Basic Certificate in Palliative Care

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Week-11

Lecture 06: Delivery Models of Palliative Care

Today, let us discuss the different delivery models of palliative care in India. And once again I thank Dr. Yashwant Yoshi for preparing this PPT.

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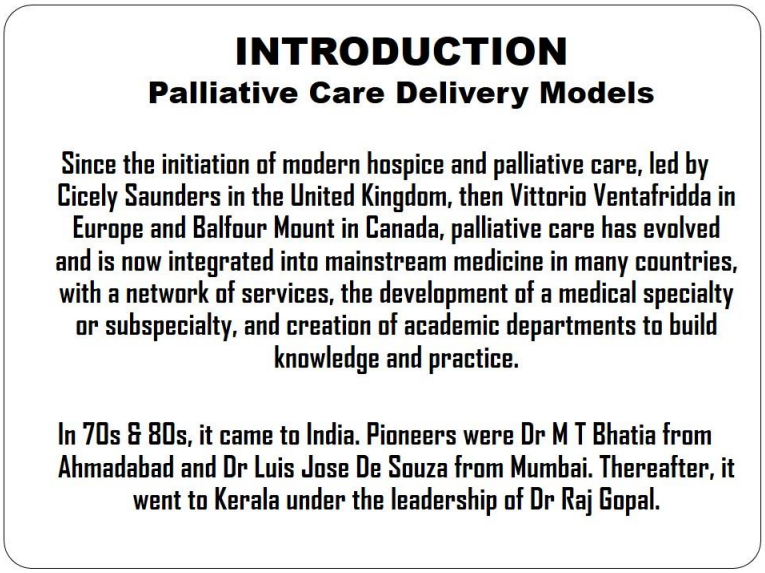

Now, to say about the introduction of palliative care delivery models. Since the initiation of modern hospice and palliative care led by Cicely Saunders in the United Kingdom, after that then Vittorio Ventafridda in Europe and Balfour Mount in Canada. Palliative care has evolved and is now integrated into mainstream medicine in many countries with a network of services, the development of medical specialty or subspecialty and creation of academic departments to build knowledge and practice.

In 17s and 80s, it came to India and the pioneers were Dr. M. T. Bhatia from Ahmedabad and Dr.Luis Jose De Souza from Mumbai. Therefore, it went to Kerala under the leadership of Dr. Rajagopal.

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And to say about the history of palliative care in India and UK, we can see that now King Ashoka he built more than 18 hospitals for elderly people and for tertiary disease patients. So, we can say that you know from there the palliative care starts.

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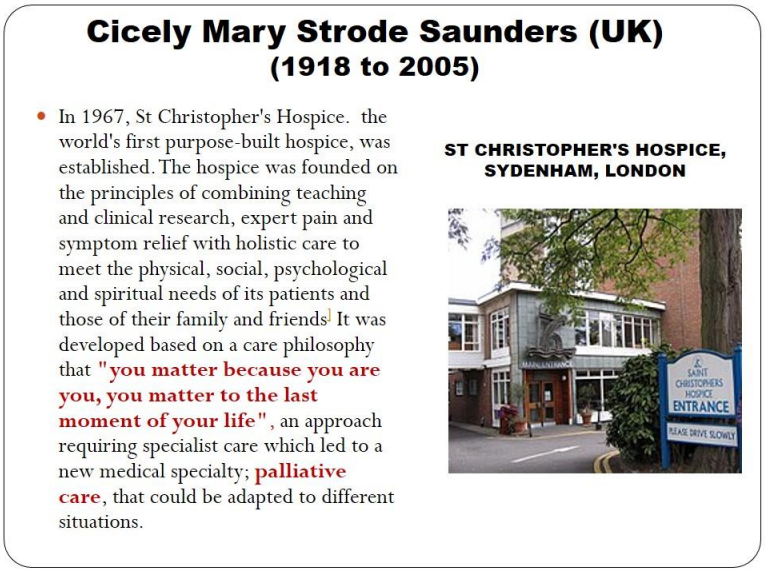

And Dame Cicely Saunders, she in 1967 Saint Christopher's hospital hospice, the world first purpose built hospital, the hospice center was established. The hospice was founded on the principle of combing, the hospice was founded on the principle of combining teaching and clinical research, expert pain and symptom relief with holistic care to meet the physical, social and psychosocial spiritual needs of the inpatients and those who are with their and those who have their family and friends. It was developed based on a care that of philosophy that you know you matter because you are you and you matter to the last moment of your life. And approach requiring specialist care which led to a new medical specialty that is palliative care that could be adopted to different situations. And coming to this founder Cicely Dame Saunders in UK.

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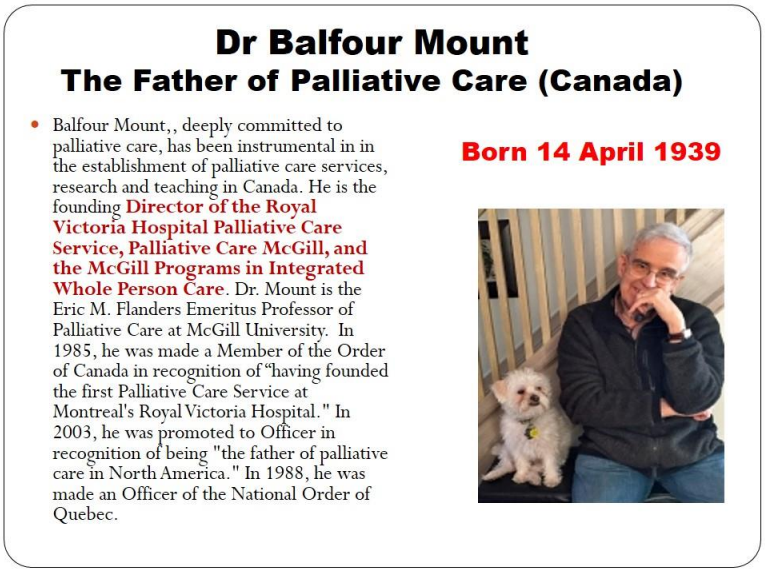

Then coming to another pioneer you know doctor Balfour Mound, the father of palliative care in Canada.

Balfour Mount you know deeply committed to palliative care has been instrumental in an establishment of palliative care services and its research and he taught many people in Canada. He is the founding director of Royal Victoria Hospital palliative care service and the palliative care McGill and the McGill program in integrated whole person care. Doctor Mount is the Eric M. Flanders emeritus professor of palliative care at McGill University. In 1985, he was made a member of the Order of Canada in recognition of having founded the first palliative care service at Montreal Royal Victoria Hospital.

In 2003, he was promoted to officer in recognition of being the father of palliative care in North America. In 1988, he was made an officer of the National Order of Quebec and he born in 14, 18 April 1939.

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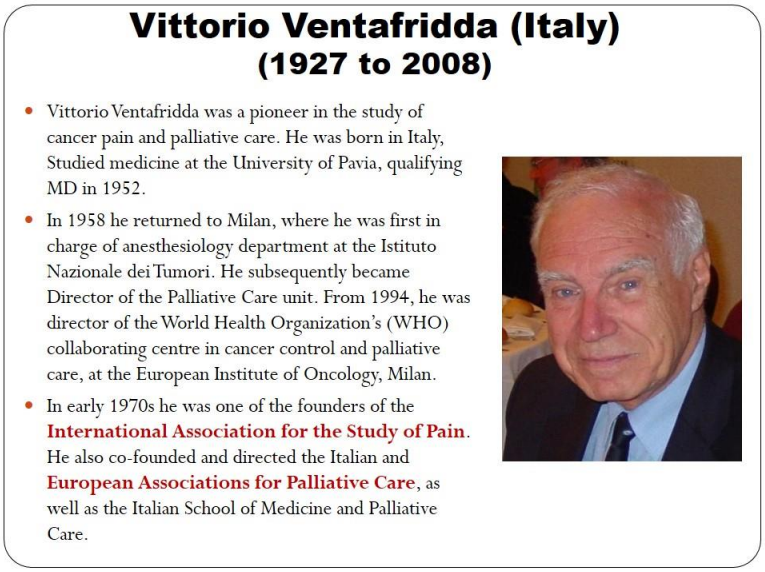

Vittorio Ventafridda. Vittorio Ventafridda was a pioneer in the study of cancer pain and palliative care. He was born in Italy, studied medicine at the University of Pavia, qualifying MD in 1952. In 1958, he returned to Milan where he was the first in charge of anesthesiology department at the Istituto Nazionale dei Tumori, department of Istituto Nazionale dei Tumori.

He subsequently became the director of palliative care units. From 1994, he was the director of World Health Organization collaborating center in cancer control and palliative care at the European Institute of Oncology, Milan. In early 1970s, he was one of the founders of the International Association for the Study of Pain. He also co-founded and directed the Italian and European Association for Palliative Care as well as the Italian School of Medicine and Palliative Care.

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Dr Luis Jose De Souza (India)

- Luis Jose De Souza is an Indian surgical oncologist and the founder of **Shanti Avedna Ashram**, a charitable trust which runs a network of hospices in Mumbai, Delhi and Goa. He has also contributed to the establishment of Indian Cancer Cell, an educational program co-sponsored by Tata Memorial Centre, Union for International Cancer Control (UICC) and Indian Cancer Society, for creating cancer awareness in schools. The Government of India awarded him the Padma Shri in 1992.

Another person, Dr. Luis Jose De Souza. Dr. Luis Jose De Souza is an Indian surgical oncologist and the founder of Shanti Avedna Ashram, a charitable trust which runs the network of hospice in Mumbai, Delhi and Goa. He has also contributed to the establishment of Indian Cancer Cell, an educational program co-sponsored by Tata Memorial Center, Union for International Cancer Control and Indian Cancer Society for creating cancer awareness in school. The government of India awarded him the Padma Shri in 1992.

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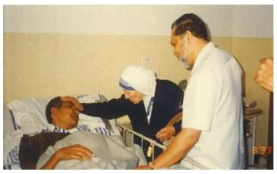
Shanti Avedna Sadan

- Way back in the 70s as a young Cancer Surgeon Dr L J DeSousa came across many patients for whom there was nothing more that the medical world had to offer – by way of surgery or medications. In such a hopeless situation they found themselves looking into the dark night of despair waiting for the end to come. In some cases it happened soon, in others it painfully lingered on. The 70s & 80s were the dark ages in Cancer Care, at least in India. That was a time when Dr DeSousa happened to visits St Christopher's Hospice in the UK. And met Dame Cicely Saunders who was a pioneer in modern Hospice Care. No one knew what a Hospice meant. Leave alone lay people even, medical professionals were not aware of the word.



To say about the Shanti Avedna Ashram and its work, we are back to 1970 as a young cancer surgeon, Dr. L.J. De Souza came across many patients for whom there was nothing more that the medical world had to offer by way of surgery or medication. In such a hopeless situation, they found themselves looking into that dark night of despair waiting for the end to come.

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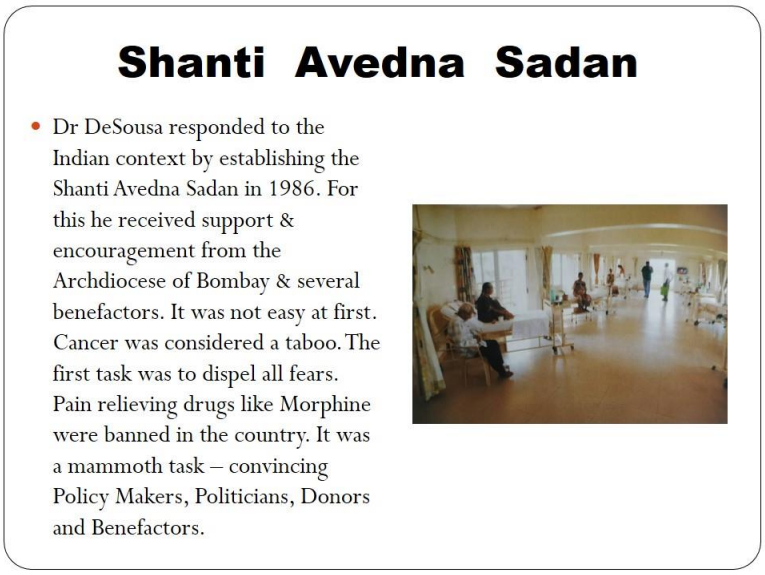

Shanti Avedna Sadan, Dr. De Souza responded to the Indian contests by establishing the Shanti Avedna Sadan in 1986. For this, he received support and encouragement from the archdiocese of Bombay and several benefactors. It was not easy at first.

Cancer was considered taboo. The first task was to dispel old fears. Pain relieving drugs like morphine were banned in the country. It was a mammoth task convincing policymakers, politicians, donors and benefactors.

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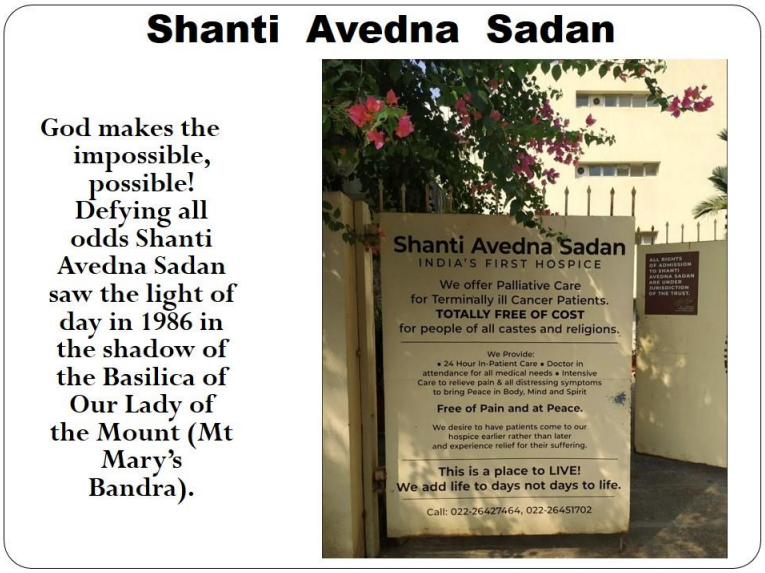

Now, to say about this Shanti Avedna, God makes the impossible possible. Defying old old Shanti Avedna Sadan, so the lights of day in 1986, in the shadow of the Basilica of Our Lady of the Mount at Bandra.

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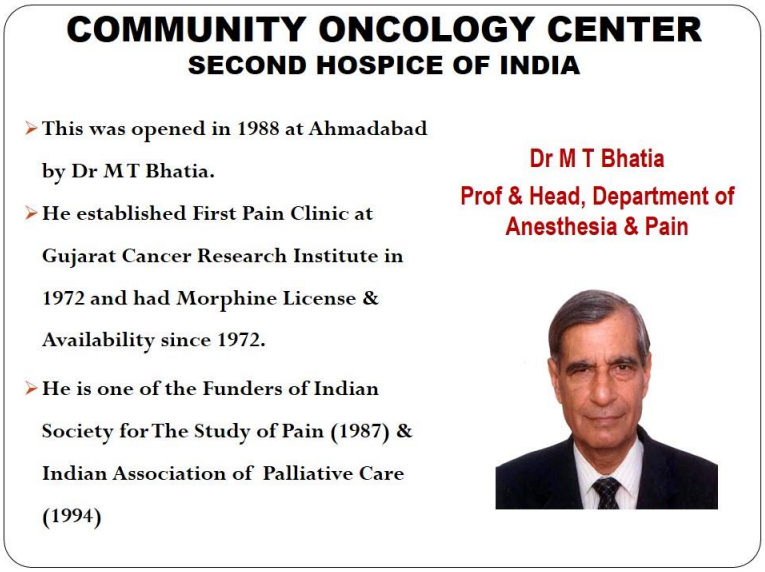

To say about the community oncology center that is second one, second hospice center in India. This was opened in 1980 at Ahmadabad by Dr. M. T. Bhatia. He established the first pain clinic at Gujarat Cancer Research Institute in 1972 and had morphine license and availability since 1972. He is one of the founders of Indian society for the study of pain and the Indian association of palliative care.

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See these are the different pictures of Shanti Avedna Sadan.

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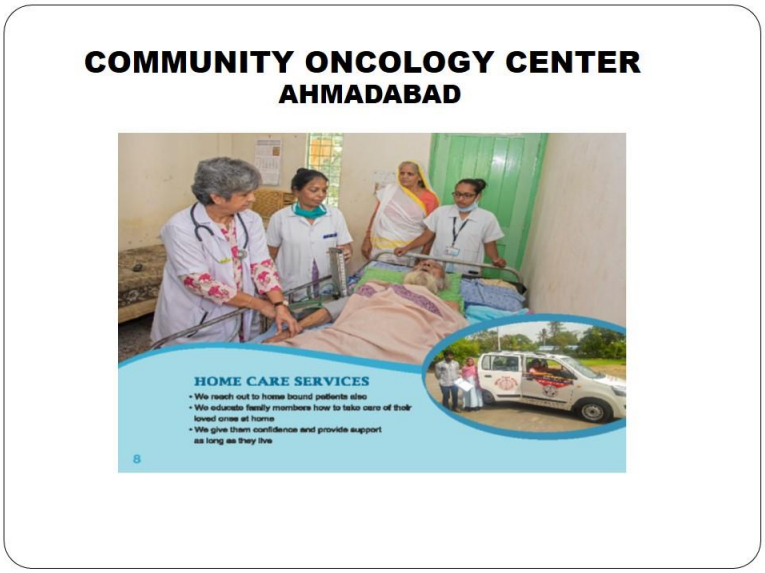

And another center is community oncology center that is Ahmadabad, they are doing home care service also.

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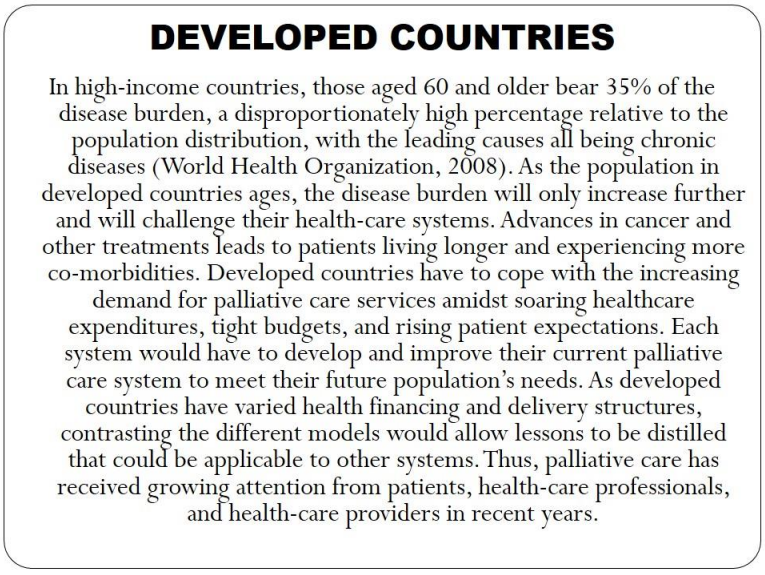

And this developed countries you know that we can have another thing that you know. In high income countries those who age 60 and older be in high income countries those who age 60 and older we are 35 percent of the disease burden. A disproportionately high

percentage related to the population distribution which is a leading cause of old being chronic diseases. This is the statistic by World Health Organization in 2008. As the population in developed countries ages the disease burden will only increases further and will change their health care systems. Advances in cancer and other treatments leads to patients living longer and experiencing more comorbidities.

Developed countries have to cope with increasing demand for palliative care services, amidst soaring health care expenditures, tight budgets and rising patient expectations. Each system would have to develop and improve their current palliative care system to meet their future population needs. As developed countries have varied health financing and delivery structures, contrasting the different models would allow lessons to distill that could be applicable to other systems. Thus palliative care has received growing attention from patients, health care professionals and health care providers in recent years.

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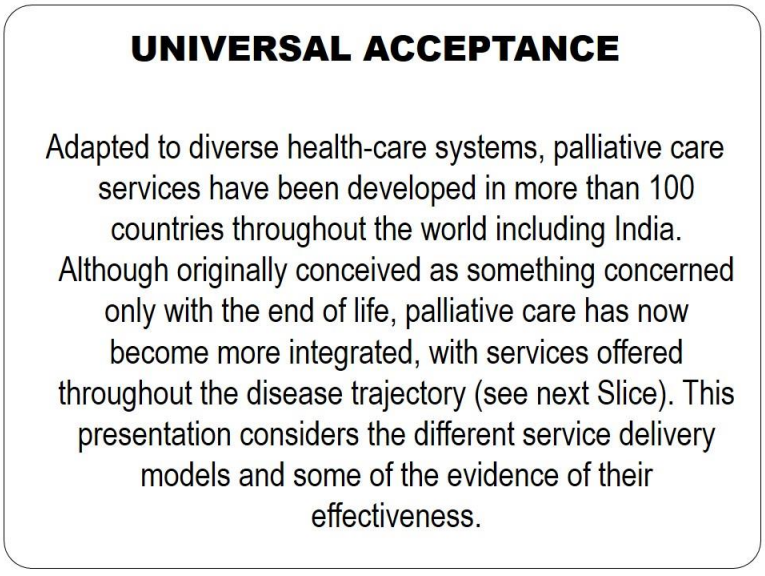

It has universal acceptance adapted to diverse health care system palliative care service have been developed in more than 100 countries throughout the world including India. Although originally conceived as something concerned only with the end of life, palliative care has now become more integrated with the service offered throughout the

disease trajectory. This presentation considers the different services delivery models and some of the evidence of their effectiveness.

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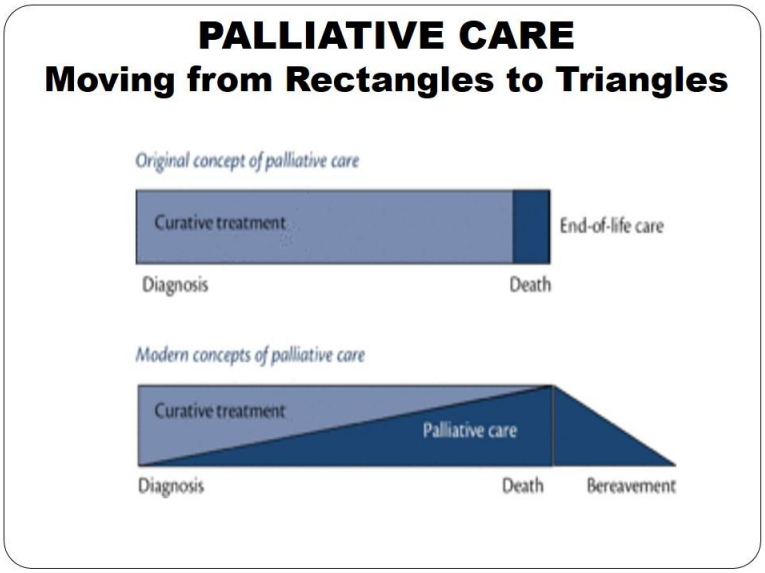

We can see that you know the slide it is the you know in the past you know only that disease when it is coming to an that end life end of life only that period this palliative care was introduced. Now, the modern concept you know that the palliative care can be started from the very beginning itself and it is there up to death and it includes a bereavement also.

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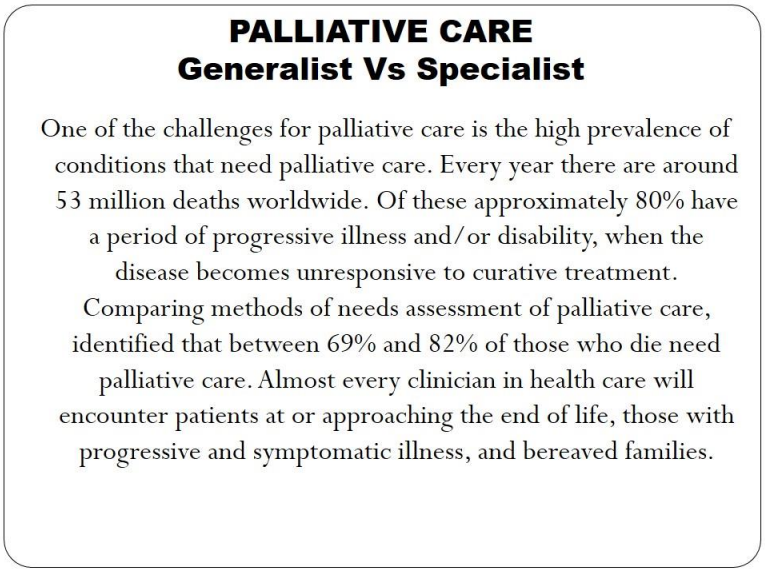

To say about the palliative care difference between this palliative care generalist and the specialist. One of the challenges for palliative care is the high prevalence of conditions that need palliative care. Every year there are around 53 million deaths worldwide of these approximately 80 percent have a period of progressive illness and disability. When the disease become unresponsive to curative treatment the disease become progressive and disability is there.

Comparing the methods of needs assessment of palliative care identified that between 69 to 82 percent of those who die need palliative care. Almost every clinician in health care will encounter patients at and or those who are approaching the end of life those with the progressive and symptom illness and bereaved families.

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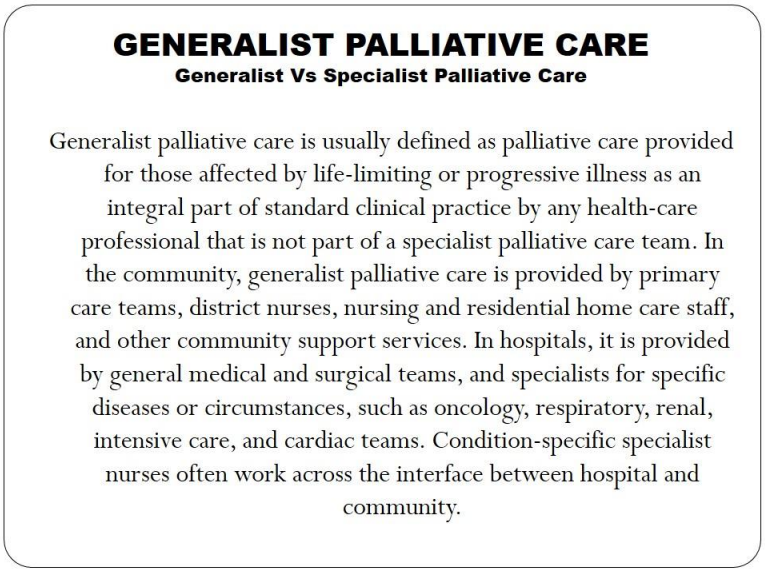

Generalist and palliative care, difference between the general, generalist palliative care is usually defined as the palliative care provided for those affected by life limiting or progressive illness as an integral part of standard clinical practice by any health care. Professional that is not a part of specialist palliative care team. The general palliative care is usually defined as palliative care provided for those affected by life limiting or progressive illness as an integral part of standard clinical practice by any health care professional that is not a part of a specialist palliative care team.

In the community generalist palliative care is provided by primary care teams, district nurses, nursing and residential home care staff and other community support services can provide palliative care. In hospitals it is provided by general medical and surgical teams and the specialist for specific diseases or circumstances such as oncology, respiratory, renal, intensive care and cardiac teams. Condition specific specialist nurses often work across the interface community between conditions specific specialty nurses often work across the interface between hospital and community.

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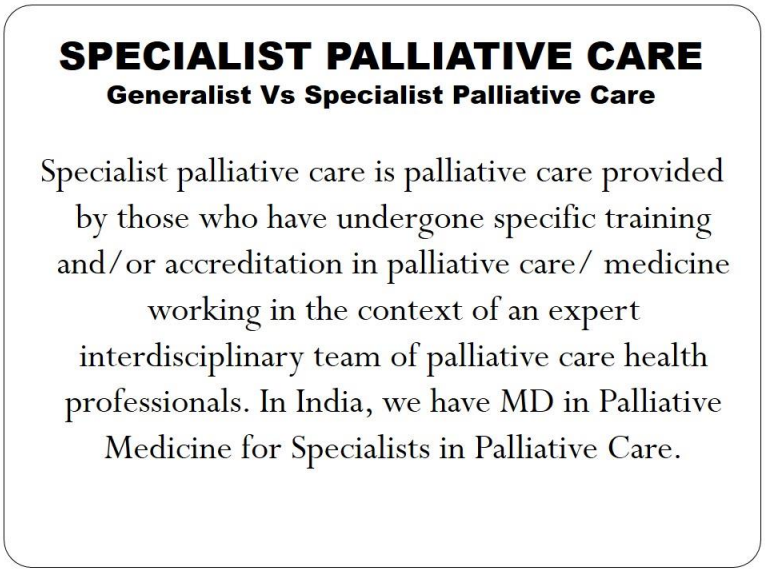

You know to say about the specialist palliative care worker they are specialist in palliative care provided by those who have undergone specialist specific training and or accreditation and that and have accreditation in palliative care medicine. And they are working in the context of an expert interdisciplinary team of palliative health care professionals. In India we have MD in palliative medicine for specialist in palliative care.

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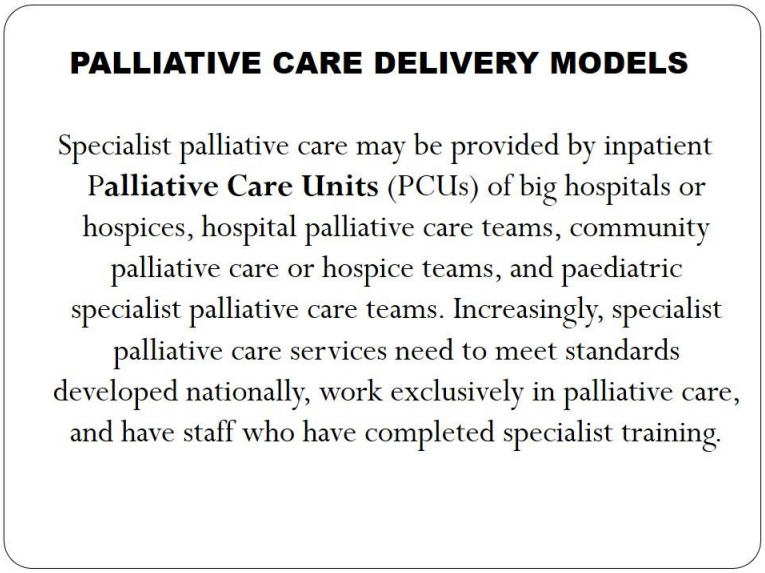

And to say about the palliative care delivery models specialist palliative care may be provided by inpatients in palliative care units of big hospitals or hospice center or in hospital where the palliative care teams are available or in the community itself where the palliative care and hospice teams are there.

And this palliative care services need to meet standards developed nationally and they have to work exclusively in palliative care and staffs are there to complete specially the staffs are the staffs have to be completed their specialist training in palliative care.

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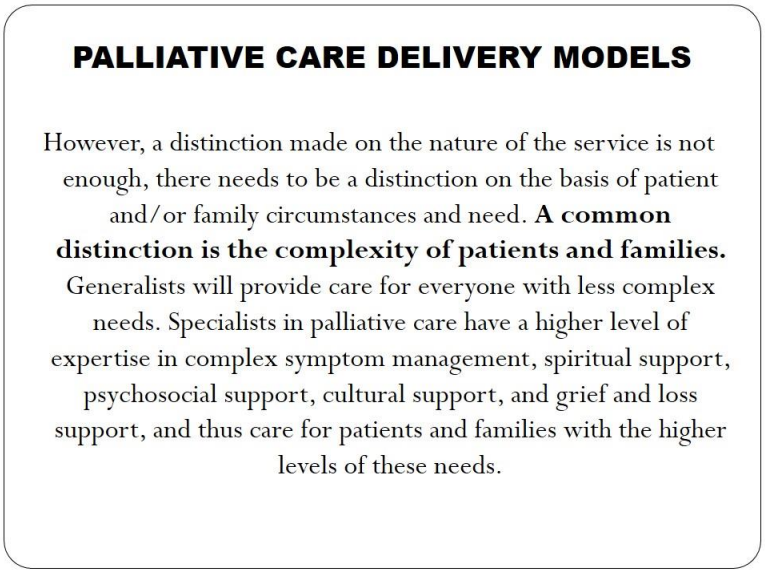

However, a distinction made on the nature of service is not enough because you know this palliative care delivery that means, you know there there needs to be a distinction on the basis of patient or family and the circumstances it is needed. A common distinction is is the complexity of patients and the families. Generalists will provide care for everyone with the less complex needs. Specialists in palliative care have higher levels of expertise in complex system management, their spiritual support, psychosocial support, cultural support and grief and low supports. Thus, they care the patients and family with higher levels of the needs.

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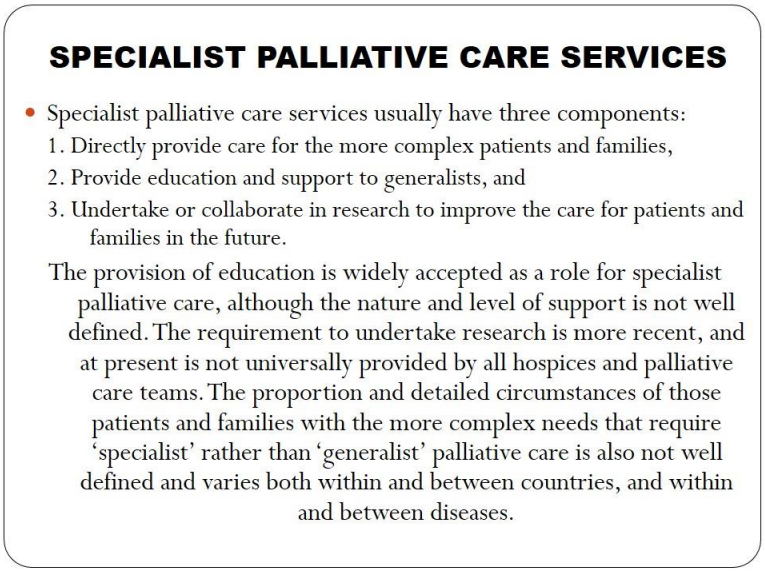

The specialist palliative care services they provide palliative care service usually have three components. One is directly provide care for the more complex patients and families. And second one is provide education and support to generalist, the third one undertake or collaborate in research to improve the care of patients and their family in future. The provision of education is widely accepted as a role of specialist palliative care.

Although, the natural level of support is not well defined. The requirement to undertake research is more recent and at present it is not universally provided by all hospital palliative care teams. The proportion and detailed circumstances of those patients and families with more complex needs that require specialist rather than generalist palliative care. And we have to define the various things within and between countries and between diseases.

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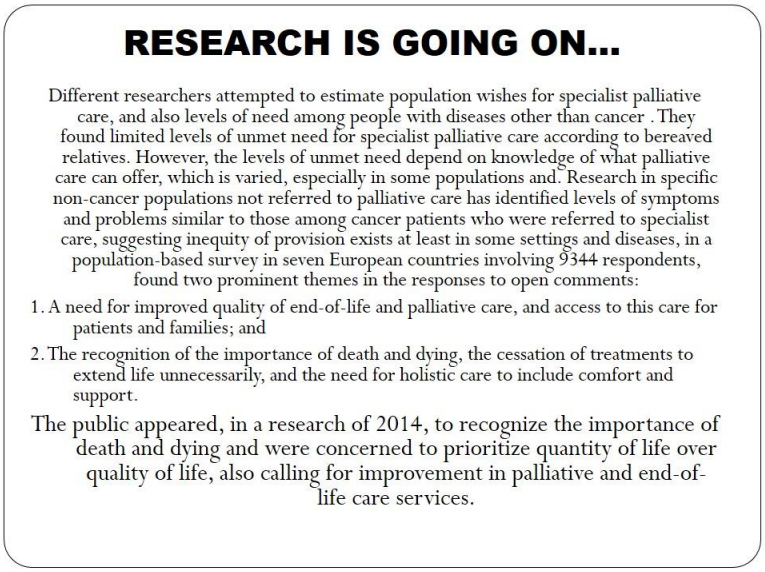

Research is going on. Different researches attempted to estimate population which has for specialist palliative care and also levels of needed and also levels of needed among people with the disease other than cancer. They found limited levels of unmet needed need for the specialist palliative care according to the bereaved family. However, the levels of unmet needs depend on the knowledge of what palliative care can offer which is varied especially in some population and the research it is going on. Research in specific non cancer populations not referred to palliative care that has to be identified and that also how to be take into consideration. A need for improved quality of end of life and palliative care is needed and access to this care for patients and family how to be met.

The recognition of importance of death and dying, the cessation of treatment to extend life unnecessarily and the need for holistic care to include comfort and support. The public appeared in a research, a publication appeared in a research in 2014 to recognize the importance of death and dying and were concerned to prioritize quality of life quantity of life or quality of life also calling for improvement in palliative care and end of life of care services.

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Delivery of Specialist Palliative care

Delivery of specialist palliative care differs slightly throughout the world but similar structures have evolved: inpatient palliative care is provided in dedicated PCUs or hospices, specialist palliative care teams offer palliative care consultations either in the hospital or in the community within home care programmes, and increasingly outpatient, day care, and respite services. Note that several PCUs offer a combination of services—for example, most inpatient PCUs and hospices also offer other services, such as, if they are based in the community, home care and day care, or if based in a hospital, hospital consultation. It is not that one specific service is better than or preferable to another: **COMMUNITY SUPPORT** is essential as evidence consistently shows that most patients want to be cared for at home for as long as possible and often to die there and yet more than half of deaths in most countries occur in hospitals

Now, delivery of specialist palliative care differs slightly throughout the world, but similar structures how evolved inpatient palliative care is provided in dedicated palliative care units or hospice. And specialist palliative care teams offer palliative care consultation either in hospitals or in community or in within home itself. And increasingly outpatient day care centers how to be we have to note that you know several primary palliative units are offer a combination of services.

For example, most inpatient of palliative care units and hospice are also offer other services such as if they are based in the community, home care and day care facilities are available and they are provided. Or if based in a hospital, hospital consultation it is need it is not that one specific service is better than other. Community support is essential as evidence based and consistently shows that most patients want to be cared for at home for as long as possible and often to die there and yet more than half of deaths in most countries occur in hospitals. Community support is essential as evidence based and constantly shows that most patients wants to be cared for at home for as long as it is possible.

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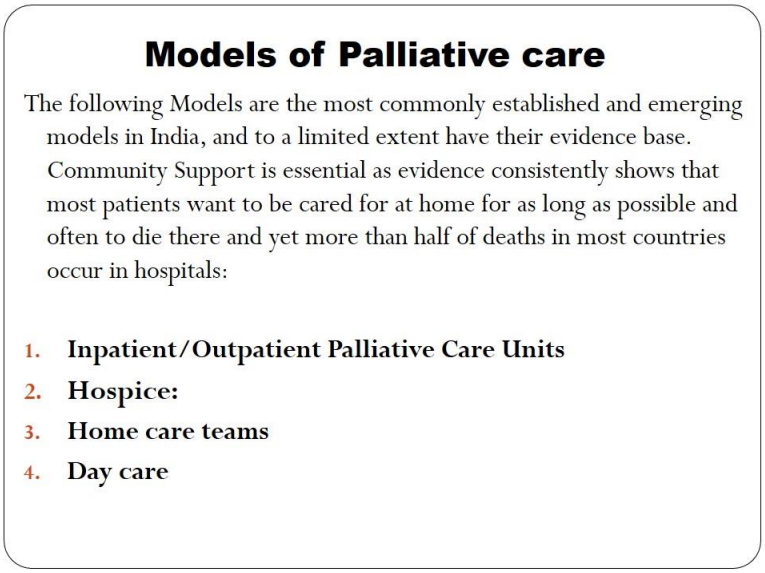

To say about the models of palliative care, we can see the following models are the most commonly and established emerging models in India.

And to a limited extent that we can see that you know community support is essential as evidence based and constantly shows that most patient the different models you know that inpatient and outpatient care units, the hospice centers, home cares teams and day care palliative care centers.

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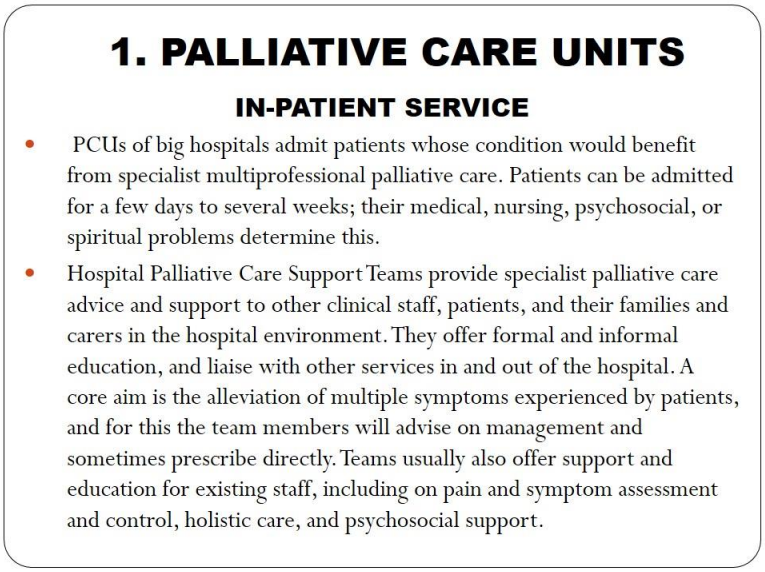

You know in the inpatient service of palliative care know the palliative care units of big hospital admit patients whose conditions would benefit from specialist multi professional palliative care. Patients can be admitted for a few days to several weeks according to their medical condition and this nursing care if it is needed and they have to provide psychosocial or spiritual problem determine this. Hospital palliative care support teams provide specialist palliative care advice and support to other clinical staff, patients and their families and other caretakers in the hospital environment. They offer formal and informal education and license with other services in and around the hospital.

A core aim is the elevation of multiple symptoms experienced by the patients and for this team, the team members will advice on management and sometimes prescribe it directly. Teams usually also offer support and education for existing staff including the pain management and its control the holistic care of the patient and the psychosocial support of the patient.

To say about the outpatient service you know the palliative output, outpatient clinics can be offered from hospital or inpatient palliative care units or hospitals. There is an increasing variety of such services with outpatient services being offered jointly with oncology, respiratory medicines and neurology services. They often meet the need to integrate services and can help to introduce patients earlier to palliative care in non-threatening way providing help with, for example, specific symptoms which are more

advanced that has to be taken into consideration. To date, however, evaluations are few and these are much more needed in future.

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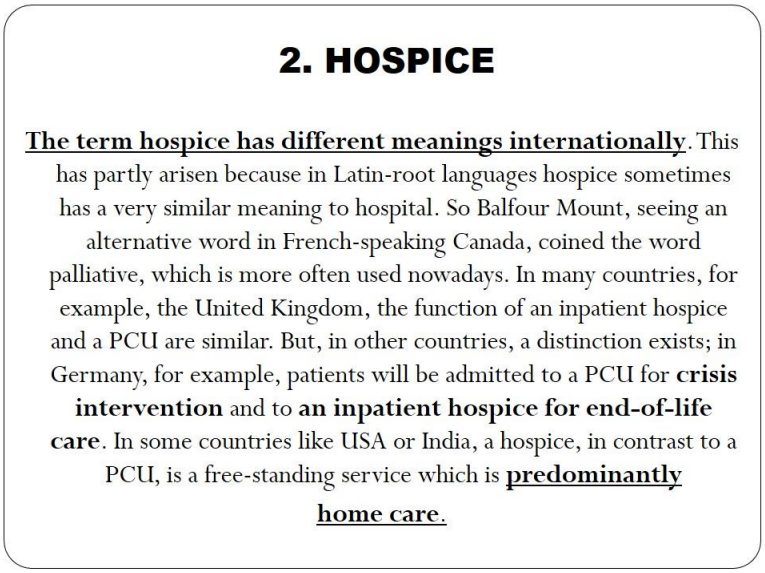

You know there is hospice centers. What is hospice? The term hospice has difference, different meaning in internationally. This has partly arisen from this has partly arisen because in Latin root language hospice sometimes has a similar meaning to hospital. So, Balfour Mount seeing an alternative word in French speaking Canada coined word palliative which is more often used in nowadays.

In many countries for example, in the United Kingdom the function of an inpatient hospice and palliative care units are similar, but in other countries a distinction exists. In Germany for example, patients will be admitted to palliative care units for crisis intervention and to an inpatient hospital for end life care. In some countries like USA or India hospice in contrast to this palliative care unit is free standing services which predominantly home care.

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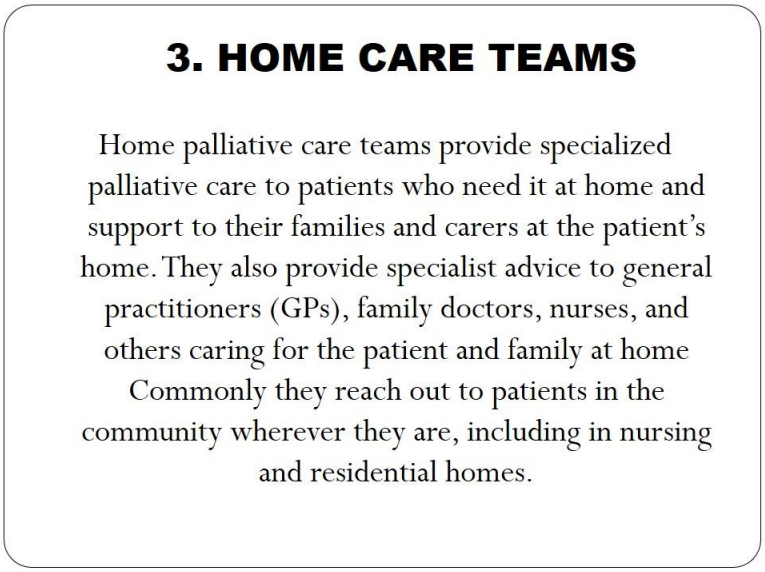

So, this home care teams you know palliative care teams provide specialized palliative care to patients who need it at home and support their family members and other caretakers of the patient. They also provide specialist advice to general practitioners and their family doctors, nurses and other caring for the patient and family at home. Commonly they reach out to the patient in the community wherever they are including in nursing and residential homes.

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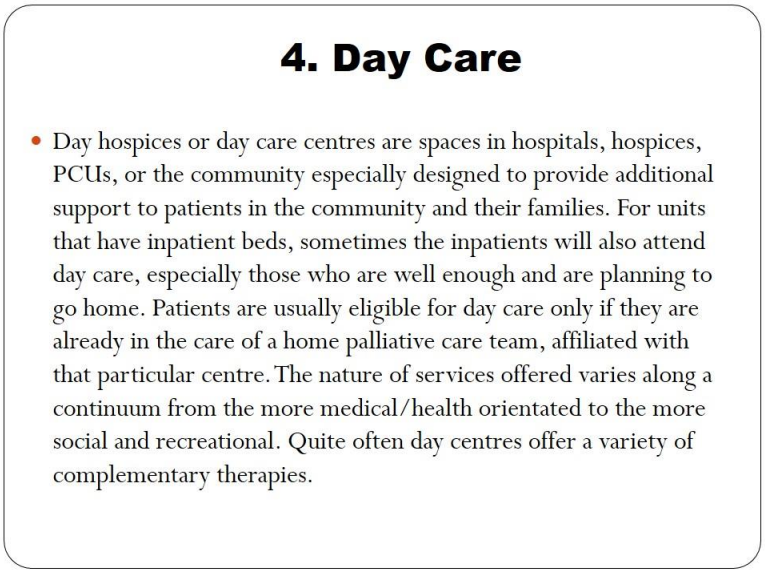

So, day care centers are there in palliative care. Day hospice or day care centers are spaces in hospital hospice and palliative care units or other community, community centers especially designed to provide additional support to patients in the community and their families. For units that have inpatient beds sometimes the inpatients will also attend the daycare especially those who are well enough and are planning to go home. Patients are usually eligible for daycare only if they are already in the care of home for palliative care team and this affiliated with a particular center.

The nature of services offered varies along a continuum from the more medical or health oriented to the more social and recreational centers. Quite often, day centers are offered a variety of complementary therapies.

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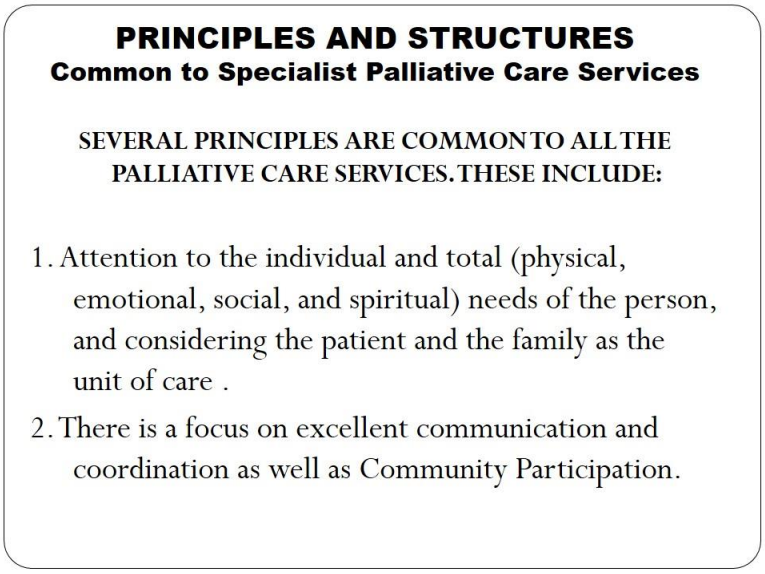

To say about the principles and structures of common to specialist palliative care centers you know. Several principles are common to all the palliative care services. They include attention to the individual in total that means, you know physical, emotional, social and spiritual care and which needs of the with, which need the patient. So, it includes the attention to the individual in total that means, you know the physical, emotional, social and spiritual aspect of the patient.

Because the patient need all these things and considering the patient and the family we have to give that also. There is a focus on excellent communication and coordination as well as community participation in palliative centers.

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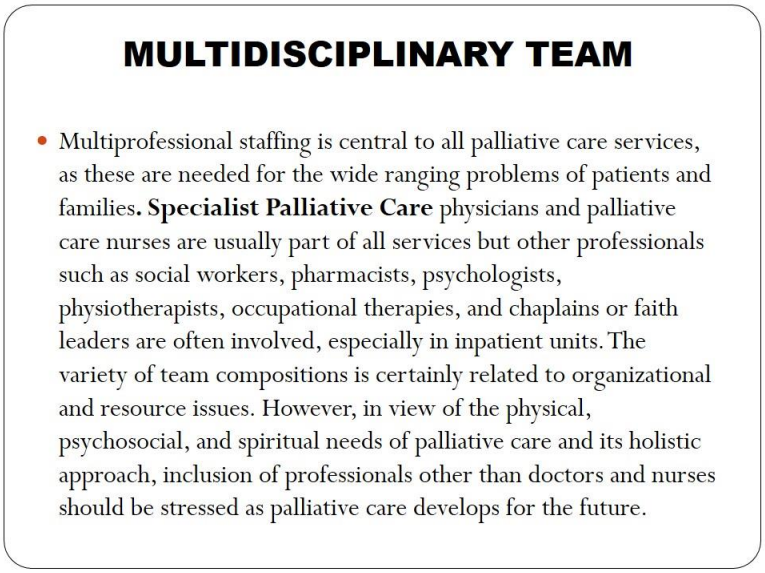

And you know this palliative care means it is a multi-disciplinary approach. A multi professional staffing is central to all palliative care services. These are needed for the wide ranging problems of patients and families. Specialist palliative care physicians and palliative care nurses are usually part of all services, but other professionals such as social workers, pharmacists, psychologists, physiotherapists, occupational therapists and chaplains for faith leader or faith leaders all are included in the team. However, in view of the physical, psychosocial and spiritual needs of the palliative care, it is a holistic approach. And it includes the professional other than doctors, nurses and the most stress is being given to palliative care. However, in view of the physical, social and spiritual needs of the palliative care and it is holistic approach that includes the professional other than doctors and nurses.

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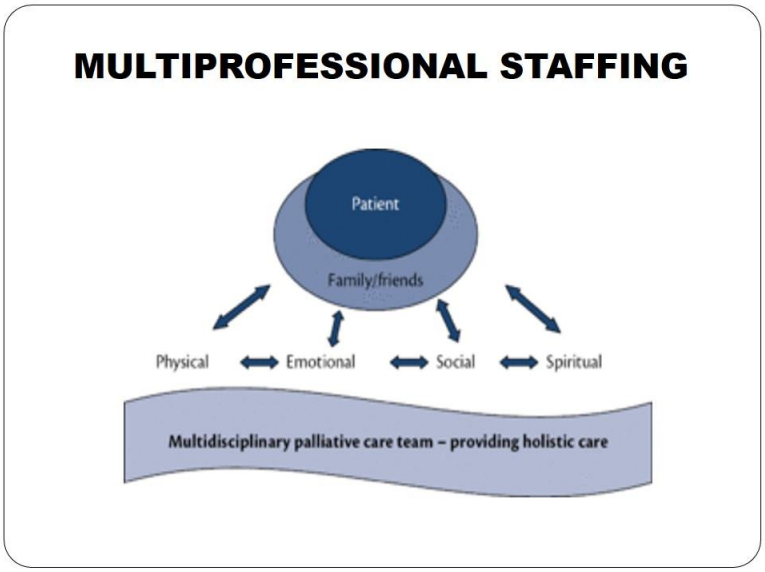

So, we can see that you know that is a patient again he is there in the family and the friends are there. So, we have to take into this consider we have to take into consideration that you know the family and friend along with this patient. And we have to take into consideration the physical aspect of the patient, emotional aspect of the patient and psychosocial aspect of the patient and the spiritual sphere of the patient. So, a multi-disciplinary team is needed for palliative care.

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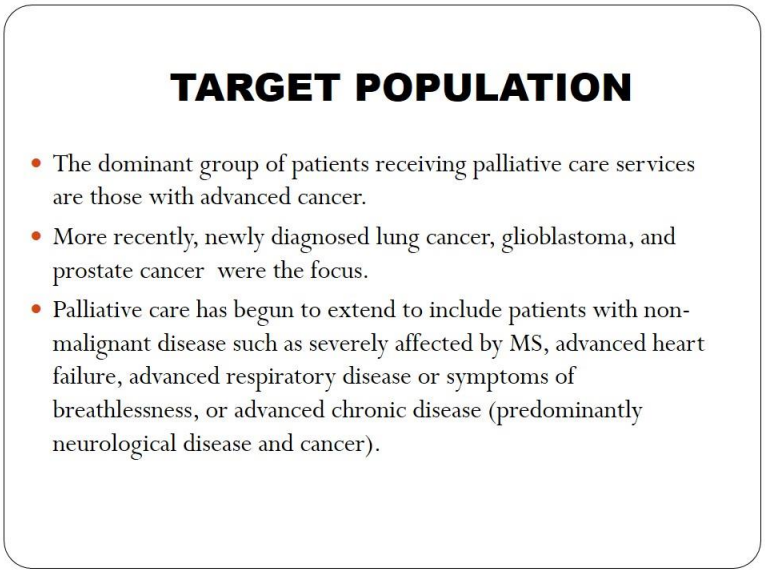

To say about the target population, the dominant group of patients receiving palliative care services are those with advanced cancers. More recently newly diagnosed lung cancer, glioblastoma and prostate cancer were the focus. Palliative care has begun to extend to include patients with non-malignant diseases such as severely affected by advanced heart failure, advanced respiratory diseases and symptoms of breathlessness just like a COPD.

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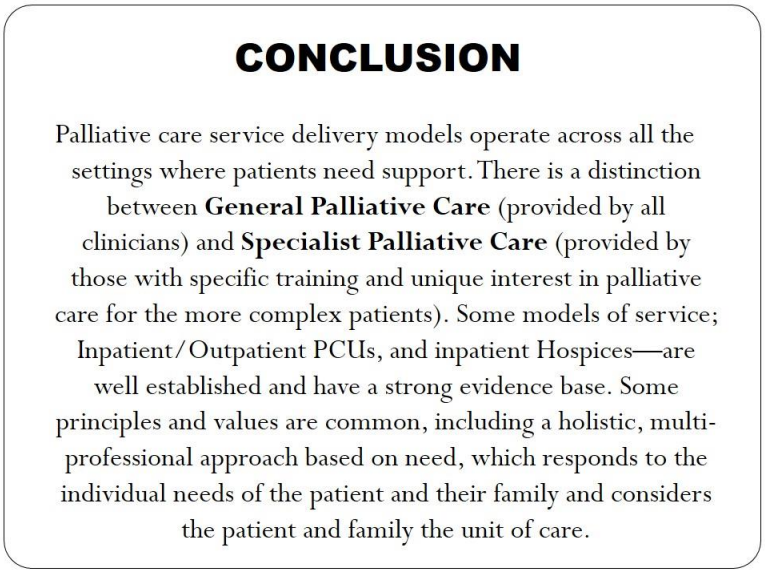

And to conclude palliative care service delivery models operate across all over the country and they the settings were the patients, the palliative care service delivery models operate across all the settings where patients need support. There is a distinction between general palliative care that is provided by the clinic clinicians and the specialist palliative care provided by those with the specific training and unique interest in palliative care for more complex patients. Some models of service and inpatients, outpatients and palliative care units and this inpatient hospice and centers are needed for the palliative care. Some principles and values are common including the holistic multi professional approach based on need which responds to the individual needs of the patient and their family and to consider the patient and family as a unit. Thank you.