
“Know About Palliative Care”

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INTRODUCTION

India has 18% of the world's population. With a crude death rate of 7/1000 and a population of more than 1.36 billion, the total number of people dying every year in India is about 9 million. Majority die in misery. There is a health transition in India, where death and disability from non-communicable diseases (NCD) is on the rise and at 42.4% .1 It is a major public health challenge of growing magnitude. The top three causes of death are ischemic heart disease, chronic obstructive lung disease and stroke ².

More people are dying of cancer than before – 15% of all deaths in 2013, up from 12% in 1990³. In India, there are 8 lakhs new cases per year⁴. Breast and cervical cancer are the most common causes in women while lung, oral and throat cancers are the commonest cancers in men with tobacco as the single most important identified risk factor. The country has a National Cancer Control Programme established in 1975-76. This contributed to the development of Regional Cancer Centres (RCCs), and oncology wings in Medical Colleges.

The prevalence rate of neurological disorders from different regions of the country is roughly 300 lakh people (excluding infections and traumatic injuries.)⁵. Progressive neurological conditions lead to poor QoL of not only the patient but also the family members.

On an average there are around 2.5 million people living with HIV and AIDS. The percentage of adult population living with HIV/AIDS seems to have dropped, yet India

still has the third largest HIV/AIDS population in the world, and remains the largest in Asia. With better access to anti-retroviral drugs, HIV infection is becoming a chronic illness with a need for life-long supervision and support.⁴

The QoL of patients with any incurable disease can be improved with Palliative Care. Palliative Care is all about looking after people with chronic and life limiting illnesses that cannot be cured, relieving their suffering and supporting them through difficult times. This is possible in any setting- hospice, hospital or at home.⁴

At the core, PC, whether it is practiced in hospital , community or hospice is a patient and family centered approach which makes use of the different skills of the PC team, a team which needs to include family members as well as Health Care Professional (HCP).

Palliative Medicine and End of Life Care: What, Why and Where?

Definitions:

PC is an approach that improves the QoL of patients with life-threatening illness, and their families through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organization).⁶

The Palliative Care approach aims to promote physical, psychosocial and spiritual well-being. It is a vital and integral part of all clinical practice, whatever the illness or its stage. The need for Palliative Care in a developing country like India is huge, where cure is often impossible, because of late presentation and limited treatment.

Why Do We Need Palliative Care?

An estimated 34 million people need Palliative care in India. Less than 1% has access. Seventy five percentage of the 8 lakh new cancer cases per year are diagnosed at a very late stage when treatment is unlikely to be of any value in preventing disease progression. Sixty percentage need Palliative care service.

million people per year experience cancer pain but less than 3% of India's cancer patients have access to adequate pain relief.⁷ In addition, the lack of knowledge and access to essential pain medication, along with the paucity and/ or high cost of health care facilities equipped to care for those with life- limiting illness (LLI), results in innumerable patients dying undignified and agonizing deaths.

When does Palliative care start?

Palliative Care starts as early as possible after the diagnosis of a LLI. At the time of diagnosis, the disease is in an acute stage. For those who have access to medical care, the disease then becomes chronic, while disease modifying therapy is proceeding, changing the disease process into a chronic illness. The focus of care changes over time as the disease progresses. The patient may be relatively well while therapy is under way.⁶

However, a point comes when the disease becomes more advanced and life-threatening. In more developed countries hospice Palliative Care is available at the end of life to relieve suffering and improve QoL. Advanced end of life care (EOLC) is instituted until the patient's death, which is followed by bereavement care.⁶

In India, where hospices are very few, options for high quality EOLC

remains limited. However, well run palliative home care services with clear communication and strong family support can go long way in helping with troublesome symptoms and family concerns. In a study of preference for place of death, Kulkarni et al found an overwhelming majority (83.03%) of respondents prefer to die at home. In the absence of a clear cut legal position of advanced directives in India, people cannot record their wishes about their EOLC. At any rate, most people lack the autonomy of ensuring that their wishes are followed.⁸

Types of Palliative Care:

Palliative Care works alongside and within other programs

- It does not replace other forms of care
- Can be integrated into existing programmes
- Should be part of the care given to everyone with LLI

The types include:

1. **Primary Palliative care** is not professional delivery of medical care at local level but helps individuals and families assume responsibility for their own and their community's health and welfare.¹⁰
 - a. **Primary Palliative care Provider:** a medical, nursing or allied health professional who provides primary care with a palliative approach to patients with a LLI¹⁰ They are the first level of contact, helping to identify people with such illness in a community. Everyone in the community should have access to it and everyone should be involved. It is essential that PC is made accessible at an affordable cost with methods that are practical, scientifically sound and socially acceptable.
 - b. **Related Sectors:** It includes education for the community on the prevalent life-timing health problems, their invention, early detection, control and appropriate management. It also includes the

promotion of adequate supplies of food and proper nutrition and the provision of essential drugs.

2. Specialist palliative Care

a. These services are provided by an interdisciplinary team of specialist PC professionals whose principal work is with patients who have an eventually fatal condition. Specialist PC services are provided in care settings including community, home hospitals, hospices and PC units.

b. **Specialist Palliative Care Provider** is a medical, nursing or allied health professional whose training is by a recognized accrediting body or who works in a specialist palliative service, if the accrediting body is not available. They have special knowledge, skills and expertise in the care of those with eventually fatal conditions, which includes management of complex symptoms, grief and bereavement. They also take care of the patient's families and carers,

c. Specialist Palliative Care services work in three key ways:

- Providing direct care to referred patients with complex needs
- Providing consultation to patients being cared for by primary care providers
- Providing support and education to services providing EOLC

3. Pediatric Palliative Care

PC for children represents a closely related and special field. It is active total care of the child's body, mind and spirit, and also involves giving support to the family.¹⁰

- Effective PC requires multidisciplinary approach that includes family and community

resources and can be well implemented even if resources are limited.

- Can be provided in tertiary care facilities, as primary care and in children's homes.

Palliative care in new setting:

When considering initiating Palliative care the following questions need to be discussed:

- Who needs Palliative care where you are working?
- What are their main problems?
- What help are they getting at present?
- What could be added to improve their care and make it more holistic?

The first three questions is to look at the needs in your setting and the last question is to look at the resources already in place and what you might do to supplement or complement them. Most PC projects started as small units when somebody noticed a group of people who needed help, they then made the most of what was already available and added the elements of care which were using people who are willing. This is more affordable and achievable in starting a whole new service and it leads to different organized agents working in partnerships. PC is not only about treatment of physical problems, so we can use some of the resources that already exist to help address patient and family concerns.

Building a Team

Team don't have to be big but they have to work together with someone who can help out in each area.

Health care workers are essential and can be trained to do excellent nursing care. Team members for different tasks can include:

- Physical: Physician, nursing, treating and prescribing
- Psychological: listening, counselling, being available
- Social-help with finances, housing, family support
- Spiritual support : prayer, counselling, carrying out rituals or rites

Building a team requires mutual respect, support and good communication. Recognizing the importance of team member's different contributions and verbalizing it is vital, for example, noticing when someone has done something well and appreciating their hard work. PC can be emotionally draining and we need to support one another, being aware when someone is exhausted and sharing their load. Good communication is what holds a team together. We must keep each other in the picture about what is going on with patients and within the team. People leave the team when they feel unprepared or unsupported. Therefore, training and supervision is very important as it increases and competence. It can be done in teaching sessions and in the job working alongside someone with experience.

All members of the team need to understand the concept of the holistic approach and appreciate the importance of physical, psychological, social and spiritual components. Volunteers can be great resource. There are usually many people in a community who want to help others. If we want them to be involved we need to let them know how much their help is needed.

When a patient dies, take time to reflect. Recognize that multiple losses are inevitably stressful and make sure everyone knows how to get help.

Lastly, take pride in your work and in the difference that you are making to your patients.

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