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A Thematic Analysis Of Resilient Experiences Of People Who Use Drugs And Are Living With Hiv Adhering To Hiv Medicine

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A THEMATIC ANALYSIS OF RESILIENT EXPERIENCES OF PEOPLE WHO USE DRUGS
AND ARE LIVING WITH HIV ADHERING TO HIV MEDICINE

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A THEMATIC ANALYSIS OF RESILIENT EXPERIENCES OF PEOPLE WHO USE DRUGS
AND ARE LIVING WITH HIV ADHERING TO HIV MEDICINE

by

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THESIS

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ABSTRACT

Human immunodeficiency virus (HIV) is a disease acquired through sex, from mother to child, sharing needles, and open wound exposure to the blood-borne virus. The disease leads to the rapid weakening of the immune system which renders the individual vulnerable to various opportunistic infections, cancer, disease progression into acquired immunodeficiency virus (AIDS), and possibly death. Unfortunately, US Latinos are disproportionately affected by HIV as they account for nearly 30% of all new HIV infections. A subpopulation disproportionately affected also are people who inject drugs (PWID) which account for 1 in 10 HIV diagnosis in the U.S.

Modern medicine has allowed people living with HIV to live long, healthy lives with the use of antiretroviral medication (ART) and the guidance of primary care physicians. However, many people, especially underserved minority populations, have a difficult time receiving treatment because of various barriers which lead to health disparities and health inequity. A few barriers include lack of health insurance, untreated mental illnesses, cultural and linguistic barriers, poor access to healthcare due to poverty, inadequate formal education, and stigma related to HIV (Greenaway et al., 2020). All of these factors negatively impact the person's ability to enter any stage of the HIV treatment cascade which includes an HIV diagnosis, linkage to care, retention in care, adherence to ART, and achieving and maintaining viral suppression. A person's continuous progression through the stages of the HIV treatment cascade is crucial for them to receive the care they need at any stage of their disease and ensure their long term health.

The purpose of this study was to understand the experiences that impact people who inject drugs (PWID) living with HIV, and residing on the U.S.-Mexico border, in seeking medical treatment and the factors that facilitated remaining in medical care. A secondary data

analysis of a qualitative study was undertaken to understand the factors that may drive an individual to enter medical treatment, remain in care, and adhere to their HIV medication. A resilience framework was employed to analyze the data. Results revealed several resilience factors which include community and social network support, individual level thoughts and behaviors that promote positive adaptation, and process of transformation that enables determination.

The study findings contribute to the understanding of the role of resiliency among Latinos who use illegal drugs and are living in a medically underserved setting. Findings may help public health and medical professionals to develop interventions to promote resilience and motivate Latinos to enter the HIV treatment cascade sooner. Moreover, interventions can be tailored to address the needs of disadvantaged populations to bridge the health equity gap in infectious disease treatment.

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LITERATURE REVIEW

THE HIV EPIDEMIC IS A DISEASE OF INEQUALITY

Human immunodeficiency virus (HIV) is a disease that affects the body's immune system. The HIV virus can be transmitted in various ways including unprotected anal and vaginal sex, sharing needles, syringes, or other drug injection equipment, and from mother to baby during pregnancy, birth, or breast feeding (Centers for Disease Control and Prevention; CDC, 2022). Behaviors that expose a person to the bodily fluids of another person who may already have HIV are considered high risk. Body fluids with high concentrations of the HIV virus in a person who is living with HIV include blood, semen, pre-seminal fluid, rectal fluids, vaginal fluids, and breast milk (CDC, 2021). These fluids must come into contact with a mucous membrane (found inside of the rectum, vagina, penis, and mouth), damaged tissue, or directly injected into the bloodstream for transmission of the HIV virus to occur (CDC, 2021).

Untreated HIV develops into acquired immunodeficiency virus (AIDS) which makes it difficult for people to fight off infections (CDC, 2021). HIV is a chronic disease as currently there is no known cure. Once a person acquires HIV, they have it for life (CDC, 2021). In 2019 the CDC reported approximately 34,800 new HIV infections in the United States. Of those numbers, 29% (approximately 10,200) were among Latino people. Latina women accounted for 13% of the new HIV infections in 2019. In 2019, the primary forms of HIV transmission among Latina women were heterosexual contact (87%) and injection substance use (13%) (CDC, 2022). Latino males accounted for 4% of the total new HIV infections. The primary forms of transmission among Latino males were male-to-male sexual contact and injection substance use (CDC, 2022).

The HIV epidemic has had a devastating effect on the health of populations and unfortunately racial and ethnic minority populations have been disproportionately affected. In the United States, racial and ethnic minority groups are the most affected by HIV, especially non-Latino whites (CDC, 2019). In 2019, Latinos accounted for 18.5% of the US population yet accounted for 24.7% of new HIV infections (CDC, 2019). Similarly, Black/African Americans accounted for 13% of the total U.S population and for 40% of new HIV infections (CDC, 2019). Non-Latino whites accounted for 28.5% of new HIV infections (CDC, 2019).

In 2019, Black/African American populations in the U.S were 8.1 times more likely to be diagnosed with HIV infection, as compared to non-Latino whites (*Office of Minority Health, 2021*). There are also disproportionate disparities in mortality rates among US ethnic and racial minorities. For example, African Americans are 6.4 times more likely to die from HIV infection than non-Latino whites. Black/African American females, in particular, are 14.5 times more likely to die of HIV infection compared to non-Latino white women (*Office of Minority Health, 2021*). Latino populations are also disproportionately affected by high HIV mortality. In 2019, both Latino males and females were four times as likely to have either HIV infection or AIDS compared to non-Latino whites (*Office of Minority Health, 2021*). Additionally, Latino men are two times more likely than non-Latino white men and Latina women are three times more likely than non-Latina white women to die from HIV infection (*Office of Minority Health, 2021*).

HIV is a concentrated epidemic as it primarily affects specific subpopulations such as persons who inject drugs (PWID), men who have sex with men, and individuals who engage in sex work (CDC, 2022). A primary form of HIV transmission among PWID is sharing drug use paraphernalia. Sharing needles, syringes, or other equipment to inject drugs puts people at risk for acquiring and/or transmitting HIV or other blood-borne illnesses (CDC, 2022). PWID make

up approximately 1 in 10 HIV diagnoses in the U.S (CDC, 2022). In 2018, it was reported that 1.2 million people in the U.S and U.S territories were diagnosed with HIV (CDC, 2022). Approximately 186,500 of those infections were attributed to injection substance use (CDC, 2022). Additionally, individuals with a substance use disorder are at higher risk of contracting HIV through sex as they may have unprotected sex while under the influence of alcohol or drugs. Individuals who have sex while under the influence of drugs are more likely to engage in risky sexual behaviors such as condomless sex or sex with multiple partners (CDC, 2022). Black/African American people have the second highest HIV incidence among people who inject drugs accounting for 26% of people living with HIV in 2018. Latinos were not far behind accounting for 22% of new HIV diagnoses among people who inject drugs (CDC, 2022).

There are many factors that contribute to the disproportionate morbidity and mortality due to HIV among ethnic and racial minority populations in the U.S. which I will discuss next.

FACTORS THAT CONTRIBUTE TO HIV INCIDENCE, MORBIDITY AND MORTALITY DISPARITIES AMONG US LATINOS AND PWID

The HIV treatment cascade refers to the recommended health care model to reduce HIV viremia at the population level. The HIV treatment cascade refers to 5 stages of HIV care that people living with HIV (PLWH) should pass through to ascertain better health outcomes and reduced HIV forward transmission (Kay et al., 2016). The 5 stages of the HIV treatment cascade include diagnosis, linkage to care (LTC), retention in care (RIC), adherence to antiretroviral therapy (ART), and viral suppression (Kay et al., 2016). The HIV treatment cascade has been useful to assess progress made in achieving national prevention and treatment goals (Guilamo-Ramos et al., 2020). The HIV treatment cascade is considered a dynamic and bidirectional care

model because HIV care engagement occurs at the individual level and because according to experts, the true nature of HIV care is nonlinear (Kay et al., 2016). Non-linearity means that it takes several attempts to get individuals linked to care and virally suppressed because a single care visit does not always lead to viral suppression for a variety of individual and structural level factors (Buchacz et al., 2015). The individual may need to be re-engaged in HIV care more than once to achieve viral suppression after being first diagnosed and/or throughout their lifetime (Buchacz et al., 2015).

The HIV treatment cascade must begin with a diagnosis. As per current CDC guidelines, healthcare providers should offer every patient who is between the ages of 13 and 64 an HIV test (Kay et al., 2016). Making testing more accessible to people through at-home HIV tests and routine rapid HIV tests with availability of results in under 30 minutes have contributed to the normalization of HIV testing at routine doctor's visits (Kay et al., 2016). Unfortunately, compared to the general population, Latinos are less aware of their HIV-positive status, and more than half of all Latinos have never been tested for HIV (Guilamo-Ramos et al., 2020). Of these numbers, it is estimated that 17% of HIV-positive Latinos are unaware of their HIV status (Guilamo-Ramos et al., 2020).

After diagnosis, the next step in the HIV care continuum is linkage to HIV care. The CDC and the Institute of Medicine indicate that individuals diagnosed with HIV should be linked to care within 3 months of the time the individual is diagnosed (Kay et al., 2016). If a person is linked to treatment within 3 months after diagnosis, they are more likely to achieve viral suppression (Kay et al., 2016). Viral suppression refers to maintaining a low blood HIV viral load (CDC, 2022). A person living with HIV can have an undetectable viral load when they have less than 200 copies of HIV per milliliter of blood (CDC, 2022). However, the proportion of

PLWH in the U.S who are linked to care within three months post-diagnosis is between 59% and 80% which is lower than the rate set forth by the National HIV/AIDS Strategy (NHAS) in 2020 of 85% (Kay et al., 2016). Unfortunately, evidence indicates that Latinos have a significantly lower rate of receiving HIV care after a positive HIV diagnosis because of various contributing social factors (Guilamo-Ramos et al., 2020) which I discuss below.

Retention in HIV care is the third step on the HIV care treatment cascade continuum. Kay et al., (2016) indicates that there is a lack of consensus about what is the best measure of retention or continuity in HIV care. However, the CDC (2022) defines it as PLWH who have had two or more visits for routine HIV medical care within a 12-month period. Retention, when defined as a minimum of two medical care visits in 12 months, has been a significant predictor of positive clinical health outcomes (Reveles et al., 2015). Research has shown that the number of missed appointments for HIV care has been associated with higher viral loads and lower CD4 counts which are the cells that help the immune system fight disease (Reveles et al., 2015). Antiretroviral therapy, also known as ART, is medication to treat HIV disease. Retention in HIV medical care is also associated with adherence to ART or medication to reduce HIV viremia. ART adherence is recommended for PLWH to maintain suppression of viral load, maintain high CD4 cell counts, prevent the progression of the virus into AIDS, prolong lifespan, and reduce the risk of HIV transmission to others (CDC, 2019). ART adherence is measured through a patient's self-report and there is no standard indicator that confirms the patient's consistency in taking ART as prescribed (Thompson et al., 2012). Typically, only a brief snapshot of a patient's three-day adherence will be monitored (Kay et al., 2016).

The final stage of the HIV care continuum is achieving viral suppression. According to the CDC (2022), when a person has a viral load is less than 200 copies per milliliter (c/mL) of

blood, he/she is considered virally suppressed. In 2019 approximately 65.5% of people living with HIV were virally suppressed (CDC, 2021). It is important to understand the factors that account for disparities in the proportion of Latinos living with HIV who fall out of the HIV care continuum. Past research suggests that acculturation, socioeconomic characteristics, and trust with medical providers impact the progression of Latinos in the HIV care continuum (Levinson et al., 2018). As stated above, Latinos are more likely to be “late testers” for HIV and are more likely to be diagnosed with later stages of HIV (CDC, 2010). Additionally, this also means that Latinos are more likely to have other complications such as opportunistic infections, lower CD4 cell counts, and hospital stays that are longer than non-Latino whites (Swindells et al., 2002).

For PWID, the CDC (2021) reported 98,290 HIV diagnosis in 2019. Of those new diagnoses, 68.0% received HIV medical care and approximately 57% were virally suppressed at the most recent viral load test (CDC, 2021). Additionally, 20% of all HIV diagnoses among Latinos were in stage 3 (AIDS) (CDC, 2021).

In the next section, I will discuss some of the factors that account for the health disparities that disproportionately impact Latinos living with HIV. Health disparities are defined as preventable health outcomes that are caused by factors that mostly affect racial and ethnic minority populations including injury, violence, and social disadvantage (CDC, 2020). Racial and ethnic minorities are likely to suffer from a variety of negative health outcomes that can be attributed to social determinants of health (SDOH). These determinants are the conditions in which people are born, live, learn, work, play, worship, and age (Office of Disease Prevention and Health Promotion, n.d.). A few examples of SDOH include experiencing discrimination, the condition in which a person lives, access to transportation, experiences with violence, the amount of and access to education, socioeconomic status, access to community resources, polluted

environment, language, and literacy skills (ODPHP, n.d.). The poor quality or lack of these resources has an impact on the health of a person. Addressing health disparities is important because it will give racial and ethnic minority populations a more equitable opportunity to achieve health.

Health disparities are caused by a variety of social determinants that contribute to worse health outcomes, and higher rates of morbidity and mortality for certain diseases and infections, especially in minority populations. This is because racial-ethnic minorities are more likely to be socioeconomically disadvantaged, have less formal education, experience racism and discrimination, and many other underprivileged circumstances (Zhang et al, 2017). Latinos face many barriers when trying to address HIV-related medical concerns such as barriers to HIV testing, prevention and treatment (CDC, 2022). Other main contributors to health inequity include poor access to healthcare due to poverty, xenophobia, mistrust in the healthcare system, and cultural and linguistic barriers (CDC, 2022). According to Del Rio (2011) other social determinants that contribute to poor health outcomes include lack of transportation, being too sick to see the doctor, and lack of resources for minimal survival (e.g., rent, bills, food) which outweigh the cost of seeing a doctor and contributes to delay in seeking HIV care among Latinos.

Latinos are the fastest-growing minority population in the United States, and it is estimated that this population will double in size by the year 2050 (Flink, 2017). Unfortunately, Latinos are less likely to receive a college degree compared to non-Latino whites. A few factors that pose as barriers to the academic success of Latinos include social and political barriers (Flink, 2017). Additionally, Latinos face challenges on university campuses that add to the stress of the already difficult workload which affects their psychological well-being and academic

success (Flink, 2017). Some of these challenges include discrimination, stereotyping, and feeling of not belonging. Not only is this a significant issue during the years of attending a university, but many factors before then are also a contributing factor to the challenges faced. Adequate education may be hindered in Latino communities because of neighborhood segregation, school segregation, language barriers, and reduced economic resources (Cianelli & Villega, 2016).

Latinos are the fastest-growing minority population to enroll in college (Jr. et al., 2021). However, in terms of college degree attainment, Latinos remain the ethnic group with the lowest proportion of college graduates (Jr. et al., 2021). Moreover, the number of Latina women who had a high school diploma compared to non-Latina white women was significantly lower. Only 64.4% of Latinas attained a high school diploma or greater compared to 88.2% of non-Latina white women (Cianelli & Villegas, 2016). Further, in 2018, Latinas accounted for 26.6% of any college degree attained compared to 51.4% of non-Hispanic white women (Jr. et al., 2021). Latino males represented only 20.7% of college graduates with any college degree compared to 44.3% of non-Hispanic white men (Jr. et al., 2021). Education has a long-term impact on the health of racial and ethnic minorities. People with more education are more likely to live longer, experience better health outcomes, and practice health-promoting behaviors such as HIV prevention (Cianelli & Villegas, 2016). How much education a person receives, and the quality of that education is reflected in increased knowledge about health, problem-solving, coping skills, and better-informed health-related decisions for themselves and family members (Cianelli & Villegas, 2016).

Latinos and other ethnic and racial minorities are more likely to experience various forms of discrimination. As cited by Guilamo-Ramos et al., (2020), The Ryan White HIV/AIDS program is one of the largest systems of care for individuals who are living with HIV with over

\$70 million dollars in increased funding designated in the presidential budget proposal for 2020. Unfortunately, Latinos with certain demographic characteristics such as undocumented status do not benefit from this program because of the infringement on civil liberties due to policies enacted by the Presidential administration which excludes or extremely restricts immigrants and sexual and gender-identity minorities from accessing health and social services in general (Crowley & Bland, 2021). For example, the Patient Protection and Affordable Care Act was signed into law in 2010 and would have provided health insurance to all people in the U.S. However, undocumented individuals were deemed ineligible to receive any coverage or services (Chang, 2019). The people who are disproportionately affected by HIV are the people who have the most challenges receiving treatment which renders the health of the Latino community one of the most negatively affected.

U.S. Latinos experience poorer clinical outcomes once diagnosed with HIV compared to non-Latino whites (Levinson et al., 2018). HIV results in physical challenges such as opportunistic infections and side effects from antiretroviral medication. Additionally, societal factors negatively affect a person's mental and emotional health. For example, people living with HIV deal with the stigma society has about the disease which leads to marginalization and discrimination. Latino populations are also prone to discrimination because of their ethnicity which contributes to the negative political climate regarding immigration in the U.S (Jones-Correa et al., 2018). In addition, Latino people who are also members of the LBGTQ+ community also suffer from the negative effect of societal homophobia. All of the above-mentioned factors can promote engagement in risk-taking behaviors and impact knowledge of HIV status, HIV care, and other needed services among Latino populations.

The Latino health paradox according to Levinson et al., (2018) is a theory that explains the relatively good health profiles such as life expectancy, birth weight and mortality from cancer of Latinos despite the challenges that this population faces such as high rates of poverty, low education, and other social determinants of health. However, compared to other diseases, HIV infection is one of the diseases where health outcomes are worse among Latinos than in non-Latino whites (Levinson et al., 2018). Levinson et al., (2017) highlights barriers to HIV care and treatment among Latinos living with HIV infection which include but are not limited to, lack of health insurance coverage, unaffordable medical expenses, fear of legal consequences including deportation, lack of social support, and limited opportunities for financial stability. A review by Geter Ferguson et al., (2019), identified clusters of barriers that affect access to HIV prevention services, ART adherence, retention in HIV care, and viral suppression among U.S. Latinos. The major barriers include stigma from medical personnel, medical mistrust, language barriers when accessing care for HIV, and fear of seeking medical services due to immigration status.

The barriers to HIV care and treatment that Latinos face are reflected in the most recent numbers of individuals who received HIV care, remained in care, and were virally suppressed issued by the CDC in 2019 (CDC, 2022). Approximately 74% of Latinos living with HIV received HIV care, 65% were retained in care and 59% were virally suppressed. The adversities and barriers faced by Latinos are also reflected in the higher HIV-related mortality rates. For example, Latino men are twice as likely to die of HIV-related causes compared to non-Latino whites, and Latina women are 3 times as likely to die of HIV infection compared to non-Latino whites (Office of Minority Health, 2021).

HIV DISEASE, VIRAL SUPPRESSION AND ADHERENCE TO HIV MEDICATION AMONG LATINOS

A major barrier to engaging Latinos living with HIV in HIV health services is stigma (Levinson et al., 2018). As cited by Li et al., (2017), various factors have contributed to the societal stigma around HIV that include homophobia and HIV/AIDS phobia. Many efforts have been made to reduce the stigma HIV stigma which include regular HIV testing and treatment services through targeted community awareness efforts (Li et al., 2017). Research has shown that these efforts have contributed to an increase in service utilization and a decrease in stigma regarding testing, prevention, and treatment (Guilamo-Ramos et al., 2020). Additionally, recent interventions regarding reducing HIV stigma that show promise are ones that involve community leaders who are PLWH and from minority-driven advocacy organizations (Li et al., 2017). A community-based research project called Community Champions HIV/AIDS Advocates Mobilization Project (CHAMP) was implemented among minority leaders in the Greater Toronto Area. This intervention aimed to assess the effectiveness of Acceptance and Commitment Therapy/Training (ACT) and Social Justice Capacity Building (SJCBC) in reducing HIV stigma (Li et al., 2017). This intervention focused on increasing the knowledge of participants by emphasizing the connection between health, equity, and social justice and building capacity in advocacy and community mobilization (Li et al., 2017). The intervention had an impact on decreasing HIV/AIDS stigma (Li et al., 2017).

Stigma continues to be an important factor that is linked to reduced treatment seeking and adherence to HIV medication among people living with HIV (Katz et al., 2013). In 2015, the CDC (2022) expanded the Medical Monitoring Project (MMP) which is a nationally representative population-based surveillance system that provides data from people who have

been diagnosed with HIV including clinical outcomes, behaviors, and quality of care. The MMP recorded the median score for people with HIV who have experienced stigma using a ten-item scale that ranges from 0 (no stigma) to 100 (high stigma) (CDC, 2022). The scale measures personalized stigma, negative self-image, concerns about status disclosure, and perceived public attitudes about people living with HIV (CDC, 2022). In 2019, the median score for HIV stigma among people living with HIV was 31 (CDC, 2022). Many efforts in research and community organizing are being made to decrease HIV-related stigma. An analysis by Katz et al., (2013), indicated that HIV-related stigma negatively affects ART adherence due to a lack of adaptive coping and social support. Additionally, social determinants which include social support and adaptive coping had a critical impact on an individual's means to overcome structural and economic barriers to adhere to ART (Katz et al., 2013).

Health care providers recommend that ART medication be taken regularly to keep the immune system working, prevent illness, and keep the amount of virus in a person's body low (CDC, 2022). Achieving viral suppression is crucial for people living with HIV because it will result in improvements in the person's health, quality of life, and life expectancy (CDC, 2022). Additionally, viral suppression helps to prevent transmission of the virus to other people through sex, syringe sharing, and from mother to child during pregnancy, birth, and breastfeeding (CDC, 2022). According to the CDC (2022), when a person who is infected with HIV has an undetectable viral load, there is effectively no risk of HIV transmission through sexual contact. For mothers living with HIV, there is a > 1% risk of the baby acquiring HIV through pregnancy, labor, and delivery. The risk of transmission is also significantly reduced when people who use drugs share syringes or other drug injection equipment if the person living with HIV maintains an undetectable viral load (CDC, 2022).

There are several factors that have been associated with reduced adherence to HIV medication and viral suppression among Latinos. Latinos face many challenges receiving HIV prevention and treatment services which in turn result in a later HIV diagnosis, poor adherence to ART, and mental health complications that may go untreated (CDC, 2010; Swindells et al., 2002). In 2019, 22% of all people living with HIV experienced depression and/or anxiety symptoms (CDC, 2022). Of those numbers, 22% were Latinos who reported experiencing depression and/or anxiety symptoms within 12 months of being diagnosed (CDC, 2022). This is troublesome because people living with HIV who experience mental health symptoms may have trouble adhering to ART and achieving viral suppression (CDC, 2022).

Homelessness is another contributor to health disparities including disparities in HIV infection and treatment. Receiving HIV care and treatment can be a challenge for people experiencing any type of homelessness (CDC, 2022). There are approximately 643, 067 people in the U.S that are experiencing homelessness on any given night (Green Door, n.d.). Approximately 1 in 10 (9%) of all people living with HIV experienced homelessness in 2019 (CDC, 2022). As cited by Chang (2019), undocumented immigrants, including Latinos in the US, are a vulnerable population that is at risk of experiencing homelessness. Latinos and many undocumented immigrants are subject to housing insecurity because of low-wage jobs that are not sufficient to cover the cost of living (Chang, 2019).

Health literacy is another important factor that impacts the health of an individual. The U.S Department of Health and Human Services, Healthy People 2030 defines personal health literacy as an individual's ability to find, understand and use information and services to advocate for any health-related decisions for themselves (Healthy People 2030, n.d.). Healthy People 2030 has set objectives to improve health literacy which include increasing the proportion

of adults for whom health care providers check their understanding of health-related information and decreasing the proportion of adults who report poor communication with their health care provider (Healthy People 2030, n.d.).

Education plays a vital role in an individual's health as it is associated with greater health literacy skills, which in turn has an impact on tackling barriers that contribute to health disparities (CDC, 2022). The National Center for Educational Statistics (2022) reported an increase in public high school graduations in the 2018-2019 school year, with a total of 86% graduations in the country. Of those numbers, 82% were reported to be among Latinos (National Center for Education Statistics, 2022). However, Latinos continue to be among the lowest populations to have received some form of a college degree compared to non-Latino whites (Schak & Nichols, 2019). In 2016, Latinos accounted for 22.6% of all college degrees attained, as opposed to non-Latino whites who accounted for 47.1% (Schak & Nichols, 2019)

Sentell & Braun (2012) conducted an analysis to understand how health literacy and English proficiency (LEP) was associated with the health status of Latinos, Chinese, Korean, Vietnamese, and white samples. Sentell and Braun (2012) used the California Health Interview Survey (CHIS) which consisted of a random-digit-dial telephone survey in 5 different languages (English, Spanish, Mandarin, Cantonese, Korean, and Vietnamese) administered to 51,048 adult participants in California. The Latino participants in the study reflected the second highest prevalence of low health literacy at 45.3%. In addition, 73.4% of Latinos had less than a high school degree (Sentell & Braun, 2012). The study also revealed that Latinos were among the populations with the poorest health status with the majority having both LEP and low health literacy (Sentell & Braun, 2012). The overall conclusion of the study was that LEP was prevalent among individuals who self-reported low health literacy (Sentell & Braun, 2012). Additionally,

individuals who reported both LEP and low health literacy had a high prevalence of poor health status (Sentell & Braun, 2012). Educational attainment, health literacy skills, and limited English proficiency have all been shown to be barriers to good health status among Latinos. Kalichman & Rompa (2000) indicate that more interventions are needed to improve health literacy because of its association with poorer health outcomes among people living with HIV.

Social support from trusted individuals such as friends and family and/or social support from support groups for people living with AIDS (PLWA) has shown to be effective in positively influencing the quality of life, increasing coping skills, and increasing empowerment among PLWA (Spirig, 1998). Studies have shown that support groups tailored to people living with HIV (PLHIV) improves a person's quality of life and retention in HIV care and can lead to positive health (Bateganya et al., 2015). Additionally, an individual living with HIV may decide to disclose the status to friends, family, or other trusted individuals to garner social support (Smith et al, 2008). Disclosing HIV status can have a positive impact on a person living with HIV because it may allow the person to cope with health concerns by increasing their perceived efficacy to enact healthy behaviors (Smith et al., 2008). Studies have shown that perceived efficacy to enact healthy behaviors among PLHIV has a positive impact on the person's health and well-being (Smith et al., 2008). However, HIV status disclosure can also cause tension and expose the individual to increased stigma and shame.

HIV PREVENTION AND TREATMENT AMONG PWID

As stated above, HIV is an epidemic that disproportionately affects subpopulations such as PWID. PWID are at increased risk of contracting HIV due to engagement in drug use and sexual risk behaviors. HIV risk behaviors include sexual encounters without condom use which

increases the risk of acquiring or transmitting HIV infection through sexual activity and sharing needles (CDC, 2022). According to the CDC (2021), Latino PWID were less likely to receive HIV medical care, achieve viral suppression, and maintain retention in care compared to other PWID from other ethnic groups. Additionally, 2019 data indicates that 78.8% of male Latinos PWID were linked to HIV care and 54% achieved viral suppression within 6 months of their HIV diagnosis. Among Latina PWID, 80.9% were linked to care and 56.2% achieved viral suppression (CDC, 2021). The factors that contribute to the increased risk of HIV and the reduced viral suppression among PWID, once diagnosed with HIV, are the same as discussed above. However, these factors are exacerbated as a result of substance misuse.

HIV DISEASE AMONG RESIDENTS OF THE US-MEXICO BORDER

Latinos living on the US-Mexico border experience many barriers that inhibit HIV testing, prevention, and treatment. In 2017, the Texas Department of State Health Services (Texas Department of Health Services [TDHS], 2020), recorded 4,391 new HIV diagnoses. Moreover, there are 90,700 people living with HIV in Texas. The Texas-Mexico border accounted for 321 new HIV diagnoses with a total of 5,120 people living with HIV (TSHS, 2020). In El Paso County alone, there were 124 new HIV diagnoses and a total of 2,179 people were living with HIV (TDHS, 2020). Latinos accounted for most new HIV diagnoses (91%) and people living with HIV (90%) on the Texas-Mexico border. Vulnerable populations that include PWID and men who have sex with men (MSM) accounted for 5% and 7% of people living with HIV, respectively (TDHS, 2020). Regarding HIV treatment, in 2017, Gardner's analysis of the numbers for PLHIV who had successfully transitioned from each step of the HIV treatment cascade in Texas and the Texas-Mexico border region revealed that PLHIV residing on the

Texas-Mexico border were less likely to report at least one health care visit or laboratory test and be retained in care compared to PLHIV in the rest of Texas. However, slightly higher numbers of PLHIV on the Texas-Mexico border were virally suppressed compared to PLHIV in the rest of Texas (TSHS, 2020).

In summary, most prior research on the factors that inhibit entering and progressing through the HIV treatment cascade has elucidated the factors that negatively impact HIV diagnoses, entrance and retainment in HIV care, and ultimately adherence to ART medication. Most of the prior research has approached the study from a deficits-based perspective. Recent advances in positive adaptation indicates that resilience promotes positive adaptation. There is a dearth of studies on HIV treatment retention and medication adherence conducted to understand the factors that promote a successful progression through the steps of the HIV treatment cascade among PLHV and to my knowledge no study has explored entrance to care, retention in care, and adherence to medications among Latinos who misuse substances. In the next paragraphs, I define resilience.

RESILIENCE: A DEFINITION

A person must encounter one or more experiences of adversity to be afforded the opportunity to demonstrate resilience. Resilience is defined as a set of behaviors over time that reflect the interactions between individuals and their environments, in particular the opportunities for personal growth that are available and accessible (Ungar, 2010a, 2010b, 2011b). To date, researchers agree that resilience must be viewed from an socioecological perspective. A person's environment and social support from friends, family, cultural influence, and community organizations contribute significantly to a person's positive coping after adverse

experiences (Ungar, 2011). According to Ungar (2011), resilience has been mostly defined as a person's individual capacity to adapt positively in the face of adversity. This definition conceptualizes resilience as an immutable individual level characteristic or trait. The most recent literature on the study of resilience debates whether resilience is a trait versus a state shaped by environmental factors. Masten (2016) uses the analogy of the spring of a rubber band to illustrate a trait-based definition of resilience as being the result of the property of a thing or substance. Masten (2016), however, argues that there is no single trait that can be interpreted as resilience and Ungar (2011) indicates that a person's access to and use of resources and proactive behavior to take control of an opportunity for self-advancement is a demonstration of resilience. Masten (2016) concludes that understanding resilience as a trait ignores the immense scientific evidence that shows how effective social environment and other external systems drive an individual to adapt after experiences of adversity.

The resilience framework has developed significantly since its emergence in the early 1980s with studies of risks among children. Since then, the definition of resilience has evolved to accommodate a more dynamic view of resilience as it began to be applied to developmental systems theory (Masten, 2016). The concept of resilience began to evolve as researchers began applying the resilience framework to studies related to an individual's genes, other biological processes, and influences of cultural processes (Masten, 2016). The shift in theory has allowed researchers to better understand resilience as we know it today, which is an individual's process and capacity to adapt after experiences of adversity, as opposed to focusing on the individual's inherited traits and abilities (Masten, 2016). Furthermore, the shift in theory has also allowed the resilience framework to become a more useful definition to promote research by including the description of processes and capacity of adaptation after experiences of adversity in any complex

system (Masten, 2016). Masten (2016) defines resilience as “the potential or manifested capacity of an individual to adapt successfully through multiple processes to challenges that threaten the function, survival, or positive development” (Masten, p. 12, 2016). Moreover, using a developmental systems perspective, Masten (2016) identifies eight central themes of resilience which I discuss below in the theoretical framework section.

There are several studies that have shown how resilience is demonstrated among individuals who have experienced traumatic events. Wyman (2003) conducted a study among school aged children who demonstrated resilience through two perspectives, within the individual and in different social settings. The study focused on understanding the adaptive strategies and protective factors that promoted positive development within children and differentiation of the factors that were deemed as context specific. The study found an association between a positive change in psychological beliefs and a behavioral and social shift (Wyman, 2003). This study exhibits the importance of a need for an individual to be engaged in 2 or more positive social settings that may promote constructive attitudes and behaviors.

Understanding the manifestation of resilience in individuals who are disproportionately affected by social determinants of health is crucial for the advancement of evidence-based practices to promote and advocate for the health of unserved and marginalized populations. Understanding the factors that contribute to resilience or to an individual’s positive adaptation after experiences of adversity, chronic stressors, and/or traumatic events may help medical and public health professionals better serve populations.

The present study employed a resilience framework to understand the experiences of PWID living with HIV who were linked to care. Employing a resilience framework will shed

light on the strengths of PWID living with HIV that could be leveraged in future interventions. Findings can inform the factors that contribute to ART adherence and sustained viral suppression and as such can significantly contribute to Latino and border health. The present study defined resilience as a complex and comprehensive socioecological phenomenon to widen the view of resilience and permit a better recognition of the motives that drive people living with HIV to remain in care and adhere to ART.

Most studies conducted to understand ART adherence among PWID have also employed a deficits-based approach. Wolfe et al., (2010) identified a few main areas of focus that past researchers have used to understand ART failure and PWID. Active substance use, an individual's attitude toward treatment and its effectiveness, and an individual's conditions such as social support have been prioritized as factors of study to understand ART failure (Carrieri et al., 2003, Malta et al., 2008). A shift from assessment of individual risks to includes environmental or social risks has been implored by HIV prevention advocates. Moreover, researchers also call for the use of a strengths-based approach including employing the resilience framework as imperative to understanding how both the individual's beliefs and behaviors and their environment and social support reinforce ART adherence.

The Reserve Capacity Model of Resilience

The reserve capacity model (RCM) was first theorized by Gallo & Mathews (2003) and highlights the strong association between a person's socioeconomic status (SES) and poor health outcomes. This framework suggests that people who are socially disadvantaged, such as racial and ethnic minority populations, are at a higher risk of experiencing traumatic events and chronic stressors more often which may result in poorer health outcomes (Gallo & Mathews, 2020).

Cano et al., (2020) suggests that defining resilience as interpersonal and intrapersonal resources of an individual may weaken the RCM framework. Cano et al., (2020) approached the study of resilience as both interpersonal and intrapersonal resources and showed enhanced effects of resilience through the reduction of intensity and occurrence of depressive symptoms among Latinx emerging adults who have been disproportionately exposed to adverse experiences and chronic socioeconomic stressors. The study referred to interpersonal factors as social support and family cohesion, and intrapersonal factors included mindfulness, distress tolerance, and emotional and regulation strategies (Cano et al., 2020). The study found that a person's interpersonal and intrapersonal resources strongly contributed to the reverse association between depressive symptoms and resilience (Cano et al., 2020).

The RCM framework may afford a fitting definition of resilience to study the factors that affect the target population of this study because participants are a socially disadvantaged population which includes ethnic minorities who misuse substances, are living with HIV, and reside on the US-Mexico border, a severely under resourced setting. The target population faces many adverse experiences such as marginalization, discrimination, and are disproportionately affected by negative social determinants of health including poverty, lack of health insurance, lack of education, undocumented immigration status, linguistic barriers, among others. The RCM framework may be fitting too because the target population is notorious for facing barriers to remain in care and as such may have suffered from opportunistic infections that may occur from the virus, as well as other illnesses such as diabetes and Hepatitis C. Through this study I hope to identify demonstrations of resilience that resemble a socioecological phenomenon.

RESILIENCE AND ADHERENCE TO HIV MEDICATION

As indicated above, managing HIV disease can be difficult for a variety of reasons. These challenges include barriers to medical treatment, experiencing discrimination and stigma, lack of social support, and overcoming financial constraints. As a result of research and medical advancements, PLHIV can live long and healthy lives. A person's adaptation to a new lifestyle that includes overcoming challenges to manage living with HIV, now a chronic health condition, can be difficult. However, a person's willingness and motivation to continue surviving is considered a form of resilience. In this study, resilience is defined as an individual's adaptation to overcome adversity, which includes the person's personal traits, capacities, access to resources, and the support of family and community (Gottert et al., 2020).

The construct of resilience has been studied using both qualitative and quantitative methods. Borge et al., (2016) highlights a few recent studies that have captured the importance of family and community support in overcoming adverse experiences which may lead to more positive outcomes, coping, adaptation, and resilience. According to case study evidence, social connectedness and/or family connectedness acts as a protective barrier (Borge et al., 2016). This research is to be considered when discussing resilience and quality of life in PLHIV due to the adverse experiences PLHIV are likely to endure because of their illness. Resilience research has paved the way for a better understanding of how social connectedness may have a positive impact on a person who has endured hardship. Although research on resilience among PLHIV has been conducted, several gaps remain including operationalization of resilience used to develop quantitative instruments which are deemed as measuring general psychological resilience and may not capture other aspect of resilience demonstrated when dealing with specific types of adversities (Gottert et al., 2019).

RESEARCH GAPS

Although extant research has been conducted to understand the factors that contribute to ethnic health disparities in HIV prevention and treatment among US Latinos, there is a dearth of research conducted to understand the experiences of people misuse substances including those who inject drugs living with HIV and residing on the US-Mexico border. Moreover, few research has explored the HIV care experiences of Latino PWID living with HIV from a strengths-based approach. To end the HIV epidemic, it is necessary to develop and implement interventions that can leverage the strengths of the most medically underserved target populations. The purpose of the study is to describe the salient themes, categories of meaning, and their relationship to shed light on the factors that promote linkage to care and adherence to HIV medication among a sample of Latino PWID living with HIV residing on the US-Mexico border.

STUDY PURPOSE

The proposed study consisted of a secondary data analysis of a qualitative study. The purpose of the study was to understand the experiences of people who misuse substances including people who inject drugs (PWID) living with HIV, and residing on the U.S.-Mexico border, in seeking medical treatment and the factors that facilitated remaining in medical care. A resilience framework was used to guide the analysis and interpretation of findings.

THEORETICAL FRAMEWORK

The secondary data analysis will be informed by the systems framework of resilience (Masten, 2016). According to this framework, there are eight principles that contribute to the developmental systems perspective on resilience which I list below:

1. The adaptation and development of a person in environments that are low-and high-risk.
2. Understanding the evolution of resilience that is influenced by interacting systems.
3. The resilience of an individual can be interpreted on multiple levels.
4. The resilience of an individual is dependent on interacting systems.
5. The resilience of an individual is dependent on interacting systems and demonstrated by the contemporary system and by the record of the child or system.
6. Living systems are reflexive which results in an unforeseeable analysis due to developing effects.
7. The constantly evolving circumstances of a system result in the transformation of resilience within an individual.
8. Resilience is not to be interpreted as a trait of an individual.

The definition of resilience in research has been adapted many times because of the numerous developing systems that may be integrated into its interpretation. However, Masten (2016) defines resilience as an individual's prospective or displayed ability to successfully adapt through adversities that threaten the transformative process of positive development.

A very important key concept to emphasize when discussing resilience is that there are no traits any individual can carry that determine their success to overcome adversity. Masten (2016)

stresses the importance of not defining resilience as a trait when conducting resilience research because an immense amount of research shows that successful adaptation to adversity by an individual is the result of interacting systems, singular circumstances, and the individual's relationships with others.

METHODS

STUDY OVERVIEW

The study is a secondary data analysis of data generated from a qualitative study which consisted of 20 in-depth interviews with people living with HIV who had injected drugs in the last month, who were receiving HIV care, and who lived in one of the sister cities of Ciudad Juarez and El Paso, TX located on the U.S.-Mexico border.

PARTICIPANTS

Participants are 20 people who inject drugs living with HIV and residing in the US-Mexico border cities of Ciudad Juarez and El Paso, Texas. Participants had a mean age of 43.5 (SD = 7.3, range 30-54). Table 1 presents demographic characteristics. As Table 1 shows, 73.6 % of participants were male, 63% had completed high school education or less, and 78% were employed part-time or unemployed. Table 1 presents other demographic characteristics.

PROCEDURE

Participants were recruited through a combination of direct outreach and participant referral. Potential participants were identified through their participation in an ongoing HIV prevention intervention, Project Encuentro, for people who use drugs living in the cities of Ciudad Juarez and El Paso. Project Encuentro participants who indicated that they were HIV positive on project surveys, or who were already known to be HIV positive, were approached in a private location, explained the nature of the qualitative sub-study, and asked if they were interested in participating. Participants who conveyed interest in participating were given an

appointment for full screening and consent. Two organizations that offer HIV prevention services in the region partnered with the research team to implement project Encuentro. Project Encuentro surveys were administered by project Encuentro staff hired for this purpose and who worked separately from partner organizations' staff delivering services. Staff delivering services at partner organizations approached potential participants and assessed their interest and willingness to participate in the study and provided contact information for Project Encuentro staff to call and set up a time for screening, consent and an interview.

MEASURES AND INTERVIEW QUESTIONS

After screening and consent, participants were asked to take part in an in-depth interview that lasted approximately an hour and a half. Before participation in the in-depth interview, participants answered a short survey asking about demographic characteristics such as age, gender, marital status, and substances used. After answering the short demographic survey, participants were interviewed by research staff conversant in the language of the interview. During the interview, participants were asked about what they knew about HIV treatment before becoming diagnosed; their initial feelings and reactions after learning that they were HIV positive; HIV disclosure to other people and their reactions; what they were told at testing about medical treatment for HIV and ways to link to care; whether they have sought treatment on either side of the border; reasons for seeking medical treatment; their experiences with their providers, including feeling stigmatized for behaviors, and their feeling that they were included in making decisions about their treatment; reasons for initiating Antiretroviral therapy (ART), including who was involved in the decision making; whether they discussed any substance use with their doctor, reasons for disclosing or not, and the results of these discussions; their experiences on

ART, including whether they received information regarding side effects and how to manage them, and any assistance they've received to improve adherence; and whether they've stopped ART and the reasons for this. Participants received \$40 as compensation for their time. The Institutional Review board of Lehigh University approved the study.

APPROACH TO DATA ANALYSIS

Descriptive statistics such as means and frequencies were computed to characterize the sample. All interviews were transcribed and all text data was coded and analyzed for key themes and patterns of responses using Dedoose software. A combination of theoretical and in-vivo coding was employed. The coding proceeded in stages, first, a preliminary coding scheme informed by the theoretical framework of resilience as defined above was developed by the PI of the study and myself. Second, the PI and me met to discuss the preliminary coding scheme and achieve consensus about the definitions of the theory informed codes including inclusion/exclusion criteria for code application. Third, four transcripts were read independently by the PI of the study and myself (the coders). Then, we proceeded to code the four transcripts independently using the theory informed coding scheme and annotating possible in vivo codes in transcripts using memos. After this first initial coding, the coders met again to discuss discrepancies in code application, for the in-vivo list and theoretical preliminary codes, and proceeded to refine both coding schemes by merging, deleting, or subdividing codes. A code book was created based on the refined coding schemes. The codebook contains the label of the code and a precise definition of inclusion and exclusion criteria. All definitions derived from the codebook are presented in the results section. The coders proceeded to re-code the four transcripts and code the remaining transcripts independently and met again to discuss

disagreements until consensus was reached. An audit trail was kept by both coders to maximize reliability in the coding process.

APPLICATION OF THE THEORETICAL FRAMEWORK AND IN VIVO CODING TO DATA CODING AND ANALYSIS

Data was content coded for facilitators to engagement in medical care, initiation and maintenance in ART, and ART adherence. These facilitators were derived from the most recent definitions of resilience and included support systems at the community and family level, psychological resources in terms of adapting beliefs, thoughts, and attitudes that allow positive adaptation. The individual was conceptualized as a complex entity surrounded by systems that may interact and may promote positive adaptation. For in vivo coding, we allowed ourselves to annotate important observations about factors that seem to allow the individual to positively adapt in the face of concrete instances of adversity or barriers. We went back to observations when finalizing codes and defining them.

REFLEXIVITY AND POSITIONALITY

Both coders kept a journal during data analysis for the purposes of engaging in reflexivity during the data analysis process. In the next paragraphs, I describe who I am as a person and discuss the potential implications of my positionality for data analysis and interpretation. I am a Latina woman living on the Texas-Mexico border who comes from a family of immigrants from Mexico. I have seen and experienced first-hand many instances of stigma, discrimination, and marginalization. I am part of a small percentage of Latinos who has a bachelor's degree. Throughout my years at the University studying for a bachelor's degree in public health, I have

been exposed to knowledge and perspectives that allow me to see the world through a lens that is empathetic, trauma-informed, and compassionate to those impacted by social determinants of health. As a graduate student, while also experiencing the hardships of the COVID-19 pandemic, I worked as a graduate research assistant at a community-based organization offering harm reduction services for PWID in El Paso, Texas. At the organization, I interacted on many occasions with PWID and heard many first-person accounts about engagement in risk behaviors including syringe sharing, and also experiences about living with blood-borne illnesses such as HIV and Hepatitis C. During these interactions I realized the extreme marginalization that PWID face. These experiences have truly humbled me but also lit a fire in me to be a voice for this population. Ultimately, this experience has had a significant impact on the expectations I have for elected representatives. I expect an elected official to make healthcare affordable and accessible to all people and to decriminalize substance use.

I consider myself privileged to have had the opportunity to pursue higher education because I know that not everyone is afforded this opportunity. The interpretations of personal accounts I analyzed were made from the lens of a person who empathizes with people who face adversity. I have personally experienced how the social determinants of health-related challenges impact a person's health and quality of life.

RESULTS

Analysis revealed 3 themes: Resilience as a system of support, resilience as individual level resources, and resilience as a reservoir system enabled by reciprocal determinism. Below, I define each theme, the codes that make up each theme, and present representative quotes.

Resilience as a System of Support

This theme captures the social capital available to individuals, and the strategic use by individuals, that enables a positive adaptation to adversity. Social capital is defined in terms of the social support provided by members of the individuals' social network and the organizations that serve the individual and family including the staff and medical providers housed in these organizations and support groups organized by the organizations. This theme reflects the idea that individuals are nested in a system composed of community and interpersonal resources that can be a source of strength which enables adaptive coping in the face of adversity. The following two codes subsumed this theme: organizational and community level resources and social network social support.

Organizational and community level resources

This code captures the support (logistical, social, and skill building) from organizations that help the individual build skills to engage in behaviors that will lead to adaptive coping. All participants (100%) made reference to the benefits of resource use including support from staff and health care providers at organizations. One participant stated that his HIV specialist assisted him in disclosing his HIV status to a romantic partner:

“I met someone and I did not tell him right away. But with time, I started taking him to my doctor, and then we explained to him and everything. He was negative and I never transmitted it to him and we lived together for 11 years” P 02, male, El Paso

This participant’s account showcases the strategic use of support provided by his health care provider which helped in strengthening a romantic bond. Other participants indicated use of support groups that assist in building skills for a variety of behaviors and to garner social support that enable well-being including support adhering to medication, to reduce or abstain from substance use, to gain family support, and to deal with negative mental health states. One participant shared the support he received from a recovery coach, which is a peer who is trained by an organization to be a source of support, to acquire social capital to troubleshoot daily hassles. One participant shared:

“He is not so much a counselor, but he is a peer. I can call him. If I give him 24 hour notice, if I know I am going to need a ride somewhere, if you need to go to a meeting or the food bank. I can even call him the same day. And so he is really pretty helpful. He’s given me lists of where all the meetings are, phone numbers, and things like that” P 09, male, El Paso.”

This participant refers to the social support provided by a peer who links him to all types of needed resources and helps him solve logistical barriers such as transportation. A participant in Ciudad Juarez shared that his provider took his HIV medication to prison when he was incarcerated:

“It’s a lie that you will be provided with you HIV medication in prison. I would go two or three days without as I had to wait for my provider to bring it to me” P

14, male, Ciudad Juarez

This participant’s provider went above and beyond his call of duty by made medication accessible which enabled adherence skills in extreme hardship such as incarceration.

Social Network Social Support

This code captures the social support capital that an individual has access to, and uses strategically, to adapt to adversity including support from family, partners, significant others, friends and neighbors which surround the individual and provide help including motivating individuals to get tested, accessing information about the illness, accessing care and adhering to medications. Support provided helped individuals to adaptively cope with illness-related adversities and included advocacy to reduce stigma, support group attendance and overall unconditional support even in the face of hardship such as infidelity and severe depression, 84% of participants shared stories about how various sources of support in their lives have enabled adaptive coping. One participant shared:

“My wife came with me to the appointment when I got my results and after we left she asked me to tell her if I had cheated on her, I did not admit it at first but then one day I decided to tell her I contracted HIV because I was cheating on her and she took it good, I asked if she wanted to pause our relationship and she said no. I felt so lucky because if it was some other woman she would have said goodbye. She has been there, when I was going to my support group she was

there. She's always been there supporting me....she goes on the internet finding stuff" P 07, male, El Paso

This participant received support from a loved one even in the most difficult of times where the significant other provided support for key tasks that are important to positively adapt to an illness including attending support groups and learning about the disease. Another participant elaborated on the support he received when he was going through suicidal ideation as a result of his diagnosis:

"When I was diagnosed I wanted to end my life....HIV is a disease that has no cure but my family helped me, they have never left me. They have never rejected me" P 12, Male, Ciudad Juarez

Family support from several immediate and extended family members provided the needed support for this participant to find the will to cope with HIV adaptively.

Resilience as Individual Level Psychological Resources and Behavioral Skills

This theme captures resilience as a phenomenon consisting of individual level resources and skills that promote individual level ability or capability to enact adaptive behaviors that enable coping with the disease. These individual level resources include adaptive psychological thoughts, beliefs that are a source of strength, and adaptive behaviors which can be considered skills that allow a healthier lifestyle. This theme is composed of two codes: Psychological and Behavioral Resources.

Psychological Resources

This code captures the adaptive psychological thought processes of individuals that allow them to adapt in the face of adversity. These thoughts include attitudes, beliefs, and motivations that are adaptive and allow the individual to positively adapt in the face of adversity. These thoughts are helpful and guide the individual to conceptualize hardship as a good thing in their lives (e.g., illness is a blessing) and are sources of strength that enable adherence to medication including will to live, desire to take care of others, and God and significant others as a support and source of motivation, 89% of participants made a reference to adaptive thought processes. One participant shared:

“I knew I was going to have this one day. I am very strong in my spiritual beliefs. I believe that God cannot give us more than we can bear. I think that he has conditioned me to bear a lot. I may not always think I can, but then I do. I was in peace. My concern laid with my daughter” P 04, female, El Paso

This participant displays beliefs that allow her to accept her disease which enabled her to cope with other responsibilities such as being a caretaker. Another participant shared how he developed a will to live which allowed him to adhere to medication:

“I was not taking my medication because I did not care about living. I was just living for living. I did not have hope. Today I want to live. I have a lot of medicine to take” P 03, female, El Paso

This participant shares how for him, a conscious desire to live motivated him to adhere to medication. Another participant indicated that his primary motivation to remain adherent was his children and grandchildren:

“I don’t want to die any longer, I now want to live, because I have a daughter for whom to live, and grandchildren” P 09, female, Ciudad Juarez

For this participant, her children and grandchildren are primary sources of motivation to live.

Behavioral Skills as Resources

This code captures the behaviors that help the individual lead a healthy life in the face of an HIV diagnosis including stopping substance use, developing needed skills such as skills to be reminded to take medications as prescribed, reducing other risk behaviors such as unprotected sex and needle sharing, engaging in other behaviors that prioritize health such as exercising, eating healthy, being proactive about seeking treatment, and adhering to other medications, 89% of participants referred to engagement in behaviors that are the result of developing skills to engage in to sustain such behaviors. A participant shared how he relies on some strategies to be reminded to take his medication as indicated while also sharing his belief that this skill is something that you have to do on your own:

“Its about just knowing that we have to do it. Its not something that other people need to tell you, it’s just a fact that you need to take them every day....I use the little pill container...and then I have my alarm to remind me....I usually take them at the same time too” P 02, female, El Paso

Another participant shares the changes he has made as a result of being diagnosed with HIV:

“It is not only about taking your medication, you have to eat healthy too, do some exercise to help the medicine do its job....I also have bipolar disorder and PTSD and I wasn’t taking any medications before so now that I have learned how to

become adherent to my psychotropic medications that's really helping me to stay well and not all over the place. When I'm not on the psychotropic meds I go through periods of depression that can be pretty severe" P 04, female, El Paso.

As this participant indicates, skills learned and applied to adhere to HIV medication have been helpful in applying them to be adherent to other types of medications which are also an essential part of her well-being. Another participant shared how he has adopted harm reduction behaviors that take considerable effort to practice:

"I have changed many aspects of my life, I don't share my syringe with my friends even if they protest. I have settled down regarding other aspects like drinking alcohol, I stopped because it is the most harmful. I have reduced the amount of heroin I consume and even in sexual relations, I now use a condom every time" P 16, Male, Ciudad Juarez

This participant continued to elaborate that he practices skills to remember to take his medication every evening. The account of this participant showcases that he has acquired fundamental skills in harm reduction which translate into other aspects of his life including taking HIV medication as prescribed.

Resilience as a Reservoir Enabled by Reciprocal Determinism

This theme captures the factors that make resilience a malleable state rather than an immutable characteristic such as a personality trait. This theme captures a process of behavioral change (enacting new roles) and psychological meaning making (choosing to think and react to hardship in an adaptive way) that may lead the individual to develop a reservoir of strength that

enables persistence in directly challenging adversity. This theme was labeled a reservoir because the stories that individuals shared captured a possible process where the ways employed to directly challenge adversity seemed to result in a positive feedback loop from people and environment that appeared to unleash determination. This theme consists of three codes: Strategic decisions and actions to circumvent hardship, Strategic perceptions and reactions to adversity that enable determination, and Perceived self as a source of strength.

Strategic Behaviors and Actions that Enable Determination

This code captures the strategic behavioral choices and actions that enable individuals to resist adversity and flourish and includes becoming an advocate, leader, educator rather than a victim, becoming more outspoken, confident, and empowered to directly challenge stigma and to disclose HIV status strategically. These choices demonstrate taking initiative such as choosing to become educated about the illness which unleashes a process that may lead the individual to become stronger to be able to refute adversity persistently. This theme captured how strategic choices such as disclosure of status, dealing with stigma, becoming educated about the disease empower and leads to sustained strength. This process unveils a cycle of reciprocal determinism that promotes positive adaptation, 68% of participants referred to making decisions and taking actions to circumvent hardship such as stigma. One participant shared:

“I was a peer educator for a while. I had an incident at the YMCA with the ladies who don’t know about HIV or anything. But one of them knew I was HIV positive, so when I left, they were talking about that. The next day I went to the Y, one of the ladies asked me directly about it, if it was true. And I told her yes....she was wondering if they can get it in the water, if they can get infected.....I experienced the stigma you know? So what I

did I stood on the top of the pool and talked to all the ladies and gave them a little class...so they won't feel they cannot talk to me or feel scared" P 02, female, El Paso

This participant chose strategically to deal with stigma by directly challenging by becoming an education, a choice that will lead to sustained empowerment. She continued to share that she received positive feedback which may have unleashed a cycle of reciprocal determinism promoting strengthening of the peer educator skills. Another participant shared how he reacts when individuals who are unrelated to him become aware of his HIV status and outwardly discriminate him by shouting expletives:

"When people that gather around places that I work become aware that I am living with HIV sometimes they laugh saying: 'sidoso, ese vato sidoso' and I respond: 'I may as well be one but I am a hard working person, I don't steal or do other bad deeds, I have a disease but I continue working" P10, male, Ciudad Juarez

This participant chose to confront outward discrimination by other individuals by being outspoken and counteracting stigma by calling attention to his positive attributes which may serve as a shield to deflect future discriminatory experiences.

Strategic Perceptions that Enable Determination

This code captures the strategic perceptions about barriers and difficulties the person experiences including negative health care experiences, barriers seeking treatment, experiences with negative side-effects of medications, depression and stigma that individuals deploy which may allow them to not desist and persist seeking care and adhering to medication. This code captured the many barriers that people faced and the process of meaning making that may strengthen determination,

77% of participants told a story about facing difficulties and the ensuing perception that enabled persistence. In response to a question asking about barriers going to medical appointments, one participant shared:

“Sometimes I don’t have money to take the bus, but I tell my partner: ‘we have to go, how ever that is,’ shame? It is not worth it to think about how others look at you, I ask for money for the bus even showing people my doctor’s appointment. I tell strangers: ‘I don’t have money for the bus, please lend me some money,’ and thank God they lend us money. That is how we are able to keep all our medical appointments” P 10, Male, Ciudad Juarez

This participant shares how even in the face of not having money for transportation and even if he is feeling shameful about asking money, he is able to react to this feeling in a way that allows him to persist in doing whatever may need to be done to remain in care. Another participant shared:

“I went to Thomason Hospital after being diagnosed but it took almost a month to set up an appointment, but that is what it takes, it takes a long time. Once I went to the appointment doctors did not give me a lot of information, just the bare facts, the minimum, at Thomason you don’t see the same doctor so I did not like that because they don’t know you. It was until I found Dr. Galanga and she helped me a lot, gave me a lot of support” P 02, Female, El Paso

This participant reacted to the negative health care experiences she endured by choosing to perceive that these difficulties are normal in this kind of medical setting and this perception may

have precluded generalizations which may have allowed her to persist in finding a provider that met her needs, even after having severe negative health care experiences.

Self as a Source of Strength

This code captures views of the self, brought about by events in their life related or unrelated to their disease, that have helped them rely on themselves and see the self as a main resource, 26% of participants (only from El Paso) referred to the self as the main source of strength to cope with difficulties. One participant shared:

“I don’t have my parents any more, so I am the person that’s always taking care of myself. I am a survivor. Independent” P 02, female, El Paso

Another participant shared how he has not disclosed HIV status and how he has been his own source of support:

“I have not told anyone, even when people know I am gay and seeing me losing weight, being sick. I dealt with some things. But I am my own support system.” P 08, Male, El Paso.

This participant acknowledges dealing with difficulties and acknowledges he has no support system but himself.

DISCUSSION

The purpose of the study was to understand the experiences of PWID living with HIV seeking medical care and remaining in treatment. Participants were residing on the U.S.-Mexico border, a medically underserved setting, characterized by severe health care provider shortages. A secondary data analysis of a qualitative study was undertaken employing a resilience framework. The study aimed at understanding the strengths that enable individuals to enter the HIV treatment cascade and progress adequately through the stages ultimately remaining in care and adherent to their HIV medication.

A thematic analysis employing theoretical and in vivo coding strategies yielded three themes which include resilience as a community and/or social support system, resilience as psychological and behavioral individual level resources, and resilience as a reservoir system that enables determination. It was very compelling to see that 100% of participants expressed receiving support from organizational and community resources and the vast majority (84%) of participants expressed feeling supported through close interpersonal relationships. These findings indicate that organizational and community resources and social support seemed to manifest as a universal resource for resilience for all participants. Examples of participant's first-person accounts include feeling support through having positive experiences with medical providers, having accessibility to ART medication, not feeling or being abandoned by loved ones after HIV status disclosure, and having a sense of belonging within community-based organizations that provide support for HIV treatment and/or substance use.

The second central theme is resilience as resources at a psychological and behavioral skills individual level which highlights the adaptive psychological and behavioral resources

individuals rely on to remained linked in care and adherent to medications. Participants expressed personal attitudes, beliefs, and motivations that demonstrated resilience and include a will to live for self and/or for loved ones and strong religious beliefs that showcase a psychological and behavioral adaptation to difficulties stemming from living with a chronic health condition. This manifestation of resilience is concordant with Masten's (2016) definition of resilience which defines resilience as an individual's potential or manifested capacity (including psychological and behavioral) to adapt successfully through multiple processes after experiences of adversity. For example, many participants expressed positive behavioral changes such as prioritizing a routine to take their medication, focusing on overall wellness through healthy eating and exercise, and reducing or stopping engagement in risk behaviors that include condomless sex, substance use, and syringe sharing.

The third central theme is resilience as a process that facilitates persistence in applying behavioral and perceptual strategies that lead the individual to positively adapt to hardship and is enabled by reciprocal determinism ultimately culminating in a reservoir of determination. This theme possibly identifies an individual's adaptation through very conscious, intentional and thus strategic behaviors and perceptions that unleash a positive feedback loop by the individual's environment (people and places) that leads to transformation. This theme emphasizes the idea that resilience is a state that is strengthened by reciprocal determinism. Some participants described personal experiences of discrimination and adversity but instead of viewing themselves as a victim, they decided to become an advocate and/or educator. This theme captured experiences of adopting a role of educator after being stigmatized, counteracting outward discrimination by elaborating on values and beliefs that underscore worth, and persistence in finding a supportive provider despite having negative experiences with health care

systems. This theme captured participants' strategic choices that lead to empowerment which may be sustained by subsequent positive results. Self as a main source of strength was categorized as being part of this theme because I reasoned that once individuals achieve that perception, the individual has reached the ultimate stage of empowerment and resilience which represents the availability of unlimited resource procurement and use, the reservoir. It was interesting to see that only individuals from El Paso mentioned the self as a source of strength. Moreover, a minority (26%) explicitly mentioned perceiving the self as the main source of support. Resilience was demonstrated in this category by a few participants who expressed relying on oneself for strength to take of self, adhere to medicine, and/or in cases where the participant was not accepted by family members.

Findings represent categorizations of firsthand accounts of participants which are significant and may be leveraged in interventions to promote positive adaptation. Findings underscore the benefits of using a strengths-based approach to understand the experiences of participants who face considerable challenges in remaining in care due to substance misuse. Findings indicate that individuals who consume illegal drugs and are living with HIV can successfully traverse through the stages of the HIV treatment cascade when a sense of trust and sense of belonging are promoted through empathetic interactions with community organizations including staff and medical providers and significant others. The results of this study supports Cano et al., (2020) suggestion that defining resilience as social support may weaken the reserve capacity model of resilience (Gallo and Mathews, 2003) which theorizes that a person's SES is a primary contributor to poor health outcomes. Many participants in this study were facing considerable strain in terms of socioeconomic resources and clearly elaborated how interpersonal and intrapersonal resources allowed them to cope with hardship. Resilience as social support is

consistent with an ecological approach and supports previous research that has identified the significance of community and social support in promoting positive attitudes and behaviors (Cano et al., 2020; Wyman, 2003). Moreover, this study also identified distinctive findings such as resilience as a process that empowers and leads to sustained determination which demonstrates the importance of exploring first person narration about participants experiences with adversity and resilience using qualitative research methods. Through this we were able to identify common manifestations of resilience as access to resources and support, individual level resources in terms of attitudes, motivations and behavioral skills, and as a malleable process.

The study's findings support a model of resilience that mirrors the socioecological framework of human development. The socioecological model views human development as influenced by a complex system of factors operating at the individual, interpersonal, community, and societal levels and their interaction. Similarly, in this study, individuals' resilience was influenced by resources at the individual level such as cognitions and behaviors, at the interpersonal level by support from the social network, and at the community level by the support provided by organizations. Resilience as a reservoir enabled by reciprocal determinism captures the interaction between person and environment whereby this interaction enabled the creation of a culture of resilience by the individual. Conceptualizing resilience as a socioecological process will facilitate intervention development to promote resilience and its evaluation.

LIMITATIONS

The study had a few limitations. First, the study was a secondary data analysis of a qualitative study designed to understand the experiences of PWID living with HIV remaining in care and adherent to medications and a resilience framework was not originally employed to develop questions and probes. This weakness may have yielded restricted stories regarding the phenomenon of resilience as interviewers could not probe further into the topic. Second, I did not engage in the data collection process which precluded fieldnotes and may have led me to interpret the data differently. Additionally, recruitment of participants may have stopped before saturation was reached as recruitment of a set sample size was proposed originally. More interviews might be needed to get a more complete understanding of the phenomenon.

FUTURE RESEARCH

The study findings point to future fruitful avenues of research employing mixed methods research. For example, the existence and definition of the theme resilience as a reservoir that is enabled by reciprocal determinism and promotes determination future research is needed to replicate this theme and to unveil a more nuanced definition and understanding of the process. This theme was developed as a result of in vivo coding. Although agreement was reached between the coders about the existence and definition of the theme, this theme generated discrepancies in coding that were resolved through consensus. The disagreement lied in reasoning about whether this is a distinct phenomenon from individual level resources. In other words, what unleashes this process? Inspection of the audit trail revealed that discussion led the coders to consider it may be an individual level resources at one point. However, conviction to honor the person as a whole and the complexity of each of their stories and potential interrelationships between codes within persons facilitated reaching consensus that this was may be a malleable state rather than a trait. Practice in promoting resilience may change if indeed future qualitative research corroborates the existence of this process and better defines it. Next steps would be to develop a quantitative instrument to assess the construct and proceed to validate it.

CONCLUSION AND IMPLICATIONS FOR PUBLIC HEALTH PRACTICE

The study revealed awareness about the importance of resource accessibility and the importance of social and community support to bridge the health equity gap amongst the most vulnerable of populations. Through this study, I was able to observe the existence of common protective factors that drive a person to a healthier overall well-being (Ungar, 2011).

Conceptualizing resilience as a socio ecological phenomenon allowed for interpretation of how experiences of adversity among PWID living with HIV have affected these individuals and the social, psychological, and behavioral factors have contributed to resilience to remain in care and adhere to ART.

MPH COMPETENCIES

The proposed study will allow me to acquire the following competencies:

A. Evidence-based Approaches to Public Health

2. Select quantitative and qualitative data collection methods appropriate for a given public health context.
3. Analyze quantitative and qualitative data using biostatistics, informatics, computer-based programming and software, as appropriate.
4. Interpret results of data analysis for public health research, policy or practice.

B. Public Health and Health Care Systems

5. Compare the organization, structure and function of health care, public health and regulatory systems across national and international settings.
6. Discuss the means by which structural bias, social inequities and racism undermine health and create challenges to achieving health equity at organizational, community and societal levels.

D. Policy in Public Health

14. Advocate for political, social or economic policies and programs that will improve health in diverse populations.
15. Evaluate policies for their impact on public health and health equity.

E. Leadership

16. Apply principles of leadership, governance and management, which include creating a vision, empowering others, fostering collaboration and guiding decision making.

MPH PROGRAM HISPANIC AND BORDER HEALTH CONCENTRATION
COMPETENCIES

1. State the principles of prevention and control of disease, and discuss how these can be modified to accommodate cultural values and practices in Hispanic and border communities.

IRB APPROVAL

The study was approved by the Lehigh University's Institutional Review Board (IRB).

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APPENDIX

Table 1. Demographic Characteristics (N = 20)

	<i>f</i>	%
City of Residence		
Ciudad Juarez	10	52.6
El Paso	9	47.4
Gender		
Male	14	73.6
Female	5	26.3
Education Level		
Less than high school	8	42.1
High school	4	21
Some College	5	26.3
Marital Status		
Single	8	42.1
Married or partnered	7	37.8
Separated	1	.05
Employment		
Employed full-time	1	.05
Employed part-time	6	31.5
Unemployed	9	47.3
Lived in Another Country		
Yes	7	36.8
No	12	63.1
Lived in Another State		
Yes	8	42.1
No	11	57.8
Insurance Type		
Employer	1	.05
Government	12	63.1
None	4	21
Stable Place to Live		
Yes	2	1.05
No	16	84.2
Drug Use		
Alcohol	15	78.9
Heroin	11	57.8
Crack	12	63.1

Note. Some percentages do not add to 100 due to missing data.

CURRICULUM VITA

My name is Valeria Duenas. I received my bachelor of science degree in health promotion from the University of Texas at El Paso in 2020. During my time as a graduate student I became an intern for Dr. Lechuga because of my interest in HIV related research. During the height of the COVID-19 pandemic I began working as a graduate research assistant at a harm reduction clinic. During this time I conducted surveys with PWID and engaged in risk behaviors, specifically sharing used needles and/or engaging in unprotected sexual activity. Additionally, I assisted the organization with the intake of clients and prepared materials for community outreach done by peers. Lastly, I trained to use the Dedoose coding software and assisted in coding qualitative transcripts.

In October of 2021 I began employment with Project Vida Health Center, a federally funded community-based organization that was founded in 1991. Since then, I have been working as a wellness outreach facilitator for a teen pregnancy prevention program in Socorro Independent School District

During the summer of 2022, I completed an internship at Project Vida Health Center as a requirement of graduation. I worked with the Capacity Development department where I aimed to recruit youth-serving professionals in SISD to evaluate the Resiliency in School Educators (RISE) curriculum using the Attitudes Related to Trauma Informed Care (ARTIC) scale for program improvements and sustainability.

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This thesis was typed by Valeria Duenas.