

### **Orphans in South Africa and the Stigma of HIV/AIDS**

As we walked casually, yet reverently through the dusty streets of Khayelitsha, children stopped their activities to watch us, waving as we passed. Paths were worn between the small shack houses, some precariously built out of rusty sheet metal, and some assembled with sturdier materials. Despite the physical destitution, I did not sense poverty. The pride, kindness and kinship shared within the community prevailed despite the circumstances. The smoky smell of barbecue wafted through the air as we passed a huddle of young children walking home, carrying backpacks. "Our neighbors are our police," the woman who gave us the tour told me when I asked about their safety. Ahead of us, a group of kids were kicking around a soccer ball in the street and, as we walked toward them, a young girl, no older than two, started to sprint down the street towards us with a wide smile on her face. With her arms outstretched, she collided into my legs, wrapping her arms around my knees. She looked up at me with complete trust and eagerness. At that moment I knew that I had the power to nourish this trust or crush it with a simple gesture. I bent down to look the young girl in the eye, and smiled back, reaching out my hand.

Stigma has many different sources and manifestations, and can be defined differently according to varying cultural norms, but at the root of all stigma is fear. Stigma creates a perpetual cycle of discrimination and prejudice, which leads to ostracism. Because stigma lies in the eyes of society, it can "persist despite

protective legislation” (Visser, Pieter). In order to reduce and transform stigma, the root perception of the negatively valued condition must be reformed.

The term ‘stigma’ originated in Greece in reference to a physical mark given with fire or a knife to individuals considered to be outsiders or inferiors. Society had the power to decide the moral status of these people and direct this “process of devaluation” (UNAIDS [http://data.unaids.org/Publications/IRC-pub07/jc982-conceptframew\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc982-conceptframew_en.pdf), p 10). Erving Goffman defines stigma as an “attribute that is deeply discrediting...that reduces a person in our minds from a whole and usual person to a tainted, discounted one” (Goffman, Erving 12). The stigmatized person internalizes a sense of inferiority, and this can lead to a “fatal deficiency of the self-system” (Goffman, Erving 14). Stigma is self-perpetuating: society is merely the catalyst; each individual reinforces and maintains it.

Stigma has always been associated with fear-provoking diseases. Leprosy, cholera and cancer have all fought to normalize (to reduce discrimination and help the disease become socially acceptable) public judgment and overcome stigma. However, stigma has firmly clung to the AIDS epidemic despite international efforts to publicly address the disease. The complexity and deeply rooted fear of the HIV/AIDS epidemic has been the most difficult obstacle in overcoming the stigma. HIV/AIDS-related stigma is strengthened by pre-existing stigmas related to sexual mores. Because HIV/AIDS is primarily a sexually transmitted disease, “people with HIV/AIDS are often believed to have deserved what has happened by doing something wrong” (UNAIDS p. 10). The cultural norms that govern everyday life, the

silence, exclusion and secrecy create many barriers that prevent the normalization of HIV/AIDS.

In South Africa, where the UN estimates that 1 in every 5 adults between 15 and 49 years of age are HIV positive (*UNAIDS REPORT ON THE GLOBAL AIDS EPIDEMIC*), stigma is the cultural norm. HIV/AIDS is inextricably interlocked with the culture: poverty, education and political action are all interwoven into the complex web that precludes the simple prevention and treatment of the disease. The confidentiality enforced by health and political authorities breeds secrecy within the home and community. Stigma proliferates from the home and failure to communicate in the family leads to large misconceptions, which fuels the stigma into the wider community.

The law of confidentiality is a two-sided ethical consideration: without the security of confidentiality, it is unlikely that people would voluntarily come forward for testing, but the secrecy surrounding HIV/AIDS also allows the stigma to manifest in the home environment, and this lack of disclosure and communication allows the disease to continue spreading. In an article published in the Washington Post, Craig Timberg stated, "Among families, an HIV infection is often kept secret. South Africa's newspapers are filled with death notices that refer euphemistically to a 'prolonged illness'" (Timberg, Craig). If an orphan does not know that their parent died of HIV/AIDS, how are they going to break the cycle of secrecy and educate their own children?

The most significant cultural aspect prohibiting the normalization of HIV/AIDS in South Africa is the traditionally conservative values that prohibit any

explicit conversation about sex. Addressing HIV requires accessing the most intimate realm and understanding the disease in the context of the social environment. Despite South Africa's liberal constitution, gender inequalities are a persistent challenge because the traditional culture is steeped in patriarchal values. Women are beginning to voice their protestation; Colleen Lowe Morna, executive director of Gender Links, declares that "South Africa is supposed to be a democracy. We should be a country that is 'of the people, by the people and for the people,' not 'of men, by men and for men'," (Women in South Africa Still Seek Equality). Gender imbalances exacerbate women's vulnerability, abandoning them to the physical and emotional consequences of limiting their sexual power.

On our first day in Capetown, we nervously and eagerly waited outside the office of SHAWCO (Students' Health and Welfare Centres Organisation), a student-driven NGO based out of the University of Capetown. Our minds were open and untainted and, as we crowded into the small office and found seats around the round table, I tried to absorb everything around me. Varkay George, the director of the program, joined us and we introduced ourselves. He explained the history of SHAWCO, mirroring it to the pertinent post-apartheid issues, unemployment, healthcare and education. The ensuing vision of SHAWCO was carefully formed to fit the needs of the townships it serves. As he spoke, I got the first glimpse of the cultural complexity and deeply rooted fear that organizations must penetrate. "Why must they bus the volunteers into the townships? Wouldn't it be easier to bring people to the resources at the University?" I wondered. "Our clinics provide basic medical care, as well as HIV testing. People will not visit a stigmatized clinic that

solely does testing, where they may be seen. They are too afraid someone they know would see them there,” George explained. The student volunteers working at SHAWCO are clearly passionate and committed to the communities, but as we said our goodbyes I was left with a lingering question that recurred throughout the trip. Even if people do get tested and are positive, how will they disclose their status to their family and community and overcome their fear of being ostracized if the community shuns them for simply setting foot into the testing clinic?

The fear that shrouds HIV/AIDS in South Africa leads to ignorance. Knowledge is skewed because word of mouth is the most common form of education about the disease. Although social stigma has been “tacitly perpetuated by the government’s reluctance to bring the crisis out into the open” (Boseley, Sarah), hearsay and rumor within the communities are more powerful than any political gesture or advertising campaign. In an article entitled “Rumor, Gossip and Blame: Implications for HIV/AIDS Prevention in the South Africa Lowveld,” Jonathan Stadler cites Treichler, the author of “How to have theory in an epidemic: Cultural chronicles of AIDS,” who observed that “The AIDS epidemic has produced a parallel epidemic of meanings, definitions, and attributions” (Stadler, Jonathan). Gossip has immense social power, and when supported by fear, “Rumors about AIDS also have the power to construct a moral panic” (Stadler, Jonathan). The ability to transform hearsay into truth lies in the self-awareness of the infected and affected.

“Once you step inside our home,” Amina announced, “You are part of our family.” Amina’s voice resonated with power, the type of power that humbly yet firmly welcomes you and urges you to see with new perspectives. Her presence was

empowering; she dominated the room with her motherly strength. She led us past the brightly painted wall that read “Welcome 2 Alnoor Orphanage,” inside to the common room. Two worn leather couches faced each other on one side of the large room, and the other side was the gathering and dining area, with three large tables that faced each other, lined with chairs. As we sat expectantly around these tables, Amina took a second to survey us, and Tulani, her assistant, began to explain the basics of Alnoor. Alnoor orphanage cares specifically for children whose parents were infected with HIV/AIDS, or who are somehow affected by the disease. Their main purpose is to “protect vulnerable orphans” (Al Noor Orphanage).

“The program must speak to the child and the child must speak to the program,” Tulani began. “We must involve the communities and take it back to the home environment, and look at how to beat the stigma there, first.” Amina cut in confidently,

“We believe that children belong to the community—we don’t believe in institutionalizing, that just creates further ostracism. We must fight the stigma by instilling a confident attitude in the children and reintegrating them into the community. Then they can teach the community to understand.”

The power of this approach became increasingly apparent to me as we visited more Non-Governmental Organizations throughout the trip. Because Alnoor works not just with the child, but also with the family and community supporting the child, the organization is disrupting the status quo of stigma, not merely providing a shelter from the harsh reality. When the children re-enter their communities with a renewed sense of worth, their attitudes can expand into the community. The basis for a paradigm shift lies in the reconfiguration of the

population's mindset and, by empowering the youth, Alnoor provides the tools for the foundation.

The tragedy of HIV/AIDS does not end with the death of the infected, it continues through the lives of the children who are orphaned as a result. These orphans are defined by UNAIDS as any "child under 15 years of age who has lost their mother or both parents to AIDS" (UNAIDS). South Africa is estimated to have over 3.95 million orphans in total, 1.4 million of whom were orphaned due to HIV/AIDS (Heywood, Mark). Due to association with HIV/AIDS, children are socially excluded and may face discrimination in regards to health care and education. Without a solid support system, children are more at risk of suffering from psychological problems and ultimately lack the resources and capacities to integrate and transition into the wider social community.

On our first night in Grahamstown at our homestay family, Carolyn, a fellow student, and I stayed up talking with our warmly welcoming parents (who are actually sisters): Gwen and Joan. Sitting around the space heater, clasping our hands around hot cups of tea, we quickly became comfortable sharing stories of our lives at home and our perspectives on our time in Capetown. Joan and Gwen both honestly and thoughtfully answered our at times blunt questions about their experiences growing up as "colored," living through Apartheid, and their personal opinions of the pertinent issue of HIV/AIDS. Both in their 70's and unmarried, they exhibit a sense of companionship, and are more than content to share a room and grow old together.

The elder sister Gwen used to work at a hospice doing home visits as a nurse. She mentioned that many times she would be asked to park the company car far from the house so that no one would know that there was a person living there with a disease such as AIDS, which is still considered a terminal illness, even though it has been proven that it is treatable. When I asked her if she'd had any experience with orphans, her face fell and she sighed before she began to speak: "There's one girl that I have been visiting since she was a child. Her mother died of AIDS when she was 5, and we discovered soon after that the mother had transmitted the disease to her daughter." The young girl moved in with extended family, but the children and adults of this family treated her poorly, verbally and physically abusing her and exploiting the government grant money that was supposed to be used towards her wellbeing. When she got older, she moved in with her grandmother, but discovered quickly that her granny was an alcoholic who also verbally abused and insulted her, crushing her spirit and demeaning her. During every visit, Gwen would ask the girl if she was taking her Anti-Retro Viral medication, which would improve her physical strength and mental spirit, but for some reason, she hid her medication and refused to take it. "I now know what the reason is," Gwen acknowledged. "She's a 20 year old girl who would rather die, because she has no hope. She is getting weaker every day, giving into the disease, because she has no love or support." This is the ultimate repercussion of social stigma and an uncaring family environment: the loss of will to live.

The growth and development of a child lies in the hands of authority figures. Parents, teachers and older role models have the power to tremendously influence

the attitude and esteem of a child. If the general home atmosphere is unsupportive and discriminatory, it is likely the child will adopt the same attitude. Not only is their mental wellbeing the responsibility of the caregivers, but a child also depends on them financially. When I spoke on the phone with Valerie, a friend of Joan's who works in Child Welfare as a Social Worker, she confirmed what we had heard in prior meetings: the Foster Care grant money that is given directly to the caregiver of an orphan is often exploited and never seen by the child. The child is left without basic care and without basic affection.

In 1995, former president Nelson Mandela developed the Children's Fund, to which he pledged one third of his Presidential salary. The fund works closely with development organizations, raising money to provide support for disadvantaged and vulnerable children. In the Fund's 2002 annual report, Mandela emphasized the importance of a sense of family, writing,

"The effects of HIV/AIDS demand a more sustained approach involving the community and the primary unit of care and nurturing, namely the family. A solid family environment is essential in paving the way for the realization of future dreams and aspirations of children." (Garson, Phillipa)

By providing a wholesome home, the Fund is supplying the framework for a long-term focus. The Fund encourages organizations to recognize not only the importance of offering basic care such as education and food, but the critical significance of ensuring that the children have "emotional support, protection and a sense of belonging" (Garson, Phillipa).

Because children are still developing cognitively, socially, physically and emotionally, they interpret and react to stigmatization differently than adults. They

are likely to be more sensitive to “peer norms” (Deacon, Harriet, and Inez Stephney) than adults and this vulnerability may lead them to internalize the discrimination and blame themselves. In a study done by the Journal of Adolescent Health in 2008, in association with the Department of Social Policy and Social Work at Oxford University, it was noted that adolescent orphans of AIDS in South Africa experience particular risks for psychological distress, especially internalizing problems such as depression. The study tested “risk factors that can operate at a community level, and that have been reported among AIDS orphans in South Africa, including bullying, stigma and community violence” (Lucie D. Cluver.). The results of the study found that AIDS orphans were more likely to report experience of stigma (55% of AIDS orphans compared to 27% of other orphans) and, as victims of stigma, they were more prone to “depression, anxiety, peer problems, posttraumatic stress, delinquency and conduct problems” (Lucie D. Cluver). The study concluded that the solution must be multi-leveled and must promote strategies to improve general education and work with the caregivers of the children.

It is imperative that community-based and governmental initiatives to reduce stigma and discrimination against children orphaned by AIDS access the personal sphere, and not simply graze the surface with public campaigns. The topic of stigmatization of AIDS orphans must be brought to the forefront of public attention because stigma is inextricably intertwined with ignorance. However, the nature and framework of this topic is complicated. If efforts are focused only on children orphaned by AIDS, this special attention may only further isolate them instead of integrating them into the community. The remedy must be developed

from within the community and must involve a shift in the ingrained paradigm about HIV/AIDS. If this were a simple task, the crisis would have been resolved years ago. The importance of grassroots organizations that have a firm and positive vision and a respected and dedicated staff is a major factor in addressing the core of the issue.

On our last day in Grahamstown, we visited two local NGO's. We were visibly drained, our minds overloaded with information, and much of what we heard from our last few visits had been reinforcements and repetitions of previous encounters. We drove across the street from our final meeting at the Raphael Center, and darted from the van in the gloomy downpour to the entryway. We were ushered into a comfortable room, decorated with cluttered sticky notes, posters, art and whiteboards filled with inspiration and ideas advocating AIDS awareness. A poster across the round table from me read "Fighting AIDS with love." A beautiful woman came in and sat proudly upright, looking at each of us directly. Her hair was pulled neatly back, and her dark skin had a healthy glow. Her name was Ntuthu Mxalisa, and with composed strength she stated: "I have been living with HIV for 11 years." Her resilience radiated around the table. She told us about the Orphans and Vulnerable Children program that does interventions and provides support for children who don't receive any at home. The only time her strength cracked was when I asked her about her experience with the stigma that children face. She paused, sighed and rubbed her hands over her face, then responded: "You don't know how nasty children can be. My 4-year old daughter knows I'm positive, but I'm scared she will be treated differently by peers if she tells them. They might not want

to play with my child.” I asked if she could tell us more about her relationship with her daughter and she smiled, and spoke with pride about how her daughter always reminds her to take her medication and is completely aware of the gravity of the disease, not wanting her mommy to “die before time.”

The solution lies in the individual. When you test positive, you have to decide which direction to take; if you command respect, people will get their view from you. Having HIV means I have the responsibility to do something. It is hard—in the eyes of the community, the moment you disclose your status, you are marked as damaged goods.

So what provided her with the hope and determination to face reality head on?

“Having a strong support system at home is the most important thing. I don’t even care what people say about me out there—I know that when I open my door, I have a loving family waiting for me.” Ntuthu’s support has allowed her to take the first brave steps in the long journey of reforming and redefining the ingrained mindset about HIV/AIDS. She is a model of constructive involvement and implementation of individual empowerment. Her courageous approach gave me hope for the eventual acceptance and advocacy of HIV/AIDS initiatives within communities.

Changing the ingrained attitudes and outlook of a nation must start with individual communities. Within each individual community, change must manifest in individuals themselves. As a new generation is born, every interaction between a child and a parent, peer, educator, or complete stranger has the potential to impact the outlook of that child. Mothers like Ntuthu and organizations like Alnoor Orphanage that empower the youth, instilling a sense of importance, dignity, confidence and resilience, are creating a hopeful future in which HIV/AIDS could become a unifying force, rather than a stigmatized Other.

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