

# Overview of HIV/AIDS Palliative Care Module Contents

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## How to Use This Module

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This section can be used in whole or in part as an introduction to the other training modules. It provides a brief overview of palliative care and its importance in HIV/AIDS care.

## Learning Objectives

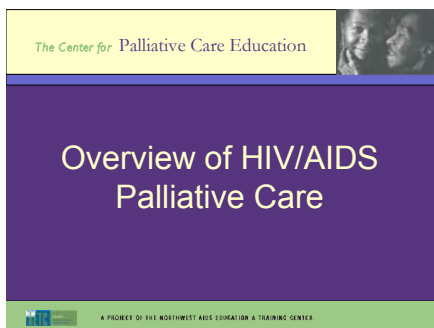
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**At the end of this presentation, participants will be able to:**

- Define palliative care and describe how our view of it has changed in the last decade.
- Describe the shifts in HIV/AIDS care since the advent of HAART.
- Understand the importance of palliative care in the care of patients with HIV/AIDS

# Overview of HIV/AIDS Palliative Care

PowerPoint Notes



## Trainer Suggestion

Introduce yourself and go over the agenda for the session. If there is time in the session and a small enough group, invite participants to introduce themselves and talk about what they are hoping to learn. Invite questions and comments throughout the presentation.

## Learning objectives

- Define palliative care and describe how our view of it has changed in the last decade.
- Describe the shifts HIV/AIDS care since the advent of HAART
- Understand the importance of palliative care in the care of patients with HIV/AIDS

## Why palliative care for people with HIV/AIDS?

- Dramatic changes in HIV/AIDS care
- Increasing body of knowledge and expanded definition of palliative care
- Shift in the trajectory of dying from HIV/AIDS
- Patients with HIV/AIDS have palliative care needs at each stage of the illness

## Slide Note

Care for people with HIV/AIDS has changed dramatically in the past decade. As care has changed, so has the trajectory of HIV/AIDS shifted to a disease less like cancer and more like chronic diseases such as diabetes or heart disease. Palliative care has also changed – it's not just hospice anymore but a larger array of treatments and services spanning a longer time period in a patient's course of illness. As we will see in the next few slides, these shifts in both HIV care and palliative care have resulted in a continuum of palliative care that has much to offer the patient with HIV/AIDS.

## What is palliative care?

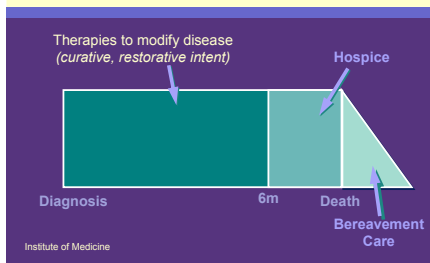
- Treatment to prevent, relieve, or reduce symptoms of a disease without effecting a cure
- Offered throughout the spectrum of illness, including at the end of life
- Includes both medical and psychosocial treatment
- Not intended to replace disease-modifying treatments such as antiretrovirals, but to augment the comfort and support of individuals and families who are living with life-threatening illness

Center for Palliative Care Education

### Slide Note

What do we mean by palliative care? To “palliate” means to alleviate or ease, and that is the main component of palliative care. It’s not about treating the disease; it’s about relieving symptoms and side effects and providing comfort care to the patient. It also involves relieving as much as possible the burden of illness on both the patient and the family.

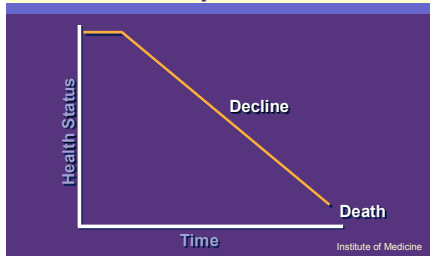
## Traditional view of palliative care



### Slide Note

In the past, we conceived of palliative care in this way. Palliative care was separate from curative care, and only happened after all treatment options had failed. Palliative care was synonymous with hospice care, and there was a standard Medicare hospice requirement that a patient had to have six or less months to live in order to qualify for this care. This view really does not work very well for people with HIV/AIDS today.

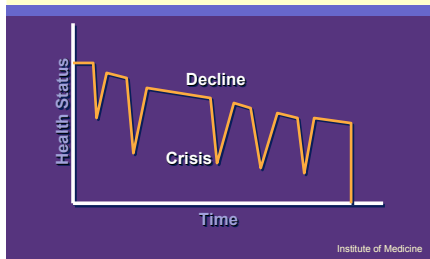
## Trajectory of dying: Steady decline



### Slide Note

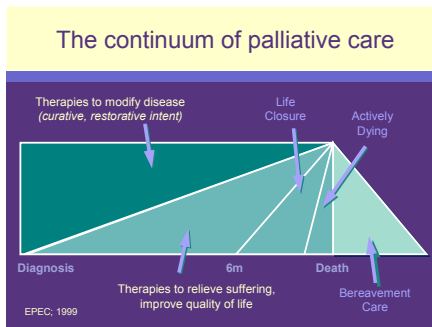
That view assumed a trajectory of death that looks like this. The decline is steady and there is an arbitrary transition point. Traditionally, treatment would stop and hospice services and palliative care would be offered at that point. While this trajectory is still relevant for some diseases, such as cancer, it is not the usual course for HIV.

## Trajectory of dying: Periodic crises



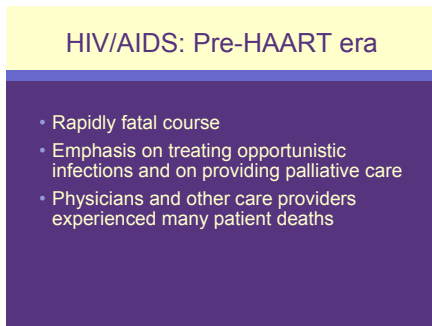
### Slide Note

This is how we perceive the trajectory of dying for many people with HIV/AIDS. People experience periodic crises alternating with periods where they return to close to baseline. A new model of palliative care is needed that takes into account the reality of this disease progression and a patient’s needs throughout the illness.



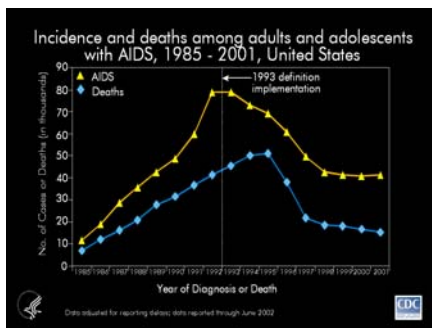
#### Slide Note

This chart shows the integration of palliative care early in the disease process. Palliative care and curative care are a balancing act. Early in the disease process, curative treatment is emphasized, but palliative care is still important to alleviate the side effects of the curative treatment, to treat other conditions that impact quality of life such as fatigue, neuropathy or depression, and to help people prepare for the future using advance care planning and by building a trusting relationship with patient, family and friends. As the disease progresses, the balance shifts, and the focus becomes much more on the patient's comfort and quality of life, as well as supporting the patient's family and friends in caring for the patient.



#### Slide Note

Now let's look at the changes in the course of HIV/AIDS and its treatment in the past decade. Prior to the advent of HAART (Highly Active Antiretroviral Therapy), HIV/AIDS was seen as a death sentence. The average prognosis was death at 10 years after HIV diagnosis; two years after AIDS diagnosis. The only treatments that providers had to offer were addressing symptoms such as fatigue, wasting or depression, treatment of opportunistic infections, and providing good end-of-life care. Clinicians used to experience multiple patient deaths per week or per month. Our definition of "success" with a patient was as much about helping a patient to have a good death as it was about providing as much quality of life as possible.



#### Slide Note

Since HARTT, there have been dramatic changes in the trajectory of HIV/AIDS. Deaths from AIDS are much less frequent. This chart shows the incidence of AIDS cases and AIDS deaths from 1985 to 2001. You will note that the rate of AIDS deaths dropped dramatically between 1995 and 1997, and has been declining more slowly since then. The estimated annual number of AIDS-related deaths in the United States fell approximately 70% from 1995 to 2001. Since 1997, AIDS is no longer in the top 15 causes of death for all age groups. As a result, many HIV providers have not had much experience in the issues surrounding death and dying.

## HIV/AIDS in the HAART era

- Chronic, manageable disease for many
- Unpredictable course with more prognostic uncertainty
- Complex treatment regimen requiring specific expertise
- Multiple symptoms with complex etiologies
- Focus of care and training on HAART and not on palliative care

### Slide Note

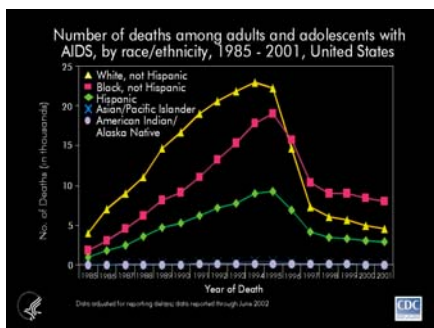
AIDS has now come to be more of a chronic, manageable disease for those patients who can successfully take a complex HAART regimen. Its course is much more unpredictable, and patients experience multiple symptoms related to the disease itself, co-morbidities, and side effects of the treatment. Much of the training to HIV/AIDS clinicians focuses on ARV therapy and all its complexities. Although, it makes sense that we would want to focus on treatment now, when for so long we had so little hope to offer our patients, we still need to help patients to cope with the unpredictable course of HIV/AIDS and to deal with the many symptoms of the disease and the many side effects of treatment. We also need to be able to offer good end-of-life care to the patients for whom HAART is not effective or who have co-infections or other fatal complications.

## Importance of palliative care in HIV/AIDS

- Many symptoms throughout the disease impact quality of life
- HAART is not a cure and has many side effects
- Complex psychosocial issues such as psychiatric illness and substance abuse
- HIV/AIDS still a leading cause of death among Americans ages 25-44
- Co-morbidities of Hep B & C and malignancies can be fatal

### Slide Note

Why is palliative care important in HIV/AIDS care? First and foremost, palliative care is an important component of care for any medical condition. Palliative care includes the management of symptoms such as fatigue, dyspnea and neuropathic pain, and treatment of side effects such as nausea, vomiting, and diarrhea. Palliative care also has much to offer in the psychosocial realm. Treatment of depression, psychosocial support for patients and families, and advance care planning all fall under palliative care. Finally, palliative care has much to offer patients at the end of life. AIDS is still a significant cause of death in this country due to the limitations of HAART and because of significant co-morbidities. Currently, AIDS is the 5<sup>th</sup> leading cause of death among all Americans ages 25-44; the number one cause of death among African-American men in this age group, and the 3<sup>rd</sup> leading cause of death among African-American women in this age group.



### Slide Note

We've touched a little on how minority and marginalized populations are disproportionately impacted by HIV/AIDS. Both incidence and mortality are higher in many ethnic groups in proportion to their percentages in the overall population. This chart shows the number of deaths among adults and adolescents with AIDS from the years 1985 to 2001. In 2001, for example, African-Americans accounted for 52-percent of all AIDS related deaths, although they made up only 12% of the population. 18% of all AIDS-related deaths were Hispanic, although they made up only 11-12% of the U.S. population.

## Importance of palliative care in HIV/AIDS

- HIV/AIDS disproportionately impacts minority and marginalized populations
- These groups often enter care later in the disease progression
- Benefits of HAART not equally distributed
- Some lack the support system to adhere to a complicated medication regimen

### Slide Note

In addition to being disproportionately impacted by AIDS, some marginalized and disenfranchised groups mistrust the health care system and/or have less access to HIV care. Some of these patients who have not been receiving regular care are diagnosed during a hospitalization when HIV is far advanced, and they are less likely to respond to antiretrovirals. Some of these marginalized groups lack support systems or have more pressing life issues such as poverty, substance abuse, or depression that make it difficult to adhere and thus benefit from HAART. Thus, these groups will have more of a need for palliative and end-of-life care.

## HIV/AIDS palliative care

- Integrated with disease-modifying therapies
- Interdisciplinary approach
- Patient & family-centered
- Focus on quality of life
- Multidimensional focus—physical, emotional, social, spiritual
- Collaboration with patient to develop care goals

### Slide Note

Palliative care is an important part of HIV/AIDS care, both at the end of life and throughout the course of illness. It can be easily integrated with disease-modifying therapies such as HAART. It offers both an interdisciplinary and a patient-centered approach with a focus on the quality of life of the patients. HIV/AIDS palliative care looks at the physical, emotional, social and spiritual aspects of the patient's life and tries to address each one in collaboration with the patient and his or her family. In some ways, HAART has made the care of patients with HIV/AIDS more difficult. Just as we need advanced training for ARV therapy, clinicians also need advanced training in palliative care.

## Contributors

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Liz Stevens, MSW	Project Manager

Visit our Web site at [uwpallcare.org](http://uwpallcare.org)

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This project is funded by Health Resources and Services Administration (HRSA) and the Robert Wood Johnson Foundation (RWJF).

## Resources

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### Palliative Care -- General Resources

#### Articles

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Aulino, F. & Foley, K. (2001). Professional education in end-of-life care: A U.S. perspective. *J R Soc Med* 94(9): 472-476. [PubMed Abstract](#).

Aulino, F. & Foley, K. (2001). The project on death in America. *J R Soc Med* 94(9): 492-495. [PubMed Abstract](#).

Back, A. (2000). Oncology and palliative care: Are oncologists evil, or just oblivious? *J Pall Med* 3: 107-8.

Back, A. & Curtis, J. (2001). When does primary care turn into palliative care? *West J Med* 175(3): 150-1. [PubMed Abstract](#).

Billings, J. (2000). Recent advances: Palliative care. *BMJ* 321: 555-58. [PubMed Abstract](#).

Billings, J. & Block, S. (1997). Palliative care in undergraduate medical education: Status report and future directions. *JAMA* 278(9): 733-8. [PubMed Abstract](#).

Block, S., Bernier, G. Crawley, L., et al. (1998). Incorporating palliative care into primary care education. *Journal of General Internal Medicine* 13(11): 768-73. [PubMed Abstract](#).

Cassel, C. & Demel, B. (2001). Remembering death: Public policy in the USA. *J R Soc Med* 94(9): 433-436. [PubMed Abstract](#).

Cassel, C. & Omenn, G. (1995). Dimensions of care of the dying patient. *West J Med* 163(3): 224-25. [PubMed Abstract](#).

Cassel, C. & Omenn, G. (1995). Caring for patients at the end of life. *West J Med* 163(3): This entire journal issue is devoted to palliative care issues. Some articles are listed separately by topic.

Gibson, R. (2001). Palliative care for the poor and disenfranchised: A view from the Robert Wood Johnson Foundation. *J R Soc Med* 94(9): 486-89. [PubMed Abstract](#).

McCormick, T. & Conley, B. (1995). Patients' perspectives on dying and on the care of dying patients. *West J Med* 163(3): 236-43. [PubMed Abstract](#).

Meghani S (2003). A concept analysis of palliative care in the United States. *Journal of Advanced Nursing* 46(2): 152-161.: Traces the evolution of palliative care in the United States. [PubMed Abstract](#).

Morrison, RS and Meier DE (2004). Palliative Care. *New England Journal of Medicine* 350(25): 2582-2590.: Reviews and critiques current practices in palliative care in the U.S. and offers suggestions for effective provision of palliative care. [www.nejm.org](http://www.nejm.org). [PubMed Abstract](#).

Quill T (2004). Dying and decision making - evolution of end-of-life options. *New England Journal of Medicine* 350(20): 2029-2032. [PubMed Abstract](#).

Quill, T., Lee, B. & Nunn, S. (2000). Palliative treatments of last resort: Choosing the least harmful alternative. *Annals of Internal Medicine* 132(6): 488-493. [PubMed Abstract](#).

Selwyn, PA and Forstein, M (2003). Overcoming the false dichotomy of curative vs palliative care for late-stage HIV/AIDS. *JAMA* 290(6): 806-814.: Uses a case study format to illustrate palliative care issues in HIV/AIDS in the era of HAART. Issues discussed include medical challenges in providing care, including symptom management; prognostic challenges; advance care planning, and the shift toward palliation..

## **Books**

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Byock, I. (1997). *Dying well*. New York, NY: Riverhead Books.

Doyle, D., Hanks, G. & MacDonald, N. (1998). *Oxford textbook of palliative medicine (2nd ed)*. New York, NY: Oxford University Press.

Faull, C & Richard, W. (2002). *Palliative care - An Oxford core text*. New York: Oxford University Press.

Ferrell, B. & Coyle, N. (2001). *Textbook of palliative nursing*. New York, NY: Oxford University Press.

Ferris, F. & Cummings, I. (1995). *Palliative care: Towards a consensus in standardized principles of practice*. Ottawa: Canadian Palliative Care Association.

Hallenbeck, J. (2003). *Palliative care perspectives*. New York, NY: Oxford University Press.

Lynn, J. & Harrold, J. (1999). *Handbook for mortals: Guidance for people facing serious illness*. New York, NY: Oxford University Press.

MacDonald, N. (1998). *Palliative medicine: A case-based manual*. New York, NY: Oxford University Press.

National Hospice Organization. Standards and Accreditation Committee: Medical Guidelines Task Force (1997). *Medical guidelines for determining prognosis in selected non-cancer diseases (2nd ed)*. Arlington: National Hospice Organization.

Quill, T. (2001). *Caring for patients at end-of-life: Facing an uncertain future together*. New York, NY: Oxford University Press.

Solomon, M., Romer, A. & Heller, K. (2000). *Innovations in end-of-life care: Practical strategies and international perspectives*. New York, NY: Mary Ann Liebert, Inc..

Solomon, M., Romer, A., Heller, K. & Weissman, D. (2001). *Innovations in end-of-life care: Practical strategies and international perspectives, volume 2*. New York, NY: Mary Ann Liebert, Inc.

## **Websites**

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**Americans for Better Care of the Dying** - [www.abcd-caring.org](http://www.abcd-caring.org). ABCD is dedicated to social, professional and policy reform to improve the care system for dying patients and their families. They provide news, a reading room, a bimonthly publication, and an online conference covering end-of-life care.

**Center to Advance Palliative Care** - [www.capc.org](http://www.capc.org). The focus of CAPC is to be a resource to hospitals and health systems interested in developing palliative care programs. They provide extensive information on all aspects of building a program, a sophisticated journal search with links to on-line publications, news updates, and links to a wide range of organizations and resources.

**Completing a Life** - [completingalife.msu.edu](http://completingalife.msu.edu). This site is a resource for *Taking Charge, Finding Comfort and Reaching Closure*. It offers an interactive CD-ROM and a website geared towards helping patients and families to learn about the practical, emotional, spiritual, and medical issues regarding advanced illness.

**Dying Well** - [www.dyingwell.org](http://www.dyingwell.org). This is the website of Dr. Ira Byock, long time palliative care physician. It includes recommended books, articles, and websites; a

discussion guide, *The Grief Series*, by Cathy Weber; and *Landmarks and Developmental Tasks for the End of Life*.

**Education for Physicians on End-of-Life Care** - [www.epec.net](http://www.epec.net). EPEC is a training program designed to train physicians on the essential clinical competencies required to provide quality end-of-life care. A handbook and video version of the training are both available, as well as slide sets on many palliative care topics.

**End-of-Life Physician Education Resource Center** - [www.eperc.mcw.edu](http://www.eperc.mcw.edu). This is a repository for high-quality, peer-reviewed educational materials and information about end-of-life issues. Course curricula, teaching modules, and self-study guides are available, as well as instruments for assessment and evaluation.

**End-of-Life: Exploring Death in America (NPR Series)** - [www.npr.org/programs/death](http://www.npr.org/programs/death). This is the website for the National Public Radio series, Dying in America. It includes transcripts which may be heard, read, or ordered; resource links; and a bibliography. A Readings section includes poetry, essays, and clinical matters; spiritual and religious texts; excerpts from fiction, plays, and scripts; and visual images. There is a section available to add your story or read others' stories on the website

**Hospice Education Institute** - [www.hospiceworld.org](http://www.hospiceworld.org). HEI is a non-profit organization with information and education about caring for the dying and bereaved. It targets both health care professionals and the public. There is a toll free number for obtaining information and referrals, and for discussing palliative care and bereavement issues.

**Hospice Foundation of America** - [www.hospicefoundation.org](http://www.hospicefoundation.org). The Hospice Foundation has extensive information about hospices - what they are, where to find them, myths and facts, personal stories and volunteering. The website includes information about teleconferences, a media center, suggested readings, weblinks, and an end-of-life database.

**Last Acts** - [www.lastacts.org](http://www.lastacts.org). Last Acts is dedicated to improving end-of-life care through the sharing of ideas and solutions by caregivers, families, and patients. This website includes news updates; a resource center; and reports on palliative care, education and training, and financing and the workplace. HIV/AIDS is a search heading for finding articles and resources.

**National Center for Death Education** - [www.mountida.edu/sp.cfm?pageid=307](http://www.mountida.edu/sp.cfm?pageid=307). The National Center for Death Education assists care-giving professionals and students in acquiring and maintaining a current knowledge base, and in developing creative and useful skills for providing care associated with end of life, bereavement, and loss. The website includes a Resource Library with materials from the sciences, anthropology, sociology, psychology, religion, art, literature, and history. All aspects of dying, death, and bereavement are represented including suicide, homicide, AIDS, terminal illness, explaining death to children, widowhood, and much more. In addition to the books and

periodicals available, the NCDE maintains an extensive audiovisual collection of videos, 16mm films, and slide presentations. Contact Judith Harding, Resource Coordinator, at (617) 928-4552, to access the library.

In addition to the above resources, the NCDE offers educational programs taught by professionals working within the death and dying field. Contact Carol Wogrin, RN, PsyD., Executive Director, at (617) 928-4649 or at [ncde@mountainida.edu](mailto:ncde@mountainida.edu).

**National Hospice and Palliative Care Organization** - [www.nhpco.org](http://www.nhpco.org). NHPCO is dedicated to expanding America's vision of end-of-life care. The site includes extensive educational information and materials available about palliative care, advance directives, and finding an appropriate hospice. The National Center for Death Education provides course and workshop materials and resources for health care professionals. Topics include all aspects of palliative care, including care involving children.

**National Hospice Foundation** - [www.hospiceinfo.org](http://www.hospiceinfo.org). HFA offers information and brochures about hospices, how to find and select a hospice program, communicating end-of-life wishes, and the medicare hospice benefit program.

**Promoting Excellence in End-of-Life Care** - [www.promotingexcellence.org](http://www.promotingexcellence.org). A program of the Robert Wood Johnson Foundation, its mission is to advance improvement in end-of-life care by supporting innovative projects to improve the quality and accessibility of palliative care. Resources developed by projects, as well as information on evaluation, is included on the website.

**Supportive Care of the Dying: A Coalition for Compassionate Care** - [www.careofdying.org](http://www.careofdying.org). A coalition of Catholic health care providers and organizations dedicated to improving the system of palliative care. Website is non-sectarian. Downloadable articles are available from their *Supportive Voice* publication. They offer organizational assessment tools and questionnaires, competency standards and system assessment tools, and a series of videos and articles on various palliative care issues.

**Zen Hospice Project** - [www.zenhospice.org](http://www.zenhospice.org). Zen Hospice Project is a fusion of spiritual insight, based on the Buddhist tradition, and practical social action. The Project has developed an innovative model for improved end-of-life care, including residential hospice care, volunteer programs, and educational efforts. It has also recently created the Institute of Dying, allowing training and dissemination of the Project's work.

# Resources

## Palliative Care Resources -- HIV/AIDS Specific

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### Articles

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Armes, P. & Higginson, I. (1999). What constitutes high-quality HIV/AIDS palliative care? *J Pall Care* 15(4): 5-12. [PubMed Abstract](#).

Corless, I. & Nicholas, P. (2000). Long-term continuum of care for people living with HIV/AIDS. *J of Urban Health* 77(2): 176-86. [PubMed Abstract](#).

Curtis, J., Wenrich, M., Carline, J., Shannon, S., Ambrozy, D. & Ramsey, P. (2002). Patients' perspectives on physician skill in end-of-life care: Differences between patients with COPD, cancer, and AIDS. *Chest* 122(1): 356-62. [PubMed Abstract](#).

Demmer, C. (2001). Dealing with AIDS-related loss and grief in a time of treatment advances. *Am J Hosp Pall Care* 18(1): 35-41. [PubMed Abstract](#).

Easterbrook, P. & Meadway, J. (2001). The changing epidemiology of HIV infection: New challenges for HIV palliative care. *J R Soc Med* 94(9): 442-48. [PubMed Abstract](#).

Foley, F., Flannery, J., Graydon, D., Flintoft, G. & Cook, D. (1995). AIDS palliative care - Challenging the palliative paradigm. *J of Palliative Care* 11(2): 19-22. [PubMed Abstract](#).

Fox, R. (2001). Palliative care in the age of HIV/AIDS: The research perspective. *J R Soc Med* 94(9): 428.

Grady, P., Knebel, A. & Draper, A. (2001). End-of-life issues in AIDS: The research perspective. *J R Soc Med* 94(9): 479-82. [PubMed Abstract](#).

Greenberg, B., McCorkle, R., Vlahov, D. & Selwyn, P. (2000). Palliative care for HIV disease in the era of highly active antiretroviral therapy. *J Urb Hlth* 77(2): 150-65. [PubMed Abstract](#).

Grothe, T. & Brody, R. (1995). Palliative care for HIV disease. *J Pall Care* 11(2): 48-9. [PubMed Abstract](#).

Health Resources Services Administration HIV/AIDS Bureau (2000). Palliative and supportive care. *HRSA Care Action* 2000(July): 1-4.

Kemp, C. & Stepp L. (1995). Palliative care for patients with acquired immunodeficiency syndrome. *Am J Hosp Palliat Care* 12(6): 14, 17-27. [PubMed Abstract](#).

Lands, L. (2002). Pain killer. *POZ* June (2002): 45-47.

Matheny, S. (2001). Clinical dilemmas in palliative care for HIV infection. *JR Soc Med* 94(9): 449-51. [PubMed Abstract](#).

Morissette, M. (1990). AIDS and palliative care: An individual appeal to health care professionals and intervening parties. *J Pall Care* 6(1): 26-31. [PubMed Abstract](#).

Nicholson, J. & Turner, N. (2000). Can the development of palliative care services meet the needs of people with HIV? *J Pall Care* 16(2): 37-43. [PubMed Abstract](#).

O'Neill, J. & Alexander, C. (1997). Palliative medicine and HIV/AIDS. *Primary Care* 24(3): 607-15. [PubMed Abstract](#).

O'Neill, J. & Marconi, K. (2002). Underserved populations, resource poor settings, and HIV: Innovative palliative care projects. *Innovations in End-of-Life Care* 4(3): 1-4 . [www2.edc.org/lastacts/archives/archivesMay02/editorial.asp](http://www2.edc.org/lastacts/archives/archivesMay02/editorial.asp).

O'Neill, J., Marconi, K., Surapruik, A. & Blum, N. (2000). Improving HIV/AIDS services through palliative care: A HRSA perspective. *J Urb Hlth* 77(2): 244-54. [PubMed Abstract](#).

Selwyn, P, Rivard, M., Kappell, D., Goeren, B., LaFosse, H., et al. (2002). Palliative care for AIDS at a large urban teaching hospital: Program description and preliminary outcomes. *Innovations in End-of-Life Care* 4(3): 1-15. [www2.edc.org/lastacts/archives/archivesMay02/featureinn.asp](http://www2.edc.org/lastacts/archives/archivesMay02/featureinn.asp).

Selwyn, P. (2001). Palliative care needs of medically-underserved persons with HIV/AIDS in an urban inner city. *Meeting Abstract, APHA* : Available on this website. [apha.confex.com/apha/129am/techprogram/paper\\_31243.htm](http://apha.confex.com/apha/129am/techprogram/paper_31243.htm).

Selwyn, P. & Arnold, R. (1998). From fate to tragedy: The changing meanings of life, death, and AIDS. *Annals of Internal Medicine* 129(11): 899-902. [PubMed Abstract](#).

Selwyn, P. & Rivard, M. (2002). Palliative care for AIDS: Challenges and opportunities in the era of highly active antiretroviral therapy. *Innovations in End-of-Life Care* 4(3): 1-12. [www2.edc.org/lastacts/archives/archivesMay02/ovessay.asp](http://www2.edc.org/lastacts/archives/archivesMay02/ovessay.asp).

Sserunkuma, R., Otolok-Tanga, E. & Kasule, K. (1998). Living with and dying of AIDS: Today's changes. *Int Conf AIDS 1998* 12(489 (abs#24249))

Stajduhar, K. & Davies, B. (1998). Palliative care at home: Reflections on HIV/AIDS family caregiving experiences. *J Pall Care* 14(2): 14-22. [PubMed Abstract](#).

Vincent, I., D'Herouville, D., Moulin, P., Bugler, C., Fraval, J., et al. (2000). Modalities of palliative care in hospitalized patients with advanced AIDS. *AIDS Care* 12(2): 211-19. [PubMed Abstract](#).

Wood, C., Whittet, S. & Bradbeer, C. (1997). ABC of palliative care: HIV infection and AIDS. *BMJ* 315: 1433-36. [PubMed Abstract](#).

## **Books**

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Alexander, C. (2001). Palliative and end-of-life care.. In: Anderson, J., (Eds.). *A guide to the clinical care of women with HIV, 2001 edition*. Rockville, MD: HIV/AIDS Bureau, Health Resources and Services Administration.

Ferris, F., Flannery, J., McNeal, H., Morrissette, M., Cameron, R. & Bally, G. (1995). *A comprehensive guide for care of persons with HIV disease. Module 4: Palliative care*. Toronto, Ont: Mount Sinai Hospital & Casey House Hospital.

Sims, R. & Moss, V. (1995). *Palliative care for people with AIDS (2nd ed)*. London: Edward Arnold.

Woodruff, R. (1999). *Palliative medicine - Symptomatic and supportive care for patients with advanced cancer and AIDS (3rd ed)*. Melbourne: Oxford University Press.

## **Videos**

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### **Midwest Bioethics Center**

[www.midbio.org](http://www.midbio.org).

*Sheila's story: A case study about a patient terminally ill with HIV*. Available for order on their website.