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# A Descriptive Review of Health Care Providers Perspective on Stigmatization of HIV/AIDS Patients: United States and South Africa

Ana I. Fonseca
*Rhode Island College*

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Running head: SENIOR HONORS THESIS

Senior Honors Thesis:  A Descriptive Review of Health Care Providers Perspective on

Stigmatization of HIV/AIDS Patients:  United States and South Africa

Ana I. Fonseca

Rhode Island College

Faculty Advisor:  Sylvia Ross

Faculty Advisor:  Dr. Carolyn Wood

Abstract

In the United States, HIV/AIDS has gone from a fatal disease to a more chronic, life-threatening condition. With the advent of new antiretroviral medications (ARV's) people are living longer with AIDS. In contrast, people in South Africa are suffering from an AIDS pandemic, often refusing to get tested for HIV or receiving the life saving ARV's they need due to social stigma. This thesis is designed to compare the issue of stigma in the United States and South Africa. Data was compiled through personal conversations and experiences in South Africa during the month of June, 2009, during my attendance in the International Scholar Laureate Program's trip to South Africa to study HIV/AIDS with a nursing delegation from across the United States and through Rhode Island interviews in the fall of 2009. Data was obtained by conversations with health professional and community members and reading of the professional literature. Social stigma continues to be an issue in both South Africa and the United States. While stigma is more of an interpersonal problem in the United States, it is an enormous barrier to access to care in South Africa.

Senior Honors Thesis:  A Descriptive Review of Health Care Providers Perspective on

Stigmatization of HIV/AIDS Patients:  United States and South Africa

Introduction

South Africa's turbulent past and history is relevant to the explosive spread of HIV in the country. The nation of South Africa had a turning point in world relations in approximately 1913 when hundreds of thousands of Africans were forced into "reserves" by the White minority, much like the Native American reservations that were formed in the United States. At this time, segregation was introduced and Native Africans were barred from taking jobs involving any skilled labor. Many South African men migrated from the reservations to hostels in the urban areas to fill jobs in the diamond and gold mines, spending a large amount of time away from family and engaging in polygamy and prostitution. When the HIV virus was identified in the early 1980's the spread of the virus to the reservations occurred, mostly to the women, at a time when prevalence of HIV was going largely unchecked.

The roots of apartheid go back long before the National Party came to power in 1948 supporting the concept of a system of systematically separating the races. In the 1940's, African miners were early protesters against a system based on racial segregation. In 1964, the then lawyer and ANC activist, Nelson Mandela, was imprisoned for life on a charge of treason as he advocated for desegregation. He was a voice for the African people and became a source of inspiration to people inside and outside South Africa.

In the 1980's, South Africa reached a crisis point internally, with rioting, protests and confrontation; while pressure mounted externally to dismantle apartheid. When Communism began to collapse in 1989 the South African government was deprived of the principle reason for its aggressive foreign policy. The will to maintain the system of apartheid began to weaken. The

most rapid increase in South Africa's HIV prevalence took place between 1993 and 2000, during the time when the country was distracted by major political changes. The first recorded case of AIDS in South Africa was diagnosed in 1982, and although initially HIV infections seemed mainly to be occurring amongst gay men, by 1985 it was clear that other sectors of society were also affected. (Avert, 2008) Towards the end of the decade, as abolition of apartheid began, an increasing amount of attention was paid to the AIDS crisis.

Nelson Mandela was finally released in 1990 and the country went to the polls in the first nonracial election, resulting in a resounding win for the ANC – under Nelson Mandela. People had lived so long in poor conditions, cultural upheaval, with no healthcare and with many leading transient lives that this sudden possibility of change in circumstances was overwhelming. The people of South Africa began living in a democracy; conditions in the townships improved dramatically, health clinics were built to serve the poor, and the people now had a voice which helped shape the government of South Africa.

In 1989 there was a shift to heterosexual infection. From 1990-94 the heterosexual epidemic exceeded the homosexual epidemic. As the country was emerging from the oppression of Apartheid, and expecting to enjoy the fruits of freedom only to encounter the devastation of the epidemic it was overwhelming. The epidemic affected young adults, and disproportionately women. In 2003, recognition of the scale and impact of the problem and the availability of free ARV therapy was made available to the public sector clinics. (Shaikh, N., personal communication, May 26, 2009.)

The South African government was initially hesitant about providing antiretroviral treatment to HIV-positive people, and only started to supply drugs in 2004 following pressure from activists. (Avert, 2008) The government was also initially reluctant to provide drugs that

could prevent HIV-positive mothers from passing the HIV on to their babies, and has been

accused of not making enough effort to get these drugs to women that need them. This is due to

the health minister at the time not believing that HIV caused AIDS therefore ARV treatment was

unnecessary to him.

During most of his presidency in the late 1990s, Thabo Mkebi did not believe HIV causes

AIDS. Mbeki viewed AIDS as some kind of a Western conspiracy and "another Western

characterization of Africans as promiscuous and Africa as a continent of disease and

hopelessness." (Avert, 2008) Thabo Mbeki's health minister displayed lemons, beetroots, and

garlic on the South African stand at an international AIDS conference in Canada in 1996,

promoting nutrition as the best way of treating AIDS. During Mkebe's speach he was booed off

the stage by thousands of doctors and researchers attending the conference.

"The HIV catastrophe has been one of the defining features of the past quarter of a

century. Although it is short-lived in the scheme of public-health crises, the pandemic ranks

among the most devastating microbial scourges in human history, one whose full impact has yet

to be realized." (Fauci, A., 2008) South Africa is currently experiencing the most severe AIDS

epidemics in the world. At the end of 2007, there were approximately 5.7 million people living

with HIV in South Africa, and almost 1,000 AIDS deaths occurring every day.(UNAIDS, 2008)

For each person living with HIV, in South Africa and elsewhere, not only does this impact their

lives, but also those of their families, friends, and wider communities.

Sixty million people have been infected by HIV worldwide since the initial identification

of the HIV virus; nearly half have died, and the toll on families, communities, and even entire

nations has been profound. (World Health Organization, 2009) It is well known that people

living through historical events often fail to recognize the significance of what they experience.

Right now, there are 33 million people living with HIV/AIDS in the world. More than 90% live in developing countries, where access to treatment is much more limited than in the developed world. President Clinton established the Clinton HIV/AIDS Initiative in 2002 to close this gap in access by negotiating lower prices for lifesaving antiretroviral treatment, and by working with governments to improve the national health care systems required to deliver crucial medicines. (The Clinton Foundation, 2009)

With antiretroviral treatment (ARV), HIV-positive people can maintain their health and often lead relatively normal lives. Most people in South Africa have access to this treatment although they resist treatment due to the magnitude of the social stigma still present in their society. (Shaikh, N., personal communication, May 26, 2009) It is thought that almost half of all deaths in South Africa and a staggering 71% of deaths among those aged between 15 and 49 are caused by AIDS. (South African Medical Research Council and Actuarial Society of South Africa, 2006)

Hospitals are struggling to cope with the number of HIV-related patients they would have to care for. In 2006 a leading researcher estimated that HIV-positive patients would soon account for 60 to 70% of medical expenditure in South African hospitals. ("Health in South Africa:  a burden that will only become heavier", 2006)

The prevalence of misinformation about AIDS in South Africa has not only hampered efforts to increase access to treatment, but has also created a climate of confusion in which prejudice toward people living with HIV thrives. HIV is sometimes seen as a disease of the poor. In South Africa, there is some correlation between extreme poverty and high HIV prevalence, although HIV is prevalent across all sectors of society. In an effort to show that AIDS affects all people regardless of politics and socio economic status, Nelson Mandela came out and told the

world that his eldest son had died of AIDS. This helped stem the stigma and shame associated with the disease somewhat and more and more people began to be tested and treated, although a great many people still refuse to be tested for HIV, mainly men.

In reviewing the onset of AIDS in the U.S., these early years of the AIDS pandemic in the U.S. proved to be incredibly difficult for the gay community in particular, and also for anyone who was diagnosed with the disease. Social stigma, hatred, fear, and discrimination created a whirlwind of injustice and lack of compassion in most Americans. This was a very dark period in our history, and even today, these issues prevail in our communities although in a more subdued and hidden form.

"Delivering HIV interventions for the people it most affects requires political will, a long-term supply of considerable financial resources, scientific and public-health vision, and dedication from all sectors of society. With these ingredients, the trajectory of our fight against the HIV/AIDS pandemic in the next quarter century could move from cautious optimism towards triumph. Absent any of these factors and history will not judge us kindly." (Fauci, A., (2008), p. 61.)

Social stigma continues to be an issue in both South Africa and the United States. A 1988 Institute of Medicine panel observed that "the fear of discrimination is a major constraint to the wide acceptance of many potentially effective public health measures" (HIV/AIDS Stigma, 2009) in the U.S. While stigma is more of an interpersonal and internalized problem in the United States, it is an enormous barrier to access to care in South Africa. (Sliney, A., personal communication, October 30, 2009.) It is important to know exactly what stigma is, how it affects people, and its subsequent consequences.

The Oxford English Dictionary defines stigma as:  "A mark branded on a slave, or criminal. Imputation attached to person's reputation; stain on one's good name. Definite characteristics of some disease (spot, sore, small natural mark on skin.)" (Stigma, 2009) Stigma is a Greek word that in its origins referred to a kind of tattoo mark that was cut or burned into the skin of criminals, slaves, or traitors in order to visibly identify them as blemished or morally polluted persons. These individuals were to be avoided or shunned, particularly in public places. (Healthline Network Inc., 2007)

What sets a person apart from others when they are stigmatized is a mark of disgrace set upon them. The person is labeled and is no longer seen as an individual but as part of a stereotyped group. Negative beliefs and feelings toward this group create prejudice which leads to negative actions and discrimination. Stigma brings experiences and feelings of:  shame, blame, hopelessness, distress, secrecy, loneliness, isolation, social exclusion, misrepresentation in the media, and discrimination. Stigma leads to a reluctance to seek and/or accept necessary help. Families are also affected, leading to a lack of disclosure and social support.

From the perspective of the stigmatizer, stigmatization involves dehumanization, threat, and aversion. Stigmatizing others can serve several functions for an individual, including self-esteem enhancement, control enhancement, and anxiety buffering, through downward-comparison. Comparing oneself to less fortunate others can increase one's own subjective sense of well-being and therefore boost one's self-esteem. (Heatherton, Kleck, Hebl, & Hull, 2000, p. 38)

Twenty-first century social psychologists consider stigmatizing and stereotyping to be a normal (if undesirable) consequence of people's cognitive abilities and limitations, and of the social information and experiences to which they are exposed. Current views of stigma, from the

perspectives of both the stigmatizer and the stigmatized person, consider the process of stigma to be highly situationally specific, dynamic, complex and nonpathological." (Heatherton et al., 2000, p. 12)

The impact of HIV-related stigma on care and prevention of HIV, as studies show, is significant. A self-reported study done in the United States evaluated the effects of concerns attributed to this stigma. The sample size for this study consisted of 204 people living with HIV. Participants with high HIV stigma concerns proved to be 3.3 times more likely to be non-adherent to their medication regimen than those with low concerns. Moreover, this study revealed that the threat of social stigma prevents people living with HIV from revealing their status to others (causing obvious health concerns for society). Clinical care directed to individuals living with HIV, researchers believed, should include considerations for patient sensitivity to social stigma (Reece, Tanner, Karpiak, & Coffey, (2007), p. 55.)

What are the causes, manifestations and effects of stigmatizing behavior in an HIV/AIDS context? The causes are many and varied and are mainly due to fear, judgmental attitudes and misinformation, both in South Africa and the United States. Perspectives such as:  HIV/AIDS is associated with abnormal or bad behavior; Infection by HIV is the result of irresponsible behavior and infection by HIV is caused by immoral behavior all lead to a negative outlook and hesitancy to seek treatment and disclose their illness. Society does not associate easily with people living with HIV/AIDS who are considered outcasts. (International Scholar Laureate Program, personal communication, May 26-June 5, 2009.)

"Stigmatization manifests in the following forms of behavior:  *Physical stigma*, where people living with HIV/AIDS are isolated physically (not allowed into shared spaces, not allowed to share clothing, eating utensils, etc.) or, in extreme cases, may even experience

forms of physical attack. *Social stigma*, when people are isolated socially and they start losing their social identity and their social structure starts dissolving (not being invited to social events, loss of communication with loved ones, not being visited, loss of friendships, etc.). *Verbal stigma*, where people use pejorative language when referred to someone living with HIV/AIDS or in reference to the illness itself. *Institutional stigma*, when people lose their jobs or any other form of discriminatory practice." (What is stigma? Causes, manifestations and effects, 2009)

The effects of stigmatization can be devastating. Stigmatization leads to feelings of anger, fear, distrust and helplessness and can be quite detrimental to the effective management of the illness. Fear of stigmatization may cause people not to go for voluntary counseling and testing. (International Scholar Laureate Program, personal communication, May 26-June 5, 2009.)

From May 26-June 5, 2009 I was a member of a nursing delegation from the U.S. travelling with the International Scholar Laureate Program to South Africa to study HIV/AIDS. It is my intention to convey information obtained from this conference from personal interviews, presentations, and various speeches from experts in the field from Cape Town, Johannesburg, and Hazy View, South Africa.

According to Dr. Mark Blecher from the Treasury Department in South Africa, the structure of the South African health care system is one in which the provincial government funds most of the care which occurs in clinics found in all townships. South Africa is a middle income country, a decade into democracy, with a legacy of huge inequity. There is a quadruple burden of disease in this country:

1. Diseases of poverty (gastroenteritis, pneumonia)
2. Diseases of lifestyle (hypertension, diabetes)

3. Trauma, and

4. HIV/AIDS (the largest number of those infected in South Africa)

The average lifespan, a health indicator, is 51 years. With a population around 48 million, it is continuing to grow despite HIV/AIDS.

The health system typology is one in which at the primary level it is free, it is funded by tax dollars, and in the private sector less than 20 percent is funded through private insurance.

In the mid 90's, the post-Apartheid government imposed a structural adjustment program to stabilize the government. This had a negative impact on health spending. Presently, the HIV/AIDS budget is 7.5 billion South African Rands, which is roughly 974 million U.S. dollars. While there are roughly 740,000 people on ARV therapy treatment, largely due to more services available for treatment, this is still a very small number compared to the 5.7 million South Africans infected with HIV. Although Dr. Blecher stated that stigma has declined in terms of HIV/AIDS, and that a lot of progress in the area of efforts in education of stigma is happening right now, the single most crucial barrier to the prevention and treatment of HIV/AIDS in South Africa remains social stigma. (International Scholar Laureate Program, personal communication, May 26-June 5, 2009.)

With 3 million HIV tests performed a year, treatment is still not starting fast enough. An identified problem is that primary health clinics are run by nurses, but nurses cannot initiate ARV treatment. They have to wait until a doctor, who comes in once a week, at most, initiates treatment for these people. (International Scholar Laureate Program, personal communication, May 26-June 5, 2009.) In terms of the public health care sector, many people are not happy with the level of care they are receiving and there is growing debate around health care reform and nationalized health care system. In addition, there are hardly any university hospitals in South

Africa, something people are looking at and hoping to change in the near future so that more research and teaching can be done in the clinical setting for doctors, nurses, and other health care givers. (Blecher, M., personal communication, May 26, 2009.)

Dr. Najma Shaikh, a public health specialist and infectious disease epidemiologist, currently the HIV/AIDS Epidemiologist in the HIV/AIDS Directorate of the Western Cape Department of Health, spoke to us concerning the HIV/AIDS Epidemic. In terms of health indicators, we looked at new infections, HIV prevalence, and mortality/deaths. The global view is that there are 33 million people living with HIV (2007). In South Africa, there are 5.7 million people living with HIV/AIDS (2007). In 2007, HIV prevalence in adults 15-49 was 10-20%. In adult men (20-64 yrs.) it was 17.9%. Adult women (20-64 yrs.) showed 20.8% prevalence. In young adults (15-24 yrs.) the prevalence was 4.5% males, 17% females, and children showed 2% prevalence. (Shaikh, N., personal communication, May 26, 2009.) What are the statistics really saying? Young women are an extremely vulnerable population; also, young children are showing up in the data due to rape not maternal transfer. Disturbing comments were made by presenters during the International Scholar Laureate Program in South Africa which was not found in the literature. Apparently, tribal healers called shangomas, advised their patients that if they had sex with a virgin they would be cured of HIV. This advice spread like wildfire to the townships. This led to a disturbing phenomenon of HIV positive men raping children at an alarming rate, some as young as two years old. (International Scholar Laureate Program, personal communication, May 26-June 5, 2009.)

Presently, 1 in every 3 pregnant women is HIV+. The locality type prevalence was 28.4% in urban informal housing (shanty towns, or townships). HIV incidence of single people is 3% per year, married couples show a 1.3% incidence, while widowed persons showed a 5.8%

incidence.  In terms of youth risk and behavior, 32% of adolescents living in peri-urban areas of

the Western Cape reported to be sexually active, with the average age of sexual debut at 14.6

years. Public health officials, faced with these numbers, initiated a campaign with the message of

abstinence, but if you cannot abstain, at least delay the age of sexual debut. The results were that

adolescents were delaying sexual debut for about one year. As in the United States, providing

condoms in schools is not a popular choice; parents object but advocacy groups are fighting hard

for this.

Due to the influence of culture, polygamy is a widely accepted practice, often involving

older men and younger women. This has led to the very high prevalence of HIV in young

women. South Africa has a male dominated culture where the voice of women is often silenced.

A woman's request for condom use often, if not always, falls on deaf ears. The majority of these

older men consumes large amounts of alcohol and primarily socializes in shebeens (beer houses).

36.1% perceived themselves as very unlikely to be HIV+, 51% reported inconsistent condom

use, 97% were in multiple sex partnerships, and 47.2% requested voluntary testing and

counseling(VTC). Those who perceived themselves most likely to be infected with HIV were

less likely to request VCT. 26% had been HIV tested over the last year. In terms of community

perceptions, 57% perceived their local political leaders to be committed to responding to the HIV

epidemic compared to 66% at the national level. (Shaikh, N., personal communication, May 26,

2009.)

The health sector response to HIV/AIDS nationwide in South Africa is as follows:  there

are 205 community mobilization projects, 5,416 peer educators in 135 high schools, 33 million

male condoms were given out in 2005, 376,626 VCT tests done (9.2%) in 2007/08, the

transmission rate was 5% in 2007/08, the partner treatment rate was 19.7% in 2007/08, roughly

740,000 patients on ARV treatment or 76% coverage in 2007/08, and there were 16 hospice

centers with 296 beds available. Despite all these efforts, HIV prevalence continues to rise. It

seems that the information being taught and marketed is not translating into action. There needs

to be a change in behavior. (Shaikh, N., personal communication, May 26, 2009.)

There was a time when women were burned alive if she disclosed that she was HIV

positive. There is a great deal of stigma in the townships of South Africa. Women today pretend

to breastfeed in public because of the huge social stigma. If a woman has a newborn and is not

breastfeeding people are going to assume the reason she is not breastfeeding is because she is

HIV positive. (International Scholar Laureate Program, personal communication, May 26-June 5,

2009.)

Participants in a current study who were not tested for HIV held significantly more AIDS

related stigmatizing beliefs than people who had been tested, including negative perceptions of

people living with AIDS, a sense that people with AIDS should feel ashamed and guilty, and the

endorsement of social sanctions for people living with AIDS. (Kalichman & Simbayi, (2003), p.

446.)

The first South African community health clinic I visited was called Masiphumelele

Clinic (which means "We Will Overcome") located right outside Cape Town. Bishop Desmond

Tutu started and funds this 20 year old clinic which is very active in pharmaceutical clinical

studies. The most current study is a microbicide clinical study which is expected to show great

promise. Masiphumelele is a primary health care clinic, primarily run by nurses where they offer

Tuberculosis (TB) testing and treatment, Antenatal care, and sexually transmitted disease testing

and treatment. Dr. Marie Helengrad gave our group a detailed presentation on her perspectives of

the Masiphumelele Clinic and her work there as the physician in charge.

As was mentioned earlier, there is a lot of migration from the Eastern Cape to the Western Cape to find jobs. These people are usually men who usually leave their families behind. Therefore Masiphumelele has a relatively young community, with only 200 people in their 60's. 64% of the population is males, although mostly females are utilizing the services at the clinic. This is mainly due to the stigma attached to even being seen in line at the clinic. Although this township has roughly 12,000 people, it is a very tight knit community. Everybody is known by their first name, and word spreads very quickly amongst the people of the township. If a person is seen in line at the clinic, people automatically assume that they must have TB or HIV/AIDS. If a mother does not breastfeed her child, people will know she is HIV positive. So what ends up happening is mothers pretend to breastfeed their newborns to avoid the repercussions of the community knowing her HIV status. The main reason men do not utilize the clinic, besides the stigma issue, is that they feel they are "strong" and do not need care unless very sick. What ends up happening is that the men are seen when they come in coughing up blood. They end up being diagnosed with TB and HIV, the new epidemic in South Africa. (Helengrad, M., personal communication, May 28, 2009.)

Adherence to treatment is a problem in Masiphumelele, as in other townships, so direct observation of medication administration is mandated to prevent TB drug resistance. Another issue which is a growing problem is that despite education and outreach programs in the community people still resist knowing their HIV status, still practice unsafe sex, and sexual debut is very early at 13-14 years old. (Helengrad, M., personal communication, May 28, 2009.)

From September through October of 2009, I conducted several personal interviews with community experts in the field of HIV/AIDS, and attended a conference on HIV/AIDS on the

25<sup>th</sup> of September sponsored by the Rhode Island Association of Nurses in AIDS Care. It was my intention to explore the issue of HIV/AIDS stigma from the perspective of care given in R.I.

HIV-related stigma is associated with poor access to specialist HIV medical care, U.S. investigators report in the online edition of the Journal of General Internal Medicine. The research also showed that a large proportion of HIV-positive individuals report "internalized" stigma. (Aidsmap News, 2009.) This is consistent with statements made by Anne Sliney from the Clinton Foundation.

There have been dramatic improvements in HIV treatment, thanks to which the prognosis of many HIV infected individuals is now considered to be very positive. "Nevertheless, HIV remains a stigmatized illness and this can threaten the emotional, mental and physical health of HIV infected individuals." (Aidsmap News, 2009.)

"Investigators from Los Angeles hypothesized that internalized HIV stigma would be associated with three key aspects of HIV care:

- Self-reported access to HIV care.

- Having a regular source of HIV care.

- Adherence to HIV treatment." (Aidsmap News, 2009.)

A total of 202 individuals were recruited to the research from HIV clinics and support services in Los Angeles. The research was undertaken in 2007. Most (56%) were women and an equal proportion African American. The mean age was 43 years and 31% were gay men. Internalized stigma was assessed using a questionnaire which scored individual's responses on a scale of 0 to 100. The overall score was 41, suggesting that well over a third of the participants had significant internalized HIV associated stigma. The investigators' first set of statistical analyses showed that individuals reporting a high level of internalized stigma were

more likely to report poor access to HIV care, to lack of a regular source of HIV care, and to have low levels of adherence to their HIV medication. (Aidsmap News, 2009.)

In my literature review I found that the concept of "drivers" of the HIV/AIDS epidemic was extremely interesting, important, and relevant. The term "driver" relates to structural and social factors, such as gender inequality, human rights violations and stigma and discrimination that are not easily measured that increase people's vulnerability to HIV infection. In Zambia (December, 2006), Peter Piot, Executive Director, UNAIDS, stressed the need to address the drivers of the epidemic:

> "It is patently clear that we need to make real headway against the fundamental drivers of this epidemic, especially gender inequality, stigma and discrimination, deprivation and the failure to protect and realize human rights. This challenge is perhaps the greatest of all those facing the AIDS response. And there can never be a technological fix for these social issues. We need positive social change – and all of us in the AIDS effort must be willing to back this. I am increasingly convinced that just expanding programmes, doing more, even much more, is not going to stop this epidemic. To reach universal access to HIV prevention and treatment care and support, we need to pay attention to the drivers." (UNAIDS, 2009)

"In the consultations leading up to the High Level Meeting on HIV in 2006, where Member States committed themselves to attaining universal access to HIV prevention, care and treatment, participants stressed again and again that stigma and discrimination, gender inequality and the marginalization of vulnerable groups constitute major barriers to universal access." (UNAIDS, 2009)

The HIV/AIDS epidemic is pretty concentrated in certain populations; African Americans, immigrants, the ACI population, gay/bisexual men, and the rural population in the U.S. There are doctors from the clinic at The Miriam providing HIV care at the ACI. These people are followed after serving their sentence and remain in the care of the clinic. This has been a very effective program as far as building trusting relationships and having people follow through with treatment, although, there is still a gap present for when people leave jail. There are no half-way houses in Rhode Island for people leaving jail and returning to society. Housing for these past offenders is a huge issue. This leaves this population in a situation where they are set up for failure. There is stigma associated with these people not only being HIV positive but the added burden of being felons. There is a gap in health insurance for these people once they are let out of prison. (MacLeod, C., personal communication, September 16, 2009.)

Using a nationally representative sample of persons receiving treatment for HIV infection, the HIV Cost and Services Utilization Study found that, as of early 1996, almost three-quarters of those surveyed (71%) were out of adherence with at least one of the six accesses to care measures used in the study. For example, 15% had fewer than two outpatient visits during a 6-month period, the minimum number necessary to provide reasonable monitoring of disease progress and treatment response. Over a 6-month period, 30% of acutely ill individuals did not receive medication to prevent Pneumocystis carinii pneumonia, a common opportunistic infection among AIDS patients. And more than a year after the introduction of two new and more effective types of HIV drugs, 41% of eligible patients still had not received a trial of either one. Though access to care is gradually improving there is a link to the possibility of stigma. The

key point being that disenfranchised groups overall remained less likely to obtain ongoing, effective care. (HCSUS, 2009)

Heather Ross, a Social Worker from the Immunology clinic at The Miriam, really has her hand on the pulse of the groups who suffer the most with social stigma and access to care. She feels that the focus for funding for preventative health is not present in the U.S. Heather gets someone who is newly diagnosed, she spends a great deal of time on explaining what preventative health is to these people. Health literacy is also a barrier which contributes to people starting therapy and then when they are feeling better they stop their medication regimen. The whole approach at the center is to do a complete assessment where if they do not have insurance steps are taken to get them insurance before they even see the doctor. They have the financial aspect already in place so that they do not fall out of care right from the beginning after finding out their HIV status. Preventative care is the biggest focus of the center, education about the disease process and management of disease is a major role. (Ross, H., personal communication, September 16, 2009.)

"Stigma is not just cultural. People are scared to get tested and to find out their status even today. There has been a huge shift recently, although there is still stigma, more people are engaged in getting primary care. Community supports are complementing the information these people are getting from their physicians. It is important to give these people information in many different ways and settings so that in the end they really 'get it'." (Ross, H., personal communication, September 16, 2009.)

The social penalty for talking about HIV/AIDS is actively hindering the fight on the disease. A recent report by the Kaiser Family Foundation found that while people are generally less concerned about contracting the disease than they were in the 1990's, misinformation is still

running rampant. 51% of people are uncomfortable having their food prepared by someone with HIV, 27% of the general population still think that HIV can be transmitted by sharing a drinking glass, and 17% think touching a toilet seat is a way of transmitting the disease. (The Kaiser Family Foundation, 2009)

According to Yolande Muoio, a Rhode Island College nursing student who worked with Cynthia MacLeod at the Immunology Clinic at The Miriam for 6 weeks, our mid-aged and older bisexuals and gay men have seen the devastation in the early 80's of the AIDS epidemic. Though, the younger gay male generation today has not seen this, and they have a feeling of indifference and don't perceive HIV as a death sentence. (Muoio, Y., personal communication, September 16, 2009.) These young people are taking more risks and having unsafe sex as a result. They figure that there are medications now to reduce the effects of HIV so why worry. This is causing a spike in new cases of HIV infection among this population group. While stigma associated with being gay and being HIV positive affects this population greatly, these men are not taking the disease seriously. Also, the IV drug users are showing a higher prevalence of HIV in the U.S., less so in Rhode Island, whereas in South Africa IV drug use is nonexistent at present. (International Scholar Laureate Program, personal communication, May 26-June 5, 2009.) "About 70 patients a year have identified as being HIV positive in the clinic in the past two years." (MacLeod, C., personal communication, September 16, 2009.)

We are seeing so little IV drug users being diagnosed with HIV, due mainly to the clean needle initiative in the state of Rhode Island. About a third of the population that come in to the clinic at The Miriam identify as men having sex with men (MSM), and a third are immigrants. These immigrants are finding out their status because Immigration requires an HIV test when you are getting your green card. Also, refugees coming into this country who are found to be

HIV positive are streamlined to Rhode Island because of our ability to get people into care. (Ross, H., personal communication, September 16, 2009.)

And a third of the people who are newly diagnosed are made up of people who don't fit the stereotype of someone who is high risk for contracting HIV. These people are finding out their status because they are symptomatic and go in to the ED or community clinics or doctors' offices for symptoms that they do not associate with HIV. With the MSM population they are finding a lot of acute cases where they have just seroconverted. There is a lot of education and knowledge in this community and although there are a lot of high risk behaviors occurring, they are getting tested every six months or every year. "There are currently 1,235 patients who are HIV positive in the state. And about 100 that are "missing" one way or another and are not showing up at the clinic." This may be due to the stigma associated with being HIV positive and its repercussions. Being seen at the Immunology Clinic at The Miriam has become a problem for HIV positive patients who wish to not disclose their status. More and more people are associating the clinic with HIV/AIDS and people do not feel their confidentiality and privacy can be kept there. So they do not show up and fall out of treatment. More funding is needed for the clinic to do more outreach activities to serve these people. (MacLeod, C., personal communication, September 16, 2009.)

A lot of times, being HIV positive is not the only problem these patients face and it is not the highest priority in their lives. The social health aspect in this clinic really tries to get to the bottom of what is going on in the lives of these people so that their needs can be addressed. What the clinic is trying to do is have a peer led initiative where patients are being trained to educate and counsel others who are HIV positive. Again, funding is limited for this endeavor. Patients

have really responded well to this type of intervention and support. (Ross, H., personal communication, September 16, 2009.)

Paul Fitzgerald, President of AIDS Care Ocean State, discussed stigma as being more "hidden" here in the U.S. and Rhode Island. "There is no political will to change stigma in HIV, instead there is community apathy. Even the medical community and the wider community don't address stigma and access to care." (Fitzgerald, P., personal communication, September 16, 2009.)

"There is a sub grouping in terms of housing where there is discrimination with people who are HIV+.  The Department of Housing and Urban Development has known about this issue for 8 years and it has not been addressed." (Fitzgerald, P., personal communication, September 16, 2009.) This issue relates to health because housing is a health care need. If housing is stabilized it leads to positive outcomes such as more adherence to the medication regimen, access to care is better, and in general, people are healthier.

Anne Sliney, an RN working for The Clinton Foundation, stated that although South Africa has the biggest HIV prevention and treatment program in the world they have the worst incidence and prevalence of HIV in the world. The profound stigma associated with HIV/AIDS in South Africa is contributing to this phenomenon. Stigma is killing people in South Africa. It is keeping people from coming in to get tested, and it is keeping people from getting treatment. Even though they have the education about the disease, it is not translating to a change in behavior.  "Something needs to be done differently not only in South Africa but in the U.S. to combat the HIV epidemic." (Sliney, A., personal communication, October 30, 2009.)

Remarks by President Obama at the signing of the Ryan White HIV/AIDS Treatment Extension Act of 2009 reiterate the fact that we are facing an epidemic of our own right here in

the U.S.  So tackling this epidemic will take far more aggressive approaches than we've seen in the past -- not only from our federal government, but also state and local governments, from local community organizations, and from places of worship.

"But it will also take an effort to end the stigma that has stopped people from getting tested; that has stopped people from facing their own illness; and that has sped the spread of this disease for far too long.  A couple of years ago Michelle and I were in Africa and we tried to combat the stigma when we were in Kenya by taking a public HIV/AIDS test.  And I'm proud to announce today we're about to take another step towards ending that stigma.

Twenty-two years ago, in a decision rooted in fear rather than fact, the United States instituted a travel ban on entry into the country for people living with HIV/AIDS.  Now, we talk about reducing the stigma of this disease -- yet we've treated a visitor living with it as a threat.  We lead the world when it comes to helping stem the AIDS pandemic -- yet we are one of only a dozen countries that still bar people from HIV from entering our own country.

If we want to be the global leader in combating HIV/AIDS, we need to act like it.  And that's why, on Monday my administration will publish a final rule that eliminates the travel ban effective just after the New Year.  Congress and President Bush began this process last year, and they ought to be commended for it.  We are finishing the job.  It's a step that will encourage people to get tested and get treatment, it's a step that will keep families together, and it's a step that will save lives." (White House Press, 2009.)

Aids stigma is effectively universal I have found, but its form varies from one country to another, and the specific groups targeted for AIDS stigma vary considerably. Whatever its form, AIDS stigma inflicts suffering on people and interferes with attempts to fight the AIDS epidemic.

"Stigma proposes effects that stereotypes have on individuals. Whether effects be negative or positive in nature, 'labeling' people causes a significant change in individual perception (of persons with disease). Perhaps a mutual understanding of stigma, achieved through education, could eliminate social stigma entirely." (Reece, Tanner, Karpiak, & Coffey, 2007, p. 73.)

In conclusion, I would like to talk about nursing roles and nursing perspectives in terms of stigma and HIV/AIDS, but first I will talk about my initial thoughts about South Africa, nursing in general and access to care. Initially, I thought that access to care was going to be the most immediate problem, I was wrong. I was also surprised that nurses in South Africa were so highly educated and trained. While they do not have a licensure exam at the end of their studies, they do put in 4,000 clinical hours before they graduate. The government pays for their college tuition and then in return they agree to be assigned to a community hospital or clinic upon completion of their studies. These nursing students have a lot of community contact while in school. Could these students use this opportunity to be educating the public about HIV/AIDS and stigma in particular? I know that HIV/AIDS is integrated into the nursing program in the beginning and it carries through until graduation. I would like to know how stigma is addressed, if at all.

I was surprised that the equipment in the public hospitals was World War II era, yet it was enough for the health care workers to do their jobs. In the private hospitals in South Africa

the equipment was state of the art. That makes me question if we, as a nation, really need all the technology and modern equipment we have to do the job? Could we do with less?

I was also interested in finding out if discrimination still exists in South Africa. I asked about 10 locals what their opinion was about this, and they said that yes, discrimination still exists towards blacks mostly but it is not as blatant as it once was. I did notice that segregation exists in terms of hospitalization. In the public hospitals all the physicians and nurses and other health care workers were black, and the patients were all black. Yet, in the private hospitals, all the health care workers were white and the patients were white. I believe that in order to make a change as far as discrimination and segregation you have to make sure you are changing the culture of the health care providers. We need diversity, not just in South Africa, but in the U.S. as well. Anytime you can provide diversity it promotes more open thinking.

Nursing values, personal, professional, and also cultural are extremely important in this discussion. One needs to have an understanding of their own value system if they plan on making a lasting change in someone else's behavior. There needs to be a determination of a values conflict. It is important to understand cultural values. Nursing is predominately a woman's profession. What is the response to this? In South Africa, the culture is male dominated. Could this be getting in the way of behavior changes through education when the people who are doing the educating are mostly women? This may explain why South Africa spends the most money on HIV/AIDS education yet they have the highest incidence rates of HIV in the world. Would it make a difference if they involved the leaders and decision makers in the community and have them help educate the population? Would this bring about more positive outcomes?

There is also the cultural norm of polygamy. This is a widely accepted practice by the men in South Africa and it is a driver of the epidemic. How can nurses bring about a change in this practice? Again, would involving leaders and decision makers in the community to talk about polygamy and the importance of having safe sex make a substantial difference in the behaviors of these men? Would nurse's involvement in political awareness and action bring about a change in this practice?

Another observation I made in South Africa was that the health care workers working with HIV/AIDS seemed extremely tired and burned out. They are constantly fighting with the government for more of what they need to combat this epidemic. There is a severe lack of resources and there is an incredible amount of frustration over the fact that people are not coming in to get tested despite their best efforts. How do nurses stay committed and avoid burn out in these circumstances? How do we keep these nurses engaged? How do you introduce the concept that changes will take time and you will not see instant results? And how should these nurses measure change? I believe it can be done in small increments. Change is so slow that you need to measure triumphs in very small accomplishments. Nurses need to tolerate long term goals and very small changes.

The magnitude of the epidemic in South Africa alone is enough to overwhelm even the most seasoned nurse. I did not see this phenomenon in the U.S. I believe it is because we have more resources and more attention is focused on HIV/AIDS. The U.S. is further along in bringing HIV/AIDS out into the open and it is more mainstream. An example of this is the fact that being gay today in the U.S. does not carry the stigma it once had say 20 years ago. There has been a change in the cultural values and norms of our society, and while it is true that the AIDS epidemic helped bring about this change, it is a change for the better in our society.

My thoughts on nursing as a profession and what it can do to battle stigma on a very personal level is simple. We, as nurses, can educate patients, families, and communities about the effects and consequences of HIV/AIDS stigma. In both countries, we need to involve parents, community leaders and decision makers, church leaders, and peer leaders in sending out the message that HIV can be prevented, and subsequently, treated. The role of the nurse can help bring about change through education and by example. If we show that we are not going to stigmatize people based on their HIV status it will go a long way. We need to advocate for patients who are HIV positive or have AIDS in our own agencies or institutions, by reaching out to our communities, and by getting involved in public policy. We as nurses need to be more pro-active in our roles in how to bring about behavioral change in our communities.

The ACTS Clinic in Hazy View, South Africa, was a shining beacon of success in the struggle to bring about change. This clinic was faith-based, it had physicians, pharmacists, laboratories and scientists, nurses, and peer led support groups. Should the nursing roles include helping to advocate for funding in multidisciplinary clinics? If we take the success of the ACTS Clinic as an example, I would definitely say yes. I can't pinpoint one solitary reason why this clinic is so successful; I believe there are many reasons.

Could it be that in this remote part of the country stigma is not as prevalent? And, why is this? People take extreme efforts to reach this clinic, not only from all over South Africa, but also from neighboring countries. What is happening in these bordering countries that are not creating the social stigma for these people to come to the clinic to be tested and treated? Could the fact that this is a faith based clinic have something to do with taking some of the stigma away? By adding a religious component to the picture perhaps people feel they are absolved of the "sin" of HIV/AIDS.

Nurses need to be active in advocacy and political activism when it comes to HIV/AIDS. This holds true in both South Africa and the United States. For the practicing nurse to provide critical information to legislators on the issue is critical. The importance of knowing and supporting the political process can change many lives. Another important point is the awareness in both countries in what can happen when an administration changes. This was the case when Nelson Mandela took office, and when Barack Obama took office. Enormous change in the availability of ARV's saved thousands of lives in South Africa when President Mandela took office. And President Obama's repeal of the law that did not allow HIV positive people to immigrate to this country helped stem the social stigma of HIV/AIDS even further.

In South Africa, we don't know exactly what women know about breastfeeding and their HIV status. We do know that women are pretending to breastfeed their babies in an effort to hide their status. What is it like for these women? What about the phenomenon of raping children in an effort to cure HIV? What is the extent and degree of this problem? How do you dispel these myths and protect these vulnerable children? Is this a legislative issue concerning child abuse? Can nurses play a political role in making changes in the laws to protect these children?

More research needs to be done in the area of HIV/AIDS and social stigma and its effects on our patients, families, and communities. I believe more support groups for people who are living with HIV would be helpful, and more peer led support groups would be extremely beneficial. If we are going to make a dent in the HIV/AIDS epidemic we need to address stigma and its consequences. A holistic approach will be needed to combat this issue. We, as nurses can be in the forefront of this fight by doing further research, by applying health education principles in our approach, and by making HIV/AIDS stigma a priority in our practice. Nurses can make an impact by lifting this stigma in their own ways, big or small.

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