Palliative care for drug-resistant tuberculosis: An urgent call to action

To the Editor: The recent article entitled 'Development of a hospital-based model of palliative care in the Western Cape, South Africa'[1] recognised the important milestone South Africa (SA) has reached in adopting a policy on palliative care and begs the question of models of palliative care for drug-resistant (DR) tuberculosis (TB).

The mortality rates for multidrug-resistant (MDR)-TB and extensively drug-resistant (XDR)-TB are 40% and 60%, respectively.[2] Of concern are a growing number of patients with programmatically incurable TB who remain smear- and culture-positive, giving rise to secondary cases. Currently there is no package of care available to these patients when treatment options have been exhausted. Therapeutic failure has become synonymous with additional failures from policy, programmatic, patient and social care perspectives.

The World Health Organization (WHO) issued the 'Declaration on Palliative Care and MDR/XDR TB',[3] which recognised palliative care as a human right and an essential component of managing patients with DR-TB, in November 2010. The World Health Assembly's resolution in May 2014[4] mandated member states to strengthen and integrate palliative care into public health systems. In March 2014, the WHO adopted the End TB Strategy with the vision of 'A world free of tuberculosis – zero deaths, disease and suffering', emphasising patient-centred care.[5]

In 2015, the SA National Department of Health commissioned a WHO-led evaluation of the DR-TB programme on the implementation of decentralisation and deinstitutionalised management of MDR-TB. The report estimates that 90% of patients who experience treatment failure will receive home-based care and only 10 - 15% of patients will require specialised long-term stay facilities.[6]

Palliative care is an essential component of universal health coverage, requiring a scalable, integrated response into DR-TB care. It must include infection control measures to mitigate transmission, symptom assessment and management, including access to opioids, to improve the quality of life of patients, while supporting their families. Patients with DR-TB experience a myriad of distressing symptoms including total pain, nausea, cachexia, dyspnoea and haemotypsis, adding to the emotional angst of confronting their mortality. Effective implementation can reduce suffering and potentially decrease community transmission with infection control, screening of contacts and retention in care.

While the search for better drugs, vaccines and diagnostic tests must be intensified, palliative care for patients with DR-TB must be provided now! This can be achieved with political leadership and allocation of resources including palliative care training for health workers. SA, a signatory to the World Health Assembly resolution, must champion the inclusion of palliative care for patients with DR-TB at the first United Nations High Level Meeting on Tuberculosis to be held on 26 September 2018 in New York with the theme 'United to end tuberculosis: An urgent global response to a global epidemic'.

T Govender

King Dinuzulu Hospital Complex, KwaZulu-Natal Department of Health, Durban, South Africa; Discipline of Public Health Medicine, School of Nursing and Public Health, College of Health Sciences, University of KwaZulu-Natal, Durban, South Africa; and Developing Research Innovation, Localisation and Leadership in South Africa (DRILL) Fellow, College of Health Sciences, University of KwaZulu-Natal, Durban, South Africa

thilo.govender@gmail.com

S Naidoo

Discipline of Public Health Medicine, School of Nursing and Public Health, College of Health Sciences, University of KwaZulu-Natal, Durban, South Africa

N Padayatchi

Centre for the AIDS Programme of Research in South Africa (CAPRISA), University of KwaZulu-Natal, Durban, South Africa

L Gwyther

Palliative Medicine, School of Public Health and Family Medicine, Faculty of Health Sciences, University of Cape Town, South Africa; and Hospice Palliative Care Association of South Africa, Cape Town, South Africa

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