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## Social Determinants of HIV Health Care: A Tale of Two Cities

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### 1. Introduction

Despite unprecedented scale up and advances in the treatment of HIV/AIDS in the last fifteen years, the great majority of individuals around the world who need antiretroviral therapy (ART) are not receiving it. Furthermore, it has now become apparent that even in locations where there is access to treatment, segments of the population do not engage in care because of multiple barriers that prevent them from accessing care, thus losing the potential benefits of ART. A social ecological framework can be applied to understand the multiple layers of factors at the individual, interpersonal and structural levels, that affect HIV clinical outcomes and consequently transmission (Stokols 1996). The institutional barriers include those imposed by the very institutions developed to care for people with HIV. Beyond institutional barriers, factors related to poverty and economics, politics, and the sociocultural and psychological context of the individual all contribute to the challenges faced by people seeking treatment.

Acknowledging the difficulties that HIV-infected individuals confront, the World Health Organization (WHO) has put forth the goal of universal access to HIV/AIDS prevention, treatment, and care (WHO 2010). In addition to improving the individual's personal health, access and treatment with subsequent virologic suppression on a population level may help decrease transmission of HIV (Das et al. 2010). Until a cure for HIV is found, individuals infected with HIV face a lifetime of requiring health care access and antiretroviral drug therapy to control the virus, in addition to the comorbidities associated with chronic HIV infection.

For those able to enter and remain in care, additional obstacles can prevent them from maintaining high levels of adherence to the available therapies. In this chapter, we will explore how the sociocultural context of a particular region can influence health care outcomes for individuals living with HIV. First, we exemplify two epidemics and two health care systems separated geographically and culturally from one another, Atlanta, Georgia, United States, and Durban, KwaZulu-Natal, South Africa, in order to illustrate how these factors can impede a successful response to ART. Following this description, we describe efforts that have been undertaken to address some of these barriers to improve engagement in health care within and beyond these settings. We also review creative approaches that can be used to maximize adherence to treatment. Finally, a course for the ultimate way forward is chartered, detailing steps necessary to address these barriers in a variety of settings around the world.

## **2. Atlanta, Georgia, USA**

### **2.1 The city too busy to hate**

Atlanta is located in the northwest corner of the state of Georgia, which is in the southeastern region of the US. Atlanta was incorporated in 1847 and began as a railroad hub, connecting multiple cities across the US. During the American Civil War (1861-1865), the city was set on fire, destroying a large percentage of its infrastructure. In the years following the Civil War, the city was rebuilt gradually, with the intention to create a modern city that was less reliant on agriculture than previously. For example, the Georgia Institute of Technology, a prominent science and engineering university, was founded in 1885 in order to advance these goals (*The New Georgia Encyclopedia*). In addition, two historically black colleges, Spellman College (for women) and Morehouse College (for men) were established soon after the Civil War.

As the population of Atlanta expanded significantly in the wake of the Civil War, tensions between blacks and whites grew, and Jim Crow laws supporting segregation of the races in housing, school, and socialization began to take effect. In 1906, on the backdrop of Georgia's gubernatorial race which highlighted racial segregation and after newspapers reported 4 incidents of alleged sexual abuse of white women by black men, Atlanta's first documented race riot occurred. The death toll for the event was approximately 25 to 40 African-Americans and 2 whites. After 3 days of fighting, city officials, prominent clergy, and newspapers proposed an end to the violence. White and black community and business leaders came together to support racial reconciliation, in order to protect Atlanta's image as a "thriving New South City." As a result of these efforts, Atlanta did not feature as a major city for civil rights infringement during the riots in the 1960s throughout the south. Furthermore, Atlanta has a strong historical connection with the Civil Rights movement of the mid-twentieth century, because Martin Luther King, Jr., preached at the Ebenezer Baptist Church, located in downtown Atlanta, and the city was seen as a major organizing center for students and other civil rights leaders (*The New Georgia Encyclopedia*).

Atlanta currently has a population of approximately 500,000 within the city limits, and 5 million in the entire metropolitan statistical area (MSA), which includes 31 counties. The racial makeup of the city is approximately 50% African-American, 43% Caucasian, 13% Asian, and 5% Hispanic. In comparison, as of 2009 the state of Georgia's population was estimated to be 9.8 million, consisting of 65% white and 30% black (*United States Census*).

Atlanta's population has grown considerably after the opening of Hartsfield-Jackson International Airport in 1980 (which is one of the busiest in the US) (Yee 2007) and the hosting of the Summer Olympics in 1996. Twenty percent of the population lives below the poverty level. Major industries in Atlanta include professional and administrative services, waste management, education, arts, and food services (*United States Census*). Savannah, located on the Atlantic Ocean, is the second largest port eastern seaboard of the US and serves as a major hub for international shipping. Much of this traffic moves through Atlanta as it passes on to other cities throughout the country. Atlanta has a confluence of racial and ethnic diversity, industry, high-quality colleges and universities, and trade that give it a uniquely metropolitan feel in this region.

### **2.2 HIV Epidemic in Atlanta and the southeastern U.S.**

According to surveillance statistics for HIV/AIDS, the southeast has been among the most significantly affected regions in the US since 2005. Georgia ranked 8<sup>th</sup> in the nation for its

reported prevalence rate of AIDS, and a substantial proportion of HIV cases in this region is diagnosed in Atlanta. The same factors that contribute to high rates of infection and advanced disease in this region also lead to poor entry and retention in care. These factors include poverty (9<sup>th</sup> most poor state in US), inadequate education (8<sup>th</sup> worst high school graduation rate in the US), substance abuse, poor access to health care, food insufficiency (Kalichman et al. 2010), and child sex trade (Longerbeam 2010). In Atlanta, crack cocaine use and homelessness impact transmission of HIV, but there is also significant transmission among heterosexuals and men who have sex with men (MSM).

It is important to point out that while 78% of HIV (non-AIDS) cases and 75% of AIDS cases diagnosed in 2008 in Georgia were among Blacks, they make up only 30% of the state population (Mangla and Gant 2008). Among cases of HIV/AIDS diagnosed in Georgia in 2008, about half (53%) occurred between the ages of 30 and 49, one quarter (28%) between ages 20 and 29, and 14% among people 50 years of age or older (Mangla and Gant 2008).

The Atlanta eligible metropolitan area (EMA) is a 20-county region designated by the US Department of Health and Human Services (DHHS) Health Resources and Services Administration (HRSA) to receive federal funding through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. As of the end of 2009, a total of 26,546 persons were living with HIV/AIDS in the 20-county Atlanta EMA; of these, 15,548 were AIDS cases and 10,998 are HIV-infected but do not yet have AIDS (eHARS Reporting System 2010). The racial distribution is 68% among blacks and 24% among whites (eHARS Reporting System 2010). The majority of cases are among men, and the main risk factor for transmission is MSM (46%), followed by heterosexual contact (8.4%), injection drug use (7.3%) (eHARS Reporting System 2010).

Within the city of Atlanta, HIV is largely concentrated in one large cluster located in downtown and southwest Atlanta that consists of 157 census tracts and covers about 180 square miles. The cluster contains 60% of prevalent HIV/AIDS cases in the Atlanta MSA, and the HIV prevalence within the cluster is 1.34% compared to 0.32% outside the cluster (Hixson et al. 2011). Thus, as a whole, the city of Atlanta has a “generalized epidemic” with an HIV prevalence of >1% (see Figure 1).

### **3. Durban, KwaZulu-Natal, South Africa**

#### **3.1 The city of gold**

Durban (eThekweni), located on the eastern coast of the Republic of South Africa, is the largest city in the province of KwaZulu-Natal (KZN). A well-known tourist destination for South Africans and international travelers, Durban is the third largest city in the Republic and one of the busiest seaports in the southern hemisphere. Durban has a population of nearly 3,500,000 including nearby townships. A very culturally diverse community, Durban’s population is 68% black African, 20% Asian (one of the largest Indian populations outside of India and largest Asian community on the African continent), 9% white, and 3% coloured. Manufacturing, tourism, finance and transport are the major industrial sectors in the city. A recent principal host city for the 2010 Fédération Internationale de Football Association World Cup, eThekweni boasts the highest credit rating in Africa for a municipality in September 2004.

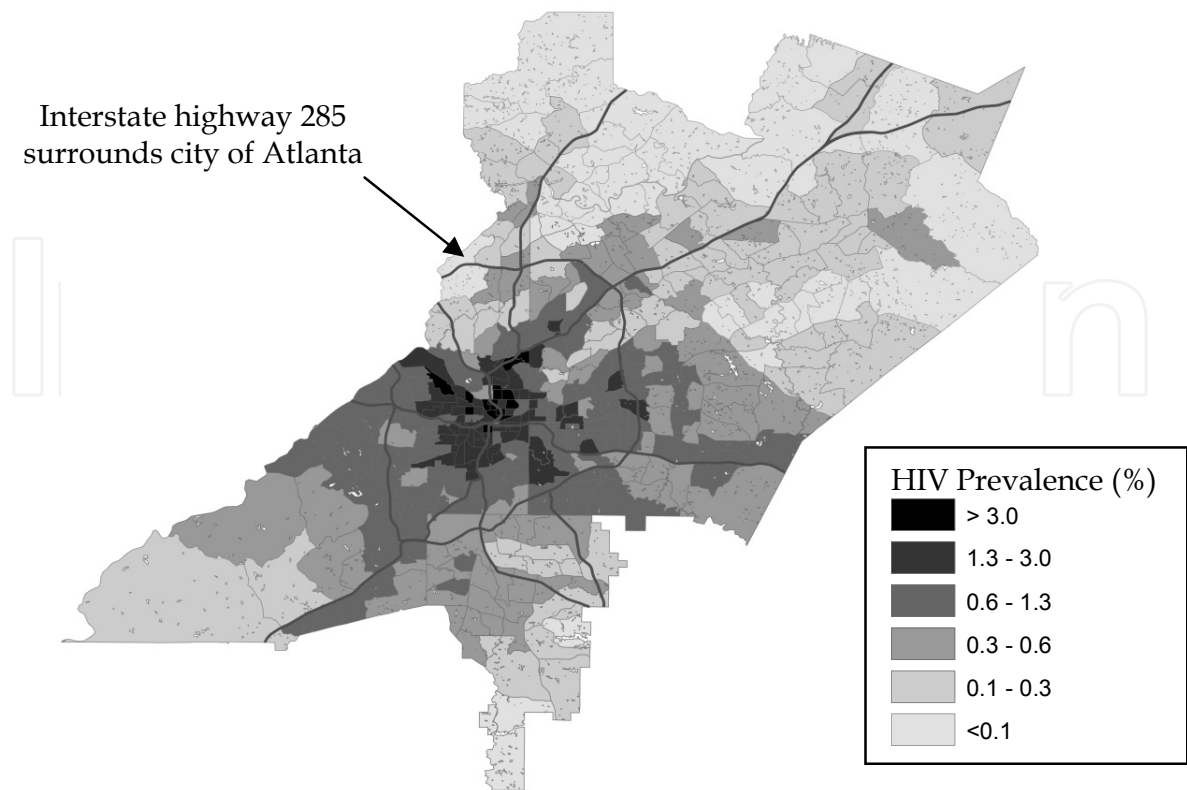


Fig. 1. HIV prevalence estimates for city of Atlanta and Fulton, DeKalb, Gwinnett, and Clayton counties, 2008 (Produced from Georgia Department of Public Health surveillance data)

The aboriginal population of KZN was believed to have settled in the area around 100,000 BC and was eventually overtaken by the Bantu expansion in 300 AD. Early exploration by the Portuguese began in the 15<sup>th</sup> century (Russell 1899). The Dutch and British later formed more lasting settlements on the coast. The peaceful relationship between the Kingdom of Shaka Zulu and the early British settlers was disrupted after tensions developed between colonists and native Africans (Bulpin 1977). This was followed by major conflicts known as the Anglo-Zulu (1879) and Anglo-Boer Wars (1880-1881 and 1899-1902). The colonizers suppressed and dominated the black South Africans (Shillington 2005). During this period, a large population of indentured laborers was brought in from India to work in the sugar cane industry, along with black migrant workers from rural areas of KZN. In 1893 Mahatma Gandhi arrived in Durban to serve as a legal adviser for an Indian law firm. The widespread denial of civil liberties and political rights to Indian immigrants inspired his struggle for Indians’ rights there and in India. By the end of the 19<sup>th</sup> century, industry, especially mining, used coercive tactics to maintain inexpensive black labor in the cities. Over time, this severely disrupted traditional family structures and eroded the rural agricultural economy of black South Africans, further increasing the income disparity (Coovadia et al. 2009). Eventually, South Africa fell under British rule upon signing the peace treaty of Vereeniging in 1902. Following unification of the Boer and British colonies, several government policies were enacted to entrench white supremacy and racial segregation in South Africa. Racial classification with whites at the top resulted in social separation, political exclusion, economic marginalization, and racial injustices (Marks and Andersson 1987; WHO 1983). In



1923, the African National Congress was formed to peacefully lobby for equal rights for all races. Their efforts were largely unsuccessful, as segregation policies were consolidated under the right-wing National Party when it rose to power in 1948, which marked the official beginning of apartheid. Nelson Mandela, along with many leaders of the ANC, was arrested and imprisoned in 1964. Domestic and international pressure finally resulted in the demise of apartheid in 1990, and the first free elections were held in South Africa in 1994, ushering in a new era with Mandela as president.

Students and staff from the University of Natal, founded in 1910 in Durban, actively protested apartheid policies. In 1950, the first medical school for black students in South Africa was established nearby, later named the Nelson Mandela School of Medicine. The University of Durban-Westville was created in the 1960s with the express intent of providing higher education for students of Indian origin. After the fall of apartheid, these universities merged to form the University of KwaZulu-Natal in 2004, which remains one of the premier academic institutions in South Africa. UKZN sponsors several prominent HIV/AIDS-related research programs that are ongoing today.

3.2 HIV epidemic in Durban and KwaZulu-Natal

Sub-Saharan Africa carries a disproportionate burden of HIV infections when compared to other regions in the world. Based on two national surveys published in 2008 and 2009, South Africa, and specifically the province of KwaZulu-Natal, are at the epicenter of the HIV epidemic with HIV prevalence estimates ranging from 15.8% among the general population over age 2 to 40% among women presenting to antenatal clinics (Health 2009; Shisana et al. 2009) (see Figure 2). With such a considerable prevalence, the odds of having a partner with

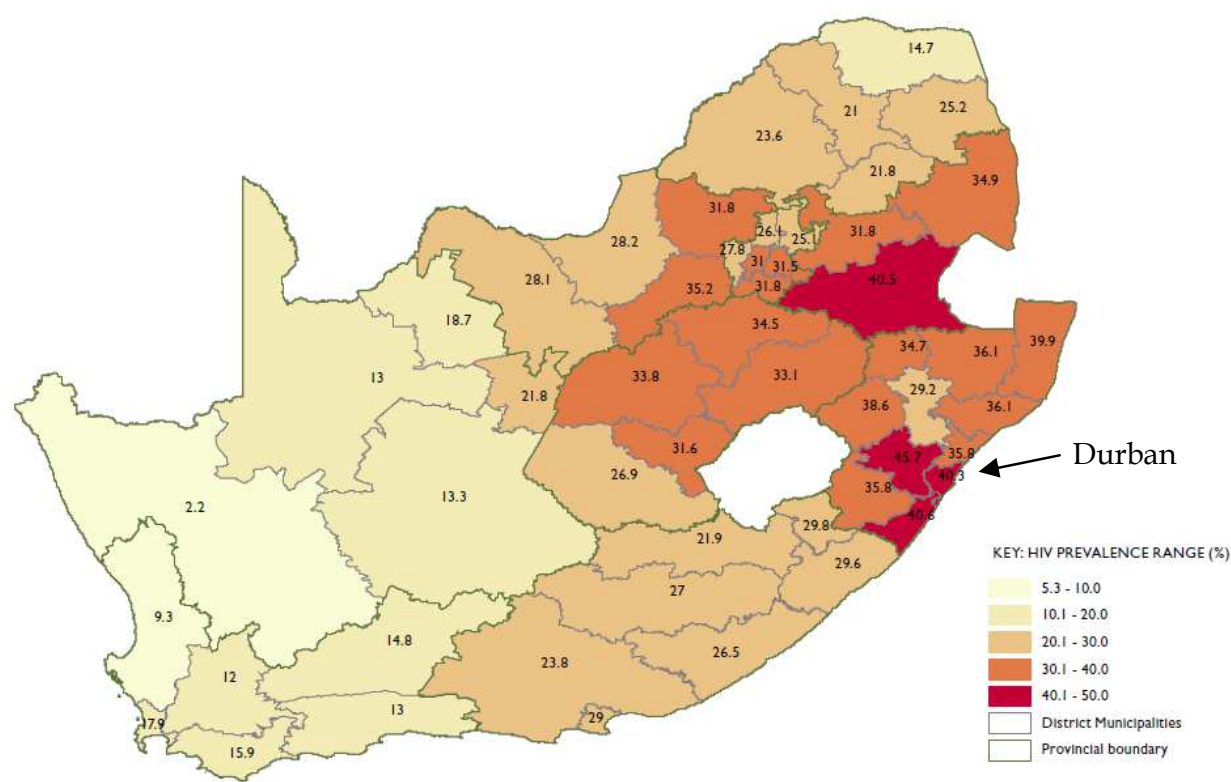


Fig. 2. HIV prevalence by district in South Africa, antenatal clinics, 2008 (Health 2009)

HIV are high, and this has overwhelmed current prevention efforts aimed at discordant couples. In addition to wealth and income disparities, various historical, cultural and political factors have directly and indirectly contributed to these substantial rates.

Until 1988, HIV in South Africa was largely restricted to the homosexual community and hemophiliacs who had received blood transfusions (Abdool Karim et al. 2009; Abdool Karim and Abdool Karim 2005). However, from that point onward, heterosexual transmission became the dominant mode of HIV transmission in South Africa. Using fear, stigma and risk profiling, the apartheid government added to pre-existing prejudices against homosexuals and blacks. After an initially slow introduction of HIV into the heterosexual community, the numbers of individuals with HIV infection grew exponentially from 1990 to 1994. HIV prevalence in pregnant women increased from 0.8% to 7.6% during this period (Ijsselmuiden et al. 1988; Gouws and Abdool Karim 2005). This contributed to a significant rise in the number of perinatal infections. By this time HIV finally became a government priority and condom distribution increased throughout the country.

In the subsequent five years, an even more rapid spread occurred throughout South Africa. In particular, certain areas of rural KZN experienced substantial increases. The main factors identified that fueled the epidemic included migrant laborers, who served as a bridge population between urban and rural community networks (Lurie, Williams, Zuma, Mkaya-Mwamburi, Garnett, Sweat, et al. 2003) and multiple, concurrent partnerships (rural wife and town wife). Also, rape and violence against women increased their susceptibility to HIV (Jochelson, Mothibeli, and Leger 1991; Lurie, Williams, Zuma, Mkaya-Mwamburi, Garnett, Sturm, et al. 2003; Hunter 2005; Wood, Maforah, and Jewkes 1998; Jewkes 2009; Dunkle et al. 2004). During this time, the Treatment Action Campaign was formed to combat the AIDS denialism that had been previously espoused by the government.

In 2003, ART was introduced into the public sector with funding from the US President's Emergency Plan for AIDS Relief (PEPFAR). It took over 5 years after PEPFAR was introduced in South Africa to see decreases in incidence rates, despite one of the largest ART rollouts in the world. Presently, life expectancy in KZN is nearly 50 years for women and 49 years for men (*Statistical Release P0302: Midyear population estimates*). In response to these overwhelming challenges, South Africa's HIV/AIDS and STI National Strategic Plan was launched in 2007 (*The HIV/AIDS Country Scorecard* 2008; HIV & AIDS and STI Strategic Plan for South Africa, 2007-2011 2007). The latest UNAIDS report has shown a sharp decline in the incidence among 18 year olds and women 15-24 years old by 2008 (UNAIDS report on the global AIDS epidemic 2010).

Bringing millions of individuals into care for chronic HIV infection has been a major challenge for South Africa. Despite a developed health care system (8.0% of GDP is spent on health care), the health care system is overwhelmed with the sheer number of individuals infected with HIV. With more than 5.6 million people infected with HIV in South Africa, it is estimated that only 36% of adults and 54% of children eligible for treatment (based upon current WHO criteria that includes CD4 T cells <350 cells/ $\mu$ L) are currently receiving it (Coovadia et al. 2009; UNAIDS report on the global AIDS epidemic 2010). In light of this, it has been no small feat to have over 970,000 individuals on ART.

Poverty in the black population created a general deterioration of health for black South Africans associated with high communicable diseases and violence-related injuries (Packard 1989). Today, over 50% of South Africans live in poverty, more than 40% experience food insecurity, and unemployment remains high (25%) (Rose and Charlton 2002; Ojikutu, Jack, and Ramjee 2007; *Statistical Release P0302: Midyear population estimates*). Government policies

have preferentially benefitted the rich, and this has further increased the overall income gap between the wealthy and the poor (Growth, employment and redistribution: a macro-economic framework 1996). However, even when treatment is provided at minimal or no cost, the substantial cost and effort required to travel long distances (and take time away from childcare and subsistence living) becomes a tremendous barrier to regular clinic and pharmacy attendance.

The seeds of the present weakened health care system were sown during the early days of colonization, and through the apartheid era and beyond, government policies further fragmented the health care system. (Coovadia et al. 2009). Traditional healers were marginalized, and health care training and delivery was racially segregated; these factors resulted in disparities in funding, and the doctor-patient ratio differed along racial lines (fewer black providers for more black patients). Similar human resource challenges exist for nursing, and this has been compounded by high rates of HIV infection among health care workers (Statistics 2007 2007; Shisana et al. 2004). The state overtook missionary hospitals that were crucial in the delivery of health care in rural areas and homelands. Also, the government contributes nearly 56% of the national health expenditure to public sector health care services, which treats 80-85% of the population. Conversely, the remaining 15-20% of the population in private health care receive 44% of the national health care expenditure (McIntyre and Dorrington 1990; Goudge 1999). As the government encouraged providers to move to the private sector and removed funding to the public sector, this increased out-of-pocket expenses for poor patients, a significant barrier to care. There are also discrepancies in quality between the public and private systems (Dennison et al. 2007; Schneider et al. 2005; Palmer 1999). Altogether, these factors result in poor integration of services (especially tuberculosis diagnosis and treatment, mental health, and substance abuse counseling), overcrowding, long waiting lists, provider fatigue, and patient dissatisfaction.

4. Comparing Atlanta and Durban

Several aspects about the HIV epidemic in both of these cities make them uniquely comparable and allow the illustration of various important facets of engagement in care. Atlanta and Durban are both mid-sized cities in wealthy countries, yet both are experiencing an HIV epidemic out of proportion to the rest of their respective regions (Table 1). There are significant disparities of income and education in both cities, which provide some explanation for the high prevalence of HIV. A history of racism, substantial migrant and transient communities, cultural denialism of sexual practices, and a thriving commercial sex trade may also contribute to the transmission of HIV in both cities.

	Atlanta MSA	Durban & nearby townships
Population	5.4 million	10.6 million
% of population Black	50%	68%
HIV prevalence	>1%	15.8% to 38.7% (KZN)
Main risk factors for HIV transmission	MSM Heterosexual, IDU	Heterosexual

Table 1. Comparison of population and HIV prevalence of Atlanta and Durban as of 2008 (CDC 2009; Mangla and Gant 2008; Health 2009; Shisana et al. 2009)



Both cities are racially and culturally diverse, which may impede efforts to treat and prevent HIV transmission, and both have gone through changes in the laws and sociopolitical environment for black individuals through the past fifty years. Martin Luther King, Jr., recognized the connection between the struggles of African-Americans and black South Africans living under apartheid rule when he said,

*"In this period when the American Negro is giving moral leadership and inspiration to his own nation, he must find the resources to aid his suffering brothers in his ancestral homeland. Nor is this aid a one-way street. The civil rights movement in the United States has derived immense inspiration from the successful struggles of those Africans who have attained freedom in their own nations."* (King 1965)

There are also some notable differences between the Atlanta and Durban. About two-thirds of the individuals living with HIV in Atlanta are African-American, but black South Africans comprise an overwhelming majority of individuals with HIV in Durban. HIV transmission in Atlanta occurs primarily through men having sex with men (51%), followed by heterosexual contact (22%), injection drug use, and other means. Transmission in Durban is primarily through heterosexual contact. Also in Atlanta, crack cocaine use contributes indirectly to the spread of HIV (Metsch et al. 2008), whereas in Durban, drug abuse is not a prominent risk factor. In the following three sections, we describe how various institutions, clinics and health care systems have identified ways to overcome barriers to HIV health care and methods to improve adherence to HIV treatment.

## 5. Engaging in care: access, entry, and retention in clinical care

Based on the social ecological framework, we have identified the three major areas impacting engagement in care are individual, interpersonal, and structural factors (Stokols 1996). Some individual factors that may limit engagement in care include personal health beliefs, substance abuse, homelessness, food insecurity, and competing life priorities. Interpersonal factors that may limit engagement in care include communication with physicians, experiences with health care staff, or the influences of social networks on health behaviors. Structural factors include institutional or systemic factors, economic, cultural and political factors. The lack of health insurance, changes in insurance status based on employment or fluctuations in income, complexity of the health system, and reduction in funding for safety net resources may all limit access, entry and retention into care.

At the political level, local and federal policy has played a pivotal role in the accessibility of HIV treatment. Even despite well-intended efforts, government policies can be complicated or ineffective at delivering or augmenting health care or fail to provide the necessary safeguards for individuals with private insurance. Although it took almost 10 years to enact, the Ryan White CARE Act finally passed in 1990 to provide a safety net of HIV/AIDS clinical care in the US (HRSA). In South Africa, HIV denialism at the highest levels of government, worked against efforts to provide care and reduce transmission, wasting valuable time which undoubtedly led to many unnecessary infections and deaths from HIV/AIDS (Chigwedere and Essex 2010).

### 5.1 Atlanta

In Atlanta, a patchwork of private providers, hospital clinics, and safety net providers such as Grady Memorial Hospital, the Atlanta Veterans Affairs Medical Center, and county health departments provide the clinical care for persons infected with HIV. An individual's

access to medical care and antiretroviral therapy depends on the type of insurance they have, as well as their ability to navigate the system designated for them. Patients who are undocumented (without legal status in the US) rely on the safety nets that have been developed, although their obstacles are even greater than those with legal status. Atlanta is one of the cities in the US eligible for Ryan White part A funds that are directed to the most severely affected EMAs. To qualify for part A funding an EMA must have reported at least 2,000 AIDS cases in the most recent 5 years and have a population of at least 50,000. These Federal funds are then distributed to various sites in the Atlanta EMA by the Ryan White executive committee, which is made up of providers, legislators, patient representatives, and other community stakeholders. Clinical sites must apply each year to the Ryan White funding committee in order to renew their funding. The state-run AIDS Drugs Assistance Programs (ADAP) help to cover the cost of antiretroviral therapy as well as other commonly prescribed medications for HIV patients, but as of fall 2010, funding for the Georgia ADAP fell short of need and a waiting list was created (*HIV Care Program: AIDS Drug Assistance Program*). Individual pharmaceutical companies have now extended assistance for antiretroviral medications for eligible patients on the waiting list, but third-party payer assistance for medications remains one of the most significant hurdles for uninsured patients in care.

The Infectious Diseases Program (IDP) at Grady Memorial Hospital treats 5,000 of the most advanced cases of HIV/AIDS in the Atlanta EMA annually, and it is one of the largest outpatient facilities for HIV-positive individuals in the US. For over twenty years, the IDP has provided integrated and comprehensive HIV health care with over 12 specialty and subspecialty services available on-site including hematology/oncology, neurology, hepatology, dental, ophthalmology, dermatology and metabolic disorders. All HIV-positive patients admitted to Grady Memorial Hospital are tracked by the Social Services department to ensure referral to the appropriate outpatient provider upon discharge and to provide support during hospitalization. Other local hospitals and providers can refer patients to IDP as well.

IDP has made distinct efforts to retain patients in care. Certain populations, such as those who are substance abusers, homeless, and/or have a psychiatric illness were found to be at high risk for virologic failure and subsequent morbidity and mortality from HIV/AIDS. These patients have been targeted for participation in the Transition Center, an open-access part of IDP in which patients can arrive as a walk-in to see a medical or psychiatric provider, attend substance abuse group therapy visits, and see a nutritionist (Cohen et al. 2011). Patients who miss appointments at IDP are contacted by "Client Trackers" who reschedule appointments. Finally, a number of support groups and case management programs run by community-based organizations (*AID Atlanta*) are available for patients to discuss the issues that impact their lives and help patients participate in HIV primary care. Peer navigators, mental health counselors, nurses, and pharmacists all serve as part of the treatment team to guide patients through the health system and the process of self-care needed for HIV management.

## 5.2 South Africa

Despite the substantial challenges facing patients and health care providers detailed above, there have been tremendous accomplishments in ART delivery and health outcomes. Many programs throughout the country have shown impressive rates of virologic suppression at

six months (90-95%) and very low rates of loss to follow up (Boulle et al. 2008; Marconi et al. 2008). These outcomes have remained outstanding even after several years of treatment (Lawn et al. 2008; Rosen, Fox, and Gill 2007). For the small percentage of patients requiring second line therapy, a substantial percentage of patients were able to achieve virologic suppression thereafter (Fox et al. 2010; Murphy et al. 2010). Although encouraging, most of these reports have been from urban clinics with adequate resources to individually and programmatically monitor and manage the large volume of patients initiated on ART. Unfortunately, early data from rural sites with fewer resources have shown more discouraging outcomes (Mutevedzi et al. 2010). Suboptimal adherence to ART has been associated with virologic failure (Nachega et al. 2006; Bisson et al. 2008), drug resistance (Braithwaite et al. 2006), and death (Wood et al. 2002).

Although programmatic monitoring has been required to maintain funding support, it has simultaneously served as a mechanism to assist clinics in assessing, assuring and improving the care delivery processes and quality of the care provided. Some clinical sites have also been fitted with electronic medical records and other electronic systems to improve the workflow and immediate access to necessary data. Another effective systematic change has been the extensive use of counselors, peer navigators, HIV educators and nurses to deliver care for patients who are doing well on treatment, particularly in areas where physician resources are limited (Sanne et al. 2010; Abdool Karim et al. 2009). This approach, known as task shifting, along with down-referral (the decentralization of care to smaller clinics without physicians) has been one way to address the limited human resources relative to the demand (Long et al. 2011; Matovu et al. 2011; Sanne et al. 2010). This approach is consistent with the development of more community-based health centers to improve access, especially in rural areas. In addition to treatment monitoring of patients on a stable regimen, the role for nurse initiation and complete follow up management of patients on ART (NIM-ART) is being assessed in a randomized trial and is being discussed at a national level in order to expand treatment access (Colvin et al. 2010; Uebel et al. 2011; Fairall et al. 2011).

Another intervention being used to improve access and retention in care has been the fast-tracking of patients in desperate need of starting ART (Geng et al. 2011). Similarly, ART initiation in the hospital after initial HIV diagnosis and/or a new opportunistic infection helps to reduce the barriers experienced when patients are discharged from the hospital. This is especially effective when combined with palliative care programs designed to address the multiple symptomatic complaints as well as psychosocial and spiritual needs of the patient. In a busy clinical program, these issues often get overlooked by providers and nurses which can erode trust in the health care team (Sunpath et al. 2011). In East Africa, programs with dedicated staff who use aggressive outreach (by using all available means of transportation) to search for patients within 30 days of a missed visit ultimately have lower lost-to-follow-up rates (Braitstein et al. 2011).

Since 75% of HIV-infected individuals in South Africa use remedies dispensed by traditional healers, it has become increasingly apparent that patients would ultimately benefit from bridging the gap between these disciplines (Shuster et al. 2009). Practitioners of western medicine are now working with traditional healers to assist in HIV education, counseling and testing in the community (Peltzer, Mngqundaniso, and Petros 2006; *Traditional healers in South Africa trained to encourage people to get tested for HIV* 2006). Consequently, this approach has been supported by the South African Department of Public Health (Ojikutu, Jack, and Ramjee 2007).

### 5.3 Examples of universal health care systems

Various health care systems and clinical settings have created structures to improve the ability of individuals to remain engaged in care. Some health care systems, such as those found in the US Department of Defense (DoD), US Department of Veterans Affairs (VA) and various European countries, have reduced or eliminated the out-of-pocket expenses for patients or have provided financial assistance through the involvement of integrated community-based organizations. In the absence of universal health care, some of the interventions include the use of patient navigators, such as those implemented in clinics across Haiti, comprehensive integrated care centers (the medical home), patient- and family-focused care, optimal use of electronic medical records for tracking and process optimization, community-based specialty care, and interventions specifically targeting drug users or other vulnerable subpopulations.

#### 5.3.1 Vancouver

In contrast to the US, Canada provides a universal health care system for all its residents that covers treatment of HIV. For example, in the province of British Columbia, health care and antiretroviral medications are provided free of charge. Almost as important as eliminating out-of-pocket expenses, this system has virtually eliminated the administrative barriers that accompany similar systems elsewhere when an individual moves in and out of various insurance programs. HIV-positive patients must register with the Drug Treatment Program (DTP) that is coordinated by the British Columbia Center for Excellence in HIV/AIDS. Despite the availability of free health care, investigators in Vancouver found that a significant number of HIV-positive individuals still do not use antiretroviral therapy, and that 40% of people who died from HIV-related causes never initiated ART (Joy et al. 2008). They also found that 16% of individuals waited until their CD4 cell count fell below 50 cells/ $\mu$ l to initiate ART (Joy et al. 2008). The findings in British Columbia demonstrate how access to care alone may not result in optimal health outcomes across all HIV-infected populations, and that multiple factors must be considered when designing interventions to improve health outcomes (Lima et al. 2010; *British Columbia Center for Excellence in HIV/AIDS*).

#### 5.3.2 Military and VA

Most health care in the US is delivered by clinics and hospitals that are privately owned and operated (community-based, academic, corporate-owned) and a smaller percentage are government-based. Since the US is a mixed market system, the payer source is divided between self-pay (12.8%) and third party insurance (87.2%). Third party insurance includes public insurance (46.4% of the total as Medicare, Medicaid and government employee insurance) and private insurance (40.7% of the total) (CMS 2011). Some of the government employee programs such as those associated with the DoD and the VA provide universal access to care for their participants. When care is received at government facilities or other participating facilities, the individual has no (or minimal) out of pocket expenses and does not pay premiums or deductibles. Studies have shown that individuals with HIV in these programs have outcomes equivalent to those reported in clinical trials with high levels of adherence and virologic suppression, as well as low rates of hospitalization and mortality, even among individuals with other significant barriers to care (homelessness, poverty, drug



use) (Marconi et al. 2010; Guest et al. 2011). Eliminating out-of-pocket expenses and streamlining health care may result in improved outcomes for HIV patients, even for traditionally marginalized populations.

#### **5.4 Overcoming the barrier of substance abuse**

HIV and substance abuse have coexisted since the beginning of the epidemic. Not only does injection drug use provide a direct pathway for HIV transmission via the use of shared blood products, but certain substances, particularly stimulants, have been associated with a high frequency of unprotected sex, providing another pathway for HIV transmission.

Various techniques have been attempted to improve rates of linkage to care among substance abusers, such as coordinated substance abuse, mental health, and medical treatment (Korthuis et al. 2011; Weiss et al. 2011; Cunningham et al. 2011). Targeted outreach programs designed to bring active drug users to engage in medical care have been implemented in many cities in the US and Canada, such as Boston, New Haven, New York, and Vancouver. These outreach programs often partner with community-based harm reduction organizations to provide the needed services in spaces that may be more comfortable for drug users (Cunningham et al. 2007; Bardsley, Turvey, and Blatherwick 1990).

For example, in New York City a partnership between Montefiore Medical Center (academic medical institution) and CitiWide Harm Reduction (community-based organization) was designed to bring HIV-positive drug users into medical care. Medical providers go to single-room occupancy hotels accompanied by the outreach teams from CitiWide to meet potential patients, offer medical services, and educate patients. Immediate needs such as prescriptions for acute illnesses may be written for patients during the outreach, and those who are interested may be referred for primary care services on-site at either CitiWide's walk-in clinic or Montefiore's primary care clinic (Cunningham et al. 2007). Investigators found that patients were more likely to keep same-day or walk-in appointments at CitiWide's walk-in clinic compared with future appointments at Montefiore (Cunningham et al. 2007). These findings emphasize the need to provide care in various ways that facilitate access to care for substance users.

In Massachusetts, a mobile van from the Massachusetts Department of Public Health targets men who have sex with men, in order to diagnose HIV earlier and prevent and treat sexually transmitted infections. Researchers found that men using the mobile van's services reported a variety of substances used, including substance use during sex, and that polysubstance users had higher numbers of male sexual partners, anonymous male sexual partners, and male sexual partners met over the internet in the previous year, when compared with non-polysubstance users (Mimiaga et al. 2008). These findings indicate that mobile van health services are a useful way to target this high-risk group.

#### **5.5 Test, Link to Care, Plus Treat (TLC-Plus)**

In order to address many of the challenges in the test-to-treat continuum for HIV infected individuals, the NIH-funded HIV Prevention Trials Network (HPTN) has started a study called TLC-Plus (Test, Link to Care, Plus Treat) in Washington, DC, and Bronx, NY, to evaluate the feasibility of a multifaceted approach to HIV prevention. The study includes a package of interventions that include expanded HIV testing, linkage to care, initiation of ART for those clinically eligible, promotion of high adherence to maintain virologic

suppression, and prevention for positives interventions. The study will also assess the patient and provider attitudes toward the initiation of ART in early HIV disease. Outcomes in the intervention communities (Washington, DC, and the Bronx, NY) will be compared to those in the non-intervention communities (Chicago, Illinois, Houston, Texas, Miami, Florida and Philadelphia). This study began enrollment in 2011 and results are expected in approximately 3 years.

### **5.6 Community-based specialty care**

Regular access to a medical provider specialized to treat HIV may be difficult for some HIV-positive patients, and the US Institute of Medicine has recently identified critical shortages in the number of providers specialized to care for HIV-positive individuals (IOM 2011). In addition, some patients may feel that attending an infectious diseases specialty clinic carries a stigma, and they may avoid care for this reason. One way that health systems have circumvented this barrier is to place HIV specialists in community health care settings. For example, Montefiore Medical Center, Bronx, NY, has a hospital-based infectious diseases clinic, as well as several community-based primary care clinics that manage HIV-positive patients by using partnerships between primary care providers and HIV specialists. Investigators found, in a retrospective review comparing those who initiated care in the hospital-based setting versus the community-based setting, that patients initiated ART at similar rates and achieved similar levels of virologic suppression (Chu et al. 2010). The findings here suggest this may be a viable way to provide appropriate HIV specialty care for patients who may find difficulty accessing more centralized care settings, and this may alleviate some of the provider shortages regarding HIV specialists in the US.

## **6. Medication adherence**

After overcoming the hurdles associated with navigating the health care system and understanding the complexities of their disease, individuals with HIV must maintain perfect adherence to difficult regimens requiring multiple doses per day or suffer the consequences of HIV drug resistance and disease progression. Overcoming many psychosocial and physical discomforts related to the diagnosis and disease are paramount to ensuring a steady pace in what would be considered a marathon of necessary therapy. The most common factors associated with poor treatment adherence include untreated depression, active substance abuse, poor insight into disease and treatment, youth, higher pill burden, more frequent dosing and forgetfulness (Nachega et al. 2011). In Sub-Saharan Africa, the cost of ART, lack transportation to the health care facility for refills, and pharmacy stock-outs are additional barriers; stigma and food insecurity were the most prevalent risk factors for poor adherence (Crane et al. 2006; Nachega et al. 2004; Weiser et al. 2003; Weiser et al. 2010).

Various approaches have been undertaken to include incorporation of religious and spiritual counseling, active substance and mental health programs as well as involvement with treatment partners and support groups. Finally, ongoing education and novel techniques to allow the incorporation of pill-taking into activities of daily living have become crucial components for successful HIV treatment.

### **6.1 United States**

In the US, efforts to improve adherence to antiretroviral drug regimens have focused both on individual and structural barriers to optimal adherence. Throughout the past 30 years, as

newer HIV drugs are developed and become available on the market, the number of pills needed for a successful regimen has decreased. Now, many patients starting their first regimen can take a single pill (co-formulated tenofovir/emtricitabine/efavirenz, known as Atripla) once a day to achieve virologic suppression. In a meta-analysis of 11 randomized controlled trials, adherence to once-daily regimens was better than to twice-daily regimens (Parienti et al. 2009). The US DHHS Adult and Adolescent Treatment Guidelines have been modified to reflect the impact of barriers to adherence on treatment response, so that regimens with fewer pills are recommended over other regimens (DHHS 2011).

Many HIV clinics have trained staff to counsel patients on medication adherence, which includes reviewing all of the medications taken prior to initiating or changing a regimen, discussing the main side effects, identifying the best ways to take the prescribed medications, and helping patients think about ways to incorporate pill-taking into their lives with contextual and designed reminders. Reminders such as alarms or pill boxes may be coupled with adherence counseling as they have been shown to enhance adherence (Simoni et al. 2006; de Bruin et al. 2010).

For those who are not able to achieve optimal adherence despite individual counseling, some health care systems have developed directly observed therapy (DOT) programs, which are modeled on the adherence programs initially developed for tuberculosis therapy. The idea behind using DOT for HIV therapy is to reduce the risk of viral drug resistance and to achieve virologic suppression, which will provide health benefits to the patient as well as reduce the risk of HIV transmission. There are many varieties of DOT programs in practice, depending on the needs of the patient population and the services available from the health care system. One of the main differences between TB therapy and HIV therapy is that for HIV, the duration of therapy is life-long, and the number of pills or frequency of doses may not decrease over time. However, the overall benefit of DOT on virologic suppression is controversial with studies finding both a lack of benefit and an overall benefit to DOT, with respect to adherence, immunologic, and virologic outcomes (Hart et al. 2010; Myers and Tsiouris 2009; Ford et al. 2009).

One example of a patient-centered DOT program can be found in New York City. Due to the barriers to adherence faced by opioid-dependent HIV-positive patients, a DOT program for HIV therapy was developed to deliver HIV medications at methadone clinics. US federal policies require patients to obtain their methadone doses from one clinic, and at the discretion of the clinic, patients may be required to attend daily or weekly observed dosing appointments. Since the patients may visit the methadone clinic frequently (every day, or at least five to six days per week), HIV medications were coupled with the observed daily methadone dose. Investigators found that patients in the DOT program achieved higher levels of adherence and virologic suppression when assessed after 24 weeks (Berg et al. 2011).

Contingency management, which consists of financial incentives for medication adherence, has also been shown to be efficacious in enhancing participation in substance abuse treatment and for reducing drug use. The use of contingency management for HIV has been shown to be effective (Petry et al. 2010), but the beneficial effect appears to wane after incentives are removed (Rosen et al. 2007). Future studies that incorporate contingency management, patient navigators, and/or peer counseling will need to be tested before contingency management can be considered as a “best practice” for the management of HIV.

## 6.2 Sub-Saharan Africa

The World Health Organization established several Early Warning Indicators in order to identify how well sites are managing ART usage and adherence. These have directly resulted in optimization of the quality of care and have assisted in the identification of vulnerable clinics (Jordan et al. 2011; Hong et al. 2010). A significant effort has been applied to ensuring high rates of adherence in various clinics throughout Africa and in particular South Africa (Mills et al. 2006). Individual adherence sessions with peer counselors and group education programs provide detailed information on HIV infection, antiretroviral medications, drug interactions, stigma, and adherence techniques (Lawn et al. 2007; Matovu et al. 2011). Many of these programs and support groups work to increase social capital and empower individuals to make health a priority (Achieng et al. 2011). Individuals who do not disclose their HIV status to intimate partners or household members may feel stigmatized and hide their pills for fear of being discovered, and disclosure of HIV status has been proven to improve adherence (Nachega et al. 2004). In Kenya, mobile phone text messages improved ART adherence over standard care (Lester et al. 2010; Pop-Eleches et al. 2011). Various methods of adherence monitoring have been evaluated to determine efficacy (Nachega et al. 2011). Pill counts (Achieng et al. 2011) and pharmacy refill monitoring (Murphy et al. 2011) have been shown to be reliable and inexpensive but not consistent across all settings. Directly observed ART has also been examined with mixed results but overall is costly and labor intensive (Nachega et al. 2010; Hart et al. 2010), as is therapeutic drug monitoring via plasma or hair sampling (van Zyl et al. 2011).

## 6.3 Haiti

In rural Haiti, a non-governmental organization, Partners in Health, has been working since 1987 to support HIV/AIDS treatment. Among the many barriers to optimal care in Haiti, i.e. poverty, food insecurity, political disruptions, a program was developed to help HIV patients take their medications. *Accompagnateurs*, or community health workers, were people chosen from the local community and trained in medication and symptom management for HIV patients. Since starting this program, patients have experienced an increase in CD4 count and reduction in viral loads, and therefore the *accompagnateurs* have been identified as a critical component of the clinical care provided for these patients (Koenig, Leandre, and Farmer 2004; Behforouz, Farmer, and Mukherjee 2004).

## 7. Improving social capital

One important factor to HIV-positive patients achieving optimal health is the ability to leverage social capital. Social capital can be defined as the value that comes from engagement in a social network. Social capital can help HIV patients achieve good health by providing psychological and physical support (e.g. food, shelter, transportation, money for medications). Stigma can inhibit the ability to leverage social capital because it interferes in the individual's willingness to seek help from others in their social network (Bangsberg and Deeks 2010). In a qualitative study conducted in Kenya, Uganda, and Nigeria, researchers found that higher levels of social capital helped HIV-positive patients to prioritize ART adherence and achieve improved health (Ware et al. 2009).

A substantial impact has occurred via the implementation of outreach programs designed to improve the social capital of various disenfranchised populations where stigma, poor health



literacy and lack of education stymie those already challenged by competing priorities. Different forms of outreach have been developed, specific to the needs of the marginalized population. These programs have attempted to improve engagement in care and to support those who are living with HIV. For example, programs in Boston (PACT – Prevention, Access to Care and Treatment), San Francisco (PHASt – Positive Health Access to Services and Treatment), and New York City (St. Luke's-Roosevelt Hospital Center's Center for Comprehensive Care) have designed successful outreach programs targeting the patients with the worst levels of engagement in care (Rosenberg 2011). The Community Health Care Van in New Haven provides prevention and treatment services for HIV, hepatitis, substance abuse, and mental illness from a medical van (HRSA). By focusing on the needs of the whole patient, including shelter, food, mental health, and medical comorbidities, and helping them to capitalize on available services and social capital, these programs have helped some of the most vulnerable patients successfully treat their HIV infection.

## 8. Conclusion

If every HIV-infected individual could know their diagnosis, enter the health care system, start antiretroviral therapy when appropriate and incorporate all the evidence-based preventive health measures into his or her life, we could potentially see a world free of HIV within generations. This is the premise behind the “Test and Treat” strategy (Granich et al. 2009). While this may seem to be a lofty goal, the examples presented here from Atlanta and Durban, as well as those from many other places around the world, suggest that even if the economic resources were made available to implement the “Test and Treat” strategy, there are individual, interpersonal, and structural-level barriers that could limit the impact of such approach (Gardner et al. 2011).

In order to combat the disparities in HIV infection rates and HIV-related morbidity and mortality, creative solutions are necessary. This chapter describes the comparison between the response to the HIV epidemic between Atlanta and Durban, highlighting important similarities and differences between the two cities. Both Atlanta and Durban are located in wealthy countries, yet both have significant racial/ethnic and socioeconomic factors that have led to continued HIV transmission and disparities in HIV outcomes. In each city, individual programs have designed solutions to improve diagnosis and engagement in care. In addition, several other programs around the world have developed their own responses to the HIV epidemic, to deliver care to those who need it within their local contexts.

Focusing on marginalized subpopulations, while difficult, is important both for reducing the disparities in HIV infection and outcomes and also for reducing community-level viral load and subsequent transmission of the virus. These subpopulations of patients may require more intensive resources or specific interventions that successfully engage them in care. For example, several different types of programs in the US, such as targeted outreach in mobile vans, DOT, and variations on the specialty clinic model, have successfully engaged marginalized patients in care. In South Africa, systemic solutions (such as actively seeking out patients who miss appointments and expanding the roles of allied health professionals) and cultural solutions (such as incorporating traditional healers into medical care) are being used to improve engagement in care and ART adherence.

As HIV continues to spread, and as patients live longer, health systems must develop strategies for HIV prevention and continued engagement in care; this will undoubtedly

require flexibility and new ideas to be tested and implemented. HIV has been touted as now being a chronic disease, but we must remember that it is an infectious chronic disease. If those infected with HIV have detectable virus circulating in the bloodstream and mucosal surfaces, transmission will continue to occur. Thus, until there is a cure, retaining patients in HIV care over a lifetime is a major challenge for any health care system, particularly for regions that lack universal access to care. Health systems' solutions will also need to address the individual, interpersonal, and underlying structural factors that lead to HIV transmission and the disparities in access to health care. As low- and middle-income countries scale up HIV treatment services, these health systems can serve as models for management of non-communicable diseases as well (Rabkin and El-Sadr 2011). Multiple layers of co-occurring interventions that target individual-level, interpersonal-level, and structural-level factors would address the many aspects of optimal HIV prevention and therapy.

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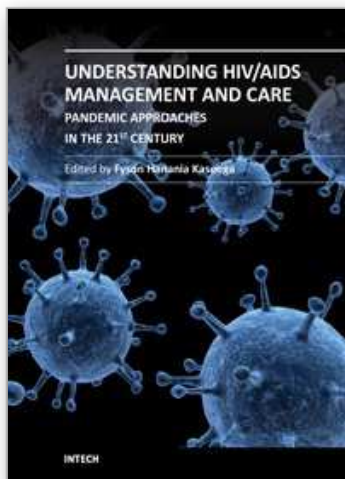
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## **Understanding HIV/AIDS Management and Care - Pandemic Approaches in the 21st Century**

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Like any other book on the subject of HIV/AIDS, this book is not a substitute or exhausting the subject in question. It aims at complementing what is already in circulation and adds value to clarification of certain concepts to create more room for reasoning and being part of the solution to this global pandemic. It is further expected to complement a wide range of studies done on this subject, and provide a platform for the more updated information on this subject. It is the hope of the authors that the book will provide the readers with more knowledge and skills to do more to reduce HIV transmission and improve the quality of life of those that are infected or affected by HIV/AIDS.

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