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## Services and Resources for People Living with HIV/AIDS in the Southcoast of Massachusetts: “Can’t Get There From Here!”

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### Abstract

*Fall River and New Bedford, two diverse and economically challenged cities in the Southcoast region of Massachusetts, are areas of substantial concern in the effort to reduce HIV incidence and to provide effective services for people living with HIV/AIDS in the Commonwealth. In these two communities, HIV disparately impacts marginalized populations, with particularly high infection and prevalence rates among men who have sex with men and injection drug users in comparison to other Massachusetts localities. This project used community-engaged research principles to conduct a community assessment guided by the social determinants of health. The primary goal of this study was to identify the gaps in resources and services and highlight challenges and barriers to treatment for people living with HIV/AIDS in Fall River and New Bedford, Massachusetts. Transportation was a major barrier in not accessing available community services and resources.*

### Introduction

A perception exists nationally that HIV prevention and treatment has removed the disease from crisis status. Advances in Antiretroviral Therapy (ART) prescription and adherence slows the progressive nature of this chronic illness, allowing those individuals who are diagnosed with the virus to manage HIV-related symptoms and live longer without complications. This is certainly the case in The Commonwealth of Massachusetts where the rate of new HIV diagnoses continues to decline (15.4 in 2012 down to 10.9 in 2014) and the number of people living with HIV/AIDS (PLWH/A) increases [1-4]. Like many localized, concentrated urban regions in the U.S., the Southeast region of Massachusetts is experiencing a heavy burden of disease [5]. This paper will characterize the community of people living with HIV/AIDS (PLWHA) in the Southcoast region of Massachusetts by outlining HIV/AIDS incidence and highlighting the specific challenges in accessing care. An interdisciplinary approach to address the unmet needs of the target community and identify experienced challenges in accessing HIV/AIDS related services provides a unique perspective to the already established body of knowledge regarding HIV/AIDS.

### Background

Approximately 1.2 million people in the United States are living with HIV [6]. Although the incidence of new HIV infection continues to drop in the Commonwealth of Massachusetts, the incidence rate consistently places Massachusetts in the top fifty percent of states nationwide [1-3]. According to the Massachusetts Department of Public Health Health (MDPH) HIV/AIDS Surveillance Program, approximately 34,000 individuals were ever diagnosed with HIV

infection and were living in Massachusetts, with or without an AIDS diagnosis [7]. Fall River and New Bedford, two diverse and economically challenged cities located in the Southeast coastal region of Massachusetts (also referred to as the Southcoast) bear a significant burden of HIV infection.

According to population estimates, there are around 89,000 individuals living in Fall River and approximately 95,000 individuals living in New Bedford [8, 9]. The population demographics for both cities are predominantly white (not-Hispanic) with more Hispanic and Black/African American diversity reported in New Bedford than Fall River [8]. Both cities have a percentage of persons living in poverty that is almost double that of the state average [9]. The geographical distribution of HIV/AIDS has a strong presence in the City of New Bedford. For all indicators, (a) annual rate of HIV infection diagnosis, (b) annual number of HIV infection diagnoses, (c) prevalence of HIV/AIDS per 1000,000 population, and (d) highest prevalence of HIV/AIDS, New Bedford is consistently ranked in the top fifteen localities in Massachusetts [9].

Vulnerable sub-groups and groups with high risk behavior exist in both cities. For the three year period 2010-2012, Fall River and New Bedford ranked first and second in Massachusetts with the highest proportions of HIV infection attributed to injection drug use (IDU) [10]. Additionally, these two cities are listed in the top ten Massachusetts cities/towns reporting the highest proportion of HIV infection attributed to male-to-male sex, with Fall River reporting 50% (n = 12) and New Bedford (34%, n = 14) of new HIV diagnoses linked primarily to this risk factor [11]. In

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subsequent data collection periods, New Bedford fell out of the top ten listing, however, Fall River remains high with the third highest state proportion rate [12]. Other marginalized sub groups in the cities also bear significant burden of HIV infection. The proportion of women diagnosed with HIV infection during 2011-2013 in New Bedford was the tenth largest in the state and both Fall River and New Bedford had rates in the state's top ten for the proportion of Hispanic/Latino individuals diagnosed with HIV [13,14].

PLWHA in Fall River and New Bedford require culturally specific resources and access to care services to prevent advancement of HIV disease and HIV-related co-morbidities that lead to disparate outcomes. However, more information is needed to understand what the culturally specific needs are in this community and how those needs can be met. The authors approached this knowledge gap using the social determinants of health (SDH) framework which focuses on the wider socioeconomic, socio-political, and structural factors that impact health. By placing social factors at the forefront of health outcomes, health becomes a "topic of social justice more broadly" [15]. It is through this social justice lens that the authors collaborated together and established partnerships with the HIV community in the Southcoast.

### Significance

Social determinants of HIV-infection, such as poverty, lack of secure housing, discrimination, and inequality facilitate HIV transmission by influencing local HIV prevalence as well as an individual's risk behaviors [5]. According to a study by Denning and colleagues, poverty stricken, urbanized communities in the U.S. met the criteria for HIV epidemic status, and shared prevalence rates of HIV similar to countries internationally known for their HIV epidemics [16]. Furthermore, the rates of HIV in these urban areas in the U.S. did not differ significantly between race (Black, Hispanic, and White) as they do when analyzing rates across the U.S. [16]. Therefore, the role of poverty is dually important as it directly affects incidence of HIV infection and then impacts the collateral determinants influencing the management of the disease.

Although HIV is often considered a healthcare provider-focused disease, management of the infection crosses numerous disciplines with various skill sets, especially when the HIV epidemic and disparate outcomes are viewed as an issue of social justice. To prevent HIV-related exacerbations and mortality, it is vital that members of the target community are engaged in the work to ensure successful adherence to HIV-related treatment. An interdisciplinary team, consisting of community-engaged researchers representing nursing and law, partnered with members of the target community. The mobilized team goal was to identify the culturally specific needs of the PLWHA community in Southcoast, Massachusetts. The specific aim of this study was to identify challenges and barriers faced by the defined community in managing and adhering to their HIV/AIDS treatment. Information gained from this study will lay the foundation for developing multidisciplinary nursing clinical research, program development, and interventions that are rotations and law clinics to address the culturally specific needs of the region.

## Methods and Materials

### Design

Following the directive to engage vulnerable populations, "in culturally relevant and address the socioeconomic milieu in which

HIV transmission occurs" [17, p. 969], the authors partnered with various community based organizations to conduct a needs and assets assessment in the cities of Fall River and New Bedford.

This assessment was two-phased. In the first phase, the authors interviewed community based providers who provide services to the target community. These providers acted in the role of key informant [18]. These key informants were selected because of their role in the community of interest (they were providers of care), their intimate knowledge of the specific data that were being collected (resources and services available in the community for PLWHA, and their willingness to share this information with the team in a nonjudgmental and professional manner [19]. Key informants were vital in securing connections to community based organizations where sustainable, multidisciplinary programming will be implemented.

Provider interviews explored what is known about PLWHA and identified various social, physical, healthcare, and distinct legal needs of the community. This information supplemented the information reviewed in the literature and was used to develop the semi-structured interview guide used to conduct one-on-one interviews with individuals from the target community. Just as important, the knowledge gained from phase one informed the research team about how to proceed in phase two of the study. This included selecting the setting where interviews would occur and strategic methods for recruiting a difficult to reach population.

### Recruitment

Multi-method recruitment occurred in various community based healthcare agencies and organizations, social service agencies, substance-abuse rehabilitation facilities, and homeless shelters located in Fall River and New Bedford Massachusetts. The primary methods of recruitment were distribution of fliers and word of mouth. The key informants and community health workers also provided assistance by referring clients to the authors. Snowball sampling rounded out the team effort. Initially, the authors excluded any individual that could not speak and/or understand English fluently. However, challenges in recruiting a diverse and adequate sample representative of the target geographical location led the team to expand the inclusion criteria to non-English speaking individuals. Recruitment of participants stopped once the interviews reached saturation, meaning the stories told by subsequent participants did not differ from prior interviews. The authors debriefed on the phone after each interview which included a preliminary impression of the interview, review of previously identified themes, and notation of possible new themes. Decisions around recruitment, especially targeting subgroups in the community, occurred at the end of the debriefing session.

### Data Collection

HIV/AIDS status was self-reported by the subject. If the subject reported that their HIV-status was positive, the interviewer reviewed the goals of the research study, obtained IRB approved informed consent, and collected demographic data. The subject completed a written demographic questionnaire collecting the following demographic data: age, race/ethnicity, sexual orientation, gender identity, relationship status, city of residence, housing situation, health care insurance, regular source of healthcare, education level, employment status, and affiliation to a faith based community. One-on-one interviews were conducted

using a semi-structured interview guide and were audio recorded using two digital audio devices. For those participants who did not speak English, a professional interpreter conducted the interview with the researcher.

### Data Analysis

Demographic data were calculated for frequencies. See Table 1 for selected sample demographics. Transcripts were read for clarity and then analyzed for themes. Coding for themes began with the extraction of data segments that identified challenges or barriers to HIV-related care in the community. Themes were generated from an across transcript analysis of codes.

### Results

The team interviewed 22 HIV-positive individuals comprised of 15 men and 7 women with an average age of 55 years. The majority of the sample completed a high school degree and reported an average monthly income of \$989.00. Six participants (27%) reported that their HIV was contracted through sexual activity and four participants (18%) identified injection drug use as the cause.

**Table 1: Demographics of Participants.**

Demographic	Frequency	Percentage of Sample
Black or African American	4	18%
White or Caucasian	9	41%
Cape Verdean	5	23%
Hispanic	4	18%
Straight	12	55%
Gay	7	32%
Lesbian	1	5%
Queer	1	5%
Married	1	5%
Single	14	64%
Employed full time	2	9%
Employed part time	4	18%
Disabled or Unable to Work	13	59%
Retired	2	9%
Homemaker or Caregiver	1	5%
Receives Healthcare in Fall River	13	59%
Receives Healthcare in New Bedford	8	36%
Receives Medicaid Benefit	18	82%
Receives Medicare Benefit	14	64%
Receive Other Type of Healthcare Benefit	5	23%

According to one community based provider, “Massachusetts is the best place in the country to be living with HIV!” Overall, the interviews conducted with participants supported this statement as they were all connected with local health, social, and legal services necessary to manage their HIV/AIDS. However, when asked to identify the challenges faced in managing their HIV-related treatment plans, an overwhelming number of participants reported transportation barriers. This fact was also reported by the community providers.

### Financial Hardship and Access Barriers to Transportation

Challenges with transportation were two-fold. First, participants highlighted the lack of financial means to purchase, maintain, and

fuel a vehicle. Second, for those that could not afford a vehicle, relying on the public transit posed significant challenges because of the geographical access and scheduling limitations. Table 2 outlines exemplary quotes, from both participants and community providers, demonstrating the two specific barriers related to transportation challenges experienced in this community.

**Table 2: Participant Quotes – Transportation is a Barrier.**

Exemplary Quotes	
“...like at one point they would give, they were giving out - cab vouchers, or different things. And honestly, I don’t need them but I know there are other people here that do. And so it is affecting them more than me.” (P103)	Financial
“You live down here? You need a vehicle. And if you get 800 bucks a month to actually get a vehicle on the road, and insure it, and maintenance and everything else is almost impossible. And just for medical appointments alone. I’m all over the place doing medical stuff...There is no way I would be able to get there without my own vehicle. I mean, it’s just tough.” (P106)	Financial
“...like if I had 10 visits that I - I had to come here a month, I’d probably get approved by transportation for four time a month. The others I have to get here by my own.” (P109)	Financial
“Because they are unable to get a driver’s license, they are unable to get transportation to get them to and from work, home, and getting medication and other services. Even though there is bus transportation to bring individuals to and from doctor’s appointments, it is not open to everyone and so many individuals face the difficulty of being able to get \$1.75 to be able to take the bus. (Community provider)	Financial
“Sometimes I want to get out of the house, or whatever, But I don’t have transportation and the insurance pays for this think that we have and they only work from like 7:00 am in the morning or 7:00 to 5:00, and then whatever is after 5:00 you have to do on your own, and economically there’s an issue too.” (P001)	Access
“I may have an appointment at 2 and the next day at 8...all the appointments are at a different time and you can’t tell the bus to pick you up. The car is almost my lifeline to the world.” (P116)	Access
“It’s not working here. That’s for real. Five o’clock they [the public buses] stop and you don’t see another bus.” (P119)	Access
“Medicaid transportation - many individuals cannot access it.” (Community Provider)	Access
“Transportation is, and has always been an issue. Many individuals do not transportation at all and require assistance. Aside from public transportation, many individuals try to obtain transportation from transportation assistance, however many of the companies require two-days advanced notice for pick up. Often there are delays due to insurance company, which results in the individual not being able to secure a ride and appointments are missed.” (Community Provider)	Access
“[paraphrased] One of the biggest challenges in accessing health care is transportation. For many PLWHA, they do not have a vehicle to access their appointments, so they rely on public transportation. In the Southcoast, transportation is severely lacking.” (Community Provider)	Access

### Discussion

According to the National Conference of State Legislators, “approximately 3.6 million Americans miss or delay medical care because they lack appropriate transportation to their appointments” [20]. Findings in the literature support this phenomenon, highlighting a more significant transportation burden in economically challenged and ethnically diverse populations [21]. For example, nearly one quarter of a sample of immigrant individuals living in New York reported that problems with transportation resulted in a missed or rescheduled clinic

appointment [22]. In a sample of Latino mothers, thirty-nine percent of participants acknowledged that lack of transportation was a barrier in keeping their child's immunizations up to date [23]. Transportation barriers are also found in the HIV population. In one study, women living with HIV in a rural area of California identified that transportation was a barrier to accessing necessary health care (31%) and just over one third (37.5%) of the sample reported that they missed a medical appointment because of transportation issues. Specifically, having to travel 31-90 minutes was a significant predictor of reporting transportation challenges [24].

In this present study, the authors identified few unmet needs in the sample. This finding must be interpreted with caution, as the recruitment of participants occurred in the community agencies where participants received their services. Additionally, methodological challenges around recruiting racial, ethnic, and gender minorities may prevent a comprehensive understanding of unmet needs in this ethnically diverse region of Massachusetts. Future studies should target those individuals who are not connected to a consistent source of care and consideration of length and distance of travel should be included.

However, these limitations do not negate the significance of the transportation challenges reported by the study's sample. In this well-educated and minimally diverse, transportation was overwhelmingly noted as a barrier to accessing HIV-related treatment. If members of this sample, which had little representation from identified high risk groups (men who have sex with men, black men and women, Latino men and women, IDUs, youth aged 13-24, transgender women report transportation barriers in managing HIV-related treatment, the burden of transportation for those in a high risk category/ies or those living in rural areas will be amplified [25]. This is an important point for researchers to consider because often, transportation barriers are considered to be problematic for only individuals who fall into low socio-economic and minority categories.

Conquering transportation barriers is multifactorial. For some, insufficient monthly income wages is a barrier to purchasing, maintaining and/or fueling an operable automobile. Meanwhile, others struggle with access to safe public transit that meet the time needs of the individual's appointments. With estimates suggesting that the, "poorest fifth of American families spend 42 percent of their incomes on transportation" it is socially just that civil society create, revise, and/or advocate for policy that ensures and provides safe, affordable, and timely transportation to and from treatment related appointments [26].

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