

## Chapter 25:

***Role of the Nurse in Resource-Limited Settings******Overview***

In Africa, as in other resource-limited regions of the world, nurses are in the best position to provide palliative care. They can be found at all levels of the health care system and are more readily available, especially in rural areas, than medical and clinical officers. Nurses are playing a pivotal, dynamic, and changing role in the course of palliative care in Africa. They have the broad range of skills required for palliative care and are often the only health professionals available. In the opinion of many, palliative care is more of a nursing than a medical field. First developed in the United Kingdom in the late 1960s-early 1970s, palliative care is a dynamic field that has expanded to meet the challenges in both developed and resource-limited settings (Coyle, 2001). The need for appropriate culturally sensitive palliative care has grown with the HIV/AIDS epidemic.

Nurses are in the unique position at this moment to shape the further development of their role in palliative care in Africa. Nursing is key to integrating effective palliative care into all levels of care, so that every person in need of such care has access to it. Nurses in Africa are responding to the needs and challenges of palliative care within the context of their own communities and health care settings.

The notion of a ‘good’ or ‘bad’ death is shaped by people’s experiences, spiritual beliefs, and culture (see Chapter 16: Spiritual and Cultural Care). It is possible for individuals to have a ‘good death’, free from avoidable distress and suffering for the patients, their families, and caregivers (Field, 1997). Achieving this ‘good death’ requires the multidisciplinary team to work together. The nurse is vital to the workings of that team.

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*‘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 a peaceful death) that he would perform unaided, if he had the necessary strength, will or knowledge’.*

– Henderson, 1958

## Why Nurses are Central to Palliative Care in Africa

Nurses are in greater supply than other health professionals in resource-limited settings, where the inadequate number of health care workers (HCWs), including nurses, prevents access to health care for many (see Boxes 25.1 and 25.2). Medical doctors are concentrated in urban areas of Africa, whereas a large proportion of the people live in rural areas. In 1996, 52% of South Africans lived in rural areas, often without electricity or clean water (HASA, 2001). In Uganda, 57% of the population live in deeply rural areas out of the reach of any HCW. Those who do manage to see a HCW often see a nurse but not a medical or clinical officer, because nurses are the only health professionals in some hospitals and in most rural health centres. However, they too are in short supply and care is often offered by HCWs less qualified than nurses (Sepulveda, 2003).

In these settings, nurses are vital providers of direct health care to entire communities. They are sought out for advice at work and in private. They are teachers and leaders in the community and advocates for patients in the health care system. They are the trainers and supervisors of community-based HCWs. As such, they become the opinion leaders who can introduce the principles of palliative care at the community level. Some countries, such as South Africa and Uganda, have taken steps to empower nurses to provide palliative care in areas that are inaccessible to other programmes — for example, through the rural outreach programme in South Africa and the development of palliative care nurses in Uganda (HASA, 2001).

The other reason nursing is central to palliative care is its range of competencies — the holistic focus of nursing on the psycho-social and spiritual as well as the physical well-being of patients and families makes it the ideal profession to assume leadership in palliative care (see next section).

### Box 25.1:

#### *Scarcity of Palliative Care in Malawi*

Malawi provides an example of the scarcity of health care professionals to provide palliative care in resource-limited countries. Malawi is amongst the 20 poorest countries in the world. In 2001 it had a population of 11.6 million and a life expectancy below 40 years (UNDP, 2003). According to the Malawi National AIDS Commission, there were 845,000 people with HIV/AIDS in Malawi in 2003. Salima District is a rural district of 300,000 people. It has suffered severe crop failures and the sick are predominantly very poor without any cash income or other financial means to support themselves. Salima town has a district hospital of 170 beds, eight government health centres, three health clinics run by faith-based organisations, two army facilities open to the general public, and a number of small private clinics. The district has one doctor (1:300,000 in population), 20 clinical officers/medical assistants who are authorised to prescribe medicines (1:15,000 in population), six registered nurses, and about 44 enrolled nurses (1:6,000 in population). Of these, 28 (including the doctor and 10 clinical officers) are hospital-based. Five out of eight government health centres are run by enrolled nurses/midwives who sometimes work alone with no other health professionals. Two of the clinical officers attended a five-day palliative care course. The nearest referral point for morphine is 100km from Salima town.

### Box 25.2:

#### *Scarcity of Health Professionals in South Africa*

In South Africa 31% of all health professional posts were vacant in 2003. HIV seroprevalence among South African health care workers (HCWs) is estimated at 16%.

*Padarath, 2004; Shisana, 2004.*

### Nursing Principles that Support Palliative Care

The principles of nursing support the holistic philosophy of palliative care. Nurses are trained to encourage patients to see value in life and carry on living. They see the patient as a ‘whole’ person and not just a ‘disease’. Care addresses all aspects of the patient’s life — physical, psychological, social and spiritual — and, where appropriate, the lives of the family and others involved in care.

The principles of nursing care are consistent with those of palliative care:

- Focus on the patient and those important to him/her as the unit of care.
- Give holistic care in response to the needs of the patient.
- Ensure continuity across the continuum of care and health facilities.
- Encourage care to be self-directed by the patient whenever possible.
- Work in partnership with patients to achieve their aims and objectives.
- Enhance the patient’s quality of life (Sims, 1995).

The essence of palliative care lies in the nurse’s relationship with the patient. Although palliative care traditionally was seen as beginning once active treatment stops, it has been applied more recently across the illness continuum (Doyle, 1998), thus enabling nurses to build up relationships with patients and their families earlier in the disease process. Building mutual trust is important when working with a person with life-threatening illness so that appropriate care can be given at all stages of illness. The nurse has a relationship not only with the patient, but, where appropriate, with the family — although care must be taken to ensure patients’ confidentiality. If patients do not wish their family to be involved in their care, the nurse must respect this — especially if patients do not wish to disclose their diagnosis to family members because of stigma.

Nurses provide role models for other carers as they engage in relationships in which they place value on the well-being of their patients. Although the amount spent per person on health care in most African countries is low relative to the need, it is important to remember that there is never ‘nothing that can be done’ for the person requiring palliative care (Sims, 1995). Whilst resources are important, the attitudes of the nurse and other carers towards the patient can mean the difference between a person feeling accepted or rejected. Nurses are in an ideal position to make that difference and influence the attitudes of others throughout the care process.

The care of the dying is essentially a nursing issue, not a medical one (Vachon, 2001). Good palliative care enables nurses to return to their roots by caring fully for people in a holistic manner as suggested by Henderson’s ‘unique function of the nurse’ (1958). Nurses traditionally have been at the forefront of care for patients with chronic, advanced disease. Once the role of palliative care nursing is identified, it is possible to train others to carry out the functions and integrate it into all nursing care (Coyle, 2001).

Although most common in developed countries, palliative care nursing is practiced in resource-limited settings, and roles are being adapted and developed according to specific needs and cultures. Whilst the nurse is vital to good palliative care, nurses typically work within a team and not in isolation. Sometimes the team includes a doctor, though usually in resource-limited settings the nurse is the team leader and main care provider.

## Components of the Nursing Role in Palliative Care

The nurse's role in palliative care is broad and varies in different contexts. It typically features a number of common elements.

### *Integration of Palliative Care Into All Levels of Service*

Nurses are important for integrating palliative care into all levels of service. Nurses can be found at all levels of the health care structure in most African countries — at the regional referral hospital, district hospitals, health centres, and in the community. As noted above, where there are no doctors or clinical officers nurses assume many duties that they have not been trained for. Besides being integrated into all levels of the health care system, specialised palliative care services should specifically be available according to a country's needs (see Box 25.3: Palliative Care Nursing in Uganda).

#### Box 25.3:

##### **Palliative Care Nursing in Uganda**

Uganda is an interesting case study regarding integration because nurses play a key role in palliative care. The country's palliative care services feature:

**Specialised palliative care services:** Two main organisations in Uganda offer specialised palliative care services, Hospice Africa Uganda (referred to as Hospice) and Mildmay International. Both are based in Kampala, although Hospice has a branch in Mbarara and one in Hoima. They are both involved in training throughout the country.

**Palliative care teams within the regional hospital:** In early 2005, planning was still underway to have specialised palliative care teams in the national and regional referral hospitals. Currently Hospice send teams into the national referral hospital and some of the regional referral hospitals, but it is hoped that each of these soon will have its own palliative care team. These teams will include a nurse who has completed the Clinical Palliative Care Course and is registered to prescribe morphine. There may eventually be a doctor in these teams, though at present the number of specialised doctors in the country remains few and much of the work falls on the nurses.

**Clinical palliative care nurses:** These are nurses who have been trained and are skilled in pain management and the use of morphine. In July 2004, a statute was passed by the Ugandan parliament empowering nurses and clinical officers who have received training to prescribe morphine for pain control in the absence of a medical officer. As of Feb 2005, 41 clinical palliative care nurses (and 4 clinical officers) had been trained or were in training. It is anticipated that there will be a clinical palliative care nurse in each of the 56 districts in Uganda, thus strengthening palliative care within the districts and the rural settings.

**Nurses at the hospital, health centre, and community levels in the districts:** Both Hospice and Mildmay have been involved in training nurses at all levels in basic palliative care issues. As the National Council of Hospice and Specialist Palliative Care Services (NCHSPCS) said, it is the right of all to receive good palliative care wherever they are, and therefore it is important that all nurses have some training in palliative care so that they can provide it at all levels (NCHSPCS, 1997).

### *Development of Teamwork*

In the palliative care philosophy the team delivers the best possible patient care, in a flexible, individual way, recognising that each patient is different and that no textbook approach exists (Donaghy, 2002). The nurse is in the ideal position to engender this philosophy and to ensure that the team shares objectives and aims and works together to realise these aims and provide high-quality palliative care (NCHSPCS, 2000).

The nurse is the team leader and the liaison between the rest of the team and the patient and family. Nurses play a vital role in the development, establishment, and overall coordination of this team. For many in the African setting this is a new concept. Doctors may find it hard, as traditionally the doctor has been the head of the health care team regardless of the setting or the speciality. For doctors to accept nurses in this coordinating role, they need to be educated concerning the purpose of the team and the nurse's coordinating role.

The conception and make-up of the multidisciplinary team varies according to the setting, availability of resources, and the patient's needs, though at the very least it is likely to consist of the patient, his or her family, and the nurse. A nurse trained in palliative care guides and supports the team and ensures that effective palliative care is given at all stages of care.

### *Assessment*

Assessment skills are central to the nurse's role in palliative care (Coyle, 2001). Effective assessment is key to establishing an appropriate nursing care plan for patients and their families (Glass, 2001) and ensuring that their needs are identified and managed. To ensure good quality of life, nurses must assess the patient in a holistic manner, on an ongoing basis, and at regular intervals. The assessment of pain is of particular importance. Nurses may need to be taught afresh the skills to assess pain and other symptoms, and they will need supervision and support as they further utilise and develop these skills.

### *Communication and Counselling*

Communication is essential for assessment, and nurses are trained in both. Honest communication promotes development of trust between the nurse and the patient and family. Time spent in unhurried communication with a patient allows the patient to share information concerning his or her way of life, spiritual beliefs, fears, anxieties, symptoms, and other matters. The bond that forms becomes a 'therapeutic relationship'.

The process of sharing may be difficult at times, as patients may not want to talk about themselves, their illness, or the fact that they are dying—and it may be culturally inappropriate to do so. Also, in providing palliative care nurses often must act as doctor, nurse, physiotherapist, and counsellor, and the multiple roles that are required of them are challenging. But even when carrying out procedures the nurse can encourage conversation. Good communication conveys to patients that they are cared for and not judged. Knowing that there is someone available to talk to if they need to can make the difference between a 'good' and a 'bad' death (Field, 1997).

### *Treatment and Prescribing as Appropriate*

An essential component of palliative care for achieving optimal physical and psychological well-being of patients is good symptom management (WHO, 1990). In isolated areas, nurses may assess, diagnose and prescribe treatment for symptom control without proper or adequate training, support and supervision and in isolation from either a medical or clinical officer. But it is vital that they be able to respond to patients' needs and provide a seamless service that will reduce distress for both patients and their carers (Mula, 2003). Different countries have different guidelines as to whether nurses can prescribe and what they can prescribe (see Chapter 35: Role of Government). In Uganda the statutes have recently been changed to allow nurses to prescribe morphine and it is hoped that this will also happen in other countries. The reality of the situation needs to be discussed. Where nurses are prescribing because there are no doctors available they clearly need training to ensure they can provide appropriate treatment.

### *Training and Supervision*

Training and supervision are important in all aspects of palliative care. The role of educator is implicit in the unique function of the nurse (Henderson, 1958). But most especially, education is key to providing palliative care in resource-limited settings (Sims, 1995), and the nurse is the best person to do this. Education should be provided at all levels—for patients, their families, community leaders and workers and other health care professionals (see Box 25.4). Whilst nurses vastly outnumber doctors in Africa, there are still not enough nurses. Care is often provided by nursing aides or community volunteers. Nurses must train and supervise these carers to give appropriate and adequate palliative care. The supervision of trained non-professional caregivers has assumed paramount importance in Africa. At the other extreme, palliative care nurses have a role in educating other health care professionals, including doctors, and in educating at the Ministry level to ensure policymakers understand and support palliative care.

#### **Box 25.4:**

#### ***Nurses Eager to Learn More About Paediatric Palliative Care in KwaZulu-Natal, South Africa***

In Kwazulu-Natal, a large, poor rural community in South Africa, the antenatal HIV seroprevalence was 36% in 2004. Limited paediatric palliative care services have been offered, even in areas where a strong palliative care presence is felt. In Ugu South and Tugela Ferry a collaboration of the Enhancing Care Initiative, KZN PLUS, Africaid, and South Coast Hospice trained home carers in paediatric palliative care and home-based care.

When nurses in the region heard about the course, they insisted that they also receive the training to ensure they:

- Have the skills to manage patients referred by the Home Carers
- Are aware of the skills home carers have
- Have the skills to supervise home carers looking after children

This example highlights the need to ensure all health professionals are sensitised, and if possible trained, in palliative care, and are not the only ones performing the work on the ground.

### *Advocacy*

Because palliative care is still a developing field in many African countries, the role of the nurse as its advocate is vital. Political vision and leadership are necessary, along with input from all sectors, to advance palliative care services. Globally, palliative care has been a neglected area yet the need is high and will continue to increase dramatically with the HIV/AIDS epidemic. The World Health Organisation promotes palliative care at the national level (see Chapter 35: Role of Government). However, advocacy is needed from HCWs in each country and nurses are in a strong position to provide this (Stjernsward, 1998). Nurses must advocate for the provision of palliative care services, training in palliative care, and the availability of essential drugs, in particular morphine. Nurses must therefore be equipped with advocacy skills so that they can participate in developing policies, procedures, and appropriate statutes at the national level to support palliative care within the country.

Nurses also have an important role in community coordination through community network meetings between different stakeholders. They help lead the formation of new partnerships between the community and other stakeholders, and can encourage forums for discussion of palliative care issues.

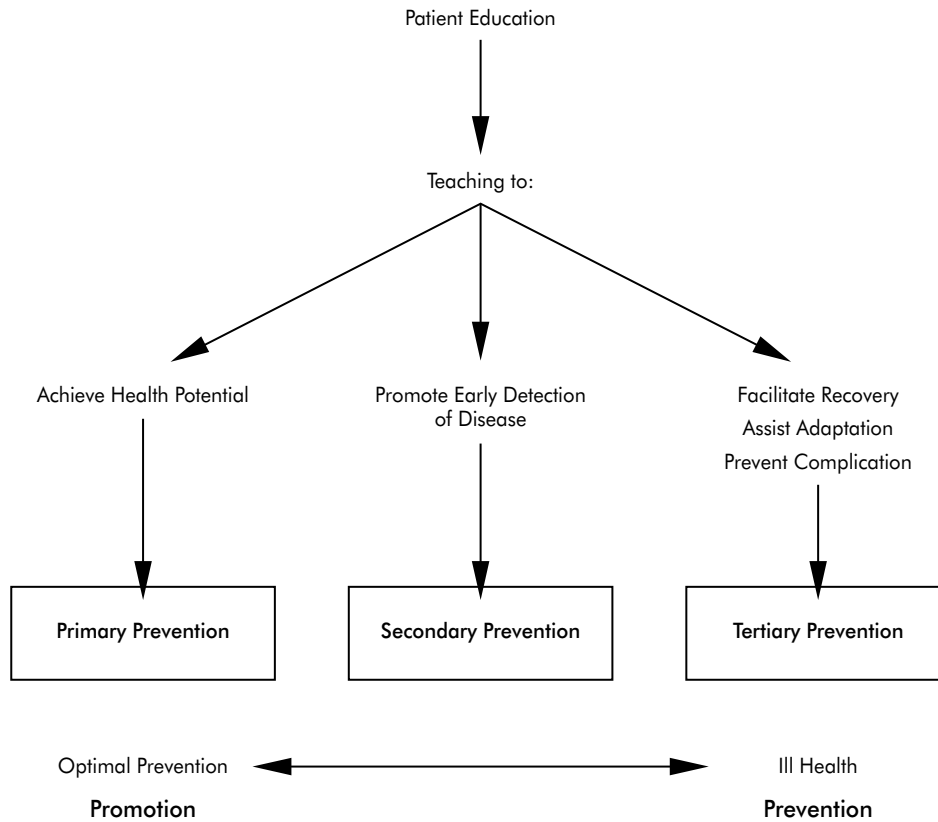
### *Health Promotion*

Through health promotion, the nurse enables a person to maximise his or her potential. In the palliative care context people with life-threatening illnesses still have the potential for health and wellness within the limitations of their disease (Russell, 1998; Oliver, 1994). By promoting health in the dying, nurses can enable patients to confront death positively, and live life to the full right to the end. The nurse cares for both the patient and the family, thereby promoting health in different ways. According to Pratt (1995), health promotion and disease prevention can be done at three levels: primary, secondary and tertiary (see Figure 25.1). There is a role for health promotion at each level in HIV palliative care. Each encounter a nurse has with a patient and family is a potential opportunity for prevention — whether on how to prevent the carer from becoming infected or promoting health in the patient.

### *Cultural Sensitivity*

There are many different cultures within African countries, and it is important for the nurse to work within these cultures. In some Zimbabwean cultures, for example, illness is seen as having a 'normal' or 'abnormal' cause. When it becomes abnormal it is seen as being sent by ancestral spirits and the traditional healers will become involved (Chavunduka, 1978). Because beliefs in witchcraft and ancestor worship are interlocked with the moral code and social structure, many individuals will only go to the traditional healers while others will combine both traditional and modern medicine. Mixing the two is not seen as a contradiction in accepting Christianity and believing in the powers of the spirit elders (Munodawafa 2001). Another cultural issue to be aware of is that it may not be appropriate for a young African female to address an elderly African male (HASA, 2001). (For more discussion on these issues, see Chapter 16: Spiritual and Cultural Care.)

**Figure 25.1: Health Promotion for Primary, Secondary, and Tertiary Prevention**



Source: Pratt, 1995.

### Challenges For Nurses Providing Palliative Care In Resource-Limited Settings

Palliative care is a rewarding yet stressful field. The challenges and stresses can be higher in resource-limited settings, where fewer resources exist and the discipline is less established. Some of the challenges for nurses are as follows:

**Role overload:** The great need for palliative care in resource-limited settings, the dependence on nurses to provide medical care in the absence of doctors and clinical officers, and the lack of enough nurses to provide all the care needed can create a role overload for nurses. Nurses need to be aware of this and concentrate on what they can achieve rather than getting stressed over what they cannot achieve (see Chapter 20: Care and Support for the Carers).

**Role conflict:** Given the variety of cultural differences and rituals in Africa, there may be times when the wishes of the patient contradict the nurse's professional and personal views. The nurse's role may also conflict with what other team members think is best, and they may not respect the nurse's opinions (Vachon, 2001).

**Lack of authority:** The lack of policies and procedures to support the role of the nurse in palliative care can be frustrating. Despite the tremendous level of responsibility they are given, many nurses must contend with a lack of authority and power, particularly with regards to the roles of nurses and doctors. In fact, in many areas of the world, especially where nursing is a woman's profession and women have low status in society, nurses receive much more training than they are allowed to use. They may function as doctors' handmaidens when they have the capacity to be high-level health practitioners.

**Need for training:** With adequate preparation and support, nurses can provide quality palliative care, and indeed are in a key position to do so. Because they often function at a level to which they have not been prepared and without supervision, they need training and support to provide the care that is needed, for example the provision of pain control and assessment (Vachon, 2001).

**Lack of resources:** In resource-limited settings, nurses need to work to overcome multiple barriers, including cultural differences and the scarcity of resources such as morphine, in order to increase the quality of life of their patients. Expert nursing care has the potential to greatly reduce the distress of patients and their families whatever the context or setting (Ferrell, 2002).

**Need for dedicated palliative care role:** Ideally, all health professionals should practise the palliative care approach and call in specialist palliative care colleagues if the need arises. Centres that provide palliative care may find it best to have a single person dedicated to management, monitoring, and responsibility for implementation of palliative care among the various community partnerships. These positions are often unsustainable and dependent on external funding.

Despite these challenges, palliative care nursing can be satisfying. Palliative care nurses have the opportunity to value each person as an individual and to enable their patients to have a 'good' rather than a 'bad' death. They can help individuals to achieve optimal levels of health and quality of life, and can help both patients and their families adjust to the possibility of death and to find meaning in suffering. But to cope with the challenges and provide good quality palliative care, nurses need support and encouragement from each other, their colleagues, the community, and officials at both local and national levels.

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