

Palliative Care in Corrections

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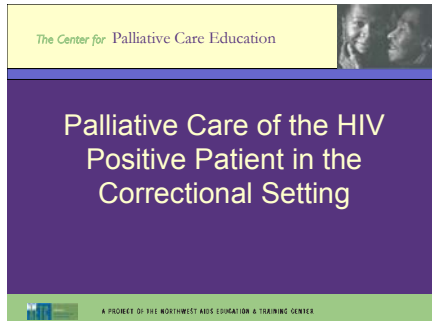
Learning Objectives

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

- Describe the characteristics of corrections settings and populations that pose special health care barriers and challenges for the HIV positive inmate
- Consider the palliative care needs of HIV positive inmates in correctional facilities
- Review models of care and best practice standards for palliative care in correctional settings

Palliative Care of the HIV Positive Patient in the Correctional Setting

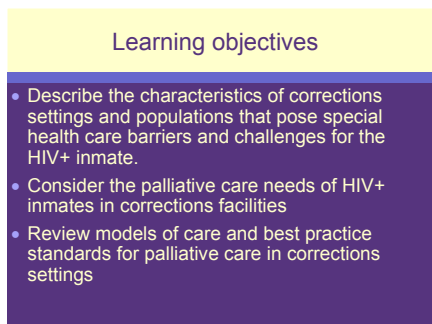
PowerPoint Notes



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.



Slide Note

Palliative care is evolving to become a standard of practice in corrections settings. The learning objectives for this session include reviewing the needs and best practices for palliative care of the HIV+ patient in corrections and looking at the characteristics of the corrections setting and populations that may be challenges for achieving this standard of care.

Trainer Suggestion

You may wish to read the beginning section – the first 6 paragraphs - of “Room Number Six,” a first person narrative of an inmate which tells the story of his relationship with a dying friend at Louisiana State Penitentiary.

West, J. Room Number Six. *Innovations in End-of-Life Care*, 2000; 2(3), www.edc.org/lastacts

After reading the selection, you can ask participants to reflect on their own experiences with inmates at end of life, and their thoughts on the needs that may or may not have been met for these patients.

Why palliative care for people with HIV/AIDS?

- Changes in HIV/AIDS care to chronic illness model
- Increasing body of knowledge and expanded definition of palliative care
- Shift in the trajectory of HIV/AIDS from dying to chronic illness management
- Patients with HIV/AIDS have palliative care needs at each stage of the illness
 - Symptom relief
 - Comfort
 - Quality of life

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 but a larger array of treatments and services spanning a longer time period in a patient's course of illness. 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 HIV treatments such as antiretrovirals, but to positively effect the quality of life of individuals and families who are living with life-threatening illness

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 curing 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.

In this session, although our focus will include end-of-life issues, it's important to keep in mind that the continuum of palliative care includes symptom management throughout the course of an illness, not just at end of life.

Trainer Suggestion

For further information on an overview of current palliative care practices, see the “Overview of Palliative Care” module.

Why consider palliative care of HIV positive patients in corrections settings?

- Increasing numbers of HIV+ inmates have palliative care needs because:
 - History of poor health care, including HIV care
 - Prevalence of HIV and co-morbidity in prison populations
 - Longer prison sentences
 - An aging inmate population - chronic illness
 - Lower death rates from AIDS
 - Incarceration as a barrier to HAART treatment adherence and to continuity of care

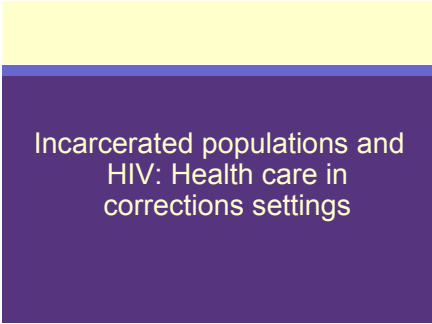
Slide Note

All of us working in the corrections setting will encounter patients with palliative care needs. Many of the patients with HIV have a history of poor general health and poor HIV care and adherence.

There is an aging population in part due to the longer sentences, mandatory sentencing laws and “three strikes and you're in” policies. And many of those patients are living to have chronic illnesses. Although we have a lower death rate from AIDS now since the advent of HAART, inmates are living with HIV and co-morbidities, and may have significant palliative care needs throughout their illness and at the end of life.

Although inmates have a constitutional right to health care, repeated incarcerations may interfere with quality HIV care. HIV+ status may be a liability in some settings, preventing work for money, stigma in housing or care, and vulnerability among other inmates. On the other hand, some HIV+


inmates get the most and best care for HIV disease in prison. Implications of both of these realities provide challenges to adherence, transitional care, and chronic care of co-morbid conditions such as hepatitis C as well as attention to complications of HIV drug therapy.



Incarcerated populations and
HIV: Health care in
corrections settings

Slide Note

This section will provide an opportunity to consider the characteristics of incarcerated populations and the health care settings in prisons and jails.



Institutional differences

• **Jails**

- County or City operated
- rapid turnover of inmates from arrest to bail or sentencing
- Shorter sentences than prisons usually
- Some jails rent housing for state inmates
- Many jail inmates have not been convicted of the crime for which they were arrested
- Usually people are jailed in or near home community, and always in area where they were charged or are being tried.

Slide Note

Palliative care of HIV patients occurs mostly in Federal or State prisons, but jails may see patients with palliative care needs too. Jails may deal more in the symptom management and the areas of psychosocial and spiritual needs. Some large jails have instituted hospice programs, utilizing outside hospice contractors to provide services in designated infirmary beds as needed.

Institutional differences

• Prisons

- State and Federal
- House sentenced inmates
- Longer sentences
- Population of inmates better known to staff, although inmates move around from one prison to another for security reasons
- Often inmates incarcerated far from home community

Slide Note

State prisons are organized by security status - low, medium, or maximum - by gender - and by specialty, for example, intake center, classification, hospital prison, prison for elderly or mentally ill, re-entry centers, work camps, and sometimes holding centers. State Departments of Corrections are not consistent in policy from state to state. Some prisons systems isolate HIV+ inmates in a particular prison or in specialty dorms within a prison. Some indicate that specialty care can more effectively be provided in these setting. These isolated settings for HIV patients have been legally challenged in some states.

Institutional differences

• Youth Detention Facilities

- Operated by state or county jurisdictions,
- Educational, health care, and detention.
- For youth up to age 18
- Some youth charged as adults are in adult prisons

Slide Note

No palliative care programs were found in these settings, but infectious diseases and mental health issues in youth in detention are significant. Rates of STDs are particularly high. Many incarcerated juveniles have parents who are incarcerated. Significantly many incarcerated adults were incarcerated as juveniles. So the prevention and public health implications are very real in this population.

HIV in corrections: evolution of an epidemic

- Reaching marginalized populations
- HAART
 - Decreasing AIDS deaths
 - Chronic illness models
 - Long term side effects of PI therapy
- Treatment failure
- Late stage –
 - Palliative care, end of life, and hospice

Slide Note

The history of HIV in corrections shows an evolution that parallels the history of HIV in the general population. Increasingly, the populations most in need of care are marginalized populations, including women, juveniles, minority, adolescents, rural populations, younger men who have sex with men. In the era of HAART, we see decreasing AIDS deaths, and a chronic illness model, so palliative care needs include treatment of HIV-related conditions as well as side effects of PI therapies. Palliative care is also needed if treatment fails, and when patients are in late stage AIDS. At this point, palliative care will include end of life care and may include hospice.

Current rates of HIV and HCV

- Rates of infectious disease higher in corrections than general population
 - Hepatitis C is 9 times higher
 - HIV is 6 times higher

DeGroot, A 2003

Slide Note

We also must consider HIV palliative care in corrections simply because of the high prevalence rate. The rates of HIV and other infectious diseases are higher among individuals moving in and out of corrections facilities than in the general population. For example, hepatitis C is 9 times higher in corrections than in the general populations, and HIV is 6 times higher.

The Health Status of Soon-To-Be-Released Inmates

NCCHC report in April, 2002*

- In 1997, 20-26% of all HIV-infected people served time
- In 1996, 29-32% of all Hepatitis C infected people served time

*The Health Status of Soon-To-Be-Released Inmates: A Report to Congress, NCCHC, April 2002

Slide Note

In 1997 Congress requested the Department of Justice to investigate the burden of disease in corrections. In April of 2002, the National Commission on Correctional Health Care produced a report of their findings which has some useful information about the prevalence of HIV in corrections. For example, the commission estimated that in 1997, 20 to 26% of all HIV-infected people served time.

Characteristics of incarcerated populations

- 2003: 2.2 million persons in U.S. jails, prisons, and juvenile facilities
- Proportion of incarcerated women is growing
- Shared risks for disease and incarceration
- Significant physical and mental health issues
- Incarcerated have poor access to health care prior to incarceration.

Slide Note

Incarcerated populations are changing in several ways. In addition to an overall growth in numbers of inmates, the proportion of incarcerated women is increasing. Patients in this population are more likely than those in the general population to have engaged in HIV risk behaviors such as substance use, unprotected sex, sex for drugs or money, and these behaviors overlap with risks for incarceration. There are other important physical and mental health issues, including histories of trauma, chronic illness, infectious diseases, and mental health disorders. This population also more than the general population tends to have poor access to health care prior to incarceration, and for some inmates, incarceration may be the first opportunity for primary or chronic health care.

Characteristics of institutions

- No standardized systems of record-keeping
- Primary mission custody, not care
- Focus on punishment, not improvement of health status
- Health care services over-burdened
- Society and taxpayers send message to punish rather than rehabilitate.

Slide Note

Individual correctional systems are reluctant to share their data because of fear of liability, competing health contractors, and security issues. Message from the public and elected officials is often punitive. Compassionate care programs are often discouraged. The nursing shortage is real in corrections facilities. Staff turnover of custody, medical, and other staff make service provision a challenge.

Corrections is part of the community

- Approximately 12 million releases each year, mostly from city/county jails (Bureau of Justice Statistics, November 2004, NCJ 205335)
- Most prisoners or inmates will return to the community
- Corrections interventions benefit public health
 - Correctional facilities crucial for risk-reduction, prevention and treatment interventions
- Collaborations among correctional, public health, and community organizations are needed

Slide Note

Incarceration presents an opportunity to improve community health – through prevention, risk reduction, and treatment interventions. It's where the disease is! Interventions will benefit not only inmates, their families, and partners, but also the larger public health. Most prisoners or inmates will return to the community - this differs from public perception.

Palliative care of HIV+ inmates in corrections settings

Palliative Care of the Incarcerated

- No consistent record keeping about:
 - Where terminally ill inmates are housed
 - How/where inmates die
- Care for terminally ill inmates in corrections settings:
 1. Services in inmate setting – majority of inmates receive services in custody
 - Care in a formal prison hospice program
 - Care in a contracted local community hospital
 2. Compassionate release from custody

Slide Note

One of the major challenges in addressing palliative care in corrections settings is the lack of consistent record keeping about housing and care of patients at end of life. There are 2 ways terminally ill inmates can be cared for. One is compassionate release, in which an inmate may formally request a termination of sentence and release to the community because of health status. This process involves formal process through the prison system, often the parole or probation boards, and then the governor. The majority of terminally ill inmates will not receive compassionate release before they die. Their request may not be processed quickly enough, and they may die or end up in a hospital before release can happen. Or, their attempt to obtain compassionate release may be futile because of disrupted family relationships. In addition, the nature of their crime may prohibit compassionate release.

For most patients, end of life care will occur in the corrections setting, either through a formal prison hospice program, or in a prison infirmary or local community hospital. At some institutions, innovative services are evolving, such as partnering with community hospice programs.

Palliative Care of the Incarcerated

- An NIC survey in 1998 reported the range and extent of end-of-life programs in adult facilities
 - 11 states and USBOP operated prison hospice programs
 - 4 states, 1 municipal prison system, and Correctional System of Canada developing first hospice program
 - 11 states considering hospice programs
 - 9 states reported offering some palliative care outside of formal hospice

Slide Note

A 1998 survey of end-of-life care programs that were available in adult correctional facilities showed only 11 states with formal hospice programs, and a number of others considering or developing new hospice services.

Hospice in corrections

- National hospice movement targets needs of terminally ill.
- Focus is on effectively managing pain and other symptoms rather than curing the illness or disorder.
- Hospice is “an interdisciplinary comfort-oriented care that allows seriously ill and dying patients to die with dignity and humanity with as little pain as possible in an environment where they have mental and spiritual preparation for the natural process of dying.”
- Increasingly applied in corrections settings

National Prison Hospice Association

Slide Note

The National Prison Hospice Association has provided a definition of hospice, incorporating the ideas of comfort orientation, dignity, humanity, minimum of pain, and in “an environment where they have mental and spiritual preparation for the natural process of dying.”

The GRACE Project (Guiding Responsive Action in Corrections at End-of-Life)

- Collected information on end-of-life programs in Federal BOP and 14 state DOCs.
- Analyzed challenges to providing quality end of life care in corrections settings
- Compiled best practice program components

Ratcliff, 2000

Slide Note

One of the major research projects addressing palliative care in corrections is the GRACE Project, a Robert Wood Johnson Foundation *Promoting Excellence in End-of-Life Care* program. It began in 1998, led by Volunteers of America, a national non-profit human service organization. There are a number of corrections palliative care programs around the country that can be traced to the GRACE project. This project analyzed the challenges to providing quality end of life care in corrections settings, and compiled a profile of program components that constitute best practices.

Challenges to providing quality end-of-life care in corrections settings

- Prisons promote conformity v. individual care planning
- Communication and health care delivery may be complicated by focus on security
- Crowding, inmate classification, and unstable staffing may conflict with treatment plans
- Health staff usually provide urgent and/or primary or chronic care; may need palliative care training
- Continuity of care is difficult to achieve in corrections settings

Ratcliff, 2000

Slide Note

Some of the challenges to end of life care are the same as those for general health care, such as the tendency to promote conformity which may be in conflict with individualized health planning, challenges to involvement of family, and focus of custody staff on security rather than service delivery.

In some states, the security designation is based on the crime that was committed, and this classification will determine the flexibility an inmate may have for their treatment plan.

Challenges to pain management

The health care provider is likely to have experienced:

- Inmates manipulating providers to obtain narcotic analgesics and other medications
- Sale or theft of prescribed medications
- Inmates being robbed, assaulted, or threatened by other inmates for meds
- Lack of full disclosure by inmates of health problems or practices

Slide Note

Pain management is an important element of palliative care, and correctional settings pose special challenges. Specifically, the trust relationship between provider and patient may be strained because of a number of factors. From the provider perspective, there may have been experiences with manipulation, sale or theft of medications, inmates being threatened or hurt by others, and a lack of disclosure of health problems or practices. Managing pain in a patient who has a history of substance use can be challenging and requires a thorough assessment of both pain and current substance use.

Trainer Suggestion

You may wish to include material from the module, “Pain management for patients with a history of substance use”, including powerpoint slides and trigger tape with discussion questions.

Challenges of palliative care at end of life

- Punishment mission conflicts with compassionate care for dying inmates
- Litigation and liability concerns promote use of aggressive management, even if the patient does not want it.
- Bias that an inmate dying is a negative event
- In-custody death may trigger investigation and negative consequences for administrators

Slide Note

One of the challenges to palliative care in corrections is the bias that an inmate dying in a correctional facility is a negative event. Prison death may trigger State level or FBI investigation, autopsy, and negative consequences for local administration. So there may be a tendency on the part of prison administration to “divert” patient death away from the corrections setting. Fear of legal challenges from inmate families may make prison administration initiate heroic measures, such as CPR or late stage treatments, fluids, intubation, or antibiotics or chemotherapy - even if these are futile and against the patients wished for a peaceful death.

“Diversion” from hospice may result in disrupted care

- To avoid in-custody death, administration may:
 - Attempt to obtain compassionate release, even at the last days of terminal illness
 - Send terminally ill inmates to local hospitals for care
- Placing the dying inmate in isolated and potentially hostile settings
- Interference with continuity of care
- Disrupting medical plan of care
- Sudden release from custody without plan for care

Slide Note

As palliative care and hospice care become more of a standard of practice in corrections settings, advance directives, effective pain management, and volunteer and visitor programs will be more common. This standard will prevent the sudden shifting of dying patients to an out of prison hospital setting for death. Palliative care strategies have been shown to be cost effective and good public relations for the prison.

If sudden transfers to local or prison hospitals does occur, pain management in particular may be disrupted.

Advance Care planning

- Advance Directives
 - DNR issues in a setting of power disparity-can be ambiguous
 - Effective advance planning can avoid going to a community hospital in shackles, under guard, to die alone.

Ratcliff, 2000

Slide Note

Although advance care planning is an essential element of palliative care, in the corrections setting there are some serious challenges. Advance directives require informed consent and free choice. In a corrections setting, the inmate-patient is essentially powerless and dependent on custody and medical staffs for all care. Extreme caution must be used to avoid any sense of coercion.

If a DNR is in place in a setting where either palliative care philosophy or hospice is in place, the inmate may die in peace in the presence of family, including inmate family. Otherwise, he or she may be shipped to a contract local hospital or a state prison hospital to die alone, among strangers, often shackled to the bed and under guard.

Family issues

- Disruption of inmates 'corrections family' relationships
- Regulations on visitors restrict inmate volunteer and family involvement
- Family's and friends' fears and/or legal issues that prevent visitation
- Perception that an inmate dying in prison reflects neglect
- Underestimation of positive prison relationships

Slide Note

Some of our patients may have become estranged from their families of origin, and after spending years in an institution, may have developed close relationships with other inmates – these become family-kinds of relationships and can be very important. So when we think of palliative care and the importance of family involvement, it's important to consider these 'corrections family' relationships. These may be disrupted by moving patients to facilities away from their "home" institution. Even when the patient is not moved, there may be restrictions that make visitation from volunteers and family very limited. Other kinds of family issues include the possible perception by family members that dying in prison represents medical neglect, or the perception by family members that the prison relationships, including those with prison health care staff, chaplain, and other inmates, are not important.

Legal rights

- Health care of convicted felons will occur at a standard equal to that in the community. It is a Constitutional right. *Estelle v. Gamble*, 429 U.S. 97 (1976)
- The courts have distinguished between punishment and brutality and upheld responsibility to provide health care for prisoners.
- Corrections developed guidelines and policies. Prisoner and advocacy groups monitor practice. Institutions which are not meeting standard risk legal and fiscal liability.
- Delivering competent medical care in corrections is in society's best interest. (Byock, I. 2002)

Slide Note

Inmate patients have a constitutional right to a community standard of health care. That increasingly means that inmates, with high rates of infectious disease, have access to care for HIV/AIDS, Hepatitis C, and chronic care for diabetes, heart disease, and other problems. Change often occurs in corrections settings as a result of litigation, as in the case of *Estelle v Gamble*.

National corrections health care organizations – such as the American Correctional Health Services Association (ACHSA), and National Commission on Correctional Health Care (NCCCHC) develop standards, provide accreditation of corrections health care units, and hold national and regional educational conferences for staff.

Positive outcomes

Positive outcomes: NIC study in 1997

Advantages of hospice approach in the corrections environment.

- Improved quality of life/experience of death
- Improved quality of medical care
- Benefits to staff and inmates
- Benefits to inmates' families and friends
- Cost benefits - decrease trips to outside hospitals
- Decreased security issues
- Good public relations with community

Slide Note

As palliative care approaches become more common in prisons and jails, these changes are perceived as positive by corrections administration and staff and the general public. Care for inmate patients can be seen as more of an appropriate standard than as a barrier to 'punishment.'

Increase in end-of-life programs in corrections

- 30 months after NIC survey, the GRACE Project conducted a new inventory of correctional hospice and palliative care programs.
 - Number of states with end-of-life programs in place or under development doubled.
 - Number of states with at least one hospice program in place increased from 11 to 19 .
 - Number of states with an end-of-life program under development has gone from 4 to 14.
 - 9 states with programs in place have plans for additional programs.

Ratcliff, 2000

Slide Note

This slide shows some of the progress that has been made in palliative care in correctional settings since the 1998 NIC Survey.

Models of Care and Best Practice Standards for Palliative Care of HIV + Inmates in Corrections Settings

End-of-Life Care Standards of Practice for Inmates
in Correctional Settings,
GRACE Project

- Profile of Program Components
 - Involvement of inmates as hospice volunteers
 - Increased visitation for families, including inmate family
 - Interdisciplinary Team
 - Comprehensive plan of care
 - Advance care planning
 - Training in pain and symptom management,
 - Bereavement services, and
 - Adaptation of the environment for comfort.

Ratcliff, 2000

Slide Note

As hospice care and palliative care programs increase in numbers, these components of care are in place in many settings. This implementation requires changes in the corrections setting, staff, and the community.

Examples of successful palliative care programs

- Oregon Department of Corrections
- Broward County Jail, Ft. Lauderdale, FL
- Federal Medical Center, Ft Worth, TX
- The Louisiana State Penitentiary Hospice Program

See reference list.

Slide Note

Some of the successes in palliative care services in correctional facilities include:

The Oregon Department of Corrections, a GRACE project which is working to implement hospice units in all prisons.

The Broward County Jail developed a hospice program as a result of increasingly longer sentences for terminally ill inmates. Hospice beds are designated in the infirmary and hospice services are contracted with a local hospice in Boca Raton.

The Federal Medical Center in Ft Worth, TX has had a hospice program, including one for women for many years. Other Federal prisons are replicating this model.

The Louisiana State Penitentiary Hospice Program is an interdisciplinary team program that provides palliative care to inmates at the state's all-male, maximum security prison in Angola, LA. This program, in contrast to Broward County, operates the hospice with corrections staff and volunteers.

Summary

- Palliative care is becoming a standard of care in corrections
- Palliative care needs of HIV+ inmates are increasing
- Corrections setting provides challenges to providing palliative care
- Increasing numbers of corrections settings are establishing high quality programs

Slide Note

In summary, palliative care is increasingly becoming a part of the standard for health care in corrections. At the same time, the palliative care needs of inmates, and in particular HIV+ inmates are increasing. While the corrections setting does provide challenges to meeting this standard of care, increasing numbers of settings are beginning to adapt their services to include palliative care.

Contributors

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Suggested Handout

West, J. Room Number Six, *Innovations in End-of-Life Care*, 2000;2(3), www.edc.org/lastacts

Evaluation Forms

We've developed evaluation forms to use with our training modules. They consist of unique identifier information about the participant, and questions aimed at gaining information about participant satisfaction and program effectiveness. You may want to adapt these forms and questions to your own evaluation needs.

- ▶ [Pre-Training Survey](#)
- ▶ [Post-Training Survey](#)
- ▶ [Follow-Up Survey](#)

* Please refer to [Evaluating Your Training Session](#) for more information.

Palliative Care of the HIV Positive Patient in the Correctional Setting

Pre-Training Survey

Thank you for completing this survey. Your input will help us improve our training program and will provide information about its effectiveness to guide future planning. Please answer these questions as best you can – if you're not sure of an answer, just give it your best try.

Date: ___/___/___ ID: Birth month: ___ Day: ___ Last 4 digits of SSN: _____

1. Please rank your current level of skill in the area of palliative care for HIV positive patients in correctional settings by checking one of the following numbers from 1 to 5:

Need more skill for basic competency		Adequate skill		Highly skilled
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. What is your level of personal comfort with working with a patient/client in this capacity?

Extremely uncomfortable		Somewhat comfortable		Extremely comfortable
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Post-Training Survey

Thank you again for your input to help us improve our training program and guide future planning. As before, please answer these questions as best you can – if you’re not sure of an answer, just give it your best try.

Date: ___/___/___ ID: Birth month: ___ Day: ___ Last 4 digits of SSN: _____

1. Please respond to the following questions regarding this training using the scale below:

	Not at all		Somewhat		Very much
Did the training hold your interest?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you learn things in the training that will be useful for your work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How understandable was the material presented to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Were the educational materials, such as slides or handouts, useful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How responsive was the trainer to the audience’s questions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you feel the trainer’s presentation was culturally sensitive?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. What were the strengths of this presentation?

3. How could we improve this presentation?

4. Would you recommend this training to someone else? Yes No

5. Please rank your current level of skill in the area of palliative care for HIV positive patients in correctional settings by checking one of the following numbers from 1 to 5:

Need more skill for basic competency		Adequate skill		Highly skilled
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. What is your level of personal comfort with working with a patient/client in this capacity?

Extremely uncomfortable		Somewhat comfortable		Extremely comfortable
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. What do you anticipate doing differently in your work as a result of this training?

8. How much did this training help prepare you to do the following:

	Not at all		Somewhat		Very much
Provide primary end-of-life care for patients with HIV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provide education and training to other clinicians on end-of-life care issues?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advocate for better palliative care in your workplace?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. Would you be willing to be contacted in one month for a brief follow-up? Yes No
If yes, what is your email address? _____

10. Please write any additional comments, thoughts, or suggestions here. We appreciate your taking the time to complete these surveys. Thank you very much!

Palliative Care of the HIV Positive Patient in the Correctional Setting

Follow-Up Survey

[This is a sample of a letter to send out to your training participants 4-6 weeks after the training.]

Hello!

About a month ago, you attended a presentation on Palliative Care of the HIV Positive Patient in the Correctional Setting, given by [presenter].

Thank you for participating in our evaluation. Your survey responses have been very helpful for planning the next steps in our training program. Thanks also for agreeing to answer some follow up questions for our evaluation. If you have a few minutes to answer the following questions, it would be very helpful.

Now that a month has gone by...

1. What changes, if any, do you feel you have made in your work as a result of this training session?
2. Please rank your current level of skill in palliative care for HIV positive patients in corrections settings:
(1=Need more skill for basic competency; 3=Adequate skill; 5=Highly skilled)
3. What is your overall rating of the quality of the session you attended?
(1=Poor; 3=Average; 5=Excellent)
4. Please write any additional comments, thoughts, or suggestions here.

Please contact me [your contact information here] if you have any questions about our project or if you'd like us to keep you informed of any upcoming training sessions. Thanks again!

Resources

Articles

Alexander, CS (2002), Palliative care in resource-constrained settings for people living with HIV and other life-threatening illnesses. *Palliative Care for Disenfranchised Populations*. Proceedings from the 14th International Congress on the Care of the Terminally Ill, Montreal, Canada.
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Anno, B. Jaye, et al, (2004). *Correctional Health Care: Addressing the Needs of Elderly, Chronically Ill, and Terminally Ill Inmates*. National Institute of Corrections, 2004 edition.

Best Practices and Standards of Care for Palliative Care in Corrections Settings
See Standards in:

Journal of Correctional Health Care, Volume 9 Issue 2, Summer, 2002. End-of-Life Care in Corrections: A Special Symposium. Appendix

American Public Health Association Final Draft Standards: Palliative Care
Hospice Care, End-of-life Decision Making, 207-217

National Commission on Correctional Health Care Standards for Health Services in Prisons and Jails: Special Needs Treatment Plans, Management of Chronic Disease, Care for the Terminally Ill, End-of-Life Decision Making, 219-231.

Bick, J. Managing pain and end-of-life care for inmate patients; The California medical facility experience, *Journal of Correctional Health Care*, vol 9, issue 2, Summer 2002, pp131-148.

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Byock, I, Dying well in corrections: why should we care? *Journal of Correctional Health Care*, vol 9, issue 2, Summer 2002, pp 107-118. [PubMed Abstract](#)

Cahal, W. The birth of a prison hospice program. *Journal of Correctional Health Care*, vol 9, issue 2, Summer 2002, 125-130.

Craig, E. & Ratcliff, M. Controversies in correctional end-of- life care, *Journal of Correctional Health Care*, vol 9, issue 2, Summer 2002, 149-158.

Craig, R. Easing the passage: the chaplain's view of prison hospice. *Journal of Correctional Health Care*,

vol 9, issue 2, Summer 2002, 159-168.

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http://hab.hrsa.gov/publications/palliative_care_in_resource_constrained_settings.htm

DeGroot, A.S. & Merchant R.C. Hepatitis B, C, and HIV post-exposure prophylaxis in correctional settings. *HEPP Report*. July/August 2003 6:7&8. pp1-5.

FMC – Fort Worth: A prison Hospice Model for the Future. National Prison Hospice Association Newsletter 3. <http://www.npha.org/ftworth.html>

Harrison, P.M. & Beck, A.J. *Prisoners in 2003*. *Bureau of Justice Statistics Bulletin*. November 2004, NCJ 205335. US Department of Justice, Office of Justice Programs.

Hospice and Palliative Care in Prisons: Special issues in corrections. September 1998. U.S. Department of Justice. National Institute of Corrections Information Center. Longmont, Colorado.

Incarceration of the Terminally Ill: Current Practices in the United States. A Report of the GRACE Project, Volunteers of America, 1660 Duke Street, Alexandria, VA. May 1, 2001.

Maruschak, L. M. HIV in Prisons and Jails. *Bureau of Justice Statistics Bulletin*. December 2004, NCJ. 205333.

NCCHC Standard for health Services in Prisons and jails (2003), *Journal of Correctional Health Care*, vol 9, issue 2, Summer 2002, pp 219-223.

O'Neill, J.F, Selwyn, P. S., & Schietinger, H., eds. (2003). *A Clinical Guide to Supportive & Palliative Care for HIV/AIDS*. US Department of Health and Human Services, HRSA/HAB.

Ratcliff, M. Dying inside the walls, *Innovations in End-of-life Care*, 2000;2(3). www.edc.org/lastacts

Ratcliff, M, Craig E (2004) The GRACE Project: Guiding End-of-Life Care in Corrections 1998-2001. *J Palliat Med* 7(2):373-9. [PubMed Abstract](#)

Taylor, P.B. Grief and hospice care for the correctional community: training, nurturing, and mentoring of staff. *Journal of Correctional Health Care*, vol 9, issue 2, Summer 2002, pp169-174.

Tighe, P. Broward county cares for terminally ill inmates: Hospice in the jail. Large Jail Network – LJN Exchange 2002. Annual Issue 2002. National Institute of Corrections, US Department of Justice.

Websites

The American Academy of Family Physicians

<http://familydoctor.org/003.xml>

and

American Geriatrics Society

http://www.americangeriatrics.org/education/forum/advance_dir.shtml

Both of these sites offer guidelines for protocols and the education of clinicians, security, and administrative personnel, legislators, and the public on end of life decision making.

American Correctional Association - Called for...”Hospice services for terminally ill offenders supported by a compassionate release program for those who qualify.”

<http://www.aca.org/>

and

Corrections.com

<http://www.corrections.com/>

Both of these sites have access to educational resources and guidelines on palliative care and end of life decision making

The GRACE Project: Guiding Responsive Action for Corrections at End-of-Life. Promoting Compassionate End-of-Life Care in Prisons and Jails. Volunteers of America is lead organization coordinating Robert Wood Johnson Foundation funded project that sponsors programs at multiple jail and prison sites.

http://www.graceprojects.org/graceprojects/grace_in_prisons.htm

National Commission on Correctional Health Care.

www.ncchc.org

National Institute for Corrections

<http://nicic.org/>

Offer guidelines for protocols and the education of clinicians, security, and administrative personnel, legislators, and the public on end of life decision making.