



**ANNUAL
HIV CONFERENCE**
of the Florida/Caribbean
AIDS Education and Training Center

May 13-14, 2011
Orlando, FL

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Palliative Care for Children/Adolescents with HIV/AIDS

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Disclosure of Financial Relationships

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Objectives

- Discuss the current knowledge about palliative care for young people with HIV/AIDS
- Describe ethical issues regarding palliative care
- Discuss the role and responsibility of the provider
- Identify how cultural, social and religious beliefs affect palliative care



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Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual).

<http://www.who.int/cancer/palliative/definition/en/>



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Definition

- **Palliative care is a treatment to:**
 - ✓ Prevent
 - ✓ Reduce
 - ✓ and/or relieve
- **the symptoms of a disease or disorder**
- It is offered **ALONG** with curative treatments throughout the course of an illness **and** at the end of life

Definition

- **Includes the following interventions:**
 - Physical
 - Social
 - Psychological
 - Spiritual
- **A multidisciplinary approach**
- **Is both a philosophy of care and the system for delivering it**

Literature Review

- **Historically, adults and children with cancer**
 - Improved outcome with access to palliative care
- **Little information on children/adolescents with HIV/AIDS**
 - 80% of those who died did not have access to DNR/hospice (2008 PACTG study)
 - No information on “palliative” care
- **Influence of**
 - HAART
 - Variable, unpredictable disease course
 - Social, economic, health disparities
 - Different expectations for treatment



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Models of Care

- **Hospice**
- **Hospital or institutional based**
- **Outpatient**
- **Community**
- **Family-centered**
- **Integrative, collaborative**
 - Early in diagnosis
- **Ongoing, disease-directed treatment as palliative**



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Ethical Issues in Palliative Care

- **Ethical Dilemma:** an irresolvable conflict of values in which all values or obligations cannot logically or practically be honored
- **Ethical Problem:** conflict between values of different persons involved
- **Ethical Relativism:** all values are true relative to the person or culture holding those values



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Ethical Issues in Palliative Care

- **Futile Treatment:** offers no benefit to the patient
- **Extraordinary Treatment:** care offers significant burden and only minor benefits
- **Justice:** determines on what basis scarce resources will be distributed
- **Beneficence/‘Do No Harm’** ... what is in a person’s good or best interest?
- **Autonomy:** component of respect for person...is the right of self determination, the right to make decisions about themselves



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Challenges

- Futility...when is enough...enough?
- Influence of culture and spirituality in end-of-life issues
- What to do when the staff are not ready to let go?



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End of Life at the Beginning of Life...Case Study

- Baby girl born Dec, 1989
- At 2 months of age, transferred to PR Medical Center from a private hospital due to severe respiratory distress and a CXR showing bilateral diffuse, fine, reticular opacification
- Mother is a 29 year-old G₄P₄A₀ who informed the physician in charge that she was afraid that “there could be something wrong with my daughter” because she just found out that the baby’s father was using illegal drugs



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Case Study

- She was admitted to hospital with diagnostic impression of PCP, later confirmed by BAL
- Started on TMP/SMX therapeutic dose
- Placed on oxyhood 100% oxygen
- CD4 count: 27 cells/mm³ and <1%
- No ARV's available



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Case Study

- HIV Elisa and Western Blot positive (mother and patient)
- 3 siblings tested negative
- Health care team decided to start the patient on Zidovudine in a “home-made liquid formulation”



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Discussion...

- What is the role and responsibility of the provider with family and patients?
- Which are her options, risks and or benefits?
- Should she be intubated if she deteriorates?

Case Study

Mom and Grandparents Decisions

- “Do everything you can...don’t let her die”
- “Keep her as comfortable as possible, please no pain!”
- “Intubate her if necessary”
- “Is it possible to use experimental drugs?”

Discussion...

- What are some of the cultural issues to be explored?
- What are you struggling with as a provider?



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Case Study

- After 4 weeks she was discharged home on AZT and TMP/SMX
- Improves gradually
- Never intubated
- One year later :
 - Patient had no hospital admissions
 - Reached milestones as expected
 - Gained weight adequately
- Her mother died when she was 2 y/o
 - She remained under her grandparent's care



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Case Study

At 4 y/o she traveled to the United States to visit her family

- After one week she developed general malaise, poor appetite and fever
- Was taken to ER and promptly admitted to intensive care unit
- ECHO revealed cardio-miopathy with very low ejection fraction
- Physician told grandparents that prognosis was very poor

Discussion....

- **Would you begin discussion with grandparents at this time to initiate palliative care?**

Case Study

- After three days, patient started to improve
- CD4 count **900 cells/mm³, 23%**
- One week later, was d/c from hospital
- After one month, returned back to PR
- Two months later, ejection fraction was 77%
- Physicians agreed that cardiomyopathy was not HIV related

Case Study

- Patient reached adolescence
- Now a 16 year-old in high school with plans to go to college
- Tired of taking medications
 - Viral load increased
 - CD4 decreased

EOL Decision-Making in the Context of Chronic Illness Paradigm

- **Adolescent's role**
 - Consider their rights and responsibilities
- **Caregivers' role**
- **Our role...**

Why is Palliative Care Important?

- It has made dramatic changes in patient care
- Signs and symptoms affect quality of life
- ARV has improved quality of life but we don't have a cure
- There are complex medical, psychological and social issues...what are these?

Spiritual Issues in HIV/AIDS Palliative Care

Addressing spiritual needs: “FICA” format

- **F**aith, belief, meaning
- **I**mportance and Influence
- **C**ommunity
- **A**ddress/Action in Care

Transitions.....

- **Most children prefer to be at home with family**
- **Family caregivers need training and support**
 - Physical care and comfort
 - What to expect as death approaches

Summary

- The process is complicated and emotionally challenging
- Palliative care provides the framework for holistic care from the time of diagnosis until patient's death
- Every clinician should be *familiar* with competencies in palliative care
- Communication is key

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