Latinos Living with HIV in Lawrence, MA:

Stigma and Discrimination as Barriers to Care

Abigail Smith, Greta Grecchi, Jorge Finke, Patrick Alvarado, Simone Miller

Donna Rivera, MSW—Clerkship Leader

Introduction

Lawrence, Massachusetts

Lawrence was incorporated in 1847. It began as a mill town that relied on Irish and Italian immigrant labor. At the turn of the twentieth century nearly half of the population was foreign-born. In the 1950s-60s after the mills closed the population demographics changed. Puerto Rican and Dominican immigration increased, and by 2000 minorities (primarily Hispanic) were reported to make up 61% of the population. Today Lawrence's population is 74% Hispanic.[1, 2] In 2012, nearly 29% of Lawrence's 77,000 residents were living below the federal poverty line, compared to 11% at the MA average.[3]

Greater Lawrence Family Health Center

The GLFHC opened more than 30 years ago in response to local emergency departments treating rising numbers of patients for unmet primary care needs. It was the first health center of its kind to offer its own family medicine residency program. Today, GLFHC has five locations and provides care to nearly 2/3 of Lawrence's population. Comprehensive HIV care is one of many services offered under the health center's model of integrated, primary care-based delivery. [4]

Ayer Mill Clock Tower, Lawernce, MA. *Source: http://sublimedays.com/2012/02/07/the-setting-of-a-clock-tower/*

Population of Focus

The population of focus is made up of residents of Lawrence, MA and the surrounding communities who have been diagnosed with HIV/AIDS—or who are at high risk of becoming infected with HIV—and are cared for by the Greater Lawrence Family Health Center and its affiliates. Given the population of Lawrence, many of these 'clients' are also Hispanic and/or "LEP" (of limited English proficiency).

Statistic	Lawrence	Massachusetts
Number of people living with HIV/AIDS (12/31/2010)	401	17,621
Prevalence rate per 100,000	491.5	273.7
Average number of HIV diagnoses (2007-2009)	17.0	607.3
Average diagnosis rate per 100,000	20.8	9.4

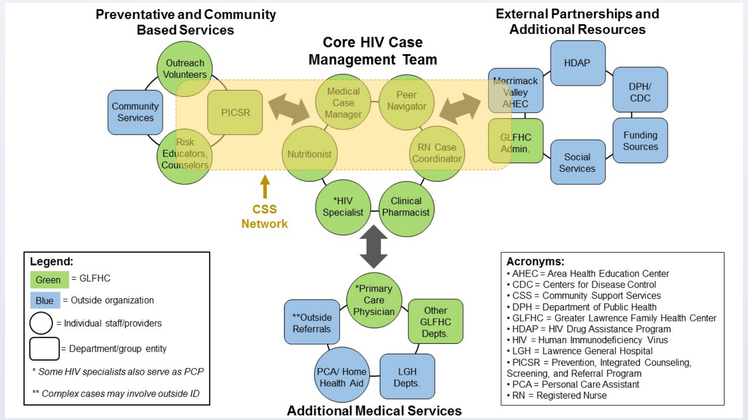
Clerkship Objectives & Activities

- Learning about the history of HIV prevention and current funding for HIV Services, such as the Ryan White Act, HIV Drug Assistance Program (HDAP), etc.
- Addressing social and cultural issues pertinent to the community and population of focus
  - Cultural competency, alternative medical practices (Botanicas, Spiritualistas)
  - Language barriers, working with medical translators
- Participating in outreach and other community-based activities
  - Visit Bread & Roses soup kitchen and Daybreak Shelter (HIV testing, Health Care for the Homeless)
  - Street outreach in high-risk neighborhoods (distribute bleach kits for IV drug users, condoms, etc.)
  - Home visits with HIV medical case manager
- Observing patient care and HIV Services at GLFHC
  - HIV Comprehensive Care Clinic
  - Inter-professionalism in HIV case management
- Supplementary work in public health and social determinants
  - Meeting with the head of HIV surveillance for MA DPH
  - MA Integrated Prevention & Care Committee meeting
  - Race, Privilege & Power Conference
- Developing and implementing a service-learning project to address a particular area of need within the population of focus.

Community outreach with GLFHC staff to homeless populations in Lawrence. Photo: Simone Miller.

Inter-professional Analysis

Inter-professional teamwork is fundamental to all levels of HIV service provided by GLFHC. Partnerships and connections span from preventative services to external and administrative resources, through the individual case management team and all additional medical services provided to patients. Further integration exists through overarching boards and networks such as Community Support Services (CSS). These relationships are shown in the schematic below:



The preventative and community-based arm provides HIV and STD testing, community education, and coordination with other community services such as soup kitchens and shelters. When an individual is diagnosed with HIV, the central case management team provides medical care and referrals and performs regular reassessment of social and medical needs to minimize potential barriers to care. The external and administrative arm provides ongoing guidance, legislature and funding, as well as linkage to social/medical services such as health insurance, SSI and housing assistance. All arms of the schematic work to minimize stigma, either at the individual, community or institutional level.

Service-Learning Project

Stigma Associated with HIV in Lawrence

After meeting with several employees of GLFHC, we learned that stigma and discrimination are perceived as persistent challenges associated with HIV infection in Lawrence.

Source: http://mappingpathways.blogspot.com

- Homophobia is still prevalent in Lawrence; homosexuals may face discrimination and be shunned by friends and family.
- Aspects of some Hispanic cultures (such as *Machismo* beliefs and traditions) may contribute to this.
- Anecdotally, some male patients prefer to tell their families that they contracted HIV from IV drug use than admit that they are MSM.
- HIV infection itself is also stigmatized regardless of behavior or how it was contracted. This may be due to a lack of education about the transmission of the disease.

Stigma and HIV Services

- Peer navigators, case managers and others currently work to reduce stigma
- Desire for further CQI addressing stigma/discrimination
- Interest in more provider training on stigma for HIV Services team

We decided to assist the HIV Services team in further exploring perceptions of stigma by designing and administering a quality-improvement survey to GLFHC employees. Questions were not directed at personal beliefs or affiliations, but asked about perceptions regarding the current status of HIV-related stigma (sources, effects, etc.) within Lawrence, and assessed interest in further provider training.

Discussion

Stigma & Discrimination Surrounding HIV

The stigma of HIV usually occurs alongside other forms of discrimination, such as racism, prejudice based on physical appearance, homophobia or misogyny and can also be directed towards those involved with what are considered socially unacceptable activities such as prostitution or drug use. Stigma not only makes it more difficult for people trying to come to terms with HIV and manage their illness on a personal level, but it also interferes with attempts to fight the HIV/AIDS epidemic as a whole.

The stigma associated with HIV can make individuals reluctant to access HIV testing and treatment. Patients may fear the social disgrace of disclosure, or fear discrimination from healthcare workers. The WHO cites fear of stigma and discrimination as the main reason why people are reluctant to be tested, disclose their HIV status or take antiretroviral drugs. Studies have shown consequences of HIV-related stigma to be:

- Loss of income/livelihood
- Loss of marriage & childbearing options
- Poor care within the health sector
- Withdrawal of caregiving in the home
- Loss of hope & feelings of worthlessness

Source: www.thestigmaproject.org

Common Beliefs & Misconceptions about HIV

Inaccurate information about how HIV is transmitted creates unwarranted fear and actions based on misperceptions of personal risk. Lack of education in the general population, and fear of contagion coupled with negative, value-based assumptions about people who are infected leads to high levels of stigma surrounding HIV and AIDS.

- HIV infection is often thought to be the result of personal irresponsibility.
- Religious or moral beliefs lead some to feel that being infected with HIV is the result of moral fault (such as promiscuity or 'deviant sex') and deserves to be punished.
- The effects of antiretroviral therapy on people's physical appearance can result in forced disclosure and discrimination based on appearance.

Survey Project

We administered 25 surveys to GLFHC staff (clinical, community-based and administrative) involved in HIV Services, and received back 22 completed surveys. Data analysis is currently in progress. A summary of results will be provided to the HIV Services CQI team upon completion.

Future Directions

Since the survey was conducted only as a quality improvement project, the results cannot be disclosed here or published externally for research purposes. The results will only be used for internal quality improvement projects by GLFHC. The survey, however, should ideally be validated, revised as indicated, and distributed more widely amongst GLFHC staff to improve sample size and QI data return. Furthermore, it would be informative to conduct a similar survey amongst HIV patients at GLFHC to quantify characterize the stigma actually experienced in the community. By comparing such results with the preliminary data from our survey regarding provider perceptions, GLFHC can move forward with providing necessary trainings and workshops for its employees, as well as continuing to better address stigma as a barrier to care among community members and patient populations.

Acknowledgements

We would like to thank Donna Rivera and everyone at AHEC, as well as the staff and clinicians at GLFHC for their education, patience and support. We would also like to thank Betsey John and the Massachusetts Department of Public Health for educating us on their work as HIV epidemiologists. Finally, we would like to thank the patients who allowed us to observe their care.