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## Palliative Care in Resource-Poor Settings: Fallacies and Misapprehensions

Richard Harding, BSc, MSc,  
DipSW, PhD

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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

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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](mailto: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.<sup>1–4</sup>

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.<sup>5</sup> 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.

We have robust evidence demonstrating the effectiveness of cancer palliative care<sup>6,7</sup> and that patient and family outcomes are improved under HIV palliative care.<sup>8</sup> Unfortunately, the studies are almost exclusively undertaken in resource-rich countries and pre-antiretroviral therapy. It is hard to imagine how we can influence change in clinical practice, allocation of funds, or medical and nursing school curricula if we lack evidence as to why palliative care matters alongside curative approaches. The very nature of a resource-poor setting indicates that we compete for those scarce resources among all other generalist and specialist groupings in health and social care.

There are further moral imperatives to address the research needs of palliative care in poor settings. In resource-rich countries, we attempt to provide “evidence-based” care and to promote and replicate models of care that are acceptable, appropriate, and effective in their setting. Surely, people in poor countries deserve the right to have care that is also evaluated and effective? We cannot be satisfied that we provide care in poor settings—we must provide technical support and resources to enable that care to be evaluated and offer frameworks for quality improvement. The time and resources allocated to research now improve access and outcomes for all the patients and families that follow.

The second moral argument is for the wise allocation of scarce resources based on methods of audit and research that enable us to ensure that we make the best use of available funds. Clinical research, health services research, and needs assessments<sup>9</sup> are essential alongside the situational analysis that Krakauer suggests. This would ensure that evidence is robust and relevant. When we discuss “poor countries,” homogeneity and replicability should never be assumed. Local health systems, prevailing diseases, somatization of illness, beliefs, clinical practice,<sup>10</sup> and drug metabolism may be expected to vary according to setting. Dr. Anne Merriman, founder of Hospice Africa Uganda, has called for “each hospice in Africa to be a centre for teaching and research in response to the current dearth of evidence, cultural, spiritual, social and even metabolic differences need to be researched in order to give the best comfort to patients and families.”<sup>11</sup>

Some of the fundamental questions to be answered are the nature and intensity of palliative care needs early in the HIV disease trajectory, and the impact of palliation on risk and adherence (thereby demonstrating our worth to HIV medicine). Although Krakauer suggests that palliative care, as defined by the World Health Organization, is “not a science, profession, or academic discipline,” it is precisely the science of palliative care research, undertaken by local academics guiding the professional delivery of clinical care, which is urgently needed in poor countries to achieve Krakauer’s goal, i.e., palliative care that is adapted to setting, addressing sometimes complex and often refractory problems. Resources are needed to build local research and teaching capacity to achieve this.

Lastly, the palliative care movement has failed to work effectively with the influential global non-governmental organizations that promote the interests of people living with HIV/AIDS. We must convince the people that matter most, i.e., people living with HIV and other progressive illnesses (whose populations will remain progressive even with availability of therapeutic regimens). Demonstrating the improvements in quality of life and a good death alongside antiretroviral therapy must surely be our responsibility. Maybe then, patients, families and other advocates, alongside practitioners, may formulate strategies to break the fallacy of cure vs. palliation.

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## Just Palliative Care? Integrated Models of Care

Liz Gwyther, MB ChB, FCFP (SA),  
MSc Pall Med (Cardiff)

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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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Liz Gwyther, MB ChB, FCFP (SA), MSc Pall Med (Cardiff), is a Senior Lecturer at the University of Cape Town, and Chief Executive Officer of the Hospice Palliative Care Association South Africa, West Cape Town, South Africa.

*Address correspondence to:* Liz Gwyther, MBChB, School of Public Health and Family Medicine, Falmouth Building, Faculty of Health Sciences, University of Cape Town Observatory, 7925, West Cape Town, South Africa E-mail: [liz@hpca.co.za](mailto:liz@hpca.co.za)

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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.”<sup>1</sup> 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”<sup>2</sup> (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.”<sup>3</sup> The South African Hospice Palliative Care Association assists member hospices and home-based care organization to implement this “accompaniment” through the