Addressing HIV-Related Stigma in New Jersey Using a Socioecological Perspective

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Images from the 1980s

Ken Meeks, 1986
http://www.nytimes.com/2011/
05/31/health/31aids.html?_r=0

THERE IS STILL
NO CURE FOR AIDS.
PROTECT YOURSELF.

People weekly
The Last Days of
RYAN WHITE

December 6, 1971 – April 8, 1990

David Kirby, an HIV/AIDS activist, near death
Surrounded by his family

How Has Stigma Been Defined?

- Goffman (1963) – stigma as an "attribute"

- Link and Phelan (2001) – stigma as a social process

- Parker and Aggleton (2003) – role of power in stigma

- Bos, Pryor, Reeder, and Stutterheim (2013) – stigma functions

"Stigma is a powerful discrediting social label that radically changes the way an individual is viewed by others and can alter how he/she sees him/herself"

- NJ HIV Prevention Community Planning Support and Development Initiative

Types of Stigma

- **Anticipated Stigma** – a belief that discrimination may occur

- **Associated Stigma** – stigma against people who work or associate with people living with HIV

- **Experienced/Enacted Stigma** – discrimination experienced due to real or perceived seropositive status

- **Internalized Stigma** – thoughts/behaviors stemming from the person's own negative perceptions about himself/herself

- **Intersecting Stigma** – stigma associated with other social categories that intersect with HIV-related stigma

- **Received Stigma** – all types of stigmatizing behavior towards people living with HIV (not limited to HIV status)
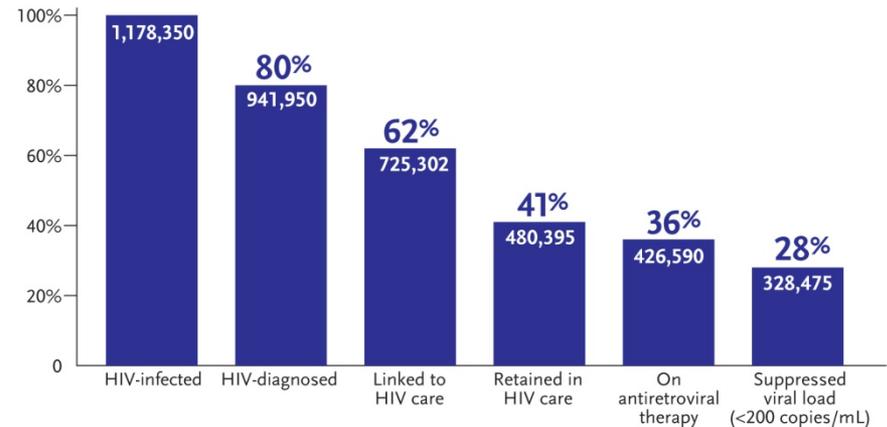
Pryor and Reeder (2011)

Four dynamically interrelated manifestations of stigma

- Public stigma
  - People's social and psychological reactions to someone they perceive to have a stigmatized condition

- Self-stigma
  - Social and psychological impact of possessing a stigma

- Structural stigma
  - "Legitimatization and perpetuation of a stigmatized status by society's institutions and ideological systems

- Stigma by association
  - Social and psychological reactions to being associated with a stigmatized person

Stigma's Impacts

- Overall poor quality of life
- Self doubt
- Delays in testing
- Poor engagement in care
- Failure to take medications
- Depression/anxiety/isolation
- Internalized stigma
- Rejection by family/friends/community
- Fears of disclosure (voluntary or involuntary)
- Increased participation in high-risk behaviors
- Exacerbation of health problems due to stress

Proportion of HIV-positive Individuals in the U.S. at Each Stage of Care

Stage	Value	Percent
HIV-infected	1,178,350	100%
HIV-diagnosed	941,950	80%
Linked to HIV care	725,302	62%
Retained in HIV care	480,395	41%
On antiretroviral therapy	426,590	36%
Suppressed viral load (<200 copies/mL)	328,475	28%

Source: CDC

Levels of Effect: The Socioecological Model

- Intrapersonal – internalized thoughts
- Interpersonal – relationships to others
- Institutional – ability to access services
- Community – environments that shape cultural norms
- Structural – local, state, and national policies

Categories of Stigma Interventions

- Brown, Macintyre, & Trujillo (2003)

    - Information-based

    - Skills building

    - Individual/group counseling

    - Contact with affected groups

- Stangl et al. (2013)

    - Structural

    - Biomedical

Stigma Reduction Strategies (Mahajan et al., 2008)

- Intrapersonal
  - Counseling, cognitive-behavioral therapy, self-help and support groups, treatment, & empowerment
- Interpersonal
  - Care and support, home care teams, & community-based rehabilitation
- Community
  - Education (social marketing and mass media) & contact with PLHWA
- Institutional
  - Training programs & policy development
- Governmental/structural
  - Legal interventions & rights-based approaches

Stigma-related Projects

- Intrapersonal: HIV-related stigma in a long-term survivor

- Interpersonal: Newark Eligible Metropolitan Area 2015 Needs Assessment

- Institutional: Clinic-based stigma intervention

- Communal: Implementation of the People Living with HIV Stigma Index throughout New Jersey

- Structural: Proposal to examine the social determinants of health in HIV and design structural intervention(s)

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HIV-Related Stigma in a Long-Term Survivor

- In-depth interview with client living with HIV since 1985
- Goal: examine how experience of stigma has evolved over the course of the epidemic
- Analyses ongoing, but some relevant quotes:
    - *If you go to [deleted] hospital - they would basically turn you to St. Michaels, because they were scared. The nurses was scared, the doctors was scared.*
    - *They came in with… looked like space suits, and oxygen masks and all of that stuff. And it made you feel like - you was… "dirty".*
    - *The stigma about the ghetto is that we're dangerous … They embrace that. Because that's the stigma put into their lives. But - it's a lot of people in the ghetto that are scared, they need policing. They don't like crime. Just like anybody else. So, release them from that… so many stigmas.*

NEMA 2015 Needs Assessment

- NEMA/HIV Health Services Planning Group
  - Ryan White Part A grantee
- Needs Assessment is part of the planning process
- 2014 Needs Assessment looked at impact of ACA on coverage
  - What are the characteristics of people ineligible for coverage and reliant on Ryan White?
  - Stigma cited as a barrier to care among Latinos and Haitians
- 2015 Needs Assessment looking at the effects of the ACA
  - What are the gaps in services/care among those with new coverage?
  - Focus groups, key informant interviews, surveys
  - Analyses are ongoing, but one key finding:
    - Ongoing need for support groups to deal with effects of stigma

Clinic-Based Stigma Intervention

- Four 3-hour workshops in HIV clinic based in Newark
- Topics
  - Session 1: Introductions, types of stigma, National HIV/AIDS Strategy
  - Session 2: Outcomes of stigma, review data, cultural competency
  - Session 3: Coping with stigma, types of interventions
  - Session 4: Plan for stigma intervention, workshop evaluation
- Baseline and follow up questionnaires
- Key findings:
  - Lack of awareness of National HIV/AIDS Strategy
  - Outcomes of stigma
  - Ability to review baseline findings seen as valuable
  - Client lack of awareness of cultural competency
  - Why is stigma hard to change?

People Living with HIV Stigma Index

- Intervention and data collection tool developed by international consortium (http://www.stigmaindex.org/)
  - Based on the Greater Involvement of People Living with HIV (GIPA) principle (http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf)
  - More than 1,300 people living with HIV (PLHIV) have been trained as interviewers and more than 50,000 PLHIV have been interviewed
- Implemented in more than 50 countries around the world
  - First study in the U.S. in Detroit
  - Looking to expand to sites throughout the U.S.
- Study in NJ being funded by the Department of Health
  - 1% sample of HIV cases in each of NJ's 21 counties (n ~ 380)
  - IRB application in process

Social Determinants and Structural Interventions

- R21 application being developed
  - School of Nursing
  - Edward J. Bloustein School of Planning and Public Policy
    - Environmental Analysis and Communications Group
  - Rutgers New Jersey Medical School
    - Department of Preventive Medicine and Community Health
- Building off the HIV Medical Neighborhood in Newark
  - Greater involvement of primary care providers
  - Primary goal to address HIV-related and intersecting stigmas
- Three phases of study
  - Epidemiological analysis
  - Study of the social determinants of health
  - Development of structural intervention

Other HIV Research at the School of Nursing

- Center for Research on HIV Management in Families and Communities
  - New Center of Excellence funded through Rutgers' School of Nursing
  - Goal is to fund development of research proposals to submit to the National Institute of Health (NIH)

- International Network of Nurses in HIV Research
  - International consortium conducting multi-site research studies
  - Next meeting in conjunction with the October meeting of the Association of Nurses in AIDS Care (ANAC)

- François-Xavier Bagnoud (FXB) Center
  - Clinical care, education, and technical assistance
  - Links research and practice through education and technical assistance.

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Conclusions

- Stigma remains a significant problem along the HIV Care Continuum

- Ending the HIV epidemic requires addressing HIV-related and associated stigmas

- Using the socioecological model helps to ensure that research and interventions consider the multiple manifestations

- The goal of the work being done at Rutgers is to ensure a more comprehensive and collaborative approach

Contact Information

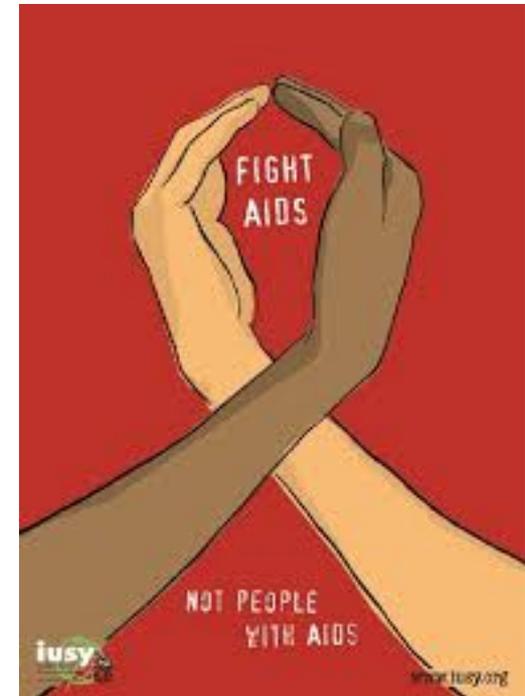## Ann D. Bagchi, PhD, BSN, RN

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Questions?

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