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EDITORIAL

Declaration on palliative care and MDR/XDR-TB

THE WORLD Health Organization (WHO) estimated a prevalence of 650 000 cases of multidrug-resistant tuberculosis (MDR-TB) in 2010. Although efforts to improve cure rates in drug-resistant TB are vital, the global average reported cure rate was 53%.[1] Meanwhile, at least 150 000 deaths occur annually due to MDR-TB.[2] Efforts to provide palliative and end-of-life care to those suffering from this condition are very limited. Some model programmes emerging in Africa, Asia and Eastern Europe have demonstrated that palliative and end-of-life care can be added to current treatment programmes. MDR-TB patients, and those affected by extensively drug resistant TB (XDR-TB), a subset of MDR-TB that is even more difficult to treat, experience severe suffering that could be addressed more effectively through systematic inclusion of competent palliative care services in TB treatment programmes.

In 115 surveyed countries, the Global Project on Anti-Tuberculosis Drug Resistance Surveillance found proportions of MDR-TB among previously untreated TB patients ranging from 0% to nearly 30% of presenting cases. The number of people who died from TB fell to 1.4 million in 2010, including 350 000 people with human immunodeficiency virus (HIV) infection.[3] However, unlike the poor success rate reported in MDR-TB, drug-susceptible TB is curable in most cases. As of January 2012, 78 countries had reported at least one case of XDR-TB to the WHO. Recent South African data show that among a cohort of XDR-TB patients, most of them co-infected with HIV, nearly a quarter died prior to initiation of treatment for XDR-TB, and almost half subsequently died in the first year of treatment.[4] TB, particularly in its most severe forms, MDR-TB and XDR-TB, can thus be considered as a life-threatening condition from the moment of diagnosis.[5]

Palliative care as defined by the WHO[6] should be provided for any life-threatening illness from the point of diagnosis through to the end of life. Efforts to extend palliative care expertise to MDR/XDR-TB treatment are still rare. Current policy and strategy on TB care and control should make a more explicit reference to palliative and end-of-life care, and the respective guidelines should be more comprehensive, addressing not only the physical dimension, but also the psychological and social suffering associated with the illness. In December 2010, a meeting of TB and palliative care experts was held in Geneva under the sponsorship of the WHO Stop TB Department, the Open Society Foundations and the Worldwide Palliative Care Alliance. The meeting resulted in a call to action to expand efforts to include palliative care in the global response to MDR/XDR-TB. We endorse the following declaration, and call upon the TB and palliative care communities to work together to improve adherence to MDR/XDR-TB treatment and cure rates, and to help relieve the suffering of all those affected by the disease, including those we are unable to cure.

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Declaration on Palliative Care and MDR/XDR-TB

Geneva, Switzerland, 19 November 2010

As a group of experts in palliative care and MDR/XDR-TB, we declare:

1 That access to palliative care for individuals (adults and children) with MDR/XDR-TB is a human right and promotes dignity.
2 That palliative care is an essential component of the provision of care for individuals (adults and children) with MDR/XDR-TB, wherever in the world that they are receiving care.
3 That palliative care should be strengthened where being provided, and integrated alongside the prevention and treatment of MDR/XDR-TB.
4 That palliative care in the context of MDR/XDR-TB should be integrated into the management of MDR/XDR-TB from the time of diagnosis until the patient reaches cure or the end of life. The problems faced by MDR/XDR-TB patients and families span multiple physical, psychological, social and spiritual dimensions. We believe that the existing WHO definition of palliative care is highly appropriate for patients with drug-resistant TB.
5 That palliative care strengthens the Stop TB strategy.
6 That, as experts on MDR/XDR-TB and palliative care, we are keen to learn from each other.
7 That we are committed to developing the agenda on palliative care in MDR/XDR-TB, and improving access to care, medications, training and capacity building, and collaborating to improve the knowledge base through research.

Palliative Care and MDR/XDR-TB Integration Meeting, November 18–19, 2010
Open Society Foundations – Worldwide Palliative Care Alliance – WHO Stop TB

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Disclaimer: Florence Bitalabeho, Masoud Dara, Ernesto Jaramillo, Barbara Milani, and Mario Raviglione are staff members of the World Health Organization (WHO). The authors alone are responsible for the views expressed in this declaration and they do not necessarily represent the decisions, policy or views of the WHO.