Cultural Narratives of HIV-Positive African American Women Living in Rural and Urban South Carolina: Place Matters

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Presenter Disclosures

Alyssa Robillard

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No relationships to disclose

HIV/AIDS in African Americans

- African Americans bear greatest burden of HIV, accounting for 44% of new infections.
- African American MSM make up greatest proportion of new infections.
- African American women account for 64% among all women.
- Most (89%) due to heterosexual contact.

Centers for Disease Control and Prevention. (2013). *HIV Surveillance Report*, 2011. Retrieved from http://www.cdc.gov/hiv/pdf/statistics_2011_HIV_Surveillance_Report_vol_23.pdf.

HIV/AIDS in the South

- South is home to largest percentage of new HIV and largest percentage of people living with HIV. (Prejean, Tang, & Hall, 2014)
- Poorer outcomes in survival for PLWHA.
- Subset of Southern states (AL, FL, GA, LA, MS, NC, SC, TN, and TX) disproportionately affected by HIV. (Reif, Safley, Wilson, & Whetten, 2014)
  - This “targeted” region also has the highest number of people living with HIV and with AIDS.

Prejean, J., Tang, T., & Hall, H.I. (2013). HIV diagnoses and prevalence in the Southern region of the United States, 2007-2010. *Journal of Community Health*, 38:414-426.
Reif , S., Whetten, K., Wilson, E., et. al. (2014). HIV/AIDS in the Southern USA: a disproportionate epidemic. *AIDS Care*, 26: 351-359.

HIV/AIDS in Rural Areas

- Varying definitions of rural. (Weissman, et al, 2013)
  - Office of Management & Budget
  - Census Bureau
  - Rural Urban Commuting Area Classification
- Largest proportion of rural cases in the South. (CDC, 2014)
  - In SC, the prevalence of HIV/AIDS in rural counties exceeded that of urban counties. (Vyavaharkar, et al., 2013)
- Psychological, physiological, and environmental challenges for rural PLWHA. (Vyavaharkar, et al., 2012; Vyavaharkar, et al., 2012 ; Phillips, et al., 2011)

Weissman, S., et al. (2013). Defining the rural HIV epidemic: Correlations of 3 definitions—South Carolina, 2005-2011. *Journal of Rural Health*, :1-10.

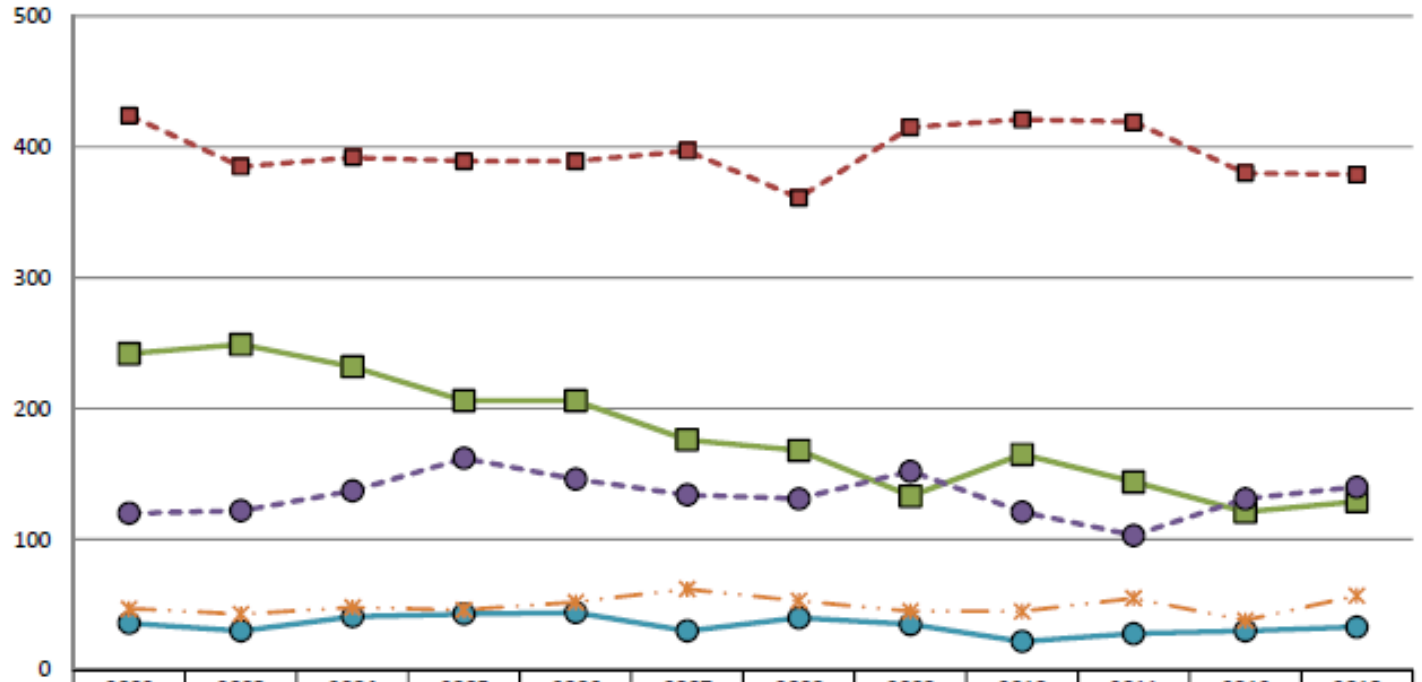
Vyavaharkar, et al. (2013). *HIV/AIDS in rural America: Prevalence and service availability*. Retrieved from

HIV/AIDS in South Carolina

- South Carolina has 8th highest AIDS rate in the U.S.
- Columbia, SC ranks 10th among Metropolitan Statistical Areas with highest AIDS rates.

South Carolina Department of Health and Environmental Control. (2013). *HIV Surveillance Report*. Retrieved from http://www.scdhec.gov/Health/docs/Surveillance%20Report%202013.pdf.

South Carolina HIV/AIDS Cases by Year of Diagnosis by Race and Sex



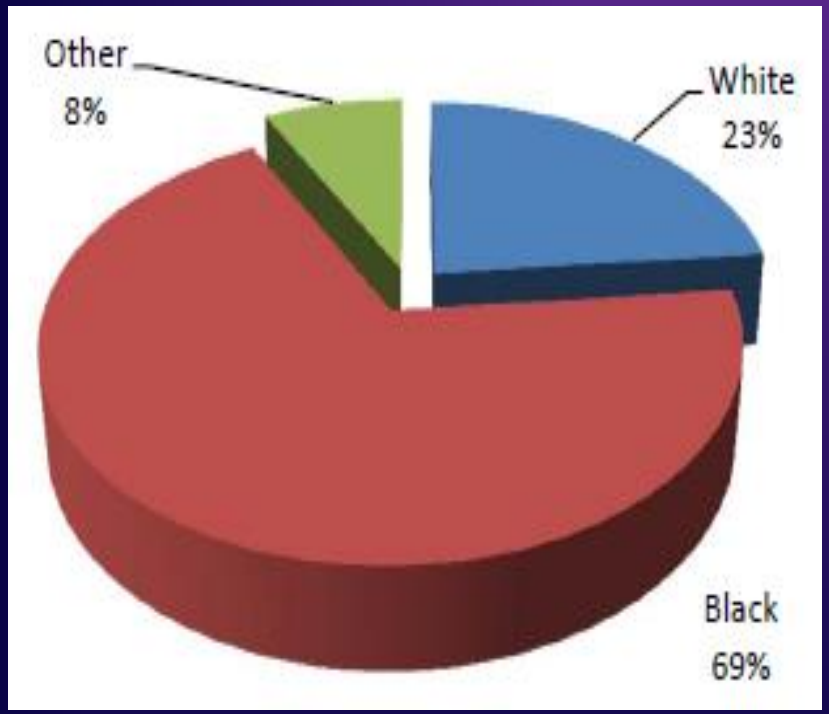
	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Black Male	424	385	392	389	389	397	361	415	421	419	380	379
Black Female	242	249	232	206	206	176	168	133	165	144	121	129
White Male	120	122	137	162	146	134	131	152	121	103	131	140
White Female	36	30	41	43	44	30	40	35	22	28	30	33
Other M/F	47	43	48	46	52	62	53	45	45	55	38	57

Note: AIDS cases are included in counts of HIV cases.

South Carolina Department of Health and Environmental Control. (2013). *HIV Surveillance Report*. Retrieved from http://www.scdhec.gov/Health/docs/Surveillance%20Report%202013.pdf.

HIV/AIDS in South Carolina

2013 Cases by Race

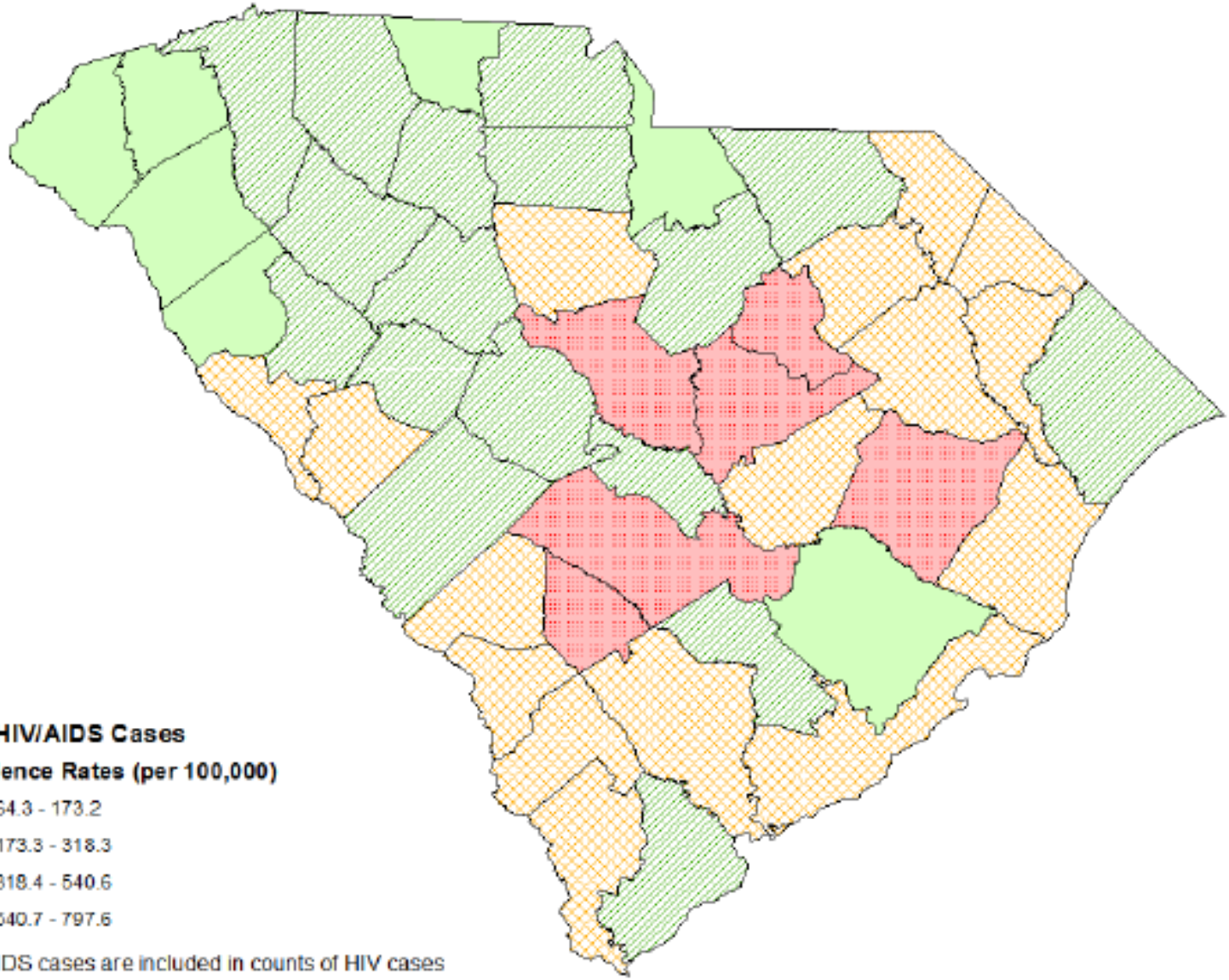


2013 Cases by Gender

- Black women made up 76% of cases among women diagnosed in 2013
- Nearly half (48.8%) of cases in Black women contracted through heterosexual contact (with another 46.3% undetermined)

South Carolina Department of Health and Environmental Control. (2013). *HIV Surveillance Report*. Retrieved from *http://www.scdhec.gov/Health/docs/Surveillance%20Report%202013.pdf*.

2013 South Carolina HIV/AIDS Prevalence

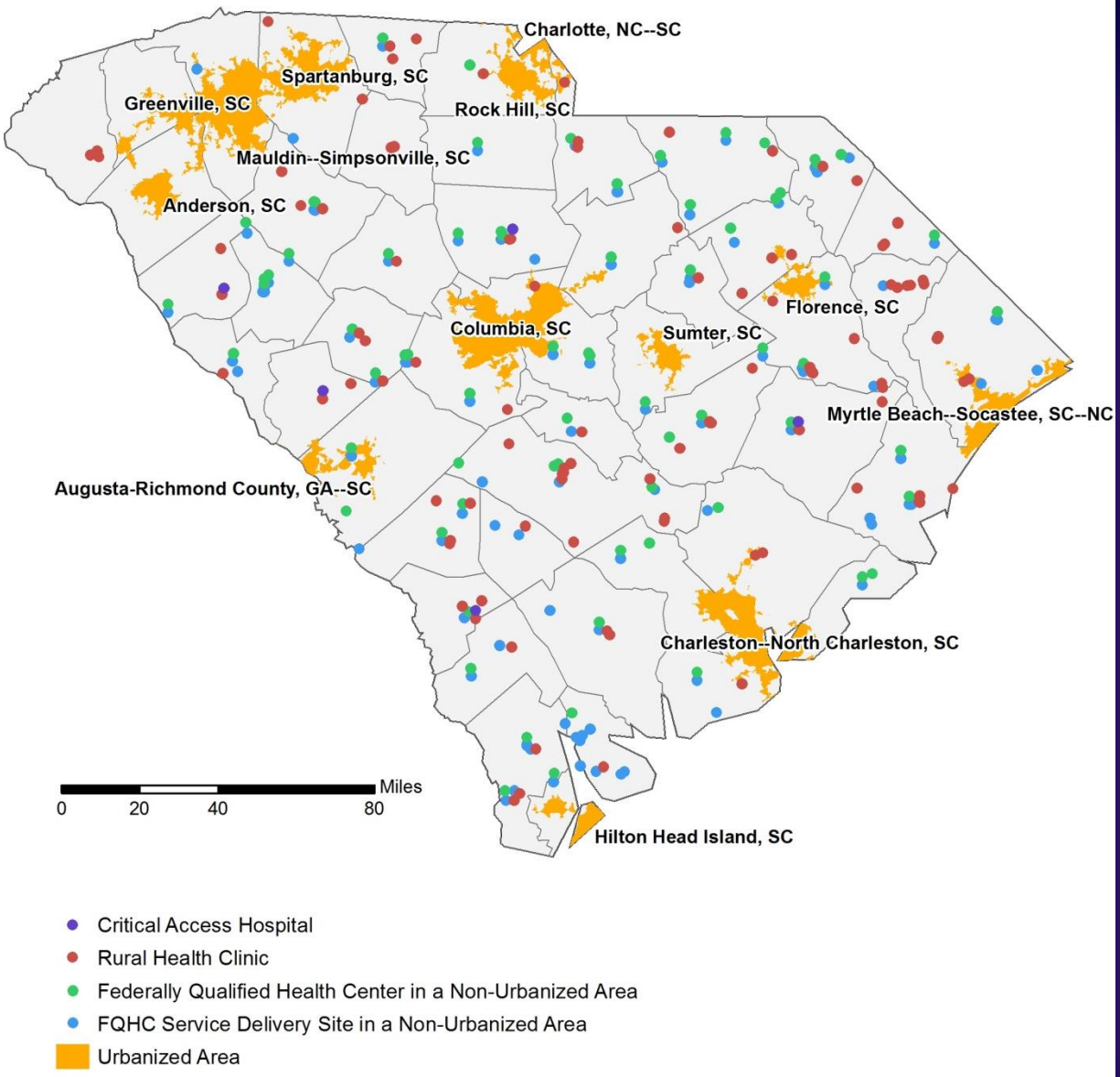


South Carolina Department of Health and Environmental Control. (2013). *HIV Surveillance Report*. Retrieved from http://www.scdhec.gov/Health/docs/Surveillance%20Report%202013.pdf.

South Carolina

- Population: 4,774,839 (U.S. Census, 2014)
- Area: 30,109 square miles (Rural Assistance Center, 2014)
- As of 2010: 66.3% population living in urban; 33.7% in rural (SC Revenue & Fiscal Affairs Office, 2014)

South Carolina Department of Health and Environmental Control. (2013). *HIV Surveillance Report*. Retrieved from *http://www.scdhec.gov/Health/docs/Surveillance%20Report%202013.pdf*.



Sources: U.S. Census Bureau, 2012 TIGER/Line.
Centers for Medicare and Medicaid Services;
U.S. Department of Health and Human Services;
December 2013.

RAC
Rural Assistance Center

Study Purpose

- To compare the cultural narratives of HIV-positive African American women living in rural and urban areas.
- To gain insight into the hardships experienced by women living with HIV and the contextual differences based on geography.

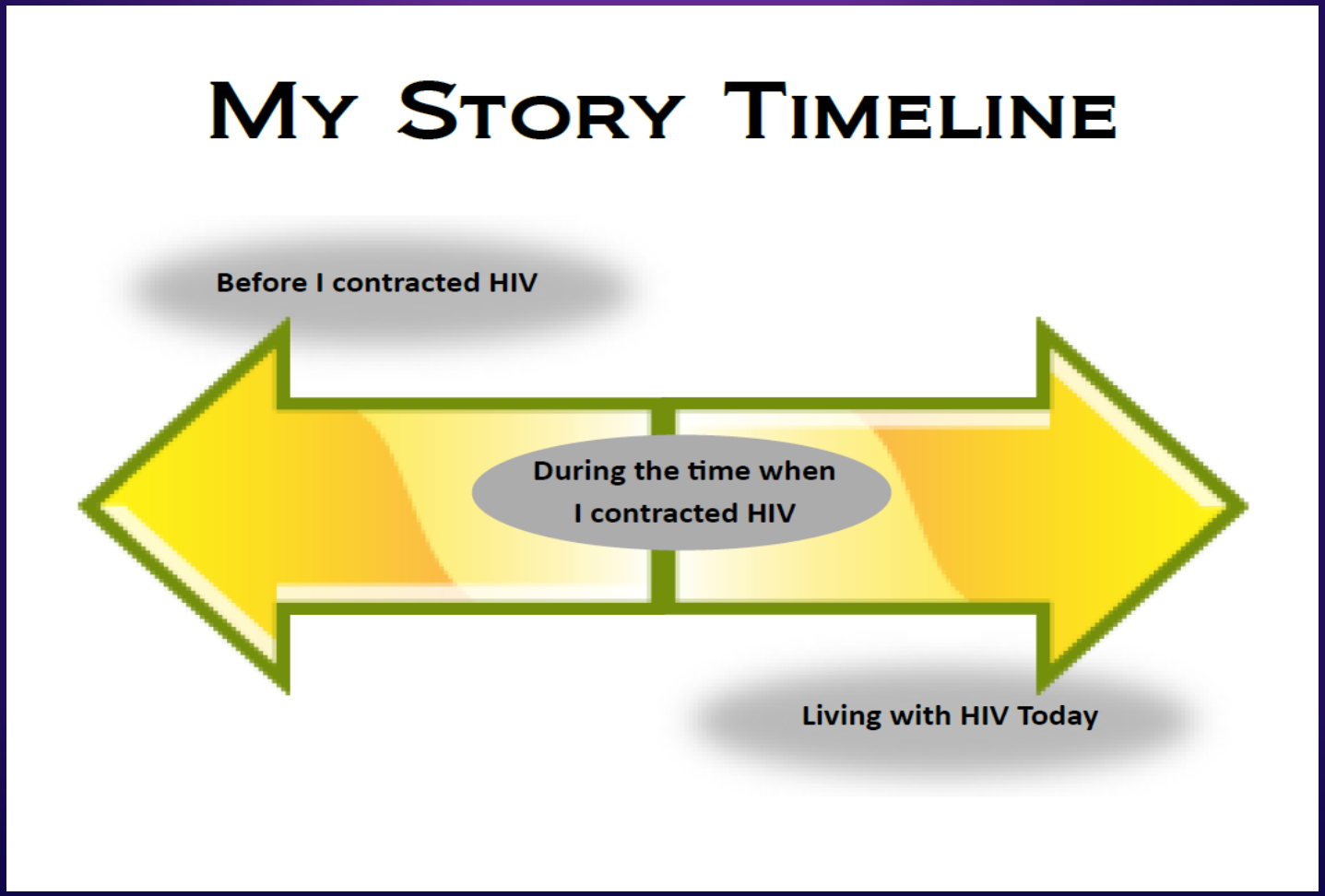
Method

- HIV-positive African American women over the age of 18 (N=25) were recruited through three local organizations serving PLWHA.
- Staff from each organization notified potential participants of the study and instructed them to contact study personnel if interested.
- Interviews were held in private offices at organizations/university, whichever more convenient.

Method

- After informed consent procedures via “letter of invitation,” women completed 1-2 hour individual private anonymous interviews.
- Participants received a $50 incentive for time/transportation costs.
- Interview guide used an ecological and chronological approach.

Method


My Story Timeline
Before I contracted HIV
During the time when
I contracted HIV
Living with HIV Today

Method

- Audio-recorded interviews were transcribed verbatim and “tagged” as either rural or urban based on participant’s assessment.
- Comparative narrative analysis was conducted through a sensitizing framework of “hardships while living with HIV,” using processes related to phenomenology.
- Analysis was completed by three Graduate Research Assistants.
- Study approved by University IRB.

Rural Hardships

Intrapersonal (Individual)	Interpersonal	Community	Institutional	Policy & Structural
Mental Well-Being	Unhealthy Relationships	Characteristics of Small Town/ Confidentiality	Confidentiality	Lack of Access to Health Care (Insurance)
Fear of Disclosure	Caring for a HIV+ child	Stigma/ Perpetuated Norms	Confidentiality Issues within a Small Town	Lack of Transportation-Access
Fear of Rejection from Future Mate	Family: Fear of Disclosure, Stigma/Discrimination, Family's Response to HIV Status, No Family Support, Changes in Family Dynamic	Relocation as a Way to Escape Stigma		Medical Negligence: HIPAA
Denial of Status	Self-Imposed Isolation	Less Education in Rural Setting	Medical Negligence	
Self-Blame for Diagnosis	Denial of Status: Sexual Partner	Traveling to Seek Care/ Privacy		
Burden of Secrecy related to Status				
Substance Use as Coping Mechanism				
Death Sentence				

Mental Well-Being: Suicide Attempts (Rural)

"I really believe it make me more depressed being there... Because when I get in-it got to the point where-and I've been in the country for the longest-that I get so depressed sometimes-now now, which I thank God… it's been four or five times that I had tried to commit suicide, from cutting myself, to trying to drive my car off into the bridge, from running into a tree. You know, taking a handful of pills, got addicted to pills. So it really doesn't help."

Self-Imposed Isolation (Rural)

"When I first found out, I excluded myself from everybody for about a year or two. You know, I stayed to myself. I kept everything dark, closed in, closed up, and didn't want to really deal with anyone. Wasn't the best mom I could be because I was so into that. It basically took over my life when I first found out I had—that I was positive. …it was really hard to deal with."

Confidentiality Issues in a Small Town (Rural)

"…where I live, you know, everybody know everybody, or whatever the case may be. So, I really can't go nowhere in [town] to seek no kinda—I don't—no nothing. Not even emergency room visit if I can help it. Everyone know everybody. By the time you leave outta there, everybody in [town] know what you done been [sic] to the doctor for and what's going on."

Lack of Transportation to Health Care (Rural)

“We don’t have transportation to any stuff. They just actually just start opening up little places around. There’s no bus service. You’re just lost. Then if you do have transportation you’re not gonna ask anyone to take you to the doctor if you gonna tell them what was the reason. So it is difficult. Very difficult.”

Urban Hardships

Intrapersonal (Individual)	Interpersonal	Community	Institutional	Policy & Structural
Death Sentence	Unhealthy Relationship: Abuse	Stigma/Lack of Education	Response by Staff Administering Test	Lack of Access to Health Care (Insurance)
Denial Of Status	Family: Stigma/Discrimination, Concern About Inability to Care for Family, Lack of Family Support, Changing Family Dynamics	Confidentiality	Poor Health Care Experiences	Lack of Transportation/ Impacting Access
Addiction/ Substance Use	Addiction Linked to Sexual Risk Behavior	Forced Work-Place Disclosure/Lack of Knowledge about Rights	Lack of Knowledge: Medical Rights; Education	Enforced Segregation (Prison)
Mental Well-Being	Privacy	Negative Reactions due to Disclosure	Circumstantial violation of Confidentiality	
Burden of Secrecy	Loss of Friends		Institutionalized Stigma	
Fear of Disclosure	Partner: Denial of Status by Sexual Partner, Partner Unaware of Status, Unprotected Partner Infidelity		Differential Treatment Due to Status	
Fear of Rejection by Future Mate			Medical Negligence	
Self-Blame for Diagnosis				
Perception of Unachievable Life Goals				

Unprotected Partner Infidelity (Urban)

“But right now I don’t feel comfortable with it, because we’re really just starting to get back with one another, and…I’ve been using condoms with him, for one, and we got back together, was trying to get back together... I found out he was messing around, and I talked to the girl and I asked her because I wanted to know if they was using condoms or not, because I’m not gonna put myself at risk of getting no sexually transmitted disease when I know what I got, so—she told me they wasn’t using no condom, so that’s why I keep using condoms with him.”

Family-Stigma/Discrimination (Urban)

“She gave me a paper cup, and she gave me a little plastic fork and a paper plate. ‘Cause we went over there for dinner. Everybody else eatin’ outta plates. I looked at—I say, ‘MJ…who the hell you think I am.’”

Institutionalized Stigma (Urban)

“They tell me, ‘Nope, you’re goin’ to Whitney B.’ Whitney B, the HIV unit. Now I imagine you got other inmates on Whitney A lookin’ over at us on Whitney B and stuff like that. You know, that’s humiliating to people that just now come in the building, just now find that they positive. You know?”

Limitations

- Findings reflect only experiences of sample and may not be reflective of all rural and urban African American women living with HIV/AIDS

Conclusion

- In South Carolina, HIV/AIDS prevalence in rural and urban areas nearly equal.
- Certain issues unique to rural areas.
  - Small town characteristics
  - Less Education
  - Access to Care/Transportation
- Community level issues most salient for rural communities

Implications

- Findings emphasize challenges faced by women living with HIV/AIDS and highlight unique challenges faced by women living in rural areas.
- Speaks to need for interventions for rural women that are responsive to hardships existing at individual, interpersonal, community, institutional and policy levels.

Acknowledgements

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Questions