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

Ann D. Bagchi, PhD, BSN, RN

University of Alabama-Birmingham Center For AIDS Research
Behavioral and Community Science Core Seminar
August 12, 2015
Images from the 1980s

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

December 6, 1971 – April 8, 1990

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

School of Nursing
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
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)
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/](http://www.stigmaindex.org/))
  - 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.
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
Instructor, School of Nursing
Rutgers University – Newark
180 University Avenue
Newark, NJ 07102
(973) 353-1042
ann.bagchi@rutgers.edu
Questions?
References


