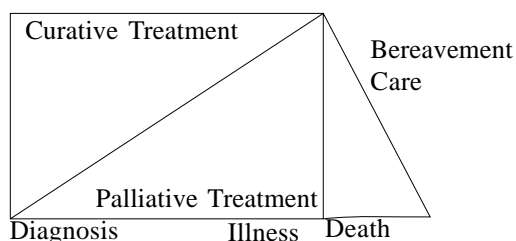




Vijaya Udumala JMJ

Palliative care aims to improve the quality of life of patients and their families facing problems associated with life-threatening illness. Palliative care is not only end-of-life care, but also includes management of all distressing symptoms, including pain. The patient's future needs should be considered at the time he or she is diagnosed with advanced cancer, so that problems can be anticipated and prevented or managed.

Fig. Continuum of Cancer Care



Palliative care can be provided by people in the family, community, health centers, and hospitals.

Palliative care is an essential element of cancer management

- The goal of palliative care is to avoid unnecessary suffering and improve the quality of life of patient with advanced cancer as well as their families, by way of emotional support, symptom control, end-of-life care and bereavement care. It addresses the physical, psychosocial, and spiritual needs of patients and their families.
- Palliative care should begin as soon as cancer is diagnosed, so that needs can be anticipated,

and preventive and treatment measures planned and put into effect.

- Palliative care can help people with advanced disease to have dignity and peace during their difficult and final phases of life.
- Freedom from pain can be considered as a human right, yet pain control remains vastly underutilized. The mechanisms for its implementation need to be strengthened.
- Using a broad combination of medical and non-medical methods, pain can be effectively controlled in 90% of the cases.
- Patients and their caregivers need training, ongoing support, and supplies for palliative care, including symptom management at home.

Why is palliative care necessary?

Even with the best preventive and screening programmes, some people are diagnosed with advanced disease or may develop such disease, and need clinical and emotional support and pain control. In many low-resource countries, people are not aware of screening programmes and many are diagnosed as having cervical cancer only when they develop symptoms, usually in late stages of the disease. In addition, facilities for the treatment of cancer may not exist or may not be accessible to many; as a result, some patients with relatively early cancers may not receive the most effective treatment. In these settings, palliative care is particularly important, as many of these patients will need relief from pain and other distressing symptoms. Adequate resources have to be made available to care for those who cannot be cured, particularly in rural areas having

Author Affiliation: Principal, St. Joseph's College of Nursing, Nallapadu – 522 005, Guntur, Andhra Pradesh.

Correspondance: Principal, St. Joseph's College of Nursing, Nallapadu – 522 005, Guntur, Andhra Pradesh.

few health services, where many patients die at home in difficult conditions.

Patients with other chronic severe diseases, such as AIDS, also need special care, and efforts should be made to create a team of health providers at all levels of the health care system with knowledge and skills in palliative care. If appropriate, patients' families should be enrolled into palliative care teams.

Principles of palliative care

Palliative care

- Provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; is intended neither to hasten nor to postpone death
- Integrates the clinical, psychological, and spiritual aspects of care; gives the patient and the family as much control and decision-making power as they desire and are able to accept
- 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 with their own bereavement
- Uses a team approach; enhances 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 surgery and radiotherapy.

Essential components of palliative care

Prevention and management of symptoms

This may include palliative radiation to reduce the size of the tumour as well as treatment for signs and symptoms, nutritional problems, bedsores, fever, and contractures.

Families should be taught how to prevent problems, where possible, as well as how to

support the patient with daily activities, such as bathing, going to the toilet, and moving around.

Pain relief

Effective pain control can be achieved in 90% of cases, using the medical management, together with ancillary non-medical methods.

Psychosocial and spiritual support

This is an important component of palliative care and requires trained providers with good communication skills.

Involving the family

The health worker can ensure that the patient and the family understand the nature and prognosis of the disease as well as the recommended treatment.

The palliative care worker must also be able to help the patient take decisions about the care. The patient and the family should have a sense of being in control with full support from the health care team whose task is to provide appropriate information, advice, and to support informed decisions.

Palliative care requires systematic and continuous application of the five steps (*five 'A's*), described below. Like other aspects of cancer care, this approach requires teamwork and adequate resources.

1) Assess: Assess the patient's status and identify the treatment assess the patient's and carers' knowledge, concerns, and skills related to the illness and the treatment.

2) Advise: Explain how to prevent and manage symptoms, and teach the requisite skills, few at a time, by demonstration and observed practice.

3) Agree: After giving information and imparting teaching skills, make sure that the

The five 'A's of palliative care: Assess, Advise, Agree, Assist, and Arrange

Demographic data	Frequency	Percentage
1. Age		
1.1 31-40	04	06.67
1.2 41-50	12	20.00
1.3 51-60	36	60.00
1.4 61 and above	08	13.33
2. Education		
2.1 Illiterate	30	50.00
2.2 Primacy school	14	23.33
2.3 High School	12	20.00
2.4 Intermediate /SSC	04	06.67
2.5 Degree and above	-	-
3. Occupation		
3.1 Employed	24	40
3.2 Unemployed	-	-
3.3 House wife	36	60
4. Family monthly income		
4.1 Rs 2001 - 3000	28	46.67
4.2 Rs 3001 - 4000	14	23.33
4.3 Rs 4001 - 5000	10	16.67
4.4 Rs 5001 and above	08	13.33
5. Socio-economic status		
5.1 Low	52	86.67
5.2 Middle	08	13.33
5.3 High	-	-
6. Area of Residence		
6.1 Urban	45	75
6.2 Rural	15	25

patient knows what to do and agrees to do it. Empower the patient to stay in charge. Support patient self-management and family care.

4) Assist: Make sure the patient and the family has enough supplies to cope with difficult situations give the required care. Give written instructions as a reminder of what has to be done, with pictures, if needed, for those who cannot read.

5) Arrange: Schedule a time for the next visit. Make sure the patient, the family, and other carers know where to go if they have questions or concerns.

Make sure the family knows when and whom to call for help

The Role of the family in palliative care
Palliative care should be available wherever patients are – at home, in hospitals, in hospices, etc. In developing countries, most patients die at home, and in such setting the family plays an important role in palliative care. If the patient

agrees, and if appropriate, the patient's family should be involved and empowered in joint decision making, should be constantly kept informed of medical decisions, including changes in carers and treatment, and should be trained in best practices of palliative care. The patient's family and other carers can be taught to give home-based care. Clinical care should be provided by health workers trained to use recommended medicines within the national legal framework. Providers of palliative or home-based care should have constant backup from first-level health workers (physician, clinical officer, or nurse) who should be available for consultation or referral when needed.

Accessing local resources for care at home

When a patient is no longer able to work or care for his / her family, meager resources may become further stretched. Money for food, supplies, and medicines is sometimes available through local, regional, or national non-governmental organizations, faith-based organizations, women's groups, and community-based organizations. A palliative care or home-

based care (HBC) programme should have links with these organizations, where possible, and provide referrals for patients and their families.

Managing common symptoms of advanced cancer

Patients with advanced cancer can suffer a constellation of physical, psychological, and emotional problems. Pain is almost always a part of the constellation and its relief should always be a part of palliative care.

Pain management

Pain relief for cancer patients

- Is vastly underutilized and, as a result, many patients suffer needlessly
- Is achievable and inexpensive
- Needs cooperation and a two-way communication between homecarers and clinical providers at all levels of the health care system
- Home-carers are closest to the patient's needs, while clinical providers offer support and medications

Major barriers to effective pain relief

- Lack of awareness on the part of health care providers and the general public that pain relief is achievable and inexpensive
- Lack of availability of pain medications due to restrictive regulatory policies.
- Even when controlled pain medications (opiates and oral morphine) are available, in principle, providers, including physicians, may be restricted by national drug control policies from prescribing or dispensing them
- Providers' unrealistic fears of promoting drug dependence in patients, and of contravening drug enforcement laws

National rules and regulations must be followed. They should be carefully checked to see whether they allow pain relief to be

administered by non-medical personnel under the supervision of doctors or nurses. If not, medical and non-medical personnel need to join forces to advocate patients' right to freedom from pain.

In the context of palliative care in national cancer control programmes, restrictive drug regulations need to be modified to allow access to pain control. Although changing policy and law is not the role of the care team, providers should advocate and demand policy change to remove barriers to access and to allow pain relief measures including opioids.

Recommendation

Cancer control programmes should ensure that opioid, non-opioid, and adjuvant analgesics, particularly morphine for oral administration, are available.

WHO's analgesic ladder

WHO has developed an effective and relatively inexpensive method for relieving cancer pain in about 90% of patients. This method is called the *WHO ladder for cancer pain relief*. It can be summarized as follows:

- **By mouth:** Whenever possible, analgesics should be given orally in order to permit wide applicability of this method

- **By the clock:** Analgesics should be given at fixed time intervals. The next dose should be given before the effect of the previous one has fully worn off, to ensure continuous pain relief

- **By the ladder:** The first step is to give a non-opioid, typically paracetamol. If this does not relieve the pain, opioids for mild-to-moderate pain, such as codeine, should be given

- **The next step** is to give opioids for severe pain, such as morphine. Additional drugs, called

adjuvants, can be used in certain circumstances; for example, psychotropic drugs may be given to calm fear and anxiety

For the individual, There is no standard dose for opioid drugs. The right dose is the dose that relieves the patient's pain.

Two rules for opiate dosage

There is no standard dose for opioid drugs; the right dose is the dose that relieves pain.

There is no ceiling dose for opioid drugs; the dose will gradually need to be increased as the patient become tolerant to the pain-relieving effects.

Non-medical methods to assist in pain control

A number of methods appropriate to local customs and culture, can be very important in helping the patient cope with pain. These methods may be used in addition to effective modern medicines, and must never lose their place and importance.

Non-medical methods

- Emotional support: the care and support of family and friends is most important in relieving discomfort during severe illness;
- Touch: stroking, massaging, rocking, and vibration
- Distractions: radio, music, helping the patient to imagine a calm scene or a happy event in their life
- Prayer and meditation according to the patient's practice
- Traditional practices, if not harmful, can be very beneficial
- The Attitude of the health care provider is also important: Listen with empathy.
- Try to understand their reactions to her illness (the different stages of grief)

- Refer to a spiritual counsellor or pastoral caregiver, according to the patient's religion and wishes.
- Avoid imposing your own views.
- Empower the family to continue to provide care.

Non-medical pain management interventions such as emotional support, physical methods (touching and massaging), distraction, prayer, meditation and other non-harmful local traditional methods should be provided only with the explicit understanding and approval of the patient and the family.

Organization of palliative care services

In resource-poor settings, palliative care is most often provided by untrained community health workers.

To be effective, these workers require:

- Training in clinical and psychological palliative care. This can be given in 1–3 weeks for those with basic medical skills
- Supportive supervision from hospice nurses or others trained in the management of psychosocial and medical problems in severely ill patients
- Essential medicines and other supplies needed for effective palliative care, provided according to a national essential drug list. The primary health care facility can arrange for regular supplies for home-based care providers and their patients
- A secure place to store medicines and a separate tracking system for pain medications, if this is required by the drug regulatory authority
- Open communication with the formal health system and access to more skilled providers for consultation and referral of patients, when needed

Team approach to palliative care

Providers at all levels of care, from specialists to home-care providers, should work together

to ensure the best quality of life and outcome for patients with advanced cervical cancer. In tertiary care settings, the team might include an oncologist, a radiotherapist, a radiotherapy technician, a psychologist or counsellor, a nutritionist, a physiotherapist, an oncology nurse, a pharmacist, a social worker, and a palliative care nurse. In resource-poor settings, it is unlikely that such a highly specialized team can function down to the level of the community where the patient lives. Strategies need to be devised for individual community providers responsible for the patient's continuing care, to allow them to link the patient and the family with the staff at the health centre and district and central hospitals.

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