

Analysis of the Efficacy and Coordination of Hyacinth Wrap-Around Services for a Comprehensive Care Approach



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INTRODUCTION

About Hyacinth

Founded in 1985 at the height of the AIDS epidemic, the Hyacinth AIDS Foundation is the largest HIV/AIDS organization in New Jersey and has been serving clients for over 30 years. Hyacinth primarily provides services in six metropolitan offices based throughout New Jersey (shown in Figure 1), including offices in Paterson, Jersey City, Plainfield, New Brunswick, Trenton, and Newark, which houses a medical clinic as well. In addition, Hyacinth provides statewide services focusing on public policy and advocacy.

By caring for clients using a wrap-around system, Hyacinth approaches effective treatment in a comprehensive manner that addresses housing assistance, combats stigma against HIV, forms communities for bonding over shared experiences, promotes good mental health, assists in the treatment of comorbidities, and advocates for improvements in public policy surrounding AIDS in New Jersey. This type of comprehensive care addresses both medical needs and human needs and emphasizes seeing clients as a whole person, thus straying from the more traditional approach to HIV treatment.

Hyacinth's mission is to help people live with HIV, slow the spread of the epidemic, and serve as a critical voice in the public debate surrounding AIDS in New Jersey ("About Hyacinth: Our Mission"). Three key strategies, shown below, are undertaken to accomplish these goals:

1. Change the narrative about HIV and reduce stigma;
2. Educate the public about HIV and HIV prevention;
3. Connect everyone to care (regardless of the level of risk) so that everyone may know his or her status.



Figure 1. Regional Hyacinth offices across New Jersey. Location 3 marks Newark, NJ, from where all the client data was collected.

INTRODUCTION

Hyacinth is proud of its accomplishments to help those affected by the HIV/AIDS epidemic and continuously strives to improve its services. This project will investigate the efficacy and coordination of its comprehensive care system and how Hyacinth can further support its clients.

About the Research Study

This research study was conducted from June to August of 2019 and used data collected at the Newark clinic. Due to Hyacinth's position as an AIDS service organization with a unique wrap-around approach towards treatment, it is important to analyze the effectiveness of the services provided and how they are coordinated to support the client in a comprehensive way. Over the course of this project, five primary topics were investigated: the demographics of the Newark client population; the viral suppression rate; the distinguishing factors of the non-virally suppressed clients as compared to the suppressed clients; the effect of stable housing and Hyacinth's housing services on treatment success; and the barriers and challenges preventing women from accessing cervical cancer screenings.

The population demographics, socioeconomic statuses, and medical trends of clients who had been active at the Newark clinic within the past fiscal year (spanning from July 1st, 2018 to June 30th, 2019) were recorded and analyzed as a follow-up research investigation to previous years' demographic data. This data was used to identify what populations are using Hyacinth services and what populations are most at risk and in need of more outreach.

In addition, the medical history of active clients who had received medical treatment from Hyacinth was tracked to calculate the average viral suppression rate and CD4 rate of the clinic. This data was then used to evaluate the efficacy of Hyacinth's clinic and separate clients into groups of virally suppressed status and non-virally suppressed status.

With the separated client populations, the next step was to conduct a deeper investigation into the non-suppressed client population and analyze the factors which may prevent them from reaching viral suppression. This was done by comparing the non-suppressed clients to the suppressed clients, after which housing was targeted as a potentially significant factor. The housing issue was then further investigated by examining the specific services received by clients using both medical and housing services at Hyacinth.

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The final step of this project was to investigate the historically low rate of cervical cancer screenings at Hyacinth and the barriers and challenges that prevent women from accessing these potentially life-saving screenings. To do so, two focus groups centered on cervical health awareness were held with clients from existing focus groups in Newark and New Brunswick to hear first-hand accounts of women clients' experiences (or lack thereof) with getting screened. The women's responses were then categorized to reflect four primary questions about their knowledge and history with cervical health and Hyacinth's role in promoting cervical cancer screenings.

CLIENT POPULATION

Background & Methods

The first stage of the research project was to gather demographic data about the clients using medical services at the Newark clinic, which allows us to understand the client population that accesses Hyacinth services and how this population changes over time. This data allows Hyacinth to assess whether the clinic is serving its target population, including those historically most at risk for HIV transmission, and how improvements can be made to better direct its services toward those most in need.

This study involved 126 active clients who had received medical services from Hyacinth at some point within the past 2019 fiscal year, lasting from July 1, 2018, to June 30, 2019. The demographic data, socioeconomic data, and HIV medical data of the clients were collected from e-COMPAS, Hyacinth's online database. The demographic data includes the age, gender, race and ethnicity, and region of residency. The socioeconomic data includes the employment status and living conditions of the client. The medical data includes HIV/AIDS status, HIV diagnosis year, transmission mode, and sexual orientation.

Population Analysis Results

Demographic Data

As shown in Figure 2, the client population consisted of 37.30% female clients, 61.90% male clients, and one transgender female client who made up 0.79% of the population. The majority of clients were middle to older aged, with 30.95% of clients aged 36-50 and 32.54% of clients aged 51-65. Similarly, clients aged 26-35 represented a fair share of the population at 26.98%, whereas clients at the ends of the age distributions at 18-25 and 65+ were a mere 5.56% and 3.97%, respectively, of the population. Regarding race and ethnicity, the greatest proportion of clients, at 73.02%, were Black/African American, with Hispanic/Latino as the second most prevalent group at 20.63%. Only 5.56% of clients identified as White while one client (0.79%) associated themselves with the "Other" category.

In order to assess whether Hyacinth Newark is properly serving its target population, the region of residency of the clients was recorded and analyzed as well. 68.25% of clients reported residing in the Newark region, while 10.32% reported residency in East Orange, 7.94% in Irvington, 3.97% in Elizabeth, and 9.52% in other regions. It is important to note that the "Other" category is comprised of all listed regions which individually did not account for over 2% of the population. Although clients were

CLIENT POPULATION

dispersed throughout New Jersey, the majority of clients were from Newark and its surrounding regions, suggesting that Hyacinth’s Newark clinic is most directly targeting Newark clients likely as a result of proximity and convenience for the clients.

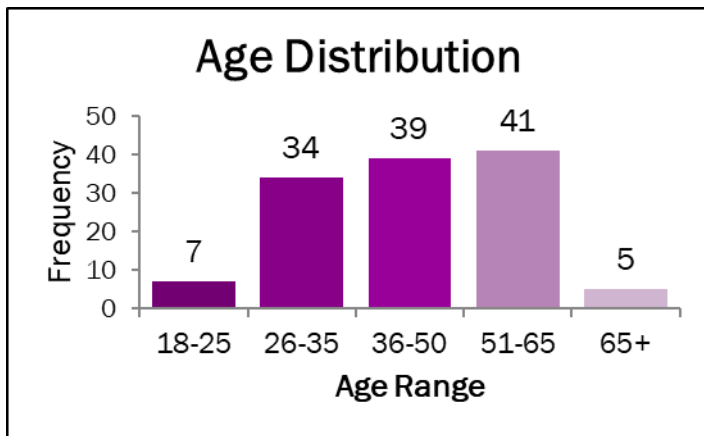


Figure 2. Histogram of the age distribution of active clients at the Newark clinic.

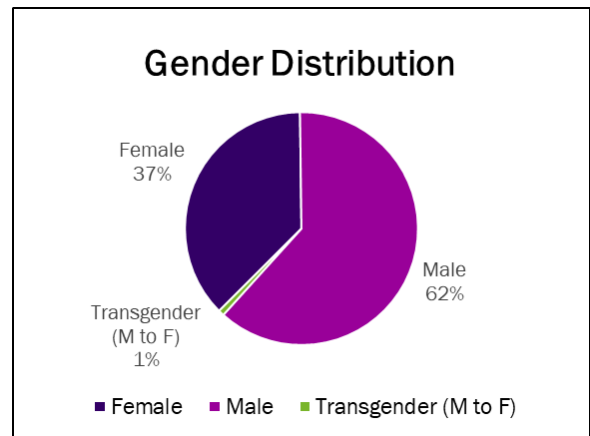


Figure 3. Gender distribution of the active clients at the Newark clinic.

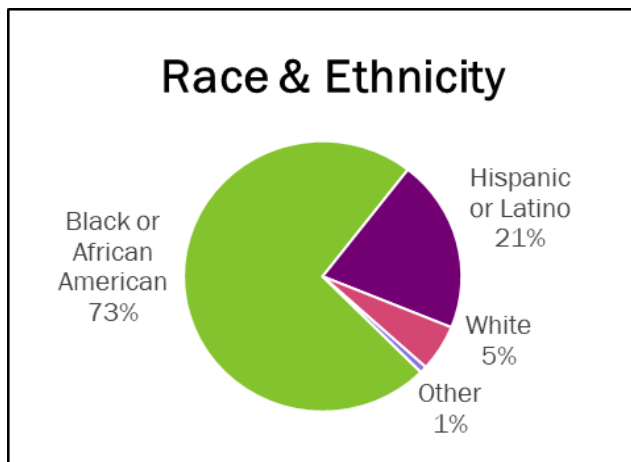


Figure 4. Race and ethnicity distribution of clients.

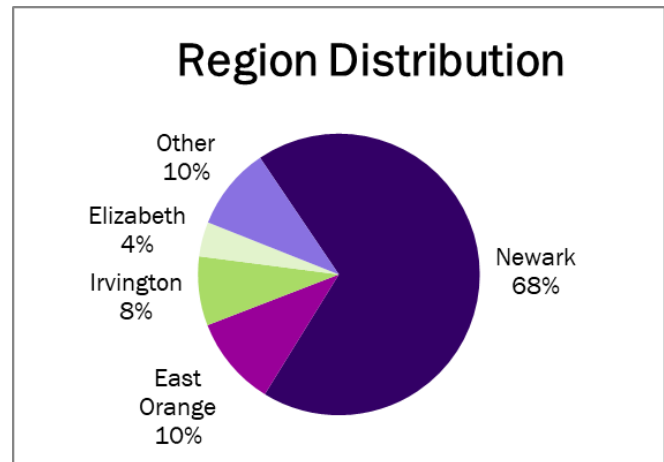


Figure 5. Distribution of the region of residency of clients.

CLIENT POPULATION

Socioeconomic Data

Of the 126 active clients at the Newark clinic, 30 (or 23.81%) worked full-time or part-time whereas 96 (76.19%) were unemployed and/or relied on Social Security as a means of income. Similarly, 71.43% of clients lived in a house or apartment whereas 22.22% reported being homeless and/or living in a shelter. 4.76% of the client population resided in prison at the time of their self-reported housing status and 1.59% lived in a group or treatment center. It is important to note that the rate of homelessness in Hyacinth's Newark client population is over 200 times the rate of homelessness throughout New Jersey, or 0.105%, as reported in January 2018 by the United States Interagency Council on Homelessness ("New Jersey Homelessness Statistics," 2018). This extraordinarily high rate of homelessness among clients warrants further research into how housing plays a role in HIV trends.

Medical Data

As for HIV specific data and related medical trends, it was found that 72.22% of the clients were diagnosed with only HIV while 27.78% of the clients had been diagnosed with AIDS at some point during their medical history. The most common mode of transmission was sex with a male at 55.81%, followed by sex with a female at 17.83%. Only 4.65% of clients reported transmission through injection drug use, with all other specific modes of transmission (i.e. sexual abuse/assault, sex with an injection drug user, blood transfusion, and genetic passing of the disease from mother to child) coming in at less than 4% each. 3.10% of clients reported having more than one risk, whereas 9.30% reported "Other" as an unspecified mode of transmission.

Sexual orientation is another demographic factor to keep in mind, where 65.57% of clients identified as heterosexual, 27.05% identified as homosexual, and 7.38% identified as bisexual. It is important to note that these proportions may not wholly reflect the client population because clients may not feel comfortable sharing their sexual orientations. This is corroborated by the observation that four of the clients in the overall client population chose not to report their sexual orientations, meaning that the population size used to calculate these proportions is 122 rather than the overall 126.

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The year of diagnosis provides valuable information that allows Hyacinth to assess whether its client population is comprised of long-term clients or clients who more recently joined. 27.78% of clients were diagnosed prior to 2000 and a similar 26.98% of clients were diagnosed between 2000-2010. However, the majority of clients, or 62.64%, were diagnosed after 2010, meaning that most of Hyacinth’s clients are relatively new to HIV treatment. This raises the question of whether the proportion differences are due to a surge of new diagnoses in the Newark area in recent years or a greater awareness of Hyacinth services throughout the area for clients who were more recently diagnosed.

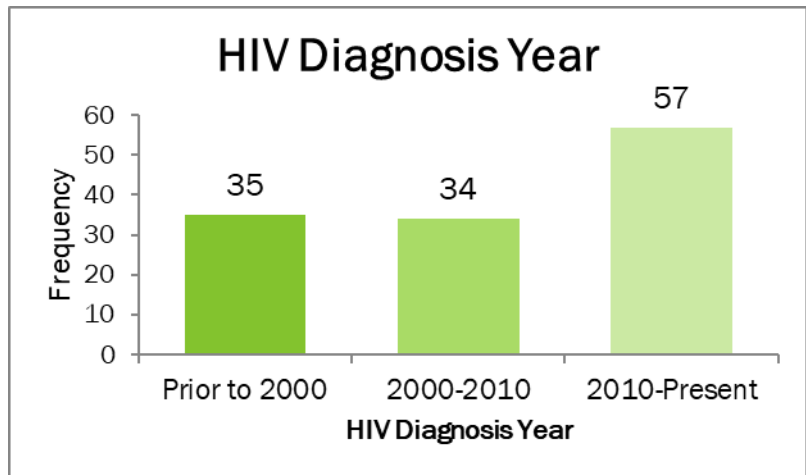


Figure 6. Histogram of the year of diagnosis of HIV for active clients at the Newark clinic.

CLIENT POPULATION

Summarized Demographics Table

<i>General Client Demographics</i>	<i>Count</i>	<i>Percentage</i>
Gender		
Female	47	37.30%
Male	78	61.90%
Transgender (M to F)	1	0.79%
<i>Total</i>	<i>126</i>	<i>100.00%</i>
Age		
18-25	7	5.56%
26-35	34	26.98%
36-50	39	30.95%
51-65	41	32.54%
65+	5	3.97%
Race & Ethnicity		
Black or African American	92	73.02%
Hispanic or Latino	26	20.63%
White	7	5.56%
Other	1	0.79%
Region		
Newark	86	68.25%
East Orange	13	10.32%
Irvington	10	7.94%
Elizabeth	5	3.97%
Other	12	9.52%
Medical Status		
AIDS	35	27.78%
HIV	91	72.22%

Transmission Mode		
Sex With Male	72	55.81%
Sex With Female	23	17.83%
Injecting Drug User (IDU)	6	4.65%
Sexual Abuse/Assault	4	3.10%
Sex With IDU	3	2.33%
Hemophilia/coagulation disorder	1	0.78%
Mother to Child	1	0.78%
More than one risk	4	3.10%
Other	12	9.30%
Sexual Orientation		
Heterosexual	80	65.57%
Homosexual	33	27.05%
Bisexual	9	7.38%
<i>Total</i>	<i>122</i>	<i>100.00%</i>
Year of Diagnosis (HIV)		
Prior to 2000	35	27.78%
2000-2010	34	26.98%
2010-Present	57	62.64%
Employment Status		
Full-time/Part-time	30	23.81%
Unemployed/Social Security	96	76.19%
Living Conditions		
House/Apartment	90	71.43%
Homeless/Shelter	28	22.22%
Prison	6	4.76%
Group/Treatment Center	2	1.59%

Table 1. Demographic, socioeconomic, and medical trend data for the active clients receiving medical services at the Newark clinic in the past fiscal year. Includes the frequency and proportion of clients in each category.

VIRAL SUPPRESSION

Background

Hyacinth's foremost mission is to address the healthcare needs of its clients. To do so, it is necessary to have a standardized way to measure the success rate of its treatment approach in reducing viral loads and increasing CD4 counts for clients receiving medical services. The viral load is the number of particles of the HIV virus present in one milliliter of blood and shows how widespread the virus is throughout the body. The CD4 count is the number of white blood cells (i.e. T-cells) per milliliter of blood that work to fight the virus and function as part of the immune system.

The two most commonly used measures of client HIV status are:

1. A viral load of ≤ 20 copies/mL of blood indicates an undetectable viral load, or viral suppression. When a client reaches the undetectable viral load, the chance of transmitting the HIV virus has reduced to virtually none.
2. A CD4 count of less than 200 CD4 cells/mL of blood indicates that the virus has progressed to the AIDS stage. A higher CD4 count indicates a better immune response.

Methods

In order to calculate the overall medical trends of the client population, I first compiled a list of 122 active clients receiving medical services at the Newark clinic. It is important to note that the number of clients used in this analysis is less than the number of active clients used for the demographics analysis due to discrepancies between Hyacinth databases: some clients were listed as active and receiving medical services at Hyacinth under e-COMPAS, but their medical data was not found in CHAMP, the database with the clients' medical histories, or in the paper files at the Newark clinic. The viral load, CD4 count, and date of collection for each bloodwork test was recorded for each client in order to calculate their medical trend over time. Due to variability between the different types of HIV blood tests and their thresholds – for instance, the undetectable point for some tests is <20 copies/mL, whereas for other tests the point might be <80 copies/mL – a measure of <50 copies/mL was considered the threshold for having an undetectable viral load. Clients who had reached a viral load of <50 copies/mL at any point during their time at Hyacinth were classified as “became virally suppressed (during any time period

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while at Hyacinth)” while clients who never reached an undetectable viral load were classified as “did not become virally suppressed.”

The 109 virally-suppressed clients then underwent further sub-categorization to determine the rate of viral suppression retainment. Only the clients who had more than one recorded bloodwork test, or 105 of the clients in that group, were included in the population used to calculate the viral suppression retainment rate. Clients who maintained a consistently undetectable viral load after reaching the threshold for the first time were listed as “remained virally suppressed.” Clients who had reached an undetectable viral load but regressed to a detectable viral load at any time period afterwards were listed as “lost viral suppression (during any time period while at Hyacinth).”

Once the overall medical trends were found, the viral suppression rate was calculated using a client pool comprised of 57 clients who met the criteria of entering Hyacinth with a detectable viral load and reaching an undetectable viral load at some point during their time at Hyacinth. Two methods were used to provide varying interpretations of the viral suppression rate: Method 1 calculated the average number of weeks it took for clients to reach an undetectable viral load, whereas Method 2 calculated the average change in copies of the HIV virus per milliliter of blood per week.

In addition to the viral suppression rate, the average CD4 growth rate was calculated using a population of 113 active clients (out of the original 122 clients) who had met the criteria of having more than one bloodwork test during their time at Hyacinth. This criterion was specified so that the CD4 count could be compared over time.

It is important to note that for the viral suppression rate and CD4 growth rate calculations, 58 and 114 clients, respectively, had qualified for the populations used to determine the treatment progression rates – however, one client in each group had rates which deviated from the mean by over five times the standard deviation, heavily distorting the calculated average rates. In order to more accurately reflect the overall population of these groups, these extreme outliers were removed from the final analysis of the medical treatment progression rates and the rates were recalculated.

VIRAL SUPPRESSION

Medical Analysis Results

Overall Medical Trends

The analysis of the overall medical trends of the Newark clinic, shown in Table 2, indicates that 89.34% of the active clients receiving medical treatment at Hyacinth became virally suppressed. It should be noted that while the Center for Disease Control considers a viral load of <200 copies/mL to be undetectable (“HIV Treatment as Prevention,” 2019), Hyacinth’s calculation of viral suppression (where <50 copies/mL is considered undetectable) is much more stringent. The remaining 10.66% of clients did not reach an undetectable viral load during any time period while at Hyacinth.

The 105 clients who had reached viral suppression and had more than one bloodwork test were then further analyzed to calculate the rate at which their virally suppressed status was retained. This information can be a useful measure of the adherence of clients to their HIV medication, which can often be disturbed by other issues the client is going through that Hyacinth may need to direct its services towards. It was found that two thirds, or 66.67%, of these clients remained virally suppressed, while 33.33% lost viral suppression at some point during their time at Hyacinth.

<i>Viral Suppression Medical Trends</i>	<i>Count</i>	<i>Percentage</i>
Viral Suppression General Trends		
Became virally suppressed <i>(during any time period while at Hyacinth)</i>	109	89.34%
Did not become virally suppressed	13	10.66%
<i>Total</i>	122	100.00%
Viral Suppression Retainment Rate		
Remained virally suppressed	70	66.67%
Lost viral suppression <i>(during any time period while at Hyacinth)</i>	35	33.33%
<i>Total</i>	105	100.00%

Table 2. General medical trends regarding viral suppression status among clients at the Newark clinic. Also includes a calculation of the viral suppression retainment rate, or the proportion of clients who remain virally suppressed after reaching an undetectable viral load for the first time.

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Treatment Progression Rates

As shown in Table 3, it was found using Method 1 that the mean number of weeks it took for clients to reach viral suppression was 29.29 with a standard deviation of 21 weeks. Using Method 2, it was found that viral loads decreased at a rate of 1786.26 copies/mL per week on average, with a standard deviation of 3308.33 copies/mL per week. These standard deviations are quite high and reflect the variability with which different clients can naturally react to their medications. Similarly, the standard deviation might be raised by clients whose viral load wavered close to 50 copies/mL but did not reach it, increasing the time it took to reach viral suppression. The CD4 rate was also calculated from the population of 113 clients to show an average growth of 1.98 cells per week with a standard deviation of 6.22 cells per week. The high standard deviation might be because the immune system's response can vary dramatically across clients and can even depend on the external circumstances affecting the individual at a certain time. However, the positive change in cells per week is a great indicator that the HIV treatment is generally effective at improving the immune system's response in clients, reducing the rate of AIDS and improving the quality of life in the long term.

<i>Treatment Progression Rates</i>	<i>Clients</i>	<i>Mean</i>	<i>Standard Deviation</i>
Viral Suppression Rate			
Method 1	57	29.29 weeks	21.00 weeks
Method 2	57	-1786.26 copies/mL/week	3308.33 copies/mL/week
CD4 Rate			
CD4 Rate	113	+1.98 cells/week	6.22 cells/week

Table 3. Viral suppression rates calculated using the average number of weeks until reaching an undetectable viral load (Method 1) and the average rate of change of HIV copies per milliliter per week (Method 2). CD4 rates calculated by finding the average rate of change of the number of CD4 cells per week. Standard deviation of all rates is also shown.

VIRAL SUPPRESSION

Comparison of Results

To determine how the effectiveness of Hyacinth services has changed over time, the results of this year's medical trends and treatment rates will be compared to medical results from the previous fiscal year of July 2017 to June 2018, analyzed by Maggie Orlova. Like my research, Orlova examined the medical trends and viral suppression rate of active clients at the Newark clinic.

Both Orlova and I used the same criteria to select clients for each population, though her pool had slightly fewer clients than mine at 104 and 122, respectively. This indicates a potential growth in the population of clients using Hyacinth services at the Newark clinic over the past fiscal year. Overall, Orlova's results were not vastly different from mine. As shown in Figure 7, she calculated that 85.58% of clients became virally suppressed while 14.42% of clients did not reach viral suppression (Orlova, 2018). Her slightly lower value for the proportion of clients who became virally suppressed, as compared to my value of 89.34%, may reflect an improvement in treatment in the past fiscal year. However, it in part may also be attributed to her using a more stringent threshold for viral suppression at <20 copies/mL, whereas my threshold was <50 copies/mL to account for the variability between the many different types of tests used. Orlova's calculations for viral suppression retention had much greater differences from my results, where our respective calculations yielded 87.64% and 66.67% for suppression retention (Orlova, 2018). This suggests that clients may not be adhering to their medical treatment as properly as earlier years, hinting that Hyacinth may need to increase its level of outreach or supportive services in order to promote proper medication management.

In her calculations of treatment progression rates shown in Figure 8, Orlova found that the CD4 growth rate was 3.759 cells/week, which is a 31% difference from my calculated CD4 rate of 1.98 cells/week. It is also important to note that my standard deviation, at 6.22 cells/week, is nearly half of Orlova's standard deviation of 12.0055 cells/week – this may be due to my removal of the extreme outliers when calculating the CD4 growth rate (Orlova, 2018). Similarly, my values for the viral suppression rate differ from Orlova's with either method, which again may be affected by the removal of outliers. My rate found using Method 1 was 3.798 weeks, or 6.9%, greater than Orlova's with a higher standard deviation as well. While the difference between the average number of weeks to reach viral suppression is not especially significant, the increase in standard deviation might be explained by the larger population size used to find the viral suppression rate as compared to Orlova's population size, at 57 and 37 clients, respectively.

VIRAL SUPPRESSION

Method 2 showed a far greater difference between the two data sets: Orlova’s rate of -2919.435 copies/mL/week had a 24.08% difference from my rate of -1786.26 copies/mL/week (Orlova, 2018). However, her standard deviation of 7208.235 copies/mL/week was over twice as large as my standard deviation of 3308.33 copies/mL/week, likely as a result of my removal of the extreme outliers. While our criteria for which clients belonged to which population was used to calculate these medical rates were nearly identical – save for the difference in the threshold for an undetectable viral load – the effects of outliers and population size on the medical rates led to significant differences which make it somewhat difficult to directly compare the two methods of analysis and their results.

Figure 4: Viral Suppression Medical Trends	Total	Percentage
	104	100%
Became Virally Suppressed <i>(during any time period while at Hyacinth)</i>	89	85.58%
Did Not Become Virally Suppressed	15	14.42%
Remained Virally Suppressed	78	87.64%
Lost Viral Suppression <i>(during any time period while at Hyacinth)</i>	11	12.36%

Figure 7. Orlova's table of viral suppression medical trends, to be compared to Table 2.

Figure 5: Viral Suppression Rate	Clients	Mean	Standard Deviation
Method 1	37	25.492 weeks	17.132 weeks
Method 2	37	-2919.435 copies/mL/week	7208.235 copies/mL/week

Figure 6: CD4 Rate	Clients	Mean	Standard Deviation
	80	+3.759 cells/week	12.0055 cells/week

Figure 8. Orlova's table of viral suppression rate and CD4 rate calculations, to be compared to Table 3.

NON-SUPPRESSED CLIENT POPULATION

Background

After the viral suppression status of each client was determined during the calculations of the overall medical trends of the Newark clinic, it was proposed that a demographic cross-analysis of the two client populations – those who reached viral suppression at some point during their time at Hyacinth and those who did not – would help shed light upon the factors that might correspond to a particular suppression status. This research is especially important to determine what factors might prevent clients from reaching viral suppression, regardless of the length of time that they have been on medication, so that Hyacinth can better direct its services towards those avenues and address those factors in the future.

Methods

The 13 clients who were identified as “Did not become virally suppressed (during any time period while at Hyacinth)” were separated from the overall client pool to form another population of non-suppressed clients. The demographics, socioeconomic data, and medical trends of the two groups were then separately calculated using client reports generated from e-COMPAS, the online Hyacinth database. These data were then compared between groups to find the distinguishing factors of the non-suppressed clients.

Population Analysis Results

Demographic Data

Due to the smaller population size of the non-suppressed client group, it is likely that proportions are slightly distorted when comparing between the non-suppressed and suppressed groups; however, some key differences reveal the major factors which may affect the chance of reaching viral suppression. As seen in Table 4, there are no significant disparities in the gender or age proportions between the non-suppressed group and the suppressed group of clients. This suggests that neither gender nor age are major factors affecting the probability of viral suppression. While the age proportions of the non-suppressed group do show slight bias to the extremes of the age bin categories (i.e. 18-25, the youngest bin, and 65+, the oldest bin), the differences are spread throughout all age bins and are likely a result of the small sample size. The proportion of Black/African

NON-SUPPRESSED CLIENT POPULATION

American clients is higher in the non-suppressed group than the suppressed group, whereas all other racial or ethnic group proportions are lower.

Socioeconomic Data

The socioeconomic factors affecting the clients appear to have the largest effect on the probability of reaching viral suppression. As seen in Table 4, the proportion of unemployed non-suppressed clients to suppressed clients was 84.62% to 75.22%, respectively, marking a nearly 10% raw difference in proportions. Similarly, the respective proportions of homeless clients were 46.15% and 19.47%, constituting an over 25% raw difference between the two populations. The data show that the housing status of the client has a significant correlation with whether the client can reach an undetectable viral load. This suggests that treatment approaches that emphasize the provision of housing services may promote the rate of viral suppression in clients. The drastic disparity between housing proportions signals a need for a deeper look into how socioeconomic factors affect the rate of viral suppression, starting with an examination of whether current Hyacinth housing services have encouraged the reduction of viral loads. This topic is further investigated in the next section of this project report focusing on the effects of housing on viral suppression.

Medical Data

Another important factor affecting non-suppressed clients may be the length of time that they have been active with Hyacinth. Out of the 13 clients who did not reach an undetectable viral load during any point of their time at Hyacinth, five had had their first appointment with Hyacinth within the 2019 year; furthermore, four of those five clients had only one appointment throughout their entire Hyacinth career. The recency of these initial client visits suggests that they are still in the early stages of the natural timeline of viral suppression, which takes an average of 29.3 weeks to reach (Table 3). Similarly, Table 4 shows that a higher percentage of clients were diagnosed with HIV in more recent years (between 2010-present) in the non-suppressed group than the suppressed group, with 61.54% and 43.36%, respectively.

These data suggest that a significant proportion of the non-suppressed client population is not virally suppressed because they began treatment too recently for their medication to effectively reduce the viral load to an undetectable level. This reflects a natural outcome of a diverse client population. The medical status (i.e. HIV or AIDS) and sexual orientation of the client do not appear to affect the probability of reaching viral suppression, given the similarities between the proportions in the non-suppressed group and the suppressed group (Table 4).

NON-SUPPRESSED CLIENT POPULATION

Summarized Demographics Table

Demographics Comparison <i>(Suppressed vs. Non-Suppressed)</i>	Non-Suppressed Clients		Virally Suppressed Clients	
	Count	Percentage	Count	Percentage
Gender				
Female	4	30.77%	43	38.39%
Male	9	69.23%	69	61.61%
Total	13	100.00%	112	100.00%
Age				
18-25	2	15.38%	5	4.42%
26-35	3	23.08%	31	27.43%
36-50	4	30.77%	35	30.97%
51-65	2	15.38%	39	34.51%
65+	2	15.38%	3	2.65%
Total	13	100.00%	113	100.00%
Race & Ethnicity				
Black or African American	11	84.62%	81	71.68%
Hispanic or Latino	2	15.38%	24	21.24%
White	0	0.00%	7	6.19%
Other	0	0.00%	1	0.88%
Medical Status				
AIDS	3	23.08%	32	28.32%
HIV	10	76.92%	81	71.68%
Sexual Orientation				
Heterosexual	7	63.64%	73	65.77%
Homosexual	3	27.27%	30	27.03%
Bisexual	1	9.09%	8	7.21%
Total	11	100.00%	111	100.00%

NON-SUPPRESSED CLIENT POPULATION

Year of Diagnosis (HIV)				
Prior to 2000	1	7.69%	34	30.09%
2000-2010	4	30.77%	30	26.55%
2010-Present	8	61.54%	49	43.36%
Employment Status				
Full-time/Part-time	2	15.38%	28	24.78%
Unemployed/Social Security	11	84.62%	85	75.22%
Living Conditions				
House/Apartment	7	53.85%	83	73.45%
Homeless/Shelter	6	46.15%	22	19.47%
Prison	0	0.00%	6	5.31%
Group/Treatment Center	0	0.00%	2	1.77%

Table 4. Comparisons of demographic, socioeconomic, and medical data between the non-suppressed client population and the virally suppressed client population.

EFFECTS OF HOUSING ON VIRAL SUPPRESSION

Background

At many HIV/AIDS care organizations such as Hyacinth, HIV/AIDS is often just one of the many problems that affects clients. Many clients also face comorbidities, housing insecurity, unstable or no sources of income, substance abuse, and more. Clients dealing with income and/or housing insecurity may find it much more difficult to consistently take HIV medication due to the prioritization of more immediate needs, such as personal safety, food and water, and proper shelter (Paudyal et. al, 2017). Several studies of housing effects on HIV treatment have found a positive correlation between stable housing and effective treatment. Researchers working with the New York City Supportive Housing Program found that “PLWH [people living with HIV] who lack stable housing exhibit low entry and retention in HIV care, poor adherence to antiretroviral therapy (ART), and a greater risk of immune system depletion and death” (Hall et. al, 2019). In contrast, supportive housing assistance led to “increased access and retention in medical care and appropriate treatment” (Aidala et. al, 2007) as well as “significantly fewer deaths and AIDS diagnoses... among chronically homeless PLWH” (Hall et. al, 2019). This relationship is seen even in the relatively small client pool at Hyacinth, where the proportion of homeless PLWH is much higher in the non-virally suppressed group than in the suppressed group of clients.

Hyacinth’s housing department is relatively new. Since starting in 2015, it has served over 200 clients at the Newark office and is continuously intaking more clients in need. Based on the relationship between housing and viral suppression observed in the previous research study (Figure 9), it may be worth looking into how much of an effect Hyacinth’s housing services provide and whether the department’s connection to medical care should be emphasized.

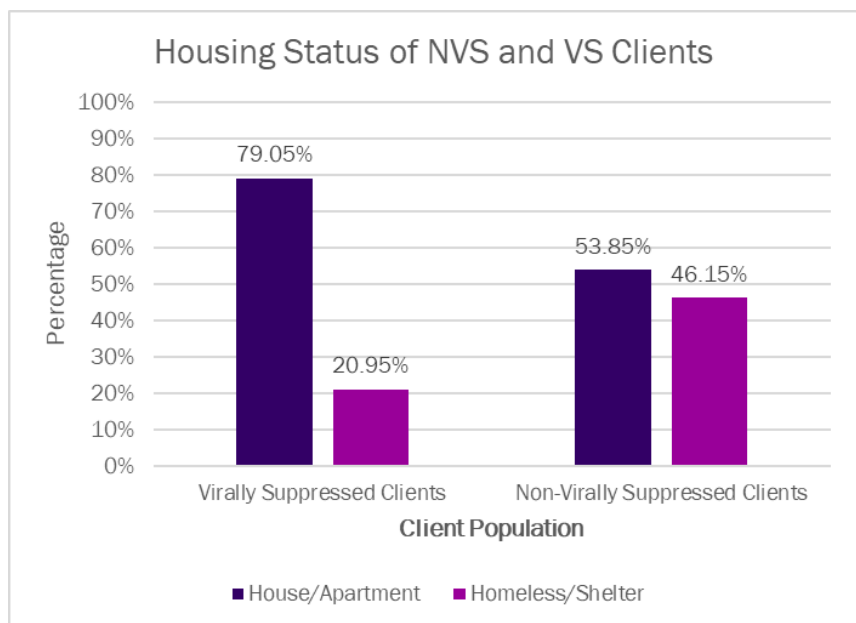


Figure 9. Graphic comparison of the housing status of clients in the suppressed group and the non-suppressed group.

EFFECTS OF HOUSING ON VIRAL SUPPRESSION

Methods

A deeper analysis of the relationship between housing and viral suppression and its application to Hyacinth services was conducted by examining the housing services Hyacinth provides in its Newark office. A total of 172 active clients were found to have received housing services with their initial intake at Hyacinth Newark since its founding of the housing department. These clients were then cross-listed with those receiving medical treatment from Hyacinth in the past fiscal year to find overlapping clients receiving both services. The housing history, the number of housing service units and housing transitions, and the HIV status of each client was then recorded from the online Hyacinth database and analyzed.

Results

Out of the 172 active clients receiving housing services, only 10, or 5.8%, had also received medical treatment from Hyacinth within the past fiscal year. The low percentage in part may be because clients who came to Hyacinth for housing services remained with their outside providers for medical services. The percentage is low enough, however, to raise concerns that there exists a service gap in the other direction, where clients who come to Hyacinth for medical purposes are not being referred to the housing department for additional services. This is especially pressing given the positive effects of stable housing on HIV treatment and the high proportion of Hyacinth medical clientele dealing with housing insecurity. Further investigation should determine more effective methods to connect Hyacinth services and utilize its wrap-around system, such as emphasizing stable housing as an essential aspect of treatment.

Two of the 10 clients who had received housing services in addition to their medical treatment had not become virally suppressed; however, given the already limited number of non-suppressed clients in the overall active client pool, it is likely that this proportion is due to chance. Due to the small sample size, it is difficult to generalize whether specific housing arrangements (such as being placed in a shelter versus an apartment) led to certain medical outcomes, especially since clients often were continuously transferred between many different types of housing. The average number of housing service units was higher in the suppressed group than the non-suppressed group, at 16 and 10 units, respectively. With a larger sample group, such a difference might suggest that greater efforts at finding stable housing (quantified through the number of service units

EFFECTS OF HOUSING ON VIRAL SUPPRESSION

performed at Hyacinth) lead to greater viral suppression. However, the limited sample size and high standard deviations (at 12.20 and 9.90, respectively) suggest that these findings are not able to be generalized easily. More extensive research at Hyacinth (and possibly collaborating with other HIV/AIDS organizations as well) would be needed to conclude the relationship between the efforts of the organization to provide housing services and the treatment success of the client.

CERVICAL CANCER SCREENING ACCESSIBILITY

Background

Cervical cancer is a type of cancer that develops in the cervix, or the opening from the vagina to the uterus, and is 99% of the time caused by cancerous strains of human papillomavirus, or HPV. Over 13,000 women are diagnosed each year, 30% of whom die from the disease (“Cervical Cancer Causes, Diagnosis and Symptoms”). Even though up to 93% of cervical cancers are preventable – making it one of the most preventable cancers to exist – it is also the 4th most common type of cancer in women worldwide. The high frequency of cervical cancer can be attributed to a lack of proper screening among women, especially women in minority ethnic/racial groups and of low economic status or lower levels of education (“Pap Tests,” 2017). Hyacinth has been working to expand cervical cancer awareness in its client population, though the rate of women clients who actually get screened after referral from the clinic has been extremely low. This raises the question of what barriers or challenges might prevent the women at Hyacinth from accessing cervical cancer screenings and how Hyacinth can assist them in getting screened consistently.

In national surveys and interviews conducted by the Center for Disease Control, women listed several factors which influenced their decision to get a cervical cancer screening. Such factors can be sorted into the following three categories, including:

- Lack of healthcare accessibility
 - No health insurance or no health care provider who can provide screenings
 - No transportation to medical centers for screening
- Lack of awareness and education about cervical cancer and the process and importance of screening
 - Not understanding what a Pap smear or HPV test is or what it is for
 - Fear of pain or discomfort during the screening
 - Mistrust of the healthcare system (i.e. doubting the efficacy of the HPV vaccine)
- Stigma surrounding women’s sexual health
 - Feeling self-conscious about body image during the screening
 - Heteronormativity in sexual health
 - Feeling shame or judgement when providing sexual history
 - Feeling uncomfortable when the doctor performing the screening is male

CERVICAL CANCER SCREENING ACCESSIBILITY

The goal of this project was to determine which of the above factors (or other additional factors) impacted the clients at Hyacinth in their decisions to get cervical cancer screenings for Hyacinth to create targeted plans for cervical cancer screening assistance.

Methods

In order to hear first-hand from the client population, we decided to form focus groups centered on cervical health awareness in Newark and New Brunswick. To recruit clients to the focus groups, a promotional flyer was created and distributed to women from existing focus groups already within Hyacinth. The Newark focus group was conducted on July 23, 2019, at the Newark clinic and lasted for one hour. A total of three Hyacinth clients were present to share their experiences, with two Hyacinth employees sharing their stories in tandem. The three Hyacinth clients in the focus group were African American women with ages ranging between 40 and 60. The New Brunswick focus group was conducted on August 1, 2019, at the New Brunswick office and lasted for approximately two hours. Four Hyacinth clients, all of whom were African American women with ages ranging between 35 and 60, came to share their experiences. It is of note that the New Brunswick focus group lasted for twice as long as the Newark group because each of the four women joined the group approximately 20-30 minutes after each other due to their individual schedules. This meant that the question-asking process (described below) had to be repeated four times, once for each client. In contrast, all three clients at the Newark focus group arrived at the same time and were asked the questions at the same time.

Four primary questions, each targeting a specific aspect of cervical cancer screenings and Hyacinth's role in promoting them, were asked, with select follow-up questions used to probe for more detailed responses. The exact questions used are found below:

1. How well do you feel that you understand what cervical cancer is and what the process of a cervical cancer screening is like?
 - a. What is your past experience with cervical cancer screenings?
 - b. How important do you believe cervical cancer screenings, such as the Pap smear, are to your overall health?
2. What role, if any, has Hyacinth played in encouraging you to get cervical cancer screenings?

CERVICAL CANCER SCREENING ACCESSIBILITY

3. What are some of the barriers or challenges that might prevent you from getting cervical cancer screenings?
4. How can Hyacinth assist in overcoming the barriers to getting screened?
 - a. How can Hyacinth better educate clients to be more aware about cervical cancer and the importance of being screened?
 - b. Would women benefit from periodic workshop sessions on cervical cancer?

After the question-asking process to gather information on the women's past experiences with cervical cancer screenings and their suggestions for improvements in Hyacinth services, the women were given informational pamphlets on cervical health awareness and listened to a brief presentation on the topic. After completing the focus group, the clients' responses were summarized and categorized based on which question they addressed, as seen below.

Newark Results

Question 1

In response to the first question on what they understood about cervical cancer and their past experiences with screening, all three clients had very diverse experiences with cervical cancer screenings. One client stated that she understood nothing about the topic. She said that the last time she went to get screened, the doctor claimed her blood pressure was too high and sent her to the emergency room; she never received her Pap smear and never returned to get screened properly. She has not gotten a cervical cancer screening in over eight years. Another client stated that she was not too familiar with HPV, but she is HPV positive with a high risk of developing cervical cancer. She has been getting screened every six months for the past few years, but she had a lapse of five years without a Pap smear before then.

The third client stated that she did not know much about cervical cancer or HPV, though she gets screened regularly at a local clinic outside of Hyacinth. After giving birth to five boys, she experienced severe pain and went through monthly excessive bleeding from her vagina. She did not understand whether the symptoms were part of cervical cancer or another issue affecting her body. After doctors expressed concern, she underwent tubal ligation but later discovered that she did not have cancer. She seemed on the verge of tears when describing her fear and distress as she went through the medical process while having no idea what cervical cancer meant, what its symptoms were, what the

CERVICAL CANCER SCREENING ACCESSIBILITY

procedures she went through did to her body, and what her cancer status was. She said that the doctors never explained to her exactly what was happening in her body. She wished she had had an opportunity to learn more about cervical cancer before going through a traumatic process of an unnecessary surgery and going through each step with fear.

When asked question 1b., a client responded that she has never put Pap smears as a priority. She stated that when she feels discomfort in her vagina, she assumes it is a yeast infection and usually purchases Monistat (a yeast infection treatment drug) to treat the pain herself. She claimed that because she was in a monogamous relationship and was not having sex as often or with as many people anymore, she did not think a Pap smear was especially necessary.

Question 2

In response to the second question on how Hyacinth has promoted cervical cancer screenings, two of the clients replied that because they get screened at clinics outside of Hyacinth's network, they have not heard much from Hyacinth itself about screenings. One client stated that she has not heard much from Hyacinth about cervical cancer screenings because the doctor at Hyacinth does not provide Pap smears, but she is asked if she has had a Pap smear whenever she visits her doctor outside of Hyacinth.

Question 3

In response to Question 3 on the barriers to getting screened, the clients responded that one of the most significant barriers was not having reminders to get cervical cancer screenings. As one client described, she called to schedule an appointment, but because the earliest available appointment was scheduled for four months later, she forgot about it when the time came. After missing her scheduled Pap smear, she was never contacted again to reschedule her screening. She also was never told about the HPV vaccination and is unsure if she received it as a child. Another client stated that the fear of the process due to a lack of understanding, along with the fear of having a negative outcome, is also a barrier to getting screened properly. All of the women in the focus group agreed that they had not talked about cervical cancer with their mothers due to cultural barriers to speaking about sexual health. Furthermore, the women also noted the pain and discomfort of the screening procedure as a deterrent. One client reported having to be snipped multiple times during a cervical cancer biopsy, and though she had anesthetic, she felt pain for several days afterward.

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The women in the focus group also mentioned that women often feel uncomfortable when the doctor performing the screening is male (as is overwhelmingly the case). Trauma and identity also played a role, as women with a history of sexual abuse might feel extra discomfort at having their cervix examined. Similarly, transgender men and people with female sexual organs who prefer to be more masculine may not associate women's sexual health procedures such as Pap smears with their identities.

Question 4

In response to the final set of questions on how Hyacinth can help promote cervical cancer screenings, all the clients agreed that periodic workshop sessions would greatly help in educating the clients on the topic of cervical cancer and dispelling fears about the process of getting screened. The clients also recommended that Hyacinth call its clients to remind them about getting Pap smears regularly since a significant barrier was forgetting to be screened. Along with Pap smear reminders, HPV vaccinations and HPV tests were also suggested as procedures that had to be discussed more among the patients and their children. The women also suggested having Pap smear reminder t-shirts to spread awareness of cervical cancer since "someone reads your t-shirt before they hear what's coming out of your mouth."

New Brunswick Results

Question 1

In response to Question 1, three of the women stated that they have heard about cervical cancer before and feel as though they have a relatively decent understanding of the disease, its causes, and its symptoms. Two of these women said that they have been regularly screened for the past few years, whereas one of them said that her screenings are not on a regular basis but occur every time she visits a gynecologist. The fourth client stated that she did not know much about cervical cancer and she only occasionally gets screened at a local hospital when she feels discomfort in her female sexual organs. Two of the women in the focus group stated that they had tested positive for HPV and remarked that they thought cervical health was very important to overall health, stressing the importance of knowing your HPV status.

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Finally, one client who gets screened regularly shared her story about recently having her first abnormal Pap smear and getting a biopsy test in the week before the focus group. She became highly emotional and began crying when sharing her fears of finding the results of the test next week, along with the pain she felt during and after her biopsy.

Question 2

Three of the four clients agreed that Hyacinth has not provided the proper education about cervical health, as they have never discussed it at length in the women's group nor been referred to a medical provider to be screened. One client stated that she was once referred by Hyacinth to be screened during a one-on-one meeting with a Hyacinth employee. The other women seemed clearly surprised by her experience and reaffirmed that Hyacinth has never mentioned it to them.

Question 3

When asked about the barriers to being screened, the women agreed that the fear of the unknown – regarding the process of the Pap smear or HPV test, the risks of cervical cancer, etc. – and the fear of pain during the procedure were major blocks to getting cervical cancer screenings. One woman described how she was kept in the dark about the procedure at her old medical provider and constantly felt apprehensive about visiting the doctor for a screening; however, after switching medical providers to one where the doctor would explain the disease and process in a clear and respectful manner, the client felt significantly more at ease. Similarly, another client mentioned that she originally doubted the importance of getting screened because she did not even know her family's medical history and rates of various diseases. She also described how the process of a Pap smear was especially painful for her because her uterus is prolapsed and requires extra manipulation to complete a Pap smear.

The client who had received a biopsy last week described how scared she feels about the topic overall. She stated that visiting the doctor was mentally and emotionally very difficult for her and that she avoids listening to the topic out of fear, even going so far as to ignore calls from the doctor and to not pay attention when the doctor describes the risks of cervical cancer. Like the other client, she also has a prolapsed uterus and finds the Pap smear procedure very painful, listing pain as another potential barrier to screenings.

CERVICAL CANCER SCREENING ACCESSIBILITY

Question 4

All four women agreed that the best way Hyacinth could raise awareness about cervical health was to discuss the importance of cervical cancer screenings during the weekly women's groups held at New Brunswick, most often on Tuesdays. They stated that many of the women in the wellness group likely did not understand much about the topic and that cervical health has only ever been brought up once or twice in passing without any deeper level of education on the topic. They thought that periodic workshops would be highly beneficial, especially when held for the wellness group where there is so much support and sharing from the members of the group. One of the women stressed the importance of conveying the message of "no pain, no gain," arguing that the women needed to understand that 2-3 minutes of discomfort during a Pap smear could save their lives.

Discussion

As revealed during the focus groups, one of the biggest issues surrounding Hyacinth's role in promoting cervical cancer screenings is the clients' lack of understanding of cervical cancer and the importance of screening. This lack of awareness is responsible for several levels of the issue, from the low prioritization of cervical cancer screenings for overall health to the fear of the unknown that might prevent women from getting screened properly. Similarly, the fear of pain appears to be a significant factor that could be addressed using a model of the "no pain, no gain" approach described by the clients in New Brunswick.

Current Hyacinth services do not appear to be sufficient in spreading awareness and educating the clients on the topic, signaling a troubling gap in care. Future directions for Hyacinth's promotion of cervical cancer screenings include holding educational workshops on cervical cancer, designating it as a regular topic for discussion during women's wellness groups, and spreading awareness through promotional means, such as t-shirts or flyers reminding women to get screened. These educational methods of spreading awareness could cover both cervical cancer and HPV, as well as how to make the process of a cervical cancer screening more comfortable for the client. This kind of education is especially important for the clients of minority ethnic/racial groups and of lower economic status or education level, of which a large proportion of Hyacinth clientele are comprised, due to their historically lower rates of getting Pap smears compared to wealthier populations.

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In addition, only one of the seven total clients present in the focus groups reported being referred to get screened by Hyacinth. Improving Hyacinth's outreach approach by increasing the number of referrals and the frequency of reminders to get screened could promote the rate of cervical cancer screenings among clients. This increased awareness of cervical health through conversation and referrals is especially important for the Newark clinic, where, unlike the New Brunswick office, Hyacinth provides direct medical care for its clients.

The clients did not mention the lack of health insurance or a healthcare provider as a barrier to getting screenings. Stigma, however, appeared to play a role in blocking access to screenings – the women mentioned how such topics about sexual health were not discussed in their families and how male doctors influenced their decisions to be screened. While the women themselves had not experienced struggles with trauma or identity when approaching a Pap smear, their awareness of the issue suggests that Hyacinth should be mindful of such factors when reminding clients to get screened as well. An extension of this investigation might involve holding a larger focus group on the same topic with a different group of women (such as the clients at other Hyacinth offices) to gather more perspectives.

CONCLUSION

Summarized Findings

This 9-week research project has investigated several aspects of Hyacinth's services, both medical and supportive, and has led to many observations of the efficacy and coordination of these services to form a wrap-around system for comprehensive care.

In the analysis of client demographics, including socioeconomic and medical trend data, it was found that Hyacinth's Newark client population primarily consists of straight Black/African American males with ages ranging from 36 to 65. Women also comprised a significant portion of the client population, along with people of Hispanic or Latino identities. The data also verified that Hyacinth Newark is primarily serving its target population of Newark and its surrounding regions. The majority of clients were unemployed and/or relied on Social Security for income. While most clients reported living in a house or apartment, the proportion of homelessness among clients is alarmingly high compared to the statewide average. Most clients are relatively new to HIV treatment, having been diagnosed sometime after 2010, possibly reflecting greater awareness of Hyacinth as a result of more fruitful outreach in recent years.

In the analysis of the medical trends and viral suppression rate of the Newark client population from the past fiscal year, it was found that 89.34% of the clients at Hyacinth reached viral suppression during any time period while at Hyacinth, where 66.67% of those clients remained virally suppressed throughout the rest of their time at Hyacinth. The viral suppression rate, calculated using the mean number of weeks it took to reach viral suppression, was 29.29 weeks, which is a 6.9% increase from the last fiscal year's calculations. Using the method of calculating the change in the copies of HIV virus per milliliter of blood per week, the viral suppression rate was -1786.26 copies/mL/week, which is a 24.08% difference from the previous fiscal year. The differences between years may be due to a slightly larger client pool and the removal of extreme outliers. This may also have affected the calculations for the CD4 growth rate; however, because the CD4 rate is positive, this suggests optimistic implications for the HIV treatment taking place at Hyacinth.

In the cross-analysis of the non-virally suppressed clients to the clients who reached viral suppression, it was found that while gender, age, race/ethnicity, medical status (HIV/AIDS), and sexual orientation showed only slight or no disparities between the two

CONCLUSION

groups, socioeconomic factors revealed significant differences. The proportion of unemployment and homelessness among non-virally suppressed clients is significantly greater than the corresponding proportion in the virally-suppressed group, showing that a deeper investigation of the distinguishing socioeconomic factors (especially housing) was needed. Similarly, the time the client has spent with Hyacinth might be a factor in the client's viral suppression status as well, since a higher proportion of non-suppressed clients were diagnosed after 2010 than the suppressed group. The recency of these initial client visits suggests that they are still in the early stages of the timeline of viral suppression, reflecting a natural outcome of a diverse client population.

In the investigation of the effects of housing on viral suppression, it was found that there is a concerning gap in Hyacinth services where clients who come to Hyacinth for medical purposes are not being referred to the housing department for additional services as often as should be the case, especially due to the high proportion of clients dealing with housing insecurity. Because the sample size of clients receiving both medical and housing services is so small, it is difficult to generalize whether the specific housing arrangement or the number of housing service units (a measure of the "effort" of Hyacinth in assisting the client in finding stable housing) has a significant effect on the viral suppression rate. More research using a larger population, possibly comprised of clients from other Hyacinth offices, would be needed to investigate this issue further.

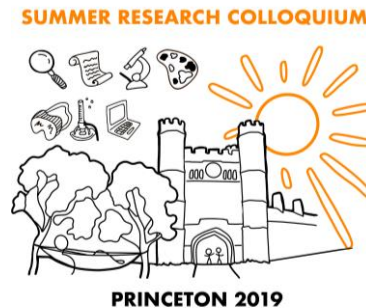
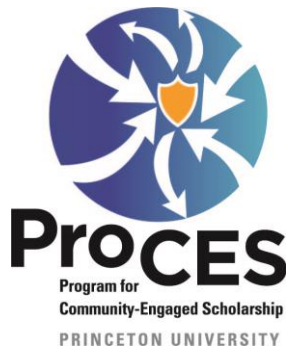
Finally, from the focus groups conducted in Newark and New Brunswick about women's cervical health awareness, it was found that the lack of understanding of cervical cancer and the fear of pain during screenings were two of the greatest barriers preventing women at Hyacinth from getting screened properly. Stigma and the lack of reminders to get screened presented challenges to the women as well. Current Hyacinth services do not appear to be sufficient in spreading awareness and educating the clients on the topic, signaling a troubling gap in care. Future directions for Hyacinth's promotion of cervical cancer screenings include holding educational workshops, discussing cervical health in women's wellness groups, stressing the importance of being screened through the "no pain, no gain" approach, and spreading awareness through promotional means. Similarly, improving Hyacinth's outreach by increasing the number of referrals and the frequency of reminders to get screened could promote the rate of cervical cancer screenings among clients.

CONCLUSION

In summary, Hyacinth has provided invaluable support for its clients and proved its dedication to helping the community over the past 30+ years of service. Improving the coordination and integration of its different departments (i.e. medical, housing, cervical health, etc.) could lead to a more thorough and efficient wrap-around system of care that supports clients in a more comprehensive way, staying true to the organization's mission of helping people living with HIV/AIDS in all aspects.

Acknowledgements

Special thanks to my mentor, Jodi Riccardi, for her support and guidance throughout the project. I would also like to thank Deloris Dockrey, Johanne Rateau, and all other Hyacinth employees for their support and kindness. Finally, thank you to Maria and Trisha from the ProCES office and to the SRC mentors.



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