Hospice Medicine in the Prison-Missouri Experiment

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Objectives
- We will discuss:
  - Hospice/Palliative medicine values
  - Correctional issues
  - Inmate volunteers/responsibilities
  - Volunteer/offender training

Huntsville, Texas
- Warden James Jones said “it’s important, because they’re people still. Of course they committed a crime and they have to do their time, and they end up dying while they’re in prison, but they’re still human beings”

What is changing?

- Inmate populations are older and much bigger
- Judges directed to longer mandated sentences for Federal, State and local
- "Three strikes" laws
- Inmates have low literacy and low health literacy
- Inmates sicker than population

Correctional demographics

- Chronic diseases: HIV/AIDS, COPD, ESRD, ESLD, hypertension
- Causes: substance abuse, addiction, limited access health care, poverty, homelessness, undiagnosed/untreated mental illness

Ethical Considerations

- Guaranteed basic level of health care-Eighth Amendment and Due Process
- "Punishment and care are generally incompatible"
- "Dying alone, in pain, without comfort, exceeds the boundaries of the permissible"
  - Dubler and Heyman
Ethical Considerations

- 609,800 prisoners (State/Federal in 2012)
- 3,409 prisoners die in prison and 960 die in jail each year (2009)
- 32% suicides, 21% heart disease, 47% chronic disease
- 125,000 inmates > 50 years old
- 35,000 inmates > 65 years old
- Prisoners age more rapidly (thought to be ten-year differential in physiologic age)

Ethical Considerations

- Limits on judicial discretion in sentencing
- "get-tough-on-crime" campaigns
- "three-strikes-and-you-are-out" laws
- Mandated longer sentences for drug-related convictions

Ethical Considerations

- Problems unique to older inmates
  - Vulnerability to predator abuse
  - Difficulty mixing with younger inmates
  - Need for special accommodations (disability)
  - Special programming
  - Proportionate consumption of health care
  - Guaranteed access to health care
Ethical Considerations

- Value of persons
  - Treat others as we wish to be treated
  - Treatment not contingent on social status, social worth, current condition, criminal record
  - Dying inmate to be treated as a **human being**

- Aristotelian thought on justice
  - **Distributive justice** = "giving every person his/her due"
  - Respect for rules of interaction among people
  - **Corrective justice** = "the setting right of a wrong"
    - Notion governs our system of criminal punishment
    - Limits freedom

Challenges of Prison Hospice

- Administrative rule vs. individual
- Crowded condition of prisons
- Drug abuse/pain management concerns
- Liability/litigation concerns
- Emphasizing security
- Frustrating treatment plans
Guiding Responsive Action in Corrections at EOL (GRACE)

- Pain and symptom management
- Family visitation/involvement
- Training
- Inmate isolation
- Volunteer involvement
- Attitude (required neutral zone)

Components of Best Practice

- Involve inmate volunteers
- Increased visitation for “family”
- IDT (MD, RN, Chap., SW and security)
- Comprehensive plans of care
- Advance care planning
- Training pain and symptom management
- Bereavement services

Inmate Volunteers

- Apply and then selected
- Trained and supervised, medical and security staff
- Responsibilities:
  - Companionship, conversation, feeding, hygiene and personal grooming, writing letters, spiritual support, telephone, moving
  - Turning, lifting, bathing, linens, dressing
Specific Criteria

- Sufficient time for training and participation
- No serious disciplinary issues
- No drug/substance abuse issues
- No suicide attempts
- Appropriate reading/writing level
- Appropriate security classification
- Successful physical/psych exam
- NPHA operational guidelines

Training Prison Inmates

- Experience of dying
- History hospice
- Scope of program
- Prison mission
- Roles of parties
  - Patient/family, inmates, correctional officers, administration, politicians, courts

Who cares how inmates die??

- Humane treatment vs. they deserve it
- American courts affirm community LOC
- Chronically ill patients already confined by disease, disability, confinement

“Precepts of Palliative Care”
- Respect for patient autonomy
- IDT approach
- Care for dying patient with family/friends
- Intensive symptom management
- Goal is quality of life
- Support for patients “inner self”
- Bereavement support for families

Inmate Volunteers
- Bond between inmates
- Share incarceration/separation family
- Share fear of dying in prison
- Share fear of dying alone

Prison Hospice Challenges
- Restrictions to inmate/staff movement
- Limited access urgent care
- Restricted pharmacy formularies
- Impediments to dispensing meds “PRN”
- Limited patient autonomy
  - Advanced directives
  - DNR
Differences

- Medical Hospice
  - Forgo directed therapy
  - Patient driven care
  - Aggressive sx control
  - Patient driven
  - Prognosis < 6 mo
  - Family involvement
  - Bereavement mandatory
  - Regulations/insur.

- Correctional Hospice
  - not required
  - Same
  - Same
  - Policy driven
  - Not required
  - Variable
  - Variable
  - Not a factor

Angola

- 85% (4300) of 5108 inmates will die there
- Largest max security prison US
- 18,000 acres with 23 mile perimeter
- 20 miles from nearest small town
- Main prison and 5 camps
  - R.E. Barrow, Jr Treatment Center for all medical and hospice care in main prison

The beginning

- 1996, partnership between Angola and University Hospital Community Hospice
- Idea of Burl Cain, Warden
- Patient care by prison staff/inmate volun.
- Congruent with national standards (NHPCO)
- Verbal agreement in 1996 still stands
Program Opens 1988

- Admission to any inmate who requests it
- Life expectancy < 6 months
- Must have DNR
- IDT – includes security and classification
- Family-defined by the PATIENT
- Volunteers-recruited and trained

Barriers

- Distance, New Orleans 130 miles to prison
- Inmates worry about MD’s given up and withdrawn care
- Hospice must be pt centered/compassion driven
- Mixed attitude inmates and staff

Volunteer Opportunities

- Three categories
  - Administrative-organization, education
  - Assist patient-support and companionship
  - Vigil-sit with patient as they actively die
  - Give their own time, no pay
  - Opportunity for personal growth
  - Introspection, self awareness
  - Sensitivity to others needs
Bereavement

- Increased awareness of EOL issues
- Importance of ritual in grieving process
- Formal funeral services held 2000
  - Free people and inmates together
  - Held in the Chapel
  - Chapel site of annual memorial

Budget

- One full time nurse (volunteer coordinator/case manager)
- Extras (food treats, toiletries, religious articles)- inmate contributions
- Training provided Hospice for no cost
- Hospice care more humane and LESS costly

Angola Hospice

- All receive specialized care
- Families provided support/consolation
- Staff feels rewarded
- Prison population gains peace of mind
- Inmate volunteers gain self-esteem
- Institution saves $ and improves image
Hospice Requirements

- Any medically appropriate inmate
- <6 months to live with signed DNR
- Prevent legal action by inmates
- IDT (Hospice Medical Director, Attending, RN case manager, Social Worker, Chaplain, Volunteer Coor., Bereavement Coor., Classification Officer, and Security)

Missouri Prison Hospice Committee

- Met every other month
- Involves whole IDT (MD, RN, Chap, SW and prison personal)
- Setting up training course for Prison personal and Inmate volunteers

Interdisciplinary Team

- Corrections
- RN
- Social Worker
- Chaplains
- MD
- Hospice Offender Volunteers
Hospice Management in the Prison

- 1 hour talk given to all the Medical Directors of all the prisons in Missouri
- Promoted a lot of discussion about end of life issues with MD's, & Chief MD
- Talked about using opioids, benzodiazepines and anti-psychotics
- Talked about signs of the EOL
- Given 3 years ago

Short films—if we have time

- “Prison Terminal: The Last Days Of Private Jack Hall”
- “Angola Prison Hospice: Opening the Door”
“Each of us must face our own Siberia,” she says. “We must come to peace within our own isolation. No one can rescue us. My cancer is my Siberia”

Terry Tempest Williams (1991) talking about her mother’s illness/death

Prison Hospice Training
JAY RISEMAN MD, FACS, FAAHPM
PRESENTED TO WARDEN’S MEETING MARCH 2016

Journaling

- Offenders were given instructions about journaling
  symptoms, signs, changes
What is an Offender Volunteer?

The function of the hospice volunteer is to provide companionship, assistance and comfort to a dying patient. The volunteer will assist with the medical care team in their efforts to maintain the psychological and spiritual well being of the terminally ill patient.

Duties of Offender Volunteers

- It is the duty of the volunteer to attend a care conference every fourteen days to review and update patient care with care team.
- Volunteers can coordinate their activities and provide an ongoing picture of the patient’s condition by documentation in the journal, a running anecdotal record on each patient detailing needs, activities, moods, concerns, etc. The journals are kept at the patient’s bedside and are read by each volunteer upon arrival; comments are added during each shift by the departing volunteer.
Objectives

- Pain/dyspnea management
- Nausea management
- Agitation management
- Increased secretions management
- Other symptoms
- Whole person care, emotional, spiritual and physical elements
Ethical and Decisional Issues in the Prison setting
JAY RISEMAN MD FACS
KANSAS CITY HOSPICE & PALLIATIVE CARE
2015

Objectives

- Discuss Confidentiality
- Discuss Patient Rights
- Discuss Advanced Directives

Some matters discussed during this presentation are handled by staff or medical staff. Offender hospice volunteers are to provide companionship, assistance and comfort to a dying patient.

End of Life (EOL) issues are things you may see when a person receives a terminal illness and/or is nearing their end of life.

You may see one issue, several or none at all. They may or may not be things the patient has awareness of, can verbalize or acknowledge.
Identify EOL Issues:

1. **GUILT** – REMORSE OVER BEHAVIOR OR NEGLECT FOR WHICH WE CAN PERSONALLY BLAME OURSELVES.

2. **REGRET** – SECOND GUESSING OR HINDSIGHT (I.E.: UNINTENTIONAL NEGLECT; UNFORESEEN SIDE EFFECTS).

Grief and Mourning in the Prison Environment (as presented by VNA Health Care Hospice)

- Become aware of your own basic goodness and have confidence that you have something to give.
- Remember, the process of grief is healing and transformative.

Stress Management

BY BETH HULISKA

2014
What Is Stress?

According to the American Psychological Assoc., stress is “your body’s natural reaction to any kind of demand that disrupts life as usual.”

What Is A Stressor?

Anything that causes a change or need for adjustment can create a “stressor.”

- Segregation
- Transfer Facilities
- Getting married/divorced
- Public speaking
- Bad news from home

Positive Suggestions For Managing Stress:

- Sleep/naps
- Maintain awareness of unhealthy responses to stress in order to avoid them
- Listening to music
- Other ideas/suggestions? (Discussion)
INTRODUCTION

- Spiritual care is a vital part of “whole person” health care
- Very important in palliative (pain control) care and end of life (hospice) care
- Spiritual care is usually done by chaplains or volunteers
- Spiritual care is also offered to patients’ families and their caregivers
- Other members of the care team may also assist in giving spiritual care

BASICS OF HEALTHCARE CHAPLAINCY

- A chaplain supports all who need spiritual care, and may or may not be ordained
- A Healthcare chaplain is someone who is specially trained to help meet the spiritual needs of those with healthcare issues
- Chaplains are trained to respond to people of many different religious backgrounds and beliefs or no religious background or beliefs.
- Chaplains are responsible for the spiritual care of all assigned patients regardless of their religious and spiritual beliefs.
Cultural Guidelines at The End of Life
Jay Riseman MD FACS, FAAHPM
Melissa Bowers, Chaplain - MPRS
Prison Committee-Missouri
WRITTEN IN COOPERATION WITH THE MISSOURI DEPARTMENT OF HEALTH & MU CENTER FOR TERRORISM AND DISASTER 2015

What is “Culture”?

• “Culture” refers to beliefs, customs, and ways of living and expressing that are associated with a group or place
• Examples are religious beliefs, national customs, ethnic traditions, social standards.
• How people respond to death is often related to culture
• As a competent and caring hospice volunteer, it is important for you to be sensitive to culture your patient’s cultural preferences.

Cultural Basics to Remember
1. Ask your patient about their beliefs, traditions, and wishes and LISTEN
2. Don’t be afraid to ask the patient questions about their beliefs, traditions, wishes. Respond respectfully.
3. Keep focus on the patient’s beliefs and traditions, not yours
4. Respect their needs by complying with their preferences (within guidelines)
5. Talk with religious/ethnic leaders and other group members if you need more information about patient’s preferences
6. Do not offer opinions or discuss your beliefs unless asked by the patient.
7. Attitude is as important as words – hold a “sacred space” when you are at bedside.
8. Keep confidences – your volunteer service is a sacred trust.
ACTIVE DYING PROCESS

DYING PROCESS

- Usually begins some time before death actually occurs
- Everyone approaches death in his/her own way

ACTIVE DYING PROCESS

Signs of Death

- No breathing
- No heartbeat
- No response
- Release of bowel and bladder
- Eyelids slightly open
- Enlarged pupils
- Eyes fixed on certain spot
- No blinking
- Relaxed jaw
- Mouth slightly open

The body does not need to be moved until you are ready.
Evaluations

- Please see handout given to offenders
- In addition, testimonials of current hospice volunteers were elicited during the training
- Some were tear jerkers and others made all of us laugh
- Graduation—at the end all the offenders were given certificates and a tee shirt designed by an inmate, instructors received a shirt and great personal satisfaction

Offender Training

- JCCC – May 2015 - 30 offenders
- CCC – September 2015- 30 offenders
- Tipton – February 2016 - 4 offenders
- Southeast – March 2016- 20 offenders
- St. Joseph – April 8, 2016-16 offenders
- JCCC – June 10, 2016
- Cameron (CCC) – August 19, 2016
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- S. James ABC News Prison Terminal: Kidnappers Care for Murderers of EOC Dec 18, 2013