

## Caring for the terminally ill

*Palliative care has been lacking in public health institutions, but Kenyatta National Hospital, reports Maore Ithula, is in the process of setting up a department for provision of the essential services required by terminally ill patients and their relatives.*

Two years ago, Kaari was diagnosed with terminal cervical cancer by a Naivasha doctor.

Although the doctor knew she would not live beyond a few months, he could not share this information with the patient because there were no institutions in the area to help her with the weighty issue of dealing with a terminal illness. Instead, the doctor referred Kaari to Kenyatta National Hospital (KNH) where he hoped she would get appropriate help.



Kenyatta National Hospital. The institution will soon introduce a department to give palliative care for terminally ill patients.

The patient moved to live with her married sister in Nairobi as she sought medication at KNH. Moses, her brother-in-law was supportive and received her with open arms.

Moses knew a few doctors at KNH, whom he hoped would assist Kaari. But the doctors at KNH also did not know how to break the bad news to Moses or Kaari. The patient and relatives rigidly believed the condition could be cured by ordinary treatment.

### Palliative care

Consequently, the doctors reluctantly admitted Kaari in the ward and continued administering all manner of drugs and other procedures although they knew the condition was terminal and palliative care was all she needed to cope. Kaari passed on after a few months later but not before weighing heavily on the family both financially and in terms of time.

Now experts say a palliative care centre must be founded at KNH to take care of the terminally ill. Patients with life-limiting conditions no longer need curative treatment. Rather they need special care that relieves symptomatic pain, soothes anxieties and emotions since the

disease can no longer be cured. Palliative care, however, has never been provided in Kenya's public hospitals. The service is only offered in hospices — exclusive institutions for the terminally ill.

Today there are six hospices in the country serving thousands of terminally ill patients. But statistics reveal that only about five out of every 20 patients referred to the hospices end up reporting there. The rest are cared for at home and in most cases they die dejected after undergoing untold suffering.

### **Obsolete institutional structures**

Palliative caregivers feel the hospices alone cannot cope with the rising demand for this service. The skeptics blame the situation on archaic legislation, patients' ignorance and poor and obsolete institutional structures in the healthcare sector.

Traditionally, palliative care has been provided in the hospices. Besides the Nairobi facility that is next to KNH, other hospices are in Meru, Eldoret, Mombasa, Kisumu and Nyeri. All hospices are non-governmental organisations depending on donor funds.

However, *The Big Issue* can reveal that palliative care services will soon be extended into the mainstream health institutions to bring the service closer to the people. Dr Esther Munyoro, a KNH anaesthetist and a palliative caregiver says such a department will be operational at the hospital next month. The plan is set to roll out to other public health institutions.

Munyoro who will head the pilot department at KNH says: "Besides helping to relieve pain on more patients with terminal ailments, it is expected that a palliative care department will help in reducing expenditure and congestion at KNH."

### **Management strategic plan**

Majority of those needing palliative care are patients with incurable maladies like cancer and HIV/Aids and their relatives.

For HIV/Aids patients, says the medic, there already exists a concrete communication structure between doctors and patients. But no such avenue has been developed for cancer patients for the Kenyan scenario.

She adds that although 50 per cent of terminally ill people who seek services at KNH are cancer patients; no mention of the condition is made in the current management strategic plan.

Munyoro emphasizes the need for a palliative care department at KNH, saying the number of terminally ill cancer patients is growing in Kenya and other developing countries because of ignorance and poverty.

"There is more terminal ailment caused by cancer in the developing world because people do not go for cancer screening at various

stages of their lives as is supposed to be the case. This is either because they cannot afford to pay the screening fees or they are simply ignorant of the need," says Munyoro.

### **Regular screening**

In the developed world, she adds, it is rare for a descendant of a cancer victim to die of the same ailment because the former will seek regular screening knowing the disease is hereditary.

As a result, tumors are often dealt with in time and finality. "More women in the west seek cervical and breast cancer screening than in the developing countries. The benefits are obvious," she says.

The medic says in the absence of a palliative care department at KNH, where most Kenyans suffering from cancer end up, has caused suffering to many patients and their relatives. When caring for the terminally ill is solely left to the patients' relatives and doctors, says Munyoro: "They both wear out sometimes. This explains why many people abandon their terminally sick relatives in hospitals," she says.

To keep pace with trends in healthcare worldwide, provision of palliative care services in the country should begin at the casualty ward soon after a condition has been diagnosed as terminal.

### **Life-limiting ailments**

KNH is the main referral hospital handling thousands of referral cases from smaller institutions in the country. Munyoro, however, reveals that more than 50 per cent of the cases referred to the hospital are cancerous diseases — most at the terminal stage.

A cancerous affliction is identified as a terminal ailment if it has reached a stage where it can no longer be cured by any known method of treatment. If detected early, cancer can be treated using drugs (chemotherapy), or killing the cancer cells with high-energy radiation (radiotherapy).

Alternatively, cancer tumors can be removed surgically in a theatre. Sometimes a combination of the three methods may be used. But if the deadly cells have spread into essential organs in the body, none of the methods can reverse the situation, and the disease is said to be a terminal condition or more politely a life-limiting ailment. This is where palliative care comes into play.

However, for a patient to effectively benefit from the service there must be proper communication between them and their doctor.

### **Lack of proper communication**

And although hundreds of patients need palliative services that are currently being offered in the hospices, few seek or use them because of the effects of poor or lack of proper communication between patients and doctors when the disease is first diagnosed.

Munyoro continues: "In the absence of a proper communication procedure, medical professionals are ethically tongue tied. They

cannot tell their patients that they are suffering from life-limiting conditions because although they have the basic skills to say so, they would be venturing into another field — palliative care.

And because such a service does not exist, doctors and nurses stick to their role of administering drugs and carrying out other treatment procedures even when they know the disease is already terminal. When they are tired or there is shortage of space, they (medical staff) will politely send the patient home.

### **Relief for physical suffering**

On the other hand, relatives, sucked dry by the medical bills ask to care for their patients at home. The trick the medics often use is allocating the patient far and wide clinic appointments in the hope that relatives will somehow give their patient palliative care for the remaining days. Few of those referred to a hospice go there because the institution is stigmatised as a place for the dying," she says.

Palliative care uses a holistic approach, with medical staff helping in providing relief for physical suffering through administration of drugs. Psychologists and counselors help in controlling emotional and psychosocial agony, while pastoral advice takes care of the spiritual pain. "Palliative care is part of continuum care provided, alongside treatment, from the time of diagnosis through the course of the disease. It becomes more intensive towards the end of life as interventions become less effective. Palliative care also goes beyond death to include bereavement care for exhausted families left behind by a long-suffering patient," says Munyoro.

### **Shortening length of hospital stay**

Palliative care is not a new concept. It began in the United Kingdom in the 1960s. Over time, it has been established that this service helps in the reduction of bed congestion in the wards, Intensive Care Units and High Dependency Units. Munyoro says the method also assists in shortening the length of hospital stay and decreases pharmacy costs. There is less time demand on the medics and nurses for complex communication and decision-making.

Munyoro says: "With an operational palliative care department, we foresee more patient and family satisfaction with the care and an increased enrolment of patients into hospices in the country. The initiative will obviously increase clinical knowledge of pain and symptom control," She says the programme is not a competition with hospices but rather, will enhance operations in the old institution.

But what does it take to start the department at KNH? Munyoro says every medical staff at the hospital has some basic knowledge on palliative care. She says: "The hospital has qualified staff including the director himself, in all fields of palliative care. We shall therefore not need to recruit fresh personnel to run the department; neither shall we need structures to house it.

### **Unfriendly law**

Essentially, the institution requires capital to take care of furniture and vehicles and ambulances needed to reach patients receiving the

care at home. And because they (patients) required to pay a subsidised fee where possible, the project will obviously be self sustaining."

But are there challenges that need to be tackled for the project to stand?

Munyoro says unless the government revises the Narcotic and Psychotropic Substance Act (1994) the project will be difficult to operate.

The Act prohibits pharmacists from stocking and dispensing some strong painkillers grouped with narcotics. Morphine, which is most crucial in the palliative care, falls into this Act. The law was formulated to fight drug trafficking in the country more than 10 years ago. Only hospices are therefore allowed to stock and dispense morphine in the country. Munyoro says the unfriendly law is in effect in all developing countries across the globe as demanded by western world.

### **National drug policy**

She says although the situation is already bad in Kenya, it is worse in some regional countries like Ethiopia which refers her patients to Kenya for morphine.

"The need to start the department at KNH is crucial. We shall therefore provide the services while we share morphine stocks in hospices until the government relaxes that law.

Munyoro says a successive palliative care programme must be based on a rational national drug policy that accepts WHO essential drugs list, including opioids (mainly morphine). "There should be a regulation that allows ready access to opioids for all patients in need," she says. She says ban of some useful narcotics has created mythological views among medics and patients at the expense of palliative care services. "Some patients will not take morphine even if it is useful in managing their suffering because they equate to taking heroin. And there exists professional apathy because some medics have little knowledge on opioids. Some doctors therefore fear that their patients might be addicted to the drug. As an expert in anaesthetics, I know this is not the case. The censorship on the ground is so bad that 'essential drug kits' disbursed to every public hospital by the government contains no pain killers at all," she laments.

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