

Dealing with a Challenging Adolescent with End Stage AIDS

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Francois-Xavier Bagnoud Center (FXB) at UMDNJ

- **First patients with acquired immunodeficiency seen in 1978.**
- **Children's Hospital AIDS Program (CHAP) began in 1984.**
- **Closure of United Hospitals in 1997 resulted in CHAP move to UH and name changed to FXB Children Center.**

FXB at UMDNJ

- **Interdisciplinary program in Schools of Nursing, Medicine and Public Health with multi grant funding (NIH, CDC, State and Private)**
- **Currently follows ~ 70 perinatally exposed newborns/yr and manages 176 children with acquired HIV ranging in Age from 0 to 28 yrs.**
- **In 2007, out of 68 babies with known perinatal HIV exposure, 1 infant was documented with Perinatal HIV infection.**

FXB at UMDNJ

- Number of deaths of perinatally acquired HIV:
 - 1994: 35
 - 1995: 21
 - 1996: 14
 - 1997: 10
 - 1998: 3
 - 1999: 5
 - 2000: 3
 - 2001: 2
 - 2002: 1
 - 2003: 0
 - 2004: 2
 - 2006: 4
 - 2007: 0
 - 2008: 3 (but 2 deaths unrelated to HIV)
- Average age of deaths: 15.5 years.

Patient X Case History

- The patient was a 15 yr old AA female with multiple admissions for complications of perinatal HIV infection that included OIs (Disseminated Nocardia, Candida Esopagitis, repeated serious bacterial infections, suspect HIV dementia, possible Pul. Tbc).
- Last admission considered to have late, end-stage AIDS with history of non-compliance only seeking medical care when a problem became intolerable.
- Unfortunately was sexually abused as a child, mother was a HIV infected prostitute, IV multi-drug abuser with possible AIDS Dementia, constantly changing homes or homeless, all requiring involvement with Child Protective Services.

Patient X Case History: Continued

- **Mother often visited under influence ETOH and drugs and often verbally combative**
- **Her only other hospital visitor was an older sister who was employed and reasonable but estranged from mother.**
- **Her hospital stay was complicated by:**
 - **Anger and hostility to most all care providers,**
 - **Refusal to take medications and to allow physical examination,**
 - **Clinical deterioration requiring PICU transfer for central lines, A-line, intubation and use of pressers,**
 - **DNR on the day she died.**

Admission Lab data

- Viral load: 83,900 copies/ml and CD4+ count : 18 cells/ μ L
- CBC: Hct: 26, Hgb: WBC: 10.2 (47% segs, 46% bands, 2% lymphs
- Chest x-ray: right infra-hilar mass with subsequent studies revealing disseminated nocardia
- Rapid strep, blood culture, throat culture, and AFB: negative
- Urine culture: Staph. Epi 100-100,000 colony forming units
- SMAC: Na: 135, K: 3.3, Cl: 103, Bicarb: 21, BUN: 10,
- Creatinine: 0.6, Ca: 8.9, liver enzymes and bilirubin wnl

Patient Behaviors : Associated Psychosocial Disorders

Behaviors:

- Noncompliant: 1,4,6**
- Hostile/ Angry : 1,3,4,6**
- Verbally abusive to staff: 1,3,4,5,6**
- Uncooperative with treatment plan: 1,4,5,6**
- Refused all measurements, blood draws, and most medications: 1,2,3,4,5,6**

Psychosocial Disorders:

- 1) Anxiety Disorder, 2) Depression, 3) Fear,**
- 4) Oppositional Defiant Behavior (ODB),**
- 5) Social Isolation (SI), 6) AIDS Dementia**

Challenge in Management of Patient X

- Adolescents' stage of development
- Impact of: psychiatric disease, HIV dementia, unstructured environment, Substance using parent
- Complex drug treatments for: Pain, HIV-Infection, OIs and Psychiatric illness with related problems of poor adherence and development of resistant strains of HIV as well as issues with addiction fear and misuse of opioids
- What we can do to alleviate the situation ?

Interdisciplinary Interventions

- Palliative Care Consult
- Social Worker from HIV outpatient clinic
- Child Life team
- Chaplain
- Multiple interdisciplinary team meetings, w/ plan of care developed and revised often
- Psychiatry consult
- Placed on waiting list for an out of state facility that manages seriously ill adolescents with psychiatric co-morbidities

Youth with perinatally acquired HIV

- All these youths are confronted with their own physical disability, isolation, and stigma, as well as the illness and death of parents.
- Among adolescents that progress to AIDS, there is 15% risk of HIV Dementia/encephalopathy as well as a 20-25 % risk of less severe but still disabling HIV associated cognitive/motor disorder
- Currently in Pediatric HIV treatment centers 20% of surviving adolescents remained asymptomatic, have low viral loads and maintain CD4+ count above 500 cells/mm.
- Many are told of their infection only after they reach puberty, often through inadvertent disclosure and after they have become sexually active

What we can do better:

- **Adolescents' psychological and physical health needs should be addressed at the end of life in order to improve Quality of Life by giving:**
 - **Personal control**
 - **Normal activities**
 - **Communication and expression**
 - **Consistent caregivers and companionship.**
 - **Consent over medical and treatment decisions.**

Jones, Barbara. *Companionship, Control, and Compassion: A Social Work Perspective on the Needs of Children with Cancer and their Families at the End of Life.* *Journal of Palliative Medicine.* Vol 9, No 3, 2006.

Focusing on end-of-life care

- **One study found a 3-month discrepancy between when physicians and parents first realize that there is no realistic chance for the child's survival.**
- **Discussions about do-not-resuscitate orders have been reported as occurring only hours before the child's death, when parents are already taxed with the emotional burden of their child's suffering.**

Hinds, P., Schum, L., Baker, J., and Wolfe, J. Key Factors Affecting Dying Children and Their Families. *Journal of Palliative Medicine*. Vol 8, Supplement 1, 2005.

Lyon ME, Williams P, Woods ER, Hutton N, Butler AM, Sibinga E, Brady MT, Oleske JM; Do-Not-Resuscitate Orders and/or Hospice Care, Psychological Health and Quality of Life among Children/Adolescents with Acquired

Immune Deficiency Syndrome. *J Palliat Med*. 2008, Apr. 11(3): 459-469.

Focusing on end-of-life care-con't

- The majority of terminally ill children die in hospitals (50% to more than 80%).
- Up to 90% of those deaths occur in pediatric intensive care units after at least a week of hospitalization.
- Hospitals have the opportunity to define excellence in end-of-life care for children and adolescents.

Hinds, P., Schum, L., Baker, J., and Wolfe, J. Key Factors Affecting Dying Children and Their Families. *Journal of Palliative Medicine*. Vol 8, Supplement 1, 2005.

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Syndrome. *J Palliat Med*. 2008, Apr. 11(3): 459-469.

Opportunities for Improvement in the Care of Patient X

- Mini- Mental Status Exam upon admission or when behavior first seem inappropriate
- Early identification of HIV dementia
- Aggressive psychiatric and psychotropic management to establish a baseline from which competence can be estimated or patient wishes about care can be elicited
- Ethics consultation and structured, on-going support for staff
- Enrollment/consultation with Pediatric Palliative and End of Life Care program and if there is no program at the hospital, **START ONE!**