Cultural Competent Care for Haitian Americans with HIV/AIDS

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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
What is Cultural Competence?

The US DHHS Office of Minority Health definition:

- 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

- chose cultural competence as the strategy to accomplish their second objective which is “Eliminate Health Disparities”

- Strategy: "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"
Why is Cultural Competency important?

• 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.

• There are continuing racial health disparities in the U.S. in the incidences of some illnesses.
Why is Cultural Competency important?

Cultural competency:

• Core competency for public health professionals.

• Core competencies: 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:

- Legally mandatory: 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: Approximately 35 million people living with HIV globally.

• Since the beginning: Around 78 million infected with HIV 39 million dead 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. DHHS Office of Minority Health has created 14 standards.

- The standards have emerged as:
  - Mandatory (must be met to receive federal funds),
  - Guidelines (suggested to become mandates at some point in time)
  - 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.

Nonetheless, 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. 4 Hs: Heroin addict, Hemophilia, Homosexual and Haitian (Brodwin 2000). Later this was proven to be untrue, in fact, the reverse was the case: Sexual tourist from the US introduced HIV in HAITI.

• Historically, many Americans, including health care providers, viewed “being Haitian” as a risk factor for HIV
Haiti History and Population

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

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): Staying warm
- Physical health: Physical health is maintained by: Proper diet, Cleanliness, Exercise, Adequate rest
- Emotional health: Excessive anger, fear, sadness are believed to contribute to illness.
Haitian Concept of Health

• Familial relationships
  - Being in harmony with friends and relatives

• Spiritual well-being
  - Prayer
  - Good rapport with the spiritual world.
  - Illness is often believed to be a result of wrongdoing
Haitian Concept of Health

• 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.
  - This belief may be manifested as passivity concerning health decisions.
Haitian Concept of Health

• **Illness is viewed in varied stages** or degrees of severity (Colin and Paperwalla 2003):
  
  - **Kom pa bon**: the person is generally not feeling well
    - Usually a brief illness with easy recovery
    - Does not restrict normal activities

• Some Haitians believe that illness may be caused by natural or supernatural
Haitian Concept of Health

- **Moin malad** (feeling sick) - Feeling sick
  - Disrupts normal activities
- **Moin malad anpil** (very sick) - severe illness
  - Disrupts normal activity
  - Patient may be bedridden
- **Moin pap réfè** (dying) - fatal illness
Haitian Concept of Health

Natural Causation:

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

Natural causation

**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, Causing headache, Stomach (kolik), Enters through mouth Causing stomach/abdominal pain Gas may move from the stomach to other places and cause pain.

Any pain is a gas: Back pain, knee pain, etc.
Haitian Concept of Health

Supernatural causation

- **Vexed spirits**: Feasts (manger morts or loas) 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.

- **Curses cast by jealous and/or angry people** may cause illness (Ex: Yo voye on Mort SIDA sou moin)

- Voodoo priests may be consulted for diagnosis and cure of supernatural
Beliefs/Practices That Might Impact Health Care Decisions

Supernatural illness causation (Colin and Paperwalla 2003)

- Many followers of Voudou believe that spirits and/or curses cause certain illness.
- 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 worsen.
Beliefs/Practices That Might Impact Health Care Decisions

- **Miracles** (Armée celeste: Army of Heaven)

- 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.
Beliefs/Practices That Might Impact Health Care Decisions

• **Social Misconduct** (Beauvoir 2006)

  • 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
Beliefs/Practices That Might Impact Health Care Decisions

• God’s Will

  • 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.
Beliefs/Practices That Might Impact Health Care Decisions

• Diagnosis Expectation (Beauvoir 2006)
  
  • Some Haitians, especially those who visit traditional healers, expect the practitioner to diagnose their problem without asking for information. (Fè chandèl, bat carte)

  • They may not be accustomed to nor obliging when confronted with many question about their health.
Beliefs/Practices That Might Impact Health Care Decisions

- 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.
Beliefs/Practices That Might Impact Health Care Decisions

• 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 subsequent visits.
Beliefs/Practices That Might Impact Health Care Decisions

• 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.
  - STD is almost always the women’s fault.
  - STDs difficult to eliminate because it is common to stop taking antibiotics once symptoms subside.
LIMITATIONS

- Access to Healthcare
- Cultural issues that may affect access:
  - Low medical literacy, Low overall literacy
  - Limited transportation options
  - Inability to communicate with caregivers
  - Lack of awareness of how to navigate the healthcare system
  - Limited availability of services
  - Few health facilities are culturally competent in caring for Haitian patients.
  - Inadequate financial resources.
LIMITATIONS

- Haitians immigrants have some of the lowest health insurance coverage rates (Saint-Jean and Crandall 2005).

- Roughly 53% of Haitians in America are insured
  - 41% have private insurance;
  - 12% have federally funded insurance.

- 48% of Haitians are uninsured.

- Other issues associated with poverty
LIMITATIONS

Healthcare Utilization Patterns

- **Language barriers**

  - There are not enough resources for patients who speak Haitian Creole, including: written resources, interpreters.

  - Many Haitians seek care from family, herbalists and religious authorities (Christian and Voudou) before consulting a healthcare provider.

  - If a disease is believed to be caused by a supernatural force (spirits, curses, social taboo violation), conventional medicine may not be considered helpful.
LIMITATIONS

- **Underinsured**
  - Lack of financial resources may delay or prevent Haitian immigrants from seeking medical attention.
  - 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

- Haitian immigrants who are undocumented may not utilize services, especially federally funded resources/services, for fear of deportation.

- 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 (Mental health is for crazy people)
The met and unmet health care needs of Haitian Americans living with HIV/AIDS

- 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

• General health care;
• Health care services specific to HIV/AIDS; and
• Culturally relevant services within communities.
General Health Care

• Seeking general health care hospital and health clinics

• Confidentiality or anonymity

• Respect and comfort
• 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.
MET NEEDS

- They appreciated, for example, health care services that are 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 would maintain their confidentiality.
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.

• Better if case manager doesn’t live in the community where services are provided.
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, cerasee (Assorosi), aloe vera (Laloi), 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:

- Accessing the health care system (problems related to the bureaucracy of the health care system);
- Housing and food (lack of resources on housing and food among participants);
- Information and trust (misinformation on HIV/AIDS and distrust between participants and service providers);
- Need for confidentiality (lack of privacy); and
- Need for culturally comfortable services (lack of culturally appropriate services).
Unmet Needs

- Healthcare Access
  - Paperwork
  - Timely service
  - Respect
- Housing and Food
- Trust and information
- Confidentiality
Unmet Needs

• Healthcare 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.
Unmet Needs

• Healthcare Access
  - 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

• Healthcare Access

- HOUSING: 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.

- FOOD: 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 status can also be intricately linked.
Unmet Needs

• Healthcare Access

  - 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

• Healthcare Access

  - INFORMATION: One of the most pervasive themes among unmet needs was “unanswered medical questions”
  - Language barrier (Creole-English) between Patient and provider,
  - Lack of translation services and difficulty of interpretation of terms related to Haitian culture

  - The types of questions that went unanswered were ones related to the nature of HIV/AIDS, how it is transmitted, and why they were being prescribed certain treatments.
Unmet Needs

• Healthcare Access

- CONFIDENTIALITY: Given the high value placed on privacy, particularly in regard to HIV/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.
Unmet Needs

• Healthcare Access

• 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.
  - 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.

  - Participants were aware of counseling and groups, but many did not believe that these were appropriate services for them.
TRADITIONAL AND SPIRITUAL HEALING METHODS

- A number of participants suggests that the mainstream health care system did not take traditional or spiritual or healing methods into account.

- In some situations, the participants disengaged from health care services and simply reverted to their own traditional or spiritual remedies.
Health Disparities

• 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.

• Haitian Americans with HIV/AIDS continue to be one of the groups that suffer the greatest in terms of lack of adequate health care (Barsky & Albertini, 2006).
TRADITIONAL AND SPIRITUAL HEALING METHODS

• Relying on spiritual healing is complicated: 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 person, never, never.
HIV/AIDS among Haitian-Born Adults in Florida

• Florida observed a noteworthy shift among both genders between the years 2005 to 2007, 2010 to 2011 and again in 2013, where the number of HIV cases among females exceeded male cases.

• Over the past ten years, the number of Haitian-born HIV infection cases has decreased by 37% among males and 27% among females. Similarly the male to female ratio has also declined over the same time period from 1:1 in 2004 to 0.9:1 in 2013.
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 variety of reason 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 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).
Conclusion

• With the Haitian-born population standing:
  - At 2% of the total population in Florida in 2012
  - 0.17% of the U.S. population that same year
  - But making up nearly 16% of black foreign-born adults living with HIV disease.

• Much more effort still needs to be done in order to decrease prevalence in this community.
Conclusion

- The most effective programs for Haitian population are comprehensive, interactive/ objective strategies for delivering prevention messages.

- Comprehensive programs should be: culturally competent, have clearly defined audiences, objectives, 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 beneficial.
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 imperative that health and social service providers adapt services to be culturally sensitive and appropriate.
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.
THANK YOU
References


