

Comparing Barriers to HIV Care in DE: Client and Provider Perspectives

Background

Do barriers to HIV care differ throughout Delaware?

People living with HIV (PLWH) in Delaware span a broad range of geographic locations, languages, races, ethnicities, sexual orientations, gender identities, and other characteristics. Understanding how barriers to HIV care differ among PLWH can inform **targeted efforts to improve HIV care delivery**.

Methods

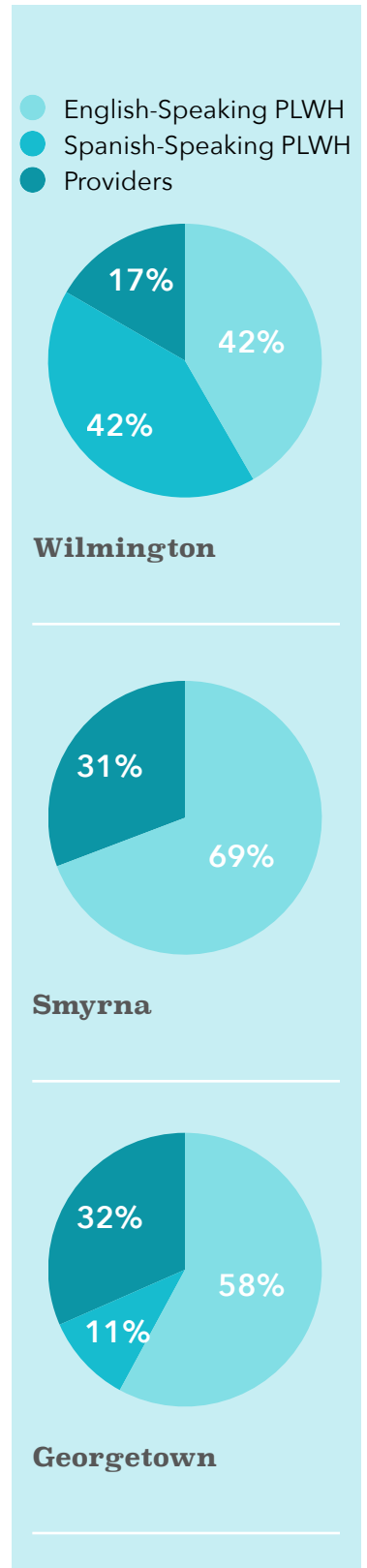
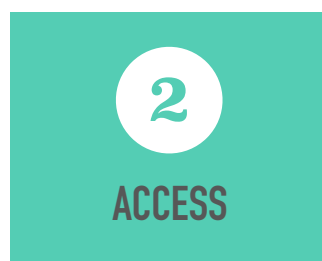
Procedures, Participants, Data Analyses

In **2017**, the William J. Holloway Community Program at Christiana Care Health System partnered with the Department of Human Development and Family Sciences at the University of Delaware to study barriers to HIV care in Delaware. The William J. Holloway Community Program serves ~65% of PLWH in Delaware, including 1,000+ annually. **Interviews** were conducted in Wilmington, Smyrna, and Georgetown. In total, 56 individuals were interviewed, including **42 PLWH** and **14 care providers**. Among PLWH, 16 identified as Black, 13 as Latino(a), 7 as White, and 5 as another race or ethnicity; 28 identified as men; and 20 identified as LGBTQ. They were an average of 46 years old and had lived for an average of 10.7 years with HIV. Interviews lasted 30-60 minutes and were **recorded, transcribed, and coded**.

Results

Differences in Barriers to Care

Transportation and **location** were the most **commonly discussed** barriers to care, with participants in **Smyrna and Georgetown** reporting more issues with transportation than those in Wilmington. Burdens with ride sharing services, parking, and distance were highlighted. Issues with building infrastructure and patients not wanting to be seen entering HIV clinics were also identified.



"A LOT OF PEOPLE DON'T FOOL WITH THE TRANSPORTATION PROVIDED. THEY DON'T WANT TO BE STUCK... YOU'LL CALL AND YOU'RE STILL WAITING."

"PARKING AT THIS SITE.... IT SUCKS. TRANSPORTATION IS A BIG ISSUE. WE NEED TO RELOCATE THIS CLINIC."

"WHEN SHE FIRST STARTED COMING HERE, IT WAS A LITTLE BIT EASIER BECAUSE THEY HAD A PERSON THAT SPOKE SPANISH. NOW, IT IS A LITTLE BIT HARDER AND A LITTLE BIT MORE STRESSFUL BECAUSE THEY HAD TO USE A TELEPHONE."

"IN METROPOLITAN AREAS, PEOPLE ARE LIVING AND COPING IN A MORE OPEN WAY. THIS AREA IS A SMALL TOWN, PEOPLE AREN'T VERY PROGRESSIVE AND EDUCATED HERE."

"THE HAITIAN COMMUNITY, THEY DON'T DIVULGE FOR FEAR OF BEING SHUNNED."

Access to primary care and specialists was identified as a facilitator of care, with benefits to overall patient well-being and HIV treatment. For example, treating mental health problems was viewed as helpful for patients to be adherent to their medication. Participants in **Smyrna and Georgetown** reported difficulty accessing primary care and specialists. Access to specialists was particularly a problem for **older PLWH** experiencing co-morbidities. **Spanish-speaking PLWH** in Georgetown reported negative impacts of not having an in-person Spanish translator.

Stigma within the community was a key barrier to care. Participants in **Smyrna and Georgetown** reported more stigma, driven by lack of education and socially conservative values. PLWH worried that others would find out about their HIV status in their "small towns" and took efforts to hide it. Similarly, stigma was identified as a bigger issue in **Hispanic and Haitian communities**, and Hispanic and Haitian PLWH disclosed their HIV status to fewer people due to fear of rejection. LGBT participants in Georgetown reported more **HIV stigma from heterosexuals** than other LGBT individuals. Internalized stigma, including feelings of shame and self-blame, was identified as a barrier to care throughout the state, undermining medication and treatment adherence.

Similarities in Barriers to Care

Several barriers to care were similar throughout the state. PLWH with **inaccurate belief systems** (e.g., one doesn't need to take medication when they feel healthy) and with **competing priorities** (e.g., work, mental health issues requiring attention) struggled with HIV treatment regimens.

Recommendations

Addressing issues related to transportation, access, and stigma may improve HIV care for some PLWH in Delaware. Results also suggest that social support and relationships with HIV treatment providers facilitated treatment. For example, one PLWH said: "the staff was really helpful in being patient and working with me in order for me to keep up with my treatment." Therefore, **strengthening relationships with family, friends, PLWH, and treatment providers** may also lead to better HIV treatment outcomes.



CONTRIBUTORS

The following individuals contributed to the study design, data collection and analysis, and/or preparation of this field report: Arlene Bincsik, RN, MS, CCRC, ACRN; Sarah Dickerson; Valerie Earnshaw, PhD; Elizabeth Hill; Ismael Medina; Natalie Reed; Karen Swanson, BSN, RN, ACRN, CCRC. Please contact Valerie Earnshaw (earnshaw@udel.edu) and/or Arlene Bincsik (ABincsik@christianacare.org) with questions.

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