



IMPROVING HIV/AIDS SERVICES THROUGH PALLIATIVE CARE: AN HRSA PERSPECTIVE

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ABSTRACT There has been a dramatic shift of the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) epidemic into poor, marginalized, and minority communities in the US. At the same time, the availability of new highly active antiretroviral treatments has made it possible for a large number of individuals to live for a much longer time with their disease. A net result is that the US is faced with an increasing number of people who are living with HIV/AIDS and are dependent on publicly supported health care services. In this paper, we review the palliative care efforts of the federal agency, the Health Resources and Services Administration (HRSA), responsible for providing Ryan White CARE Act HIV/AIDS care to medically underserved populations. In addition to supporting traditional hospice care, HRSA's HIV/AIDS Bureau has begun a series of initiatives that apply a broader concept of palliative care to its HIV programs in hospital- and community-based settings. Our interest is not to substitute palliation for access to new HIV therapies, such as highly active antiretroviral treatments, but to ensure that our health delivery systems attend to the alleviation of symptoms and suffering along with the provision of antiretroviral and other necessary treatments. HRSA's HIV/AIDS Bureau is organizing a broader provision of palliative care for its clients and actively contributing to improving care for the disenfranchised internationally.

The human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) epidemic in the US continues to evolve and present new challenges to our health care institutions, providers, and public health facilities. This paper discusses one of these new challenges: the need for palliative and end-of-life care for people living with HIV/AIDS. Two trends make this issue particularly relevant for the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (DHHS). First, there has been a

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dramatic shift of the HIV/AIDS epidemic into poor, marginalized, and minority communities in the US.^{1,2} Second, the availability of new highly active antiretroviral treatments (HAARTs) have made it possible for a large number of individuals to live for a much longer time with their disease.³

The discipline of palliative care offers a body of clinical knowledge, a conceptual approach to patient care, and a framework for organizing HIV services. The World Health Organization has defined palliative care in this way:

Palliative care: affirms life and regards dying as a normal process; neither hastens nor postpones death; provides relief from pain and other distressing symptoms; integrates the psychological and spiritual aspects of patient care; and offers a support system to help the family cope during the patient's illness and in their own bereavement.^{4(p11)}

In 1998, HRSA, in consultation with experts in palliative care and HIV, developed a working definition of palliative care for HIV/AIDS (this project was the National Evaluation of the Canadian Palliative Care Module conducted under the direction of the National AIDS Education and Training Centers Working Group in 1997):

Palliative care is patient- and family-centered care, which optimizes quality of life by active anticipation, prevention, and treatment of suffering. Respectful and trusting relationships are the foundation used by the interdisciplinary team throughout the continuum of illness to address physical, intellectual, emotional, social and spiritual needs and facilitate patient autonomy, access to information, and choice.⁵

This definition summarizes the caring perspective that must underlie HRSA-provided services—an approach that treats the whole person and their family regardless of their socioeconomic status, culture, or community.

THE CONTINUING NEED FOR PALLIATIVE HIV CARE

While deaths from AIDS have decreased from about 50,000 a year in 1995 to 17,000 in 1998, HIV diagnoses have remained relatively stable at about 40,000 new infections each year. This means the number of people living with AIDS in the US, approximately 297,000 individuals at the end of 1998, will continue to increase as people live longer.^{6,7} In the US, the majority of individuals with AIDS are aged 50 years or younger and African-American; many are intravenous drug users, and an increasing number are women.⁷ Almost two-thirds of infected women are mothers of children under 20 years old.⁷ The HIV Costs and Services Utilization Study (HCSUS), the recent national study of individuals diagnosed with HIV/AIDS in the US, indicates many of the 600,000 to 900,000 individuals estimated to be infected are not in care or, if in care, are unemployed, poor, and lack private health insurance.⁸ The disparities in deaths by race, ethnicity, and gender are evident in these and other reports on AIDS.⁹

The net result is that the US is faced with an increasing number of people who are living with HIV/AIDS, who are poor and marginalized, and who are dependent on publicly supported health care services. These are the people that the Ryan White CARE Act (CARE) was designed to serve. Since 1991, the CARE Act¹⁰ has been a payer of last resort, a safety net, for people and their families living with HIV/AIDS. Administered by the HIV/AIDS Bureau in HRSA, the CARE Act funds a range of services, from detection of infection; through clinical care, pharmaceutical purchasing, and case management; to end-of-life and palliative care.¹¹ The total annual budget for fiscal year 1999–2000 is approximately \$1.5 billion.

Through the CARE Act authorities, HRSA has undertaken a range of initiatives intended to secure a high quality of life for all people living with AIDS regardless of their socioeconomic status. Palliative care has become an increasingly important component of these activities for several reasons. Most important, despite the hope offered by HAART, it is clear that, for most, HIV remains a fatal disease. Second, regardless of the ultimate outcome, HIV infection causes considerable pain and suffering in physical, emotional, practical, and spiritual dimensions. Third, the treatments for HIV cause a wide range of side effects that decrease quality of life and can foster nonadherence to therapy.

HEALTH RESOURCES AND SERVICES ADMINISTRATION CHALLENGES IN PALLIATIVE CARE

As HRSA has explored palliative care as a means of improving quality of life for people being served in CARE Act programs, several challenges have emerged. There is a widespread misunderstanding that palliative and terminal care—end-of-life or hospice care—are synonymous terms.¹² While palliative care may have its most obvious role near the end of life, it has much to offer to individuals struggling with the side effects of therapy early in the course of HIV infection. For example, pain relief can be provided for the neuropathy caused by some drugs used to treat HIV/AIDS. HRSA's view is that palliative care should not be construed only as medical care; it includes psychological, legal, and social services. Palliative care offers support to loved ones and family and to the provider seeking a rational system of organizing care and services for a patient facing a long and often uncertain disease course.¹³

The conceptualization of palliative care as equivalent to terminal or end-of-life care is, in some ways, an outgrowth of the unique way in which hospice care is financed in the US. It is the Health Care Financing Administration hospice benefit, not the field of palliative care itself, that links the provision of palliative

care to the last 6 months of life.^{14,15} Under Health Care Financing Administration benefits, palliative care is viewed as a short-term benefit that begins when curative care ceases. In many other countries, palliative care is incorporated routinely into disease management much earlier in the course of a disease.¹⁶

Palliative care and aggressive cure-oriented care, by definition, are not incompatible. The concept of an abrupt demarcation between treatment of disease and palliation of suffering is, again, an outgrowth of domestic financing structures and other misunderstandings rather than intrinsic to the discipline of palliative care. The cancer model, with its more predictable dying trajectory, has dominated thinking in palliative care.¹⁷ The processes of living and dying from AIDS tend to be more extended and can shift from critical illness to periods of extended health. Classifying with certainty that these patients are “dying” is often difficult, and the transition from a patient’s need for curative care to palliative care is often unclear.¹⁸

This clinical uncertainty has an important implication for service delivery and financing methods: Palliative care services should be accessible in the earlier stages of an illness. The confusion in definitions has made the public discussion around palliative care, on occasion, problematic. Palliative care is never intended to be an alternative to curative care, but rather an intrinsic component of and a complement to quality care. HRSA’s interest is not to substitute palliation for access to HAART and other services, but to ensure that our health systems attend to the alleviation of symptoms and suffering, along with provision of antiretroviral and other necessary treatments. Most of the US is underserved when this broad concept of palliative care is considered.¹² A challenge for HRSA is the development of an HIV palliative care program that meets the needs of all individuals.

HEALTH RESOURCES AND SERVICES ADMINISTRATION INITIATIVES IN PALLIATIVE CARE

In addition to supporting traditional hospice care, HRSA has begun a series of initiatives that apply the broader concept of palliative care to its HIV programs.

SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE

The Special Projects of National Significance (SPNS) program supports the development, evaluation, and dissemination of new and innovative models of HIV care.¹⁹ Beginning in fiscal year 2000, HRSA is investing \$6 million in the development of five palliative care models and an evaluation center that target very underserved populations. The attempt is to define what palliative care means for these communities and to establish the linkages, organizational structures, and

financing methods necessary to support palliative services for these populations. Figure 1 summarizes the questions addressed by the SPNS projects, which started in October 1999 and will continue for 3 years.

The clients served by these projects represent populations affected by HIV who now are in need of palliative care: homeless individuals, the uninsured, substance abusers, the mentally ill, rural residents living in poverty, and people in or transitioning from correctional facilities. SPNS is addressing palliative care needs that transcend the traditional residential or home health hospice programs. Three projects are creating palliative care interventions that will coexist with curative treatments in ambulatory and inpatient medical settings. One project is providing residential services for homeless individuals whose illnesses are not being controlled through HAART therapy. A third program is building a transitional case management model for individuals in jails who move either to a prison hospital system or into the community. Figure 2 summarizes the projects.

The Palliative Care Evaluation Center located at Columbia University's Joseph L. Mailman School of Public Health is working with Dr. Irene Higginson of the King's College School of Medicine and Dentistry and St. Christopher's Hospice in London to implement a cross-site evaluation. The center is responsible for documenting the findings of each SPNS demonstration project and disseminating results to the broader public health community. The evaluation will not only address achievement of service delivery objectives, but also will assess impact on the community (e.g., removal or minimization of barriers to care) and evaluate

What are the end-of-life needs for AIDS patients in populations outside the mainstream of health care?

Given the difficulty in predicting death from AIDS, at what point in the continuum of care should palliative services begin?

Can palliative services keep people in care long enough to allow advanced care planning and psychosocial, spiritual closure prior to death?

What types of outreach and palliative care services increase use of hospice care delivered either at home or in a home-like environment?

What types of medications are appropriate for AIDS patients with multiple diagnoses such as substance abuse and/or mental illness?

To what extent does palliative care vary for different groups of patients with advanced disease and their families, especially individuals who may be homeless, substance abusers, uninsured, and/or mentally ill?

What types of linkages between hospice care and community-based providers are most effective in delivering palliative and end-of-life care?

What is the cost of palliative and end-of-life care for different groups of individuals?

FIGURE 1 Key questions for Special Projects of National Significance palliative care models.

SPNS Project	Setting	Intervention	Sample Measures
University of Maryland, Baltimore	Inner-city teaching hospital	Expanded interdisciplinary palliative care team enhanced with addictions and peer outreach specialists.	<ul style="list-style-type: none"> • Number of unplanned ER visits • Individual quality of life • Patient control of symptoms • Client/support person satisfaction with care • Meeting patient's goals
Montefiore Medical Center, New York City	Large urban medical center	Mobile palliative care team for special populations; coordination of HIV care with end-of-life services.	<ul style="list-style-type: none"> • Prospective assessment of symptom prevalence and evolution • Quality of life and client satisfaction • Qualitative assessment of family/provider satisfaction
Catholic Community Services of Hudson County, New Jersey	Community-based residential facility	Residential facility to be established in collaboration with HOPWA providing skilled personal care services for referrals from other Ryan White providers.	<ul style="list-style-type: none"> • Quality of life • Functional capacity • Caregiver needs • Family/significant other satisfaction
Volunteers of America – GRACE project	Large county jail systems	Comprehensive service plan including follow-up after release; linkages and agreements with community developed; provision of end-of-life care in jails.	<ul style="list-style-type: none"> • Access to care in jail and in communities • Client retention • Discharge planning • Continuity of services • Inmate/family perceptions and satisfaction
AIDS Service Center, Northeastern Alabama	Rural clinic in foothills of Appalachia	Clinic-based hospice care team providing home visits; integrated with substance abuse program.	<ul style="list-style-type: none"> • Patient/family satisfaction • Provider and caregiver satisfaction • Increase family knowledge of patient care protocols by 20% • Cost analysis
Columbia University, New York City	SPNS evaluation center	Cross-site evaluation of all five SPNS projects and provision of evaluation technical assistance to individual grantees.	Definition of program measures of successful palliative care <ul style="list-style-type: none"> • Continuum of care • Impact on barriers to access • Referral networks • Meeting service delivery objectives • Patients/family satisfaction

FIGURE 2 Overview of Special Projects of National Significance palliation projects.

standards of care according to both technical and cultural competency criteria.

DEVELOPING PALLIATIVE CARE PROCEDURES FOR CORRECTIONAL INSTITUTIONS

The Division of Bioethics at Montefiore Medical Center, New York City, is coordinating a consensus-building effort for the HIV/AIDS Bureau to draft guidelines on palliative and HIV/AIDS care in correctional institutions. Legislators, regulators, state correctional administrators, wardens, and medical staff are working together on a National Advisory Group to develop draft standards that then will be circulated throughout the community. Working with the National Commission on Correctional Health Care, HRSA plans to have standards for HIV palliative care included in the commission's guidelines. This effort is based on recent

Supreme Court decisions that caregivers have an obligation to address a person's pain and suffering at the end of life. While the financing of health care is a responsibility of state and other federal agencies, HRSA can use its experience in underserved communities affected by HIV to establish standards for compassionate palliative care in correctional settings. Our AIDS Education and Training Centers—regional and national centers that provide clinical consultation, education, and training for clinicians serving people with HIV/AIDS—will play a critical role in providing the support and resources needed by practitioners in correctional settings.

EDUCATION AND TRAINING

The AIDS Education and Training Centers (AETCs) in the HIV/AIDS Bureau trains physicians, nurses, pharmacists, and other health professionals in clinical HIV practice. The 15 AETC centers across the country are rethinking their training efforts in light of the changing epidemic and changing treatments.

In 1997, the Pacific AETC undertook an evaluation of the Canadian Palliative Care Module²⁰ for use in the US. The medical and consumer participants liked the problem-oriented approach and recommended that HIV palliation in the US also include women's and children's issues and appropriate palliative care for active substance users. The 1999 AETC grantee guidance incorporates this emphasis into the entire AETC mandate by stressing that, because HIV/AIDS remains a fatal disease and a disease that causes many symptoms that erode quality of life, the need for high-quality palliative care education also is important. HRSA's Bureau of Health Professions supports a number of training programs for individuals who are from and who serve minority and ethnic communities in the US. The HIV/AIDS Bureau is discussing ways to work with their health training to incorporate palliative care.

RESEARCH AND EVALUATION

Many of our health measures, such as quality of life and health outcomes, are based on curative models. HRSA is exploring ways to support a broader approach to measuring quality-of-life and palliative care outcomes. The international HIV-related palliation research that has been conducted indicates differences in the receipt of palliative care by race, income, gender, and age.²¹ Through the SPNS projects and partnering with palliation research centers, we hope to strengthen research on differences in receipt of care in the US.

HIV HOSPICE SUPPORT

HRSA CARE Act programs continue to support hospice and home health care targeted to end-of-life care. In 1998, 21 cities and 16 states allocated CARE Act

funds to both institutional and home hospice care (Tables I and II). While few patients use these services, the patients served by them are poor and from minority populations—the individuals targeted by HRSA's larger palliative care effort.

INTERNATIONAL CONSULTATION

HRSA has extensive experience in delivering HIV care to underserved and poor communities, but when it come to palliative care, it is the more comprehensive work in some other nations that provides models for the US. To this end, the HIV/AIDS Bureau is undertaking a series of international meetings and seminars to exchange information and to develop a comprehensive US model for palliative care. For example, HRSA cosponsored the "Palliative Care: Global Issues and Challenges" seminar at the recent *Fourth International Conference on Home and Community Care for People Living with HIV/AIDS* (Paris, France, December 5–9, 1999). Speakers on palliative care included individuals from Brazil, Cambodia, Puerto Rico, France, Kenya, and the US. Varying cultural perspectives on the

TABLE I 1998 Title I Hospice Funding

Cities	Amount, \$	% of City Care Act \$
Atlanta, GA	64,330	0.5
Austin, TX	170,000	6.0
Baltimore, MD	171,298	1.4
Bergan-Passaic, NJ	7,440	0.2
Caguas, PR	26,438	1.9
Chicago, IL	104,528	0.7
Cleveland, OH	80,000	3.3
Houston, TX	132,826	1.0
Jersey City, NJ	100,000	1.9
Los Angeles, CA	2,233,390	7.3
Ponce, PR	50,602	2.3
Sacramento, CA	104,897	4.4
San Antonio, TX	97,793	3.3
San Diego, CA	75,000	0.9
San Francisco, CA	731,940	2.0
San Jose, CA	144,563	5.9
San Juan, PR	100,000	0.9
Santa Rosa, CA	11,262	0.9
St. Louis, MO	2574	0.1
Tampa, FL	2,000	0.0
Washington, DC	107,451	0.6
	Total 4,518,332	Average 2.2

nature of death and how cultures organize the time around dying were presented eloquently.

The interdisciplinary character of palliative care in diverse national settings offers many lessons for health systems development in the US. We believe that technology transfer in palliative care for impoverished communities can occur in many directions, rather than the traditional information flow from north to south. The demographics of the HIV/AIDS epidemic in this country now include population groups that are being devastated by the disease in developing countries. This is our window of opportunity to use our significant resources in collaboration with international partners to develop new paradigms that not only meet the needs of HRSA's client population, but also can contribute to improving care for the disenfranchised in many parts of the world.

CONCLUSION

Palliative care offers much to our efforts to address the AIDS epidemic in terms of reduction of human suffering, optimization of pharmacotherapies, and management of the cost of long-term care. HRSA's efforts are evolving—HRSA is looking forward to applying the results of the multiple initiatives and consultations within the agency. Palliative care is adding to our understanding of HIV care

TABLE II 1998 Title II Hospice Funding

State	Amount, \$	% of State RWCA \$
Arizona	9,027	0.2
California	193,344	0.3
Colorado	27,999	0.6
Florida	8,043	0.0
Georgia	50,383	0.3
Maryland	413,992	2.8
New Jersey	72,000	0.3
North Carolina	190	0.0
Ohio	81,944	0.9
Oregon	1,895	0.1
Pennsylvania	40,611	0.2
Puerto Rico	525,050	3.1
Tennessee	4,701	0.1
Virginia	258,021	0.7
Washington	43,100	0.7
West Virginia	40,000	4.3
	Total 1,770,300	Average 0.9

through its use of interdisciplinary care teams and its comprehensive approach to caring for individuals and families. In turn, HIV care provides the opportunity to expand palliative care to underserved populations—ethnic minorities, very poor communities, the uninsured, and youth and children. Palliative care at HRSA will be shaped by both HRSA activities and the many external projects that are occurring throughout the world. It is a work in progress.

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