



# Undergraduate Journal

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### The Power of a Different Reality: Finding Strength in Sheila

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One of my favorite anonymous quotes reads: “Attract what you expect, reflect what you desire, become what you respect, and mirror what you admire.” Before my time at Notre Dame, I do not think that I interpreted the “becoming” or “mirroring” aspects of this saying correctly. I strived to become those who I was intimately familiar with; those who were most like me. I wanted to mirror the actions of people, I now realize, who share almost an identical background to my own. While respecting and mirroring the beliefs of those most like oneself is by no means harmful, this past semester, I have learned that remaining within one’s comfort zone will not result in optimal self-growth. To expand upon this original quote, I think that the best advice may be to first interact with a wide variety of individuals with different backgrounds, beliefs, and experiences to exhibit a comprehensive mindset. If humankind avoids interaction with diverse backgrounds, then their mindset remains unchallenged, and ultimately, resistant to change.

This spring, I took a course called “Writing for Social Justice” at Notre Dame. Our class partnered with South Bend organizations that serve marginalized individuals who each, as we learned, hold a unique, unrepresented story to share. The purpose of this course was to meet with an individual from one of these services, listen to her story with an open mind, and transcribe her words. With this class, I learned that one vital way to interact with those who represent a different background, those who have a unique story to share, is to listen. Sheila, a blind South Bend resident living with HIV, shared her story with me through a series of interviews. I remember at our initial meeting, Sheila admitted that she has had a “crazy life,” one that she would not wish upon anyone. Due to the suffocating stigma surrounding HIV at the time of her diagnosis and the resulting lack of medical care, Sheila was left to navigate the infection without much guidance. While Sheila’s story is most definitely difficult, it speaks to her strength, resilience, and faith as well. This story challenges me to be a better person by both “respecting” and “mirroring” Sheila’s unwavering perseverance. Additionally, this account emphasizes that because African Americans continue to be disproportionately affected by HIV mortalities and diagnosis rates, this virus remains a threat to human dignity. By sharing Sheila’s story, I hope to demonstrate the potential for growth in listening to another’s perspective and emphasize that the HIV poses a disproportionate threat to African American individuals.

Sheila’s story begins in 1983 with her husband. The two were happily married, and by listening to her soft words and gentle tone, I could immediately tell that he was an integral aspect of Sheila’s life. Sheila spoke openly about her husband’s drug use. Following the birth of their first son, he struggled to find work. To support the family, Sheila’s husband began selling drugs. Sheila soon found, however, that “he really was his own best customer.” Though Sheila admitted that she considered herself an “enabler” of her husband’s actions, as the interviews continued, it seemed as though she was at peace with her past. After one day, finding her husband unconscious, Sheila realized that “things have got to change.” Sheila chose to admit her husband in a 90-day rehabilitation program that ultimately resulted in a routine AIDS test. When her husband called to admit that the results were positive, Sheila was devastated. At the time, Sheila

was pregnant and feared that her own positive diagnosis may endanger the unborn baby's life. When Sheila described the period of waiting for her test results as the "worst two weeks of her life," I was surprised. I soon, however, realized that my understanding of HIV posing minimal risk to both pregnancy and a mother's life is sheltered. Assuming that individuals have access to medication, resources, and information regarding HIV transmission is unrealistic. For example, during Sheila's pregnancy, the stigma surrounding the virus was so suffocating that many doctors refused her case. Despite the dirty looks and heartless denials, Sheila persevered to find a physician willing to deliver her son. Though his HIV test returned negative, Sheila would never recover from the fear of losing her child.

Sheila's terror when describing her pregnancy as one of her most difficult trials led me to investigate the consequences AIDS may pose to pregnancy. When Sheila was pregnant with her son, she feared for his safety due to a lack of reliable information regarding HIV transmission. Today, however, sufficient sources are discussing the probability of AIDS transmission, prevention, proper medication, and local resources. According to the U.S. Department of Health and Human Services, a diagnosis of HIV does not necessarily preclude a healthy pregnancy, though the virus can be passed while in labor while giving birth, or during breastfeeding (Pregnancy and HIV, 2018). However, with proper care, the possibility of transmitting HIV through pregnancy can essentially be reduced to zero. Before effective treatment was available in the United States, about 25% of mothers living with HIV passed the virus to their children; numbers such as this reveal why Sheila was so frightened for her son's health. Today, with proper treatment, only about 1% of mothers transmit the virus through pregnancy (Pregnancy and HIV, 2018). However, research suggests that while available information and treatment are improving, certain populations remain especially vulnerable to HIV transmission. According to the CDC, in 2017, 64% of perinatal HIV infections were diagnosed within the African American community (Pregnancy and HIV, 2018). While I originally assumed that her fear of HIV transmission would be diminished in the modern context, this statistic regarding African American HIV pregnancies allows me to realize that many women likely still endure a trauma like Sheila's.

Though Sheila's son was physically unaffected by his initial lack of medical attention, her own health was permanently damaged by stigma and insufficient resources. After the birth of her son, Sheila described herself as "in the closet." She battled the virus privately, fearing that her children may be teased if word of her condition spread. Negative stigma and fear of discrimination persuaded Sheila to neglect the virus. Additionally, because neither Sheila nor her husband showed physical effects, Sheila refused to take medication; Sheila, as she describes, was a "non-believer." Sheila admitted that it was practically impossible to find a doctor who was willing to provide aid. While one may be quick to assume that Sheila was negligent with her health, access to HIV treatment, especially among African American individuals, remains a challenge. For example, in 2016, for every 100 black individuals living with HIV, only 61 received "some HIV care" (CDC, 2020). Furthermore, only 47 of the 100 diagnosed individuals were retained in care (CDC, 2020). Before speaking with Sheila, I had little understanding of the poverty, stigma, and lack of healthcare that contribute to disproportionately high rates of HIV among African American individuals. Because of these risk factors, though African Americans represent just 13% of the United States, as of 2010, nearly half of the people living with HIV are black (HIV and AIDS among African Americans). Much like Sheila, many of these individuals may be struggling to find resources for treatment or fighting to protect their children from unjustified stigma. Listening to a story so different from my own has given me the empathy to

understand that these African American individuals without access to HIV treatment are not negligent about their health, but rather threatened by a complex web of injustice.

After avoiding medication for years, Sheila, as she described it, “reached her downfall.” Sheila admitted that in the late 1990s, she began having seizures. Eventually, as the seizures progressed, brain surgery was necessary. Sheila, rather bluntly, stated that she almost died, had brain surgery, and returned from the hospital blind. Sheila chose to share little detail regarding complications but implied that the surgery left her blind. I understand Sheila’s reluctance to describe her time in the hospital: I think that Sheila attributes her blindness to her initial aversion towards medication. Sheila’s near-death experience in the hospital “really opened [her] eyes”: she realized that HIV is “for real” and began to take medication. While learning to navigate the world as a blind woman, Sheila’s husband became ill. Sheila, still recovering herself, had no choice but to send her husband to New Jersey to stay with his mother. Instead of recovering, Sheila’s husband declined rapidly. I could tell how difficult it was for Sheila to discuss her husband’s death. He passed away two days after Christmas, and Sheila described the heartbreak she still feels each holiday season. In describing his passing, Sheila stated that she does not blame her husband for the consequences of the virus. Instead, Sheila turned to her faith: she believes that God introduced AIDS into her life so that she could “see” something. I found Sheila’s acceptance of hardship and lack of bitterness towards her husband inspiring. Sheila reminded me that life is best experienced with forgiveness and trust rather than anger and regret. Choosing love over accusations will bring about peace, no matter the potential hardship.

Recently blind and widowed, Sheila was tasked with raising her three small children, finding employment, and battling her grief. Sheila describes this period following her husband’s death as another great downfall. As a single mother, she feared that child protection services would take her children. Sheila struggled to manage her grief, health, and household. Eventually, Sheila decided that she “wasn’t just going to lay around and feel sorry for [herself] and cry all the time.” Sheila soon found support from an organization called AIDS ministries that provided financial aid, childcare, and transportation. As her spirits lifted, she found employment. Sheila treasured the independence she felt while working as a blind employee. This independence gave her the confidence to share her story with pride rather than hide from the virus. Sheila became an advocate of Imani Unidad, a South Bend organization concerned with HIV awareness and prevention. As our interviews ended, I found Sheila’s final words fascinating. Sheila stated that by battling HIV, her life has come to purpose. Sheila believes that God spared her life so that she may be an example to others. Sheila recognizes that when people see a blind woman working, they are inspired. However, while these bystanders may be moved from her visible disability, Sheila admits that most people do not know her story. Sheila told me that if people knew about her virus and considered all her hardships, they would think “wow, how in the world does she still make it.” Sheila reminded me that without hearing someone’s perspective, there is no foundation to understand him or her. To truly grow and learn from others, humankind must make the effort to listen to diverse individuals recount their stories in an authentic manner.

In our initial meeting, Sheila told me that she aspired to make a Lifetime movie out of her story. She explained that she has had a crazy life, one that she wouldn’t wish upon anyone. However, despite the hardship, Sheila knows that her story is one of success. While Sheila struggles with kidney issues, her HIV poses no threat to her life. She lives with her loving family, works independently, and volunteers in South Bend. Many who are diagnosed with HIV become a statistic rather than a story. Compared to other racial groups in the United States, African Americans continue to face the most severe burden of HIV (CDC, 2020). Hearing

Sheila's story revealed the troubling truth: the 7,053 black individuals with diagnosed HIV who died in 2017 deserve to be recognized (CDC, 2020). Hearing that the rate of diagnosis in African American women is 15 times as high as that of white women concerns us, yet the effort to listen to these women's stories and alleviate the common burdens is non-existent (Charles, 2019). We must not let feelings of discomfort or pride prohibit us from asking others their stories. By listening to a variety of narratives and identifying common societal difficulties, change is possible. To prevent further discrimination and transmission within the African American community, the poverty rate and stigmas surrounding HIV must first be addressed. As referenced by the CDC, low-income often leads to unstable housing and limited access to medical care (HIV and African Americans, 2020). As long as the poverty rate disproportionately affects black individuals, HIV transmission and infection will as well. Additionally, stigma and fear regarding the virus may prevent individuals from seeking services or being tested. Society cannot allow a lack of information or unnecessary fear to dictate individual safety. HIV awareness must be normalized, especially within the African American community, to prevent test or treatment reluctance.

Listening to Sheila recount her life in an authentic manner was a life-changing favor that I may never fully repay. Not only did I develop as an empathetic individual who will look to "mirror" Sheila's courage and "become" her strength, but I learned the value in maintaining an open mind as well. Remaining within one's comfort zone will lead to naive assumptions and stereotypes. For example, prior to interviewing Sheila, I knew so little about the harrowing effects of HIV. Listening to Sheila speak authentically about her challenges allowed me to realize that just because treatment or guidance may be available to some individuals, certain groups are unjustly affected by HIV. While reading about issues in the media such as homelessness, disability, and AIDS may ignite conversation, there is a vital component missing: first-hand accounts. I think that the distinction between learning from the oppressed rather than about the oppressed is what fosters the deepest empathy; putting a personal story with the statistic will lead to a burning desire for both justice and change. Thanks to Sheila, I want to spend my life hearing as many diverse accounts as possible to fight for this much needed change, and ultimately, enhance my own narrative. I want to learn from, mirror, and become the best qualities of those who, much like Sheila, represent the power in a reality different from my own.

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