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Determinants of HIV Treatment Disparities in the Latino Population of South Carolina

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DETERMINANTS OF HIV TREATMENT DISPARITIES IN THE LATINO POPULATION

OF SOUTH CAROLINA

By

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Submitted in Partial Fulfillment

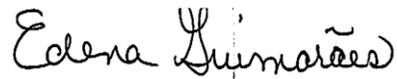
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I. Abstract

The Latino population in the United States faces a heightened risk in terms of contracting HIV/AIDS and experiencing negative health outcomes from said infection. HIV/AIDS continues to disproportionately impact ethnic/racial minorities, and the Latino population exemplifies this unfortunate trend, with Latino Americans making up around 18.4% of the national population, but nearly 30% of the HIV/AIDS infections (US Office of Minority Health, 2021). More enduring changes to the current resources available to this population will need to be made in order to address this disparity. Thus, the current study examined social determinants, how they increase risk of infection, and how they contribute to the greater incidence of negative outcomes in the Latino population. These topics will be explored thoroughly throughout this thesis to explain the need for resources tailored to this population. Research was conducted in conjunction with PASOs, an organization focused on improving education, advocacy, and leadership development for Latinos in South Carolina. This research explored on HIV positive Latino community members in South Carolina will be presented and compared with published research to bolster the evidence found in the field. This project also includes the development and distribution of a bilingual map resource that will assist in both navigation of available HIV treatment resources and preparation of patients for their experience in their most accessible HIV treatment center.

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II. Introduction

Human immunodeficiency virus (HIV) treatment and care should be initiated immediately upon a positive diagnosis and continue throughout the rest of the patient's life (Hall, et al., 2013). Antiretroviral treatments and case management provides ongoing access to care as well as viral suppression, which lowers the risk of HIV transmission (Carey, et al., 2019). In order to effectively manage HIV treatment for HIV positive patients, such patients must be referred to and continue to participate in care and treatment. HIV positive status is a heavy burden to bear, but with proper treatment and care, it can be managed.

Different cultural backgrounds may impact the weight of this burden as such backgrounds may affect an individual's access to quality treatment and care (Hall, et al., 2013). In HIV positive Latinos, these barriers to accessing treatment may include stigma, language barriers, citizenship status, cost, and numerous other factors, some of which will be explored throughout this thesis.

The South Carolina Department of Health and Environmental Control (SCDHEC) reports that in 2018, Latinos represented 6% of the population in South Carolina (SC) and accounted for 5% of people living with HIV and AIDS, acquired immunodeficiency syndrome (PLWHA). It is important that HIV care teams follow the Center for Disease and Control and Prevention's (CDC) HIV Continuum of Care guidelines when treating PLWHA to ensure that everyone receives equitable care. The HIV Continuum of Care's steps include diagnosis of HIV infection, linkage to HIV care, receipt of HIV care, retention in care, and achievement and maintenance of viral suppression (HIV.gov, 2020). When looking at the 2018 numbers of PLWHA engaged in the steps of the HIV Continuum of Care in SC, however, the percentage of Latinos (54% received any care; 42% retained continuous care; and, only 48% had viral suppression) as

opposed to their White (67%, 52% and 61%, respectively) and African American (70%, 55% and 59% respectively), counterparts (SCDHEC, 2019) was shockingly low. This research looked at: 1) providing tailored resources that address barriers to accessing HIV treatment for HIV positive Latinos; and 2) advising SC HIV treatment providers on how to best serve this target population. The study consisted of analyzing qualitative data from two focus groups, one with HIV positive and the other with HIV negative Latino community members. A map of HIV treatment centers in SC that offer bilingual services and Spanish materials was developed from this data.

When considering factors that impact access to quality healthcare, the importance of patient-provider communication cannot be understated. Latino patients tend to rank much higher in terms of unmet support in healthcare than non-Hispanic or Latino, white counterparts, with much of the available research connecting many of these disparities to a lack of adequate patient-provider communication (Moreno et al., 2018). The Latino Commission on AIDS most recent report reveals, “Care for HIV-positive Latino clients is keeping up with demand, but bilingual/bicultural employees remain scarce in the state of South Carolina (Latino Commission on AIDS, n.d.). It is also important to note that Latinos have a high level of mistrust in health care systems which can result in the decision to forgo clinical visits and/or choose not to adhere to medical regimens (Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STTD, and TB Prevention, 2020).

With the availability of a bilingual map resource, patients will be more prepared for their visit with providers and more knowledgeable on what services will be in use (virtual interpreting, on-site interpreters, bilingual providers) during their visit to a clinic to receive treatment. The research and development of this resource is aimed at improving patient preparedness for patient-provider interaction in order to eliminate this as a determinant that may be influencing

the disparities in perception of care and retention in care among the HIV-positive Latino patient population.

III. Methods

The team at PASOs began by conducting provider interviews via telephone to assess interviewees' perception of HIV and AIDS treatment and Care for Latino PLWHA in their facility. Seven individual interviews were conducted with healthcare providers at different HIV treatment facilities across the state. These interviews were used to develop questions to be used in focus groups containing HIV positive Latinos and members of the Latino community in SC.

PASOs bilingual/bicultural staff collaborated with various stakeholders and HIV prevention and treatment organizations and agencies throughout the state to recruit eligible participants. Emails to stakeholders, English and Spanish recruitment flyers, and the snowball techniques were all used to find eligible participants. Interested Latinos were provided contact information to a bilingual/bicultural doctoral student for enrollment purposes. Recruitment and communication efforts with stakeholders and HIV organizations was particularly challenging because of the COVID19 (Coronavirus associated with SARS-CoV-2) lockdown occurring locally and nationally. The 7 PM July 15, 2020 virtual focus group began 10 minutes late due to technology issues some participants had logging into the web link. Five HIV + Latinx currently in care participated in the virtual focus group, in which two individuals joined the group between 20-30 minutes late.

The focus group lasted approximately 75 minutes. The doctoral student collected participant demographics during the enrollment period via telephone. For confidentiality purposes, respondents were told they could use a "fake" name if preferred. Three of the four chose to be called a different name. The focus group took place virtually and no cameras were used by anyone. Five project workers (two bilingual/bicultural Arnold School of Public Health

faculties, a PASOs staff person, a doctoral student, and an undergraduate student) took part in the focus group to ensure participants were appropriately logged in, assist with any technical issues, to facilitate the focus group, and to take notes. Three of the five project workers took notes in both Spanish and English. The focus group was recorded with permission from the responders. Each participant was emailed a \$50 Visa gift card as compensation for taking part in the focus group. The respondents were asked a series of 10 open-ended questions to gather information on their perception of the HIV care and treatment services they are currently receiving. Ultimately, only 5 HIV positive Latinos and 9 community members were recruited and interviewed for these focus groups.

The literature search for this thesis was conducted using the University of South Carolina's Thomas Cooper Library database in the months leading up to the thesis defense date, October, 2021 to April, 2022. Pubmed and Google Scholar were also used to supplement the research done via the University Database. Key search terms included: "HIV Treatment"; "HIV Treatment for Latino Patients"; "Racial Disparities in HIV Care"; "Disparities in HIV Treatment"; "Racial Differences in HIV Incidence and Outcomes"; "HIV positive Latino Patients"; "Racial Disparities in HIV Treatment Adherence"; and "Healthcare Issues Disproportionately Affecting Latino Patients". Search results were filtered to prefer English or Spanish results, the authors preferred languages. Literature was hand-picked regarding its relevance to disparities in HIV treatment for the Latino population.

In preparing for this thesis, invaluable insight was gained by attending one of several Latino Community Conversations hosted by United Way of the Midlands in order to build upon an understanding of the perceived most-pressing issues facing the Latino community in South Carolina today. The meetings consisted of Latino leaders from different parts of the state and

different sectors of the workforce, whom are both powerful in their influence and respected greatly in the Latino community in the state. These meetings helped to shape decisions regarding necessary resources, targeted interventions, and an overall plan of action for the task of addressing the issue of disparities in HIV treatment faced by this population. For meetings that were less accessible due to location (in different parts of the state) or scheduling issues, notes from the United Way of the Midlands Executive Board were provided for review in order to incorporate any new or different information into formulating a plan for resource building.

In order to construct the bilingual map, the interactive maps available on the SCDHEC website were utilized and filtered to show all of the facilities in the state that currently offer HIV treatment and care, and a list with contact information for such facilities was created. This list was utilized to formulate three guiding questions: 1. “Do you have bilingual staff or available translation services?”; 2. “Do you carry and distribute information in Spanish regarding the patient's condition and treatment plan?”; 3. “Do you consider yourself to be flexible and understanding of cultural differences that may impact the treatment of Latino patients?” These questions were asked of the facilities and the responses were recorded and analyzed in order to construct a map of locations, color coded to indicate which, if any, of these resources they possess and utilize when treating Latino patients.

The map was constructed using the arcGIS system made available through the University of South Carolina’s Thomas Cooper Library. The map was then printed and distributed using the University of South Carolina’s Honors College Senior Thesis Grant funding. Distribution centers included an online platform containing information for Latino patients, treatment centers, churches, PASOs, and other Latino community centers in South Carolina.

IV: Part I: Exploring HIV Treatment Disparities for Latino Patients

HIV/AIDS imposes an appreciable toll on racial and ethnic minorities and disadvantaged populations in the United States. In particular, American Latinos have been disproportionately affected by HIV/AIDS due to a unique set of cultural and social determinants. Although Latinos compose about 18.4% of the national population, this population accounted for an estimated 30% of cases of HIV/AIDS nationwide in the year 2019 (US Office of Minority Health, 2021). According to the CDC, only 84% of Latinos suffering from HIV/AIDS have been diagnosed, and only about 49% are retained in care (CDC, 2018). Too few Latinos are being diagnosed with HIV/AIDS and among those diagnosed, a shocking number have not adhered to treatment for various reasons. This thesis intends to explore and expose the determinants of these treatment disparities in an effort to educate and advance the path to defeating any barriers to receiving or continuing care for these patients.

It would be an inadequate review of the determinants facing this priority population if this thesis failed to address the factors that make Latinos more susceptible to contracting HIV/AIDS than their non-Latino white counterparts. Although the existence of social determinants for poorer health outcomes including low education and high rates of poverty in the Latin American population cannot be denied, Latinos tend to have surprisingly good health profiles. This inconsistency is often referred to as the Latino health paradox, but in the case of HIV infection, the trend fails to persist, evidenced by the fact that Latinos make up around 20% of the cases of HIV/AIDS in the United States even though they comprise less than 25% of the national population (Levison et al., 2018). Even more stunning are the statistics of poor health outcomes after Latino patients are infected when compared with the more favorable outcomes of

their non-Latino white counterparts. These statistics highlight an unaddressed health disparity that demands further research and immediate intervention.

Once a Latino becomes infected with HIV, the first step to treating the illness is receiving a diagnostic test. Lower diagnostic testing rates persist among married Latinos especially. Familismo (or family pride) can often cause reluctance toward admission of sexual maladies or sexually transmitted infections especially if the healthcare provider is of the opposite gender or is not seen as a trusted advisor by the patient (Chong, 2002). Gender roles and attitudes, including assumed marital fidelity and anti-homosexuality, play a large role in Latino culture that make the thought of a positive HIV diagnosis and its associated stigma extremely frightening for this population. A portion of this barrier to care relates to health insurance coverage, with Latinos being the largest uninsured racial or ethnic group at 17%. Composing a significant part of new HIV infections in this community are immigrants, but HIV testing in Immigration and Customs Enforcement health centers tends to focus on symptoms rather than routine HIV testing in disagreement with CDC recommendations (Levison et al., 2018).

After the diagnosis has been assigned, patients are susceptible to delay in pursuing treatment and outpatient care for their illness. Many Latinos are anxious about the disclosure of their sexuality, infidelity, and their infection to family members and partners. Although this first step toward receiving care is difficult, research has shown that many Latinos express interest in receiving treatment before subsequently discontinuing their treatment program.

There have been many proposed determinants attempting to explain this lack of adherence to treatment among Latinos, but perhaps the most frequently encountered in research is the low health literacy of this general population. Failing to adhere seems to result from a

broad range of issues, ranging from forgetfulness to feeling ill or depressed (Kalichman et al., 1999). All of these factors, however, seem to correlate with a low health literacy and understanding of the importance of available antiretroviral drugs and therapies. Patients that lack an understanding of the significance of adhering to treatment are less likely to be retained and much more likely to experience a sense of hopelessness in relation to their diagnosis. Some of this low health literacy may be due, in part, to a language barrier for Latino patients whose primary language is Spanish. Another proposed explanation is the cultural difference from typical Hispanic/Latino paternalistic care and the more independent and choice-based care found in the United States.

Latino patients are also accustomed to having ample time to familiarize themselves with their healthcare providers in order to establish rapport and a comfortable speaking environment in which they can share their personal health matters (Chong, 2002). Additionally, a portion of this population that have recently immigrated is accustomed to lengthy and personalized meetings with their providers to discuss the factors in their life that they believe may be contributing to their illness. The fast-paced, commercialized healthcare system in the United States imposes strict consideration of schedules, abbreviated medical visits, and the ever-climbing cost of healthcare and pharmaceuticals on Latinos, especially harming those who have not yet learned to navigate these services.

Many Latino communities in South Carolina are traditionally underserved and often face conditions that perpetuate a low socioeconomic status. Lower socioeconomic status is associated with lower health literacy, meaning less understanding of medical terminology and practices, cultivating patients that cannot advocate for themselves in medical settings. If proper care is not taken to ensure that the patient understands the gravity of the diagnosis and the vitality of

treatment, it follows that patients will continue to prematurely halt pursuit of care. For this reason, South Carolina needs a map - accessible both online and at community centers - that will present the locations for treatment and indicate the different services which they offer so that patients can proceed to receive treatment with accurate expectations of what the clinical interaction will or will not involve.

V: Part II: Bilingual Map of HIV Treatment Centers in South Carolina (Español)

Proveedores de Cuidado Médico Contra el VIH en Carolina del Sur



19/4/2022

1:2,888,959
0 20 40 80 mi
0 30 60 120 km
Sources: Esri, HERE, Garmin, FAO, NOAA, USGS, © OpenStreetMap contributors, and the GIS User Community

VI: Major Findings

The focus group consisted of 5 total participants comprised of four males and one female. The average age of the participants was 47, with the youngest being 33 years old and the oldest 68. Two of the participants were from Mexico and the other three came from Colombia, Puerto Rico, and Venezuela. Two are currently living in Columbia, while each of the others reported living in Simpsonville, Gaston, and Greenville. All participants acknowledged at least 11-14 years of school completion with the exception of one responder who completed 18 years. Lastly, the average age of HIV diagnosis was found to be 15 with the lowest being 6 years and the oldest, 26.

There are four themes that emerged from the focus group: I came here for health and a better life; HIV means death; I am not sure what HIV care and treatment services mean; and, South Carolina lacks HIV resources for Latino communities. While many may seem self-explanatory, all are deserving of greater detail.

Many factors in Latin America contribute to the difficulty of HIV prevention, treatment, and care for citizens. Stigma, social, economic and cultural factors can create barriers and mistrust of the healthcare system provided in those countries. The participants who moved to the United States (US) acknowledged that the political, social, and economic factors in their countries made it difficult for them to survive there, especially with an HIV diagnosis. One responder stated:

“... la situación política de mi país. Le negaron la ayuda y los medicamentos. Cosas manejadas por militares, pedían cosas que no eran válidas como hablar bien del gobierno, ser de un partido político para recibir tratamiento.”

English translation: "...the political situation in my country. They deny help and medications. Things are handled by the military, they ask things that are not doable like speak well about the government, be part of the current political group to receive treatment."

Although another Latino reported that his country is touted as a leader in HIV treatment, the healthcare system is far too bureaucratic as explained in his comment:

"Vine porque la aseguradora me daba medicación por tres meses pero luego hay que validar la documentación y suspenden el tratamiento por meses. En el trabajo se enteraron y fui despedido porque la ley no protege la privacidad."

English translation: "They found out at work and I was fired because the law does not protect one's privacy."

Participants indicated that there were major barriers that deemed it almost impossible for them to feel safe and/or accepted by the HIV system of care in their native countries. Seeking a drastic change to improve their HIV outcome and their livelihood, four of the five participants made bold moves to the US to improve their opportunities for securing a better life.

Although medical advancements related to HIV care and treatment have drastically improved the lives of many suffering a positive diagnosis, it appears Latinos still oftentimes fall prey to the misconception that an HIV+ diagnosis means death. When asked, "What were your perceptions of HIV prior to receiving a diagnosis?" every respondent used terms like:

"Significaba muerte" (signifies death),

"No hay tiempo, poco tiempo" (there is no time, little time)

"Ya no hay oportunidad de nada" (there is no opportunity for anything),

"Fatalista" (it's fatal),

"La muerte es lo primero que se me ocurre" (death is the first thing that comes to mind).

Although a cure for HIV continues to elude scientists across the globe, new innovations in medicine and care have made it possible to dramatically slow the progression of the disease. In fact, many people today live with HIV, rather than die with HIV. This is not to say that people with HIV will not experience complications with the disease, but with the proper HIV care, treatment, and management plan, HIV-infected people can live full and healthy lives.

Regular and sustained HIV care and treatment, which includes initiating and maintaining antiretroviral therapy (ART), receiving ongoing and regularly scheduled care with healthcare providers, case managers, and drug counselors to address medical, mental health, substance use or structural issues is important to significantly lower one's viral load. The HIV Continuum of Care provides a conceptual framework to help guide people diagnosed with HIV through different stages of care. As previously mentioned, the steps include diagnosis, linkage to care, receipt of care, retention to care, and achievement and maintenance of viral suppression (HIV.gov, 2020).

When asked, "What does HIV-related care and treatment services mean to you?", the majority of participants responded with information characteristic of an HIV 101 health education primary prevention activity. The following are examples of how the responders described their perception of HIV-related care and treatment services:

"No infectar a la gente" (not to infect people)

"Precauciones" (take precautions)

"Cuidarse" (take care of yourself)

"Usar preservativos" (use condoms)

"No tomar licor, ir a fiestas" (don't drink liquor, go to parties)

"No comparto nada con nadie" (don't share anything with anyone)

These aforementioned descriptions provided by the focus group need to be considered when attempting to make strides in improving retention of care for this population. Ensuring that HIV care and treatment providers communicate what the HIV Care Continuum is and how it works will help to increase opportunities for the HIV-positive Latino population to become and remain fully engaged in their HIV care and treatment. It is important for those who are HIV-positive to understand that they must seek and remain in care, a task that can be difficult considering a language barrier to care.

Lastly, South Carolina Lacks HIV Resources for Latino Communities. An unsurprising but disappointing finding to most residents and professionals in South Carolina, the state remains inadequately prepared to provide quality or equitable public health and emergency preparedness services to Spanish-speaking residents. This fact grows more negatively impactful as the growth of this population in the state continues. For the HIV-positive Latino group, lack of Spanish-friendly HIV resources was mentioned by all focus group representatives. As one participant stated:

“Tengo una preocupación...en SC para las personas Hispanas es muy limitado, sino que hay una barrera, pero hace falta una persona que ayuda a los Latinos. Hace falta asesoría legal”

English Translation: I am worried...things are very limited for the Hispanic people in SC, there is a barrier because there is no one who can help Latinos. There is no one to provide legal advice.

Other participants added:

“Hacen falta recursos” (resources are needed).

“Las agencias son todos americanos, y no ayuda con la renta, con comida. Si no tenemos papeles no quieren darte nada” (the agencies are all American and they don’t help with rent, with food. If we do not have papers, they do not want to give us anything)

“... aquí no hay mucha ayuda” (there is not much help here).

In examining these findings, three guiding questions were developed in order to assess the availability of Spanish resources for patients in HIV treatment centers across the state of South Carolina. There are thirty-four providers in South Carolina, and all were interviewed via telephone. Six of the thirty-four explicitly indicated that they have bilingual staff that speak directly with HIV patients. Twenty-four of the providers reported that they either have interpreters on-site or available via remote services. Most clinics stated that they have Spanish resources, although many reported having less resources in Spanish than in English and three of the clinics denied having access to these resources in Spanish at all. Though many of the clinics could definitely benefit from additional oral and written resources in terms of Spanish-speaking patients, all clinics considered themselves understanding and flexible with regard to meeting the needs of Spanish-speaking patients.

These findings bolster the need for more bilingual resources, cultural competency training for providers, and more Spanish-speaking medical professionals in the HIV treatment setting in South Carolina. In order to provide the “better life” that many Latinos come to the United States seeking, South Carolina needs to improve the number of resources tailored to this population. The map resource developed as part of this project aims to make strides toward this goal by ensuring that patients feel well-equipped to attend healthcare visits and remain in treatment for HIV. Further, outlining which resources are available is a necessary step to ensure

that the patients may make an informed decision on which center best fits their needs linguistically.

VII: Limitations

Due to the fact that data collection occurred during the COVID-19 pandemic, the people who participated in the focus groups hosted by PASOs were mostly recruited from the HIV treatment clinic. These are the people who are retained in treatment, which may present a biased set of data and perspectives from these sessions.

Owing to these limitations, along with the small sample size, the collected themes and results were compared with data taken from larger studies in order to expand both the scope and reach of this study. The data from the team at PASOs was compared with data collected on different demographics as well as with other data focused on similar target populations, i.e., relating to barriers encountered by Latino community members seeking HIV treatment.

VIII: Recommendations

The perspectives of Latino patients and HIV care providers culminate in this essay to present a compelling argument for the expansion and distribution of resources targeted to this population of HIV-positive Latino patients. In response to this need, the thesis proposes a bilingual map as a small-scale fix for this large-scale, far-reaching disparity in care. This research could be extended to support many more strategies to address this issue, such as offering cultural competency training for the HIV care providers in South Carolina (and in other states) and ensuring the availability of bilingual resources at clinics.

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