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Definition of Terms

The following definitions were developed by the Workgroup on Palliative and End-of-Life Care in HIV/AIDS to assist readers of this report.

Caregiver

Any member of the patient's network of family or friends who provides emotional support and/or physical care for the patient. At times, a person might be employed to serve in this role.

Culture

A pattern of values, beliefs and behaviors shared by people with similar ethnic backgrounds, languages, religions, family values and/or life views, which provides them with their identities and a framework for understanding experience.

Disease Management

A comprehensive plan for managing the entire trajectory of HIV/AIDS that maximizes patient function and quality of life through disease-specific management, education and supportive care.

Disease-Specific Care

A preferred term in discussing HIV/AIDS treatment options, which are aimed at slowing or reversing the overall course of the underlying disease process. The essential goal of antiretroviral therapy is to suppress viral replication, with the hope of restoring more normal immune function.

Family

Connotes those who have a close connection to an individual, regardless of their genetic or legal ties.

Interdisciplinary Care Team

A team of caregivers from different professional disciplines and/or services who work together to deliver palliative care services focused on care planning, optimizing quality of life and support for the individual and/or family. This team is accountable for the assessment of physical, psychosocial, spiritual and bereavement needs of both the patient and the family, assuring that a palliative care plan is carried out across all care settings.

Palliative Medicine

The medical discipline focused on the relief of suffering and the promotion of quality of life.

Patient-Family Focused Care

Interdisciplinary care that targets the patient and family as the unit of care, recognizing the impact of illness on the family as well as the patient.

Spiritual Counseling

Supportive counseling for the patient's belief and value system; support of the essence of the person and facilitation of spiritual growth and closure near the end of life.

Types of Therapies

Antiretroviral (ARV) therapy is designed to suppress viral replication. Highly active antiretroviral therapy (HAART) refers to a combination of three or more of these drugs that typically target the virus at multiple points in its replication cycle, providing potent and durable suppression of viral replication that permits immune recovery. Therapy in advanced disease also requires prophylaxis for opportunistic diseases that take advantage of the patient's weakened immune system, such as *Pneumocystis Jiroveci* pneumonia or *Mycobacterium avium* complex. These latter therapies might be continued until the time of death in order to prevent the development of opportunistic infections that will further impair the patient's quality of life.



EXECUTIVE SUMMARY

HIV/AIDS is at best a chronic progressive illness that causes significant morbidity and is still incurable. For many, it remains rapidly fatal. But for other patients and their families, the advent of highly active antiretroviral therapy (HAART) brings quality of life issues and an end-of-life trajectory that differ significantly from what was seen in the early stage of the epidemic. The success of HAART for HIV/AIDS has led to a diminished emphasis on palliative care as an integral part of HIV/AIDS care. Yet at the same time, changes in the trajectory of the disease due to HAART and difficulties faced by patients unable to take HAART point to a need to address quality of life and incorporate palliative care into the standard of care for HIV – from the time of diagnosis to the end of life.

This report, written by the *Promoting Excellence in End-of-Life Care* Peer Workgroup on Palliative and End-of-Life Care in HIV/AIDS, an interdisciplinary group of clinicians and researchers, provides an assessment of unmet needs of HIV patients and their families with respect to comfort, quality of life and caregiver support, and calls for the re-integration of palliative care into the continuum of HIV care. The assessment is relevant to a growing number of adults, adolescents and children living with HIV/AIDS in the United States. The Workgroup used the definition of palliative care put forth in *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS 2003 Edition*, published by the U.S. Department of Health and Human Services' Health Resources and Services Administration HIV/AIDS Bureau:

Palliative care is patient- and family-centered care. It optimizes quality of life by active anticipation, prevention and treatment of suffering. It emphasizes use of an interdisciplinary team approach throughout the continuum of illness, placing critical importance on the building of respectful and trusting relationships. Palliative care addresses physical, intellectual, emotional, social and spiritual needs. It facilitates patient autonomy, access to information and choice.

The Workgroup on Palliative and End-of-Life Care in HIV/AIDS identified the following high priorities for improving clinical care and health service delivery in response to the most pressing needs of HIV patients and their families. The Workgroup calls on clinicians, educators, researchers, policy-makers and health care funders and payers to:

- Recognize the importance of *concurrent palliative care with disease-specific treatment* in the management of HIV/AIDS:
 - paying particular attention to difficult decision making; and
 - acknowledging the stress this care delivery places on the patient, family and staff alike.
- Integrate *methods of care that effectively serve a diverse population* of complex patients while receiving HAART therapy, including:
 - children, adolescents and people of varied ethnicities; as well as
 - patients who have psychiatric illness, comorbid conditions and/or challenging social and life circumstances.
- Incorporate adaptations of care delivery that *reflect and respond to the specific needs of people in their own communities*.
- Establish and promulgate *comprehensive palliative care guidelines* for HIV clinicians, to be integrated with the treatment guidelines put forth annually by the U.S. Department of Health and Human Services (DHHS). These guidelines will address symptom control, comfort and quality of life.
- Define and create *palliative care curricula* relevant to the particular needs of patients with HIV/AIDS.
- Identify through *research*:
 - methods of symptom management throughout the continuum of illness; and
 - sentinel events in the trajectory of dying for patients when HAART fails, or for whom other illnesses such as liver or renal failure supervene.

- Initiate *policies* that support the integration of palliative care into HIV disease management. These policies will:
 - include adequate funding for Ryan White CARE Act programs, as well as expanded medication coverage;
 - clearly recognize the importance and inclusion of interdisciplinary teams; and
 - clarify issues of guardianship and advance care planning.
- Provide *adequate funding and payment mechanisms* to support the integration of palliative care into existing systems of HIV disease-specific care.

The recommendations accompanying this report address these important priorities and are intended to serve as an agenda for change.

WORKGROUP OVERVIEW

In 1997, *Promoting Excellence in End-of-Life Care*, a national program of The Robert Wood Johnson Foundation, received 678 Letters of Intent in response to a Call for Proposals for fewer than 25 grants to develop innovative palliative care programs. In an effort to tap this interest and energy and prompt rapid change, "Peer Workgroups" were created, composed of interested clinicians and researchers who are working to extend palliative care to special populations of patients in challenging domains and specific niches of medicine.

Seven workgroups were created in areas with critical patient need that indicated readiness to address end-of-life issues: Amyotrophic Lateral Sclerosis (ALS); The Children's International Project of Palliative/Hospice Services (ChIPPS); Critical Care; End-Stage Renal Disease (ESRD); HIV/AIDS; Huntington's Disease; and Surgeon's Palliative Care. Each workgroup was asked to assess the existing

evidence base; to identify resources, gaps and products for the field; and to develop Recommendations to the Field.

The *Promoting Excellence* Workgroup on Palliative and End-of-Life Care in HIV/AIDS convened in August 2001, consisting of 21 members representing HIV clinicians, nurses, palliative care specialists, educators, social workers, spiritual care providers and government representatives. Chaired by Carla S. Alexander, M.D., of the University of Maryland School of Medicine in Baltimore and Anthony Back, M.D., of the University of Washington in Seattle, the group divided into four subcommittees who met over 18 months to address the Workgroup's charge: Clinical Care, Social Context and Dimensions, Education, and Research.

This report from the Workgroup discusses the importance of concurrent palliative care with disease-specific treatment in the management of HIV/AIDS in the era of highly active antiretroviral therapy. The report offers Recommendations to the Field to improve the comfort and quality of life of patients, families and caregivers affected by this disease – throughout the trajectory of illness and particularly in its advanced stages.

INTRODUCTION

History of the Epidemic

In its early history, the AIDS epidemic was a terrifying, mysterious plague that was rapidly fatal. Clinicians, nurses and others who dedicated themselves to the care of patients during these early years became palliative care specialists of necessity. While much hard work was done in supportive care, and the prevention, early detection and aggressive treatment of opportunistic complications staved off death temporarily, HIV/AIDS care largely meant offering symptom relief, comfort and emotional

support as the disease inexorably progressed. AIDS activists and care providers did as much in the 1980s as any other group to advance the cause of greater access to expert palliative care and to elevate end-of-life care onto the national policy agenda.

The mid-1990s saw the beginning of an unprecedented transformation in the treatment of HIV/AIDS – and with it, the attitudes of patients, affected communities and health professionals changed toward palliative care. The advent of HAART led to a steep drop in annual U.S. AIDS deaths, from a peak of 50,000 deaths in 1995 to fewer than 15,000 deaths just three years later – despite a virtually constant rate of new HIV infections. Nevertheless, HIV care providers, people at risk, social service organizations and the general public have come to think of HIV/AIDS as a manageable, chronic disease.

These trends also created a gap between the HIV clinicians and palliative care specialists who previously shared a mutual understanding and expertise. The dramatic transformation of the AIDS epidemic cannot be overstated and represents a triumph of activism and research. But ironically, among the casualties of this success have been the awareness of, zeal for and expertise in palliative care that characterized AIDS care during the 1980s and early 1990s. Then, hospices in large American cities were filled with young men dying from AIDS. Now the two fields have diverged.

Living and Dying in the Age of HAART

HIV clinicians who are coming of age in the HAART era may have little appetite for and no didactic training in palliative care, as well as little hands-on experience. Many feel that introducing end-of-life issues is “disloyal” to the compelling drive to continue antiretroviral therapy, even in patients with far-advanced disease receiving “salvage” therapy. Amidst a

strong current of therapeutic optimism, spurred by new scientific developments, attempts to focus on end-of-life issues may appear defeatist, negative, even traitorous to the quest for life. The growing cadre of palliative care specialists produced in the 1990s likewise have little experience with AIDS and feel ill-qualified to manage the increasingly complex treatment regimens that characterize current HIV care, even near the end of life. Narrowing this gap in the age of HAART has been difficult.

Informal caregivers, many of whom also belong to affected communities and are exhausted by the emotional demands of the unrelenting deterioration and death they faced during the epidemic's first 15 years, have been understandably relieved to "medicalize" the care of HIV. There is a sense of having "been there, done that" with respect to end-of-life care – and certainly no desire to go back. At the same time, communities at risk have been only too glad to accept the vision of HIV as a chronic disease, to stop going to funerals, to focus on the problems of living with HIV rather than of dying from AIDS. To many, people who are dying of AIDS today may serve as unpleasant and unwelcome reminders that the disease is still lethal.

People continue to die from HIV infection and its related complications. The HIV/AIDS epidemic in the U.S. can no longer be considered stable; rates of infection are climbing. There are approximately 40,000 new cases and 15,000 deaths per year in the United States, and there are worrisome trends toward increasing incidence among high-risk groups. Because people survive much longer after infection, the prevalence of HIV/AIDS has gone up dramatically. For some people with HIV, the advances in HAART came too late. Some individuals had acquired drug resistance as a result of early, suboptimal treatment and are unable to derive maximum benefit from HAART.

Others are unable to tolerate antiretroviral medications. Many more are unable to reap the benefits of these therapies, due to psychosocial factors such as poverty, limited access to care (either due to lack of insurance coverage or by living in a rural or underserved area), unmet basic needs such as adequate food or housing, and concomitant psychiatric illness and/or substance abuse. Still others may see their HIV "successfully" treated, only to succumb to end-stage liver or kidney disease, malignancy or treatment-related complications.

What is different now about palliative and end-of-life care in HIV/AIDS is not *how* people get sick and die, but *who* is getting sick and dying and *when* they are doing so. Despite the 20-plus year duration of the epidemic, people with HIV/AIDS are often marginalized and stigmatized, either because of the disease itself, or because of broad social attitudes toward the groups from which they are disproportionately drawn – women, people of color, gay and bisexual men, substance users, the mentally ill, the poor and the incarcerated. For these groups, barriers to care are still formidable, and the most marginalized and disenfranchised groups fare the worst. Unfortunately, the benefits of therapy and other advances in HIV/AIDS care have not been equally distributed among the poor and people of color. AIDS case fatality rates have fallen far less, for example, for African Americans than for whites. And although the Ryan White CARE Act provides a care delivery structure for the indigent and those individuals with poor insurance coverage, not all patients have access to a full continuum of coordinated care.

Populations infected with HIV/AIDS today represent all life cycles, including children and adolescents of infected parents and elderly individuals who often remain ignorant of their own infection. Entire families infected with and affected by HIV/AIDS are not uncommon. Adolescent survivors of perinatal HIV deserve



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specific mention. Many people, lay and professional, assume they have already died and therefore do not need care. In fact, many are living into adulthood with myriad challenges. Most are orphaned. Some experience severe disruption in their home and family lives, necessitating foster care placement. They are uniquely at risk for having no clear health care proxy to assist with important decisions regarding care, especially at the end of life. Many experience isolation because of absences from school or stigma from their appearance, i.e., short stature or delayed puberty. As family members die of AIDS, the adolescent experiences loss at the same time his or her own disease is progressing because of multi-drug resistant failure.

A Better Future Is Possible

The time has come to call for a shift in the current clinical paradigm of HIV care. It is clear that there are still important roles for *both* HIV

specialty care *and* palliative care expertise in the optimal management of HIV/AIDS. But the unique set of barriers to providing concurrent specialty and palliative care are also clear. While people are living longer with the new complicated therapies, the disease is more compelling and difficult to manage than it once was. Complicated therapies demand better symptom management, and most HIV specialty clinicians are not trained in the discipline of palliative medicine, including symptom management. Longer survivals bring comorbidities that further complicate care and make patient prognoses difficult to predict. The persistent stigma and social attitudes toward HIV disease and the death it represents often preclude good communication about goals of care. HIV/AIDS remains a progressive disease with restorative – not curative – outcomes, where goals of care must be adjusted regularly.

The shift in health care provider awareness and training away from palliative and end-of-

life care needs modification. There are no clearly defined comprehensive care guidelines that integrate palliative and end-of-life care with HAART. Palliative care is not a luxury; it is an integral component of providing the highest quality of care possible. Attention to symptom control, comfort and quality of life issues are in fact characteristics of the best standard of care possible, and attention to the palliative care issues raised in this report will ensure that patients receive the full benefit of antiretroviral therapy.

Recognizing the goals of comfort, quality of life and anticipatory guidance, palliative care is no longer restricted to hospice care. Newer delivery models of palliative care encompass disease-modifying treatments as well as supportive services that often span long periods of time. Innovative programs integrating palliative care into HIV care are demonstrating systems of care in which an interdisciplinary team can manage complex biomedical issues, cultural considerations and patient preferences to maximize quality of life in cost-effective ways.

A hopeful and improved future for HIV care is envisioned in the Recommendations to the Field accompanying this report. The Workgroup on Palliative and End-of-Life Care in HIV/AIDS identified gaps in health service delivery systems and in the base of clinician knowledge and skills, and created this set of recommendations for clinicians, educators, researchers, policy-makers, funders and health care payers, to advance further development and integration of palliative care throughout the trajectory of HIV disease. These recommendations address the specific challenges of the new clinical aspects of HIV disease, the intersection of these with the psychosocial aspects of HIV disease, and the need for new integrated delivery models based on interdisciplinary teams. They are applicable to HIV-infected people and HIV-affected families of all ages, including children and orphans.

CHALLENGES AND OPPORTUNITIES FOR CHANGE

Clinical Challenges and Opportunities

Reintroducing Palliative Care into HIV Care

Individuals with advanced HIV/AIDS are experiencing changed end-of-life needs. Both HIV specialty health care providers and palliative care professionals must address these needs so that patients may derive optimal benefit from medically and socially appropriate end-of-life care.

Complex Challenges and a Shift in the Causes of Death

As effective treatment for HIV has become available, the causes of death for HIV-infected people have shifted dramatically (although the Workgroup noted that very limited research has been conducted to document this). Complex medical comorbidities often complicate care. Some conditions, such as liver disease due to chronic hepatitis B or C infection, were less likely to cause death earlier in the epidemic, due to the much-shortened life spans of people with symptomatic HIV infection. These conditions now occur disproportionately in people with HIV/AIDS because they are transmitted via the same routes as HIV. End-stage renal disease is multi-factorial, a consequence not only of uncontrolled hypertension or diabetes, common comorbid conditions in certain subpopulations, but also of direct renal injury caused by HIV itself (HIV-associated nephropathy). Non-lethal problems that directly impinge on quality of life, such as xerostomia or peripheral neuropathy, may result from both direct effects of HIV itself and/or the adverse effects of antiretroviral therapy.



Palliative care is not a luxury; it is an integral component of providing the highest quality of care possible.

All of these conditions require palliative care expertise.

Many patients, for reasons conscious or unconscious, are never diagnosed as HIV positive or initiate antiretroviral therapy before presenting to hospital emergency departments with opportunistic infections or other evidence of advanced disease. This was the norm prior to the availability of effective therapies but is now viewed as a failure of prevention or early intervention. The ability to remain under care is also a pervasive problem. People detected earlier in the course of their illness and who are able to maintain regular health care follow-up may have “controlled” disease but may develop long-term toxic effects of therapy. Unfortunately, there are patients who are unable to comply with medical follow-up and antiretroviral therapy because of compromised mental health, social circumstances or mistrust of the health care system among all infected subpopulations, resulting in poorer quality of life and survival outcomes.

Continuity of care is often problematic for HIV-infected individuals with multiple diag-

noses. A patient with HIV who also has chronic viral hepatitis and ongoing substance abuse problems might be shuffled between an addiction program, a hepatology clinic and an HIV clinic with little coordination of care. This lack of continuity allows clinicians and patients to avoid adequate planning time for end-of-life issues, including necessary psycho-spiritual goals to be accomplished prior to death. Consequences include poor adherence to treatment plans, diminished quality of life, the possibility of shortened survival, a crisis management mode instead of attentive end-of-life planning, and unplanned use of expensive acute and intensive care resources.

Because manifestations of advanced HIV disease have changed with more effective therapy, it is increasingly difficult to predict prognosis. It is important to note that the final months of HIV/AIDS disease may be no more predictable than the episodic decline seen in people with congestive heart failure or ALS. Many AIDS patients may die of an acute episode of infection requiring hospital or even ICU admission. In most settings, deaths of

Who's Dying Of AIDS Now? Long-Term Survivor

Timothy was 65 years old and had advanced AIDS. He lost his long-term partner ten years ago to AIDS and said he "didn't have any friends left." Timothy became frail because of liver failure due to hepatitis C, and he was hospitalized due to drug reactions. He was then able to move in with his cousin, where he lived comfortably for three years until his cousin died from pancreatic cancer. With nowhere to live, and suffering from multiple-loss grief, Timothy was once again hospitalized, where staff had difficulty empathizing with him ("he's lived longer than most people"). Timothy was eventually transferred to a skilled nursing facility and died after an acute care hospitalization. *Palliative care could have provided grief counseling, life closure and advance care planning that could have prevented the hospitalization at the end of life.*

HIV/AIDS patients from end-stage liver or renal disease and from cancer presently outnumber deaths from AIDS-related opportunistic infections. Clinicians caring for these patients must be able to foresee and manage not only the classic complications of AIDS but also these other complications not traditionally viewed as consequences of immunosuppression.

Moreover, the long-term impact of HAART use is still unknown. This uncertainty causes emotional and spiritual distress and fosters avoidance of end-of-life discussions on the part of clinicians and patients. Patients and their families may be denied appropriate planning for life completion and closure. Patients often die without holding necessary and important conversations. There is a need for a bridge or a parallel track – palliative HIV care – to allow for better symptom management in early disease and patient preparation for end-of-life care for all HIV-infected individuals.

An Opportunity for Change: The Importance of Integrating Palliative Care into HIV Care

The *Promoting Excellence* Workgroup on Palliative and End-of-Life Care in HIV/AIDS recommends the reintroduction of palliative care as a standard component of HIV care, in the same way that HAART and prophylaxis against opportunistic infections are now established practice. HIV care is intense and complex, and the integration of palliative care and its characteristic interdisciplinary teams complements care with HAART. The Workgroup advocates the integration of palliative care in the patient's course from presentation to death, initiating palliative care discussions at the time of diagnosis and emphasizing the patient's quality of life. The recommendations for change contained in this report are based on the following definition of palliative care, set forth in *A Clinical Guide to Supportive and Palliative*

Care for HIV/AIDS 2003 Edition, published by the U.S. Department of Health and Human Services' Health Resources and Services Administration HIV/AIDS Bureau:

Palliative care is patient- and family-centered care. It optimizes quality of life by active anticipation, prevention and treatment of suffering. It emphasizes use of an interdisciplinary team approach throughout the continuum of illness, placing critical importance on the building of respectful and trusting relationships. Palliative care addresses physical, intellectual, emotional, social and spiritual needs. It facilitates patient autonomy, access to information and choice.

Several recent studies point to the importance of integrating palliative care into HIV disease-specific care. The recently published "Study of the Supply, Demand and Use of Palliative Care Physicians in the United States,"¹ conducted at the State University of New York at Albany and funded by the U.S. Health and Resource Services Administration (HRSA), cites six recommendations to assure that palliative care services are available to patients with HIV/AIDS. The recommendations emphasize that clinicians and allied health professionals working with HIV/AIDS patients must have demonstrated skills in palliative medicine and pain and symptom management, and need training in communication to facilitate timely discussions of treatment options and end-of-life concerns (see Appendix A for list of recommendations from the study).

The Workgroup on Palliative and End-of-Life Care in HIV/AIDS members identified the following important clinical issues in the treatment of HIV/AIDS:

- Anticipation and prevention of side effects related to HAART;
- Interdisciplinary team care where direction in care is taken from the patient-family unit;
- Pain management for patients with HIV and those with substance abuse;
- Management of the individual impact of complex medical regimens and serious psychiatric issues for persons living with HIV disease;
- Attention to spiritual concerns throughout the disease as well as near the end of life;
- Decision making about HAART for patients and caregivers with psychosocial issues that interfere with adherence;
- The need for clear guidelines for appointing a health care proxy decision-maker for patients unable to make decisions independently (including minors and adults with communication and cognitive barriers); and
- Development of clinical policies and programs that address the needs of patients of all ages from infancy through adolescence into adulthood.

Despite increasing acknowledgment of the importance of palliative care in clinical practice, the current DHHS and International AIDS Society-USA treatment guidelines for the management of HIV/AIDS care do not address palliative care. Instead, these guidelines separately address, in different documents, various aspects of HIV care, such as antiretroviral treatment and diagnosis and prevention and treatment of opportunistic infections. There are no U.S. Public Health Service guidelines that address an integrated, more holistic approach to the overall management of HIV disease. Addressing the total care needs of people with HIV disease, and integrating aspects of palliative and end-of-life care into current treatment guidelines will help health care providers remember to address these issues proactively – and will ensure the integration of palliative care into overall HIV care. In addition to establishing

Good HIV care is more than antiretroviral therapy ...

Marjorie is a 52-year-old Asian American woman with advanced AIDS. She cannot tolerate antiretroviral therapy. After four months of fevers, weight loss, severe chest pain and shortness of breath, during which she has been prescribed several courses of empiric antibiotics for presumed pneumonia, she is admitted to the local hospital's ICU with respiratory failure. Marjorie is intubated and ventilated. Diagnostic studies show large pleural effusions; fluid is obtained and reveals a primary lymphoma of the pleural space. A week later, with a large chest tube in place, Marjorie is successfully extubated, to the delight of the ICU team. But she continues to complain of severe and worsening chest pain. The oncologist visits and describes a difficult course of chemotherapy that has some chance of containing her lymphoma, if she can be on HAART at the same time. Marjorie balks, stating that she has tried HAART and cannot tolerate it and doubts she could manage the chemotherapy. The oncologist states, "Well, in that case, there's nothing we can do for you, medically." He writes her a prescription for acetaminophen with codeine and discharges her directly to home from the ICU. *Palliative care could have provided follow-up, continued communication about the feasibility of chemotherapy and a new HAART regimen, and symptom control.*

clinical standards and guidelines that integrate palliative care into the standard of disease-specific HIV care, health care systems must include palliative and end-of-life issues in continuous quality improvement programs.

An Interdisciplinary Team Approach to Care

The medical and social complexities of HIV disease dictate a team approach to care. An interdisciplinary team takes its direction from the quality of life being experienced by the patient and family as a unit of care, rather than following a strict medical model directed at containment of the disease alone. An interdisciplinary team attends simultaneously to the patient's psychological and spiritual needs as well as the medical needs throughout the illness, and even more so at the end of life. The team approach to care works successfully in diverse settings.

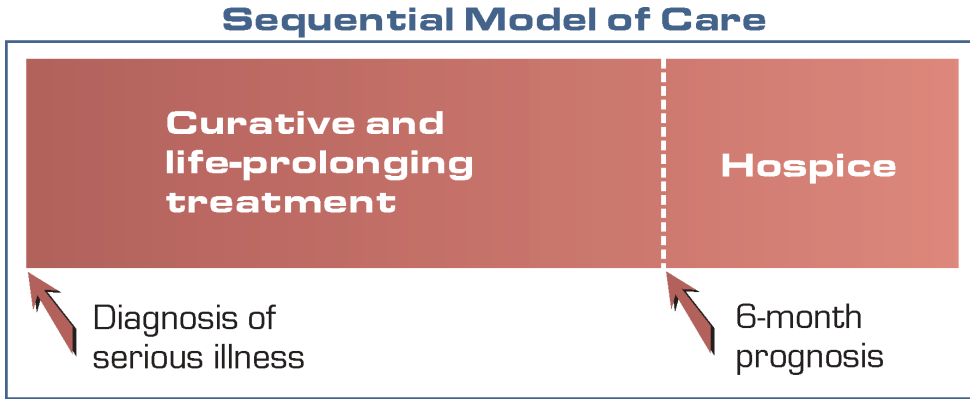
Clinicians frequently need to focus on Maslow's hierarchy of needs before attending to any part of HIV care. In striving to meet these basic human needs, a clinician working alone may feel emotionally drained and not able to provide appropriate care during the dying process. Without the support of an interdisciplinary team, clinicians and support staff often experience the fatigue and frustration called "burnout."

Concurrent Care

The traditional medical model has compartmentalized palliative care from curative or restorative care, introducing patients to its benefits in a sequential fashion only after life-prolonging treatment is deemed futile. The now outdated Medicare hospice benefit, which includes establishment of a prognosis of six months or less to live, reflects this traditional health care delivery model, by requiring that patients forego life-prolonging care in order to qualify for hospice support and palliative care. This "either-or" dilemma has been referred to

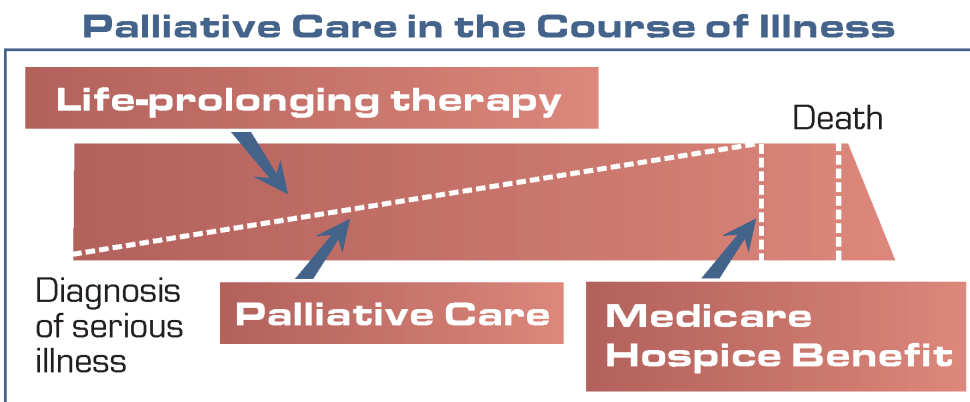
as the “terrible choice” and promotes a sequential model of care, forcing a division between care directed at prolonging life and care directed at comfort and quality of life.

TABLE 1:



A concurrent model of care, in contrast to the sequential model, is responsive to patients' and families' needs throughout the course of illness. The simultaneous care model, successfully utilized in cancer therapy as well as with some HIV/AIDS populations, illustrates the concept of integration and concurrent care. This model eliminates the “either-or” choice of pursuing curative or restorative care versus focusing on palliation.

TABLE 2:



Typical Service of Palliative Care

Typical Features of Palliative Care Programs

An interdisciplinary team approach to care;

Ongoing communication among patients, families and providers;

Advance care planning and patient-centered decision making;

Formal symptom assessment and treatment of physical and psychosocial symptoms related to antiretroviral therapy as well as to manifestations of the disease;

Care coordination (also known as case management) to streamline access to services and monitor quality of care;

Spiritual care;

Anticipatory guidance in coping with illness and issues of life completion and life closure;

Crisis prevention and early crisis management;

Bereavement support; and

24/7 availability of a clinician who is knowledgeable about the case.

The Psychosocial Dimensions of Care

A Disease of Social Consequences

HIV/AIDS remains a disease with severe social consequences and primarily affects those who are already socially disadvantaged and marginalized. The litany of social woes that accompany infection may include bereavement and loss of relationships, unemployment, disability, burdensome health care costs and demands, stigma and ostracism, and fear of premature death. With so many different cultures represented among the HIV-infected, patients may be susceptible to suffering in ways unfamiliar to the traditional health care field. Health care providers for these populations need to be equipped with basic sensitivity to and familiarity with relevant cultural differences, particularly concerning attitudes toward suffering and death.

Because of the social contexts of HIV transmission, people with HIV/AIDS are also at increased risk for heroin, cocaine or amphetamine dependence, alcoholism and other substance use disorders, as well as both affective and thought disorders. These psychiatric diagnoses always complicate care, often requiring the marshaling of social services and mental health professionals. Such patients may be challenging and frustrating to treat. The health care provider must be attuned to these difficulties and prepared to acknowledge, seek help with and manage his or her own responses to issues associated with patients' lifestyles and behaviors.

Management of chronic pain in people with histories of opioid abuse, for example, is always a clinical challenge, and pain is frequently under-treated for fear of encouraging or playing into addiction. A solid understanding of addiction medicine is therefore essential for the provider of AIDS palliative care, particularly as it affects the appropriate use of

Multi-Generational HIV Infection

psychoactive drugs and narcotics at the end of life. Management of symptoms may vary according to how long the person is expected to live and the existence of a home caregiver support network.

Families and HIV/AIDS

Palliative care in HIV/AIDS is greatly affected by the extent to which the individual is established in a family, career, lifestyle or culture. Social reconciliation may be difficult to accomplish for people who have rejected and been rejected by their families and other community support. As a consequence of all these factors, many people dying of AIDS still die alone, ashamed, alienated and unprepared.

Attention to needs and lives of families of HIV-infected individuals is an important component of palliative care but not an easy thing to do. Infected individuals may find primary support with their families of origin or they may preferentially rely on families of choice. Individuals who have left behind their families of origin and have not created families of choice will need different support systems. Infection of members from multiple generations plague many families affected by the HIV/AIDS epidemic; these families have support needs that continue over years and across generations. Effects of multiple losses (death from AIDS or violence, lack of job or income, lack of a sense of a future) often complicate the ability of health caregivers to provide the kind of support they would like to give and may make it difficult for infected adolescents to maintain hope for the future.

Caregiving and HIV/AIDS

Caregivers of people with HIV disease ride the same prognosis "roller coaster" as the person with the disease. Therefore, caregiver issues for both families of origin

Simi's family is not unusual in her neighborhood. She has been a patient of the local HIV clinic since she was born to her HIV-infected mother 17 years ago. She has two siblings, a sister who is 11 and also HIV-infected and a 16-year-old brother who is not infected. Simi has struggled with persistent opportunistic infections, hospitalizations and chronic symptoms related to her HIV disease and medication side effects. Simi's father died of AIDS ten years ago, and her mother, Diane, is currently dying of advanced AIDS and is under the care of hospice at home. Diane's common-law husband of eight years died of AIDS earlier this year. His death was particularly hard on the children because he seemed so much healthier than Diane, and he loved the children dearly. Diane's sister, struggling with caring for her own four children and crack addiction, provides Diane's care. Simi's physical condition is poor and increasingly challenging, due to the emotional stress of her mother's approaching death. Diane's mother, Simi's grandmother, who also has AIDS and Hepatitis C, acquired from her husband who died five years ago, is unable to care for her grandchildren due to her dialysis schedule and severe fatigue. Diane's brother and sister-in-law died of AIDS five years ago, leaving healthy twin 6-year-old girls – who are now in the care of the sister-in-law's mother. HIV/AIDS affects Simi's entire family in every aspect of their lives – socially, financially, emotionally, spiritually and psychologically. *For Simi, palliative care helps with access to primary medical care, case management that coordinates home care and hospice care, bereavement support, medications through the Ryan White and ADAP programs, mental health counseling, special home tutoring, legal services, and social service support such as rent assistance, transportation and temporary housing.*

Caregiver Stress

For many months John cared for his 42-year-old male partner of 20 years, Marvin, at home with hospice support. Marvin suffered from dementia, but all of his symptoms were well controlled by palliative interventions, including psychiatric management. When Marvin was transferred to a hospice facility shortly before his death, John was left at home exhausted and suicidal, experiencing feelings of loneliness, isolation and failure, having lost the work and responsibilities that added meaning and purpose to his daily life. *Palliative care could have provided support for John while Marvin was home, anticipatory guidance about planning for inpatient hospice and follow-up bereavement counseling.*

and families of choice must be addressed in management of those dying of HIV disease. Information from the broader network of caregiver support needs to be adapted for those who care for people who are stigmatized and ostracized. Infusing palliative care into mainstream practice, including the preservation of hope and respect for the needs of family caregivers, is central to the concept that a patient and family should be the ones to determine care needs. The overriding principle and goal must be to form a partnership with caregivers based on mutual trust and respect. Because HIV is a communicable disease, it is not unusual that a person's caregiver may also be HIV-infected. This adds even greater complexity to their support needs as they face their own impending death and palliative care needs, wondering "who will care for them" as they live to survive their loved one.

For those people nearing the end of their disease, the resource of an interdisciplinary team of professional care providers is invaluable to assist the family in the care of their loved one. Often families of people with HIV/AIDS feel isolated, ashamed and fearful on many levels. They may not be perceived as traditional family members and may not feel empowered to advocate and intervene on behalf of the ill person as a biological family member might do, or they may feel isolated from their religious community and neighbors because of stigma. An interdisciplinary hospice or palliative care team can be helpful to the family in sorting out issues of isolation, shame and fear often felt by patients and families and can offer supportive counseling as well as hands-on caregiving.

Hospice and HIV-Specific Care

Hospice is a subset of palliative care – palliative care is the discipline, and hospice is a way of delivering palliative care to patients, who are acknowledged to be dying, and their families. Although the delivery of palliative

care is not restricted to hospice, hospice care remains a valuable resource at the end of life; many consider it the “gold standard” for palliative care. Hospice is the model interdisciplinary team, extending the physician’s reach, and changing the venue of care delivery from clinic to home. It is important for professional caregivers for those with HIV disease to form educational linkages with hospices and others who specialize in palliative care.

Innovations are necessary to make hospice services more widely available to HIV/AIDS patients and their families. This may require the elimination of some barriers that currently exist. Clinicians dramatically underutilize hospice care and refer patients inappropriately late, often with only 24 to 72 hours to live.² Hospice is seen as an all-or-none package, with the belief that all disease-modifying treatment must be set aside for a patient to access hospice (the “terrible choice”). Usually eligibility and reimbursement mechanisms limit hospice to patients who are expected to have six months or less to live. Traditional hospice principles and practices may be irrelevant or inappropriately applied for people of different circumstance, including HIV-infected people and their families. And home-based hospice care – predicted on the availability of a stable, safe, clean home environment and the presence of family caregivers – is not available for everyone.

Patients and families often put up their own barriers to hospice care, equating hospice with imminent death. Uninformed HIV patients with other serious personal problems may have little accurate knowledge about their disease, its treatments and palliative care, and their rights to access appropriate care. Those who view themselves as victims of discriminatory social structures might meet the shift from disease modifying to palliative efforts with hostility.

Use of hospice is increasing nationally with more than 885,000 people receiving these

Gaps in Hospice Care

Phillip is a 48-year-old African American man with a long history of heroin abuse, diagnosed with AIDS and Hepatitis C during a hospitalization in 1999 for *Pneumocystis Jiroveci* pneumonia. He lives alone with no family or dependents but has a rich social and spiritual life through his church. He subsists on monthly disability payments. He has been free of heroin use for the past four years on a daily dose of maintenance methadone. Phillip has had multiple prolonged bouts of disabling constitutional symptoms from *Mycobacterium avium* complex (MAC) infection, including fevers and drenching sweats, abdominal pain, diarrhea, profound fatigue and weight loss. These symptoms abate only when he takes a simple but effective HAART regimen, in addition to two or three medications specific to MAC. Despite this treatment, his CD4 count is very low, and he suffers frequent opportunistic infections. Now, severely wasted and in constant pain from peripheral neuropathy, Phillip comes to terms with dying and asks his physician about hospice care. He is informed that no local hospice will accept him on HAART and that to be eligible he will need to stop the drugs that control his symptoms. Also, he has nowhere to receive hospice care – the hospices require that he have someone at home to care for him. Alternately, he could enter a skilled nursing facility, but his Medicaid insurance covers only a small number of notoriously unsavory nursing homes in the area – and none will accept a patient on methadone maintenance. *Patients like Phillip should not have to choose between HAART and hospice and should have access to skilled nursing facilities.*

Hospice Barriers

Two-year-old Carrie has progressive AIDS and is cared for by her mother, Shawna, who is responsible despite her continuing substance use. She has a new baby, however, and lives in a “dangerous” neighborhood where many residents distrust the health care system and health care organizations. A pediatric HIV interdisciplinary team has been intensively involved with Carrie, however, since her initial diagnosis at birth. The team recommends the involvement of hospice, but Shawna’s fear of death and reluctance to involve new people in Carrie’s life cause her to balk and reject the suggestion. Shawna wants to continue working with the HIV care team, and delays hospice involvement, unconsciously depriving Carrie of the optimal comfort she needs in her final days. Ultimately hospice is called when Shawna realizes Carrie’s pain and discomfort, and Carrie receives the monitoring and comfort she needs – but only in her last week of life. *There are now innovative palliative care services that provide a bridge between HIV/AIDS care and hospice, but these programs are not yet widely available.*

services in 2002. However, the average length of stay has declined from 64 days in 1992 to 51 days in 2002.³ The national median length of stay for hospice is 26 days, and in 2001, 37 percent of those served by hospice died within seven days or less of initial referral. But many innovative demonstration projects across the nation are revealing that palliative care modeled on hospice care can be provided concurrently with disease-modifying care. This integrated approach is not only well accepted by patients and their families, but may even conserve health care dollars.⁴ More demonstration projects illustrating collaborative provisions of existing services in delivering palliative care to people with HIV disease, concurrent with disease-modifying treatment, are needed to validate the best mechanisms for providing palliative care from the point of diagnosis to death.

Acknowledging Spiritual Dimensions

The spiritual dimension of a person’s life encompasses the beliefs, values and practices that give his or her life meaning and a sense of wholeness. These values have a profound effect on the way someone views the end of life and on decisions made about care. The patient’s attitude toward dying and the decisions made may be at odds with the health care provider’s belief system, which can result in feelings of conflict. Although a provider’s own spiritual beliefs can be a source of strength personally and can enhance the patient-provider relationship, providers must be careful not to impose them on the patient. In palliative care, it is important that providers consider spirituality an integral part of physical, emotional and mental health and learn how to assess and address spiritual beliefs. A provider’s comfort with the patient’s spirituality may play a significant role in the clinician-patient relationship. See Appendix B for



Caregivers of people with HIV disease ride the same prognosis “roller coaster” as the person with the disease.

description of “FICA,” a tool to help health care professionals in taking a spiritual history.

Chapters on spiritual, psychiatric and cross-cultural issues are included in *A Clinical Guide to Supportive & Palliative Care for People with HIV/AIDS 2003 Edition*, published by the U.S. Health and Resource Services Administration.

Clinical Education Challenges and Opportunities

The Challenge: A Call for Palliative Care Training

With the advent of antiretroviral therapy, many young clinical providers have not experienced the scourge of AIDS deaths, as did health care providers in the early years of the epidemic. These providers often shun the term “palliative care” because it is equated with death and doesn’t seem germane to their practice. The once overlapping and the now separate worlds of HIV disease-specific care and palliative care must become parallel once again, and palliative care must be reintroduced in HIV provider training. Similarly, palliative care providers must be educated in the need for

integration in HIV care. The real challenge at this time is to re-integrate the two types of care to improve the support offered people living with HIV disease and to make advance care planning a part of disease management.

Unfortunately, due to time, logistics and cost constraints, national palliative care training is not yet readily accessible to most clinicians. While curricula are being developed, it will be of great importance that those with the knowledge of HIV management are included as members of the team to adapt palliative techniques to the specifics of HIV disease.

The Opportunity: Emerging Models in HIV Education

Although excellent and successful, most palliative care educational opportunities are designed as general-purpose palliative care curricula; they do not highlight the emerging palliative care issues relevant to antiretroviral therapy and other aspects of HIV/AIDS clinical care. However, some national programs are emerging that can be adapted for palliative care specific to HIV/AIDS: the EPEC (Education on Palliative and End-of-Life Care) program based at Northwestern University;

EPERC (End of Life/Palliative Education Resource Center), an online community of educational scholars sponsored by The Robert Wood Johnson Foundation and the University of Wisconsin; the American Association of Colleges of Nursing ELNEC (End-of-Life Nursing Education Consortium) Project; Veterans Administration (VA) training resources; the Harvard Program in Palliative Care Practice; and the West Coast Center for Palliative Education and Research (WCCPER) at the University of California Davis. These programs can be held up as models for expanding other training programs.

A palliative care core curriculum includes topics such as pain and symptom management, ethical and legal issues, communication, cultural considerations, quality care at the end of life, and grief, loss and bereavement. The Workgroup on Palliative and End-of-Life Care in HIV/AIDS notes the importance of innovative educational programs in palliative care that teach attitudes as well as content, such as the Harvard program, that combines content-based learning with reflective sessions that enable clinicians to explore their own values. Most successful training programs include written and didactic material, interactive discussions, and practical exercises such as role modeling and role-playing with people living with HIV/AIDS and cultural exposure to various ethnic and socioeconomic groups. Clinicians in the University of Washington (UW) Center for Palliative Care Education at the Northwest AIDS Education and Training Center (NW AETC) program hold communications retreats, using practice sessions with actors to provide clinicians mentored feedback by faculty specially trained in communication skills.

The University of Washington NW AETC Center for Palliative Care Education program focuses specifically on palliative care for HIV/AIDS patients. It is the result of collaboration

between the Health Resources Services Administration (HRSA) and The Robert Wood Johnson Foundation (through the *Promoting Excellence in End-of-Life* program), and was formed to serve as a national resource on HIV/AIDS palliative care. As such, the NW AETC Center for Palliative Care Education was contracted to develop curricula for the national AETCs; this curriculum is divided into modules addressing the following topics:

- Overview of HIV/AIDS palliative care;
- Advance care planning;
- Communicating with patients and families:
 - Communicating with patient and families about end-of-life care, and
 - Giving bad news;
- Cross-cultural issues in HIV/AIDS palliative care;
- Pain and symptom management:
 - Assessing and managing pain in HIV/AIDS,
 - Palliative management of dyspnea in HIV/AIDS, and
 - Complementary medicine and HIV/AIDS palliative care;
- Psychosocial and psychiatric issues:
 - Helping patients have a good death, and
 - Psychiatric issues in HIV/AIDS palliative care.

More educational programs such as this one that address the contemporary realities of HIV disease are needed. A needs assessment survey of HIV/AIDS clinicians and educators throughout the northwest, conducted by the UW Center for Palliative Care Education, revealed an interest in training in palliative care topics, particularly in managing pain, addressing cultural needs, managing emotional suffering and ethics.

It will be important for emerging programs to include core concepts, such as the following "Seven End-of-Life Care Domains." The *Promoting Excellence in End-of-Life Care* Critical Care Peer Workgroup developed these

domains specifically for critical care settings, but they are applicable to HIV/AIDS care:

- Patient- and Family-Centered Decision Making;
- Communication within the Team and with Patients and Families;
- Continuity of Care;
- Emotional and Practical Support for Patients and Families;
- Symptom Management and Comfort Care;
- Spiritual Support for Patients and Families; and
- Emotional and Organizational Support for Clinicians.

Research Challenges and Opportunities for Change

Pre-HAART Studies

Early in the epidemic, numerous cohort studies described the natural evolution of HIV disease among those infected, and later described the impacts of prophylaxis for opportunistic infections and therapy for HIV itself. But as the epidemic spread, currently affected populations did not necessarily conform to these original observations, making it more difficult to describe affected populations. The population living with HIV/AIDS is much less homogenous than it was at the outset; witness the heterosexual spread of the epidemic worldwide. Likewise, while the demographics of affected populations have shifted, principles of disease, prevention, diagnosis, treatment and management have all been dramatically modified since the advent of HAART and indeed are in constant evolution. Although some literature from the pre-HAART era remains relevant, there is a need to re-evaluate care needs and psychosocial aspects of the disease.

The current research for HIV/AIDS is focused on disease-specific therapies and coping

techniques, with a dearth of attention to palliative and end-of-life care concerns. Now, with significant improvement in response to combination antiretroviral therapy and survival time, it is imperative to investigate the management of both short- and long-term consequences of therapies, as well as to clarify methods for optimizing quality of life through the very end of life. Existing research needs to be complemented by new research pertinent to HAART, particularly related to the prevention and control of side effects that impact adherence. Concurrent studies to evaluate the effectiveness of controlling side effects of ARV therapy would be useful for improving adherence.

New Frontiers for Research

Research to identify sentinel events in the trajectory of dying for patients for whom HAART begins to fail, or for whom other illnesses such as liver failure supervene, is critical. Research is needed to address symptom management concurrent with salvage therapy when antiretroviral therapy regimens have failed. With thorough informed consent, it is ethically acceptable and clinically essential to incorporate study designs that include groups receiving “no antiretroviral therapy with intensive palliative and supportive care” and groups treated with “new antiretroviral therapy with intensive palliative and supportive care.”

Symptom and Quality of Life Research

Effectively integrating palliative care into HIV care will dictate a need for a continuing focus on pain management and symptom control for all populations affected by HIV. Studies are needed to target how to prevent or to eliminate symptoms recognizing that they may be disease-related, therapy-related or unrelated to the disease process. Symptom surveys done in the pre-HAART era⁵ document

a problem incidence similar to that in the HAART era, but symptom prevalence is not the same now for those with controlled disease.^{6, 7} While those in care may now have long-term effects, e.g., lipodystrophy and increased risk of cardiovascular problems, those unable to adhere to therapy experience clinical decline parallel to the experience of the pre-HAART era.⁸ The field needs to examine these HAART era populations to characterize the daily impact of symptoms of HIV itself, as well as those due to the medicines used to control HIV.

The AIDS Clinical Trials Group (ACTG), the largest HIV clinical trials organization in the world, plays a major role in setting standards of care for HIV infection and opportunistic diseases related to HIV/AIDS in the U.S. and the developed world. Established by the National Institutes of Health to conduct controlled evaluation of new therapies with the primary goal of improved HIV disease management, the ACTG has also evaluated the prevalence of symptoms and quality of life. The ACTG Outcomes Committee has collected quality of life data in drug trials for the past decade. Health-related Quality of Life (HrQoL) now includes two components – the ability to perform daily activities (function) and how one experiences daily life (well-being).

The Pediatric AIDS Clinical Trials Group “Pediatric Late Outcomes Protocol” follows HIV-infected children and youth into young adulthood to determine the incidence and severity of disease and treatment-specific symptoms and conditions. It measures quality of life and includes specific data collection regarding palliative and end-of-life care for pediatric patients. All recommendations for the Adult ACTG must apply also to the Pediatric ACTG.

Two areas of potential focus to be explored in collaboration with the ACTG include symptom management and end-of-life management. Much like other chronic disease entities, there

are barriers to completing this type of research that could provide direction on how to provide the best care and support to patients at the end of their lives. Qualitative studies are needed to capture more of the experience of advanced HIV/AIDS disease care and life challenges and survival strategies of people living with disease, caregivers and professional care providers. New tools need to be developed and tested to assist surveying people living with cognitive impairment associated with long-term HIV infection. One barrier that exists is the vast variation of definitions that clinicians apply to palliative care.

A New Standard for HIV Clinical Trials

Clinical and health service delivery studies into palliative domains of care and quality of life for HIV patients and their families are essential. Further study is necessary to investigate the potential advantages (in terms of quality of life and survival) of intensive palliative care with and without antiviral treatment for patients with advanced disease. ACTG investigations might also incorporate a category of “desire for intensive palliative care” as a study endpoint or reasons for withdrawal from clinical trials.

The Adult AIDS Clinical Trials Group Longitudinal Linked Randomized Trials (ALLRT) Protocol allows patients who are on treatment protocols to be followed despite the end of the original or “parent” protocol. This ongoing study will contribute prospective data about HIV positive patients and the disease process for an additional five years. The secondary objectives of this study include quality of life and outcomes information. While the objectives were not designed to specifically address “palliative care or end-of-life issues,” much of the information collected is related to these issues. However, a standard of care must be advanced in HIV trials that includes



The message of this report, encouraging clinicians, educators and researchers to fully integrate palliative care into HIV disease management, can only become reality through policy change and commitments from those who pay for clinical care and those who fund clinical and health service delivery research.

palliative care and encompasses assessment of palliative outcomes.

Appropriate management of HIV or treatment-related side effects, such as diarrhea, could improve study subject retention in clinical trials. The same clinicians conducting HIV clinical trials provide care to a cohort of patients who are at the end of the spectrum of HIV disease. Research on this cohort of patients could benefit future patients facing physical, emotional and spiritual end-of-life issues.

Now that people with HIV can expect a longer life with treatment and prevention, more focus must be directed at maximizing the disease-free interval. In the same manner of treatment for cancer 20 years ago, studies must systematically evaluate the effectiveness of supportive therapies for those undergoing multi-drug regimens as well. All of these issues have implications for policy-makers and funders as well as researchers.

The Workgroup on Palliative and End-of-Life Care in HIV/AIDS proposes to the field the research agenda in Appendix C.

Policy Challenges and Opportunities for Change

The message of this report, encouraging clinicians, educators and researchers to fully integrate palliative care into HIV disease management, can only become reality through policy change and commitments from those who pay for clinical care and those who fund clinical and health service delivery research.

Confronting the Challenges of Existing Policies

Inequities of access still exist for people with HIV/AIDS, due to insurance status, ethnic barriers or socio-economic status. The *Promoting Excellence in End-of-Life Care* Workgroup on Palliative and End-of-Life Care in HIV/AIDS identified the following as the most significant overriding policy issues facing the U.S. with regard to HIV/AIDS care:

- The AIDS Drug Assistance Program (ADAP), an essential component of the Ryan White CARE Act, must be maintained and expanded.
- The Ryan White CARE Act is in need of re-evaluation and re-structuring to allow better

access to its programs for all people with HIV/AIDS, and to encourage the provision of palliative care concurrently with disease-modifying treatment.

- Legal barriers to optimal HIV/AIDS care for minors and adults who have lost decision-making ability still exist and must be addressed.
- Reimbursement rules and regulations often preclude the integration of palliative care into the model of care (e.g., the rule that patients must be determined to have only six months to live to, or may need to “give up” HAART to access the Medicare hospice benefit).
- As HIV becomes a chronic disease, there is a developing cohort of aging patients. Long-term coverage must be expanded.

The Ryan White CARE Act: Challenges and Prospects for Improvement

Special populations, such as the underinsured, those in correctional facilities, children and adolescents, and those with cultural beliefs and practices prohibiting full access to care, are underserved populations that can benefit from funding for health care under the Ryan White CARE Act administered by the HIV/AIDS Bureau of Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services. However, access to care is not always guaranteed. Moreover, safety net providers in community and migrant health centers, Healthcare for the Homeless Centers, AIDS community-based organizations, community and teaching hospitals and other health care entities that receive Ryan White funding seldom have training in palliative care.

Programs supported by Ryan White CARE Act funds are essential to the delivery of HIV/AIDS health care across the nation. The communities most affected by HIV are more dependent on social services and Ryan White

CARE Act funds and programs, including the important ADAP medication program. Passed in 1990, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act not only funds primary care services for underserved people with HIV/AIDS, it also supports the AIDS Educational Training Centers (AETCs) and the AIDS Drug Assistance Program (ADAP). ADAP provides medications for the treatment of HIV disease and can also be used to purchase health insurance for eligible patients.

The Ryan White CARE Act has immensely improved access to HIV/AIDS care for underserved people but must expand to cover patient needs in more varied settings. Although the Ryan White CARE Act 2000 Reauthorization changed funding formulas for several titles, and redirected funds to reflect the diverse population now being served and to meet current needs, the act still deserves examination. Previously, Ryan White funds could not be used for the inpatient setting – except for inpatient hospice – that could be used to preclude hospitalization. For populations with unstable living situations and few caregivers, it may be necessary to house patients in a long-term care setting for a full course of antibiotics or for physical rehabilitation following a long hospital course.

Currently, local planning councils play a major role in determining how Ryan White CARE Act Title I funds are distributed. But funding priorities established by these planning councils based on the historic nature of the disease may no longer be what is needed in a given community, now that treatment is improved. It may be essential to reprogram or redirect funds currently allocated for other services to cover costs of pharmaceuticals used for treatment of the virus, as well as medications needed to control symptoms. An example of a way to accomplish this would be to shift a portion of Title I funding directly to

the states for ADAP, and HRSA would need to specifically include medications for symptom management in the ADAP guidance. Currently, ADAP funds are awarded to each state according to a formula based on HIV and AIDS prevalence, and each state determines which medications will be included on its ADAP formulary. In this country, as in many resource-poor settings, it is fiscally sound to assure that monies are placed where the need is greatest in terms of supporting treatment and care. Guidelines for use of ADAP funds must include provisions for drugs used for symptom control, e.g., pain management for ARV therapy and prophylaxis for opportunistic infections.

Issues of Guardianship

Issues of guardianship and health power of attorney need attention and careful legal evaluation, to assure that those with the patient's best interests at heart are eligible to participate in decision making. Particularly with the growing sub-population who are mentally ill, and with children in foster care, the question of who can stand in the role of decision-maker is not a trivial one.

Funding Challenges and Opportunities for Change

The Challenge: Maintaining Funding Levels

Although HIV/AIDS has been a well-supported disease, inadequate funding for HIV/AIDS programs is now an issue on every front. The Workgroup on Palliative and End-of-Life Care in HIV/AIDS acknowledges that funding levels for HIV/AIDS care are falling while costs of medical care are rising.

HIV/AIDS is no longer a lucrative fund-raising arena as it once was. A decrease over the past few years in the number of donors to HIV/AIDS programs and support organizations

Guardianship

Joe is a 12-year-old mentally challenged HIV-infected child who has been raised in foster care after being abandoned in the newborn nursery by his HIV positive mother who actively abused IV drugs. He has been fortunate to live with the same foster parents throughout his lifetime, and they are the only parents he has known. The foster parents did not adopt Joe because, due to local regulations, the family would then lose their financial stipend and the Medicaid coverage needed for his care. His foster parents have provided consistent care, tests and treatment for Joe. Joe's HIV disease has progressed over the past few years, and he is now in the hospital ICU on a ventilator for an acute illness; he is not improving. The health care team needs to discuss goals of care, consideration of "do not attempt resuscitation" (DNAR) orders and consideration of withdrawal of the ventilator – but Joe's foster parents are not full guardians and cannot consent to these decisions. The local governmental foster care agency is technically Joe's guardian, but no one at the agency knows Joe personally, and agency policy precludes agreeing to DNAR or ventilator withdrawal. Unless the hospital ethics committee urges a court to issue a DNAR order, or to make Joe's foster parents his full legal guardians, he will languish in the ICU and not receive the full benefits of optimal end-of-life care. *Joe falls into cracks between existing policies and is denied the benefits of timely, personalized medical decision making.*

The Uninsured

Paul is a 32-year-old man who worked in fairly well paying construction jobs yet chose not to purchase medical insurance. When he became ill, he was not eligible for state and federal assistance programs. His family lived in a rural town and because they were fearful of stigma, they sought no assistance in caring for him at home. He was eventually hospitalized with an acute episode and declined rapidly. A DNAR order was written, and he was transferred to a residential hospice program. There he received palliative care and after two months recovered sufficiently to be released to the care of his parents. Although they still struggled with stigma, his parents were able to accept him back and sought the support necessary to care for him. Paul is now receiving assistance from the ADAP program, receiving medication and doing well.

Palliative care helped Paul recover some quality time – palliative care is not simply hospice care.

(as a result of the perception that the disease is no longer a plague), and of volunteer staff, has resulted in less community-based fundraising. Assuring adequate funding for those who “fall through the cracks” of existing systems of care is an ongoing problem, and one that local communities cannot address alone. Adequate state and federal funding is necessary to meet the needs of those populations disproportionately affected by HIV and with little access to care and services. Compounding funding dilemmas, state Medicaid programs are suffering reductions in funding, which are impacting HIV and AIDS patients' ability to seek care and medications. Additionally, traditional Medicaid infrastructures are being sacrificed to funding reductions.

Adding to the complexity of the funding crisis, there is an important and long-overdue international focus on the importance of bringing HAART to Africa, Asia, India, South America and other resource-constrained settings. This focus is shifting attention from issues of death related to HIV/AIDS failure in the United States and potentially jeopardizes funding for U.S. programs.

Reimbursement Disparities

Reimbursement issues complicate the end-of-life scenario for people with HIV/AIDS. People with limited insurance coverage may have a capitation on drug expenditures leaving them with inadequate coverage over the long haul. People with multiple psychosocial issues and other concurrent medical problems who have difficulty complying with rules and regulations often become ineligible for health care assistance. People aging into Medicare may lose access to HAART drugs, due to an inability to afford the medication unless they become impoverished and qualify for Medicaid.

Possibilities for the Future: Essential Palliative Care Discussions

Clinicians, HIV care teams and patients alike believe that better palliative care might lead to savings in health care dollars in the long run, but reimbursement systems must be put into place to allow the introduction of palliative care services simultaneous with HIV disease-specific care. Population-based demonstration projects that will validate the potential for cost savings must also be implemented.



Clinicians, HIV care teams and patients alike believe that better palliative care might lead to savings in health care dollars in the long run.... Population-based demonstration projects that will validate the potential for cost savings must also be implemented.

Superimposed on any such discussion is the failure of the United States health insurance system to provide any coverage at all for over 40 million Americans and inadequate coverage to many millions more. The numbers of uninsured in the U.S. are rising yearly, and many states are reducing Medicaid benefits as they struggle to compensate for large budget shortfalls. Ryan White CARE funded programs, safety net health care providers, community-based service organizations and state and local initiatives cannot consistently cover gaps in coverage for essential medical care. Discussion of reimbursement for HIV-related palliative services must take place in the context of a larger discussion of inadequate access to and reimbursement for other essential medical services.

BEYOND THE U.S.

This document is intended for use in the United States and focuses on pertinent action plans for health service delivery, funding mechanisms and public policy in the U.S. Recommendations regarding palliative care remain applicable in resource-poor settings where home-based care and the relief of significant symptoms such as pain may be the only treatment available for people with HIV/AIDS.

In the year 2003, much attention turned to the growth of the HIV/AIDS epidemic in resource-constrained countries. The U.S. Agency for International Development (USAID), the Centers for Disease Control (CDC), the Department of Defense (DOD) and HRSA are all responding to the epidemic in sub-Saharan Africa and the Caribbean in different ways. A Global AIDS Fund has been established from private, public and government donations to promote care and treatment while continuing prevention efforts. HRSA, as the primary funding agency for indigent care in this country, is accustomed to working with vulnerable populations and is asserting leadership in delivering comprehensive care, including palliative care, as part of this effort.





RECOMMENDATIONS TO THE FIELD: A ROAD MAP FOR CHANGE

The *Promoting Excellence in End-of-Life Care* Workgroup on Palliative and End-of-Life Care in HIV/AIDS recommends the integration of palliative care into HIV/AIDS disease management throughout the course of illness and not just at the brink of death. The Workgroup holds that truly excellent care for HIV/AIDS must always include not only the latest antiretroviral and disease-specific therapies but also pay equally diligent attention to symptom relief, quality of life, and psychosocial and spiritual needs. This emphasis must be reflected in every decision, statement and policy issued by every social body that stands to influence the ways care is provided for HIV/AIDS. To that end, the Workgroup endorsed the following recommendations to provide clinicians, educators, researchers, policy-makers, funders and health care payers an agenda for change that will improve quality of life for patients, families and caregivers and increase access to optimal palliative care to complement current disease treatment and management.

Recommendations for Clinicians

The Workgroup on Palliative and End-of-Life Care in HIV/AIDS calls on the *Department of Health and Human Service's (DHHS) Public Health Service* to include palliative care in the DHHS treatment guidelines for HIV/AIDS care. Likewise, other influential bodies that issue HIV/AIDS treatment directives, including the International AIDS Society (IAS), the American Academy of HIV Medicine (AAHIVM) and the HIV Medicine Association (HIVMA), must include palliative care in their comprehensive clinical guidelines.

The Workgroup calls on the *Panel on Clinical Practices for Treatment of HIV Infection* and the *Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children* to include guidelines for palliative and end-of-life care in published treatment guidelines for adults, adolescents and children with HIV infection.

The Workgroup calls on *clinicians, HIV provider communities* and *accrediting bodies of clinical professionals* to establish a standard of care for HIV/AIDS that integrates a palliative approach throughout the spectrum of care and across all settings. This standard of care must include competencies in:

- The interdisciplinary model of care and collaborative decision making;
- Effective communication;
- Pain and symptom management throughout the continuum of illness, including management to improve Health-related Quality of Life (HrQoL).
- Patient-focused and family-centered care;
- Establishment of goals of care throughout the continuum of the illness, including advance care planning, anticipatory support and guidance related to adaptation to illness;
- Cultural and spiritual sensitivity and understanding of their relationship to wellness and illness;
- Assessment and management of end-of-life care and the dying process, including but not limited to pain and symptom management, withdrawal of life prolonging interventions and issues of life closure; and
- Bereavement care and referral.

The Workgroup calls on *clinicians, HIV provider communities* and *health care systems* to include palliative care and end-of-life issues in continuous quality improvement programs.

Recommendations for Clinical Educators

The Workgroup on Palliative and End-of-Life Care in HIV/AIDS calls on *educators at all levels of clinical training* to advance a standard of care for patients of all ages with HIV disease (including children and adolescents) and their families that integrates palliative services and interventions, to improve comfort and quality of life throughout the continuum of care. The Workgroup asks educators to:

- Develop clinical guidelines and best practices regarding palliative care and end-of-life care in HIV disease, creating uniform standards for core palliative HIV care within existing curricula.
- Mandate palliative care as a part of HIV education; curricula must include core concepts and reflect the clinical standard of care at every level of training.
- Include core content in palliative care in the proposed Certificate of Added Qualification (CAQ) for HIV medicine.
- Create clinical educational programs and resources regarding care transitions for individuals with advanced HIV disease.
- Extend credentialing programs to all disciplines working with HIV populations, including social workers, nutritionists, dentists, and others, modeled after HIV provider credentialing programs.
- Include the management of complications and symptoms prevalent in or specific to HIV disease in all palliative care education programs, fellowship trainings and certifications.

The Workgroup requests that the *Health Resources and Services Administration (HRSA)* mandate that its safety net providers (e.g., federally funded community and migrant health centers, Health Care for the Homeless Clinics and recipients of Ryan White CARE Act funding) receive training in palliative care.

The Workgroup calls on *professional organizations* (AIDS Action, National Organizations Responding to AIDS [NORA], the National Hospice and Palliative Care Organization [NHPCO], the American Academy of Hospice and Palliative Medicine [AAHPM], National Hospice and Palliative Care Nurses Association [NHPCA], et al.) to:

- Develop and disseminate interdisciplinary training modules that include management of symptoms (comorbidities and substance abuse), and psychosocial, spiritual and

cultural aspects encountered at critical turning points in overall HIV disease management.

- Educate the public, especially communities at risk, and those infected and affected by HIV, regarding the purposes and availability of palliative care, and empower them to demand attention to caregiver support, quality of life and excellent symptom management.

Recommendations for Researchers

The Workgroup on Palliative and End-of-Life Care in HIV/AIDS calls on *researchers and research agencies* to:

- Define the set of palliative care and end-of-life issues that are specific to, more prevalent in, or more severe in the setting of HIV/AIDS than with other life-threatening conditions.
- Conduct clinical and health service delivery studies into palliative domains of care and quality of life for HIV patients of all ages, including children and adolescents and their families.
- Address salvage therapy when existing antiretroviral therapy regimens have failed, incorporating study designs that include groups receiving “no antiretroviral therapy with intensive palliative and supportive care” and groups treated with “new antiretroviral therapy with intensive palliative and supportive care.”
- Advance, within HIV treatment trials, a standard of care that includes palliative care and encompasses assessment of palliative outcomes.
- Incorporate within the Adult and Pediatric AIDS Clinical Trials Group (ACTG) investigations a category of “desire for intensive palliative care” as a study endpoint or reason for withdrawal from clinical trials.
- Investigate palliative aspects of family caregiver experience, exploring both burdens and benefits of caregiving.

- Conduct demonstration projects involving collaborations of existing services – including social services, corrections, homeless shelters, housing, health services and care delivery, and hospice services – in delivering palliative care to people with HIV disease and their families, including those with concomitant problems of substance abuse.
- Investigate the cost impact of addressing patient and family needs related to comfort and quality of life earlier in the trajectory of the illness, including models of home-based care and appropriate symptom management.

Recommendations for Policy-makers

The Workgroup on Palliative and End-of-Life Care in HIV/AIDS calls on members of the *U.S. Congress* to:

- Expand eligibility requirements and funding for federal Ryan White CARE Act programs, to accommodate the rising prevalence of HIV in certain populations (e.g., adolescents, heterosexuals, people of color).
- Continue and expand the AIDS Drug Assistance Program (ADAP) at federal and state levels, and include palliative care medications on ADAP formularies.
- Expand current statutes to enable coverage for long-term care with the goals not only of minimizing acute care hospitalizations but also of enhancing patient autonomy, independence and quality of life.

The Workgroup calls on *policy-makers at the Centers for Medicare and Medicaid Services (CMS)* to:

- Revise hospice regulations to allow for continued payment for HIV medications through ADAP for eligible patients who elect to receive the Medicare hospice benefit but who wish to still receive antiretroviral therapy.

- Develop and conduct population-based demonstration projects blending palliative care with best practices of HIV care, including substance users, homeless individuals and incarcerated populations in these projects.

The Workgroup calls on *HRSA administrators of the Ryan White CARE Act program* to:

- Integrate palliative care into the continuum of care for all ages, including children and adolescents, funded by the Ryan White CARE Act.
- Coordinate policies, regulations and reimbursement between Ryan White programs (especially the AIDS Drug Assistance Program), Medicare and Medicaid, to address the aging of the HIV-infected population.
- Assure that individual states adequately match Ryan White CARE Act funds, to make certain that state programs maximize federal dollars.
- Change Ryan White guidance to planning councils to mandate care and treatment as top funding priorities, with emphasis on attention to palliative needs and advance care planning.

The Workgroup calls on *policy-makers within governmental agencies, in AIDS support organizations (ASOs) and other agencies* to:

- Make palliative care coordination and interdisciplinary outpatient services available to people with advanced HIV disease of all ages and their families.
- Develop consistent policies for bureaus of prisons and state departments of corrections regarding palliative care and end-of-life care for people with HIV.
- Include palliative care as an integral part of HIV care within all pertinent program guidelines.
- Build capacity for home-based HIV palliative care in rural areas.
- Create flexible and responsive mechanisms for guardianship and assistance with health

care decision making for all dependent people – children, adolescents and dependent adults – as well as provide guidance and education for guardians, courts, lawyers, judges and state attorneys general that protect all dependent people.

The Workgroup asks the *American Bar Association* and *American Health Lawyers Association* to convene a group to:

- Evaluate legal protections for privacy and confidentiality in the context of HIV/AIDS.
- Remove legal barriers to optimal HIV care for minors and adults who have lost decision-making capacity.

The Workgroup asks *policy-makers at all levels and in all arenas* to enact the following in coordinating efforts to improve the quality of care and quality of life for people with HIV disease and their families:

- Develop policies that require palliative care availability whenever disease-specific therapies are offered concurrently (including antiretroviral medications or medications to prevent or treat opportunistic infections).
- Develop clinical standards for agencies, hospices and Ryan White programs that integrate palliative care into the continuum of care of people of all ages with HIV disease.

Recommendations for Health Care Funders

The Workgroup on Palliative and End-of-Life Care in HIV/AIDS calls on *funders of clinical and health service delivery* to:

- Provide expanded funding for successful demonstration projects in which disease-specific and palliative interventions are provided simultaneously.
- Fund studies of the efficacy and cost effectiveness of palliative care with sufficient power to answer questions about access, quality and impact on cost of care at a national level.

- Convene a funders conference, involving the Health Resources Service Administration (HRSA), the Centers for Medicare and Medicaid Services (CMS), private grant makers and third-party health care payers, in order to delineate areas of funding responsibility in advancing clinical standards, training and research into palliative care for HIV patients of all ages and their families.
- Convene an expert consensus conference to design and implement studies of concurrent disease-specific and palliative care programs.
- Fund educational opportunities for HIV clinicians in palliative care and for palliative care clinicians to participate in HIV mini-fellowships, preceptorships and observerships.
- Support research into expanding community hospice programs as an effective part of the continuum of care.

Recommendations for Health Care Payers

The Workgroup on Palliative and End-of-Life care in HIV/AIDS calls on *health care payers* to:

- Establish reimbursement mechanisms for inter-agency networking and non-traditional services, including housing and social services, that improve quality of life and can provide alternatives to costly institution-based care.
- Update managed care organizations' reimbursement schedules to reflect advances in disease stratification, to enable coverage of comprehensive assessment of symptoms, functional status and patient-family needs.
- Update payment schedules and standards for HIV disease management to include palliative care.
- Develop and disseminate billing mechanisms for palliative care delivered concurrently with disease-specific HIV care.

- Create mechanisms to reimburse palliative care consultations by individual palliative care consultants and interdisciplinary teams.
- Create reimbursement mechanisms for home-based care and other palliative care needs earlier in the trajectory of the illness.

End Notes

- ¹ Salsberg E. Study of the Supply, Demand and Use of Palliative Care Physicians in the U.S. Center for Health Workforce Studies, 2002.
 - ² National Hospice and Palliative Care Organization, www.nhpco.org.
 - ³ National Hospice and Palliative Care Organization, www.nhpco.org.
 - ⁴ *Financial Implications of Promoting Excellence in End-of-Life Care*, 2002. Missoula, Mont.: *Promoting Excellence in End-of-Life Care*, 2002.
 - ⁵ Alexander CS. "Palliative and end-of-life care," in *A Guide to Clinical Care of Women with HIV: 2001 Edition*, Anderson J, (ed.). Health Resources and Services Administration: Rockville, Md., 2001.
 - ⁶ Matthews W, McCutchan J, Asch S, Turner B, et al. "National estimates of HIV-related symptom prevalence from the HIV cost and services utilization study." *Medical Care*, 38: 750-762, 2000.
 - ⁷ Cunningham W, Shapiro M, Hays R, Dixon W, et al. "Constitutional symptoms and health-related quality of life in patients with symptomatic HIV disease." *American Journal of Medicine*, 104: 129-136, 1998. [duplicate]
 - ⁸ Unpublished data from SPNS projects on palliative care sponsored by HRSA.
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HIV/AIDS PALLIATIVE CARE WORKGROUP MEMBERS

Carla S. Alexander M.D., Co-Chair
Assistant Professor of Medicine
University of Maryland School of Medicine
Institute of Human Virology
Palliative Care Program
Baltimore, Md.

Anthony Back, M.D., Co-Chair
Associate Professor
University of Washington
Seattle, Wash.

Jean Anderson, M.D.
Associate Professor, Gynecology & Obstetrics
Johns Hopkins University
Baltimore, Md.

Paul Brenner, M.Div.
Consultant
San Francisco, Calif.

Jeffrey Burack, M.D., M.P.P., B.Phil.
Assistant Adjunct Professor of Bioethics and
Medical Humanities, Joint Medical Program and
School of Public Health
University of California, Berkeley
Assistant Clinical Professor of Medicine
University of California, San Francisco
Attending Physician, East Bay AIDS Center
Berkeley, Calif.

Ira Byock, M.D.
Director
Promoting Excellence in End-of-Life Care
The University of Montana
Missoula, Mont.

J. Randall Curtis, M.D., M.P.H.
Associate Professor of Medicine
University of Washington
Seattle, Wash.

Judith Feinberg, M.D.
Professor of Medicine
University of Cincinnati
Holmes Hospital
Cincinnati, Ohio

Marshall Forstein, M.D.
Director of Adult Psychiatric Residency Training
At the Cambridge Hospital
Harvard Medical School
The Cambridge Health Alliance
Cambridge, Mass.

Pat Gibbons, B.S.N., CHPN
Director, Beacon Place
Hospice & Palliative Care of Greensboro
Greensboro, N.C.

Nancy Hutton, M.D.
Associate Professor of Pediatrics
Johns Hopkins University School of Medicine
Director, Pediatric and Adolescent HIV/AIDS Program
Medical Director, Harriet Lane Compassionate Care
Johns Hopkins Children's Center
Baltimore, Md.

Harlee S. Kutzen, M.N., ACRN
Principal Investigator, PalCare Project Director
HIV Division
Louisiana State University Health Sciences Center
New Orleans, La.

Frederick Meyers, M.D.
Professor and Chair
Department of Internal Medicine
University of California, Davis
School of Medicine
Sacramento, Calif.

Galen Miller, Ph.D.
Executive Vice President
National Hospice and Palliative Care Organization
Alexandria, Va.

Margaret Perrone, R.N., CRNH
Coordinator, Palliative Care Program
Institute of Human Virology
University of Maryland Medical System
Baltimore, Md.

Tammy Powell, R.N., ACRN
Clinical Trials Manager
University of Cincinnati
Cincinnati, Ohio

*Gary Reiter, M.D., FACP
Director, River Valley HIV Clinic
Associate Director, Hospice Life Care
River Valley HIV Clinic
Holyoke, Mass.
*Deceased

Peter Selwyn, M.D., M.P.H.
Professor and Chair
Department of Family and Social Medicine
Montefiore Medical Center
Albert Einstein College of Medicine
Bronx, N.Y.

The Rev. Edward Sunderland, C.S.W.
Department of Social Work
New York Presbyterian Hospital
Columbia Presbyterian Medical Center
New York, N.Y.

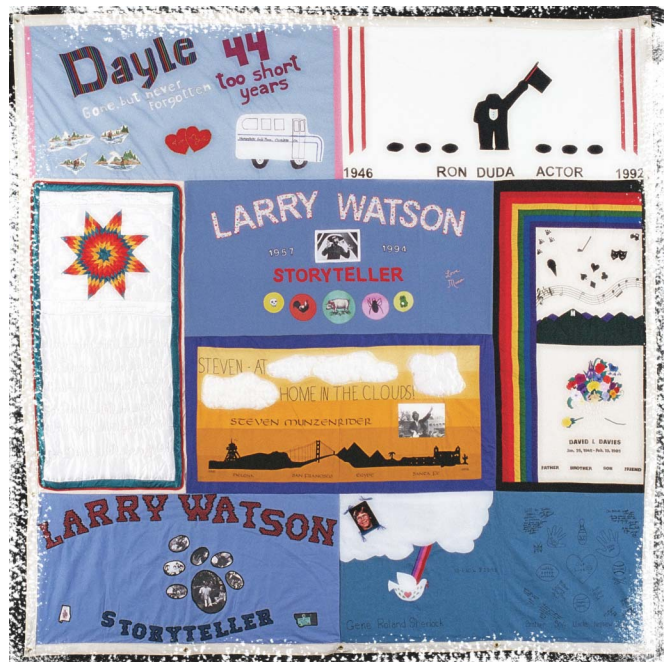
Advisors

Joseph F. O'Neill, M.D., M.P.H.
Deputy Coordinator and Chief Medical Officer
Office of the Global AIDS Coordinator (S/GAC)
U. S. Department of State
Washington, D.C.

Robert Redfield, M.D.
Professor of Medicine
University of Maryland School of Medicine
Director of Clinical Care and Research
Institute of Human Virology
Baltimore, Md.

Peer Workgroup Director

Susan Jo Bumagin, M.Ed.







APPENDICES

APPENDIX A

Study of the Supply, Demand and Use of Palliative Care Physicians in the United States: List of Recommendations

The recently published “Study of the Supply, Demand and Use of Palliative Care Physicians in the United States” conducted at the State University of New York at Albany cites six recommendations to assure that palliative care services be available to people with HIV/AIDS:

- Require clinicians and allied health professionals working with HIV/AIDS patients to demonstrate understanding and skills in palliative care, including the ability to discuss end-of-life concerns with patients.
- Require communication training for clinicians treating HIV/AIDS patients, to facilitate timely discussion of treatment options, including end-of-life issues.
- Explore ways to assure that the resources of palliative care programs are available to HIV/AIDS patients, either through consulting or direct service.
- Address under-treatment of pain for HIV/AIDS patients. Women, children and past or current substance users are identified as particularly vulnerable for under treatment. Dialogue between treating clinicians and palliative care physicians may support development of protocols and treatment for individual patients to more effectively manage pain.
- Require a demonstration of skills in palliative medicine as a component of clinician job requirements within programs providing HIV/AIDS treatment.
- Include testing in palliative care in professional re-certification for specialties such as Infectious Diseases.



APPENDIX B

Taking a Spiritual History

FICA: Taking a Spiritual History

F – Faith and Belief

“Do you consider yourself spiritual or religious?” or “Do you have spiritual beliefs that help you cope with stress?” IF the patient responds “No,” the clinician might ask, “What gives your life meaning?” Sometimes patients respond with answers such as family, career or nature.

I – Importance

“What importance does your faith or belief have in your life? Have your beliefs influenced how you take care of yourself in this illness? What role do your beliefs play in regaining your health?”

C – Community

“Are you part of a spiritual or religious community? Is this of support to you and how? Is there a group of people you really love or who are important to you?” Communities such as churches, temples and mosques, or a group of like-minded friends can serve as strong support systems for some patients.

A – Address in Care

“How would you like me, your health care provider, to address these issues in your health care?”

Christina Puchalski, M.D., The George Washington Institute for Spirituality and Health, 1996.



APPENDIX C

Proposed Research Agenda

- I. Organization and Delivery of Care Studies:
 - A. Models of care, including home care, day care, assisted living and skilled long-term care (including cost effectiveness studies of different models, using quality-adjusted outcome measurements and total costs, including expenditures averted, prevention of lost work time by caregivers, etc.):
 1. Availability/accessibility of hospice care to people with HIV/AIDS;
 2. Availability/accessibility of non-hospice palliative care to people with HIV/AIDS.
 - B. Use and impact of interdisciplinary teams on all phases of HIV management.
 - C. Development of reliable, valid measures for:
 1. Access to services;
 2. Quality of care and family/caregiver support; and
 3. Costs.
 - D. Local and regional patterns of gaps in available services.
- II. Clinical Care Studies focused on disease in post-HAART era:
 - A. Evaluation of prevalence, prevention and management of symptoms related to use of antiretroviral therapy during induction, maintenance and salvage therapy, and how these impact adherence as well as quality of life.

- B. Guidelines for withdrawal/cessation of HAART and prophylaxis of opportunistic infections in late-stage HIV disease.
- C. Clarification of important psychological and emotional decision-making junctures in management and demonstration of optimum methods for accomplishing this communication.
- D. Clinical epidemiology of advanced HIV/AIDS and death-related data, e.g., cause of death and place of death.
- E. Prognosis and surrogate markers for late-stage HIV disease.
- F. Evaluation of appropriate timing, method and documentation of end-of-life planning.
- G. Documentation of appropriate prognostic indicators to assist decision making during advanced and end-stage disease.
- H. Delineation of clinical issues and therapeutic responses to timing and setting of death, grief and bereavement.
- I. Patient preferences for care in advanced AIDS, including:
 1. Desire for/benefits of continuing HAART; and
 2. Features/qualities/location of palliative care.
- J. Caregivers for people with advanced AIDS: their needs and priorities.
- K. End-of-life care in people with chronic substance abuse and HIV/AIDS.
- L. End-of-life care in people with end-stage liver disease and HIV/AIDS.
- M. End-of-life care in people with end-stage renal disease and HIV/AIDS.
- N. Treatment of specific symptom complexes:
 - Chronic pain, including neuropathic pain;
 - Gastrointestinal symptoms: nausea, anorexia, diarrhea;
 - Weakness and fatigue; and
 - Cognitive dysfunction and psychiatric symptoms in palliative HIV care.

III. Quality of Life and Family Experience Studies:

- A. Refinement of existing and development of new interventions to improve quality of life, including interpersonal, emotional, social and spiritual domains of human experience.
- B. Measurements of quality of life with advanced HIV disease that encompass interpersonal, emotional, social and spiritual domains of human experience.
- C. Efficacy of palliative interventions that improve quality of life in advanced HIV disease.
- D. Measurement of caregiver experience (stress, burden and quality of life).
- E. Community attitudes toward dying with AIDS.

IV. Studies on Impact of Ethnicity and Culture on End-of-Life Research

- V. Documentation of and clarification of models to identify and relieve patient/family and staff-related stress and burnout related to caregiving and to accumulated multiple loss.
 - A. Meaning of palliative care to AIDS providers; also their knowledge, attitudes and beliefs about it.
 - B. Educational experience and needs in palliative and end-of-life care of HIV care providers.

VI. Reimbursement and Access to Care Studies:

- A. Descriptive studies;
- B. Interventions; and
- C. Demonstration projects.

VII. Educational Needs Research:

- A. Professional training and development;
- B. Patient education tools; and
- C. Public engagement studies.



APPENDIX D

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