Cultural Competent Care for Haitian Americans with HIV/AIDS

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Swen Kiltirelman Konpetan Pou Ayisyen/Ameriken Ki Gen VIH/SIDA

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OBJECTIVES

- •What is Cultural Competence?
- What is Haitian/American concept of health
- Value patients' cultural beliefs
- Using Cultural Competence To Improve the Quality of Health Care for Haitian/Americans with HIV/AIDS









OBJEKTIF

- •Ki sa kompetans kiltirel vle di?
- •Ki jan Ayisyen/Ameriken konsevwa la sante?
- Ki enpotans kwayans kiltirel yo genyen pou pasyan ?
- •Itilizasyon konpetans kiltirel pou amelyore kalite swen sante pou Ayisyen/Ameriken ki gen VIH/SIDA?









What is Cultural Competence?

 The United States Department of Health and Human Services Office of Minority Health defines cultural competence as "having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors and needs presented by consumers and their communities".









What is Cultural Competence?

•"Healthy People 2010: Understanding and Improving Health defines cultural competence as "The design, implementation, and evaluation process that accounts for special issues for select population groups (ethnic and racial, linguistics) as well as differing educational levels and physical abilities" Because of the increasing diversification of our country, cultural competence is a necessary skill to help improve public health and eliminate ethnic and racial health disparities.









Why is Cultural Competency

- m Collula competency is essential to help reduce health disparities between ethnic groups. There are continuing racial health disparities in the U.S. in the incidences of some illnesses.
 - •Cultural competency has also been named as a core competency for public health professionals. Core competencies are defined as skills necessary to be proficient at the practice of public health. In addition, one of the Essential Services of Public Health is to "assure a competent public health and personal health care workforce."









Why is Cultural Competency important?

•Cultural competency is also mandated by law in some situations. Title VI of the Civil Rights Act of 1964 states, "No person in the United States shall, on ground of race, color or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance". Both the Surgeon General and the Joint Commission on the Accreditation of Healthcare Organizations maintain that cultural competency is essential to provide adequate care.









Why Haitians?

- •While HIV shows no discrimination, the Haitian American community is overrepresented among groups affected by HIV/AIDS and yet remains underserved in health care and social services.
- During the 1970s and 1980s, no other immigrant group underwent more prejudice than the Haitians.









Why Haitians?

- •An estimated 830,000 people with Haitian ancestry live in the United States, up from 290,000 in 1990 (Buchanan, Albert, & Beaulieu, 2010).
- •Florida has the highest number with 376,000 and New York follows with 191,000 (Buchanan, Albert, & Beaulieu, 2010).









Impact of HIV/AIDS among Haitians

- •In 2013, there were approximately 35 million people living with HIV globally.
- •Since the start of the epidemic around 78 million have become infected with HIV and 39 million people have died of AIDS-related illnesses.
- •Unfortunately, since there is no specific category for Haitians in the U.S. Census, it is expected that most Haitians indicate the category "black" (1990 Census) or "black or African-American" (2000 Census) as their racial category, making it difficult to capture the actual number of Haitians living in the country.









HIV/AIDS among Haitian-Born Adults in Florida

- •In 2012, there is an estimated 19 million people residing in Florida. According to the 2012 United States Census Bureau, Haitian-born individuals make up approximately 2% (N=287,502) of Florida's total population
- •In 2013, of the 47,439 adult black people living with HIV disease in Florida, Haitian-born adults account for 16% (n=7,455). Each year, the majority of black foreign born adults reported with HIV disease were Haitian born









HIV/AIDS among Haitian-Born Adults in Florida

- •Among both male and female Haitian-born adults living with HIV disease, the greatest proportion of cases reported through 2013 were among those aged 50 or older. More specifically, 64% of cases among Haitian-born males were aged 50 or older and 49% of cases among Haitian-born females were aged 50 or older
- •In Florida, there were 7,455 Haitian-born adults living with HIV disease reported through 2013

Haitian-born adults represent the majority of case deaths over the past ten years









How is Cultural Competency Achieved?

 There are many different theories on how to create Cultural Competency. The U.S. Department of Health and Human Services' Office of Minority Health has created 14 standards. The standards have emerged as either mandates (must be met to receive federal funds), guidelines (suggested to become mandates at some point in time) or recommendations.









How is Cultural Competency Achieved?

Over the years, health care services have used a range of strategies to try to ensure that these populations, and indeed all people affected by HIV/AIDS, have access to proper care despite the stigma.

Although Haitian Americans with HIV/AIDS continue to be one of the groups that suffer the greatest in terms of lack of adequate health care









Haiti History and Population

• In the early 1980s, shortly after the discovery of HIV/AIDS in the US, Haitians were blamed for bringing the virus to the States (Brodwin 2000). Later this was proven to be untrue, in fact, the reverse was the case.

Historically, many Americans, including health care providers, viewed "being Haitian" as a risk factor for HIV

In the 1980s, the Centers for Disease Control prohibited blood donations from anyone of Haitian national origin









The traditional Haitian concept of health is based on the balance and equilibrium of several factors (Colin and Paperwalla 2003):

- •Hot (cho) and cold (fret)
 - o Staying warm
- Physical health
- o Physical health is maintained by: § Proper diet § Cleanliness § Exercise, Adequate rest
- Emotional health
 - o Excessive anger, fear, sadness are believed to contribute to



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- Familial relationships
 - o Being in harmony with friends and relatives
- Spiritual well-being
 - o Prayer
 - o Good rapport with the spiritual world.
- o Illness is often believed to be a result of wrongdoing









As long as a person looks well, they may be considered as healthy. This includes:

Clear, healthy complexion and color

Normal body weight/ fair amount of body fat

Without significant physical pain

Si Bondye Vle / "God willing" (Colin and Paperwalla 2003)

Many Haitians believe that God is the ultimate decider of health, illness, life and death.

- o This belief may be manifested as passivity concerning health decisions.
- Illness is viewed in varied stages or degrees of severity (Colin and Paperwalla 2003):

Kom pa bon (not feeling well) – the person is generally not feeling well

- o Usually a brief illness with easy recovery
- o Does not restrict normal activities







Some Haitians believe that illness may be caused by either

- natural or
- supernatural









- Moin malad (feeling sick)- Feeling sick
 - o Disrupts normal activities
- Moin malad anpil (very sick) severe illness
 - o Disrupts normal activity
 - o Patient may be bedridden
- Moin pap refe (dying)- fatal illness









Natural causation

- o Sometimes referred to as Maladi Bondye
- o Believed to be allowed by God
- These ailments usually are not chronic
- •o Irregular circulation (flow of blood) is thought to cause natural illnesses.









Natural diseases may also be

Food Particularly leftovers § Believed to cause gas and consequently illness and pain.

Gas § Gas may enter the body through an orifice/opening (ears, mouth)

§ Gas may be present in various places in the body causing pain in that region.

§ Head (van nan tet or van nan zorey § Enters through the ear § Causes headache

§ Stomach (kolik) Enters through mouth §Causes stomach/abdominal pain

§ Gas may move from the stomach to other places and



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Natural diseases may also be caused by:

- ☐ Gas may move from the stomach to other places and cause pain.
 - ☐ Extremities ☐ Back ☐ Shoulder ☐ Other organs
 - ☐ Certain foods are believed to cause gas: ☐ Leftovers ☐ Beans
- Air
- Imbalance of cold and hot
- Bone displacement

Natural illnesses are typically treated with herbal home remedies.

 \square If these treatments do not work, western healthcare may be consulted.



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Supernatural causation

o Vexed spirits

§ Feasts (manger morts) are prepared and offered to protector spirits.

§ If this and other rituals to honor the spirits are not performed, the

angered spirit may cause calamity and illness in the unfaithful.

o Curses cast by jealous and/or angry people may cause illness.



Supernatural illness causation (Colin and Paperwalla 2003)

o Many followers of Voudou believe that spirits and /or curses cause certain illness.

o Treatment for supernaturally caused illnesses is usually sought from a Voudou

practitioner.

§ In fact, some believe that if conventional western medical

treatment is sought for a supernaturally caused illness, it will



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- Miracles
- o Some Christians believe in miracles.
- § Consequently, they may delay seeking treatment while waiting on a miraculous healing.
- § This belief may also affect the decision to discontinue life support once it is started.
- Social Misconduct (Beauvoir 2006)









Social Misconduct (Beauvoir 2006)

o Some Haitians believe that certain illnesses are caused as a result of taboo

violation or being disrespectful to elders.

§ If this is the case, the ailing may try to "right" the "wrong" to restore

balance instead of consulting a doctor for treat









God's Will

o Many Haitians believe that God ultimately decides matters of life and death, health and illness.

§ This belief may be manifested as an external locus of control that is the belief that matters of health, life and death are out of the individual's control.

§ Some healthcare providers may interpret the Haitian attitude of passive acceptance as fatalism.









Diagnosis Expectation (Beauvoir 2006)

o Some Haitians, especially those who visit traditional healers, expect the

practitioner to diagnose their problem without asking for information.

§ They may not be accustomed to nor obliging when confronted with many

question about their health.









- o Some may give a brief synopsis of the problem and expect the doctor to figure out the cause (which is what traditional healers do to commence their healing session).
- § They may give great detail about surrounding environment, time of day and even what they were wearing, as these are important information when diagnosing supernatural illnesses.
- o The patient may nod or frown depending upon the healthcare provider's analysis
- of their symptoms.
- § The provider's ability to analyze and explain the cause of symptoms/complaints may determine if the patient will return for







- •Sexually transmitted diseases (STDs) are a common health problem in Haiti. The rates can be attributed to the acceptance of the polygamous lifestyles of men.
- •Also, due to their health belief system, many Haitians do not associate STDs with sexual intercourse. Haitian men are generally not willing to use contraceptives. In addition, STDs are more difficult to eliminate in this population because it is common to stop taking antibiotics once symptoms subside.









High-Risk Health Behaviors

•Many Haitian immigrants don't see the importance of exercise or feel they don't have the time. For Haitians in the U.S., having the time to go to the gym is viewed as a luxury.

One study that analyzed cardiovascular risk factors in Afro-Caribbean individuals in the U. S., found that 26% of their sample smoked, and 67% of their sample was overweight. These results could be interpreted as a change in lifestyle as Haitians assimilate to U.S. culture.

•In traditional Haitian culture, being fat means being healthy, whereas being thin indicates poor health.

Traditionally, Haitians tend to seek care from a biomedical practitioner only when all other options are exhausted. Illness is associated with not being able to work.









LIMITATIONS

- Access to Healthcare
- Cultural issues that may affect access:
- •o Low medical literacy o Low overall literacy o Limited transportation options o Inability to communicate with caregivers o Lack of awareness of how to navigate the healthcare system o Limited availability of services
- •§ Few health facilities are culturally competent in caring for Haitian patients. o Inadequate financial resources
- •§ Haitians immigrants have some of the lowest health insurance coverage rates (Saint-Jean and Crandall 2005).
- •§ Roughly 53% of Haitians in America are insured- of these 41% have private insurance; 12% have federally funded insurance.
- •§ 48% of Haitians are uninsured. o Other issues associated with poverty









LIMITATIONS

Healthcare Utilization Patterns

Language barriers

o There are not enough resources for patients who speak Haitian Creole, including:

written resources, interpreters./Alternative Resources

o Many Haitians seek care from family, herbalists and religious authorities

(Christian and Voudou) before consulting a Western doctor.

Supernatural forces

o If a disease is believed to be caused by a supernatural force (spirits, curses,











LIMITATIONS

Underinsured

- o Lack of financial resources may delay or prevent Haitian immigrants from seeking medical attention.
- o Haitians immigrants have some of the lowest health insurance coverage rates
- § Roughly 53% of Haitians in America are insured- of these 41% have
- private insurance; 12% have federally funded insurance.
- § 48% of Haitians are uninsured.









LIMITATIONS

Fear of Deportation

o Haitian immigrants who are undocumented may not utilize services, especially

federally funded resources/services, for fear of deportation.

o It is fairly common for documented Haitian immigrants to avoid federally funded

services for fear that their utilization may hinder other relatives from immigrating

to the US in the future.

Less than 1% of Haitians utilize emotional and/or mental health services









The met and unmet health care needs of Haitian Americans living

- The Haitian American population has a high poverty rate, which affects rates of HIV transmission, treatment opportunities, and access to health insurance (Ryan, Hawkins, Parker, & Hawkins, 2004).
- •Given the growing population of Haitian Americans, as well as the barriers to health care services for this population, it is particularly important to gain better understandings of which health care needs are currently being met, and which are not.







MET NEEDS

- (a) general health care;
- (b) health care services specific to HIV/AIDS; and
- •(c) culturally relevant services within communities.









General Health Care

SEEKING GENERAL HEALTH CARE
HOSPITAL AND HEALTH CLINICS
CONFIDENTIALITY OR ANONYMITY
RESPECT AND COMFORT









MET NEEDS

General Health Care: SEEKING GENERAL HEALTH CARE

They would go for help if there were a serious problem, but not for HIV or AIDS because of the stigma around HIV/AIDS and the secrecy that many individuals and families use to guard themselves.

One of the most frequently reported uses of health care was related to pregnancy, which was also a common occasion when women were tested for HIV.

They appreciated, for example, health care services that were not specific to serving people with HIV/AIDS. That way people would not know why they were at a particular facility. These participants also tended to trust that their health care professionals

Health Care Services Specific to HIV/AIDS

- Accessibility
- Testing
- Medication
- Referrals









MET NEEDS

Health Care Services Specific to HIV/AIDS

- •ACCESSIBILITY Case managers and outreach workers seemed to be particularly important for facilitating access into the health care system and helping people navigate through the services.
- Creole speaking Haitian case managers were especially successful in that they, more so than any other personnel, were able to convince Haitians to access or return to care.









Culturally Relevant Care Within Communities

SPIRITUALITY

A number of participants suggested that the mainstream health care system did not take traditional or spiritual healing methods into account. In some situations, the participants disengaged from health care services and simply reverted to their own traditional or spiritual remedies, as one participant

USE OF TRADITIONAL REMEDIES

Some participants reported using both western medicine and traditional remedies,









USE OF TRADITIONAL REMEDIES

 A number of participants reported that they, or people they knew, used traditional remedies including teas, oils, cerassie, aloe, rum with honey and lime, orange tea, baths, ginger, other herbs, and plants. People who wanted traditional remedies – variously referred to as root medicine, bush medicine, or herb medicine – were able to have these needs met through family members, voodoo priests, mambos (female witch doctors), and other personally known providers within the Haitian community









Unmet Needs

The unmet needs centered on five themes:

- •(a) accessing the health care system (problems related to the bureaucracy of the health care system);
- (b) housing and food (lack of resources on housing and food among participants);
- (c) information and trust (misinformation on HIV/AIDS and distrust between participants and service providers);
- (d) need for confidentiality (lack of privacy); and
- •(e) need for culturally comfortable services (lack of









Health Care Access

PAPERWORK
TIMELY SERVICE
RESPECT
Housing and Food
Trust and Information
Confidentiality









Health Care Access

- •PAPERWORK concern with the bureaucracy of the health care system and particularly the difficult paperwork: what documents were required, how to fill out certain forms, and where to get documentation if they did not have it.
- •TIMELY SERVICE Various participants suggested that health care services were not provided in a timely manner. Some delays were caused by not having the requisite paperwork and having to wait for documentation.







RESPECT

•Some participants expressed feeling accepted and treated as a human being worthy of respect by health care providers. Some of these seemed surprised at how well they were treated, unsure of what type of reception they would receive, given that they were Haitian and HIV positive. Some mentioned that having **Haitian staff members** helped them to feel comfortable with services.







Unmet Needs

Housing and Food

- Some people were living in homes where they lived in fear that others would find out they were HIV positive. Others were stigmatized in their homes and wanted to find alternative accommodations but could not afford to live on their own.
- •Taking medication without adequate food can cause side effects as one participant noted "sometimes when you take your medications without eating, it makes you feel bad and weak." As another participant explained housing and HIV









Trust and Information

TRUST

A number of people received clear information but did not trust their health care providers: "They think because you look good, they say the doctor's lying, don't listen to them, they're lying." Certain participants even suggested that the medication prescribed by doctors, not AIDS, is what kills people.









Unmet NeedS

INFORMATION

One of the most pervasive themes among unmet needs was "unanswered medical questions" Given the lack of Creole-speaking health care providers or translators, some of the difficulties may have been related to language, particularly when a participant was not fluent in English and the health care provider did not speak Creole or French. The types of questions that went unanswered were ones related to the nature of HIV/AIDS, how it is transmitted, and why they were heing prescribed certain treatments.







Confidentiality

Given the high value placed on privacy, particularly in regard toHIV/ AIDS, In terms of geographical access, some participants did not necessarily want services too close to where they lived, but rather ones that were accessible by public transit.









Confidentiality

Problems with privacy included:

- having to go to AIDS-specific clinics where everyone would know they had AIDS;
- being given food or transportation coupons that could identify them as recipients of AIDS-related support;
- being picked up at home by a vehicle identified with an AIDS organization; and a
- belief that health care providers would report their AIDS status to police or immigration officials or gossip about them within the Haitian community.









Culturally Appropriate Services

MENTAL HEALTH SERVICES

Many Haitians with HIV/AIDS simply get stressed out or depressed and give up on life.

They do not eat or take care of themselves. Implicit in these stories was the lack of culturally appropriate services to deal with these mental health issues, not just the physical health services for people with HIV/AIDS.

Participants were aware of counseling and groups, but many did not believe that these were appropriate services for them







Culturally Appropriate Services

TRADITIONAL AND SPIRITUAL HEALING METHODS

A number of participants suggested that the mainstream health care system did not take traditional or spiritual healing methods into account. In some situations, the participants disengaged from health care services and simply reverted to their own traditional or spiritual remedies.









TRADITIONAL AND SPIRITUAL HEALING METHODS

Relying on spiritual healing is complicated by the fact that HIV can be heavily stigmatized in Haitian church communities. A number of participants noted that they would not feel comfortable disclosing their HIV/AIDS to anyone at church. One health provider stated: The church's policy on HIV/AIDS is "don't ask, don't tell." People with HIV/AIDS were not able to turn to church for support for HIV/AIDS, explicitly anyhow. Sometimes, they will just tell people at the church that they have cancer. [People at my church] say let's pray for people with cancer, people with sugar (diabetes). Never put attention on HIV positive











Clinical and Policy Implications

Social service providers in the United States have long known the importance of providing culturally sensitive services to diverse populations. When services are for HIV positive people of Haitian ancestry, this can be especially important for a variety of reasons that we have seen in Beliefs/Practices That Might Impact









Clinical and Policy Implications

- These beliefs affect the type of care they seek and the timing of that care.
- Studies document the cultural practice of seeking health care services from traditional root workers, Houngan, or family members
- Health care providers need to be aware of and sensitive to these practices rather than deny their effectiveness.
- Clinicians that are culturally sensitive may be able to better educate and treat the individual with mainstream medical practices.









Clinical and Policy Implications

- An early effort to provide more culturally sensitive prevention techniques was conducted in Boston in the late 1980s. These efforts attempted to understand "what's at stake" for the community rather than simply correcting false beliefs about HIV (Farmer & Kim, 1991, p. 217).
- This example illustrates how health care providers can effectively engage the Haitian American community in designing culturally appropriate education and prevention services
- The Center for Community Health Education and Research in Boston has been delivering culturally sensitive case management services to the Haitian community since the mid-1990s (Jean-Louis et al., 2000).









Stigma impacts

• Stigmatization of Haitians as AIDS carriers had multiple long-term effects including feeling rejected by society, low self-esteem, self-doubt, difficulty developing intimate relationships, and rejection by fellow Haitians in their community (Santana & Dancy, 2000).









- •The stigmatization of those with HIV cause Haitians not to seek care for fear of being alienated and isolated from friends and family (Barsky & Albertini, 2006).
- "My family, the moment that they know you have that sickness, they wouldn't even walk by the place where you sleep" (Barsky & Albertini, 2006, p. 74)









•Several cultural characteristics were impeding access to treatment including a strong sense of pride and self-reliance, a high value for personal privacy, and a predilection for avoiding stress. These characteristics can lead to people delaying treatment until it is an emergency situation, which can be deadly when dealing with HIV.









- •The belief system about the causes of illnesses that was previously discussed discourages Haitians from seeking treatment from the mainstream medical community.
- •One study found that being Haitian was related to higher rates of refusal of routine HIV testing at urgent care centers (Liddicoat, Losina, Minhee, Freedberg, & Walensky, 2006).









- •Language and communication barriers were a strong impediment in accessing service (Holcombe, Parsons, Giger, & Davidhizar, 1996).
- •The predominant language among Haitians is Creole and many families continue to speak Creole after they have moved to the United States. They often rely on family and friends for translation, which can exacerbate the issues regarding privacy, shame, and stigma.









Transtheoretical model of changes











Transtheoretical model

- It may be helpful if care providers see Haitians as in precontemplation or contemplation stages rather than in denial about their HIV/AIDS status (DiClemente, 2003).
- •The population seems more amenable to an educational approach rather than a psychotherapy approach (Barsky & Albertini, 2006).
- •The U.S.-based Haitian population would also benefit from education on the U.S. health care system to empower them to more effectively access services for







Transtheoretical model

- Rather than putting all the power in the hands of the current providers of services, why not guide Haitians through the maze that is the U.S. health care system. It must feel very foreign to them and certainly that lack of understanding must impede access to care.
- The empowerment and education would travel through the Haitian community and result in a snowball effect of increased health care efficacy.









Conclusion

•With the Haitian-born population standing at approximately 2% of the total population in Florida in 2012 and approximately 0.17% of the U.S. population that same year but making up nearly 16% of black foreign-born adults living with HIV disease highlights much effort that still needs to be done in order to decrease prevalence in this community









Conclusion

- •The most effective programs for reaching the Haitian population are comprehensive, interactive/ objective strategies for delivering prevention messages.
- •Comprehensive programs should be: culturally competent, have clearly defined audiences, objectives, interventions, and be based in behavioral and social science theory and research.
- •Since the main mode of exposure to HIV infection for both Haitian-born men and women is heterosexual contact, focusing on altering HIV-risk behaviors would be the most









Conclusion

- •To ensure that Haitian Americans living with HIV/AIDS access appropriate services, health care providers need to ensure their programs and staff address cultural attitudes, beliefs, and expectations.
- •In particular, clinicians should demonstrate respect; provide confidentiality and privacy, and address language barriers, transportation needs, housing, and family needs.









SUMMARY

The findings emphasize the need for health care practitioners to pay close attention to the education levels of their Haitian patients, as well as their mental health status. The data also suggest that once these individuals are linked to care and offered assistance with their daily challenges there is a high likelihood that they will maintain an adequate level of adherence to care









SUMMARY

- •Improved quality of care is the outcome measure that indicates whether implementing training programs, policies, and culturally or linguistically appropriate standards makes a difference
- •For Haitian Americans living with or affected by HIV/AIDS to maximize the quality and length of their lives, it is important that health and social service providers adapt services to be culturally sensitive and









KEY MESSAGES

- Culturally sensitive health care services are provided.
- Clinicians need to understand the traditional and spiritual healing methods of the Haitian American community.
- They must show respect and provide confidentiality and privacy.
- They should consider accessibility issues such as language barriers, difficulty navigating bureaucratic systems, transportation, housing, and family needs.
- Whenever possible, Creole-speaking case managers, doctors, and nurses should be utilized.
- Providing culturally sensitive services will translate into greater access and more effective health care for this population









For future study

- To implement research based on direct observations or provider—patient interactions at various health care facilities. To determine the culturally informed meanings of health care issues for Haitian people more generally.
- More importantly, although there is a high incidence of HIV and AIDS in the Haitian community, policy makers and service providers should look beyond HIV and AIDS to broader notions of health care









THANK YOU

Aprender que hay personas que te ofrecen las estrellas y otras que te llevan a ellas. –Esa es la diferencia entre quien quiere y quien ama.

— Mario Benedetti









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•Unfortunately, one of the three contexts in which they reported feeling stigmatization was:

By health care providers who would isolate them or order HIV tests for them simply because they were Haitian. Santana and Dancy (2000) found that these feelings were compounded by racism toward blacks and by stereotypes of Haitians as poor, illiterate, and living illegally in this country.







