A holistic continuum of support services for terminally ill patients

Paul Kalyesubula talks to Anne Merriman on the work of Hospice Africa

In 1993 Faustine Mugerwa (not her real name) brought her sick husband to Nsambya Hospital. 'After admission various tests were conducted, he was eventually diagnosed with colon cancer', she recalls. In the same year Hospice Africa Uganda had started seeing patients within the hospital so they were recommended to enroll for its services.

'The very first medication we received was oral morphine. This was prescribed as a pain-relieving drug. Indeed, the pain substantially reduced. My ailing husband was able to walk again without support,' Faustine says. 'To our amazement it was not only the physical pain that was reduced but our anguish and desperation as a family… The strong psycho-social support structure provided by Hospice enabled us to cope as a family.'

At the height of the HIV/AIDs scourge in the late 1980s and early 1990s, Dr Anne Merriman was perturbed by the fact that there were virtually no palliative care packages in Uganda for HIV and cancer patients. 'Families helplessly watched on as their relatives perished in agony. Thus, we started providing pain-relieving drugs to chronically ill patients.' This intervention to reduce the pain of terminally ill patients birthed Hospice Africa Uganda.

'There was urgent need for a remedy to the immense pain suffered by people with chronic conditions like cancer and HIV/AIDs,' explains Dr Rose Kiwanuka, the outgoing country director of Palliative Care Association of Uganda (PCAU). As one of the very first staff at Nsambya hospital to be inducted into palliative care by Dr Merriman, Dr Kiwanuka is a passionate advocate for oral morphine as an element of palliative care.

She says: 'Unlike the injectable, oral morphine has an advantage of being absorbed directly by the liver. Besides, it is also taken in smaller dosages and has less negative reactions on patients. A dosage of oral morphine is just one third of that of the injectable with a shelf lifespan of up to one year.'

Dr Merriman was initially frustrated by resistance to oral morphine since it was associated with an addictive drug. However, morphine was eventually not only embraced but also included on the essential medicines list.

Palliative care is a pain-management intervention essentially discharged in four forms: home-based care; consultancy to hospitals; training of medical personnel, communities and caretakers; and community outreach programmes, including roadside clinics.

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Dr Merriman says, 'As a community-focused model, palliative care seeks not only to reach but also to engage communities in the provision of palliative care … At Hospice, we cannot have a presence in all areas but we strategically build the capacity of health centers, families and communities to manage patients and members respectively with terminal conditions.'

Relieving the burden

One of the most significant burden families' encounter in caring for terminally-ill members is the financial cost. An enormous amount of family resources-including labour and finances are drained in the course of managing an illness. Against the background of the strain chronic illnesses impose on family resources, home-based care entails health centre staff providing services to patients within their home settings while building the capacity of caretakers.

'Importantly this model relieves families from the financial burden, and prolonged stay in the hospitals. For out-patients, it's cost effective in terms of time and transportation,' says Dr Merriman. Home-based care integrates training of caretakers to provide basic palliative care within the domestic setting with supervision of hospital community outreach personnel.

'For purposes of sensitivity to the pre-existing conditions of patients, palliative care is premised on the attributes of aptness to patient circumstances. Once we have identified the pre-existing conditions of a patient – even before the emergence of the chronic condition – we're able to come up with an intervention that addresses the multi-dimensional circumstances.'

The spiritual approach is employed to support the efficacy of bio-medical, psycho-social and counselling interventions.

There are glaring gaps in health personnel specialised palliative care, such as designated spaces for palliative care within health facilities. In terms of coverage, Dr Merriman points out that the numbers of patients they can treat has shrunk since the 1990s due to financing gaps.

On the other hand, a degree in palliative care as well as a degree and diploma programmes in palliative health are being offered by Makerere University and Mulago School of nursing, respectively. To enhance collaboration among organisations providing palliative services, the PCAU was born as a membership-based organisation. This provides a platform for harmonising palliative care services and has got a membership of over 20 organisations and 250 individuals.