STIGMA AND VULNERABILITY AMONG AFRICAN AMERICAN WOMEN LIVING WITH HIV

Faith E. Fletcher PhD, MA
Assistant Professor
Department of Health Behavior
University of Alabama at Birmingham School of Public Health

Fordham University Research Ethics Training Institute
July 11, 2019

ACADEMIC LENS

- Public health
- Behavioral science and intervention development
- Community-engaged research
- Ethics
  - Tuskegee University (2004)
  - Michigan State University (2006)
  - Fordham University (2013-2015)

OVERVIEW OF HIV HEALTH DISPARITIES

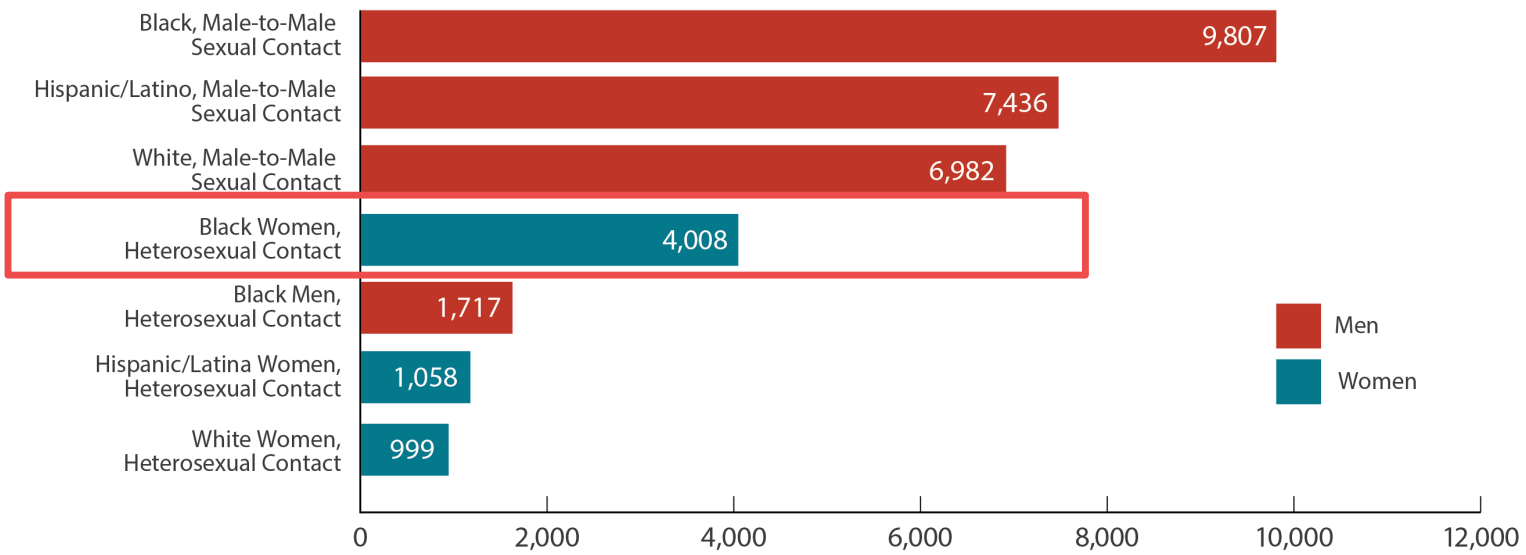
THE BIG PICTURE:
HIV DISPARITIES IN THE UNITED STATES

- HIV/AIDS remains a major public health crisis in the United States
  - Prevalence: 1.2 million persons living with HIV
  - Incidence: 38,739 persons diagnosed in 2017
  - Disparity: African Americans continue to bear the greatest burden of HIV
    - African Americans make up 12% of the US population, but 44% of new HIV diagnoses.

- Approaches
  - Integration of HIV surveillance and prevention (data-to-care)
  - Pre-exposure prophylaxis or PrEP (2012 FDA approval)
  - Increase access to care and improve health outcomes for HIV+ persons (i.e. treatment as prevention) (90-90-90)

HIV DISPARITIES

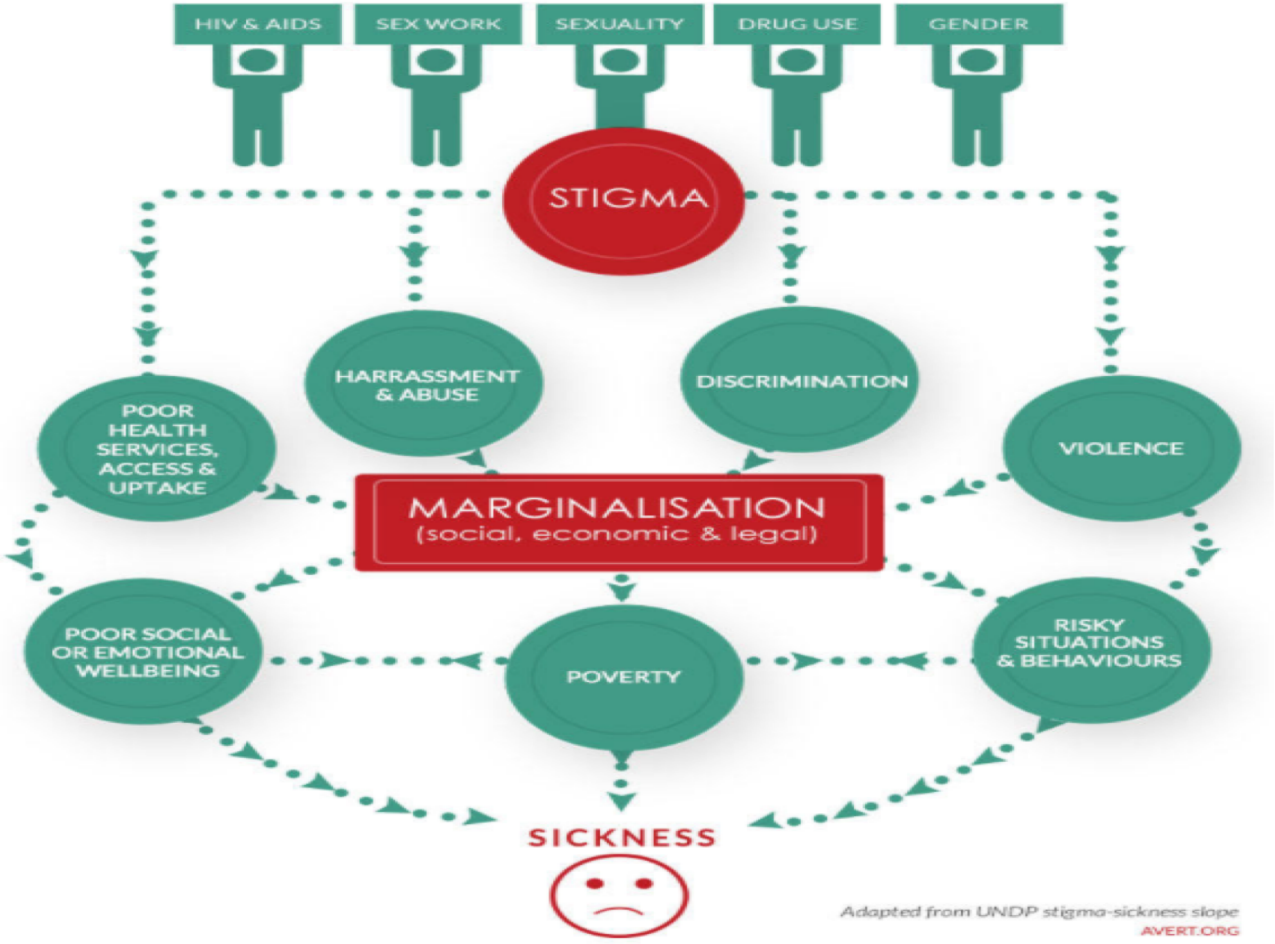
Estimated New HIV Infections in the United States, 2017 for the Most Affected Subpopulations



FACTORS THAT INCREASE HIV VULNERABILITY

- Socioeconomic factors
  - Access to health care and HIV preventive services
- High rates of incarceration
- Power imbalances
- Homophobia
- Intersectional vulnerability/marginalization
- HIV/AIDS related stigma

COMPOUND MARGINALIZATION



INTERSECTIONALITY AND AA WLWH

- Intersectionality is a lens through which you can see where power comes and collides, where it interlocks and intersects (Crenshaw, 1991).
  - "overlap" of "multiple levels of social injustice", or "injustice squared"
- Intersectionality framework offers a constructive lens through which to contextualize the health inequities faced by women living with HIV (Rice, 2018).
- Intersectional stigma as a concept seeks to characterize the convergence of multiple stigmatized identities within a person or group and to address their effects (Bowleg, 2012).
  - 1) one or more co-existing health conditions such as HIV, mental illness or substance use disorder; 2) sociodemographic characteristics such as racial, ethnic, gender, sexual orientation and immigration status; and 3) behaviors/experiences such as substance use and sex work (NIH, 2018).

EXAMPLE 1

Study Purpose: To explore how African American women living with HIV (N=42) in the US South recount, conceptualize, and cope with stigma at the interpersonal, community, and institutional levels

Funding Sources: UIC's Building Interdisciplinary Careers in Women's Health K12 Program; Centers for Disease Control and Prevention Grants for Public Health Research Dissertation R36

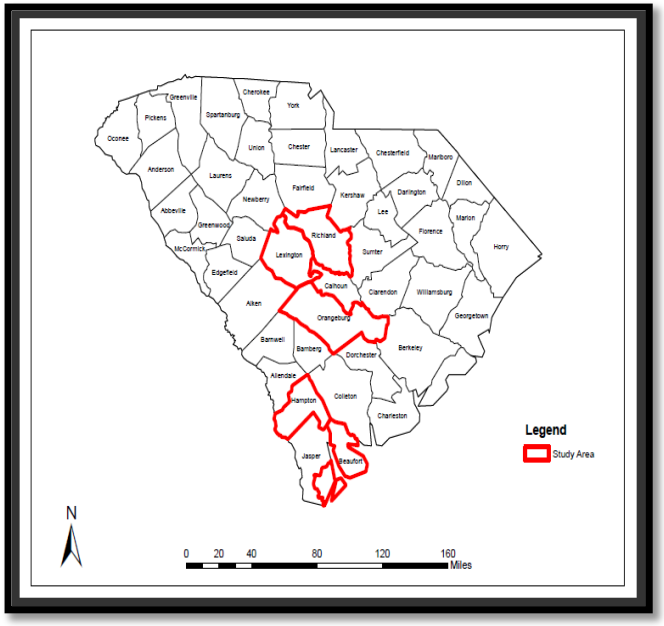
Published Manuscript: Fletcher FE, Annang L, Kerr J, Buchberg M, Bogdan-Lovis L, Philpott-Jones S. "She Told Them, Oh That Bitch Got AIDS": Experiences of Multi-Level HIV/AIDS- Related Stigma among African American Women Living with HIV/AIDS in the South. AIDS Patient Care and STDs. 2016 Jul;30(7):349-56. doi: 10.1089/apc.2016.0026. PMID:27410498.

PUBLIC HEALTH RELEVANCE OF STIGMA

- Reduces HIV preventive behavior and reduction strategies (Chesney 1999; Garcia 2015; Brown 2003) (i.e. HIV testing, condom use, PrEP)
- Poorer treatment engagement and retention
- Reduces status disclosure (Vyavaharkar 2010)
- African Americans report more social rejection (i.e. due to multiple marginalized identities)
    - **An enhanced understanding of stigma (individual, interpersonal and structural level) experienced by HIV-positive African American women is needed.**

METHODS

- Participants
  - African American, HIV-positive women residing in South Carolina
  - Recruited from clinics or AIDS Service Organizations
- Face-to-face interviews (N=42)
- Qualitative analysis
  - Data analyzed by two research team members with NVivo software
  - Content analysis: inductive and deductive approaches



INTERVIEW QUESTIONS

- How did you find out that you were HIV positive?
- Who have you shared your HIV/AIDS status with?
- Please describe the things that you do to cope with being HIV-positive.
- Please describe your experiences with the health care system.
  - Please tell me about any advice or opinions that healthcare providers have given to you about becoming pregnant.

INTERVIEW CHALLENGES

- Building rapport
- Crying triggered by discussion of childhood trauma, sexual violence, stigma, rejection, isolation and aspects related to HIV acquisition
- Disinterest in original research topic
- Discussion of stigma in conference room within a healthcare setting
- Feeling the “weight” of women’s stories as a researcher

SOCIODEMOGRAPHICS CHARACTERISTICS

Variable	Total (N=42)
Age, mean (SD)	37.7 (9.2)
Annual income, no. (%)	
Less than $10,000	31 (73.8 %)
Job status, no. (%)	
Unemployed	28 (66.7 %)
Educational level, no. (%)	
Some high school High school graduate Some college College graduate GED	8 (19.0 %) 10 (23.8 %) 16 (38.1 %) 3 (7.1 %) 4 (9.5 %)
Marital status, no (%)	
Single	30 (71.4 %)
Mode of HIV acquisition, no. (%)	
Sexual intercourse with a male	36 (85.7%)
Seeking HIV/AIDS care, no. (%)	41 (97.6%)

STIGMA AND DISCRIMINATION

Table 1. Major Themes Related to Stigma and Discrimination	
Theme and Definition	**Quote**
Interpersonal-level refers to immediate social environment impacting direct interpersonal interactions.	*My mom found out I was HIV, you know, she didn't want me to be around my kids, she didn't want my kids to sleep with me. It hurt because it, I mean, my kids can't catch it, you know what I'm saying, by touching and kissing on them.* [Age 19; Diagnosed in 2007]
Community-level refers to immediate social circles as well as within their broader community.	*I'm more depressed than anything. I don't look towards tomorrow. A few people come around and it's like a clique and where I live in housing most of the people have it [HIV]. And people in the area they know about that housing situation so they automatically start talking. My family has pretty much disowned me.* [Age 47; Diagnosed in 2009]
Institutional-level refers to larger societal structures and institutions.	*I would take my prescriptions to the pharmacy two towns over because I didn't want to run into anybody or have anybody in the pharmacy filling AZT for me in my hometown. It's a small town.* [Age 33; Diagnosed in 1998].
Intersectional stigma refers to co-occurring overlapping stigmas imposed by various sources on multiple levels.	*It is so hard on women today who are HIV positive because there are so many things that we have to deal with that the opposite sex does not have to deal with. As a woman living with HIV today, as a black woman, living in this world today, I feel like I have to continue to stand.* [Age 35; Diagnosed in 2000].

OVERVIEW OF FINDINGS

- Many participants described HIV stigma at various levels, with experiences overlapping in multiple levels of the Social Ecological Model (McLeroy 1988).
  - Intersectional stigma (HIV stigma, racism, sexism, poverty)
- In many cases, disclosure made women more vulnerable to stigma and discrimination.
- Experiences of HIV stigma at multiple levels led to minimal or no “safe spaces” for HIV-positive women.
- Consequences of stigma included loss of privacy and confidentiality; loss of autonomy; loss of identity; loss of employment; loss of dignity; loss of loved ones, embarrassment; and isolation.
- HIV/AIDS stigma permeated the research process.

ETHICS OF RESEARCH: LESSONS LEARNED

- In settings where populations face social exclusion, stigma, and discrimination, experiences of marginalization at multiple levels renders individuals unable to feel comfortable in places that are generally considered to be safe spaces for non-infected individuals (Fletcher, 2016)
- Marginalization can sharpen ethical tensions and ultimately permeate and complicate the HIV/AIDS research process.
  - Safety of both research participants and research staff
- Acknowledging vulnerabilities experienced by both individuals and communities who face multiple stigma(s) is critical to informing the research process and tailoring participant protections to a particular sociocultural context (Fisher, 2014)

ETHICS OF RESEARCH WITH VULNERABLE POPULATIONS

EXAMPLE 2

Purpose: To describe ethical challenges and lessons learned related to conducting qualitative research with African American WLWH; and to make recommendations to improve ethical research practices for engaging African American WLWH in qualitative research.

Funding Sources: UIC's Building Interdisciplinary Careers in Women's Health K12 Program; Centers for Disease Control and Prevention Grants for Public Health Research Dissertation R36; National Institute on Drug Abuse (Grant 1R25DA031608-01) Fordham University HIV Prevention Research Ethics Training Institute

Manuscript accepted: Fletcher FE, Rice WS, Ingram LA, Fisher C. Ethical Challenges Related to Conducting Qualitative Research with African American Women Living with HIV in the South: Lessons from the Field. Journal of Health Care for the Poor and Underserved 2019.

RESEARCH WITH AA WLWH

- African American women bear a disproportionate burden of HIV/AIDS in the United States (U.S.).
  - Social marginalization experienced in everyday life heightens HIV vulnerability and hinders HIV treatment and care among AA women.
  - AA women might experience overlapping stigmas due to marginalized identities (i.e. HIV status, race, gender, poverty, and geographic location).

- Stigma, discrimination, and social isolation often undermine HIV research and jeopardizes the safety of both research participants and research staff.

- Immersive engagement and interaction in everyday environments through qualitative research can present unexpected ethical challenges.
  - Going to people's homes, jobs, and natural environments

ETHICAL CONSIDERATIONS IN QUALITATIVE RESEARCH

- Prolonged immersion in other people's lives
- Intensely intimate and sensitive questions
- Emergent design
- Relationships, access, rapport, acceptance
- Friendships, betrayal, abandonment
- Reporting raw data – participants' words
- Changes to protocols and procedures

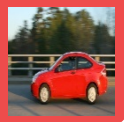
Place that is mutually safe and private for both the participant and researcher

INTERVIEW SETTINGS

Clinics/ASOs (n=19)

Participants' homes (n=12)

Hospital room (n=1)



First author's car (n=8)

PURPOSE

- To describe ethical challenges and lessons learned related to conducting qualitative research with African American WLWH; and to make recommendations to improve ethical research practices for engaging African American WLWH in qualitative research.

METHODS

- To guide the analysis and categorize encountered ethical dilemmas, we used the principles from the Belmont Report—respect for persons, beneficence, and justice
- Utilized field notes and observations resulting from ethical dilemmas germane to the interviews.
- The codebook was refined and finalized through an iterative process.
  - The final codebook was used to analyze data from interviews by identifying emerging themes, ideas, and perceptions from open-ended responses.
  - All coding differences were resolved after consensus was achieved.

CASE #1: INTERVIEW WITH SANDY IN HER HOSPITAL ROOM AND IN THE PRESENCE OF HER HUSBAND

Sandy contacted me early one morning about scheduling an interview. I agreed, and asked her to identify an interview location that provided her with privacy, comfort, and convenience. Sandy explained that she was pregnant, near-term, and admitted into the hospital. **She suggested her hospital room as the preferred interview setting**. In light of her pending delivery, I suggested delaying the interview. However, Sandy explained that she was admitted into the hospital for monitoring, but felt fine. She added that this was the best time for her to complete the interview because she had nothing else to do. **Although I had reservations about interviewing Sandy in the hospital, I agreed to meet her there to assess the situation**. When I arrived, Sandy was in good spirits and seemed to be doing well. After explaining the interview process to Sandy, assessing her level of agreement/consent with the interview plan, and observing the potential interview setting, I was reassured and did not believe that the interview setting posed any risks to her. **Sandy's husband was also in the room**. I expected that he would leave the room before we commenced the interview. **When I realized that Sandy's husband intended to stay, I explained to Sandy that the interview contained sensitive questions and that it was best for her husband to leave the room so that she could speak freely**. She responded by saying that anything she shared with me, she could share in front of her husband. **Sandy also informed me that her husband was aware of her HIV status.** Her husband confirmed that he was informed of his wife's status. **Despite my concerns related to conducting the interview with Sandy's husband present, I commenced the interview with Sandy under the circumstances that she preferred.**

CASE #2 INTERVIEW WITH SHELLY IN MY CAR

Shelly was my first scheduled home interview. **Per conversations with women and clinic staff, women wanted me to visit their homes to mitigate transportation barriers**. I looked forward to conducting Shelly's interview in her everyday environment. **When I arrived at Shelly's home, she came to the door and immediately stated that I could not enter her home**. I didn't fully understand as Shelly initially had recommended her home for an interview. Since I was no longer welcomed in Shelly's home, **I asked for other interview location suggestions; she immediately recommended my car.** I said okay. We walked towards my car, which was parked in front of her house. As soon as Shelly entered my car, she pulled out a cigarette and began smoking. It was close to 100 degrees that day, and I couldn't open the windows because I knew the background noise would interfere with the audio recording. I was slightly irritated by the smoke, but understood that many WLWH smoked as a coping mechanism. I **noticed that Shelly was anxious, so I asked her if everything was okay. She revealed to me that she had not disclosed her HIV status to the people that she lived with, but still wanted to participate in the study. Despite unexpected interview circumstances, I commenced the interview with Shelly in my car.**

CASE #3: INTERVIEW WITH AMBER IN HER HOME

One of the first interviews that I conducted in the Low Country region of South Carolina was with Amber. The Low Country is a geographic and cultural region along the coast of South Carolina. I traveled alone to most of my interviews, but I traveled with a classmate to the Low Country interviews since they were further away. My classmate, a native of South Carolina, was familiar with the Low Country region neighborhoods that I was scheduled to visit for my study. **He expressed concerns about my safety particularly related to conducting Amber's interview at her home. I reassured him that I would be fine. However, he elected to ride with me to Amber's home and waited in my car until I finished.** When I entered Amber's apartment, I immediately felt a sense of uneasiness upon observing the physical environment. **Her apartment was in disarray; the area where I sat during the interview was less than 10 feet away from a large, menacing, barking dog; the dog's training pad was soiled and there was a strong stench**. Despite my impression of circumstances, I commenced the interview. **About half way through the interview, our conversation was interrupted by aggressive knocking on the door. It was Amber's landlord, who served her an eviction notice**. Amber pleaded for one more day to pay rent/meet residence requirements. He said no. The exchange was unfriendly. **Amber returned to the interview, seemingly demoralized and embarrassed. I offered to return another day to complete her interview**. **Amber insisted that we continue the interview and stated that she needed the $25 compensation. Despite unanticipated turn of events, I continued Amber's interview.**

CASE STUDIES: ETHICAL DILEMMAS

Case #1: Interview with Sandy in her hospital room and in the presence of her husband

- Was near delivery and admitted for early monitoring
- Hospital room was Sandy's preferred setting
- Sandy's husband was present during the interview, and knew that she was HIV-positive

Case #2: Interview with Shelly in my car

- Did not allow me to interview her in her home
- Had not disclosed her status to her housemates/partners
- My car was her preferred interview setting

Case #3: Interview with Amber in her home

- Home was in disarray
- Served an eviction notice during the interview
- Desired to continue interviewing
- Expressed need for compensation

PRINCIPLES IN PRACTICE

- **Respect for persons**
  - Diminished autonomy and participant vulnerability as concepts lack clarity
  - Engage participants in the resolution of ethical dilemmas to truly respect/optimize their autonomy
  - “Making judgements solely on the basis of ethical expertise and opinions does not acknowledge individuals as moral agents with the right to judge the ethicality of investigative procedures in which they participate” (Fisher, 1993)

- **Beneficence**
  - Researchers, IRBs and other authorities don’t always know what’s “best” for participants.
  - Participants may be best suited to assess their own research risks and harms (Corbie-Smith, 2018) as experts of their lived experiences.

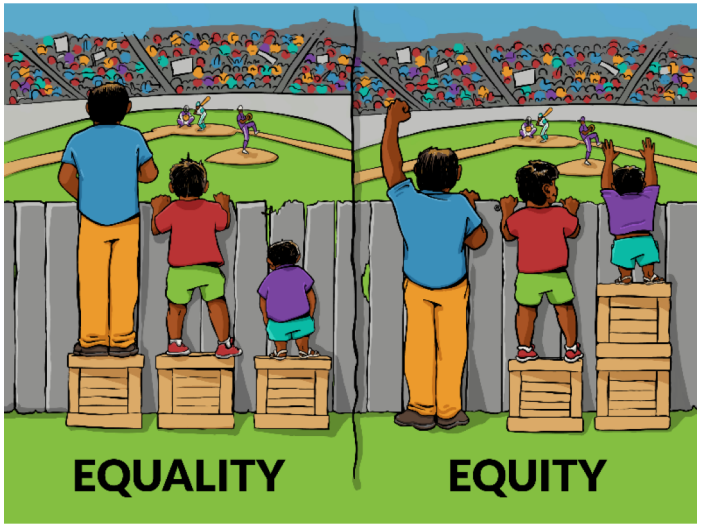
- **Justice**
  - Mitigating barriers to research engagement may require non-traditional settings or practices
  - Compensation as coercive for economically disadvantaged populations

LESSONS FROM THE FIELD

- **Tension between scientific goals and ethical obligations**
  - Scientific duties require implementation of scientific methods, ethical responsibilities require protecting the welfare of participants
- **Lack of empirical guidance**
  - Need for robust empirical evidence to provide guidance for investigators engaging traditionally underrepresented populations in scientific research
- **Need for practices that help identify investigator biases and positionality**
  - Reflexivity (knowledge construction, self-awareness)
  - Insider/outsider perspective
- **Moral responsibilities of health equity researchers**
  - Witnessed structural violence, and indignities experienced by populations “targeted” in research

EMPIRICAL ETHICS AND SOCIAL JUSTICE

- Ethics of protecting the privacy and confidentiality of vulnerable and already stigmatized populations
  - "Mutually safe space for researcher and participant"
  - Marketing materials, snowball or chain sampling, interview locations
  - May extend beyond IRB regulations and procedures
- "Hard-to-reach" populations
  - Understand the research experiences of participants
  - Develop strategies "with" populations to better reach those most burdened by health disparities



RESEARCH ETHICS RELATED PROJECTS

- Genomics Research Participation among Women Living with HIV: A Mixed-Methods Approach to Understanding Women's Perceived Benefits, Harms, and Informational Needs
  - University of Alabama at Birmingham Women's Interagency HIV (WIHS) Supplement (PI: Mirjam Kempf)/ National Institutes of Health / National Health Genome Research Institute Social and Behavioral Research Branch Vence Bonham Lab (PI: Vence Bonham)
- "Economic and Social Vulnerability" in "Considerations Based on Study Population
  - 3rd edition IRB Management and Function, to be published by Jones and Bartlett in 2020
- Addressing ethical challenges in US-based HIV phylogenetic research
  - NIH Working Group on Ethical Issues in HIV Phylogenetic Research

ACKNOWLEDGEMENTS

- Study Participants
- Fellowships
  - NIH/NIDA HIV and Drug Use Research Ethics Training Institute
  - UIC's Building Interdisciplinary Careers in Women's Health K12 Program
  - National Cancer Institute R25T-funded Postdoctoral Fellowship
  - Centers for Disease Control and Prevention Grants for Public Health Research Dissertation R36
- Collaborators
  - Celia Fisher, PhD; Fordham University Center for Ethics Education
  - Janet Turan, PhD; University of Alabama At Birmingham
  - Mirjam Kempf, PhD; University of Alabama at Birmingham
  - Vence Bonham, JD; NIH/NHGRI Social and Behavioral Research Branch
  - Lucy Annang Ingram, PhD, MPH; University of South Carolina
  - Stephen Sodeke, PhD; Tuskegee University

References

- HIV in the Southern United States. 2016; https://www.cdc.gov/hiv/pdf/policies/cdc-hiv-in-the-south-issue-brief.pdf. Accessed February 1, 2019.
- HIV by Group. 2018; https://www.cdc.gov/hiv/group/index.html. Accessed February 1 2019.
- Bowleg L. The problem with the phrase women and minorities: intersectionality-an important theoretical framework for public health. Am J Public Health. 2012;102(7):1267–1273. doi: 10.2105/AJPH.2012.300750
- Intersectional Stigma (NIH) https://news.med.virginia.edu/deansoffice/2018/12/nih-promoting-reductions-in-intersectional-stigma-prism-to-improve-the-hiv-prevention-continuum-r01-r21-r34-clinical-trial-required/
- **Fletcher FE,** Annang L, Kerr J, Buchberg M, Bogdan-Lovis L, Philpott-Jones S. "She Told Them, Oh That Bitch Got AIDS": Experiences of Multi-Level HIV/AIDS- Related Stigma among African American Women Living with HIV/AIDS in the South. AIDS Patient Care and STDs. 2016 Jul;30(7):349-56. doi: 10.1089/apc.2016.0026. PMID:27410498
- Watkins-Hayes C, Pittman-Gay L, Beaman J. 'Dying from' to 'living with': Framing institutions and the coping processes of African American women living with HIV/AIDS. Soc Sci Med 2012;74:2028–2036.
- Rice WS, Logie CH, Napoles TM, et al. Perceptions of intersectional stigma among diverse women living with HIV in the United States. Soc Sci Med. Jul 2018;208:9-17.
- **Fletcher FE,** Fisher C, Floyd N, Buchberg M, Hotton A, Ehioba A , Donenberg G. "Where Did This [PrEP] Come From?" African American Mother/Daughter Perceptions Related to Adolescent Preexposure Prophylaxis (PrEP) Utilization and Clinical Trial Participation. *J Empir Res Hum Res Ethics.* 2018 Feb 1:1556264618755919. doi: 10.1177/1556264618755919. [Epub ahead of print]
- Castillo-Mancilla JR, Cohn SE, Krishnan S, Cespedes M, Floris-Moore M, Schulte G, Mildvan D, Smith KY (2014). Minorities Remain Underrepresented in HIV/AIDS Research Despite Access to Clinical Trials. *HIV Clinical Trials, 15*(1), 14-26. doi:10.1310/hct1501-14
- Fisher, C. B. (2014). HIV prevention research ethics: An introduction to the special issue. *Journal of Emipirical Research on Human Research Ethics, 9*(1), 1-5. doi:10.1525/jer.2014.9.1.1
- Pre-exposure Prophylaxis for the Prevention of HIV Infection in the United States – 2014 Clinical Practice Guideline <*http://www.cdc.gov/hiv/pdf/PrEPguidelines2014.pdf*> (2014).
- Wingood GM, Diclemente RJ, Mikhail I, et al. HIV discrimination and the health of women living with HIV. Women Health 2007;46:99–112.
- McLeroy KR, Bibeau D, Steckler A, et al. An ecological perspective on health promotion programs. Health Educ Q 1988;15:351–377.
- Crenshaw, K., 1991. Mapping the margins: intersectionality, identity politics, and violence against women of color. Stanford Law Rev. 1241–1299

References

- Maxell JA. Qualitative Research Design: An Interactive Approach. Thousand Oaks: Sage Publications, 2005.
- Farmer P. Pathologies of Power: Health, Human Rights, and the New War on the Poor. London, England University of California Press, Ltd; 2005.
- Fisher CB. A relational perspective on ethics-in-science decisionmaking for research with vulnerable populations. IRB. Sep-Oct 1997;19(5):1-4.
- Logie, C.H., James, L., Tharao, W., Loutfy, M.R., 2011. HIV, gender, race, sexual orientation, and sex work: a qualitative study of intersectional stigma experienced by HIV-positive women in Ontario, Canada. PLoS Med. 8, e1001124.
- Reflexivity. 2008 http://www.qualres.org/HomeRefl-3703.html. Accessed February 1 2019.

Questions/Comments

Email:fletch95@uab.edu

THANK YOU FOR LISTENING!