

Commentary

Palliative Care and Social Justice

Peter A. Selwyn, MD, MPH

A fundamental contradiction within our health care system is that medical services are defined by vertically distinct, even diagnosis-specific specialties, whereas patients do not generally experience their illnesses or symptoms in terms of such silo-like distinctions. The structure of this system is remarkably rigid, durable, and reinforced in our systems of education, resource allocation, financing, and insurance. This rigidity of structure, which often translates into a rigidity of thinking, can have adverse consequences both on a patient and system level. It is critical for palliative care clinicians, educators, and policy makers to examine the ways in which our discipline has both arisen within this larger system of rigid subspecialization, and may run the risk of contributing to further fragmentation and undesirable outcomes, unless some of these underlying contradictions are challenged and overcome.

The article by Krakauer¹ in this issue makes an important statement, which is both simple and profound—it is unethical, unjust, and unacceptable to promote or condone a global system, which in effect offers disease-modifying therapy to the rich and palliative care to the poor. This potential division has been

particularly stark with respect to HIV/AIDS in the developing world, where sometimes efforts to implement palliative care and antiretroviral therapy programs have developed in parallel or even at odds with each other, when clearly from the perspective of the patient and the clinical trajectory of the illness, these distinctions are meaningless and counterproductive. As Krakauer rightly points out, not only is it the right thing to do on a societal and ethical level to provide disease-modifying therapy and palliative care for patients with AIDS, it is also the right thing to do on an individual patient level, because for diseases such as AIDS and tuberculosis, the best and most effective palliative interventions may well be antiretroviral or anti-tuberculous therapy. Moreover, AIDS clinicians would do well to address patients' needs for pain and symptom management, which are both typically underdiagnosed and may also contribute to poorer adherence and engagement with HIV-specific therapy. It is never "either/or," and we do our patients a disservice by continuing—whether consciously or not—to reproduce these artificial and dysfunctional distinctions.

For a brief period in the early years of the AIDS epidemic in the developed world, AIDS care and palliative care clinicians worked closely together, or were even the same people, in many settings where the only care for AIDS was palliative and end-of-life care. Thankfully, with the advent of highly active antiretroviral therapy (HAART) and the expansion of other therapeutic options in the past two decades, the field of HIV has developed its own expertise, just as palliative care has further established itself as a clinical and academic discipline. However, as the disease has evolved, we have seen the emergence of a false dichotomy between curative and palliative care, which does not serve the patient well and does not fit the evolving nature of the disease, which continues to have both disease-specific and palliative implications.² It is unfortunate that there is still such little overlap between the worlds of palliative medicine and HIV medicine: a side-by-side review of the abstract books from the major international meetings in each discipline (e.g., the International Conference on AIDS,

Peter A. Selwyn, MD, MPH, is Professor and Chairman, Department of Family and Social Medicine, Montefiore Medical Center, Albert Einstein College of Medicine, Bronx, New York, USA.

Address correspondence to: Peter A. Selwyn, MD, MPH, Department of Family and Social Medicine, Montefiore Medical Center, Albert Einstein College of Medicine, 3544 Jerome Avenue, Bronx, NY 10467, USA. E-mail: selwyn@accom.yu.edu; or pselwyn@montefiore.org

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the International AIDS Society biannual meeting, and the annual scientific assembly of the American Academy of Hospice and Palliative Medicine) for the past five years reveals that well under 5% of published abstracts from the HIV/AIDS meetings have concerned palliative care topics, and vice versa (unpublished data). This is a gulf that must be acknowledged if we are to make meaningful progress towards treating all of the patients and families who are living with HIV/AIDS on a global basis.

At the same time as it is important for clinicians to communicate more effectively across disciplines, it is equally important to address the important cross-cutting policy and planning issues. It is just as unconscionable for there to be such limited access to opioids in the developing world³ as it is for there to be such limited access to antiretroviral therapy in the developing world,⁴ where the majority of HIV-infected persons now live. Neither of these health care disparities is any less egregious: for those advocating for antiretroviral rollout programs to be working in isolation from those advocating for increased opioid availability is at best inefficient and at worst counterproductive. The challenge for all of us is to learn how to overcome the deeply ingrained structures and thought patterns, which somehow make this separation seem normal and logical.

In addition to the ethical and clinical arguments, it should also be noted that even in the area of cost-effectiveness, making antiretroviral therapy available to the large populations of HIV-infected young adults in many heavily affected countries could have potentially important benefits on a social and economic level as well, given the impressive treatment effectiveness of HAART.⁵ Brazil has been cited as an example of a quasi-developing country where a decisive investment in universal access to antiretroviral therapy in 1996 has had a significant impact on morbidity, mortality, and the “social capital” of a whole cohort of young adults who otherwise would have been prematurely removed as productive members of society.⁶ This argument has been made for other areas in the developing world as well, and as the cost of generically manufactured antiretroviral regimens continues to decrease, these calculations will only become more compelling.⁷

Sometimes in palliative care we may have the “luxury” of not thinking about the possibility of affecting patients’ long-term prognosis, because

we often receive patients at the end of a long process with no further perceived therapeutic options. Yet, I am sure others have had the same experience I have had, of seeing a patient with “end-stage AIDS” referred to a hospice or palliative care program, who has miraculously returned to health with effective antiretroviral therapy, in what has been described as the “Lazarus Syndrome.”⁸ This is not always possible, but it is important to step outside of the distinctions, which may inappropriately confine patients within too-limited options, to do what is right for patients to meet their needs. In such a setting, it would be clinically and ethically unacceptable not to offer patients a trial of effective antiretroviral therapy if this had not yet been attempted or accepted. As long as we use this grounding principle—to strive to meet patients’ needs, whatever they may be, with whatever means we may have available—this will help us to overcome the false dichotomies and rigid distinctions that will otherwise try to insinuate themselves at every juncture or decision point in care. Once palliative care decides as a matter of principle not to offer antiretroviral or other disease-modifying therapy even if this might help relieve suffering, it stops being true to its core principles, and becomes just another self-justifying and self-perpetuating subspecialty. Rather than presenting a radically different orientation—to guide care according to the needs and goals of the patient, not according to the disease in the abstract or the logic of the subspecialty itself—it retreats to being simply another example of business as usual. As Krakauer implies, if palliative care is truly “just,” it must respond to suffering with whatever it takes to relieve it, within the limits of what is available, but without losing sight of and advocating actively for what is possible. To do any less than this will not serve our patients, but will only promote our own marginalization, and will reinforce the rigid and dysfunctional structures that once led to the motivation to create the innovative, patient-centered model of palliative care.

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Palliative Care in Resource-Poor Settings: Fallacies and Misapprehensions

Richard Harding, BSc, MSc,
DipSW, PhD

The modern palliative care movement pioneered end-of-life care for malignant disease patients in developed countries. Since then, the public health approach has advocated global expansion and integration from the

Richard Harding, BSc, MSc, DipSW, PhD, is a Senior Lecturer, Department of Palliative Care, Policy and Rehabilitation, King’s College London School of Medicine, London, United Kingdom.

Address correspondence to: Richard Harding, BSc, MSc, DipSW, PhD, Department of Palliative Care, Policy and Rehabilitation, King’s College London School of Medicine, Western Education Centre, Cutcombe Road, London SE5 9RV, United Kingdom. E-mail: richard.harding@kcl.ac.uk

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point of diagnosis for all life-limiting progressive conditions. Despite advances in coverage, inequalities persist irrespective of setting. Even in resource-rich countries, the poor and socially excluded are less likely to access palliative care, achieve optimum relief of pain and symptoms, or die in their preferred place.^{1–4}

In resource-poor settings, the implications of poverty for palliative care access are greater, where the burden of progressive disease (primarily HIV and cancer) is enormous and public health systems generally weaker. The resulting tension in allocation of finite resources to potentially curative or palliative care is explored by Krakauer in this issue. Krakauer should be congratulated for tackling this complex and important debate.

The unhelpful distinction between curative and palliative resources is even less useful in poorer countries. The burden of disease and background poverty fueling incidence mean that rather than thinking about whether curative *or* palliative care need greater resources, the basic epidemiological truth is that *both* need increased attention compared with resource-rich countries.

Krakauer considers the need for integrated care, embracing the curative and offering palliative care as appropriate—whether that is antiretroviral therapy or opioids at the end of life, as palliative care establishes itself as a required element of the care pathway. This argument is generally accepted however, it also raises a problem in advocating for, and implementing, integrated curative and palliative care alongside new treatments in resource-poor settings. This problem is the lack of research evidence to guide appropriate models of care in poor settings.

Despite a growth in the number of palliative care services in poorer countries, we still lack the evidence to support calls for integration of curative and palliative care.⁵ In order to effectively advocate to clinicians, policy makers, funders, and educators, we need to demonstrate the effectiveness of palliative care alongside treatments, and to offer models of care that are locally appropriate and have proven effectiveness in terms of both costs and outcomes. Unfortunately, this is where a fallacy arises—that the allocation of resources to palliative care research is inappropriate where resources are generally scarce.