

Master's Thesis

***Predictors of Barriers to Medical Care Amongst People Living with HIV in New York City:  
Changes from 2002 to 2017***

Author: Gagarin Zhao

Certificate: Applied Biostatistics

Thesis Type: Research Report

Thesis Sponsor: Angela Aidala, PhD

Approved in New York on May 4, 2020

*Department of Sociomedical Sciences*

*Mailman School of Public Health, Columbia University*

*In partial fulfillment of MPH degree requirements, for graduation May 2020*

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## Abstract

**Background.** Studies have shown that barriers to medical care remain a notable issue in the HIV epidemic. However, few researchers have examined how individual characteristics such as race, gender, poverty, mental health, physical health, and age affect different types of barriers to long-term medical care.

**Aims.** This study addressed these limitations by analyzing data from a prospective cohort of HIV-positive individuals in New York City.

**Method.** The sample consisted of HIV-positive individuals in New York City (N = 1329). Self-reported experience of barriers to medical care were obtained. Three non-overlapping cohorts recruited approximately four years apart between 2002 and 2017 were used: 2002-04, 2008-11, and 2015-17. Data was examined using a repeated cross-section design with multivariable logistic regression.

**Results.** There was fluctuation overtime in participant report of different types of barriers with indication of improvements over time. Gender and mental health component score (MCS) were found to be the most strongly associated with barriers to medical care. Between 2002-04 and 2008-11, low mental health functioning (MCS) became less of a barrier to care; one point lower on the MCS scale is associated with lower odds of reporting barriers (AOR: 0.969 decreased to 0.915). Males had comparatively lower odds of reporting barriers between 2002-04, but on average had more than twice the odds of experiencing barriers compared with women in 2008-2011 (AOR: 0.665 to 2.167).

**Conclusion.** The final model showed inconclusive but encouraging signs that there have been reductions in barriers to HIV medical care over the past 15 years.

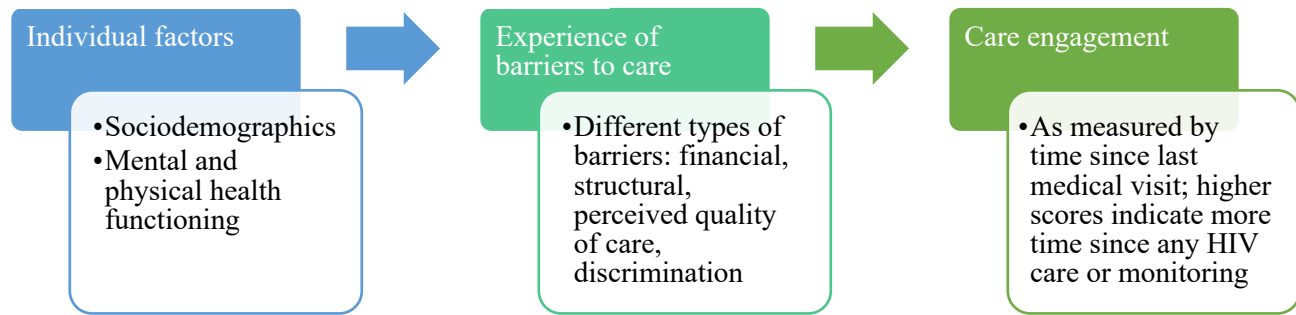
## **Background and Significance**

**Barriers to care.** The introduction of highly active anti-retroviral therapy in 1996 has prolonged the lives of many people who were diagnosed with HIV in the past several decades, effectively transforming HIV from a death sentence to a chronic illness (Deeks et al., 2013). Nevertheless, due to various barriers to care, many HIV-positive individuals find it difficult to access consistently necessary HIV care. For example, based on an interview conducted by the ACE (Assess. Connect. Engage.) Team, 30% of 905 adult people living with HIV (PLWH) in New York City reported that they had issues with being in HIV care, most readily due to “competing responsibilities” (HIV Epidemiology and Field Services Program, 2019).

Direct effects of barriers to care include low engagement and retention in care, which lead to suboptimal HIV health and higher HIV transmission (Dombrowski et al., 2015; Yehia et al., 2015). Several studies have reported qualitative data on barriers to care along the HIV continuum from diagnosis, entry into and retention in care, but quantitative data on prevalence and predictors of barriers to care in HIV is sparse (Christopoulos et al., 2013; Kempf et al., 2010; Quinlivan et al., 2013). Moreover, potential methods of barriers to medical care classifications have been proposed, but categories have not been readily adapted for in studies specifically involving PLWH (Carrillo et al., 2011). The current study aimed to analyze quantitative differences in prevalence and predictors of different types of barriers to care following a novel classification of PLWH-specific barriers to medical care.

**Trends in HIV care.** Since the introduction of HAART, morbidity in PLWH has shifted dramatically from HIV-related infections and neurological complications to chronic comorbid illnesses such as hypertension, diabetes, and chronic kidney disease (Phair & Palella, 2011). Studies tracking long-term trends in HIV barriers to care and engagement in care have been limited. Given the availability of longitudinal data during the current study, it becomes important to analyze possible changes in PLWH perceptions due to the evolving research and treatments for HIV, the changing of the surrounding culture, and introduction of new health interventions (Stangl et al., 2013). As examples, HIV-related stigma reduction interventions and inclusive LGBT-targeted health clinics have flourished in the past several decades, bringing many changes to the landscape of HIV care especially in urban areas, slowly changing the meaning of what it means to be HIV-positive (Fisher et al., 2017). More studies than ever have been published in recent years that not only address HIV clinical outcomes, but also HIV-related social issues such as discrimination and mental illness (Martos et al., 2017). The unique availability of continuous and consistent data on barriers to medical care since 2002 as provided by my data source gave me the opportunity to examine the extent to which many changes in and around HIV have affected perception of barriers to care, associated personal factors, and engagement in care.

Figure 1: Conceptual model for analysis



**Predictors of perceived barriers.** Care engagement and ART adherence have increased dramatically in recent decades. A 2013 study indicated that individual, relationship, community, health care system, and policy factors can all contribute to engagement in care (M. J. Mugavero et al., 2013). Whereas most previous studies examine the direct association between individual patient characteristics (such as age, race, gender, and substance use) and differential engagement in care, the current study investigates barriers to care perceived by patients as predicted by individual factors. Subsequently, different types of barriers to medical care will be explored as predictors of care engagement (Figure 1).

Evidence has suggested that many sociodemographic and other individual factors amongst PLWH are associated with various care outcomes such as ART uptake, care engagement, and viral suppression. For example, African-American PLWH still experience lower care engagement and low adherence to ART than their White counterparts, leading to adverse clinical outcomes (Dasgupta et al., 2016; Freeman et al., 2017). Black men and women with HIV have considerably higher mortality rates (Cargill, 2013). Men and women have also indicated that they experience different types of barriers to care (Kenagy et al., 2003). Nevertheless, few studies have quantified these disparities, especially over time.

Another potential predictive factor, poverty, has been shown to have influences on uptake of medical services in PLWH, but this has been understudied in the specific context of barriers to

medical care (Muthulingam et al., 2013). Physical location based on self-reported borough of residence at the time of interview was also considered as a potential predictor of perceived barriers to medical care, because many participants seek care outside of their borough of residence (Yomogida, Messeri, et al., 2019). It can be reasonably deduced that the abovementioned factors can also influence reporting of barriers to medical care amongst HIV-positive populations, a relationship that I explored.

Further, barriers to care have been shown to have a negative effect on health-related quality of life (Yomogida, Zhao, et al., 2019). I aim to explore the inverse effect that negative health can have on patient experience of barriers to medical care. Poor physical health may affect an individual's ability to take public transportation to seek medical care. Poor mental health may be associated with worsened trust in healthcare providers to deliver adequate care and in the competency of the healthcare system, especially when mental illness is combined with a physical illness such as HIV (Cunningham et al., 2007; Loeb et al., 2012). The current study explored the link between physical and mental health functioning and their effects on the outcome of barriers to medical care in conjunction with other individual factors.

Additionally, persons newly diagnosed with HIV are at a higher risk of poor linkage to care (Bhatia et al., 2011). It can therefore be hypothesized that the longer one has been diagnosed with HIV, the more adequately they are linked to care to and retained in care, thereby experiencing fewer barriers to care. Consequently, time since HIV diagnosis was analyzed as a possible predictor of reported barriers to care. The current quantitative explorations of the association between individual factors and barriers to care are helpful for development of targeted interventions to reduce barriers to care that are directly predicative of HIV care engagement, ART adherence, and viral suppression for PLWH in urban areas.

**HIV Care engagement as a function of perceived barriers.** As previously noted, perceived barriers to care are closely associated with HIV care engagement. Successful retention in care has been attributed to reduced barriers to care, early linkage to care, and a supportive and flexible treatment environment (Mugavero et al., 2013). Continued engagement with HIV primary care maximizes ART adherence, improves health, and reduces morbidity and mortality in PLWH (Giordano et al., 2007). A 2013 study estimated that of the 1,148,200 persons living with HIV in 2009 in the United States, 81.9% had been diagnosed, 65.8% were linked to care, 36.7% were retained in care, 32.7% were prescribed antiretroviral therapy, and 25.3% had a suppressed viral load ( $\leq 200$  copies/mL) (Hall et al., 2013). PLWH in NYC are even healthier on average, with their health metrics improving every year. Surveillance data showed that of approximately 90,800 people living with HIV in NYC in 2018, 93% were diagnosed, 87% received care, 83% received ART, and 77% were virally suppressed, an improvement from prior years (HIV Epidemiology and Field Services Program, 2019). Revealing potential factors that improve care engagement and retention contributes to positive health outcomes for PLWH. The current study presents an exploratory analysis of trends in reported barriers to care associated with medical care engagement.

### **Data Source**

The Community Health Advisory & Information Network (C.H.A.I.N.) Project was the data source for this research report. The C.H.A.I.N. study is a prospective cohort study that has been conducted since 1994 with samples of PLWH in New York City and since 2001, the Tri-County region. C.H.A.I.N. collects data through in-person interviews that capture the diverse views and opinions of PLWH. Participants were recruited using probability sampling methods, first randomly selecting a stratified sample of medical and social service agencies serving



PLWH, then working with agencies to recruit a representative cross section of their clients. Three cohorts were recruited, and participants followed up over time for 5-8 years with interviews completed every 12-18 months. Interview topics include: (1) quality of life with respect to health, physical, psychological and social wellbeing, (2) need for health and social services, (3) health and social services access, utilization and satisfaction; (4) sociodemographic characteristics; (5) housing and other aspects of living situation; (6) sex and drug use behaviors; and (7) informal caregiving from friends, family and volunteers. C.H.A.I.N. interviews continue to this day, but only data collected between 2002 and 2017 were used in the present analysis.

## **Methods**

**Barriers to care classification.** For purposes of the current analysis, data regarding barriers to care were based on a standardized measure of 15 questions, mixed in nature. My first aim addressed the issue of classifying the question items into distinct types of barriers to care. I first conducted latent class analysis (LCA) as an exploration of how the 15 questionnaire items clustered together based on data from 2002-04. However, there was not well-defined statistical result regarding the number of categories within the question item, nor which categories there would be. Thus, I elected to perform a theoretical approach instead.

Classification for barriers to medical care was based on a previous model of categorization for barriers to care: the Health Care Access Barriers Model (HCAB), which categorized health care access barriers into three types: financial, structural, and cognitive (Carrillo et al., 2011). Financial barriers include cost of care and health insurance issues. Structural barriers involve institutional and organizational issues, such as problems with transportation, childcare, or other logistical barriers aside from cost of care and insurance. Cognitive barriers involve knowledge and communication barriers. This category was renamed

“quality of care” barriers because the term “cognitive” typically refers to a patient’s cognitive impairments; “quality of care” better suits questionnaire items and the purposes of the current analysis. Barriers regarding trust and understanding were included in this category. The three categories were insufficient in the classification process of C.H.A.I.N. questionnaire items regarding barriers to care, as there are several questions that touch upon discrimination based on stigma that went beyond knowledge and communication barriers. Consequently, I added a fourth category dedicated to items that are related to feelings of discrimination.

**Changes in prevalence of barriers to care.** When asked if they experienced different barriers to care, participants were able to answer with the type of service where they experienced that barrier: “Medical”, “Social”, “Both”, or “Neither”. Almost all questions were asked in every interview period from 2002 to 2017 with the exception of Q13 regarding discrimination due to drug use (See Box 1). In the current context, participants were reported as having experienced barriers to medical care if they answer “Medical” or “Both”. From 2015 onwards, participants were asked during interviews whether they required mental health, substance use, food/nutrition, or housing services when they encountered barriers. However, I will not be using this information in my analysis as this it was not available in all study periods. Statistical analyses were performed using RStudio.

All study periods between 2002-2017 were used for the prevalence analysis. For examination of prevalence of perceived barriers, the same participants can be included repetitively in multiple study periods, with the cohort refreshed by recruitment of new participants in 2002, 2008 and 2015. Other study periods contain follow-up data from participants recruited during previous periods. Participants are able to answer each item regarding barriers to care as either “yes” or “no” (Box 1). The proportion of participants who

answer “yes” to each item was calculated for each study period, and the values were averaged to produce a barrier category proportion for each of the four types of barriers determined by the previous step. An overall proportion of participants who indicate that they experience barriers to medical care was also produced by calculating the mean proportion of individuals who report that they experienced any of the barriers to care in the past six months. Issues with childcare was not included in this step of the analysis as the mean proportion would be underestimated due to the small number of people who have children in our sample.

**Predictors of barriers to care.** When examining the predictors of barriers, the same four barrier categories were used to categorize individual items in the questionnaire. All 15 questions were used in analyses when they were available regardless of whether they were present across all study periods. As such, a participant was considered as someone who experienced a certain type of barrier if they answered “yes” to any of the items under each category. For instance, an individual would be categorized as someone who experienced barriers to medical care in the quality of care barriers category if they answer “yes” to one or more of the Questions 1, 3, 4, 8, 9, and 11 (Box 1). An overall barriers variable was created to indicate if participants answered “yes” to one or more questionnaire items.

A repeated cross-section design was used for analysis. To circumvent within-subject differences, only the baseline (i.e. first interview) data for each participant between 2002 and 2017 were taken. The resulting dataset contained unique participants who completed baseline or first interviews in 2002-04, 2008-11, or 2015-17 (N = 1329). the time interval between and within interview periods for the groups examined were approximately evenly spaced from one another chronologically (Table 1). Consequently, two to three years of data collection are

separated by approximately four years between each data collection period. The individual groups were treated as three cross-sectional datasets for comparison.

*Table 1: Dates of each baseline interview data collection periods and sample size*

<b>Date Collection Period</b>	<b>N</b>
<b>July 2002 – May 2004</b>	693
<b>June 2008 – Sept 2011</b>	319
<b>May 2015 – Dec 2017</b>	317

The full model predictors for barriers chosen were gender, race, borough, whether a male participant has reported any same sex behavior (MSM), whether the participant live below the poverty line, mental functioning summary score, physical functioning summary score, and years since HIV diagnosis. An interaction term between gender and MSM was included because only men can answer the MSM item. Mental health and physical health were operationalized using the SF-36 health status questionnaire (Ware et al., 2001). It is one of the most frequently used multi-item measurements for health-related quality of life (HRQOL). The SF-36 is comprised of multi-item scales assessing physical function, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems, and emotional well-being. Both variables for the mental component summary (MCS) and the physical component summary (PCS) range from 0-100. Higher values indicate better health.

Stepwise model selection was conducted to select individual-level covariates and control variables using the Akaike information criterion (AIC) for the baseline interviews of the 1329 baseline interviews across all participants from 2002 to 2017. Gender, race, borough, whether a

male participant has reported any same sex behavior (MSM), whether the participant live below the poverty line, mental functioning summary score, physical functioning summary score, and years since HIV diagnosis were initial variable included in the full model, later narrowed down to a second model aimed to predict reporting of perceived barriers. Eighty percent of the data was used for training and 20% was used for testing.

A logistic regression analysis was conducted in modelling the adjusted odds ratios (AORs) of experiencing barriers to care for each type of barrier and overall, as predicted by race, household poverty, and physical health scale scores. An interaction term between poverty and race was added due to previous literature indicating a link between the two variables under several health contexts such as cardiovascular disease and total knee replacements (Goodman et al., 2016; Ross et al., 2018).

**Care engagement.** Care engagement was measured using the continuous variable months since last primary care visit as assessed during baseline interview. For my analytical purposes at this time, larger numbers suggested worse care engagement, under the assumption that the participant did not receive any care recently including no visit for HIV monitoring. However, many C.H.A.I.N. participants have chronic comorbidities that indicate they should be visiting their doctors more frequently (Angela Aidala & Maiko Yomogida, 2019; *Monitoring HIV Care in the United States*, 2012). Months since last primary care visit are expected to be less than the often-used indicator of a single visit within six months. The measure is more sensitive in detecting PLWH who have comorbid conditions that require visits and monitoring more often than every six months. Consequently, months since last primary care visit will not be an accurate or complete measure of care engagement. Nevertheless, analyzing months since last primary care

visit as a part of an exploratory analysis may give rise to preliminary findings that rationalize future studies linking barriers to care to care engagement.

Linear regression was used to estimate the effects of perceived barriers on months since last primary care visit, adjusting for age, gender, ethnicity, poverty, mental health functioning, physical health functioning, and an interaction term between poverty and ethnicity.

Determination of the final model was based on model selection from the previous analysis.

Univariate analyses were performed for the four types of barriers individually, as well as a multivariable linear regression of months since last medical appointment on financial, structural, quality of care, and discriminatory barriers. The four types of barriers to care were individually analyzed for periods 2002-04, 2008-11, and 2015-17 (Table 1).

## **Results**

**Categorization of barriers of medical care.** First, quality of care barriers involve communication, and patient-provider care experiences. Six items: Q1, Q3, Q4, Q8, Q9, and Q11 were included in this barriers category. Q1 was categorized as a quality of care barrier because it related to language barriers. Similarly, items Q3, Q4, Q8, Q9, and Q11 related to fears and qualms while receiving care so they were also categorized as quality of care barriers. These classification choices were supported by recent patient-centered research to address health disparities in clinical settings (Lewis et al., 2012). Secondly, Q2 was the only item belonging to the financial category. Thirdly, structural barriers were defined as logistical issues that came about in the process of attempting to receive medical care: Q5, Q6, Q10, Q14, and 15. Q6, Q10, Q14, and Q15 were related to lack of transportation, childcare, and issues with hours and the process of seeking an

*Box 1: Barrier items and their designated type of barrier*

**C.H.A.I.N. Project: Final Questions Used for Analysis of Barriers to Care Experiences**

*At any time in the last 6 months, did you ever delay or not get the assistance you thought you needed...*

***Quality of care***

Q1. Because the staff at the office or clinic do not speak your language?

Q3. Because you didn't trust the providers to be confidential about your HIV status?

Q4. Because you felt the staff at the office or clinic was not competent to deal with your problem?

Q8. Because you weren't sure that the staff at the office or clinic would understand your problems?

Q9. Because you felt that the staff is not good at listening to your problems or needs?

Q11. Because you were nervous or afraid of what the doctor/service provider might say?

***Financial***

Q2. Because it cost too much or it wasn't covered by insurance?

***Structural***

Q5. Because you didn't know or weren't sure where to go?

Q6. Because it was difficult to get transportation there?

Q10. Because you needed someone to take care of your children? \*

Q14. Because it took too long to get an appointment to see a medical provider?

Q15. Because the office or clinic was not open at a convenient time? \*\*\*

***Discrimination***

Q7. Because the staff at the office or clinic are often not polite, are disrespectful, or are insensitive to your needs?

Q12. Because the staff or provider treated you differently because of your sexual orientation?

Q13. Because the staff or providers thought you were using drugs? \*\*

\* Only participants with children were able to respond to this question.

\*\* This question was no longer asked after 2007.

\*\*\* This question was added to the survey in 2013.

appointment. Q5 was categorized as a structural barrier because it was perceived to be a signal of a lack of available resources rather than participants' lack of knowledge about resources. Lastly, the discrimination category was added to the HCAB categories above. Q7, Q12, and Q13, which indicated experiences of overt discrimination from drug use, sexual orientation were included in this category. Q7 indicated experiences with staff at medical offices who were rude or disrespectful for unspecified reasons.

**Changes in prevalence of barriers at different interview periods.** For this trend analysis, all nine interview periods were used, and participants can belong to multiple periods, with new participants interviewed in 2002-04, 2008-11, and 2015-17. Overall, the proportion of people who perceived barriers to medical care was calculated by taking the mean proportion of the four categories. In 2005-06 there was high prevalence of perceived barriers across all categories and overall. Although prevalence fluctuated from year to year, the proportion of individuals who reported barriers to care were lower in recent years (2015-17) than in earlier years (2002-04) in every barrier category. In the first four interview periods (2002-08), more individuals experienced structural barriers than financial barriers. This relationship is reversed in most later interview periods. Interviews completed during 2013-15 had the lowest reported proportion of perceived barriers to medical care, with average at 1.0% and only 0.6% of individuals reported that they experienced discriminatory barriers (Table 2).

The questionnaire items used in every study period were identical to ensure consistency of measures. The mean prevalence of structural barriers does not include barrier to childcare (Q10) in this analysis, as the number of participants who have children is low and Q15 was not included, as the question was only answered by participants in interviews after 2013.



*Table 2: Average proportion of participants who reported each type of barriers to medical services, by interview period, 2002-2017*

<b>Interview period</b>	<b>Financial</b>	<b>Structural</b>	<b>Quality of care</b>	<b>Discrimination</b>	<b>Any</b>	<b>Total N</b>
<b>2002-04</b>	4.2%	5.3%	3.6%	3.9%	4.3%	624
<b>2004-07</b>	2.9%	3.9%	3.0%	3.5%	3.3%	546
<b>2005-07</b>	4.4%	7.6%	5.4%	4.9%	5.6%	475
<b>2007-08</b>	3.8%	4.0%	3.3%	4.2%	3.8%	394
<b>2008-09</b>	3.5%	3.0%	3.2%	3.2%	3.2%	570
<b>2008-11</b>	1.9%	2.0%	1.3%	1.6%	1.7%	626
<b>2011-13</b>	1.7%	1.5%	1.5%	1.4%	1.5%	521
<b>2013-15</b>	1.5%	1.2%	0.8%	0.6%	1.0%	529
<b>2015-17</b>	3.2%	2.6%	1.6%	2.1%	2.4%	531

**Odds of experiencing different types of barriers.** Following model selection described above, age, race, poverty, physical component score, and mental component score were found to be final predictors for the model. Additionally, my research aims concern the effects of gender, so it was kept in the final model. I adjusted for the possible interaction between race and poverty in the model, but these interaction parameters were not significant predictors in any barrier category or overall, and thus will not be presented in the results section. Transgender status was included as a predictor in the final model, but results were not significant, so the results will not be presented.

A majority of participants in the sample for this analysis were male, Black or Latino, and below the poverty line (Table 3). There were very few transgender individuals and very few individuals who were not White, Black, or Latino in the three samples, so they were not included

in the results section. The mean physical health summary score across the sample is overall higher in 2015-17 than in 2002-04 and 2008-11. The mean mental health summary score is lower in 2015-17 than in 2002-04 and 2008-11 (Table 4).

*Table 3: Sample demographics at baseline interviews*

	<b>2002-04</b>	<b>2008-11</b>	<b>2015-17</b>
	<b>N = 693</b>	<b>N = 319</b>	<b>N = 317</b>
<b>Gender</b>			
Female	270	121	74
Male	408	196	243
Transgender	15	2	0
<b>Race</b>			
White	64	24	15
Black	382	172	158
Latino	237	113	120
Other	10	10	24
<b>Household Poverty</b>			
Above poverty line	117	94	82
Below	534	218	235
NA	42	7	0

*Table 4: Univariate statistics for physical health scores (PCS) and mental health scores (MCS)*

*at baseline interviews*

	<b>2002-04</b>	<b>2008-11</b>	<b>2015-17</b>
	<b>N = 693</b>	<b>N = 319</b>	<b>N = 317</b>
<b>PCS</b>			
Mean	41.89	44.34	52.30
Std Deviation	11.27	12.02	8.88
Median	42.53	45.91	54.03
Minimum	8.87	15.43	21.21
1 <sup>st</sup> Quartile	33.47	36.45	48.41
3 <sup>rd</sup> Quartile	50.67	54.25	58.74
Maximum	69.93	68.94	70.35
<b>MCS</b>			
Mean	42.75	42.41	37.99
Std Deviation	12.39	8.94	7.91
Median	42.85	43.06	38.23
Minimum	9.59	15.81	15.12
1 <sup>st</sup> Quartile	32.84	36.08	32.64
3 <sup>rd</sup> Quartile	52.98	48.40	43.75
Maximum	70.57	70.59	61.80

*Table 5: Adjusted Odds Ratios (AOR) of experiencing barriers to medical care by sociodemographics, physical health summary score, mental health summary score*

	Any Barriers			Financial Barriers			Structural Barriers			Quality of care Barriers			Discriminatory Barriers		
	2002-04	2008-11	2015-17	2002-04	2008-11	2015-17	2002-04	2008-11	2015-17	2002-04	2008-11	2015-17	2002-04	2008-11	2015-17
<b>Age (in years)</b>	0.969**	0.983	1.003	0.994	1.035	1.014	0.982	0.924**	0.997	0.968*	0.989	0.975	0.954**	0.989	1.007
<b>Household poverty</b>	0.521	0.301	0.876	0.398	0.122	†	0.363	†	0.882	0.866	†	4.454	0.612	0.709	†
<b>Male vs. Female</b>	0.665*	2.167**	1.545	1.085	6.813*	0.832	0.674	6.485**	1.638	0.614*	1.062	1.395	0.878	1.495	1.853
<b>Black vs. White</b>	0.591	0.837	0.383	0.514	0.224	†	0.251**	†	0.248	0.718	†	0.960	0.487	0.864	†
<b>Latino vs. White</b>	0.360	0.370	0.145*	0.134*	0.080*	†	0.251*	†	0.147*	0.646	†	†	0.411	0.979	†
<b>PCS</b>	0.987	0.988	0.937**	0.989	1.026	0.998	0.982	0.922**	0.937**	0.98	0.996	0.918**	0.979	0.982	0.958
<b>MCS</b>	0.969**	0.915**	0.998	0.972	0.876**	1.030	0.960**	0.897**	0.99	0.967**	0.926**	0.996	0.980	0.915**	0.955

\*  $p < 0.1$ ; \*\*  $p < 0.05$ ; † Values were over or underestimated and had  $p > 0.99$ . Model controls for an interaction term between poverty and ethnicity. MSM, borough, years since diagnosis, and the interaction term between gender and MSM were *not* included in the final model.

AORs were removed from the table if they were statistically insignificant and inflated (Table 5). Poverty was not found to be a significant predictor in this model. Respondents' race/ethnicity was not found to be a consistently significant predictor of all types of barriers in 2008-11 or 2015-17. Gender was a significant predictor of reporting any barriers to care in the first interview period, 2002-04 (AOR: 0.665) indicating the odds of men reporting experience of any barriers to medical care was lower than women. In the next period, 2008-11, the odds ratio for men vs. women grew so the odds of men reporting any barriers to care was more than double the odds of women reporting experience of any barriers to medical care (AOR: 2.167). This pattern replicated itself across all types of barriers, with men having much higher odds of experiencing structural and financial barriers in 2008-11.

In the first interview period (2002-04), analysis showed that better mental health was associated with statistically significant lower odds of reporting any barriers to care (AOR: 0.969). In 2008-11, the odds ratio was lower, indicating a decrease in experience of any barriers to care associated with better mental health functioning (AOR: 0.915). This improvement was observed to be statistically significant in both structural and quality of care barriers. In 2015-17 mental health functioning was no longer a significant predictor of any types of barriers.

#### **Exploratory analyses of care retention as related to barriers to medical care.**

Descriptive univariate statistics showed that most participants saw their doctors very recently. The mean and maximum months since last medical visit was lower in 2008-11 and 2015-17 than 2002-04 (Table 6). Following regression analysis, none of the barriers were statistically significant predictors of recency of medical visit (Table 7a and 7b). In the univariable analyses, barriers to medical care included in the models are not predicative of months since last visit for all three analysis periods. At 90% significance level in the multivariable regression in 2002-04,

those who face discriminatory barriers experience on average a 4.72-month delay in seeing their doctors compared to those in the analyzed sample who did not report discriminatory barriers. Interestingly, during the same study period, for participants who faced structural barriers, it has been on average 3.46 fewer months since they have seen their doctors (Table 7b).

*Table 6: Univariate statistics for months since last medical visit, baseline interviews only*

	<b>2002-04</b>	<b>2008-11</b>	<b>2015-17</b>
	<b>N = 693</b>	<b>N = 319</b>	<b>N = 317</b>
Mean	1.82	1.22	1.22
Std Deviation	12.55	3.05	1.45
Median	0.00	1.00	1.00
Minimum	0.00	0.00	0.00
1 <sup>st</sup> Quartile	0.00	0.00	0.00
3 <sup>rd</sup> Quartile	1.00	2.00	2.00
Maximum	244.00	48.00	6.00

Table 7a: Results of univariable exploratory linear regression of months since last medical appointment on barriers to medical care

	2002-04			2008-11			2015-17		
	Beta	(95% CI)	P-value	Beta	(95% CI)	P-value	Beta	(95% CI)	P-value
<i>Univariable analyses</i>									
<b>Intercept (Financial)</b>	2.54	(-7.58, 12.67)	0.622	2.48	(-1.62, 6.58)	0.235	-0.909	(-2.92, 1.10)	0.374
<b>Financial barriers</b>	-0.853	(-6.30, 4.59)	0.758	-0.632	(-2.54, 1.28)	0.515	0.306	(-0.47, 1.08)	0.440
<b>Intercept (Structural)</b>	3.23	(-7.10, 13.56)	0.539	2.02	(-2.15, 6.19)	0.341	-1.01	(-3.06, 1.03)	0.330
<b>Structural barriers</b>	-1.28	(-0.48, 2.22)	0.473	0.334	(-1.01, 1.68)	0.625	0.146	(-0.42, 0.71)	0.610
<b>Intercept (Quality of care)</b>	0.905	(-9.31, 11.12)	0.862	2.11	(-1.98, 6.20)	0.311	-1.14	(-3.17, 0.89)	0.271
<b>Quality of care barriers</b>	2.67	(-0.85, 6.18)	0.137	0.330	(-0.91, 1.57)	0.599	0.440	(-0.21, 1.09)	0.184
<b>Intercept (Discriminatory)</b>	0.542	(-9.64, 10.72)	0.917	2.11	(-1.97, 6.20)	0.309	-0.907	(-2.92, 1.11)	0.376
<b>Discriminatory barriers</b>	3.97	(-0.03, 7.98)	0.0520	0.429	(-1.08, 1.94)	0.577	-0.0694	(-0.95, 0.81)	0.876

Model controls for age, gender, ethnicity, poverty, mental health functioning, physical health functioning, and an interaction term between ethnicity and poverty. MSM, borough, years since diagnosis, and the interaction term between gender and MSM were not included in the final model.

Table 7b: Results of exploratory multivariable linear regression of months since last medical appointment on barriers to medical care

	2002-04			2008-11			2015-17		
	Beta	(95% CI)	P-value	Beta	(95% CI)	P-value	Beta	(95% CI)	P-value
<i>Multivariable analyses</i>									
<b>Intercept</b>	2.03	(-8.33, 12.39)	0.701	2.17	(-2.06, 6.41)	0.314	-1.15	(-3.22, 0.91)	0.273
<b>Financial barriers</b>	-1.42	(-7.06, 4.23)	0.622	-0.632	(-2.56, 1.29)	0.519	0.279	(-0.52, 1.08)	0.492
<b>Structural barriers</b>	-3.46	(-7.44, 0.51)	0.0873	0.249	(-1.30, 1.79)	0.752	-0.0199	(-0.63, 0.59)	0.949
<b>Quality of care barriers</b>	1.59	(-3.12, 6.31)	0.508	0.0200	(-1.83, 1.87)	0.983	0.610	(-0.18, 1.40)	0.130
<b>Discriminatory barriers</b>	4.72	(-0.72, 10.15)	0.0887	0.318	(-1.75, 2.39)	0.763	-0.513	(-1.53, 0.50)	0.321
<b>Age (in years)</b>	0.0165	(-0.11, 0.15)	0.804	-0.0174	(-0.06, 0.02)	0.375	0.00576	(-0.02, 0.03)	0.666
<b>Household poverty</b>	-0.00968	(-7.08, 7.06)	0.998	-1.10	(-3.73, 1.53)	0.411	1.19	(-0.287, 2.67)	0.114
<b>Male vs. Female</b>	-0.269	(-2.47, 1.93)	0.810	-0.479	(-1.25, 0.29)	0.220	0.0689	(-0.33, 0.47)	0.736
<b>Black vs. White</b>	0.315	(-6.25, 6.88)	0.925	-0.266	(-2.31, 1.77)	0.798	0.142	(-0.99, 1.27)	0.805
<b>Latino vs. White</b>	0.254	(-7.14, 7.66)	0.946	-1.10	(-2.79, 1.58)	0.428	0.409	(-0.75, 1.57)	0.489
<b>PCS</b>	0.0446	(-0.05, 0.14)	0.362	0.00846	(-0.03, 0.04)	0.636	0.0216	(0.00, 0.04)	0.0418
<b>MCS</b>	-0.0877	(-0.18, 0.00)	0.0533	0.00677	(-0.04, 0.05)	0.778	0.0147	(-0.01, 0.04)	0.183

Model controls for an interaction term between ethnicity and poverty.



## Discussion

**Main findings.** Analysis of C.H.A.I.N. data on possible predictors of barriers to medical care explored several understudied factors among HIV-positive individuals in urban areas. First, barrier questions were sorted into different classifications: financial, structural, quality of care, and discriminatory. These categories were based classification of barriers in prior studies with the addition of discriminatory barriers. Second, I analyzed overall trends in barriers to medical care over the past 15 years, which showed decreased prevalence in barriers in all categories. Third, there was a decrease in odds of experiencing barriers to care comparing 2002-04 to 2008-11 as predicted by the mental health component score (MCS). This improvement can be at least partly attributed to the efforts from community health organizations and the New York City Department of Health, who in the past few decades made bold efforts to end the HIV epidemic through promoting innovative and best treatments, implementing coordination of care, and improving sexual health equity (*Ending the Epidemic (EtE) Is Our Strategy to End HIV/AIDS in New York City*, 2017).

More informative results were revealed in modeling odds of experiencing different types of barriers as predicted by age, physical health component summary score (PCS), mental health component summary score (MCS), poverty, gender, and race. This analysis was preliminary but offered guidance for future analyses. In most interview periods and for most barrier categories, older individuals were more likely to report that they experienced barriers to care than people who are younger. Female participants were significantly more likely than male participants to experience barriers in the first interview period. In later interview periods, the adjusted odds ratios reversed, with male participants significantly more likely to report they experienced

barriers to care. In fact, in 2008-11, the odds of men experiencing barriers to medical care were more than six times that of women in financial and structural barrier categories.

The last goal of the current analysis was to explore the linkage between barriers to care and care engagement, particularly whether different types of barriers are predicative of time since last medical visit. There were no statistically significant findings based on the dataset analyzed. However, the conceptual model tested during the analysis paves the way for potential analyses regarding the effects of barriers to care on care engagement, using different methods of operationalizing care engagement.

**Limitations.** Utilizing C.H.A.I.N. data had noteworthy and rare advantages. It provided a wide range of longitudinal information on PLWH, which gave me the breadth of variables to choose from and a large enough sample size to gain significant findings. However, given the numerous options for parameters to test and analyze, it was difficult to determine which ones specifically would be a part of the final models.

Because the barriers portion of the C.H.A.I.N. survey was not initially designed by the creators to be separated into different categories, the barrier groups were inevitably unequal in the number of items they contained. Differences in number of questions for each category possibly underestimated the extent to which some categories of barriers appeared in the data and introduces higher amounts of error to categories with comparatively fewer items. In the final two analyses participants were deemed to have experienced a particular type of barrier if they have faced any of the individual barrier items belonging to a barrier category. For instance, participants have fewer opportunities to report that they experienced a financial barrier (one item) as opposed to a structural barrier (five items). In future studies regarding different types of barriers to medical care, questionnaire items will ideally be designed with barrier classifications

in mind, aiming for equal number of question items for each barrier category. Another step to maximize accuracy would be to weigh the items based on how harmful the barriers are to receiving proper medical care.

Further, evidence-based classification for barriers to medical care is not a well-researched area. Methodologically, a theoretical taxonomy of barriers was chosen over latent class analysis (LCA) based on the 15 question items after an early exploratory LCA analysis failed to capture any distinct barrier categories. LCA is a statistically robust approach to analyzing underlying classifications. Perhaps using a larger or different sample in the future could give rise to statistically significant LCA results on barrier categories.

Another possible limitation was the usage of time since last medical visit as the measure for care engagement. Months since last medical care visit was selected over quality of medical care when analyzing effect of barriers on care engagement. Because care engagement was only measured in this analysis through months since last medical visit, I potentially failed to capture other dimensions of care engagement. For example, recent research suggest synthesis of five measures to assess care retention: missed visits, appointment adherence, visit constancy, gaps in care, and the Human Resources and Services Administration HIV/AIDS Bureau (HRSA HAB) performance measure for retention in HIV care (Michael J. Mugavero et al., 2010). Evidently, different metrics will need to be developed for analyzing good engagement in care for PLWH with multiple comorbid chronic conditions for whom more frequent medical visits would be indicated.

There is weak evidence in the current analysis confirming a directional trend over time. In the future, expansion of the sample size through inclusion of multiple data points from the same subjects would be an important improvement. Generalized estimating equation (GEE)

accounts for within-subject correlation but was not pursued due to the exploratory nature of the current study. For a follow-up study, GEE could offer more robust estimations of the effects of predictors on experience of barriers to medical care with inclusion of more data over time.

Another issue related to sample size for the first interview period was around double the size of the latter analysis periods, which could have led to errors in estimation and explain why some parameters were not statistically significant in the last two analyses of the study.

**Implications.** These data offer an early quantitative view of the predicative value of individual factors such as race, gender, poverty, health functioning, and age, on barriers to medical care within urban PLWH communities. New York City has supported the expansion and developing programs to be supportive and inclusive of vulnerable HIV-positive populations over the past few decades since the beginning of the epidemic. The efforts of both the government and community-based organizations can be credited for these improvements. The current data support further investment into programs that specifically target the reduction of barriers to medical care and offer incentives to target specific types of barriers. Although the exploratory analysis of barriers to care as predictors of care engagement in the current study did not show significant findings, a follow-up analysis could explore different measures of care engagement.

Rarely do we have the opportunity to analyze long-term changes to the lives of PLWH. The current findings provide a first glimpse into quantifying the immense amount of changes that have taken place in the past decade and a half in relation to important factors that contribute to the wellbeing of PLWH.

## Literature Cited

- Angela Aidala, & Maiko Yomogida. (2019). *Housing Need, Housing Assistance, and Engagement with HIV Medical Care 2018-2* (C.H.A.I.N. Report). Columbia University Mailman School of Public Health.
- Bhatia, R., Hartman, C., Kallen, M. A., Graham, J., & Giordano, T. P. (2011). Persons Newly Diagnosed with HIV Infection are at High Risk for Depression and Poor Linkage to Care: Results from the Steps Study. *AIDS and Behavior*, 15(6), 1161–1170.  
<https://doi.org/10.1007/s10461-010-9778-9>
- Brown, L. B., Getahun, M., Ayieko, J., Kwarisiima, D., Owaraganise, A., Atukunda, M., Olilo, W., Clark, T., Bukusi, E. A., Cohen, C. R., Kamya, M. R., Petersen, M. L., Charlebois, E. D., Havlir, D. V., & Camlin, C. S. (2019). Factors predictive of successful retention in care among HIV-infected men in a universal test-and-treat setting in Uganda and Kenya: A mixed methods analysis. *PLOS ONE*, 14(1), e0210126.  
<https://doi.org/10.1371/journal.pone.0210126>
- Cargill, V. A. (2013). Linkage, engagement, and retention in HIV care among vulnerable populations: “I’m sick and tired of being sick and tired”. *Topics in Antiviral Medicine*, 21(4), 133–137.
- Carrillo, J. E., Carrillo, V. A., Perez, H. R., Salas-Lopez, D., Natale-Pereira, A., & Byron, A. T. (2011). Defining and Targeting Health Care Access Barriers. *Journal of Health Care for the Poor and Underserved*, 22(2), 562–575. <https://doi.org/10.1353/hpu.2011.0037>
- Christopoulos, K. A., Massey, A. D., Lopez, A. M., Geng, E. H., Johnson, M. O., Pilcher, C. D., Fielding, H., & Dawson-Rose, C. (2013). “Taking a Half Day at a Time:” Patient

- Perspectives and the HIV Engagement in Care Continuum. *AIDS Patient Care and STDs*, 27(4), 223–230. <https://doi.org/10.1089/apc.2012.0418>
- Cunningham, C. O., Sohler, N. L., Korin, L., Gao, W., & Anastos, K. (2007). HIV status, trust in health care providers, and distrust in the health care system among Bronx women. *AIDS Care*, 19(2), 226–234. <https://doi.org/10.1080/09540120600774263>
- Dasgupta, S., Oster, A. M., Li, J., DPE, & Hall, H. I. (2016). Disparities in Consistent Retention in HIV Care—11 States and the District of Columbia, 2011–2013. *MMWR. Morbidity and Mortality Weekly Report*, 65(4), 77–82. <https://doi.org/10.15585/mmwr.mm6504a2>
- Deeks, S. G., Lewin, S. R., & Havlir, D. V. (2013). The end of AIDS: HIV infection as a chronic disease. *The Lancet*, 382(9903), 1525–1533. [https://doi.org/10.1016/S0140-6736\(13\)61809-7](https://doi.org/10.1016/S0140-6736(13)61809-7)
- Dombrowski, J. C., Simoni, J. M., Katz, D. A., & Golden, M. R. (2015). Barriers to HIV Care and Treatment Among Participants in a Public Health HIV Care Relinkage Program. *AIDS Patient Care and STDs*, 29(5), 279–287. <https://doi.org/10.1089/apc.2014.0346>
- Ending the Epidemic (EtE) Is Our Strategy to End HIV/AIDS in New York City*. (2017). New York City Department of Health and Mental Hygiene. <https://www1.nyc.gov/assets/doh/downloads/pdf/ah/ete-strategy.pdf>
- Fisher, H. H., Essuon, A., Hoyte, T., Shapatava, E., Shelley, G., Rios, A., Beane, S., Bourgeois, S., Dunbar, E., & Sapiiano, T. (2017). The Changing Landscape of HIV Prevention in the United States: Health Department Experiences and Local Adaptations in Response to the National HIV/AIDS Strategy and High-Impact Prevention Approach. *Journal of Public Health Management and Practice*, 1. <https://doi.org/10.1097/PHH.0000000000000575>

- Freeman, R., Gwadz, M. V., Silverman, E., Kutnick, A., Leonard, N. R., Ritchie, A. S., Reed, J., & Martinez, B. Y. (2017). Critical race theory as a tool for understanding poor engagement along the HIV care continuum among African American/Black and Hispanic persons living with HIV in the United States: A qualitative exploration. *International Journal for Equity in Health*, 16(1), 54. <https://doi.org/10.1186/s12939-017-0549-3>
- Giordano, T. P., Gifford, A. L., White, A. C., Almazor, M. E. S., Rabeneck, L., Hartman, C., Backus, L. I., Mole, L. A., & Morgan, R. O. (2007). Retention in Care: A Challenge to Survival with HIV Infection. *Clinical Infectious Diseases*, 44(11), 1493–1499. <https://doi.org/10.1086/516778>
- Goodman, S. M., Mandl, L. A., Parks, M. L., Zhang, M., McHugh, K. R., Lee, Y.-Y., Nguyen, J. T., Russell, L. A., Bogardus, M. H., Figgie, M. P., & Bass, A. R. (2016). Disparities in TKA Outcomes: Census Tract Data Show Interactions Between Race and Poverty. *Clinical Orthopaedics and Related Research®*, 474(9), 1986–1995. <https://doi.org/10.1007/s11999-016-4919-8>
- Hall, H. I., Frazier, E. L., Rhodes, P., Holtgrave, D. R., Furlow-Parmley, C., Tang, T., Gray, K. M., Cohen, S. M., Mermin, J., & Skarbinski, J. (2013). Differences in Human Immunodeficiency Virus Care and Treatment Among Subpopulations in the United States. *JAMA Internal Medicine*, 173(14), 1337. <https://doi.org/10.1001/jamainternmed.2013.6841>
- HIV Epidemiology and Field Services Program. (2019). *HIV Surveillance Annual Report, 2018*. New York City Department of Health and Mental Hygiene.
- Kempf, M.-C., McLeod, J., Boehme, A. K., Walcott, M. W., Wright, L., Seal, P., Norton, W. E., Schumacher, J. E., Mugavero, M., & Moneyham, L. (2010). A Qualitative Study of the

- Barriers and Facilitators to Retention-in-Care Among HIV-Positive Women in the Rural Southeastern United States: Implications for Targeted Interventions. *AIDS Patient Care and STDs*, 24(8), 515–520. <https://doi.org/10.1089/apc.2010.0065>
- Kenagy, G. P., Linsk, N. L., Bruce, D., Warnecke, R., Gordon, A., Wagaw, F., & Densham, A. (2003). Service Utilization, Service Barriers, and Gender among HIV-Positive Consumers in Primary Care. *AIDS Patient Care and STDs*, 17(5), 235–244. <https://doi.org/10.1089/108729103321655881>
- Lewis, V. A., Larson, B. K., McClurg, A. B., Boswell, R. G., & Fisher, E. S. (2012). The Promise And Peril Of Accountable Care For Vulnerable Populations: A Framework For Overcoming Obstacles. *Health Affairs*, 31(8), 1777–1785. <https://doi.org/10.1377/hlthaff.2012.0490>
- Loeb, D. F., Bayliss, E. A., Binswanger, I. A., Candrian, C., & deGruy, F. V. (2012). Primary Care Physician Perceptions on Caring for Complex Patients with Medical and Mental Illness. *Journal of General Internal Medicine*, 27(8), 945–952. <https://doi.org/10.1007/s11606-012-2005-9>
- Martos, A. J., Wilson, P. A., & Meyer, I. H. (2017). Lesbian, gay, bisexual, and transgender (LGBT) health services in the United States: Origins, evolution, and contemporary landscape. *PLOS ONE*, 12(7), e0180544. <https://doi.org/10.1371/journal.pone.0180544>
- Monitoring HIV Care in the United States: Indicators and Data Systems* (p. 13225). (2012). National Academies Press. <https://doi.org/10.17226/13225>
- Mugavero, M. J., Amico, K. R., Horn, T., & Thompson, M. A. (2013). The State of Engagement in HIV Care in the United States: From Cascade to Continuum to Control. *Clinical Infectious Diseases*, 57(8), 1164–1171. <https://doi.org/10.1093/cid/cit420>



- Mugavero, Michael J., Davila, J. A., Nevin, C. R., & Giordano, T. P. (2010). From Access to Engagement: Measuring Retention in Outpatient HIV Clinical Care. *AIDS Patient Care and STDs*, 24(10), 607–613. <https://doi.org/10.1089/apc.2010.0086>
- Muthulingam, D., Chin, J., Hsu, L., Scheer, S., & Schwarcz, S. (2013). Disparities in Engagement in Care and Viral Suppression Among Persons With HIV: *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 63(1), 112–119. <https://doi.org/10.1097/QAI.0b013e3182894555>
- Phair, J., & Palella, F. (2011). Renal disease in HIV-infected individuals: *Current Opinion in HIV and AIDS*, 6(4), 285–289. <https://doi.org/10.1097/COH.0b013e3283476bc3>
- Quinlivan, E. B., Messer, L. C., Adimora, A. A., Roytburd, K., Bowditch, N., Parnell, H., Seay, J., Bell, L., & Pierce, J. K. (2013). Experiences with HIV Testing, Entry, and Engagement in Care by HIV-Infected Women of Color, and the Need for Autonomy, Competency, and Relatedness. *AIDS Patient Care and STDs*, 27(7), 408–415. <https://doi.org/10.1089/apc.2012.0434>
- Ross, K. M., Guardino, C., Dunkel Schetter, C., & Hobel, C. J. (2018). Interactions between race/ethnicity, poverty status, and pregnancy cardio-metabolic diseases in prediction of postpartum cardio-metabolic health. *Ethnicity & Health*, 1–16. <https://doi.org/10.1080/13557858.2018.1493433>
- Stangl, A. L., Lloyd, J. K., Brady, L. M., Holland, C. E., & Baral, S. (2013). A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: How far have we come? *Journal of the International AIDS Society*, 16, 18734. <https://doi.org/10.7448/IAS.16.3.18734>

- Ware, J., Kosinski, M., & Dewey, J. (2001). *SF-36(R) health survey: Manual & interpretation guide* (3rd ed.). QualityMetric.
- Yehia, B. R., Stewart, L., Momplaisir, F., Mody, A., Holtzman, C. W., Jacobs, L. M., Hines, J., Mounzer, K., Glanz, K., Metlay, J. P., & Shea, J. A. (2015). Barriers and facilitators to patient retention in HIV care. *BMC Infectious Diseases*, *15*(1), 246.  
<https://doi.org/10.1186/s12879-015-0990-0>
- Yomogida, M., Messeri, P., & Irvine, M. (2019). *Service Needs and Utilization New York City: 2015-2017* (No. 2018–1a; C.H.A.I.N. Report). Columbia University Mailman School of Public Health and New York City Department of Health and Mental Hygiene.  
<https://nyhivstg.wpengine.com/nyhiv-archive/pdfs/chain/CHAIN%20Briefing%202018-1%20Location%20of%20Services.pdf>
- Yomogida, M., Zhao, G., & Aidala, A. (2019). *Place of Residence and Location of Services: Updates* (No. 2018–1; C.H.A.I.N. Briefing). Columbia University Mailman School of Public Health.