

6. Finlay IG, Higginson IJ, Goodwin DM, et al. Palliative care in hospital, hospice, at home: results from a systematic review. *Ann Oncol* 2002;13(Suppl 4):257–264.

7. Higginson IJ, Finlay IG, Goodwin DM, et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manage* 2003;25(2):150–168.

8. Harding R, Karus D, Easterbrook P, et al. Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence. *Sex Transm Infect* 2005;81(1):5–14.

9. Higginson IJ, Hart S, Koffman J, Selman L, Harding R. Needs assessments in palliative care: an appraisal of definitions and approaches used. *J Pain Symptom Manage* 2007;33(5):500–505.

10. Roll IJ, Simms V, Harding R. Multidimensional problems among advanced cancer patients in Cuba: awareness of diagnosis is associated with better patient status. *J Pain Symptom Manage*, Epub ahead of print.

11. Merriman A. Pain in developing countries. *Hosp Uganda J Palliat Care* 2001;4(4):9–17.

Just Palliative Care? Integrated Models of Care

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In his article describing unequal access to medical care for the poor, Krakauer makes an important statement that palliative interventions should be integrated with

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DOI of original article: 10.1016/j.jpainsymman.2007.11.015.

preventative and disease-modifying interventions. He goes to the heart of a major misunderstanding—providing palliative care implies the withdrawal of active treatment. This misunderstanding persists despite a number of statements emphasizing the active nature of palliative care. The World Health Organization (WHO) definition of palliative care includes the assertion that palliative care “is applicable early in the course of illness, in conjunction with other therapies that are implemented to prolong life.”¹ In writing about HIV and palliative care, O’Neill and Barini-Garcia describe palliative care as “complementary care, and not alternate care, and therefore should not be provided only when disease-directed therapy fails or is unavailable”² (Fig. 1).

Integration of disease-oriented care and palliative care is important to provide optimal care for the patient. Separation of the two approaches results in patients experiencing a sense of abandonment by their doctors, and doctors experiencing a sense of failure if the disease continues to progress to a stage where it is not curable. This is true for poor patients, who, as Krakauer notes, may not be offered expensive disease-specific treatment, and for rich patients, when high-tech, disease-specific treatment fails. Initiating a palliative care approach alongside curative treatment demands that the doctor engage with the patient as a partner in management, keeping the patient fully informed of the stage of the disease, and the risks and benefits of treatment. This helps in preserving realistic hope and developing a relationship of trust.

Integrated Care in Practice

Paul Farmer, in an article written for the Council on Foreign Relations, describes “a growing awareness that not only doctors and nurses are needed to deliver medical care: many are learning that proper ‘accompaniment’ — closely supervised home-based therapy, social and psychological support, and help with everyday tasks including feeding families — is what poor patients with HIV/AIDS need most of all.”³ The South African Hospice Palliative Care Association assists member hospices and home-based care organization to implement this “accompaniment” through the

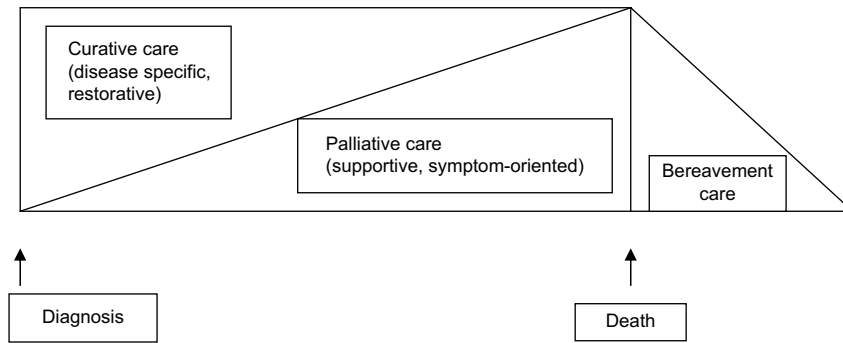


Fig. 1. Integrated model of care: including both curative and palliative. Source: World Health Organization. Cancer pain relief and palliative care. Geneva: World Health Organization, 1990.

Integrated Community-Based Home Care (ICHC) program. Important elements of this program are treatment support for disease-specific care, such as antiretroviral treatment; early identification and treatment of opportunistic infections; management of distressing symptoms; emotional support; and social support, including facilitating access to social grants, economic empowerment programs, and care of orphans and vulnerable children.

The ICHC program emphasizes networking with clinics and hospitals and promotion of prevention programs. Many South African hospices also provide antiretrovirals to enhance the roll-out of treatment where state services have not yet been able to meet the need. Palliative care in its truest form responds to the needs of the individual patient with life-threatening illness and his/her family members, and is very much more than an “alternative to disease-modifying treatment” or “helping people die with less pain.”³

There are a number of effective community-based home care programs in resource-poor settings, from the PIH program in Haiti of accompagnateurs, to the Kerala Neighbourhood Network,⁴ to the National Palliative Care program in Vietnam.⁵ Internationally, palliative care workers have called on governments to respond to General Comment 14 of the International Covenant of Economic, Social and Cultural Rights (ICESCR), which includes palliative care as a human right.⁶ In resource-poor settings, the response to suffering needs to be greater, as argued by Krakauer. We are all aware that people living in extreme poverty may lack access to food and adequate shelter, face greater risk of disease, or be forced to accept dangerous working conditions. They also have limited

access to health care and are often living in an unhealthy environment without potable water, safe disposal of sewage, and overcrowded conditions.

Resource constraints apply not only to financial resources but also to educational opportunities for the community and opportunities for employment. Lack of human resources in health is as much a challenge in providing health care in these settings as lack of technology and affordable medicines.

Krakauer describes the public health strategy for effective palliative care developed by the WHO. This is a simple, effective, and economical way to ensure the integration of palliative care into the formal health care sector. Palliative care is indeed cost-effective care. A key requirement is that health care professionals are trained in palliative care and develop the knowledge, skills, and attitudes to deliver this care according to the patients’ needs. Essential palliative care medications are affordable, and many countries have all the required medicines included in the essential medicines list. Many awareness programs are being offered in developing countries to ensure the availability of opioids to manage pain effectively.

The imperative to respond responsibly to the suffering of the poor includes integration of disease-specific care with palliative care. As described by Krakauer, scientific research, including needs analysis and service evaluation, would assist health service providers to adapt models of integrated care appropriate to the community in order to provide optimal care to patients with life-threatening illnesses and their family members.

References

1. Sepulveda C, Marlin A, Yoshida T, Ullrich A. Palliative care the World Health Organization's global perspective. *J Pain Symptom Manage* 2002; 24:91–96.
2. O'Neill JF, Barini-Garcia M. HIV and palliative care. In: O'Neill JF, Selwyn PA, Schientinger H, eds. *A clinical guide to supportive and palliative care for HIV/AIDS*. Health Resources and Services Administration, US Department of Health and Human Services, 2003: 1–3.
3. Farmer P. Available from <http://www.foreignaffairs.org/20070301faresponse86213/paul-farmer-laurie-garret/from-marvelous-momentum-to-health-care-for-all-success-is-possible-with-the-right-programs.html>. Accessed May 17, 2008.
4. Kumar SK. Kerala, India: a regional community-based palliative care model. *J Pain Symptom Manage* 2007;33(5):623–627.
5. Krakauer EL, Ngoc NTM, Green K, Kham LV, Khue LN. Vietnam: integrating palliative care into HIV/AIDS and cancer care. *J Pain Symptom Manage* 2007;33(5):578–583.
6. Committee on Economic, Social and Cultural Rights. General Comment 14, The right to the highest attainable standard of health (Twenty-second session, 2000) U.N. Doc.E/C.12/2000/4(2000).