

Certificate in Integrative Palliative Care – 3
Dr. Geeta Joshi
Dr. Piyush Gupta
Dr. Col. Yashavant Joshi
International Institute of Distance Learning
Indian Institute of Technology, Kanpur

Week-01
Lecture 03: Basics of Palliative Care

Hello. Good morning everyone. Myself Dr. Geeta Joshi. I am director of IIDL, the institute which is supporting this course in association with NPTEL. I am practicing in Ahmedabad in a community oncology center as a chief executive officer. Let us start our training with basics of palliative care.

(Refer Slide Time: 00:49)



- Ravi, a 25 years old man
- Fell from coconut tree 6 months ago
- Underwent an operation on back
- He becomes "Paraplegic" following surgery
- Doctors says "Take him home. Nothing more can be done"
- Ravi is now bed-ridden
- He develops bed-sores, wounds with smelling discharge
- He has lots of pain, can not lie on his back
- He is in severe "DISTRESS"
- He & his family members do not know what to do?

Do you agree with the doctor's remark that 'nothing can be done' for Ravi?

What is palliative care? I start my lecture with a story of a young boy, Ravi, who fell down from a coconut tree and he injured his back. He had to undergo surgery, following which he became paraplegic and he became bedridden. At the end of almost one and a half to two months treatment, doctor said, now you take this boy home and nothing more can be done.

Now Ravi is bedridden at home, not able to walk, he has got severe pain in all the muscles, body pain, he has developed bed sores, wounds and smelling discharge and he has got lots of pain in that. He is in severe distress. Now he and his family member

doesn't know whom to contact and what to do about his problems. Now, do you agree with the doctor's remark that nothing can be done for Ravi? The answer is no.

(Refer Slide Time: 01:47)



- Ravi, a 25 years old man
- Fell from coconut tree 6 months ago
- Underwent an operation on back
- He becomes "Paraplegic" following surgery
- Doctors says "Take him home. Nothing more can be done"
- Ravi is now bed-ridden
- He develops bed-sores, wounds with smelling discharge
- He has lots of pain, can not lie on his back
- He is in severe "DISTRESS"
- He & his family members do not know what to do?

Palliative Care Always

There is palliative care always.

We can give palliative care to this type of patients.

(Refer Slide Time: 01:53)



What is Palliation?

From Latin verb – palliare, To Palliate (v.t.) means...

1. To cause something to appear less serious or offensive
2. To relieve symptoms of a disease without curing

"You are a Bridge!"

Now, what is palliative care? Palliation. It is a Latin word like in medical profession we have got many words developed from Latin dictionary. It means that to cause something to appear less serious or offensive. So you cover something very nicely and make it less

offensive.

So palliation also means to relieve symptoms, to relieve physical problems, psychological problems and spiritual problems of a patient and make him as comfortable as possible.

(Refer Slide Time: 02:40)

What is Hospice?

The word "**Hospice**" is derived from the Latin word 'hospitum', which means hospitality
(It is resting place for people who are very sick & Dying)

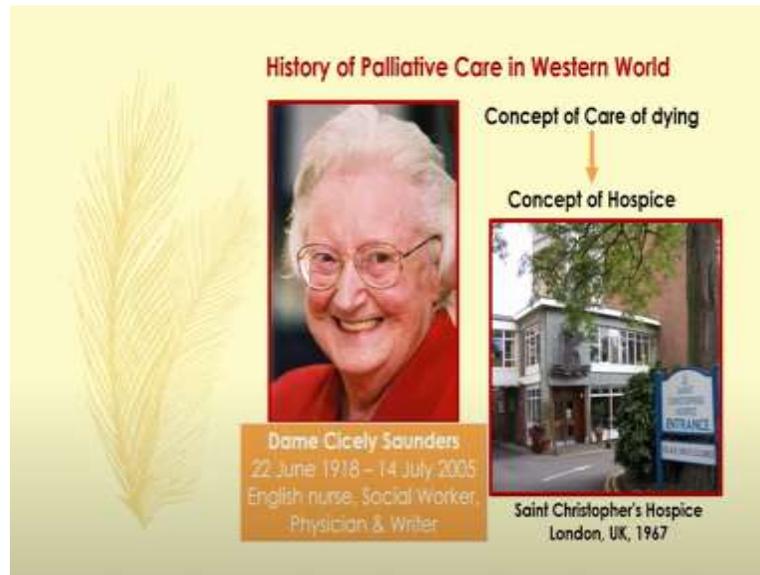
It is different from "**Hospital**"
(It is healthcare set up for active medical care)

86%
of people who need
palliative care do not
receive it

World hospice &
palliative care day

So you are a bridge connecting between the patient and family on one end and a treating doctor on other end and you are providing comfort to the patient and as per WHO World Hospice and Palliative Care Day statement almost 86% of the patient who needs palliative care doesn't have access to it so that is what palliation means. Another word you will come across is hospice. The word hospice is developed again from latin word it means shelter so it is different from hospital where all curative and very fast track procedures are taken up with the patient and patient is intention is to diagnose, to cure in palliation in hospice the aim is to give care to the patient and so when it is given these type of patients are admitted that place that institute is called hospice.

(Refer Slide Time: 03:35)

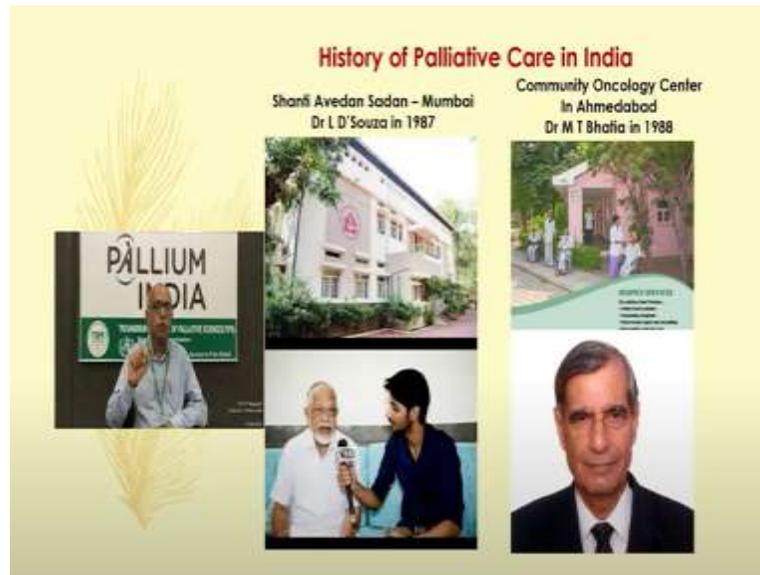


The history if you see history of palliative care in western world it started with Dame Cicely Saunders.

She was a nurse and Angelica, and she used to go from home to home to take care of critically ill patients. Following this, she established the first hospice in London, UK in 1967, which is called St. Christopher Hospice. She also studied, people were not accepting her consent concept of palliation hospice and also thing because she is a nurse. She underwent study and become a doctor.

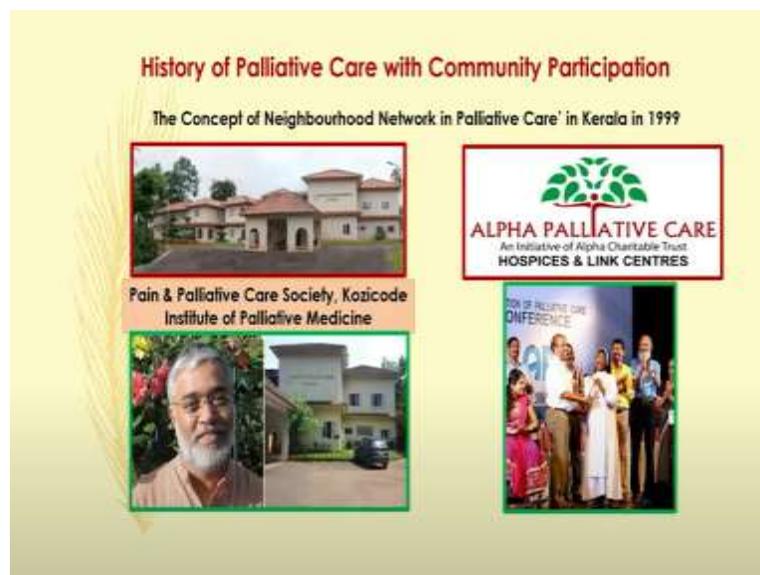
So she was a physician and writer and this is how the word palliative care and hospice spread in western world.

(Refer Slide Time: 04:24)



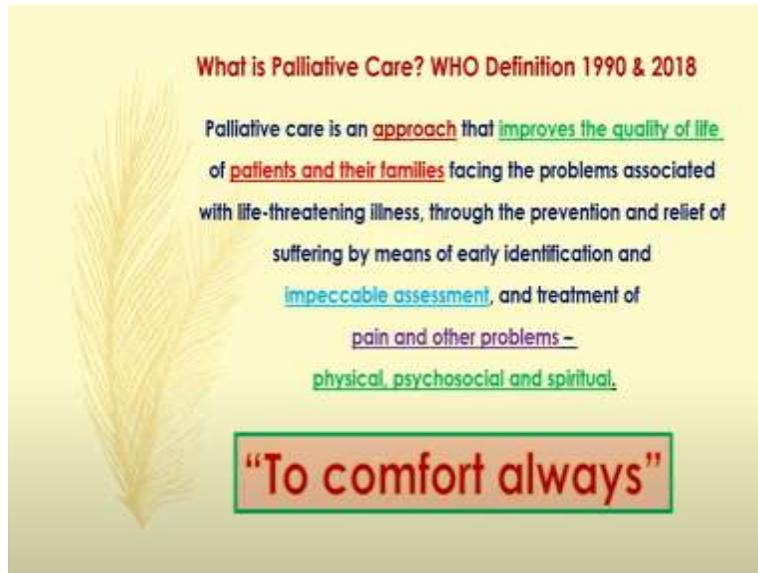
In India, the first hospice was built in Mumbai in 1987 by Dr. L.D' Souza, following which the very next year, the first Hospice of Gujarat came up, in Ahmedabad in 1988 by my teacher Dr. M.T. Bhatia and presently I am Chief Executive Officer of this hospice. In South, Dr. Rajagopal, now Padma shri, Rajagopal established a NGO, Pallium India, which does work about the awareness, creating awareness, advocacy, training and providing services on palliative care.

(Refer Slide Time: 05:14)



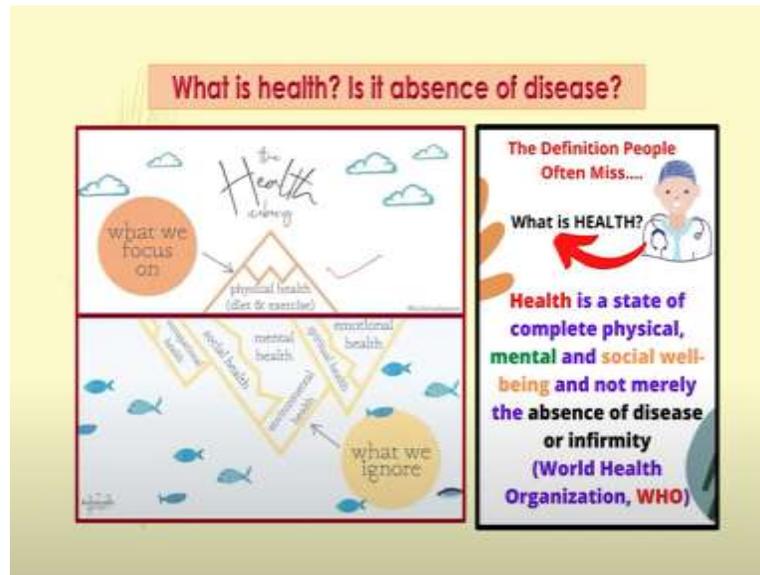
Many NGOs in south but the very popular are the institute of palliative medicine in Kozhikode and alpha palliative care chairman is Mr. Noordin.

(Refer Slide Time: 05:25)



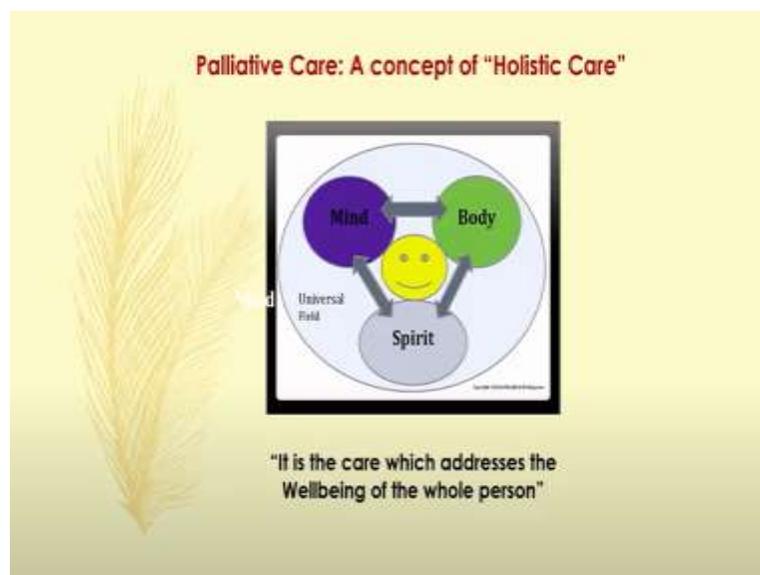
So this is how is the scenario of palliative care in India. WHO gave definition of palliative care in 1990 and then revised in 2018. It says that palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illnesses through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problem and physical psychological and spiritual problem. So palliative care addresses people who are suffering from life threatening illness not only patients but their family also and it gives early identification and treatment to the pain, other problems and other psychosocial and spiritual problems. The aim is to comfort always.

(Refer Slide Time: 06:30)



If we come to the basic definition of health, does it mean it is absence of disease? So what we see here, health is only physical health. But there are lots of things underneath like it has an emotional component, mental component, environmental health, occupational health, social health and so many other things. So the definition people often miss what is health is health is a state of complete physical, mental and social well-being and not only mere absence of the disease. This is the definition given by the health by WHO.

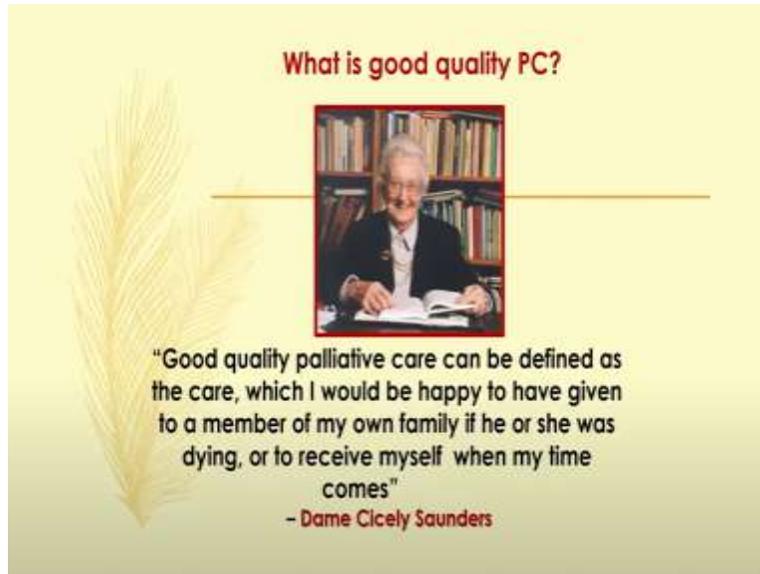
(Refer Slide Time: 07:11)



So, palliative care also means holistic care where you are treating a patient for his body, for his mind problem and for his spiritual problem.

So, it is a care which addresses the well-being of a patient as a whole person and not only physical us.

(Refer Slide Time: 07:31)



What is good quality PC?



"Good quality palliative care can be defined as the care, which I would be happy to have given to a member of my own family if he or she was dying, or to receive myself when my time comes"

- Dame Cicely Saunders

What is good palliative care. Again this definition is given by name cicely saunders she says the good quality of palliative care is the one which you give to your loved one your own family members or it is a one which you will expect others to give you when you fall sick or when you are suffering from some terminal illness and this is what is the best quality of palliative care you can learn you can teach to others and you can practice.

(Refer Slide Time: 08:00)

Why Palliative Care is needed?

- ✓ Change in Disease demographics: increased incidence of Life Style Diseases Like, Hypertension, Diabetes, Stroke, Kidney, Lung & Liver disease.
- ✓ Rise in Incidence of Cancer and HIV / AIDS: Patients report for treatment In very advanced, incurable stage. They need Palliative Care only
- ✓ Increase in Life Expectancy: In 1990 it was 57.86 years. In 2017 it has Increased to 69.16 years
- ✓ Change in dying process: Most of the people die in hospital, increasing Healthcare cost. <10% sudden, unexpected cause (MI, accident). Death is considered as "Medical Failure"

In India, 3-4 people per 1000 population need Palliative Care [1.2 billion] Only 5 million has access to it.

Why palliative care is required if you see the disease scenario nowadays Most of the diseases are lifestyle diseases, and these lifestyle diseases include hypertension, diabetes, cancer, HIV, AIDS, paraplegia, and so many other diseases, stroke, kidney disease, etc. So with increase in lifestyle disease there is a increased chances these are the long lasting illnesses or maybe lasting throughout your life and the stage may come when this disease becomes incurable or it becomes very advanced and here disability or deformity does come to the patient and this patient requires palliative care.

Secondly there is a rise in incidence of cancer and HIV where AIDS, where these are again also at one stage they become incurable they advance the disease advances and the patient needs only palliative care thirdly life expectancy in India has increased tremendously. In 2019, it was 57.86 years. In 2017, it has increased up to almost 70 years. So, the more older population in our community, the more chances of lifestyle diseases, or non-communicable diseases and the more complication does occur as the age advances and patient may develop some disability or some deformity and some long lasting illness.

Lastly, there is a change in dying process. Nowadays you will see everyone dies in hospital, in ICU, on ventilator, with oxygen and what not. Even a person staying in a Jopadpati or a slum area, when he becomes ill, critical, they call 108 ambulance and rush to the hospital. So if everybody knows palliative care and palliative care principles or guidelines are in place in ICU setup and all, the people who are with advanced stage of disease need not go die in hospital but they can be cared at home and they can die in with their relatives nearby their family members nearby this all factors increases the need for

palliative care in India almost three to four people per 1,000 population need palliative care and only 5 million has access to it.

(Refer Slide Time: 10:42)

Who needs Palliative Care?

- Cancer
- HIV/AIDS
- Dementia
- Progressive neurological disorders
 - o Parkinson's disease
 - o Multiple Sclerosis
 - o Motor Neurone Disease
 - o Stroke
- End-stage organ diseases
 - o Lung, Heart, Kidney, Liver
- Old age
 - o old people dying as a consequence of the ageing process

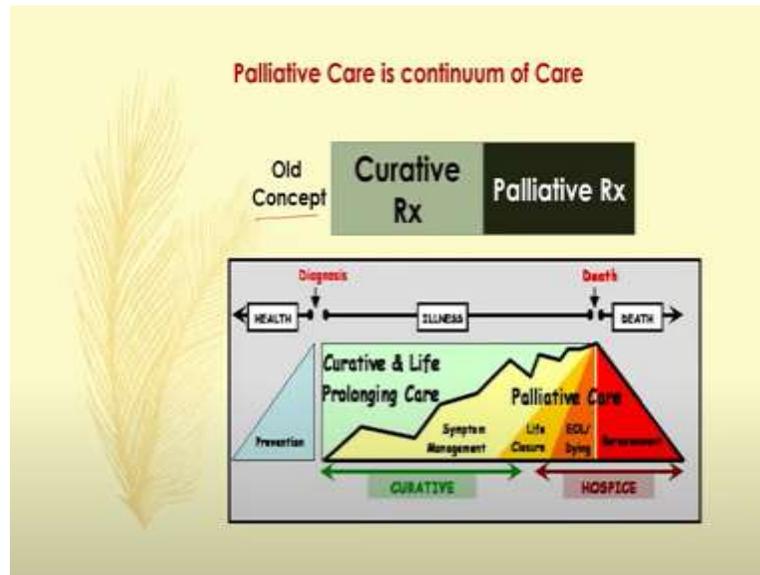
PALLIATIVE CARE FOR CANCER AND NON-CANCER PATIENTS

The slide features a central text box with the title 'PALLIATIVE CARE FOR CANCER AND NON-CANCER PATIENTS' in red. To the right of the text box are four small images: a woman in a hospital bed, a person in a hospital bed with medical equipment, a person in a hospital bed, and a person sitting on a chair.

Who needs palliative care? We already discussed people who are suffering from lifelong illnesses, life limiting illnesses, non-communicable diseases, incurable state and they need palliative care.

So the list is here cancer, HIV-AIDS, dementia, progressive neurological disease like Parkinson disease, multiple sclerosis, stroke, paraplegia etc. and end-stage organ failures like liver, heart, lung, and kidney failure they need palliative care. Even old age people who has aging process and has developed disability they need palliative care.

(Refer Slide Time: 11:22)

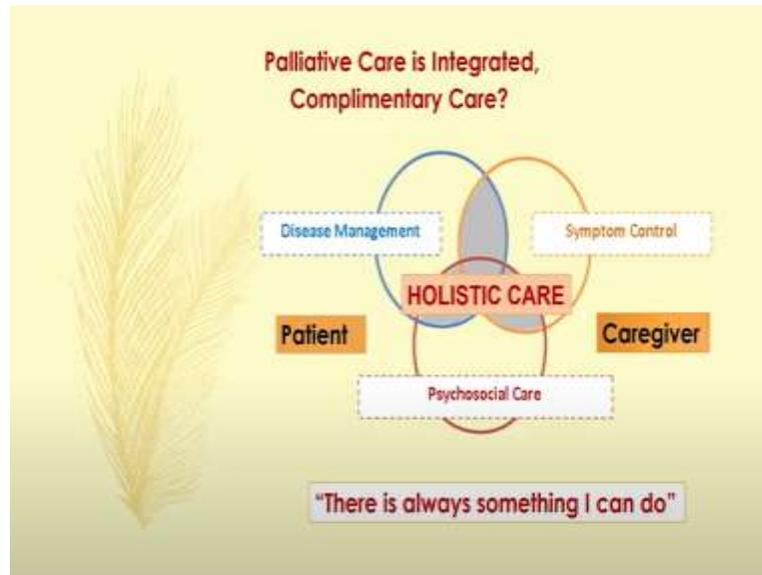


So palliative care is there for cancer and non cancer patients. When to start palliative care.

As per old concept after the curative treatment is over one can go for the palliative treatment. But as per new concept it should start right at diagnosis of the patient. So, once patient is diagnosed of cancer, HIV or chronic kidney disease like that they should be referred to the palliative care department. So there is a rapport is established initially patient undergoes more of a curative treatment and less of a palliative treatment. And suppose disease advances and he becomes not responsive to the curative treatment then more of a palliative care is required.

At one stage we come to know now this patient is likely to die. He is not he is not responding to any other curative treatment then this stage is about one to six months and this stage is called end of life and here also there he needs only palliative care and end of life care is a specialty and here patient has many problems like pain, many symptoms, many psychosocial issues, then he has lots of worries, he has anxiety, he has fear of death and all those things is taken care of by counseling and communication and proper end of life care is given. This can be given at home or in hospice. Such patient can be admitted in hospice also the palliative care doesn't end here. After death of patient palliative care team goes and visit the family at home and give bereavement support and they talk to them they attend to their worries their problems and how they feel about the after death of the patient that is what is palliative care is.

(Refer Slide Time: 13:38)



So, palliative care is not a separate entity as such it is integrated with other mode of treatment or curative treatment so it is a complementary care. So at one side you are giving disease management treatment to the patient like chemotherapy, radiotherapy or dialysis and all that at the same time you are relieving his symptoms and providing psychosocial care, psychosocial support And this is what is holistic care given to the patient and not only patient but also caregivers. So, the first slide which we show that nothing more can be done is absolutely wrong. There is always something I can do for this type of patient and that is what palliative care is. Where palliative care is can be given.

It can be given as a outpatient patient department where patient comes, attends a palliative care physician and takes medicine and goes home. Patient having severe symptoms, pain, they can be admitted in hospital for few days. Patient having advanced stage of disease and having lots of difficult symptoms, psychosocial issues and requires lots of nursing care, they can be admitted in hospice and can stay there till end of life. There is a concept of day care unit also. In Delhi, CanKids are having a concept of day care unit for the children requiring palliative care.

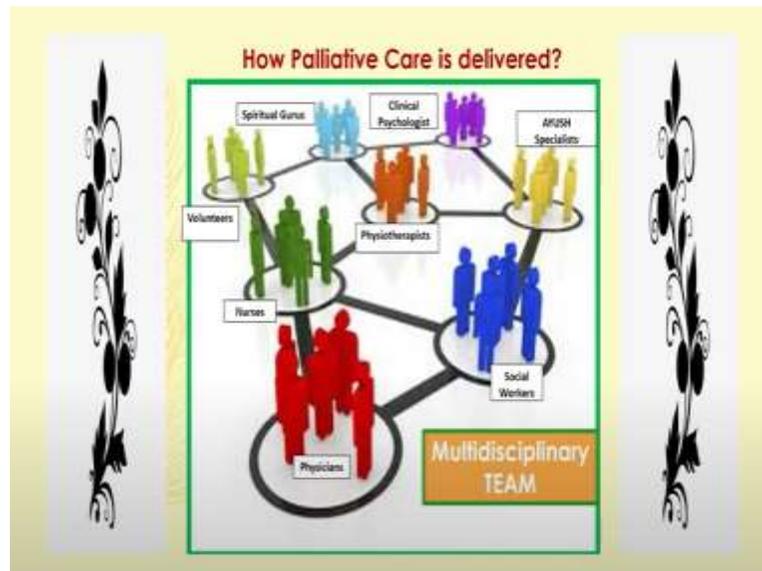
Parents can bring the children to this day care unit from morning to evening and they can be looked after by the volunteers and nurses.

(Refer Slide Time: 15:32)



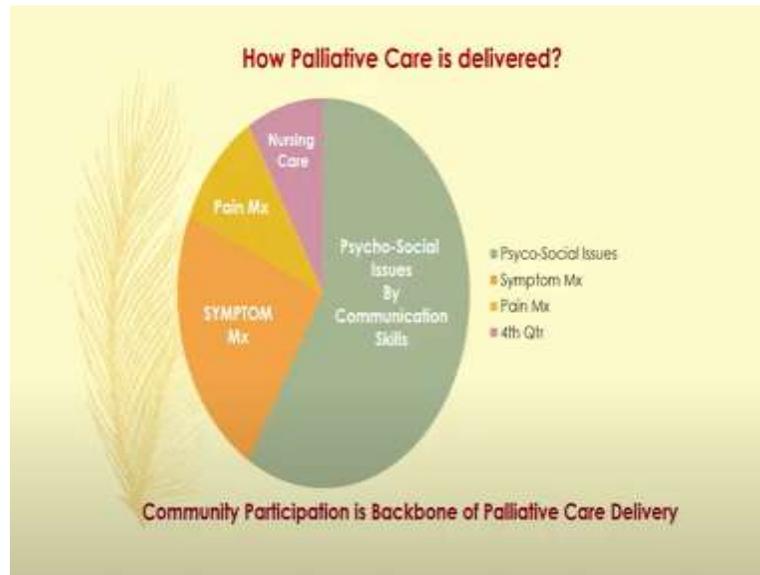
So this is how palliative care can be given.

(Refer Slide Time: 15:34)



Secondly palliative care is not only given only by physician it is a teamwork. Multi-disciplinary team which can include nurses social workers, psychologists, volunteers, spiritual gurus who can give spiritual talk to the patient, Ayush specialist, physiotherapist and many more. So it is always multidisciplinary team.

(Refer Slide Time: 16:03)



So how palliative care is given? Suppose you take a patient, then patient might have pain, you manage his pain by many analgesics or procedure whatever he might have symptoms like nausea vomiting constipation diarrhea you treat whatever medicine you know about and how you practice in your your speciality. Then he needs nursing care.

Many of these patients have got very foul smelling wound, foul smell from the mouth. They require nasogastric tube feeding and all such things. So they should be given nursing care. They might be with the catheter and all that. Apart from that, patient has so much of psychosocial issues, so much worries, anxiety, no social support, no financial support.

So all this is provided through a proper communication and counseling by your team members. So community participation and multidisciplinary team is the backbone of palliative care delivery.

(Refer Slide Time: 17:10)

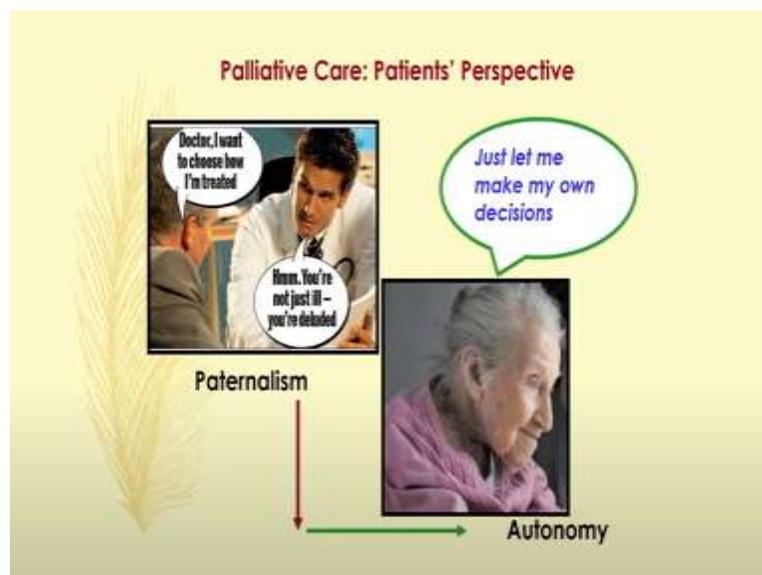
**Palliative Care is identifying
Serious Health Related (SHR) sufferings**

Ques	Nil 0	Mild 1	Moderate 2	Severe 3	Excruciating 4
Pain & Symptoms					
Psychology					
Social issues					
Spiritual issues					

**score > 2 need palliative care, and ensured followed up,
until the score reduces to < 2**

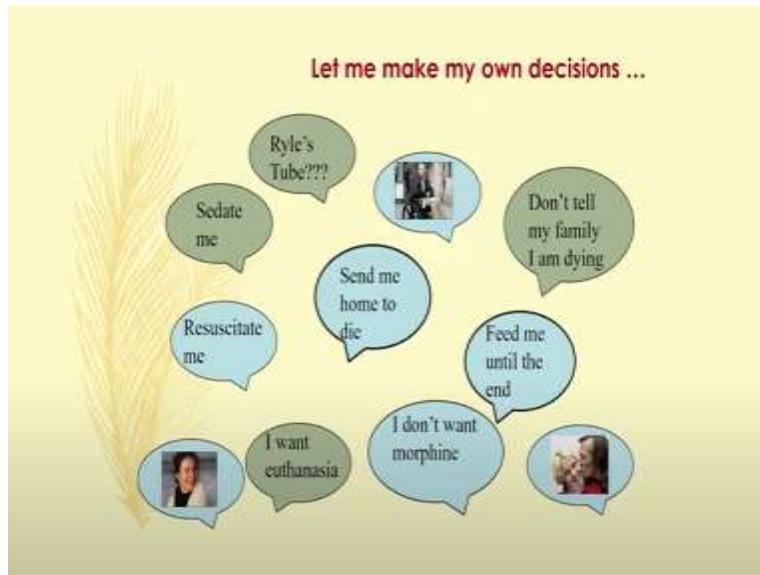
How you identify the palliative care need of your patient you write down the problems of the patient on one end like pain, symptoms, psychological issues, social issues, spiritual issue and give it number whether it is mild, moderate, severe and very severe. If your score is for any symptom your score is two or more then this patient needs palliative care. So, always you can use this arbit chart arbitrarily and define that whether this patient needs palliative care or not.

(Refer Slide Time: 17:46)



What is different about palliative care? You must have visited sometimes a physician or a surgeon or ENT specialist and what they do they just listen to patient for a while, go through the file and reports and write down the treatment and say you take this treatment, that's all. In palliative care it is not how it differs from such other specialty that in palliative care we always listen to patients importance to the patients perspective what you want whether you want admission to the hospice or not whether you want feeding to be inserted or not. So, it is always patient autonomy is given priority patient will decide about his treatment. And it is not paternalism like it is practiced in many other specialties.

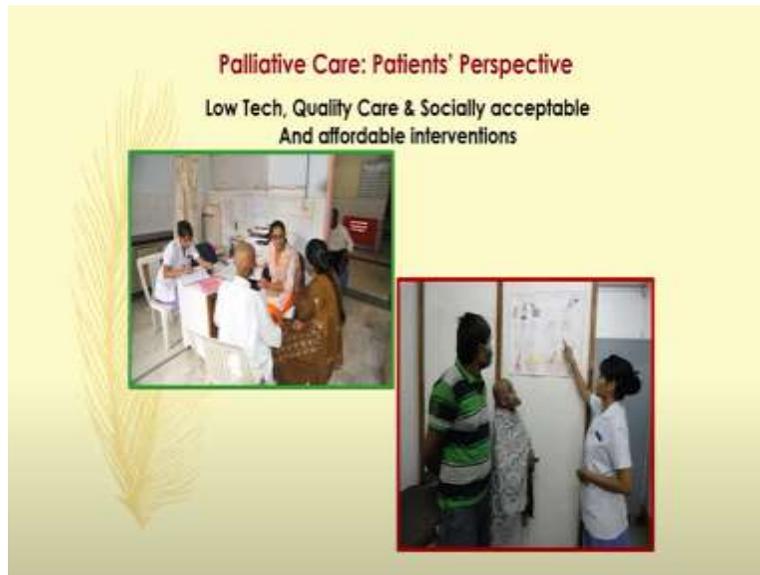
(Refer Slide Time: 18:41)



So patient can take decision about admission to the hospice, about ryles tube insertion, whether to give me sedation or not, whether to feed me until the end and whether to resuscitate me, whether I should get morphine or not.

So all such decisions are taken by patient or caregiver and we discuss each and every point with the patient and caregiver, explain them advantage and disadvantage and whatever decision they take you remain with the patient. You are, you say I am there for you suppose he refuses your treatment it does not mean that you will stop all treatment for him in spite of that you always remain with the patient help them in taking decision whatever decision they take always support them. Thirdly, palliative care is a tender loving care. We always speak very nicely to patient, listen to them and very personal care is given to the patient.

(Refer Slide Time: 19:58)

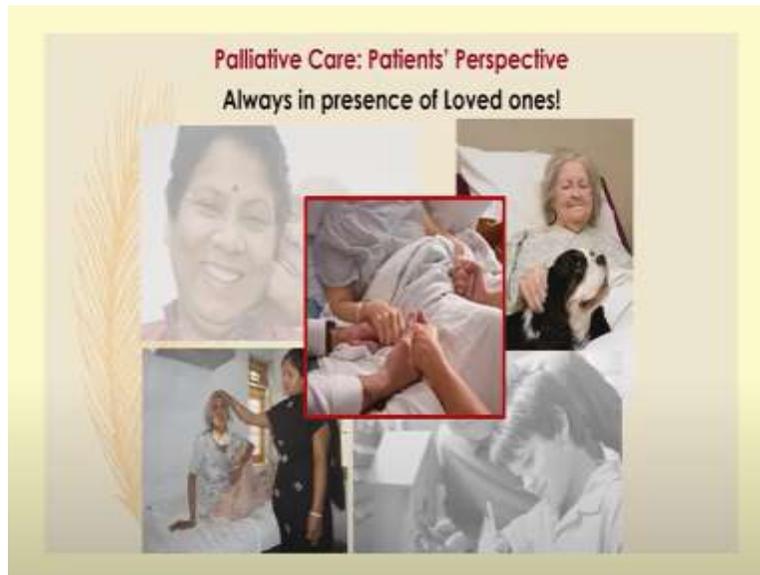


Thirdly, palliative care is low technology, high quality care and it is with the socially acceptable norms.

So palliative care is not hi-fi care where patient is kept in ICU or special room and given or attached to many machines and laboratory investigation and this and that bare minimum intervention are done. We always treat the pain and symptom with the pharmacological treatment like with medicine as well as non-pharmacological treatment like patient is made comfortable, patient is given certain type of food, patient is given certain type of environment and all such things. So it is always low technology, high quality care not very costly medicine. Like in cancer patient they have got very bad wound and it requires metrogel dressing. Now, this Metrogel ointment outside comes very costly and it has got less percentage of Metrogel.

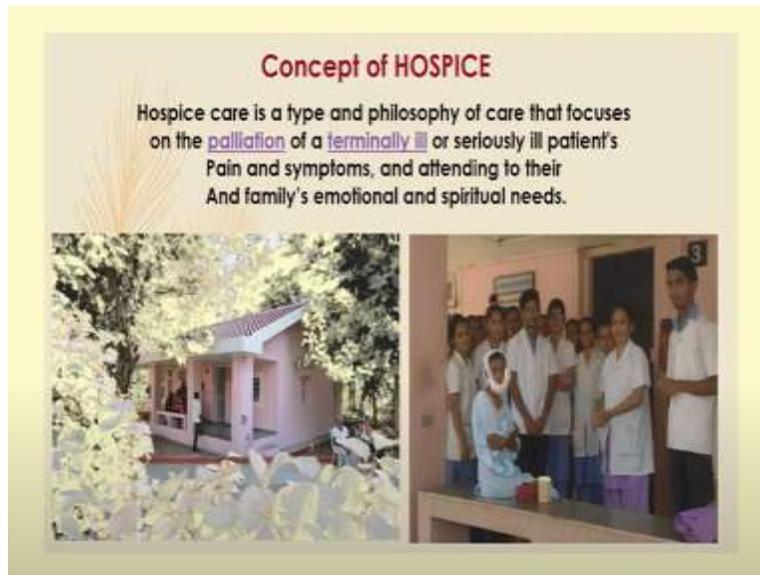
So, we teach them how to prepare Metrogel ointment at home from the Metrogel tablets. The Metrogel tablets are crushed in which Vaseline and normal saline is added and patient can make the ointment at home and it can be used. So this is, this my nurse shows on the chart how to prepare the ointment. So always low technology, cost effective care and with socially acceptable, affordable intervention.

(Refer Slide Time: 21:40)



Always in presence of loved one. We never leave patient alone, always caregiver family members are always there and that is why during end of life patient is admitted in hospice where he can stay all his family member come and meet him and not like ICU care where the patient is kept alone in the ICU room in a AC room and separated by curtains from the family and other relatives. The concept of hospice hospice we discuss it is a institute which provides care to the dying patient, not only dying patient even patients who need palliative care who has difficult symptoms can be admitted for hospice for a few days and can then can be discharged at home.

(Refer Slide Time: 22:30)



So, hospice is a concept and here pain and symptom and family's emotional problems are attended. This is the hospice where I am practicing this type of huts are there and where patient each room there is one patient and patient feels at home in very good surrounding and all and nurses are there to support the patient. These are various activities in my hospice complex.

(Refer Slide Time: 23:00)



This is a caregivers meeting open in the garden, this is one yoga session taken up laughter yoga by Archana Rao she comes from Bangalore every year and care is given and patient is, patient and family members are educated, they are taught how to take care of themselves, how to give ryles tube feeding, how to do dressing and also things are taught to them so when they go home they can look after themselves without depending on other paramedics or other nursing staff from surrounding.

(Refer Slide Time: 23:47)



These are the paintings done by one of my patients in hospice. He was a painter and he had a very bad head and neck cancer, oral cancer. And he remained with us for almost four months. And during last few months, he painted all this on canvas and they are lying, displayed in our hospice.

This is the basic concept about hospice. Thank you very much.