

Special Article

Just Palliative Care: Responding Responsibly to the Suffering of the Poor

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Abstract

The disproportionate suffering of the world's poor from AIDS and cancer has generated efforts to promote palliative care as an affordable alternative to expensive disease-modifying therapies. These well-intentioned efforts stem from a wish to respond to the suffering of the poor as quickly and widely as possible and from the view that only inexpensive interventions are feasible in poor settings. Such efforts also may be informed by the cautious attitude of palliative care in rich countries toward disease-modifying treatments for patients with advanced life-threatening illnesses. Yet, acceptance of unequal access for the poor to life-saving medical services that are badly needed and potentially feasible is unjust. Although palliative interventions to relieve the disproportionate physical, psychological, and social suffering of the poor are essential, they should be integrated with preventive and disease-modifying interventions for major killers, such as acquired immunodeficiency syndrome and cancer. *J Pain Symptom Manage* 2008;36:505–512. © 2008 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative care, social justice, poverty, AIDS, cancer

Calls for Palliative Care for the Poor

Poverty, among other social inequalities, is a major risk factor for suffering and premature death.¹ Many life-threatening infectious diseases, including acquired immunodeficiency syndrome (AIDS), primarily afflict the poor, most of whom also lack access to treatment.² Poverty is also a risk factor for certain cancers, particularly those causally linked to infections, such as hepatitis B and C, human papilloma

virus (HPV), human immunodeficiency virus (HIV), and *Helicobacter pylori* gastritis, and the percentage of the world's cancer cases and deaths that occur in developing countries is rising.³ Pain, dyspnea, and other forms of distress, both physical and psychosocial, are very common among advanced AIDS and cancer patients, and the psychosocial consequences of debilitating or stigmatized illnesses are especially severe among the poor.^{4,5}

Growing awareness of the massive scale of unnecessary suffering and death from AIDS in developing countries has generated efforts to rapidly scale up antiretroviral (ARV) therapy, and recently, interest also has grown in scaling up palliative care. According to its definition by the World Health Organization

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Accepted for publication: December 5, 2007.

(WHO), palliative care's goal is "the prevention and relief of suffering."^{6,7} Nothing is more fundamental, not only to palliative care but to medicine in general, than relieving the suffering of the sick.⁸ It is medicine's moral imperative. Palliative care pursues its goal through relief of pain and other distressing symptoms in AIDS and cancer patients and psychosocial support for patients and their families. The importance of these tasks has prompted assertions that palliative care is a fundamental human right.^{9,10} Yet, palliative care, like HIV/AIDS and cancer treatment, is unavailable to most in the developing world.¹¹

In light of the prevalence of suffering caused by HIV/AIDS and cancer and the difficulty and complexity of making treatment available to all who need it, palliative care has been proposed as a more achievable and affordable alternative to disease-modifying treatment for HIV/AIDS and cancer in poor settings.¹²⁻¹⁶ "Insufficient access to care for both cancer and AIDS patients makes palliative care the only humane and feasible response in many contexts."¹² By calling attention to the injustice of massive and unnecessary poverty-related suffering and death, and by calling for an effective response, proponents of palliative care promote social justice. However, should the response in any context ever be just palliative?

Some Assumptions in Palliative Care

The justifiability of any approach to relieving the suffering of the sick depends on the social and economic context, on what patients in a given context need. In rich countries, palliative medicine has grown rapidly over the last 50 years based, in part, on the assumption that everyone has access to up-to-date preventative and disease-modifying interventions for HIV/AIDS, cancer, and other life-threatening illnesses. In these countries, palliative care has arisen in response not only to suffering directly attributable to disease but also to suffering inadvertently ignored or exacerbated as medicine has focused increasingly on diseases rather than patients, and on sustaining life indefinitely.⁸ Trainees in palliative medicine learn to weigh carefully the potential benefits and burdens of disease-modifying and life-

sustaining treatments for patients with advanced life-threatening illnesses, as these treatments often may be harmful or "futile."¹⁷ In general, palliative care's mission in rich countries has not included fighting for access to preventive or disease-modifying interventions for HIV/AIDS or cancer. On the contrary, it has developed as a corrective measure for resource-rich medicine gone somewhat awry.¹⁸

International development and health officials also frequently have made an assumption about disease-modifying interventions. They have assumed that measures such as ARV therapy would not be cost-effective or feasible in poor settings.¹⁹ Although ARV therapy and other interventions that once seemed prohibitively expensive or complex have now been successfully scaled up in poor settings,²⁰ a double standard persists in thinking about appropriate medical care for rich and poor. It often is assumed that inexpensive and low-tech interventions are the only ones feasible for the poor. Both assumptions appear to be influencing the thinking of opinion leaders in palliative care justifiably attuned to the limits and potential detriments of resource-rich medicine.

"They Want Us to Get Comfortable with Dying:" Perceptions of the Poor

How might promotion of relatively inexpensive palliative care as an alternative to more expensive disease-modifying therapies, such as ARV therapy, be perceived in poor settings? In the United States, a presentation promoting palliative care for African Americans prompted a well-known community leader, Dick Gregory, to ask whether the point was for African Americans "to get comfortable with dying."²¹ The context of this suspiciousness about palliative care is the history of African Americans' "vulnerability to an untimely death" owing to violence, denial of health care, second-class care, and abuse in medical research projects, such as the Tuskegee Syphilis Study.²² Today, minorities and the poor continue to be denied equal access to medical services despite their greater overall morbidity and mortality.^{23,24}

Inhabitants of postcolonial Africa, Latin America, and Asia also have remained highly

vulnerable to untimely death, not just in spite of relief projects, but often because of them. Structural adjustment and development projects emanating from wealthy nations frequently have exacerbated social instability and poverty, resulting in increased morbidity and mortality.²⁵ The poor also have suffered from ethically questionable medical research and from physician-assisted police activities.^{26–28} Further, brand-name pharmaceutical companies have consistently ignored opportunities to make available much needed treatments for virulent infectious diseases that afflict the poor,²⁹ and despite its large aid projects, the U.S. government has repeatedly prioritized corporate profit over the health and lives of the poor.^{29–31} The result, in the words of one commentator, is a “global Tuskegee experiment” in which the poor are denied access to effective life-saving treatment readily available to the rich.³²

The mistrust generated around the world by health care and relief projects failing to reduce—or exacerbating—the suffering of the poor and their vulnerability to untimely death has stymied research and halted immunization campaigns and other public health projects designed to benefit the poor.^{33–37} This has led to more unnecessary suffering. Available evidence suggests that palliative care initiatives may meet with similar suspicion.^{1,38–42}

The lack of palliative care for the poor is unacceptable, but as Dick Gregory’s comment suggests, even the most well-intentioned efforts by Western and international organizations to pilot and scale up palliative care for AIDS and cancer sufferers in poor countries risk serious misunderstanding. They risk being perceived as “false charity,”⁴³ as helping poor people to die with less pain because that is more cost-effective and feasible than helping them to live.⁴⁴ For the sake of those in need of palliative care, it is crucial that advocates of palliative care appreciate this risk and take special care to avoid misunderstanding.

Responsible Palliative Care for the Poor

Efforts to scale up palliative care for AIDS and cancer patients in poor countries would be unjust if not linked to or accompanied by efforts to simultaneously pilot and scale up

comprehensive HIV/AIDS care, including ARV therapy, or cancer control programs. Following its WHO definition, palliative care is fundamentally not a science, profession, or academic discipline, but a response to the call of suffering. As a response, the structure and function of palliative care should be dictated by the call. Palliative care in poor countries must differ from that in rich countries primarily because the poor suffer greater morbidity and mortality than the rich and yet have access to less health care goods and services to remediate this disadvantage. The suffering of the poor with AIDS or cancer in Africa, Latin America, or Asia demands not the same response as that provided the rich, but greater ones that address each local cause and type of suffering. Where HIV/AIDS, tuberculosis, or potentially preventable or curable cancers afflict the rural poor, and where ARV therapy, tuberculosis treatment, and prevention, early detection and treatment of these cancers are not available, methods to redress these deficiencies must be found, as they have been in other poor rural settings.⁴⁵ Efforts also are necessary to identify the specific causes of suffering in a given setting. Qualitative research and “situation analyses” have demonstrated that people with the same disease who live in different social, economic, cultural, and geographic settings may suffer in very different ways.^{7,46,47} Situation analyses also can reveal the most important local barriers to HIV/AIDS care, cancer care, or palliative care.^{48,49} For these reasons, situation analyses should guide the response.

In any setting, the suffering of the poor demands a comprehensive clinical response based on the situation analysis, which integrates, as needed, disease prevention and diagnosis, curative and disease-modifying treatments, and palliative care, including pain and symptom control as well as psychological and social supports.⁵⁰ The “false dichotomy” between disease-modifying treatments for HIV/AIDS or cancer and palliative care must be overcome. Even patients near death from AIDS may recover and lead functional lives with ARV therapy. Further, uncomfortable symptoms in AIDS patients are sometimes best treated with ARV therapy or aggressive treatment of opportunistic infections, whereas pain and symptom control and psychosocial support may improve adherence to ARV therapy and quality of life.^{51,52} Palliative care’s

relative inattention to disease prevention and cautious attitude toward disease-modifying treatments, however justified in resource-rich settings, is not justified in resource-limited areas where such interventions could relieve needless suffering and prevent needless death among the poor. These interventions include not only treatment of opportunistic infections and ARV therapy for people with AIDS, but also directly observed therapy, short-course (DOTS) for tuberculosis, second-line therapy for multi-drug resistant tuberculosis, and vaccination for childhood illnesses. They also may include treatment of *Helicobacter pylori* gastritis and vaccination for hepatitis B and HPV. Palliative care is not more or less essential than any of these interventions. This view is reflected in the WHO guidelines for national cancer control programs, pioneered by Stjernswärd, which consist of four pillars: prevention, early detection, curative treatment, and palliative care.⁵³ Palliative care for the poor must recognize not only the limits of resource-rich medicine but also its own. It must recognize its dependence on seemingly unaffordable interventions and its indistinctness from state-of-the-art medicine if it is to effectively respond to the suffering of the poor. Although palliative care endeavors to correct the delicts of medicine in rich countries, in poor countries, its own current ambitions may require some correction.

The WHO has identified a public health strategy for effective national palliative care programs that consists of four parts:

1. National palliative care policies and guidelines that incorporate palliative care into the public health system;
2. Laws and regulations that make readily and responsibly available opioid analgesics and other essential palliative care drugs;
3. Education in palliative care for health care providers, government officials, patients, and caregivers;
4. Implementation of clinical palliative care programs.⁵⁴

Ministries of Health should integrate these measures into—and thereby strengthen—national programs in HIV/AIDS and cancer treatment, geriatrics, and primary care.^{13,55} Large funders of comprehensive HIV/AIDS treatment in poor settings, such as the United States President's Emergency Plan for AIDS

Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis and Malaria, should encourage recipient governments to develop palliative care following this general strategy or earmark funds to support it. International donors who assist poor countries to acquire, store safely, and responsibly dispense ARVs and other medications to treat HIV-related disease should include opioid analgesics and other essential palliative medications in their support packages.⁵⁶

Evidence suggests that community- and home-based care models are most conducive to effective treatment of HIV/AIDS and tuberculosis in poor settings, as they are to palliative care.^{45,57,58} The same community- and home-based care program that addresses any one of these issues can be adapted to address the others as well as additional local health needs, such as prevention and primary care of cardiovascular and diarrheal disease and perinatal complications, harm reduction, nutrition, and social supports.⁴⁷ Programs with a limited purview, such as hospices focused on pain and symptom control and psychosocial support, may require additional resources and expertise or new alliances in order to take on added responsibilities, such as ARV therapy or tuberculosis treatment. Yet, where the latter are not readily available, the necessary resources or alliances should be sought. The Mai Hoa Center in Ho Chi Minh City, Vietnam, provides an example. The center opened in 2001 as a hospice for homeless AIDS patients. Initially, no ARV medications, tuberculosis treatment, or strong opioids were available and the staff was not trained in their use. Yet, pain, dyspnea, and symptoms of tuberculosis were very common, and all patients died. Patients with severe terminal distress were placed in a "screaming room," where the staff could be with them yet out of earshot of the other patients. Staff burnout and attrition were constant problems. In response to the obvious need, the Center used its scant resources to obtain small supplies of standard tuberculosis medications and generic ARVs, enough to treat just a few patients, and found volunteer physicians willing to train the staff in their use and supervise treatment. Encouraged by the recovery of these patients, the Center sought and established alliances with the regional tuberculosis center to supply tuberculosis treatment,

a nongovernmental organization funded by PEPFAR to supply ARV medications, and the local district hospital to supply morphine when needed. Despite accepting only the sickest and most abjectly poor patients, deaths are now rare at the Center, pain is well controlled, many patients have recovered and returned to the community, and staff morale is now good (Fig. 1).

Conversely, HIV/AIDS and cancer treatment programs should seek ways to integrate palliative care. The WHO's series of manuals on Integrated Management of Adolescent and Adult Illness provide guidance for combining primary, preventive, and palliative care with disease-modifying treatment for HIV/AIDS at district and community levels in poor settings.^{59,60} National and local governments should endeavor to provide these services as a package. Several innovative programs that have begun integrating community-based palliative and disease-modifying therapy for poor patients with HIV/AIDS or cancer are described in the literature.^{45,61–66}

Finally, research is needed to guide optimal integration of disease-modifying treatments and palliative care and to assess the benefits. Scientifically rigorous situation analysis of causes of suffering and barriers to care in a given location would not only make possible the best,

most informed response, but would permit follow-up studies to measure the success of the response in reducing suffering. A “toolkit” of standardized surveys, adaptable to local cultural, economic, and clinical situations and translatable into any language, could be developed for this purpose. Within countries, optimum care could be promoted by studies to elucidate differences between social and cultural groups not only in causes of suffering but also in values and beliefs concerning medical decision making, directly observed therapy, preferred location of care, death and dying, opioid analgesics, and similar issues.^{1,67,68} As palliative care services are introduced, studies could assess differences in outcomes between patients who receive HIV/AIDS or cancer care integrated with palliative care and those who do not. For example, more study is needed to elucidate whether and to what degree palliative care, including pain and symptom relief and psychosocial supports, can improve adherence to ARV and cancer therapy and even reduce mortality.⁵²

Conclusions

Palliative care is a human right for people with AIDS or cancer, and providing it to all



Fig. 1. Integrated palliative care and disease-modifying therapy for AIDS and tuberculosis. (a) This cachectic homeless man was sent to an AIDS palliative care center in Ho Chi Minh City for terminal care. He had been diagnosed with advanced AIDS and hepatitis C cirrhosis that was presumed to be the cause of his painful tense ascites. He had symptoms suggestive of tuberculosis, but his sputum revealed no acid-fast bacilli, and thus, he had not been treated. No studies had been performed on his ascitic fluid. At the palliative care center, his painful ascites were relieved with oral morphine and large volume paracentesis. Standard treatment for tuberculosis was initiated. Within two months, the patient's ascites and fevers resolved and antiretroviral therapy was initiated. (b) Within several months, he had regained his previous weight and strength and had begun working at the center. He has since then reconciled with his family (permission to print photos granted by patient).

who need it is a medical and moral imperative. However, as understood in its fundamental sense as a response to suffering, palliative care has a special responsibility to those who suffer the greatest morbidity and mortality: the poor. Because of great disparities in access to effective interventions for HIV/AIDS and cancer, it is imperative that efforts to pilot and scale up palliative care for the poor be accompanied by or integrated with efforts to pilot and scale up comprehensive HIV/AIDS and cancer care, including HIV and cancer prevention and ARV therapy for the same populations. Although a corrective for resource-rich medicine neglectful of pain and suffering, palliative care must also embrace state-of-the-art preventive and disease-modifying interventions where they can prevent large-scale, unnecessary suffering and death and yet are not available. In this way, palliative care can best avoid the unfortunate result of some charity and development projects: perpetuation of suffering even as they attempt to alleviate it. It will uphold medicine's fundamental responsibility, codified in the Hippocratic Oath, to keep the sick from harm and injustice. Indeed, it can become a standard bearer of social justice. Palliative care must and can respond to the suffering of the poor, but it must always respond responsibly.

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