



Palliative care is on the move – *masihambe!*

Palliative care is on the move. This discipline began with the committed care of dynamic and powerful individuals like the late Dame Cecily Saunders. Initially aimed at people with cancer, it now embraces a trans-sectoral and multidisciplinary approach towards the overall management of problems associated with any life-threatening illness and beyond.

Delivery of this level and quality of care is now needed beyond the traditional hospice model. Most hospices in South Africa have recognised this and serve the communities in which they are situated through outpatient services and home care far more than through in-patient units. There are about 35 000 patients under the care of over 70 hospices which are members of the Hospice Palliative Care Association (HPCA) of South Africa. These hospices have some 600 beds available for admission. Patients are admitted to a hospice bed for three main reasons, namely symptom control, family relief (respite care), and terminal care.

The article presenting the research findings of Kirk and Collins (p. 101) is a welcome reminder that palliative care is very much part of the medical care that should be offered in a general hospital. The benefit of improved quality of life among patients referred to the hospital palliative care team is invaluable, and should be available to every patient. Palliative care therefore extends beyond the realm of the so-called soft skills of supportive services alone, and into mainstream medical care.

It may be said that if doctors do not apply the principles of palliative care in everyday clinical practice, then they are at best offering suboptimal medical treatment. Another stronger view has been expressed, namely that those who do not apply these principles are incompetent and uncaring.

The definition of palliative care formulated by the World Health Organization (WHO) in 2002¹ clearly sets out the wide application of this discipline in terms of its scope and extent, and the high standard of care to which we should all aspire. The ideal of impeccable physical, psychosocial and spiritual care of the patient's burden of need is both daunting and obvious.

The definition of palliative care should be explored further and should always be considered in the context of the needs of patients and the profile of the health system requiring the service. There is bound to be some robust discussion around this. Each of us has a particular context, and the definition should serve all. Some different definitions of palliative care preceding the latest WHO definition are compared in an article by Webster and Kristjanson.² Each definition has advantages and disadvantages. In the African and South African situation the special needs of people with AIDS, children with AIDS, children with cancer, people with non-malignant terminal illness, those in the gradual decline of frail old age, and other

conditions must be covered by any definition that is to be widely accepted.

Many people have contributed to the process of defining and understanding what constitutes palliative care, including one of the pioneers in the field in South Africa, Dr Selma Browde. Her initiative has led to the establishment of hospital palliative care teams in this country. Dr Browde also developed and published an expanded definition of palliative care³ that has merit, although it misses the core principal that palliative care is different from other disciplines, like family medicine, in that it focuses on 'life-threatening illness'. The principles of palliative care apply to every kind of care, but the discipline is distinct.

The personal nature of the care required and the strong personalities of the doctors, nurse practitioners, psychologists, social workers, spiritual counsellors and others who have led developments in the field since the 1960s (although only since 1979 in South Africa) have led to much personal thought, private discussion and academic description of what we do. This has resulted in a somewhat fragmented and misplaced idea of what palliative care really is. There has been an element of reluctance within the establishment to accept that the discipline of palliative medicine is legitimate and valuable to all patients and to other members of the multidisciplinary team treating the patient. The mistaken idea that palliative care is only the soft skill of comforting a patient on the deathbed is still abroad among the medical profession and the public. The comfort and solace offered by family members or by home-based care workers is not comprehensive palliative care. Also, good diagnostic skills and symptom control do not constitute palliative care. Merriman and Kaur⁴ correctly point out that 'Pain and symptom control without supportive and holistic care [is only] anaesthesiology'.

These confusions and limitations would be addressed, at least in part, if all involved in the field begin from the same starting point. Adoption of the current broad WHO definition of palliative care is recommended as it could be said to include all patients if we apply some aspects very generally. The particular needs of the HIV-infected population and those suffering from AIDS should be a special consideration in the South African context. It may be helpful to lobby the WHO to develop the definition and perhaps to adapt it to include the particular needs of the HIV-infected and affected.

The WHO definition of 2002¹ is repeated here to remind us that the umbrella body for the main providers of palliative care in South Africa, namely the HPCA, has adopted this definition as the starting point for the work they undertake: *'Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early*





identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'

It should be remembered that the hospices represented on the HPCA and that are the main deliverers of care in the community work together to care for some 35 000 patients daily in South Africa. Most do not have inpatient units. However, these hospices are not the sole providers of palliative care in the country. Many clinicians from specialist and generalist backgrounds deliver palliative care to their patients, and many non-medical professionals are also involved without being part of a formal hospice arrangement. The multidisciplinary team concept may be best practised in a formal setting where the discipline of ward rounds, academic meetings and informal discussions can benefit the members of the team and the patients treated there, but this is not the only model of care in the field.

A group of interested multidisciplinary professionals and supporters has begun the process of establishing the Palliative Care Society of South Africa. The aims of this group have yet to be established, but objectives are likely to be support of each other in this demanding field of practice, sharing of ideas and concepts, developing a research and learning agenda, and advocating for aspects of palliative care delivery such as accessibility, language policy and more. It is hoped that much of the work of the society will be undertaken on the Internet, with few formal meetings but very productive outputs. Enquiries may be directed to Joan Marston, advocacy officer of HPCA (advocacy@palliativecare.co.za), or visit www.palliativecaresa.co.za.

The following extract from the Korea Declaration on Hospice and Palliative Care of March 2005⁵ should be the goal of the next phase of the work in palliative care in South Africa:

- *Make hospice and palliative care services comprehensive in nature and better integrated into the health care system*

- *Strive to make hospice and palliative care available to all citizens in the setting of their choice including acute care hospitals, long-term care facilities (nursing homes), and residential hospices and in the patient's home.*

Every individual has the right to pain relief. Since affordable and effective methods exist to relieve pain and most other symptoms, cost should not be an impediment.

Hospice and palliative care must be provided according to the principles of equity, irrespective of age, race, gender, sexual preference, ethnicity, faith, social status, national origin and the ability to pay for services. Palliative care must be available to all populations including vulnerable groups such as prisoners, sex workers and drug users.

The experience gained from the hospice and palliative care of cancer should be extended to the care of people with other chronic incurable diseases worldwide.

The deep and overwhelming needs of our patients should move each of us involved in the field of patient care to incorporate the principles of palliative care into the everyday practice of medicine. We cannot deliver impeccable care in isolation, but only within the supportive environment of a multidisciplinary team, approaching the sense of vitality in the discipline expressed by Webster and Kristjanson as 'the capacity to live and develop'.² *Masihambe!*

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1. World Health Organization. Palliative Care. 2005. www.who.int/hiv/topics/palliative/care/en (last accessed 23 September 2005).
2. Webster J, Kristjanson L. 'But isn't it depressing?' The vitality of palliative care. *J Palliat Care* 2002; **18**: 15-24.
3. Browde S. Expanding the definition of Palliative Medicine and integrating it into the mainstream. *S Afr Med J* 2001; **91**: 732-733.
4. Merriman A, Kaur M. Palliative care in Africa: an appraisal. *Lancet* 2005; **365**: 1909-1911.
5. 2nd Global Summit of National Hospice and Palliative Care Associations. Korea Declaration on Hospice and Palliative Care. March 2005.