

## Palliative care in chronic disease



The World Health Organization definition of palliative care<sup>[1]</sup> describes palliative care as ‘an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness’. It also states that palliative care ‘is applicable early in the course of illness, in conjunction with other therapies that are implemented to prolong life’, and in describing palliative care for children that ‘It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.’

These statements contained with the definition of palliative care require that we review traditional concepts of palliative care as end-of-life care for cancer patients, consider the provision of palliative care for people who have other chronic diseases, and address palliative care needs early in the disease trajectory. Two articles in this edition of *SAMJ* describe palliative care needs in patients with chronic illness. Farrant *et al.*<sup>[2]</sup> describe palliative care needs in HIV-positive patients on highly active antiretroviral therapy (HAART). The authors found a high symptom burden despite patients being on treatment, and recommend that detailed symptom assessment and control should be part of HIV care. The need for palliative care in HIV alongside HAART has been well established through research in different settings, including in HIV clinics in London, UK.<sup>[3]</sup>

In the second article, Van Niekerk and Raubenheimer<sup>[4]</sup> report a survey of patients in public hospitals in Cape Town and identify palliative care needs in patients with chronic illness, commenting that ‘the greatest burden of disease was found in the general medical wards’. They report that 54.8% of patients admitted to medical wards met the requirements of need for palliative care. They comment particularly on the palliative care needs of young patients with renal failure.

Although palliative medicine is a specialty in the UK and palliative care is provided in many hospitals in the developed world, in South Africa palliative care is largely viewed as a non-governmental organisation function and as such a community-based service. It is important to recognise that patients’ palliative care requirements should be assessed by a doctor, and the care plan to address palliative care needs in conjunction with treatment aimed at controlling the disease should be developed by the doctor assessing these needs. This assessment and initiation of a management plan should take place in hospital, and requires that clinicians are skilled in palliative care and have knowledge of community-based palliative care services that will provide continuity of care for patients with advanced illness. It also requires that staff in the community-based services are skilled in palliative care of patients with progressive advanced illness, whether this illness is organ failure, HIV, tuberculosis, progressive neurological disorders or cancer.

The National Department of Health’s Strategic Plan for the Prevention and Control of Non-Communicable Diseases 2013-17<sup>[5]</sup> states that ‘Careful liaison and interaction between different levels of health care i.e. primary, secondary, and tertiary levels and with central and specialised hospitals is needed; including appropriate promotive, preventative, curative and palliative services at all levels.’

Currently there are few palliative care services in hospitals in South Africa. Early hospital-based services were established at Charlotte Maxeke Johannesburg Academic Hospital and Steve Biko Academic Hospital. Partnerships with local hospices have demonstrated effective models of hospital palliative care in Stellenbosch and Grahamstown.

The Gauteng Centre of Excellence for Palliative Care at Chris Hani Baragwanath Academic Hospital (CHBAH) provides a particularly comprehensive and successful model of hospital-based palliative care with close collaboration with the Oncology Department at CHBAH, an effective training programme for undergraduates and in-service training at the hospital as well as an outreach service into the community.<sup>[6]</sup>

The Abundant Life programme<sup>[7]</sup> established at Victoria Hospital in Cape Town and adapted for the South African setting from the UK Gold Standards Framework, as described by Van Niekerk and Raubenheimer,<sup>[4]</sup> has proved successful in assisting patients with organ failure and their family members and in reducing the number of hospital admissions for this group of patients. A report on this programme also demonstrated cost savings to patients and to the hospital.<sup>[7]</sup> The Abundant Life approach has also been assessed as a possible programme for patients with advanced progressive disease in the community health centre (CHC) to improve patient outcomes.

With successful models of community-based palliative care (hospice services) and current best practice models of hospital and CHC palliative care, the time is ripe to extend these services so that palliative care is available to all patients requiring this care in conjunction with treatment directed at the disease.

The Hospice Palliative Care Association of South Africa (HPCA), together with partners FHI 360, the Foundation for Professional Development and SA Partners, has recently been awarded a grant from the US Agency for International Development (USAID) to integrate comprehensive care and support-palliative care into the South African health system to achieve better patient outcomes. The Care and Support for Improved Patient Outcomes (CaSIPO) project will work closely with government departments to identify policies and procedures and to assist in implementing an integrated care and support-palliative care package for health and welfare structures in hospitals, clinics and communities.

Recent global and local advocacy efforts have established recognition of palliative care and pain control as a human right.<sup>[8,9]</sup> In light of these efforts, the HPCA presented a petition<sup>[10]</sup> to the National Minister on Human Rights Day 2012, calling on the government ‘to ensure that palliative care is accessible, available and affordable to South Africans facing advanced illness, and to ensure that at the end of their lives patients are treated with dignity and experience relief of suffering’.

At the recent palliative care conference co-hosted by the African Palliative Care Association and the HPCA, the South African Deputy Minister of Health, Dr Gwen Ramakgopa, hosted a meeting of delegates from African health ministries. These delegates included the ministers of health from Uganda and Kenya and the Deputy Minister of Health from Malawi, and representatives from 34 African health ministries. The outcome of the meeting was a consensus statement recommending six objectives for African governments. These objectives include development of policy frameworks for palliative care, including palliative care in health budgets, ensuring the availability of essential palliative care medicines, integrating palliative care training into medical and nursing schools, and sharing palliative care best practices.

The research studies by Farrant *et al.*<sup>[2]</sup> and Van Niekerk and Raubenheimer<sup>[4]</sup> emphasise the need for palliative care for patients with chronic disease. Recognition by clinicians and National Department of Health (NDoH) officials of the importance of

palliative care in providing a comprehensive service to patients with chronic disease, the experience and expertise of palliative care providers in South Africa and the support of funders such as USAID have come together at a time when the NDoH has embarked on an ambitious plan to improve health care for all South Africans. Collaboration between government, palliative care providers and funders will ensure a better quality of life for patients, both adults and children, living with chronic disease.

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