

# Nursing Practice

**TRENDS AND ISSUES**

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Modupe Olusola Oyetunde

# Nursing Practice: Trends and Issues

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Modupe O. Oyetunde

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## Introduction to Palliative Care Nursing: The Unique Role of the Nurse

Adenike ONIBOKUN

### Learning Outcomes

At the end of this chapter, the reader should be able to:

1. Understand the meaning of palliative care and palliative care nursing.
2. Clearly articulate who we are and what we do, so that others, particularly the patient, family and carer, will also understand our contributions to their care.
3. Articulate their unique contribution to palliative care nursing.
4. Meet the challenges involved in palliative care.
5. Reflect on those challenges, so that the roles and responsibilities in light of the changing dynamic of palliative care can be appraised.

### Historical Perspective

Palliative care has its origins in the 1960s in the UK with the emergence of the hospice movements led by Dame Cicely Saunders (1918-2005), a nurse, social worker and physician. It started with a research at St Joseph's Hospice, where Dame Cicely was allowed to experiment by giving regular dosages of drugs to four patients. This apparently simple practice was a novel approach at the time, observed with some skepticism. However, skepticism soon turned

to interest as the results showed a marked improvement in the quality of these patients' lives. By the time Dame Cicely left St Joseph's, she had observed and documented over 1,000 cases of patients dying of cancer. Her scrupulous records provide the basis of this fundamental area of research (Du Boulay & Saunders, 1993). Dame Cicely's pioneering work was soon followed by others and in 1963, Professor John Hinton recognized the physical and mental distress of dying in the ward of a London teaching hospital (Hinton, 1963). He later developed groundbreaking work on the progression of the awareness and acceptance of dying over time – one of the few longitudinal studies conducted with terminally ill patients and their families (Hinton, 1999). His research revealed different patterns of progression, influential factors such as depression and anxiety, and the relationship between patients and their relatives' awareness and acceptance.

In the early 1970s, palliative care in the UK saw its first large-scale epidemiological survey, led by Professor Ann Cartwright and her team (Cartwright, Hockey & Anderson, 1973). Drawing from a random sample of deaths in 1969, Cartwright (1991) reported the experiences of 785 patients and their families in the last year of life, which was compared with those of 639 patients in 1987. In this comparative study, several changes were recognized: increasingly, more people were dying alone, were older, with prolonged and unpleasant symptoms, were in institutional and hospital settings, with improved home help though with fewer home visits, and with a greater awareness of the disease and dying.

### Overview of Palliative Care

This is a patient and family centred care that optimizes quality of life by anticipating, preventing, and treating suffering.

Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice (NCP, 2006; CMS, 2008).

### Definition of Palliative Care

Palliative care is an active, total care of the body, mind and spirit (National Cancer Policy Board, Institute of Medicine, 2012). It is a form of comfort – giving care that recognizes cure or long-term control of disease is not possible. The primary goal of palliative care is quality of life.



Plate 13.1: Dame Cicely with a patient at the hospice  
Source: Cicely Saunders International

Palliative care has also been defined as 'both a philosophy of care and, an organized highly structured system for delivering care', provided by an interdisciplinary team (NCP, 2013). Palliative care, as a philosophy of care, uses a combination of active and compassionate therapies intended to comfort and support individuals and families facing life-limiting illness. It may be combined with treatments aimed at reducing or curing the illness,

or it may be the total focus of care. Palliative care strives to meet physical, social, emotional, psychological and spiritual needs of patients, while remaining sensitive to personal, cultural, and religious values, beliefs and practices. Above all, palliative and optimal end-of-life care focus on improving the quality of living to the fullest extent possible (Steinhauser, 2000; WHO, 2012).

All put together, palliative care is about:

- **Family:** Palliative care strives to support the patient's family during a very stressful and difficult time.
- **Living:** Allowing the patient to live the best life possible with their family and friends.
- **Friends:** Community palliative care can also support caregivers, friends and those in the patient's community when needed.
- **Hope:** Hope is a central part of palliative care. Hope for a cure is always important to everyone involved with the patient. When cure is not possible hope may be transitioned to other forms such as hope for comfort and happiness for the patient and family.

### What is Nursing

Florence Nightingale, the first palliative care nurse stated thus: 'I use the word nursing for want of a better word.' She further said: 'The very elements of nursing are all but unknown' (Nightingale, 1860).

Another great nurse, Virginia Henderson (1966), defined the unique function of the nurse this way: 'To assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge.'

- The most succinct and relevant definition of palliative care is Virginia's definition of nursing: 'Nursing is primarily

assisting the individual in the performance of those activities contributing to health and its recovery, or to a peaceful death.'

- The definition of nursing given by Henderson emphasizes the unique role of the nurse in maintaining both quality of life and quality of death. Nursing is a profession within the health care sector focused on the care of individuals, families, and communities so that they can maintain, attain, or recover optimal health and quality of life. Apart from the many things that nurses do, they are also in a pivotal position to improve care for the dying patients and their families by challenging current end-of-life practices in their various settings.

Palliative care nursing has been defined as:

the assessment, diagnosis, and treatment of human responses to actual or potentially life-limiting illness within the dynamic caring relationship with the patient and family in order to relieve or reduce suffering and optimize health (wholeness, integrity of the person, quality of life, and function). Therefore palliative care nursing is a sub-specialty nursing practice that continues to evolve as the art and science of nursing and palliative care evolves (Lynch *et al.*, 2011).

The American Nurses Association (ANA) (2010b, 2010c) states that, 'The aims of nursing actions are to protect, promote, and optimize health; prevent illness and injury; alleviate suffering.'

According to the Hospice and Palliative Nurses Association (HPNA), the goal of hospice and palliative nursing is 'to promote and improve the patient's quality of life through relief of suffering along the course of the illness.' 'The nurse's fidelity to the patient requires the provision of comfort and includes experts in the relief of suffering, whether physical, emotional, spiritual, or existential' (ANA, 2010a).

### Role of Nursing in Palliative Care

Nursing plays an essential role in assuring that patients experience their best quality of life at the end of life, and are as respectful at death as possible (ANA, 2010a). In promoting quality of life and relief of suffering, it is essential that nurses attend to the cultural and spiritual considerations of care, as to the physical considerations of pain and symptom management.

### Special groups and cultural consideration

It is essential to assess culture since it will influence communication of a serious or life limiting illness and how it is discussed and described. It is important for nurses to role model the honouring of culture. There are unique issues related to the care of children with life limiting illnesses and how they are communicated with. Examples include respecting language barriers, physical contact, eye contact, and gender related care according to cultural practices. Moreover, there may be norms that dictate the discussion of limitations of life sustaining treatments, code status, and organ donation.

Death rituals and traditions are often affected by culture in terms of rituals in the dying process and post death, care of the body, which may differ from infants, to children, to adults, particularly in respect to autopsy, and disposition (Folle & Maranec, 2011).

### Spirituality

Spiritual issues commonly arise for patients with serious illness as they seek for the meaning of their lives. They may need strength to endure their mortality. The nurse must assess spirituality and religion and provide simple actions to show the importance of this domain (i.e. providing presence, attended listening, and bearing witness) (Baird, 2010).

### Where is Palliative Care Delivered

Palliative care being a philosophy of care, can be delivered

a variety of settings, including institutions such as hospitals, inpatient hospices and old peoples' homes as well as in people's homes. What constitutes specialist palliative care and hospice care varies both within and across countries. In the UK for example, the early development was marked by the construction of dedicated separate buildings as inpatient hospices. In the USA, a hospice programme tends to refer to community-based support. Most patients receive palliative care from their usual health care providers. In the UK this means that most patients with advanced illness are in the care of the primary health care team, consisting of general practitioners, community nurses and associated health and social care professionals. Care is therefore delivered in patients' homes where they spend the majority of their time during their final year(s) of life. Moreover, home is overwhelmingly the preferred place of care for the majority of people. General practitioners and community nurses may make referrals to the specialist palliative care providers. Specialist palliative care services themselves offer a range of provision, from a single specialist nurse to a comprehensive multidisciplinary team. Specialist palliative care services have developed an array of different types of provisions including inpatient units, hospices, hospital teams, community teams, complementary therapies, counselling and psychological support, spiritual and religious support.

In summary, palliative care programmes can be provided in:

- Acute care settings.
- Home care services.
- Pain and symptom management clinics.
- Hospice and/or home health facilities.
- Managed health care systems.
- Clinics working with patients with chronic illnesses such as end of stage renal disease (ESRD) or renal failure, cancer, HIV/AIDS, heart failure, Alzheimer's disease, etc.



Palliative care services in Africa are more developed and more organized in most parts of South and East African countries when compared with West African countries. There is greater awareness and acceptability of palliative care services by all stakeholders, including policy makers in these countries; consumers are able to access palliative care services at affordable fees in health institutions and communities. In contrast, the growth of palliative care education and services in Nigeria is still at the rudimentary stage, when compared with what obtains in advanced parts of the world. However, the few initiators currently championing the course of palliative care in Nigeria are creating more awareness while advocating for government and public support.

#### Who provides palliative care

The broad overview of the types of individuals who constitute the palliative care work force that may be engaged in providing both paid and unpaid palliative care include:

**Table 13.1: Providers of palliative care**

Patient's care	Families, friends and neighbours.
Nursing care	General nurses and specialist nurses.
Medical care	General practitioners, specialists in palliative medicine, specialists in other areas of medicine.
Social care	Social workers.
Spiritual care	Chaplaincy, faith advisors.
Therapists	Occupational therapists, physiotherapists (physical therapists), art, drama, and music therapists.
Psychological care	Counsellors, clinical and health psychologists, psychotherapists, liaison psychiatrists.
Specialist staff	Nutritionists, dieticians, pharmacists.
Support staff	Care assistants, administrative, domestic, gardeners, transport, and other workers.

#### Knowledge and skills required in the provision of palliative care

Providing palliative care successfully requires special knowledge and skills from a variety of health care professionals working collaboratively as an interdisciplinary team. Each team member has a role in paying close attention to controlling symptoms and providing psychosocial and spiritual support to both the patient and his or her family members. However, nurses report a lack of preparation in dealing with palliative and end-of-life (EoL) care in the intensive care environment (Adenipekun, Onibokun, Elumelu & Soyannwo, 2005; Zomordi & Lynn, 2010).

Health care professionals involved in the provision of palliative care must receive appropriate education if they are to be effective in helping the person who is dying to feel supported and cared for. The education needs to include a range of topic areas and focus on skill development in communication, clinical assessment, ethical decision-making, and teamwork.

All cancer nurses (in fact all nurses), regardless of the setting in which they practice, need to be knowledgeable about palliative care. However, the depth of the knowledge they require will vary from setting to setting. For example, the nurse working in a cancer-screening clinic may need to know (as an elective) what palliative care is as a philosophy of care; while a nurse on a palliative care unit must know (compulsory) a great deal about managing pain and other symptoms, talking about death and dying, and providing emotional support. Whereas the former nurse may learn about palliative care through several lectures, the latter nurse requires a more in-depth structured programme or course of study. A nurse on a palliative care unit must know (compulsory) a great deal about managing pain and other symptoms, talking about death and dying, and providing emotional support.

Cornel (2003) discriminates between two types of nurses working in specialist palliative care; those who have additional

in various contexts including inpatient hospices and in the patient's home, and the clinical nurse specialist.

### Quality of Death and Palliative Care

Quality of life is a common phrase among health care professionals, but quality of death is yet to gain the well-deserved attention too. In Nigeria, like most parts of the world, open and free discussion about death and dying is still a taboo (Economic Intelligence Unit, 2010).

Also, palliative and end-of-life care nursing is not yet fully embraced by the professionals in Nigeria, despite its inclusion in the famous definition of nursing given to us by Virginia Henderson:

The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge (Henderson, 1966).

The definition of nursing given by Henderson emphasizes the unique role in maintaining both quality of life and quality of death. Nursing is a profession within the health care sector focused on the care of individuals, families, and communities so that they can maintain, attain, or recover optimal health and quality of life. Apart from the many things that nurses do, they are also in a pivotal position to improve care for the dying patients and their families by challenging current end-of-life practices in their various settings. However, nurses report a lack of preparation in dealing with end-of-life (EoL) care in the intensive care environment (Zomordi & Lynn, 2010; Adenipekun, Onibokun, Elumelu & Soyannwo, 2005; Onibokun, Ajayi, Aiyemowa & Ojo, 2011).

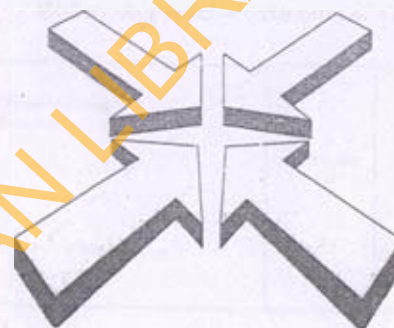


Fig. 13.1: Quality of life model

Source: Ferrel *et al.* (1991)

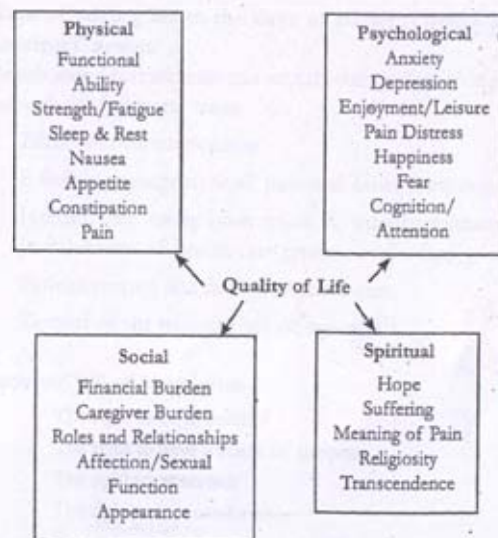


Fig. 13.2: Domains of quality of life model

### Goals of Palliative Care

1. To achieve good palliative care that ensures people living with life limiting illnesses live their lives with minimum discomfort and in the place of their choice.
2. Planning with the patient; rather than planning for the patient, issues relating to his or her care.
3. Involvement of family members and other unofficial carers in discussions relating to the disease process, line of management, with the consent of the patient if able, thereby respecting his or her rights.
4. Provision of effective support services for unofficial carers.
5. Communicating comfort always.
6. Fostering coping and nurturing hope when discussing the future with people living with life-limiting illnesses and their caregivers.

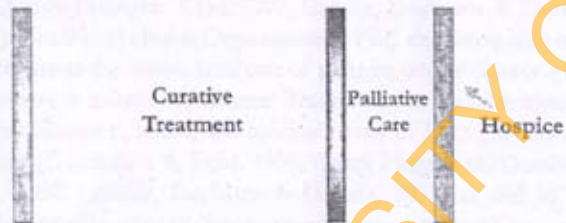


Fig. 13.3: Current practice of hospice and palliative care

### Major Problems of Terminal Illness

Individuals experiencing any life-limiting illnesses are faced with many physical, social and psychological problems. Some of the major challenges are pain and other symptoms such as, anorexia, weight loss, fatigue, cough, anxiety and preparatory grief. Others include loss of income, broken marriages and altered family process, as well as dependency.

### Modern Approach-continuum of Care

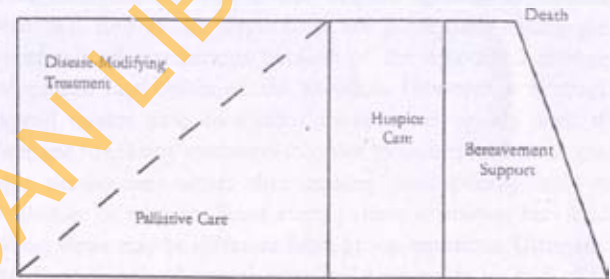


Fig. 13.4: Continuum of care

Source: NCP (2009)

### Ways of adding life to the days of patients living with life-limiting illnesses

Health care professionals can enrich the quality of a patient's life through the following ways:

- Effective communication.
- Effective management of pain and other symptoms.
- Holistic care using both multi & interdisciplinary approach (involvement of health care professionals/family/volunteers).
- Patient-centred and family-oriented care.
- Respect of the patient's bill of last rights.

### Patients' bill of last rights

- The right to be in control
- The right to have a sense of purpose
- The right to reminisce
- The right to be comfortable
- The right to touch and be touched
- The right to laugh

The right to be angry or sad  
 The right to have a respected spirituality  
 The right to hear the truth  
 The right to be in denial

Barbus (1975).

### Nurses' Role in the Provision of Quality and Culturally Sensitive End-of-Life Care

The Institute of Medicine defined optimum end-of-life (EoL) care as an experience that is free from avoidable distress and suffering for patients and their families, in accord with the patients' and families' wishes, and reasonably consistent with clinical, cultural, and ethical standards (Donaldson & Field, 1998; Medicare, 1990). Standards for a good death include symptom management, patient-and-family focused care, and spiritual well-being for both patients and families (Donaldson & Field, 1998; National Consensus Project for Quality Palliative Care, 2009; Gazelle, Buxbaum & Daniels, 2001). The World Health Organization (1990), defined quality end-of-life care as the 'active total care of patients whose disease is not responsive to curative treatment.' This definition includes meeting the psychological, social, and spiritual needs of both patients and families (Donaldson & Field, 1998; Finlay, Higginson, Goodwin, *et al.*, 2002; Gazelle, Buxbaum & Daniels, 2001) as well as the definitions of quality of care provided by the National Consensus Project (2009) and National Quality Forum (2006).

#### End-of-life care: Best practice

Health care providers need to be aware of how to be sensitive to the cultural and religious beliefs of their patients when counselling them on end-of-life care; bearing in mind that end of life beliefs, customs, and values vary widely depending on the cultural and religious background and inclinations of individual patients. Care at the end-of-life should recognize, assess, and address the

psychological, social, spiritual, religious issues, and cultural taboos, realizing that different cultures may require significantly different approaches. End-of-life discussions are particularly challenging in cross-cultural interactions because of the emotional intensity involved and high stakes of the situation. However, it is crucial to spend quality time to discuss these issues openly with the patient and/or family members in order to understand their own unique perspectives rather than making assumptions based on their culture or religion. Since every patient is unique, his or her personal views may be different from group traditions. Ultimately, these discussions and negotiations will help guide an end-of-life plan that provides the patient comfort and respect in his or her final days (Quality Interactions, 2009).

The following are a few tips for culturally competent end-of-life care in general.

- Spend time to educate patients/families about the nature of palliative care (i.e. not "giving up" on the patient) but do not attempt convincing them as this may heighten any underlying mistrust.
- Mistrust and fear that costly treatment will be withheld may lead patients to pursue aggressive care at the end-of-life over palliative care. Try to build trust and be open and honest with patients about what is happening and explore their preferences.
- Do not assume that because a patient is from a particular cultural or religious background that their end-of-life decisions will reflect the customs and values of that group.
- Ask patients and families how they prefer to receive clinical information and make medical decisions – the patient may want to leave it to the family.
- It is important to inquire with the patient and family about any traditional end-of-life rituals that they may want enforced, e.g. religious ceremonies, planning one's funeral, last rights, etc.

- Patients often appreciate when health care professionals ask about spirituality, especially as related to end-of-life discussions.
- It is important to respect the patient's end-of-life wishes even though they may differ from your personal beliefs.
- ALWAYS ASK.

### Past Efforts, Current Issues, and Future Prospects of Palliative Care in Nigeria

In the early 1990s, Dr Anne Merriman, a British woman who had earlier worked in Nigeria, attempted to introduce palliative care in Nigeria. Unfortunately, her efforts met with resistance. She later moved to Uganda, in East Africa to establish Hospice Africa Uganda (HAU).

Also, Professor Duncan (a physician) and Mrs Fatumbi (a nurse) in Lagos made some efforts to revitalize palliative care in Nigeria; however these also had some challenges.

In 2002, Professor Olaitan Soyannwo and her team in Ibadan re-awakened palliative care initiative and later established the Centre for Palliative Care, Nigeria (CPCN); a non-governmental and not-for-profit sharing organization. Its membership of volunteers includes health care professionals, other professionals and the lay public.

The organization has collaborated with the University College Hospital (UCH) Ibadan, and the University of Ibadan, Ibadan Nigeria to establish the hospice and palliative care unit in a Nigerian tertiary institution, the first of its kind; to facilitate the provision of services and the training of students.

Through advocacy, training, and research, CPCN has continued to play a leadership role by planting and mentoring other palliative care centres in Nigeria.

### Training Needs in Palliative Care Nursing in Nigeria

Since the goal of quality palliative care is to address quality of life

concerns, it then becomes absolutely necessary for members of the palliative care team to possess adequate correct and current knowledge in this field. Also, the importance of interdisciplinary approach to care must be ensured.

Currently in Nigeria, nursing curricula in most nursing education programmes (diploma and tertiary), are deficient of current global health and nursing issues such as, comprehensive and multidisciplinary pain management, palliative and end-of-life care nursing (perhaps this may also be said of MBBS education).

This gap has implications for stakeholders, like NANNM, N&MCN, GNAN, ANNE, MDCAN, and other health care professionals who are responsible for medical education in Nigeria.

The University College Hospital (UCH) Ibadan, being the premier teaching hospital in Nigeria, was the first to have a comprehensive hospice & palliative care unit, functioning with a multidisciplinary team. The management of UCH has also supported the training of many health care providers working in this facility.

Many patients who need this specialized care and their families have benefitted from the quality services provided by the staff of the UCH hospice & palliative care unit.

The unit is also assisting in the training of students by providing them with "hands on" experience.

### Recommendations

For quality palliative and end-of-life nursing care to be achievable in Nigeria, there are some basic factors, which need consideration:

- Strengthening of nursing education through curriculum review.
- Continuing education and in-service education opportunities, to improve end-of-life care.
- Public awareness on the benefits of palliative and end-of-life care should be intensified to educate patients and the general public on their rights to demand and receive a higher standard of care at the end-of-life.

- Health care system changes are needed to care for and eliminate barriers such as regulatory constraints on prescribing opioids.
- However, central to all health care reform is the need for educated professionals to direct this change.
- Agreeing with the views of Malloy (2003) and Ferrell, Viran & Viran (1999), nurses as professionals dedicated to patients' comfort even at the end-of-life; Nigerian nurse leaders should begin the revolution in end-of-life care by paying more attention to the education curricula of nurses at various levels.



Plate 13.2: UCH hospice & palliative care unit team

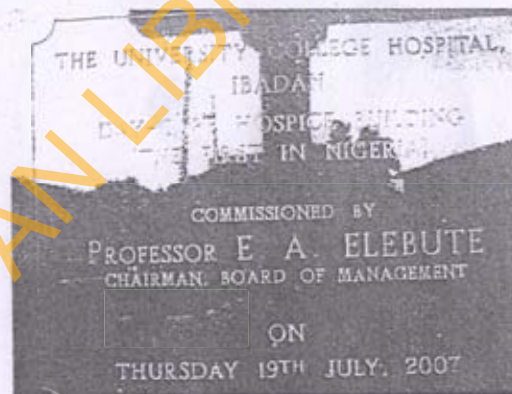


Plate 13.3: Commemoration plaque for the commissioning of the UCH hospice/palliative care unit



Plate 13.4: Health care professionals at a palliative care training workshop



Plate 13.5: UCH hospice & palliative care team members



Plate 13.6: Team spirit in action



Plate 13.7: To comfort always

Source: NCP (2009)

### Conclusion

Palliative care as a philosophy of care uses a combination of active and compassionate therapies. As nurses, irrespective of where we practice, we have obligations to prevent illness among the populace, ensure prompt and quality care if and when they are ill, and promote peaceful death if and when they cannot be cured. These are part of our moral, legal and professional obligations. Providing palliative care successfully requires special knowledge and skill from a variety of health care professionals working collaboratively as an interdisciplinary team. Each team member has a role in paying close attention to controlling symptoms and providing psychosocial and spiritual support to patients and family members.

Health care professionals involved in the provision of palliative care must receive appropriate education if they are to be effective in helping the person who is dying to feel supported and cared for. These educational needs include a range of topic areas and

focus on skill development in communication, clinical assessment, ethical decision-making and teamwork.

As a palliative care nurse, people need your COMPASSION; they also need your COMPETENCE.

Finally, as health care professionals, we must always be aware that our patients are people first. They have a life, loved ones and a place to call home. With this in mind, we need to develop a plan of care that helps our patients continue to enjoy all those things, which will enable them live while dying. This is the motto for palliative care – best practice.

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## Child Abuse and Teenage Pregnancy: Nursing Implication for the Intriguing Duo

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### Learning Outcomes

At the end of this chapter, the reader should be able to:

1. Define child abuse and neglect and their types.
2. Identify the various risk factors predisposing to child abuse and neglect.
3. Define teenage pregnancy and determine the link between child abuse/neglect and teenage pregnancy.
4. Explain the likely impact of child abuse, neglect and teenage pregnancy on the individual, family and community.
5. Identify community health nurses' role in prevention and early identification of child abuse/neglect; developing prompt interventions for those already affected.
6. Explain the likely effects of teenage pregnancy on the mother, child, family and community, and also identify possible community health nursing interventions to ameliorate these challenges.

### Introduction

Vulnerable families are those whose physical and emotional resources are so insufficient that critical tasks and family functions