

Brooke Chase, CODM, Laura Cousineau, MLS, Richard Duncan, DMD, MS, Allison Evans, COM4, Page Gupton, CHP, Jejo Koola, COM3, Jeni Luehrs, COP, David Perry, COGS, Teresa Stanley, COP, Benjamin Thomas, COM2, Jessica Tillman, MPH, BSN, RN
Medical University of South Carolina, Charleston, SC

INTRODUCTION

Target Population

AIDS (acquired immunodeficiency syndrome) was first reported in the United States in 1981 and has since become a worldwide epidemic. AIDS is caused by HIV (human immunodeficiency virus). By killing or damaging cells of the body's immune system, HIV progressively destroys the body's ability to fight infections and certain cancers.

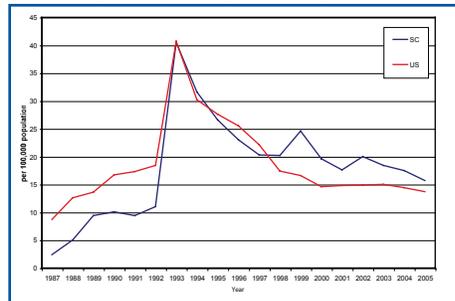
Demographics:

- ❑ Ages 35-39 have the highest prevalence
- ❑ In South Carolina (SC), African Americans are 9x as likely as whites to be diagnosed
- ❑ Male-to-male sexual contact is the leading cause

Prevalence

| Through December 2005 | SC | US |
|---|-------|-------|
| AIDS Prevalence Rate (Current cases): per 100,000 | 182.9 | 176.2 |
| HIV Prevalence Rate (not AIDS): per 100,000 | 179.2 | 136.5 |
| AIDS Incidence Rate (New diagnoses): per 100,000 | 15.7 | 14.0 |

Figure 1.
AIDS Annual Rates of Reported Cases
per 100,000 Population by Year

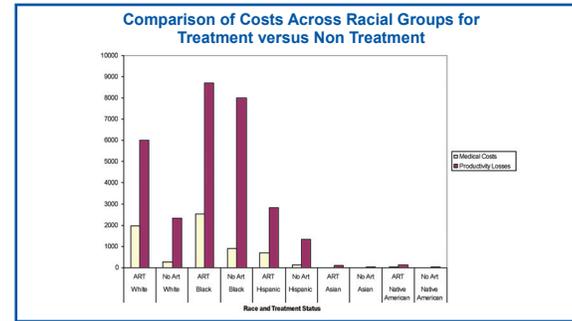


Severity

- ❑ Survival was greater for persons diagnosed before the age of 35.
- ❑ In the US, estimated number of AIDS-related deaths decreased 4% from 2001 through 2005.

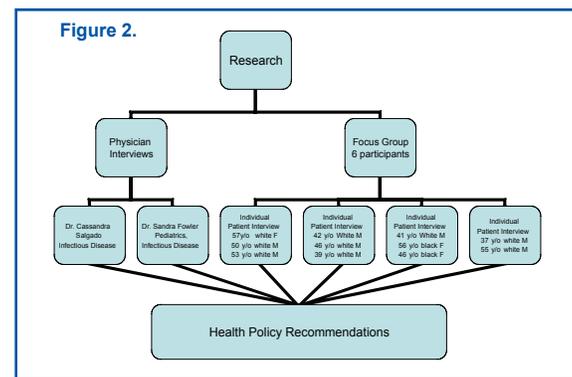
Evidence of Health Disparities

- ❑ 1993: A study reported that 65% of dentists refused treatment once learning their patients were HIV positive.
- ❑ 2000: minorities comprised 78% of HIV-infected women and 80% of HIV-infected pediatric patients
- ❑ 2005: HIV/AIDS patients reported being discriminated against by physicians, dentists, nurses, and staff.
- ❑ HIV/AIDS disproportionately affects people of a lower socioeconomic status
- ❑ In rural SC, many healthcare providers lack resources & knowledge to effectively treat their patients.
- ❑ NIH spends ~10% of its nearly \$1B budget on research for an AIDS vaccine,
 - However, the AIDS Drug Assistance Program (ADAP) has a 3 month waiting list in SC.



Based on data from: J Acquir Immune Defic Syndr, Volume 43(4), December 1, 2006:451-457

METHODS



RESULTS

Life with HIV/AIDS—the Physician's Perspective (an interview with two Infectious Disease physicians)

How do most of your patients get coverage? How are medications paid for?

- ❑ Insurance—especially Medicaid or Medicare (30-40% of MUSC clinic patients)
- ❑ Ryan White Grant for routine health care
- ❑ ADAP covers medications; waiting list is about 450 people right now
- ❑ Many drug companies have assistance programs until patient can get ADAP

What are your biggest challenges?

- ❑ Lack of education (both patient and provider) about available resources
- ❑ Resources are exhausted very quickly—often gone by first quarter, no additional funding after
- ❑ Discrimination based on funding: often a reflection of socioeconomic status or lack of access to care
- ❑ Discrimination not seen much in hospital care
- ❑ \$\$\$\$\$\$\$\$\$\$\$\$ (or lack of it!)

What are your patients' biggest barriers to care?

- ❑ Insurance, Medications (access, side effects, compliance), Education (understanding the relationship between the virus and risks, the medications, and care decisions)

What resources are available?

- ❑ Pharmacological company drug assistance programs
- ❑ Ryan White covers counseling by psychologist
- ❑ LowCountry AIDS Services
- ❑ Social worker at MUSC clinic

What are the major healthcare concerns of the population?

- ❑ Transportation: greatest barrier to care (Medicaid buses once a day)
- ❑ Facilitating adherence
- ❑ Complete ecology (uninvolved caregiver, lack of understanding, lack of trust, culture of the patient)

What are the areas needing improvement, especially for children?

- ❑ Children completely covered until the age of 18: after 18, the patient must enroll in ADAP (placed on a wait list)

Life with HIV/AIDS—the Patients' Perspective (from interviews with seropositive individuals, n=11)

- ❑ 10 of 11 required a case worker to coordinate care
- ❑ 9 of 11 had concomitant psychological issues
 - 5 of 11 cited breakthroughs in treatment of their HIV/AIDS through psychological counseling
- ❑ 9 of 11 endorsed the perception of being stigmatized
- ❑ 9 of 11 received Medicaid and/or Medicare
 - 8 of 11 cited financial difficulties in living with HIV/AIDS
 - 1 of 11 had been put on a waiting list for ADAP and was temporarily unable to receive treatment
- ❑ 8 of 11 requested greater information about the disease and its treatment
 - 8 of 11 indicated a willingness to help teach other seropositive individuals
- ❑ 6 of 11 cited receiving assistance from a peer counselor (though all in different states)
 - 3 of 11 requested some form of peer counseling for themselves
- ❑ 7 of 11 voiced a desire for more personal health care
- ❑ 5 of 11 initially refused anti-retroviral treatment, but each eventually changed at the counsel of a physician
- ❑ 5 of 11 endorsed instances of perceived lesser care due to their HIV status
- ❑ 7 of 11 were satisfied with the care they are currently receiving
- ❑ 5 of 11 had a history of substance abuse
- ❑ 2 of 11 cited difficulties with transportation
- ❑ 6 of 11 cited faith/perspective as intrinsic to their living with HIV
- ❑ 3 of 11 proposed nationalized health care

Life with HIV/AIDS—the Patients' Voice (from interviews with seropositive individuals, n=11)

"From the beginning of treatment, there was a strong dichotomy between good doctor and bad doctor...[treating HIV/AIDS is] a great way to practice excellent medicine." - 41 y/o WM

Financial issues

"There's no middle of the road...no one knows how to bridge the gap from receiving your health to receiving your lifestyle, personal, psychological and social well-being." - 41 y/o WM

"I can't have a job that pays you enough to live and still get the medical benefits." - 37 y/o WM

"[I'm moving back to France] because I can't live with HIV here...I can't afford to live here...it's like a Catch-22 situation" - 55 y/o WM

Personal health care

"Policies are so generic, they can't see the individual...look at me, don't look at your system." - 42 y/o WM

"Nobody's listening to me...[at appointments there's] nothing—just takes bloodwork. There's been a lot of times I come out of there in tears." - 51 y/o WF

"I feel like there's not enough compassion in any of it" - 39 y/o WM

HIV and stigma

"[I] felt infected, dirty, unclean...I didn't know anything about it" - 46 y/o BF

"People are scared...how do you get them to open up?" - ibid

"Like I was a leper" (53 y/o WM), "It's like being a leper..." - 56 y/o BF

"[I was in a] much lonelier place...a modern-day leprosy" - 41 y/o WM

Importance of the Health Care Provider

"[I] would have been scared to death without the doctor's counsel" - 50 y/o WM

"My hero" - 56 y/o BF, speaking of her Infectious Disease doctor

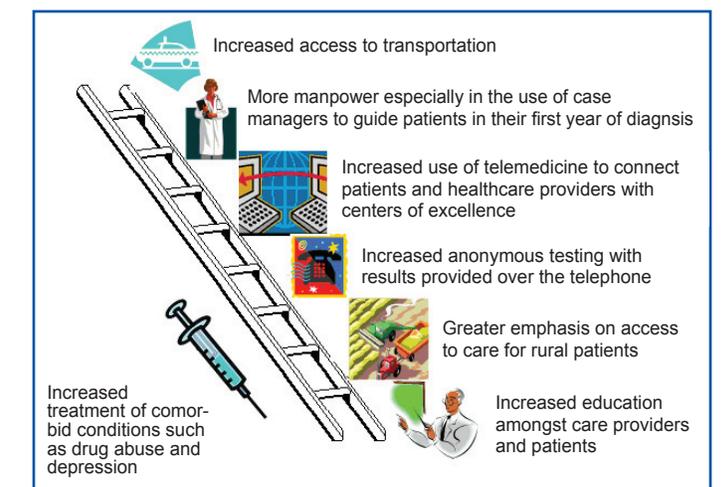
"I think I've just been lucky...having a doctor who was so proactive...And he worked with on what I wanted...[He] became a friend" - 53 y/o WM

Need for broader care and greater education

"If I only had the Infectious Disease clinic, I'd still be a mess." - 46 y/o BF

"There's more that can be done..." - 56 y/o BF

Health Policy Recommendations



Recommendations for next Scholars

- ❑ Choose a specific topic to institute change
- ❑ Learn about topic first semester, take action second semester
- ❑ Take our research info as springboard and continue moving forward