Providing Hope in the midst of Despair: A Person Centered Response to the AIDS Epidemic: Ethical Principles Moving Forward

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Most recently….
Catholic Deacon
Cumulative U.S. AIDS Cases
as of 2/83  N~1,000

Each point = 30 cases
Cumulative U.S. AIDS Cases
as of 5/85  N~10,000

Each point = 30 cases
Cumulative U.S. AIDS Cases as of 7/89  N~100,000

Each point = 30 cases
Cumulative U.S. AIDS Cases
as of 12/95  N~500,000

Each point = 30 cases
Cumulative U.S. AIDS Cases
as of 9/97  N~626,334

Each point = 30 cases
Principle 1:

- Denial and stigma fuel the HIV epidemic and foster despair!

Facing the reality of this terrible epidemic is the first step to responding.

Denial (or as they like to say in AA “DeNile”) is not a river in Egypt...it is natural and is a perfectly human response...and must be resisted
HETEROGENEITY OF HIV IN AFRICA

Sources: UNAIDS 2004 estimates used unless recent national population-based HIV survey available.
HETEROGENEITY OF HIV IN AFRICA
A TALE OF THREE EPIDEMICS

Manzini, Swaziland

Kampala, Uganda

Dakar, Senegal
DECLINING HIV PREVALENCE IN GENERALIZED EPIDEMICS (1-1)

- National HIV prevalence declines reported in Uganda, Kenya and Zimbabwe

- HIV prevalence declines also reported in urban Burkina Faso, Burundi, Ethiopia, Malawi and Rwanda

- Declining HIV prevalence also observed in Haiti, Barbados and Bahamas
ANTENATAL PREVALENCE IN KAMPALA, 1985-2003
Success in Uganda

- Uganda was devastated by the HIV epidemic---28% of pregnant women in Kampala were infected by 1990!
- All of the country mobilized--from the president to the bishops to celebrities. National leadership can never be underestimated. Human capital is more potent than financial capital.
- Now the rate of infection in pregnant women is around 5%.....testing is widespread.....sexual behavior changed......
- Uganda created its own language, sensitive to its own culture and community to respond to the AIDS pandemic...for example, ”zero grazing”

**UGANDAN RESPONSE**
Principle 2:

- The response to the HIV epidemic must be owned by the community
- The language…the tone…the message has to be from the community for the community
- This is done with partnership and respect.
Partnership is key...both with professionals and with those in the community that are sympathetic...and with those at risk.
A Novel HIV Testing Campaign in Philadelphia

Engaging African American Religious Leaders

We Have Been Tested for HIV. Have You?

Get Tested for HIV

To Find A Testing Center Near You Call:

1-800-985-AIDS

Billboard to be displayed throughout the city
ANTENATAL HIV PREVALENCE IN KENYA: SENTINEL SURVEILLANCE 1990-2003

Percent

5.1 6.3 7.4 8.5 9.5 10.4 11.2 11.9 12.5 13 13.4 12.8 10.6 9.4 6.7
Kenya: Changes in “ABC” indicators between the 1998 and 2003 Demographic and Health Surveys (DHS)

“A”
Never-married aged 15-24 who have had sex in the past year

<table>
<thead>
<tr>
<th>Year</th>
<th>Young men</th>
<th>Young women</th>
</tr>
</thead>
<tbody>
<tr>
<td>1998</td>
<td>56%</td>
<td>41%</td>
</tr>
<tr>
<td>2003</td>
<td>32%</td>
<td>21%</td>
</tr>
</tbody>
</table>

“B”
Multiple partners in the past year, ages 15-49

<table>
<thead>
<tr>
<th>Year</th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>1998</td>
<td>30%</td>
<td>17%</td>
</tr>
<tr>
<td>2003</td>
<td>21%</td>
<td>4%</td>
</tr>
</tbody>
</table>

“C”
Condom use last higher-risk sex, ages 15-49

<table>
<thead>
<tr>
<th>Year</th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>1998</td>
<td>44%</td>
<td>4%</td>
</tr>
<tr>
<td>2003</td>
<td>47%</td>
<td>2%</td>
</tr>
</tbody>
</table>

Note: The graph shows the percentage of men and women for each category in 1998 and 2003.
Principle 3:

- Behaviour change is not only possible but will happen if there is honesty...communicate the risks...and provide the tools...and care
Comparison of Uganda and South Africa, 1987-2000

Source: UNAIDS Epidemiological Fact Sheets (UNAIDS 2002a, UNAIDS 2002c)

Fig. 1. Urban antenatal HIV prevalence in South Africa and Uganda. Source: UNAIDS Epidemiological Fact Sheets (UNAIDS, 2002a,c).
Why are rates of HIV so high?

- Acute infection and concurrent sexual partnerships drive high rates of HIV
Half of transmission in first 5 months
Wawer et al, 2005

Why are rates of HIV so high?

- Acute infection and concurrent sexual partnerships drive high rates of HIV
- Low Circumcision rates
- High rates of STDs
- No Community mobilization → churches, government leaders, business, youth... did not respond at the leadership level
- MULTIPLE PARTNERSHIPS is the #1 driver of the epidemic
HIV testing and treatment are cornerstones of prevention

Without HIV testing, prevention is almost impossible
Without treatment and support, HIV testing is almost impossible

It Is Time to Implement Routine, Not Risk-Based, HIV Testing

Curt G. Beckwith,1 Timothy P. Flanigan,1 Carlos del Rio,2 Emma Simmons,2 Edward J. Wing,1 Charles C. J. Carpenter,1 and John G. Bartlett3

1Brown Medical School and the Lifespan/Tufts/Brown Center for AIDS Research (CFAR), Providence, Rhode Island; 2Emory University School of Medicine and Emory University CFAR, Atlanta, Georgia; and 3Johns Hopkins School of Medicine and Johns Hopkins University CFAR, Baltimore, Maryland
Success of HIV treatment: ART (AntiRetroviral Therapy)

- Three medicines taken once or twice a day
- Sometimes the medications are combined in a few pills
- Produced at low cost and high quality by Indian generic manufacturers
- These medications can totally suppress HIV (not cure the virus but total suppression)
- Cost of ART per person/year often < 100$
- Treatment can be effective for a lifetime with total restoration of health
HIV and AIDS care: Antiretroviral therapy works!
Treatment requires ART and support: both medical and social. Family support very important
St Mary Mission Hospital
In Nairobi, Kenya
6,500 deliveries → 80% agree to HIV testing with excellent PMTCT

Kibera slum in Nairobi, Kenya
HIV treatment is prevention!

- Among HIV + men in treatment on ART:
  - Marked decrease in unprotected sex
  - ART decreases HIV in the blood, semen, and other body fluids with decreased transmission
  - Estimated 90% reduction in transmission risk among Ugandan men on treatment
HPTN 052: Prevention of HIV through treatment

- Randomized controlled study of discordant couples with the HIV+ person CD4>350---this is a threshold above which we don’t recommend ART

- 1/2 received ART …1/2 were observed until the CD4 hit treatment threshold…all couples were counseled re safer sex

- 96% reduction in HIV transmission to HIV-partner

- NB…over 50% reduction in TB among HIV+ person
Hope....

- And Despair
Hope....

- HIV treatment is so effective and so CHEAP
- Treatment can prevent transmission
- Many of our patients are starting families with the realistic hope of taking care of their grandchildren

And Despair

- Treatment is not available in many, many parts of the world due to limited resources, corruption, and a lack of care
- Transmission ramps up in the midst of “hopeless…helpless”

Principle 4: The tools of HIV testing and treatment are integral to responding to the epidemic
Stigma:
HIV is the leprosy of our age
Stigma is an impediment to testing and treatment
Love and acceptance are the antidotes to stigma “We can not do great things on this earth...only small things with great love”

Mother Teresa of Calcutta
Mother Teresa’s philosophy:
We are all broken and we are all in need of healing and love…and God asks us to step forward and with our hands show His love to others
Embraced: a heartfelt gesture changed perception of AIDS: 1987
Principle 5: Care and respect for the person has to be at the heart of responding to the epidemic

*Person centered response versus risk centered response*
Person centered response always starts with “how are you doing…how can I help”. The person is the center of attention.

Risk centered response…the risk is the focus and the person matters because that is how one can change the risk behaviors

Are we MSMs…IDUs…CSWs…

No  *Who are we?*
Person centered response versus a risk centered response to HIV/AIDS

**Person centered**
- What do you need? How are you vulnerable? Abused? Exploited?
- Cup of coffee? Talk? Substance abuse treatment? Safe place for the night?
- Have you been HIV tested? Are you worried about getting infected?
- Sex work as inherently exploitative
- Drug addiction (ie substance abuse) causes severe pain and harm

**Risk centered**
- Focus on unprotected sexual acts
- Condom promotion to avoid HIV exposure
- The person seen as a vehicle for viral transmission
- Sex work viewed as value neutral
- Goal: HIV negative test not addressing harm to the person
- CNN Focus: Condoms, needles, negotiation
Two approaches: Person vs risk behavior

- A 15 yo boy…young man is working the streets…sniffing glue…sex work…grim…depressing
- Recognize exploitation, abuse, pain, damage, despair, hopelessness.
- Drop in center that’s safe with hot shower, washing machine, coffee and a sandwich…listen
- HIV testing, treatment, condom availability, other medical care
- Offer to help escape slavery of sexual exploitation, trafficking, and drug use
- Be there for him

- A 15 yo sex worker having unprotected sex with men and women…sometimes transactional for food, money, or drugs …or a roof …or just because high.
- Motivational intervention to desensitize condom reluctance…encourage and incentivize condom use.
- Serial HIV testing and condom promotion
- Decriminalization of sex work and intent to change social norms regarding sexuality
Person centered response
Thank you for listening
Thanks to care givers, PLWAs, family members, and so many others who have responded to the HIV and AIDS epidemic with tender loving care.
Case study 1: Mississippi has high rates of HIV and some of the highest death rates from HIV and AIDS in the nation. The highest HIV rates are in Jackson MS. You are asked to visit the Hinds County House of Corrections (the jail serving the greater Jackson urban area). You are asked to suggest applied research projects to help address the epidemic.

At your 2 hour visit, you find out that HIV testing is offered to inmates during weekly health classes provided by an “outside” health counselor. Inmates that request testing are then referred to the medical clinic for an HIV blood test. Results are provided in approximately 1 week from the visit. “Positive patients” are evaluated with CD4 and VL (viral load) testing and referred for treatment according to standard guidelines.

What do you suggest?
Case study 2: A 22 yo student at a RI university goes to student health and requests an HIV test. A rapid test is available but will cost $25. A standard test is free. The student has engaged in MSM anal intercourse (receptive) and requests a rapid test. It is -. He returns to his dorm and checks out his symptoms of sore throat, fever, and swollen neck lymph nodes on the internet. He is concerned re “acute HIV” and returns to student health and requests an HIV VL. It returns +. He is referred to you in the clinic. Two other MSM students also test + for HIV after having negative tests the previous year. The head of student health asks you to come by to visit and requests our help evaluating and responding to this “outbreak”?

What do you suggest?