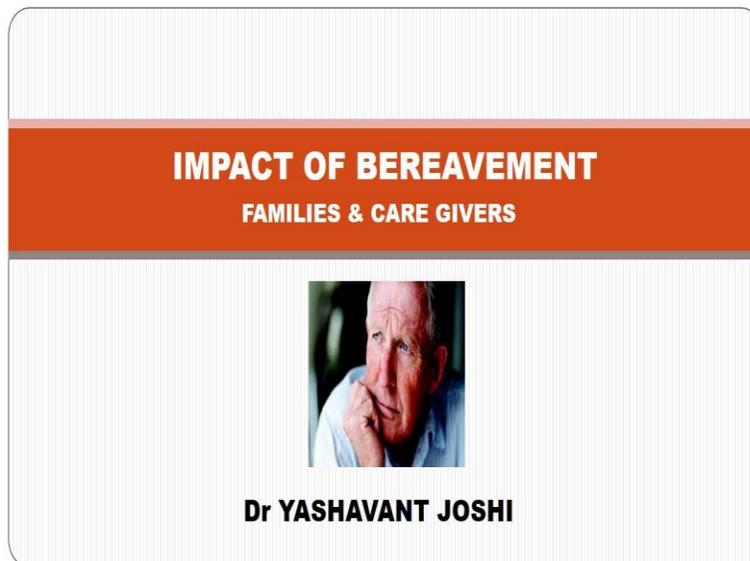


Basic Certificate in Palliative Care
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Week-06
Lecture 03: Impact of Bereavement on Family

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Week number 6 and lecture number 3. Hello friends. So now we are basically talking about death and then thereafter the effect of death and that is the bereavement. We must understand one thing that life is like this. We are not immortals. We are just mortals.

We come and we have to go. There is no doubt about it. Whoever takes a birth, he or she has to die because that is a system. That is our life and that we need to accept.

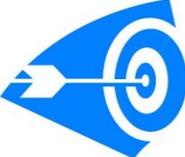
Life is like a kite, kite, kite in the sky. What is the life of that kite in the sky and how much far, how much farther it can go? Maybe somewhere, one day, two days, somebody will cut that kite also. So, this is how it happens. A kite is being cut by somebody else,

some competitor whereas life gets cut, gets shortened by almighty or whatever the reason may be whatever you understand it you know.

In Hindi, the same way there is a very good Shairi (Hindi word meaning poetry). Patang si hain zindagi, kahaan tak jayegi, patang ho ya umru ek na ek din kath hi jayegi (Hindi phrase meaning Life is like a kite, how far will it go, one day it will pass). So if this is the life, then the best way is just to accept it you know. But however, some of us do not accept and that is where the issue of bereavement and grief comes in.

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Objectives...



- To understand stages of grief by various models
- To recognize and assess the common reactions of grief and its effect on health of carers
- To find out the factors which make “complicated grief”
- To find out vulnerable groups in which bereavement become difficult to face.
- To understand principles of bereavement support and role of palliative care in it.

The objective of this lesson is to understand stages of grief by various models to recognize and assess the common reaction of grief and its effect on health of carers, to find out the factors which make complicated grief, to find out vulnerable groups in which bereavement becomes difficult to face like children and elderly people and to understand principles of bereavement, support and role of palliative care in it.

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WHAT IS BEREAVEMENT?

Bereavement is the process of adjusting to the death of a loved one.

Grief is a normal psychological response to the death or other major loss that one has during the bereavement process.

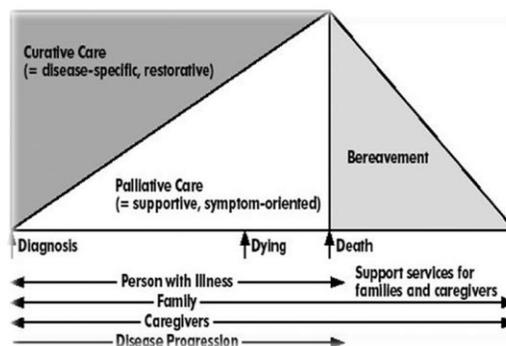


What is bereavement? Bereavement is the process of adjusting to the death of a loved one. So it comes immediately after the death when a human being, when a person tries to adjust to that particular shock. And what is a grief? Grief is a normal psychological response to the death, normal psychological response to the death or other major loss that one has during the bereavement process. So, this is the difference between bereavement and grief. Bereavement is the process of adjustment whereas grief is a psychological response and that generally occurs during the process of bereavement.

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WHAT IS BEREAVEMENT?

MODEL OF PALLIATIVE CANCER CARE: ADAPTED FROM FERRIS ET AL.



What is bereavement now? Earlier you see the palliative care people believe that it is just end of life treatment, you know. So, that myth is gone. We start giving palliative care treatment as soon as the sickness starts. Sickness, sickness starts here at the point of diagnosis. So, here onwards you can see the palliative treatment has started. Somewhere in between the dying process, if that disease is like this that it is not curable, we are giving curative cure.

We are trying, but a time comes when we understand that curative cure is just not possible. So, at the same time we start palliative care which is symptom oriented, pain management oriented, supportive care we call it. And dying process is somewhere here, it starts between this. Dying process is generally like this. And when nothing can happen after all we are not God, doctors are not God.

One has to go. So, the time come, it is here when the death occurs. Thereafter because of shock, because of the loss of the loved one, the grief and bereavement. Now, we have said it time and again that palliative care is totally different from other medicine streams, other medical field of modern medicine, they stop treatment here only when the death occurs and their only job is just to sign the death certificate and that is the end of it. But my dear friends, no, in palliative care we continue and now our focus is on the family members, the caregivers and that is where we take part in the bereavement process or the grief process which may last for few days altogether.

We remain with them. Our principle is be with them when they need us. So, this is where after death, bereavement process comes till they accept reality. And what is the reality? Whoever has come to this planet sometime he or she has to leave the planet. If there is a birth, there is always a death also.

When this acceptance, this feeling comes into a mind, then thereafter, okay fine, that is what God wanted it. After all the deceased person had lived his life, why to grieve so much now? And then show carries on. Here also the person you see diagnosis to dying to death, person with illness, the family is from here, person with illness remains with us till death. Palliative care is being provided. But the family and the caregivers from the

diagnosis to the end of bereavement process they remain with the palliative care specialist.

So that is where the palliative care can go. This is what the start of bereavement and the process of palliative care specialist, what they do.

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5 STAGES OF GRIEF

- **Denial**- “Well I haven’t really been grieving.”
- **Anger**- “Why is this happening? Life is so unfair!”
- **Bargaining**- “I’d do anything to change things. Please just name it and I’ll do it!”
- **Depression**- “life is hopeless.”
- **Acceptance**- “I think she/he would want me to move on. So that’s what I’m going to try to do.”



Ross EK. On death and dying. London: Tavistock, 1970.

Stages of grief, we call it DABDA. This is basically ROSS model. We will have a separate lecture on this.

Ross was a doctor and she found out a grief process goes through five stages. First comes immediately when the death occurs, the near ones, the loved ones, the close family members say, no, no, theek hai (Hindi word meaning it's fine) it's fine. He has died, she has died. I am not really grieving. It has happened, I accepted it.

This is the denial stage. It is there, that shock is still there. But as a human being, as a person, they say, they deny it. No, I am okay. It had to happen, so it just happened.

But slowly and slowly, maybe in couple of hours, the denial turns into anger. Why is this happening? Why the life is so unfair? Why he left me? And I am all alone now, he has gone and nobody is there to look after me. And therefore, that person starts getting

angry. He gets angry because he doesn't understand the whole process. He is not ready to accept, yes, it had to happen.

At some stage, he had to go, he had to die, but he doesn't want to accept. So when you don't accept a thing, you get angry. So that is the second stage of anger. Then maybe after few hours, you start bargaining. Okay, I had to do anything to change things, please just name it and I will do it.

If he can come back, I am ready to give. We in our tradition, we say to that extent, I will give my years of life, balance years of my life, if we can call him back from heavenly about, but it just cannot happen, starts bargaining with God. God doesn't listen because this is also not in his power. Once a person is gone, but the person is died, God, I am just saying it because I haven't seen any evidence or proof, but I am saying it, whoever has died has never returned. So when the person doesn't come back, the depression life is hopeless, my God just see he is gone.

I am trying, I am requesting God to send him back. I am giving my years also, but the person is not coming back. The depression goes on for few days, depends on the strength, mental strength of that person. It may go on for few days, few weeks, month, maybe a month, two months. Finally the beautiful stage of acceptance starts.

Yes, nothing can be done. The person is dead, he just cannot come back. I still have to live my life for the sake of others, for the sake of children, for the sake of anybody and for that I must accept it. And he will also want me to do my job. This is my responsibility. Up in the heaven also will think in his or her absence, I will do my duties perfectly, 100% and I must go on.

So this is the stage of acceptance. Five stages, you deny first, you get angry, start bargaining with the God or with the system whatever it may be. When things do not happen the way you want it, you get depressed and then finally, normally what happens when the child gets too tired, child is crying this and that, he wants a particular toy and a mother is unable to get a toy. For one hour or two hour, child will cry, lots of tears in the eyes and finally he will get tired and he will go to sleep.

Peace of mind. Similarly here also, a person tries, gets anger, goes under depression, may be crying but nothing happens, so he just accepts the fate.

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REACTIONS OF LOSS

Physical	Emotional
<ul style="list-style-type: none">• Hollowness in stomach• Headache• Shortness of breath• Weakness in muscles• Oversensitivity to noise• Dry mouth• Loss of appetite, illness• Sleep disturbances• Increased use of medicines, alcohol & tobacco	<ul style="list-style-type: none">• Shock and numbness• Feeling of anger• Guilt• Loneliness – feeling alone• Loss of enjoyment• Anxiety – fear of breaking down• Depression – due to long sadness• Relief – now the suffering of the deceased has ended



Schieffer SJ, Keller SE, Cimerino M, Thornton JC, Stein M. Suppression of lymphocyte stimulation following bereavement. JAMA 1983;250:3747.

Reaction of loss, physical loss, physical reactions, hollowness in stomach, headache, shortness of breath, weakness in muscles, oversensitivity to noise, dry mouth, you cannot speak sometimes, loss of appetite, you don't, no hunger at all, illness, sleep disturbances, you can't sleep, increased use of medicines, alcohol on tobacco because these are the things generally it is being felt that such things, they relieve your tension. So you drink, you smoke and other things. These are basically physical things which can be visibly seen on those people who are under grief. Emotional, shock and numbness, feeling of anger, guilt, guilt comes in when I could have really, it was the time that I would have done lots of seva to him or her when he was sick, you know, lots of service but I couldn't do it because I was busy with my work.

So that sort of guilt, we already spoke about guilt and regrets in earlier lessons. Loneliness, loss of enjoyment, anxiety, depression and relief.

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REACTIONS OF LOSS

Behavioral

- Crying
- Absent mindedness
- Restlessness over activity- searching for deceased
- Social withdrawal
- Change of home
- Suicidal thoughts

Attitudes

- Low self esteem
- Hopelessness
- Suspicion- doubting others
- Having a sense of the presence of the deceased
- Preoccupied with thoughts of the deceased
- Search for meaning and purpose of life



Reaction of loss, behavioral loss, crying, absent mindedness, restlessness, social withdrawal, you don't speak to anybody, you remain just aloof in your own room, change of home, you leave one home, you go to another home, change your residence and sometimes if behavioral reaction is too extreme and you are too weak, then suicidal thoughts, without him or without her, how am I going to live, what is the use of this life? This generally happens when the people are very close. It happens generally between wife, husbands, lovers or the very much loved children if they die, this can happen to, this particular behavior can take place in the mind of mother or father or something like that, you know. Suicide thoughts because without him or her, life is nothing.

Loneliness, low self-esteem, hopelessness, suspicion, doubting others because things couldn't be improved by anybody including specialist doctors also, nurses also. After spending lots of money in modern hospitals, nothing could be done. So suspicion starts around. Having a sense of the presence of the deceased, preoccupied with thoughts of the deceased, search for meaning and purpose of life, you keep thinking about your loved one.

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Effect of These Reactions on Health

- Predisposes people to physical mental illness
- Increase the risk of cardiac events¹
- Exacerbates existing illness and health threatening behavior such as smoking, drinking and drug abuse
- May lead to depression²
- Clegg found that 31% of 71 patients admitted to a psychiatric unit for the elderly had recently been bereaved³

1. Prigerson et al, 1997

2. L Fallowfield, D Ratchiffe et al.(2001)Psychiatric morbidity and its recognition by doctors in patients with cancer ,British Journal of Cancer ; 84(8), 1011–1015

3. Clegg F. Grief and loss in elderly people in a psychiatric setting

In:Chigier E, ed.(1988)Grief and mourning in contemporary society, Vol 1.Psychodynamics. London: Freund:1918.

Effects of these reactions on health predisposes people to physical and mental illness. If you do not stop, do not control these reactions, then you might get into the crutches of physical and mental illness. Risk of cardiac events, exasperates existing illness and health threatening behavior such as smoking, drinking and drug abuse and may lead to depression finally.

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When Bereavement Becomes Difficult?

- Mode of death- untimely, unexpected death which causes more severe and prolonged grief.
- Nature of relationship- close and dependent relationship leads to difficult bereavement
- The unavailability of quality supportive network like family and friends
- concurrent stress because of family problems like financial, unemployment, retirement
- Previous losses- multiple losses in past
- Habit of alcohol, smoking, suicidal behavior in carers
- Personality*

*Martin T and Doka K(2000) Men don't cry...women do. Taylor and Francis, Philadelphia



When bereavement becomes difficult, mode of death, untimely, unexpected death which causes more severe and prolonged grief, untimely, a child dies, you know or a husband dies in an accident. So such things, they are very cruel and this is what you just can't understand, can't take it in and therefore your grief is severe. Nature of relationship, very close, your own son, own daughter, own sister, something like that you know.

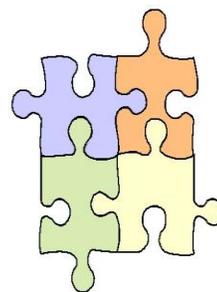
The unavailability of quality supportive network. Dr. Geeta Joshi earlier told you that supportive network is very much required in our life to manage our stress and to manage this condition, this type of condition. You must have some friends, somebody in your support group, somebody may be from your family, own family to whom you can speak to anything, anytime. You need to burst that bubble of pressure and therefore to support people will come into actions.

Concurrent stress because of family problems when somebody dies and particularly that person is the only earning member of the family. So, income is gone and when no income, financial burden, unemployment. Previous losses, earlier also in the family people have lost lives and frequently we are losing the lives of our own family members. Habit of alcohol, smoking, suicidal behaviour in careers and personality, some people are weak by personality, very very soft, emotionally not stable.

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In Whom Bereavement Becomes Difficult?

- Children*
- Confused elderly and those with learning difficulties. Repeated explanations and supported involvement in important events, such as the funeral have been shown to reduce repetitive questions by confused elderly patients.



Gerry R. Cox, Robert Bendiksen;(2002) complicated grieving and bereavement;
Baywood

In whom bereavement becomes difficult, basically children because and particularly small children they do not know what is life.

They just do not know, they do not understand that one has come here and one has to go. No, they have not seen the life. So, when they find somebody, some important member of the family is missing, they really do not know and other people, elders, they cannot answer in correct form. Then confuse elderly and those with learning difficulties, repeated explanation and supported enrollment in important events such as the funeral have been shown to reduce repetitive questions by confused elderly parents.

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PROFESSIONAL HELP



- Non-judgemental listening, encouraging talking about the deceased and expression of feelings
- Anticipatory guidance - Many difficulties can be avoided in bereavement, provided professionals had involved family members in decision making, provided information regarding prognosis of disease and checked out what people understand before the death
- Being there for them
- Providing information when requested regarding illness, death and how to register a death

Chapman KJ, 1998 coping hope and anticipatory grief in family members in palliative home care cancer Nurs ; 21(4):226-34

Professional help can be given, non-judgmental listening, encourage talking about the disease and expression of feeling non-judgmental.

Just keep listening to the people who are in the grieving process. Let them speak whatever they want to speak. Encourage talking, let them talk, talk, talk. Like in our society, we have a system of crying and if a person is not crying, if a husband has died and wife is not crying, we are hiring people who are crying and who will make her cry. In fact, there is a movie, there was a whole movie called Rudaali.

This is a system of our society. I do not like that particular system. The crying is being imposed on the wife because the husband has died and she is supposed to cry in grief in the mourning period. Mourning period lasts for about a month. So that period.

Anticipatory guidance, this is what is required. Anticipatory guidance means we know that this person is not going to survive. Doctors will tell us prognostication, we know there is diagnosis and then prognosis. Means what is going to happen about this disease. This disease, will it be cured or it will not be cured? If it will not be cured, when the end is going to come. So that is not a precise thing, but yes, generally it is true.

So anticipatory guidance can be given to the people around that this case is not going to be right now. It will deteriorate further and it cannot be cured and finally it is leading to the final stage and that is death. So people will start accepting slowly and slowly and thus the shock effect will be listened when actually the death occurs. Being there for them, you should be there with them because even your presence matters that yes, these are my friends, they are here in support.

Remain silent, you do not have to say anything at all. Sometimes you can just help them around. Do not have to utter a single word. If they say something, help them, help them, otherwise just stay there in some corner, sit down there. But be there, your presence will matter hell of a lot and the tension of death will come down. Providing information and request regarding ill, death and how to resist death.

Somebody will do this, all these things in the society. This I have seen number of times when my friends and close relatives dying, there are people all around, they have got the experience also of doing such thing, where to register, where to take him, the crematorium grounds, smashaangri. So this is all will help.

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WHEN TO GIVE HELP?

People are likely to be changed by the experience of grieving. Most of the people, are able to adjust over a period of time and they function well and enjoy life again.

Give help if any of the following apply to bereaved person

- If he/she cries more for long period like more than one year.
- The intense emotions aren't subsiding.
- Not sleeping and have symptoms of depression or anxiety
- When the strain of caring for a terminally ill person for more than six months is done by carer.
- Relationships are suffering.
- Becoming accident-prone.



E. Alessandra Strada, 2013; Grief and bereavement in the adult palliative care setting

When to give help? When he or she cries more for long period like more than one year. This is too much. For one whole year, one is in a grieving process that means they do not want to forget the deceased, they want to just keep him in, keep in his mind, in his memory alive.

So it is not good. That final stage of grief was what? Acceptance. It has not been accepted, the reality has not been accepted, it is not good. It will bring that person under depression. The intense emotions are not subsiding, crying, crying, not talking to anybody, sitting in just one corner on one chair only, not cooking, nothing. I mean, she or he had just gone like a sort of, you know, dead body.

The body is there, but it is not working, no emotions, no emotions, nothing, not sleeping. And in such a case relationships are suffering and they become accident prone. What will happen? We do not know at all. If he goes out, might get accidental death. So in such cases, it is necessary to provide help by the family members and others.

If not, then we can get some professional help also, some psychologist or counsellors.

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Role Of Palliative Care

- The general lack of understanding and social pressure try to keep bereaved person's feeling private so bereaved people may feel isolated and find it hard to seek help
- Professional Support is offered to bereaved people without asking for help, if deceased was taking treatment under palliative care services.
- Support from volunteers, provided with training, supervision and back up from suitably qualified professionals, has been shown to be useful
- Counselors, Psychologists, social workers and community nurses have the skills to work with the minority of bereaved people

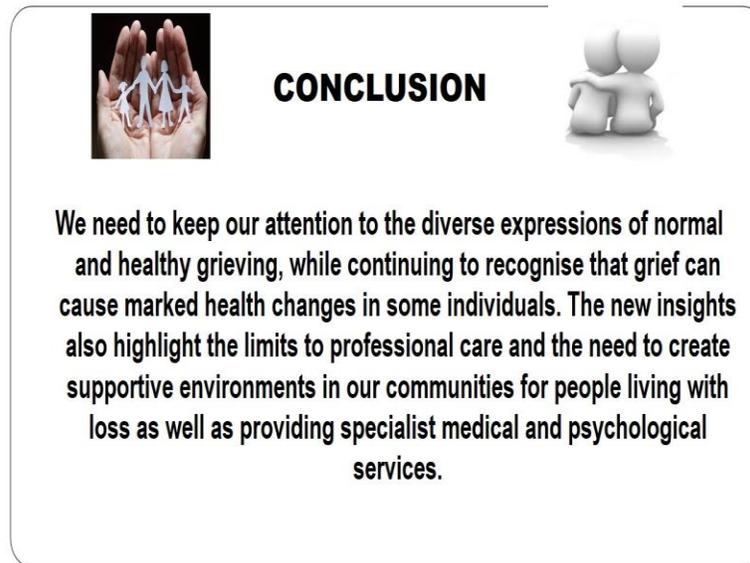
Parkes CM, Relf M, Coidrick A. (1996) counseling in terminal care and bereavement. Leicester: BPS books.

Role of palliative care. The general lack of understanding and social pressure try to keep bereaved persons feeling private. So bereaved people may feel isolated and find it hard to seek help.

They do not seek help because they become very private. Professional support is offered to bereaved people without asking for help if this is what taking treatment under palliative care service. So, if palliative care treatment was being given by some clinic, palliative care services, community based palliative care centres or hospitals or anything, so naturally these people will give. It is a part of our palliative care system. They will give this treatment of bereavement support, but not, then also you can go and request this professional people to come for your help. Support from volunteers who have been provided with training, supervision and backup from some suitably qualified professionals.

Counsellors, role of counsellors is really good, but unluckily we do not have given that role to the counsellors. We think what the use of it is. As an elderly person, I can give correct advice why to hire a counsellor, but we just forget one fact that this counsellor have been trained scientifically. They have got a system of counselling, the ways and means of counselling properly and they will get, they will derive great benefits if you hire them.

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CONCLUSION

We need to keep our attention to the diverse expressions of normal and healthy grieving, while continuing to recognise that grief can cause marked health changes in some individuals. The new insights also highlight the limits to professional care and the need to create supportive environments in our communities for people living with loss as well as providing specialist medical and psychological services.

So, in the end my dear friends, it is better that if we accept the reality as early as possible, but at the same time there are people who are not mentally very very strong, they cannot take up that thing.

I give you my own case in the, I said I was in the army and way back in 2002, we are about to fight the war with Pakistan when late Prime Minister Atal Bihari Vajpayee was there and we are deployed on borders. At the time I was posted in a research laboratory in Dehradun and all of a sudden I got a call. I was recalled to join the border forces. The day I was to leave Dehradun, I got a telephonic message that my mother is no more.

Old, aged more than 80 years old. On the same day I got the message, but I could not do anything at all. When I had to catch a train, I caught a train and then went to Ahmadnagar, reported on duty and after few days I told my officer in charge that this is the problem, my mother is no more. But I could not tell you earlier because I cannot as a senior officer give such a reason that I want to go home when I am supposed to go and join the border forces. Then thereafter on 10th or 11th, I got leave and I went back and attended full rites.

So this is what happens. You need to understand the situation, but again I told you it requires very strong and logical mind and everybody cannot do it. We need to keep our attention to the diverse expression of normal and healthy grieving. Normal and healthy grieving. Mine was normal and healthy grieving.

I just said I have got my own duty to perform. I cannot just go, leave it halfway and go and attend to the bereavement process of my mother. No. I have to go report to my station first and then as and when I get time, I will go. Normal and healthy. While continuing to recognize that grief can cause marked health changes in some individuals, those individuals who have not learnt anything, who do not know what is the death like, who have not gone to crematorium or a grave ground to buries or to cremate some people, for them it is a first experience.

The new insights also highlights the limits to professional care and the need to create supportive environments in our communities for people living with loss as well as providing specialist medical and psychological services. In the final, I will just tell you that this is the theoretical thing. What happens? Bereavement and grief. But in society, we are very strong society. Why don't we have so many psychologists with us? Because we generally do not require psychologist.

If something of major loss comes to us, we just take it. We have been taught in our childhood by our parents that this is what God's willing, God is doing this. What can we do it? If God is doing, then nobody else can help us. We surrender ourselves to God and that is how such a big shock and depression and all those things do not occur to us, do not come to us. Very very rare cases that people do not come out of grief and take more time. I have not seen anybody in my more than 70 years of life that people had gone to grieving process for more than one year.

They just become normal and they start leading a normal healthy life. Of course, they keep remembering. Normally, I remember my parents. In fact, whenever I come out of my home, I always salute them. This is my remembrance, you know. So this is a process which we must understand and see this is what palliative care is doing and no other medical field. Thank you friends.