Palliative Care

Introduction
Palliative care is the holistic care of patients with advanced progressive illness who are not responsive to curative treatment. Management of pain and other symptoms and provision of psychological, social and spiritual support are critical. The ICN Code of Ethics for Nurses affirms that one of the fundamental responsibilities of the nurse is to “alleviate suffering” which is a cornerstone of good palliative care.

The goal of palliative care is to achieve the highest quality of life for patients and their families. Palliative care aims to:

- Provide relief from pain and other distressing symptoms.
- Neither hasten nor postpone death.
- Affirm life and regard dying as a normal process.
- Integrate the psychological and spiritual aspects of patient care.
- Offer a support system to help patients live as actively as possible until death.
- Offer a support system to help the family cope during the patient's illness and in their own bereavement.

Palliative care improves the quality of life of patients and their families in dealing with the problems associated with life-threatening illness, through prevention and relief of suffering by means of early assessment, identification and management of pain and other physical, psychosocial and spiritual problems.

What are the Components of Palliative care?
Palliative care is delivered on a continuum involving a number of elements depending on the status and needs of the patient. These include:

Pain management: Patients living with a life-threatening illness may experience pain. Nurses work with patients and their families to identify the source of the pain and ways to relieve it. Pain may be managed with drugs or by other means such as massage therapy and relaxation techniques.

Symptom management: Often people have to deal with a variety of symptoms that can include loss of appetite, nausea, weakness, breathing difficulty, bowel and bladder problems and confusion. These symptoms can be distressing for the patient and palliative care can help provide a relief.
**Social, psychological, emotional and spiritual support:** Palliative care focuses on the person as a whole and offers a wide range of support services to the ill person. It also offers bereavement support and can help the family work through emotions and grief regarding the illness and death of a loved one.

**Caregiver support:** Family members and others are often concerned about whether they will be able to cope, especially when palliative care is provided at home. Palliative care services that help the family cope include:

- advice and assistance from health care providers such as nurses and doctors who are skilled in providing palliative care;
- instruction on how to care for the person (how to give medication, prevent skin problems, recognize signs, call for help, etc.);
- home support services that provide assistance with household tasks such as meal preparation, shopping and transportation;
- relief for the caregiver. Sometimes a volunteer stays with the person so the family caregiver can go out. In other situations, the person who is ill may go to a day program or enter a hospital or long-term care facility for a short period of time.

**Settings for Palliative Care**

Palliative care services can be provided in the home, in community-based settings like nursing homes, palliative care units, and in hospitals. People who are dying need to be able to move freely between these places, in response to their medical care and support needs. The pattern of care will be different for every individual, and may depend on factors like: geography, services in the area, and the needs and desires of the person, their family members and friends. In general, palliative care is best provided within close proximity to the person's local environment and community.

**Home**

This is the predominant setting globally for the terminally ill. Care at home is generally provided by relatives and friends. The health system sometimes provides support to families and other care providers. Where home-based palliative care services are available, they are most commonly provided by community or public health nurses visiting people in their homes. The home-based model has become more dominant with the increase in HIV/AIDS and other illness such as multiple sclerosis, stroke and cancer.

**Hospitals**

In most western countries, the majority of people are cared for and die in hospitals, but there are growing concerns about the quality of care and use of invasive treatments even for terminal illness and during the end of life. Hospital based palliative care teams usually involve nurses and other
professionals and are predominantly available in Western Europe and North America. Nurses play a key role in direct care and in an advisory capacity in multidisciplinary teams to advance palliative care in hospitals.

**Day care and drop-in clinics**
Palliative care is also provided through day care services and drop-in clinics in hospitals, hospices and in the community. In some countries, these services may be taken to people’s homes, thus providing family members and other carers “time off” from the burden of care. However, unless the health team is well staffed with competent nurses and other professionals, the quality of care, such as pain management, can be compromised due to restrictive nursing practice acts that do not allow prescriptive roles for nurses.

**Hospices**
Hospice can be in freestanding facilities, hospitals, and nursing homes and other long-term care facilities. Palliative care in hospices provides a homelike environment and requires a team-oriented approach. Nursing care is focused on caring for the person and their families. Nurses work together with doctors, social workers, chaplains, therapists and voluntary staff to support the terminally ill and the family members with their needs and concerns.

Regardless of where it is provided, palliative care should be respectful of religious and cultural beliefs of the person and family receiving care. The principles of palliative care should be adapted to the setting and the needs of those receiving care.

**Nursing roles in palliative care**
Issues of death and dying are highly emotional human experiences and competent and compassionate care can make a difference to the pain and suffering of the patient and the family. ICN, in its position statement on Care of Dying Patients and Their Families, affirms “…the nurse’s role as fundamental to a palliative approach that aims to reduce suffering and improve the quality of life for dying patients and their families through early assessment, identification and management of pain and physical, social, psychological, spiritual and cultural needs”. Palliative care is a nurse-led service that involves complex decision-making and leadership. Nursing roles and competencies in palliative care involve three main areas:

**Working with dying patients and their families:** Nurses are expected to establish and maintain a therapeutic relationship. In doing so, the nurse communicates effectively and provides information, emotional and spiritual support to the patient and the family. The nurse works to create environments conducive to peaceful and dignified death, and to effectively manage of symptom control, including pain management.
Working with health and social care professionals: Nursing roles include coordinating services, making referrals to other services, such as financial help and advice, and supervision and training of others including family care providers and assistive nursing personnel.

Working with managers, policy makers and planners: Nurses work with managers, policy makers and planners in team building and support, setting goals and priorities, managing resources, monitoring care outcomes, supporting staff to deal with a sense of “collective loss” when caring for dying patients, and providing overall nursing leadership to ensure quality of care.

Challenges in palliative care
A key aspect of palliative care is effective pain management and control. One of the main challenges is access to pain medication, especially opioids. These drugs need to be legally acceptable, affordable and available when needed. Nurses have a key role in developing national guidelines on the availability, prescription and safe storage of opioids and other drugs used in palliative care. Other challenges include restrictive nursing practice acts that limit nursing functions in prescribing medicines for pain control, lack of specialised training in palliative care and poorly developed home-based nursing and support services.

Ethical issues
Palliative care raises ethical issues and dilemmas for nurses and other health care providers. These issues and dilemmas are best addressed by adhering to the following principles:

- respect for the patient’s and family’s needs and choices;
- open communication tailored to each patient’s and family’s needs and preferences;
- full involvement of patient and family in care;
- agreed goals of care, negotiated with the health team, patient and family; and
- regular assessment and review of goals and needs.

Ethical and legal issues differ widely and nurses should be aware of their professional codes of conduct.

Useful websites:
International Council of Nurses: www.icn.ch
International Association for Hospice and Palliative Care: www.hospicecare.com
Donation and interlink site for donations to developing countries:
www.hospicecare.com/clearinghouse_donate.htm
National Hospice & Palliative Care Organisation (NHPCO): [www.nho.org](http://www.nho.org)
National Council for Hospice and Specialist Palliative Care Services: [www.hospice-spc-council.org.uk](http://www.hospice-spc-council.org.uk)
Help the Hospices: [www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)
Palliative Care Matters. Provides palliative care information for health care professionals: [www.pallcare.info](http://www.pallcare.info)
Palliative Drugs: [www.palliativedrugs.com](http://www.palliativedrugs.com)
European Association of Palliative Care: [www.eapcnet.org](http://www.eapcnet.org)

For further information, please contact: [icn@icn.ch](mailto:icn@icn.ch)

The **International Council of Nurses (ICN)** is a federation of more than 130 national nurses associations representing the millions of nurses worldwide. Operated by nurses and leading nursing internationally, ICN works to ensure quality nursing care for all and sound health policies globally.

TG/2006

**References**


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