

Correspondence

Quality HIV Care to the End of life

TO THE EDITOR—We read with interest the recent proposed national and multi-agency human immunodeficiency virus (HIV) quality care measures published in *Clinical Infectious Diseases* [1]. This is an important development in ensuring comprehensive and appropriate quality care. The authors propose 17 measures to enhance outcomes for infected persons, and they note the limitation that these measures do not reflect all aspects of HIV care. The priorities for selection of measures included prevalence of the condition, consensus of care standards, potential for improvement, scientific soundness, and feasibility. One essential dimension of care for which these criteria can easily be met was omitted in the discussion.

In 2008, >17,000 people with AIDS (3.8% of those with AIDS) died in the United States [2], and ~2 million HIV infection-related deaths occurred worldwide [3]. At the recent International AIDS Society conference, attendees rightly celebrated the successes of antiretroviral therapy (ART), which has radically reduced morbidity and mortality for those with access. However, parallel sessions were held on HIV-related mortality and morbidity, malignancies, and complications of long-term infection and treatment. (All abstracts and plenary sessions can be accessed at <http://www.aids2010.org>.) Increasingly prevalent complications, such as cardiovascular disease (MOSY0303), renal disease (MOSY0304), liver failure and liver cancer (FRPL0104), and brain impairment (MOSY0305), are emerging as treatment begins earlier. Dramatic increases in incidence of non-AIDS-defining cancers (primarily anal and

prostate cancers) in the aging HIV-infected population were reported from the United States, whereas a stable incidence of lung cancer and Hodgkin-lymphoma led to an increase in prevalence (WEAB0101). Higher incidence, and younger age at diagnosis were found for a number of cancers, compared with the findings for the general population in the United States. Additional primary data revealed a need for palliative care among children, who have a high prevalence of cardiac dysfunction (MOAB0405).

The mortality findings were of particular interest. Among socially disadvantaged persons in the United States, HIV-related mortality is beginning to increase again, after dramatically decreasing with increased access to ART (TUAC0105). The same effect was recorded among South African miners (TUAC0104). Retrospective data from Brazil highlighted the impressive decreases in HIV-related mortality with universal ART access, yet 121,346 of 382,012 patients still died over the 10-year follow-up period (TUAC0102). With clear evidence of a high prevalence of need, it is striking that presenters reporting mortality rates consistently failed to make recommendations that palliative or end-of-life care should be provided for those who die.

The criteria of scientific soundness and potential for improvement for the proposed quality measures can also be met, as a systematic review of outcomes under HIV palliative care demonstrated its ability to improve a number of domains, including pain, symptoms, and psychological morbidity [4].

Consensus of care standards are provided by the World Health Organization's

definition of palliative care, which defines HIV palliative care to address the physical, psychological, social, and spiritual needs of patients and families at the end of life as essential care [5]. Feasibility of implementation was addressed in a conference plenary on HIV care and support in which Gwyther gave an overview of a wide range of successful models of care delivery, particularly in resource-limited settings (FRPL0103). A large body of evidence demonstrating the multidimensional and burdensome range of problems that patients experience throughout the disease trajectory into the final stages of life shows the feasibility of measuring these outcomes [6, 7].

To determine whether adequate attention is being directed to HIV palliative care at the end of life, we conducted a systematic review of the 6068 abstracts accepted at the conference. Using search terms “palliative,” “terminal,” “end of life,” “hospice,” “advanced,” and “dying” (intersected with “or”), our inclusion criteria were primary data on the needs, experiences, care, or outcomes of patients at the end of life. Twenty-six abstracts were identified: 2 systematic reviews; 7 reports of patient and family need; 1 report of staff need; 10 descriptions of care services and interventions; 4 discussions of law, policy, and human rights; and 1 abstract on palliative care professional training. Of the 26 abstracts, only 1 reported patient outcomes under palliative care (THPE0399). Although 6.1% of the global HIV-infected population died during 2008, only 0.4% of presentations at the International AIDS Society conference addressed their care.

It seems that the quality care needs of those who die as a result of HIV infection

are consistently overlooked. In light of the evidence of high mortality rates in the presence of public ART programs, the focus on quality care advocated in the proposed measures should continue to the end of life.

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