The Color of HIV

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For Louise, who grew up in Wake County, in a rural town of 4,000 where Blacks are clustered on the poorer south side, H.I.V. has quietly joined poverty, drugs and prison stints as part of the tattered fabric of daily life. The oldest of four siblings in a family that struggled to make ends meet on her father's factory wages, Louise became sexually active at 13. Nice homes and good jobs seemed reserved for Whites on the other side of town. The dead-end jobs where most Blacks ended up made school seem irrelevant. Sex, she said, was an easy way to pass time, and a drug dealer's ready supply of cash outweighed whether he had come from—or might soon go to—prison or jail.

''Most of the guys I dealt with had a drug charge at some time," she said. ''I remember this one guy, I saw the gold in his mouth and I thought, 'Ching, ching. He can give me what I want.' But then I was also thinking, 'Is this really what I want?'" She was dumbfounded, she said, when a blood test she took as part of a gynecological exam when she was 19 showed she was H.I.V. positive. She never found out how or where the former prisoner who infected her had picked up the virus, though she assumed it was from sex because she never saw him use intravenous drugs. ''When you think about the things that might happen, you think as long as you don't have a baby you're O.K.," Louise said. ''You think about the guy you're dating, how he might violate probation and go to jail again and you'll be alone. But you never think that he could have this disease. You never think about that." [1]

While Louise is correct when she emphasizes that HIV is something "*you* never think about," she would be better off using the collective *we*. As communities, we avoid thinking about what is difficult, especially when the subject is divisive. When the issues brought up are uncomfortable or taboo. Indeed when the answers to questions no one wishes to ask are not easily discernible or are ultimately unwelcome. For Louise and far too many of us, HIV/AIDS has become a topic that we never think or talk about, even when reason and morality compel us to do so. Those that suffer the most as a result of our communal inaction are not the 'average' citizens, when 'average' is synonymous with white, straight, and socioeconomically stable. Rather it is those who occupy the margins: the poor, the homeless, the members of racial and ethnic minorities, drug users, and any other individuals who, for a variety of reasons, are not welcomed into the inner circle of society. The cases of such marginalized persons are many and diverse. The story of Louise is that of a young, HIV–positive African American woman, whose struggles prompt us to discuss the extent to which her race, financial situation, gender, and sexual experience are related to her HIV status. However, her case also speaks to that of a larger population. This discussion is then best framed as follows: we must work to understand the valences of Louise's story, while connecting her experiences to those of HIV–positive African Americans whose stories too often go untold.

The Color of the Epidemic

The human immunodeficiency virus, like all other viruses, is indiscriminate in transmission. Viral cells do not assess the target

for susceptibility before entering into and colonizing the host, yet statistics evaluating the virus's spread would suggest otherwise. HIV breeds amid specific social conditions, and in the United States we observe its proliferation among many of the nation's minority groups. Epidemiologically speaking, it has become an undeniable fact that in the United States the color of the epidemic is and has been shifting, since its identification, from white to black.

In 2010, African Americans accounted for 44% (20,900) of new HIV infections among adults despite representing only 12% of the national population. Men accounted for 70% (14,700) of these cases, and Black men who have sex with men—typically the highest risk group for HIV transmission—numbered 10,600 in new cases (only 600 behind their Non-Hispanic White counterparts). On the whole, African Americans are eight times more likely to contract HIV than are whites. African American males are seven times more likely than white males, and African American women are 20 times more likely than white women, to contract HIV.[2]

What is most worrisome about available data is the inverse relationship between new infections within the two racial groups. Since the late 1980s, the number of newly infected African Americans has exceeded whites, and African Americans now account for roughly 510,100 of Americans with HIV, while whites number 382,600.[3] Neither number is cause for elation, however the ever–steady increases in new and total infections for African Americans point to a disturbing reality of the HIV epidemic: that public health programs, which have shown success among whites, have had a limited effect on the African American population.[4] These data can be explained by the fact that African Americans face considerably more obstacles in the fight against HIV than do whites; that while one group has shown a decrease in new infections because of programs targeted to 'the society's needs', still another has been so unaffected by these programs that in 2012 an estimated 22,581 African Americans (compared to 13,921 whites) were diagnosed with HIV.[5]

However, critics might assert that the high rate of new infections among African Americans can be explained in any of three ways: (1) African Americans participate in high–risk acts more frequently than whites, (2) African Americans do not engage in care as actively or consistently as whites, and (3) different subpopulations must be targeted differently, and that African Americans have not been effectively targeted while whites have.

As for the first of the three points, we know the claim that African Americans engage in more high–risk activity than whites to be inaccurate. African Americans have been shown to engage in less lifetime use of illicit, needle-requiring drugs, and be less likely to use drugs during adolescence than their white counterparts.[6] In addition, despite having a generally younger age of first sexual encounter, higher incidences of contraception use were reported among African Americans adolescents.[7]

While the second point may hold statistical truth,[8] we must also note that African Americans are much less likely to be prescribed anti-retroviral treatment on their first visit to an HIV clinic than are whites,[9] and that this first encounter is extremely important in determining the level of future engagement with the health-care provider. The clinical experiences of individuals are unique, however any element of racism, stigmatization, or unequal treatment—overt or subliminal—experienced by patients on this first visit decreases the likelihood that they will seek future treatment with the same provider or at all.

The third point quite clearly adds credence to the increased-barriers claim. Public health campaigns ought to be constructed with the entire target population in mind, while also acknowledging—and confronting—the specific obstacles groups might face in receiving care. In the case of HIV, the target populations have expanded over the years from only certain 'vulnerable groups'

(i.e. IV drug users, men who have sex with men, sex workers, migrants, etc.) to the larger adult and adolescent communities. All individuals who have sex are at risk of acquiring HIV. The fact that large scale prevention programs, and even targeted attempts by public health officials at working within the African American population, have shown marginal success in decreasing the number of new infections among African Americans speaks to the obstacles towards prevention, transmission, and treatment that are not being met. In order to understand why those who occupy the margins of society are so deeply affected by the HIV epidemic, and why African Americans face considerably more obstacles than whites, we must engage in a critical reflection on the society from which these groups are marginalized and the living conditions of high-risk persons.

Instability and the Transmission of HIV

The efficacy of discussion is limited by the power of language, and continued use of the phrase 'marginalized' does not get at the full picture of what the word is often invoked to describe, nor does it allow readers of pieces on HIV—often those fortunate enough to be pursuing higher education or already established in academia—to get as true an understanding of 'marginalized' living as possible. The problems with 'marginalized' as a descriptor are that it is used to describe a number of disparate groups and that it leaves little room for deeper analysis. We are better suited to use the term 'instable', since it allows for an exploration of the extent to which stability is present in—or absent from— an individual's life, and in which specific areas stability is lacking. 'Instabale', more so than 'marginalized', speaks to the individual experience of an HIV patient, the stigmatization he or she faces, and even the circumstances that perpetuate the spread of HIV. Therefore reflection will be most effective if we adopt a terminology best suited to analysis.

James Keenan, S.J., a Catholic moral theologian and ethicist who has written extensively on the Catholic response to HIV/AIDS, asserts that "HIV breeds specifically where there is social instability, whether that means…those who are affected by civil strife", economic collapse, or uncertain employment, "those who are forced into sexual activity", or are victims of partner infidelity.[10] For Louise, instability is a product of her living environment, sexual activity, and relationships. Her dad's limited income and many dependents place the family in a difficult situation—one that is characteristic of families and people straddling the poverty line. Choices are limited in terms of daily life, and become even more limited when financially burdensome problems arise. With little to aspire to in the way of future employment, Louise assigns nearly no value to education. And what is troubling, other than her self-removal from an educational setting, is that she then looks for entertainment from other sources. It is these other time-occupying activities, particularly the choice to become sexually active without prior sexual education, that are high risk for HIV transmission.

Louise's race undoubtedly plays a dominant role in her life as well. The effects of dark skin color on livelihood in contemporary American society are numerous and well-established elsewhere (and frankly a discussion in this setting would fail to do the topic justice).[11] But at the very least it can be said that having been born into a southern, rural town separated along racial lines, it is likely that Louise experiences racial separation and racism in more areas than just neighborhood division.

In the article commenting on Louise's case, Louise explains that her family refused to believe that a relative of theirs had died from AIDS, instead attributing his passing to sickle cell anemia. Stigmatization was felt so deeply within her own family, Louise says, that when she was diagnosed with HIV, she insisted on seeking care in a neighboring town.[12] Many HIV-infected people share the same apprehensions about revealing their status

to loved ones and friends since they fear rejection and isolation. Therefore, we can see that instability is perpetuated not just by social structures and economic status prior to infection, but also by relationships and stigmatization post-infection.

Notice how, although Louise actively chooses to pursue a sexual relationship and disengage from her schoolwork, the instable circumstances which prompt her to do so—her living environment—predate these decisions and even her birth. In other words, she was born into a situation that guided her towards the decisions she made, and her circumstances ultimately work to her detriment. From the onset, her social setting perpetuates instability, leaving the possibility for a stable, formative environment virtually nil. All of us are products of some greater environment, and it not just those who are most severely harmed that evidence this. Yet it is precisely those most negatively impacted that deserve our greatest attention. In recognizing the harm caused to an individual or population by their circumstances, we turn to a discussion of structural violence, which provides a social framework for evaluating the larger impacts instability has on Louise and African Americans.

Structural Violence and the Incarceration Endemic

Structural violence, a term coined by sociologist Johan Galtung in the 1960s, describes the economic, political, legal, religious, cultural, and social structures that stop individuals, groups, and societies from reaching their full potential.[13, 14] Structural violence is deeply connected to the existence of a social machinery of oppression that works, whether deliberately or unconsciously, against instable populations. Often these systems seem so ordinary that they appear almost invisible, however the fact remains that certain institutions, societal practices, and beliefs ultimately serve to further suppress the already marginalized. We see violence enter the lives of all instable persons, whether they are impoverished, homeless, Black, Latino, homosexual, transgendered, or a member of any other minority group.

Louise's case indicates the effects of structural violence on the individual. Particularly for the residents of the poorer side of her town, poverty is a source of violence. Poverty deprives people of opportunity, diminishes the humanity and dignity of a person, and feeds into itself in a seemingly never-ending cycle. Lack of socioeconomic stability and a dearth of respectable employment prevent Louise from reaching her full potential and incite her to explore high-risk behavior. Nationally, African Americans constitute 25.8% of the 42.7 million Americans (14.3% of the total population) who fall below the federal poverty line—that is 9.5 million Americans who, like Louise, face a severe economic burden on top of violence derived from other institutions.[15] It is then not surprising that a 2010 study found the HIV prevalence among heterosexual people living in poverty to be four times higher than the national average.[16]

While the effects of poverty are immense, poverty is not the only source of structural violence. For the greater African American population, one of the major sources of contemporary violence is the criminal justice system. As Robert E. Fullilove, associate dean of the Mailman School of Public Health at Columbia University, explains, "The war on drugs took the group that was at greatest risk for HIV infection and made sure that they would be locked up." Today African Americans males are incarcerated at a rate higher than any other subpopulation in the United States. As of December 2013, Blacks composed 36.4% (549,100) of the total inmate population—a number notably disproportionate to the overall Black populace.[17] Additionally, it is estimated that 1 in 3 Black males will be imprisoned at some point during their lifetime.[18]

With such a high percentage of the population facing imprisonment, structural violence is seen first in the impact of incar-

ceration on those connected to the incarcerated individual; and with the vast majority of incarcerations involving males, Black females like Louise are placed at increased risk. Nina Harawa et al. summarize well the effects of high incarceration on the non-incarcerated African American population, saying incarceration patterns "negatively impact African-American communities by reducing opportunities for economic and educational advancement; diminishing political participation; decreasing the numbers of available sexual and marriage partners for African-American women; disrupting existing sexual relationships and family lives; and changing norms related to sex, monogamy, violence, and drug use."[19]

Incarceration invariably increases the risk of HIV infection for inmates as well, both during and after a sentence. Unprotected sex, rape, and needle sharing (for either tattooing or drug injection purposes) are all potential high-risk actions within a prison setting. Prisoners are placed at further risk by many prison's policies forbidding the distribution of condoms, as well as the lack of prison-provided drug treatment programs—both of which represent a failure on the part of prison officials to respond to high incidences of sexual and drug-related transmission in jail.

Although it might seem backward to identify a system as violent that punishes individuals for their transgressions of codified law, we must recognize the circumstances that incite people to engage in criminal activity in the first place, the general lack of appropriate governmental response to the problems in crime-heavy communities, as well as whether or not the laws are being equally enforced. Since incarceration often compounds with other incidences of structural violence, as crime tends to predominate in low-income environments, we then see how, just as was the case with poverty, incarceration plays into a continuous cycle of instability. Poverty begets crime. Crime begets imprisonment. Imprisonment begets poverty. We perpetuate structural violence in our failure to address the problems that lead individuals to incarceration in the first place, and commit further injustices by returning them to their unchanged pre-incarceration circumstances, knowing full well that they are extremely vulnerable upon reentry to society. (Injustices evidenced in part by recidivism rates: a 2005 study by the Bureau of Justice Statistics study shows that after 5 years, 76.6% of felons had been rearrested.)[20]

The "tattered fabric of daily life" that Louise's case mentions is a summation of the many other forces acting against African Americans that ultimately serve to increase the risk of HIV transmission. Lane et al. expand on Louise's commentary, noting that instances of residential segregation, disproportionate incarceration (as previously mentioned), and the influence of gangs all result in constrained social-sexual networks with a limited number of sexual partners. Because so many males are incarcerated, women have fewer potential partners who are not HIV-infected, leading to high-risk behavior: Thomas Clodfelter, a former felon with HIV who now counsels other ex-convicts, says that "a lot of women…are looking for a man to give them a sense of strength, a sense of authority…men come out of prison, they're all big, got muscles, looking good…and the women, they're all up on them. It's not like people don't know they're putting themselves at risk. They just don't care."[21] And in the treatment and prevention of HIV, limited access to healthcare and STD clinics hinder the ability of the individual to seek further information or receive consultation about infection.[22]

In the end, people are not at risk for HIV simply because of their being marginalized, but because their lives and social settings lack the means and stability needed to live safely - free of societal pressures and practices that we know to be detrimental to the health of a population. Structural violence perpetuates instability and adds fire to the already roaring blaze that is HIV/AIDS.

Female Agency and the Remodeling of Masculinity

'"When you think about the things that might happen, you think as long as you don't have a baby you're O.K."

Louise's relationships with her drug-dealing partners exemplify incarceration-resultant instability, as well as a much larger problem facing women in a time of HIV: non-agency. Loss of agency is the result of continuous suppression of women, owed to a global androcentric mindset, patriarchal institutions, and traditional female roles. Gillian Paterson, in her piece "Escaping the Gender Trap: Unraveling Patriarchy in a Time of AIDS," asserts that subordinating female gender roles are present in virtually all cultures irrespective of a woman's HIV status, that women are unjustly blamed, stigmatized, and burdened by HIV because of gender role imbalances, and that these imbalances only further worsen when a woman is HIV–positive.[23]

Pre-HIV gender roles are at work in Louise's outlook on her relationship: *when you think about the things that might happen… as long as you don't have a baby you're O.K.* While she appears cognizant of a danger of sexual relationships, Louise never considers that her partner is possible of causing more harm than simply getting her pregnant. As a society, we must actively suppress the notion among sexually active adolescents that a baby is the most harmful outcome of a sexual relationship. Education is an excellent tool for such preventative measures, but teaching about prevention, like imprisoning criminals, is a means only towards allaying the larger problems that already exist.

It would be easy to say "women must also be encouraged to find agency in relationships," however that would forego the much needed discussion about what *men* must be encouraged to do. It is not fair or adequate to say that it is up to women to find agency in a relationship, as that places the onus entirely on the already burdened party. The ongoing movement towards general female equality is absolutely essential, but there must be a simultaneous movement demanding change in male culture. Men must realize that masculinity is defined not by the ability to subjugate others, but rather by an intense maturity and knowledge about ones place and impact. Nowadays many people call for a renunciation of 'traditional masculinity,' which is often associated with the violent and sexually hyperactive tendencies of men, but negative commentary about the role of men does no more good than it does for women. A positive valuation of masculinity must be grounded in a positive valuation of the human—in what it means to be a moral being.

Christian tradition teaches that justice is the guiding virtue for this moral education, as it reminds us that we are part of a collective humanity, and that we must respond to all members with impartiality and egality. But while such an education is often grounded in a religious context, morality extends beyond the confines of religion. Community leaders must impress the universality of moral conduct, leading by example. Moral education should ultimately lead to a more profound understanding of the sexual rights of women, since, as Paterson reminds us, "HIV will not be brought under control until women are better equipped to influence the terms of sexual encounters."[24]

The Response to Racial and Gender Inequality in a Time of HIV

If we accept that there is clear racial disparity in the proliferation of HIV/AIDS, that inequality is due in large part to subjugation of minority groups through violent structures and all consequences thereof, and that structural violence (gender norms included) is perpetuated through improper response, the question we find ourselves asking is: where do we go from here?

First, we must acknowledge that public health officials confronting racial health disparities understand the social determinants of health, but lack the means to challenge these constructs. Pub-

lic health officials have adopted a human rights framework and language in response to the HIV/AIDS pandemic, drawing upon the essences of Catholic moral and social teaching in a secularized fashion. However this framework does not always succeed in impelling others to act, especially those who can make the difference.

Second, those who are capable of fixing these broken systems are political figures that see little advantage in addressing structural violence and criminal justice disparities because the problems in question are so deeply rooted that nothing short of system reformation will be effective. While one would hope that politicians could be more easily convinced to act on morality alone, the current state of the political establishment does not lend itself to the cooperation necessary for institutional overhaul and appropriation of funds necessary to combat structurally violent systems. Therefore the impetus for change must come from the larger American public. We see the potentially constructive temperament of many regarding racial injustice in the response to the Black Lives Matter movement, so there is hope that racial disparities will be elevated to the status of 'politically worthwhile'. The difficulty of changing societal practices will inevitably lie in our actual response once political consensus is reached, and we will then find ourselves asking what we should do in specific. Whatever the response, it must be cognizant of the dignity and rights of all Americans, not just those who wield wealth and political power.

Third, the stories of individuals like Louise can be powerful educational tools. It takes courage to be open about ones HIV experience, so we must encourage loved ones, friends, and neighbors to be honest about their experiences both for their own betterment and that of others struggling with an HIV–positive diagnosis. Louise tells us she views her own story "as testimony, so people will start to be honest."[25] Perhaps it is these individual cases that best supplement public health's human rights framework, simultaneously shifting the HIV/AIDS paradigm from 'we never talk about it' to 'we must talk about it.' It is saddening, though, to think that after 30 years of suffering from HIV/AIDS, the American public still remains largely impartial to the epidemic.

Frederick Douglass reminds us, "Where justice is denied, where poverty is enforced, where ignorance prevails, and where any one class is made to feel that society is in an organized conspiracy to oppress, rob, and degrade them, neither persons nor property will be safe."[26] Are we not ashamed that the words of an abolitionist from nearly 150 years ago still ring emphatically true today? Let us not be remembered by future generations for inaction in a time of great need, but rather for the conscience and compassion to address our society's most profound shortfalls.

ENDNOTES

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