

WHAT IS CHANGING IN PALLIATIVE CARE?

The definition of palliative care:

The World Health Organization (WHO) had defined palliative care in 1986. At that time WHO said that “palliative care is the active total care of the person whose disease is no longer responsive to curative treatment. Control of pain and other symptoms as well as social emotional and spiritual support is paramount”.

This definition was crisp and meaningful. The phrase ‘active total care’ conveyed a lot. *Active* implied that the disease process and the physical problems are actively treated to the end. *Total* care meant that in addition to the physical problems and the disease, psychological, social and spiritual issues were also attended to and that the whole person received care. But in this 1986 definition, the part “no longer responsive to curative treatment” caused a problem. It came to the situation where patients would suffer pain and other problems sometimes for years during the phase of curative treatment without relief and only after the oncologist has declared the patient “no longer responsive to curative treatment”, could palliative care start. There is an obvious and needless injustice to the patient here and this was the major reason why the definition had to be changed.

In 2002, the WHO redefined palliative care. The new definition was: “Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” While admittedly longer and less crispy, this definition effectively lifted the restriction in the name of a diagnosis or phase of disease. Please note that it does not even say chronic diseases, meaning that suffering even during acute illnesses, or in an intensive care units, could qualify for palliative care. In addition, this definition added several foot notes:

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.

- Intends neither to hasten or postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated.
- Will enhance quality of life, and may also positively influence the course of illness.
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The last one among the foot notes is particularly worthy of note. It clarifies that palliative care is applicable early in the course of illness. "In conjunction with other therapies" means, as chemotherapy is proceeding for cancer or as antiretroviral therapy is proceeding in a person with HIV, physical, psychological, social or spiritual problems including pain and other symptoms should still be addressed.

In other words, palliative care needs to go hand in hand with disease-specific treatment.

Subsequent to this definition, the palliative care community has had numerous discussions on the subject. They have generally agreed that this early introduction of palliative care could take several forms.

- Palliative Approach:** This means, for example, that the oncologist and oncology nurses study and understand principles of palliative care so that they include it as part of their disease-specific treatment.
- Generalist Palliative Care:** This involves any clinician or nurse learning enough palliative care so that he or she can give part of their time for specific palliative care activity. Usually the training for this does not take the form of a course, a degree or a diploma, but very often may be a few weeks or months of palliative care education and typically such a doctor or nurse would work in palliative care full time or part time.

- c. **Specialist Palliative Care:** Here, nurses and doctors would undergo advanced training programs like diplomas or degrees in palliative care and take on a consultant role helping out with major problems while leaving day to day management to generalist palliative care personnel.

The world health assembly resolution on 24th May 2014 and integration of palliative care in health care.

The world health assembly (the decision making body of the world health organization) came out with a resolution declaring that palliative care should be an essential part of all healthcare. It urges member states to develop, strengthen and implement palliative care policies which integrate evidence based, cost effective and equitable palliative care services in the continuum of care. It also goes on to giving more detailed instructions about how this is to be achieved. This brings up the point which indicates an ongoing change of a shift in focus from disease-centered treatment to person-oriented care. This comes also in the background of a growing awareness that access to pain relief and to palliative care is a fundamental human right and hence, this means, if a patient is in agonizing pain, in most cases such suffering is unnecessary and hence when low cost modalities of treatment are available, denial of such care is a violation of human right.

The implication of this declaration over the next few years is likely to be a change in the approach of the healthcare system from palliative care being a “good to have” entity to a “must do” duty.

1. Effect of palliative care on survival:

It has been recently proved that concurrent palliative care along with cancer treatment actually improves survival. By treating pain and suffering and by offering emotional support, it improves the general condition of the patient and improves adherence to treatment. A study by Temel et al found that patients with non-small cell cancer of the lung survived for an average of three months more when they received palliative care along with cancer treatment. (*Early palliative care for patients with metastatic non-small-cell lung cancer. Temel JS, Greer JA. N Engl J Med, 2010, Vol. 363. 733*).

2. Palliative care as a human right:

The UN Special Rapporteur for Torture, reaffirmed that the failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment. Governments must guarantee essential medicines – which include, among others, opioid analgesics – as part of their minimum core obligations under the right to health, and take measures to protect people under their jurisdiction from inhuman and degrading treatment. The UN Special rapporteur said, “When the failure of States to take positive steps, or to refrain from interfering with health-care services, condemns patients to unnecessary suffering from pain, States not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment.”

<http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session22/Pages/ListReports.aspx>

The Indian scene - current status:

Unfortunately, even today, palliative care reaches less than 2% of the needy. However, there have been several positive developments recently.

1. The Medical Council accepted palliative medicine as a medical specialty and announced an M.D course in palliative care in 2010. A 3 year MD program was started in Tata Memorial Hospital in 2012, but even today in the end of 2015, no other institution in the country has been able to follow suit. And despite an assurance to Supreme Court of India in 2012, the Medical Council of India and Indian Nursing Council are yet to include palliative care in undergraduate curriculum.
2. In 2012, the Ministry of Health announced a National Program in Palliative Care (NPPC) for the current five-year plan (http://palliumindia.org/cms/wp-content/uploads/2014/01/National-Palliative-CareStrategy-Nov_2012.pdf). Unfortunately, the proposed budget allocation did not materialise. However, a small part of NPPC - approximately 2% of the originally proposed budget - is being rolled out to those states which would like to start palliative care services. For this each state has to submit a program implementation plan to Ministry of Health. A model PIP can be viewed at <http://palliumindia.org/cms/wp-content/uploads/2014/01/Model-PIP-under-NPPC-MOH-Delhi.pdf>.

3. After 19 years of advocacy, in 2014, the Indian Parliament passed an amendment of the infamous and draconian Narcotic Drugs and Psychotropic Substances (NDPS) Act of India (<http://www.indiacode.nic.in/acts2014/16%20of%202014.pdf>). It shifted the power for legislation regarding opioid analgesics from the state governments to the central government. Following this, in May 2015, the Department of Revenue of Government of India also notified the new state NDPS rules. (<http://palliumindia.org/cms/wp-content/uploads/2014/01/Gazette-Notification-No.285-regarding-NDPS-State-Rules-and-Procedures-dated-05-05-2015.pdf>). As they are being implemented in 2015, all states would now have a uniform rule, necessitating only a single governmental approval issued by a single agency for procuring and dispensing morphine.