

# VIEW FROM THE OBSERVATORY

## Palliative Care in Swaziland

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It was not until 1990, when a British nurse, Stephanie Wyer MBE, founded Swaziland Hospice At Home, that palliative care was introduced into Swaziland. Until then, terminally ill patients were sent home from hospital to be cared for by their families until they died. The lack of social services and the absence of any home-based care increased the physical and emotional pain experienced by both patients and their families.

In Swaziland, terminal illnesses are mainly due to cancer and HIV/AIDS. The lack of an effective cancer screening programme and early cancer treatment programmes have a direct bearing on the growing number of terminally ill patients. Most patients' cancers are diagnosed late, when there is no hope of a cure. If a cancer can be detected early, there are no chemotherapy or radiotherapy departments to treat the disease in Swaziland, and the majority of patients cannot afford to access treatment in South Africa.

HIV/AIDS is presently the major cause of terminal illnesses and challenges palliative care in Swaziland and other countries in the Sub-Saharan region. Unlike in industrialised countries, where HIV/AIDS has been turned into a chronic illness, in Swaziland and other non-industrialised countries AIDS is a terminal illness. According to the 2002 HIV sentinel serosurveillance report, 38.6% of 15–49-year-old pregnant Swazi women are HIV positive. Most affected are women aged 20–24 years (45.4%) and 25–29 years (47.7%), frequently regarded as family breadwinners – the economic power of the country.

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Swaziland has a population of about 1 million people: approximately 200,000 are HIV positive, an estimated 30,000 are terminally ill, and AIDS-related deaths are calculated at 20,000 per year. In a country with less than 2000 hospital beds, home-based care is highly challenged. With around 28,000 AIDS clients needing home-based care and antiretroviral drugs being unavailable within the public hospital, the need for accessible, affordable, quality palliative care services is vital.

Presently, there are 4 major non-governmental organizations providing palliative care – Swaziland Hospice At Home, the Salvation Army, Hope House, and Parish Nursing.

Swaziland Hospice At Home has only 4 nurses covering the 4 regions of Swaziland. Each nurse is assigned to a region and they make home visits to the patients. Considering a fair distribution of HIV-positive people within the regions, each region has approximately 5000 terminally ill AIDS patients – and the hospice nurses visit terminally ill patients regardless of the disease. According to the SHAH annual report 2001–2002, 673 patients were visited during this period.

By contrast, the Salvation Army provides home-based palliative care services to AIDS patients in and around one city. They do not, therefore, cover the whole country or even one region. Hope House is an in-patient unit. They have 16 houses in which each patient occupies one house. Parish Nursing is a church-based organization where 30 retired nurses provide home-based care services to terminally ill clients.

All these palliative care service providers have received a basic introduction to palliative care. This is presently provided by SHAH, which at the moment does not have any fully trained palliative care nurses or doctors. The trainers are basing their training on experience and some workshops they might have attended on palliative care.

There is a need for the introduction of professional palliative care studies in the country. Only one nurse (the author) has been trained to BSc (Hons) level in palliative care nursing, although another nurse (Jabulani Gamedze) is studying for a diploma in palliative care. These two nurses have more than 10 years' experience in the field of palliative care and need to be fully utilized by the country in palliative care training.



## PROGRESS IN PALLIATIVE CARE

The different palliative care organizations experience similar challenges. These include: a lack of funds; limited medications and other supplies; and the poverty of clients and their families. Despite the growing palliative care workforce, the majority of terminally ill clients do not have access to palliative care.

Though Swaziland is highly affected by HIV/AIDS and droughts, it is considered to be a middle-income country; hence, it is difficult for palliative care organizations to access support from industrialised countries and international organizations. Due to the poor economy, in which HIV/AIDS has a direct impact, it is also difficult for these organizations to access support from local companies and organizations. These palliative care organizations are, therefore, struggling to pay salaries to their staff and to buy medication for their clients.

While we would like to ensure control of our clients' physical symptoms, starvation is the first symptom we face in Swaziland, and it is practically and professionally not possible to push a client to take a tablet or medication on an empty stomach. As a result, palliative care-givers are forced to scout for food to give to their clients as a first line of intervention.

All Swazis have a relative or friend who has died or is sick due to HIV/AIDS, and the palliative care providers are also infected or affected by the disease. As they care for their clients, they are themselves emotionally challenged. There is, therefore, a need for 'caring for carers' structures to be put in place for palliative care providers.

Though there are challenges facing palliative care in Swaziland, a number of successes have been achieved. The government fully recognizes palliative care as a speciality, hence more than 300 nurses and 20 doctors have been trained in basic palliative care by SHAH since its inception. On his return from a recent conference in The Hague (The Netherlands), the author initiated a national palliative care association. This association will help standardize palliative care practice and training, and ensure support for palliative care providers. The future of palliative care in Swaziland looks bright as co-ordination and collaboration is strengthened by this association. We are now looking forward to palliative care research, which will help inform and improve the quality of care and support provided to terminally ill clients and their families.