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Investigation of Factors Affecting the HIV Continuum of Care in Tennessee

Elaine Loudermilk
East Tennessee State University

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by

Elaine Loudermilk

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Dr. Megan Quinn, Committee Chair

Dr. Shimin Zheng, Committee Member

Dr. Robert Pack, Committee Member

Dr. Jonathan Moorman, Committee Member

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ABSTRACT

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Introduction: Factors contributing to the HIV continuum of care (HCC) for adults in Tennessee (TN) have not been studied in depth with known predictors for HIV risk, specifically adverse childhood experiences (ACEs), among low annual income or sexual minority groups [lesbian, gay, bisexual, or transgender (LGBT)].

Methods: A mixed methods study design was used to assess factors related to the HCC. Quantitative analysis used the TN Behavioral Risk Factor Surveillance System data to examine at risk and ever tested for HIV, to (1) investigate ACEs among adults with low-income (<$25,000 annually) in 2016-2017 and (2) among LGBT in 2018. Descriptive statistics and multiple logistic regression (MLR) analysis stratified by TN grand division were performed. Qualitative analysis included 11 interviews with persons living with HIV (PLWH) receiving care at a local clinic to evaluate surveillance questions related to ACEs and the HCC to develop a culturally appropriate survey.

Results: Quantitative results found that among LGBT (N=262) and low-income (N=3258) adults living in TN, the proportion at risk for HIV and ever tested for HIV was highest in East TN (LGBT at risk – 45.53%; LGBT ever tested for HIV – 58.32%; low-income at risk – 8.14%; low-income ever tested – 52.05%). Among adults with low-income, MLR revealed 1-3 ACEs decreased the odds of HIV risk in East (aOR: aOR: 0.54, 95% CI: 0.52-0.56) whereas 4+ ACEs

increased odds of being at risk in Middle TN by 32 times (aOR: 31.86, 95% CI: 29.83-34.02) compared to adults with no ACEs. Among LGBT, MLR estimated odds of HIV testing were 33 times higher among adults in West TN at risk for HIV compared to those not at risk (West TN, aOR: 33.59; 95% CI: 31.97-35.96). Qualitative analysis results provided a 55-question survey related to ACEs, HIV transmission risk, and barriers to HIV care.

Discussion: Regional differences were revealed among LGBT and low-income populations; low-income and ACEs were associated with being at risk and ever tested for HIV. ACEs and HCC surveillance were considered relevant by PLWH at the clinic. Additional research including piloting the survey and longitudinal studies are necessary to improve the HCC and quality of life among PLWH in TN.

DEDICATION

This dissertation is dedicated to those who have been stigmatized, discriminated against, or mistreated throughout their life and/or as a result of their chronic disease condition, specifically as it relates to HIV or AIDS. May you find peace, community, and healing.

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ACRONYMS AND ABBREVIATIONS

ACEs – Adverse Childhood Experiences

AIDS – Auto Immune Deficiency Syndrome

ART – Antiretroviral Therapy

BRFSS – Behavioral Risk Factor Surveillance System

CBO – Community Based Organization

CDC – Centers for Disease Control and Prevention

COE – Center of Excellence for HIV/AIDS

ETSU – East Tennessee State University

HCC – HIV Continuum of Care

HHS – U.S. Department of Health and Human Services

HIV – Human Immunodeficiency Virus

HP 2020 – Healthy People 2020

IDU – Injection Drug Use

IPV – Intimate Partner Violence

LGBT – Lesbian, Gay, Bisexual, Transgender

MMP – Medical Monitoring Project

MMS – Male to Male Sexual contact

MSM – Men who have sex with men

MTF – Male-to-female

NHAS – National HIV/AIDS Strategy

NHIS – National Health Interview Survey

NHBS – National HIV Behavioral Surveillance

PEP – Post Exposure Prophylaxis

PLWH – Persons Living with HIV

PrEP – Preexposure Prophylaxis

TDH – Tennessee Department of Health

TN – Tennessee

UNAIDS – Joint United Nations Programme HIV/AIDS

US – United States

Chapter 1. Introduction

Statement of the Problem

Human Immunodeficiency Virus (HIV) remains a significant public health issue in the United States (US) and is now both a chronic condition and an infectious disease. Treatment exists to achieve viral suppression which prevents persons living with HIV (PLWH) from progressing to Acquired Immunodeficiency Syndrome (AIDS) through reducing HIV RNA levels in the blood to an undetectable level (AIDSinfo, 2016). Currently, the lifetime treatment cost of one HIV positive adult is just under $400,000 in 2010 dollars (Centers for Disease Control and Prevention (CDC), 2017b). Totally, across the entire US, the life time treatment cost for HIV diagnoses are nearly $16.6 million not including reporting delays; thus this number is largely underestimated (CDC, 2017b). With available programs to help fund treatment in the US, the challenge for public health practitioners and physicians remains in determining what factors deter PLWH from staying retained in care and ultimately achieving viral suppression through adhering to HIV treatment regimen.

To achieve viral suppression globally, the Joint United Nations Programme HIV/AIDS (UNAIDS) set a 90-90-90 goal to end the HIV/AIDS pandemic by 2030 (UNAIDS, 2020). The UNAIDS 90-90-90 goal is defined as: by 2020, 90% will be tested for HIV/AIDS and know their status; by 2020, 90% of PLWH will be linked to care and started on antiretroviral therapy (ART); by 2020, 90% of PLWH will be virally suppressed (UNAIDS, 2020). Compared to the UNAIDS 90-90-90 goals, the US falls short. Domestically, the Division of HIV/AIDS Prevention along with the National Center for HIV/AIDS, Viral Hepatitis, and STD, and TB prevention track the US's progress towards ending the HIV epidemic.

In 2019, the CDC HIV Prevention Progress Report 2019 was published providing detailed information about where the US is making progress, achieving goals, or not making progress at all (Mccray et al., 2019). The total number of PLWH in 2016 was 1.1 million (CDC, 2018a). Of these 1.1 million, only 49% were retained in care and 51% virally suppressed (CDC, 2015, 2018a). With only half of PLWH virally suppressed, approximately 500,000 people in the US were still able to transmit HIV from person to person. The CDC estimates that 1 in 7 people living with HIV/AIDS are unaware of their serostatus making HIV transmission more likely (CDC, 2017a).

Additionally, the US also uses the National HIV/AIDS Strategy (NHAS) indicators to follow progress on how well targets are achieved for ending the HIV epidemic (HIVgov, 2017). NHAS focuses on four priority areas with goals to achieve within the next five years: testing and linkage to care across the US, retaining PLWH in care, viral suppression, and access to Preexposure Prophylaxis (PrEP) (CDC, 2019c). The US made progress on several indicators but has not yet achieved targets for priority areas relating to men who have sex with men (MSM), specifically gay and bisexual men overall, young Black gay and bisexual men, and PLWH living in the southern US; in fact, progress for targets have remained stagnant or continue to move in the wrong direction (HIVgov, 2017).

To achieve viral suppression, PLWH must be adherent to their HIV/AIDS treatment. Achieving viral suppression requires being adherent to HIV medication; this means an individual must attend all appointments and take HIV/AIDS medication as prescribed 90-95% of the time in order for treatment to decrease the chances for HIV drug resistance and viral mutation (U.S. Department of Health and Human Services (HHS), 2018). Ultimately 100% adherence is

necessary to avoid the development of AIDS and AIDS-associated comorbidities (U.S HHS, 2018.

Surveillance of HIV/AIDS in the US

Aligning with the President's recent initiative proposing to end the HIV epidemic in America within the next ten years, the CDC receives funding for surveillance and campaigns addressing national and state health disparities (Mccray et al., 2019). Specifically, the following surveillance systems use federal funding to help meet NHAS 2020 goals in the US:

- The National Health Interview Survey (NHIS) started in 1957, has been updated every decade, and collects data on a broad range of health topics including HIV testing, reasons for not testing for HIV, reasons for delayed medical care, sexual orientation, mental health, and health insurance (CDC/National Center for Health Statistics, 2018).
- The National HIV Behavioral Surveillance (NHBS) was created in 2003 by the CDC to examine populations at high risk for HIV and is useful in monitoring the impact of the NHAS (CDC, 2016). This surveillance system collects information on HIV risk behaviors, HIV testing, and the use of HIV prevention services (CDC, 2016).
- The Medical Monitoring Project (MMP) aims to answer important questions that can help improve engagement in care among PLWH in the US, determine what the met and unmet needs are of PLWH, and examine factors that play a role in PLWH retention in care (CDC, 2018c).The primary objectives for MMP have been to collect local and nationally representative data that estimate the risks and clinical outcomes of HIV positive individuals receive HIV care (Team, 2017). The population of individuals for MMP interviews are all HIV-diagnosed persons aged 18 years of age or older living in the US (Team, 2017).

- Behavioral Risk Factor Surveillance System (BRFSS) collects data on more than 400,000 individuals annually through random digit telephone dialing; data collection is primarily focused on chronic diseases, risk behaviors, and preventive actions (National Center for Chronic Disease Prevention and Health Promotion | Division of Population Health, 2015).

For the purposes of this dissertation, BRFSS data were used to examine the burden of traumatic life experiences on HIV testing in the state of Tennessee (TN) as well as the risk and odds of testing for HIV among sexual minority groups. All other surveillance sources did not collect data on childhood trauma and/or did not contain enough responses for sexual orientation other than heterosexual, HIV Continuum of Care (HCC) data, or could not provide access to their data due to limited resources.

Health Disparities among PLWH in the US

Despite a drastic reduction, greater than 60%, in HIV incidence since the mid-1980s, (CDC, 2019a) HIV prevalence in the US remains unequal among sexual minority groups, specifically adult males who identify as gay or bisexual (Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, 2018). Of the nearly 40,000 new cases of HIV in the US in 2017, 70% were among gay or bisexual men (Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, 2018). Gay and bisexual men, Black MSM, Black women, and individuals between the ages of 20 and 29, accounted for the majority of all new HIV diagnoses in 2016 and 2017 (CDC, 2019b; CDC, 2018a). More specifically, Black/African American men aged 25-34 who identify as gay or bisexual make up the highest proportion of new diagnoses followed by ages 13-24 (Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB

Prevention, 2018). The third highest group of adults affected are White men, ages 25-34, who identify as gay or bisexual (Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, 2018).

In addition to CDC findings, a systematic review and meta-analyses assessing the prevalence of HIV and HIV risk factors among transgender populations found that 27% of male-to-female (MTF) transgender were HIV seropositive (Herbst et al., 2008). Perceived risk for HIV was also low among this population based on findings that a large majority of MTF transgender practiced HIV risk behaviors, however, did not think of themselves as high risk for HIV infection (Herbst et al., 2008).

Disparities are also apparent by geographic region with the Southern region of the US, encompassing the state of TN, making up over half of the new cases of HIV since 2012 (CDC, 2018b). Furthermore, half of new HIV diagnoses among transgender lived in the Southern US (CDC, 2018b). With the Southern US carrying the most cases of HIV compared to the rest of the nation, linkage and retention in care are paramount. Yet, compared to the UNAIDS 90-90-90 goal, the proportion of PLWH aged ≥13 years receiving medical care for HIV who are living in the Southern US is between 58-80% (CDC, 2017b). Even more concerning, less than 70% among these individuals were retained in HIV care, and less than 80% were virally suppressed among the same age group across 41 states and the District of Columbia (CDC, 2017b). In the Southern US specifically, retention in care and viral suppression were less than 63% (CDC, 2017b).

Retention in care and viral suppression are critical to prevent new HIV infections and progression to AIDS. Nonadherence to HIV medication can be a result of behavioral barriers, mental health diagnoses, and a direct consequence of the patient-provider relationship (Fauci et

al., 1998). Socioeconomic status, stigma, inconsistent access to medications, and denial all contribute to an individual's medication adherence for HIV treatment (Fauci et al., 1998). Further, literature findings suggest nonadherence is most common among minority groups who have experienced life traumas (Dale et al., 2014; Pence et al., 2012; Sauceda, Wiebe, & Simoni, 2016). Thus, investigating life traumas among PLWH is significant in understanding difficulties to being retained in HIV care, long-term HIV adherence, interventions to achieve viral suppression, and to secure and enforce policies to protect those at risk for and living with HIV/AIDS.

Barriers and Facilitators to HIV Care in the US

Retention in HIV care is defined as initiating and maintaining antiretroviral therapy for HIV/AIDS for which lower viral loads and higher CD4 cell counts are achieved (CDC, 2018a). In 2013, the CDC monitored retention in care by using multiple laboratory tests as an indicator for retention in care (Firth, Schafer, & Greene, 2014). Findings suggest face-to-face visits represent the most important part of the HCC leading to viral suppression (Firth et al., 2014). Unfortunately, among the 1.1 million people in the US with HIV, only 86% have received a HIV diagnosis, 63% were retained in medical care, and only 51% were virally suppressed (CDC, 2018a).

Several studies indicate barriers to HIV treatment adherence and retention in care among PLWH are attributed to mental health, substance abuse, stigma, distance to a clinic and the affordability of HIV treatment (Bing et al., 2001; Crane et al., 2010; Eberhart et al., 2014; Grierson, Koelmeyer, Smith, & Pitts, 2011; Pence et al., 2012; Relf et al., 2019; Whetten, Reif, Whetten, & Murphy-Mcmillan, 2008). For example, alcohol use disorder and drug use (Azar, Springer, Meyer, & Altice, 2010), poor mental health, and urbanicity have been linked to

decreased HIV treatment adherence (Durvasula & Miller, 2014). Anecdotal evidence from health departments and HIV providers support literature suggesting adverse childhood experiences (ACEs) and other life traumas [such as intimate partner violence (IPV), homelessness, imprisonment, etc.] have a significant impact on PLWH adherence to HIV/AIDS treatment. Conversely, little literature exists on the burden of ACEs when examined in its entirety as an ACEs score or with the use of the entire ACEs questionnaire with other life traumas among clinics treating for HIV.

Barriers to HIV care currently appear to be similar to those reported 10 years ago (e.g. substance use, depression, and level of readiness) (Moneyham et al., 2010). Quotes from participants in individual interviews studying a HIV positive population described the nature of specific barriers to HIV care even more as one participant stated, "Crack kept me out of care, crack cocaine. It kept me out of care and on the streets for many years" (Moneyham et al., 2010). Another participant stated, "The only problem I had was myself…I stood in my own way. Honestly, for me, the care was there, I wasn't willing. I had something better to do (Moneyham et al., 2010)." Additionally, a systematic review conducted in 2016 reported patient barriers to HIV medication adherence from over 120 published studies with similar findings building on the previous to also include depression, forgetfulness, alcohol/substance misuse, stigma, and distance to clinic as patient reported barriers to HIV medication adherence (Shubber et al., 2016).

Structural barriers to HIV care in addition to stigma, such as housing, food insecurity, and lack of transportation, have also been found to be significantly associated with decreased treatment adherence of less than 85% which is lower than the 2020 goal for viral suppression among PLWH (S. Kalichman, Kalichman, & Cherry, 2016; UNAIDS, 2020). Moreover, time to treatment and geographic region also play a role in HIV adherence (Amico et al., 2007; CDC,

2018a; Korthuis et al., 2008). A study utilizing implementation science aimed to understand barriers and facilitators among HIV clinics to improve linkage to care across the US, and similar needs were found among PLWH: structural barriers (housing), substance abuse, and mental health needs (Maulsby et al., 2017). Poor literacy level and very low socioeconomic status (having Medicare or Medicaid) have also been linked to poor adherence and viral suppression (Rebeiro et al., 2018). Furthermore, PLWH from a separate study who reported nonadherence to HIV care stated reasons that could be preventable with the right interventions in place, such as housing and substance abuse, level of readiness to adhere, and the speculation of medical mistrust (Gwadz et al., 2014). Despite the rigor of publications examining PLWH barriers to viral suppression and adherence, the burden of life traumas coupled with the examination of confounders such as homelessness, food security, and the impact of living in specific geographic regions, in terms of rural versus urban residency, are lacking.

Traumatic Experiences and HIV/AIDS

Adverse Childhood Experiences

ACEs are the emotional, physical and/or sexual abuses and household dysfunction experienced among adults before the age of 18. These experiences include having grown up with parents who were mentally ill, incarcerated, misused substances or alcohol, involved in IPV for which the child witnessed, in addition to the physical/sexual/and emotional trauma experienced as a child. When children experience and witness abusive environments, permanent and nonspecific changes in the function and structure of the brain occur causing a variety of effects as the child grows into an adult (Anda et al., 2006). These changes in the brain are linked with risk-taking behaviors that have been found to increase the odds of HIV transmission, mental health issues, substance abuse, along with several other chronic diseases that ultimately could

reduce the quality and longevity of life for individuals with ACEs scores higher than 4 and specifically among those who experienced abuse (Anda et al., 2006; D. W. Brown et al., 2009; Dube, Anda, Felitti, Edwards, & Croft, 2002; Fang, Chuang, & Lee, 2016; Loudermilk, Loudermilk, Obenauer, & Quinn, 2018; Pence et al., 2012; Whetten et al., 2008). Similarly, a study from 2012 determined through mediation analysis that total lifetime trauma had a negative effect on HIV medication adherence (Pence et al., 2012).

Histories of trauma, such as ACEs, are expected to be substantially higher in PLWH than the general population of the US (Briere & Elliott, 2003). Research has discussed a variety of individual life traumas, such as childhood physical and/or sexual abuse, IPV, and sexual assault and/or abuse to name a few (Briere & Elliott, 2003; LeGrand et al., 2015; Pence et al., 2012; Sauceda et al., 2016; Smith, Smith, & Grekin, 2014) having a role in PLWH HIV treatment adherence. Despite this information, little research exists to explain how trauma impacts the motivation and readiness to adhere, while also controlling for correlates that interfere or facilitate adherence, to HIV treatment regimen.

Quantifying the burden of childhood trauma in addition to other life traumas such as domestic violence/IPV in this population could provide a better avenue for improving retention along the HCC. Further, if certain traumatic experiences were found to be more likely to decrease medication adherence, interventions based on findings could be implemented by healthcare teams and medical professionals for improving their retention in care.

Domestic and Intimate Partner Violence

Domestic violence includes IPV and is defined as physical, sexual, and/or psychological aggression, and/or stalking that occurs on a continuum where the victim has had an intimate, dating, or previous marriage with the offender (CDC, 2019; “Domestic Violence | OVW |

Department of Justice," 2014). IPV is common, affecting 1 in 4 women and 1 in ten men in their lifetime (CDC, 2019). According to a national survey, IPV that starts early in adolescence or high school can lead to IPV into adulthood (CDC, 2019).

IPV can occur in several forms: physical, sexual, psychological aggression, and/or stalking (CDC, 2019). With nearly 1 in 5 women and 1 in 7 men reporting severe IPV and 10% of women and 2% of men reporting stalking in the US, injury and death as a result are a serious concern (CDC, 2019). Moreover, the lifetime emotional and financial costs of lost time of work, medical bills, damages, and legal fees amount to significant challenges within the US (CDC, 2019). Even more concerning, recent studies have found a significant link between experiencing physical and sexual IPV and increased diagnosis of HIV/AIDS (Sareen, Pagura, & Grant, 2009). Research suggests IPV increases the incidence for HIV/AIDS internationally (Abuya, Onsomu, Moore, & Piper, 2012; Chiang et al., 2015), however in the US there have been inconsistent findings (Campbell et al., 2008). A study conducted in South Africa among 129 perinatal HIV-infected female youth discovered approximately one-fifth had experienced physical and/or sexual IPV in the past year; one-third had experienced IPV in their lifetime (Kidman, Violari, & Kidman, 2018). A separate study examining the intersection of IPV against women and risk for HIV infection in the US concluded that African HIV-positive women had a higher rate of IPV compared to HIV-positive women in the US (Campbell et al., 2008).

A recent study using National Epidemiologic Survey Alcohol and Related Conditions data examined how IPV affected HIV/STIs in men and women in the US; IPV mediated the relationship between sexual abuse and HIV/STIs (M. J. Brown et al., 2017). A different study conducted in Alabama consisting of qualitative interviews of HIV positive women in abusive relationships described domestic violence in relation to HIV (Lichtenstein, 2005). Women who

were interviewed portrayed HIV risk in relation to IPV as first being a "captive body" for which the woman lost the ability to protect herself and her freedom against sex, endured confinement, and was ultimately deprived and isolated by their intimate partner (Lichtenstein, 2005). This subsequently led to becoming infected with HIV (Lichtenstein, 2005). From this same study, other women saw these particular women who were infected with HIV and involved in these kinds of relationships as having lax morals, promiscuity, or living in poverty and having low self-esteem (Lichtenstein, 2005). This perception represents stigma and discrimination, personal beliefs that have long impacted the individuals living with HIV/AIDS and affecting their quality of life and treatment adherence (Editors, Stangl, & Grossman, 2013). PLWH who experience stigma have been studied in relation to adherence, and stigma has been correlated with delayed enrollment in HIV treatment; thus, stigma and discrimination remain a challenge as they discourage individuals to access HIV treatment services (Gesesew et al., 2017; Peterson, 2009; Shrestha, Altice, & Copenhaver, 2019; UNAIDS, 2018).

Research indicates a relationship exists between psychological stress as a result of trauma and HIV treatment adherence. Alarmingly, a meta-analysis of psychological trauma and posttraumatic stress disorder among HIV-positive women from the US revealed the estimated rate of IPV was 55.3%, twice the national rate (Machtinger, Wilson, Haberer, & Weiss, 2012). Furthermore, a more recent study screening for violence in conjunction with viral load suppression among African-American who were HIV-positive determined that 70% of their population were survivors of violence; women with this history were less likely to be suppressed compared to those without a history of violence (Espino et al., 2015). However, depression and substance use also play a role in decreased adherence and present challenges in addition to

PLWH experiencing stigma and IPV (Derose et al., 2014; S. Kalichman et al., 2016; Relf et al., 2019; Shrestha et al., 2019).

HIV Continuum of Care in Tennessee

As of 2015, the state of TN ranked 16th out of all 50 states for prevalence of HIV with adults and children combined (CDC, 2015; Tennessee Department of Health (TDH), 2019). In the state of TN for year 2017, the rate of new HIV cases was 10.6 per 100,000 (TDH, 2019). By region, the highest rates were in Middle and West TN, with Davidson County at 21.1 per 100,000 and Shelby County at 25.7 per 100,000 respectively (TDH, 2019). Davidson and Shelby counties were greater than the rate of new HIV diagnoses in the Southern region of the US (16.1 per 100,000) and almost more than double the rate of HIV in other regions in the US, specifically the Northeast (10.6 per 100,000), the West (9.4 per 100,000), and Midwest (7.4 per 100,000) (CDC, 2018b).

Counties with the highest rates of PLWH between 1982-2015 were primarily metropolitan areas of TN (Shelby, Davidson, and Hamilton counties) (Plan, 2016). Rural regions with similarly high rates were Carter (greater than 256.6 per 100,000) and Johnson (150.1-256.6 per 100,000) neighboring Washington County (Plan, 2016) where part of this dissertation collected data among PLWH.

TDH data were requested and obtained to examine the HCC by region (East, Middle, West, and Appalachian). In the state of TN, HIV testing can be conducted at health departments or in private practice medical facilities. The data provided below in Table 1 describe the persons newly and previously diagnosed with HIV along with total HIV tests by region as of December 31, 2018. These values were reported by health departments in TN and do not include testing at private practice clinics in TN.

Adults tested, newly diagnosed and PLWH were described among cisgender and transgender adults along with self-reported transmission risk categories (male to male sexual contact (MMS); injection drug use (IDU); MMS and IDU; heterosexual contact; perinatal exposure; other), age groups of adolescents and adults, as well as by race/ethnicity. The final table displays the HCC with adults diagnosed, linked to care within 30 days, retained in care, and ultimately virologically suppressed.

Among cisgender males, there were 46,466 HIV tests performed with 286 new diagnoses. The majority of testing occurring in West TN (16,312 tested; 125 new diagnoses) followed by Middle TN (15,607 tested; 95 new diagnoses), Appalachia (10569 tested; 48 new diagnoses) and East TN (10,084 tested; 48 new diagnoses). Among cisgender females, there were a total of 45,400 tests conducted with 56 new diagnoses. The greatest proportion of testing occurred in West TN (18,389 tested; 37 new diagnoses) followed by Middle (13,331 tested; 9 new diagnoses), Appalachia (9,333 tested; 9 new diagnoses), and East regions (8,751; 9 new diagnoses). Among transgender persons, 120 tests were conducted with 8 new diagnoses. The highest number was seen in West TN (77 tested; 6 new diagnoses) followed by Middle (27 tested; 2 new diagnoses), Appalachia and East regions (11 tested; 0 new diagnoses).

By age, adults between ages 18-34 made up majority of those tested and new diagnoses (57,422 tested; 243 new diagnoses) followed by those aged 35-54 (25,896 tested; 90 new diagnoses). By race, Non-Hispanic Black adults comprised majority of HIV testing with 47,850 tested and 216 new diagnoses followed by Non-Hispanic White adults with 36,106 tested and 101 new diagnoses. MMS sexual contact was reported as transmission risk among cisgender males, heterosexual sexual contact among cisgender males, and “other” among transgender persons with some having reported injection drug use.

Table 1.1.

Persons newly and previously diagnosed with HIV, and total tests by region, Tennessee, 2018

	West			Middle			East			Appalachia			Tennessee		
	New dx	Prev dx	Total Tests	New dx	Prev dx	Total Tests	New dx	Prev dx	Total Tests	New dx	Prev dx	Total Tests	New dx	Prev dx	Total Tests
Gender															
Cisgender male	125	242	16312	95	73	15607	53	23	10084	48	22	10569	286	341	46466
Cisgender female	37	107	18389	9	10	13331	9	5	8751	9	6	9333	56	125	45400
Transgender person	6	4	77	2	1	27	0	1	11	0	1	11	8	6	120
Age group (years)															
0–17	3	4	919	0	0	814	0	1	552	0	1	600	3	5	2351
18–34	115	164	22182	76	39	18691	43	18	11794	39	17	12419	243	225	57422
35–54	44	146	9468	25	34	7553	17	10	5344	16	11	5634	90	192	25896
≥55	6	39	2209	5	11	1907	2	0	1156	2	0	1260	14	50	6317
Race/ethnicity															
Non-Hispanic black	141	308	27035	58	50	12136	10	11	4495	12	10	4631	216	373	47850
Non-Hispanic white	17	35	6287	34	26	13101	47	14	12250	41	16	13140	101	76	36106
Hispanic	8	5	1042	10	5	2466	5	4	1609	4	3	1637	26	14	5694
Other	2	5	414	4	3	1262	0	0	492	0	0	505	7	9	2336
Transmission risk															
Cisgender male															
Male-to-male sexual contact (MMS)	63	95	1004	48	36	2340	26	6	637	25	6	672	143	139	4475
Injection drug use (IDU)	1	2	214	0	1	244	2	1	362	2	1	402	3	4	912
MMS and IDU	1	3	13	3	3	32	4	1	31	4	2	31	9	7	103
Heterosexual sexual contact	14	26	10869	5	6	6169	2	0	2176	3	0	2603	25	32	20047
Perinatal exposure	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Other	0	0	1	0	0	0	0	0	0	0	0	0	0	0	1
Unknown	46	116	4211	39	27	6822	19	15	6878	14	13	6861	106	159	20928
Cisgender female															
Heterosexual sexual contact	16	43	11761	1	3	6889	3	2	3117	2	2	3601	21	49	22806
Injection drug use (IDU)	0	3	176	0	1	153	3	1	364	3	2	383	3	5	1001
Perinatal exposure	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Other	0	0	240	0	0	348	0	0	65	0	0	81	0	0	690
Unknown	21	61	6212	8	6	5941	3	2	5205	4	2	5268	32	71	20903
Transgender person															
Any sexual contact	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Injection drug use (IDU)	2	0	2	0	0	1	0	0	3	0	0	4	2	0	6
Any sexual contact and IDU	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Perinatal exposure	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Other	4	4	75	2	1	26	0	1	8	0	1	7	6	6	114
Unknown	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Overall	**168**	**353**	**34778**	**106**	**84**	**28965**	**62**	**29**	**18846**	**57**	**29**	**19913**	**350**	**472**	**91986**

Source: Evaluation Web, accessed May, 2020.
New HIV diagnoses: persons diagnosed with HIV during January 1–December 31, 2018 and resided in Tennessee at the time of diagnosis
For new diagnoses, age group refers to the age at the time of HIV diagnosis.
Previous HIV diagnoses: persons diagnosed with HIV on or before December 31 and resided in Tennessee on December 31, 2018
For previous diagnoses, age group refers to age as of December 31, 2018.Hispanics can be of any race.
Transmission risk categories are mutually exclusive; heterosexual sexual contact includes high risk heterosexuals and persons who had sexual contact with someone of the opposite sex and said no to injecting drugs; other includes blood transfusion and hemophilia; unknown indicates no identified risk (NIR) and no reportable risk (NRR).
— represents data not available.
West: Benton, Carroll, Chester, Crockett, Decatur, Dyer, Fayette, Gibson, Hardeman, Hardin, Haywood, Henderson, Henry, Lake, Lauderdale, Madison, McNairy, Obion, Shelby, Tipton and Weakley counties.
Middle: Bedford, Cannon, Cheatham, Clay, Coffee, Davidson, DeKalb, Dickson, Fentress, Franklin, Giles, Grundy, Hickman, Houston, Humphreys, Jackson, Lawrence, Lewis, Lincoln, Macon, Marshall, Maury, Montgomery, Moore, Overton, Perry, Pickett, Putnam, Robertson, Rutherford, Sequatchie, Smith, Stewart, Sumner, Trousdale, Van Buren, Warren, Wayne, White, Williamson and Wilson counties.
East: Anderson, Bledsoe, Blount, Bradley, Campbell, Carter, Claiborne, Cocke, Cumberland, Grainger, Greene, Hamblen, Hamilton, Hancock, Hawkins, Jefferson, Johnson, Knox, Loudon, Marion, McMinn, Meigs, Monroe, Morgan, Polk, Rhea, Roane, Scott, Sevier, Sullivan, Unicoi, Union and Washington counties.
Appalachia: Anderson, Bledsoe, Blount, Bradley, Campbell, Cannon, Carter, Claiborne, Clay, Cocke, Coffee, Cumberland, DeKalb, Fentress, Franklin, Grainger, Greene, Grundy, Hamblen, Hamilton, Hancock, Hawkins, Jackson, Jefferson, Johnson, Knox, Lawrence, Lewis, Loudon, McMinn, Macon, Marion, Meigs, Monroe, Morgan, Overton, Pickett, Polk, Putnam, Rhea, Roane, Van Buren, Warren, Washington and White counties.

Persons who lived in TN and were newly diagnosed with HIV by TN region between January 1 and December 31, 2018 are displayed in Table 2. The overall rate of PLWH newly diagnosed in 2018 was 11.3 per 100,000 with the greatest rate in West TN (22.2 per 100,000) followed by Middle TN (9.1 per 100,000) then Appalachia (7.1 per 100,000) and East TN (6.8 per 100,000). Age was divided into PLWH 0-17, 18-34, 35-54, and ≥55. The overall rate was highest among adults 18-34 (30.8 per 100,000), followed by adults 35-54 (12.6 per 100,000). By region, the greatest proportion of newly diagnosed PLWH lived in West TN (58.8 per 100,000) followed by Middle TN (24.5 per 100,000), then Appalachia (19.4 per 100,000) and East TN (19.0 per 100,000). By race, the rate of Non-Hispanic Blacks newly diagnosed far surpassed other races at a rate of 39.7 per 100,000 followed by Hispanics (14.2 per 100,000).

A total of 22 adults identifying as transgender were newly diagnosed with HIV with the majority living in West TN (N=12) followed by Middle TN (N=8). A rate could not be calculated due to the small sample size, however the rate of newly diagnosed PLWH was 18.5 and 3.9 among cisgender males and females respectively per 100,000. MMS sexual contact among cisgender males, heterosexual sexual contact among cisgender females, and any sexual contact among transgender persons were the most common transmission risk factors reported.

Table 1.2.

Persons newly diagnosed with HIV by region, Tennessee, 2018

	East		Middle		West		Appalachia		Tennessee	
	No.	Rate	No.	Rate	No.	Rate	No.	Rate	No.	Rate
Gender										
Cisgender male	130	11.0	205	15.3	270	36.0	141	11.3	605	18.5
Cisgender female	33	2.7	35	2.5	65	8.0	37	2.8	133	3.9
Transgender person	2	—	8	—	12	—	2	—	22	—
Age group (years)										
0–17	1	0.2	2	0.3	10	2.7	1	0.2	13	0.9
18–34	97	19.0	158	24.5	210	58.8	105	19.4	465	30.8
35–54	47	7.6	70	9.8	100	25.1	53	8.2	217	12.6
≥55	20	2.6	18	2.6	27	6.2	21	2.6	65	3.4
Race/ethnicity										
Non-Hispanic black	47	31.5	112	31.8	288	46.1	49	31.8	447	39.7
Non-Hispanic white	99	4.7	101	4.9	39	4.9	112	5.1	239	4.8
Hispanic	16	16.1	20	10.6	16	20.2	16	14.8	52	14.2
Other	3	3.9	15	11.8	4	7.3	3	3.7	22	8.5
Transmission risk										
Cisgender male										
Male-to-male sexual contact (MMS)	89	—	138	—	140	—	98	—	367	—
Injection drug use (IDU)	7	—	3	—	1	—	7	—	11	—
MMS and IDU	6	—	8	—	6	—	7	—	20	—
Heterosexual sexual contact	21	—	23	—	37	—	22	—	81	—
Perinatal exposure	0	—	0	—	2	—	0	—	2	—
Other	0	—	0	—	0	—	0	—	0	—
Unknown	7	—	33	—	84	—	7	—	124	—
Cisgender female										
Heterosexual sexual contact	22	—	24	—	36	—	24	—	82	—
Injection drug use (IDU)	6	—	0	—	1	—	6	—	7	—
Perinatal exposure	0	—	1	—	1	—	0	—	2	—
Other	0	—	0	—	0	—	0	—	0	—
Unknown	5	—	10	—	27	—	7	—	42	—
Transgender person										
Any sexual contact	2	—	6	—	10	—	2	—	18	—
Injection drug use (IDU)	0	—	0	—	0	—	0	—	0	—
Any sexual contact and IDU	0	—	0	—	0	—	0	—	0	—
Perinatal exposure	0	—	0	—	0	—	0	—	0	—
Other	0	—	0	—	0	—	0	—	0	—
Unknown	0	—	2	—	2	—	2	—	4	—
Overall	**165**	**6.8**	**248**	**9.1**	**347**	**22.2**	**180**	**7.1**	**760**	**11.3**

Source: Tennessee enhanced HIV/AIDS Reporting System (eHARS), accessed August 1, 2019.
New HIV diagnoses: persons diagnosed with HIV during January 1–December 31, 2018 and resided in Tennessee at the time of diagnosis
For new diagnoses, age group refers to the age at the time of HIV diagnosis.
Hispanics can be of any race.
Transmission risk categories are mutually exclusive; heterosexual sexual contact includes high risk heterosexuals and persons who had sexual contact with someone of the opposite sex and said no to injecting drugs; other includes blood transfusion and hemophilia; unknown indicates no identified risk (NIR) and no reportable risk (NRR).
— represents data not available.
Rates were calculated using the US Census Bureau 2017 Population Estimates.
West: Benton, Carroll, Chester, Crockett, Decatur, Dyer, Fayette, Gibson, Hardeman, Hardin, Haywood, Henderson, Henry, Lake, Lauderdale, Madison, McNairy, Obion, Shelby, Tipton and Weakley counties.
Middle: Bedford, Cannon, Cheatham, Clay, Coffee, Davidson, DeKalb, Dickson, Fentress, Franklin, Giles, Grundy, Hickman, Houston, Humphreys, Jackson, Lawrence, Lewis, Lincoln, Macon, Marshall, Maury, Montgomery, Moore, Overton, Perry, Pickett, Putnam, Robertson, Rutherford, Sequatchie, Smith, Stewart, Sumner, Trousdale, Van Buren, Warren, Wayne, White, Williamson and Wilson counties.
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Appalachia: Anderson, Bledsoe, Blount, Bradley, Campbell, Cannon, Carter, Claiborne, Clay, Cocke, Coffee, Cumberland, DeKalb, Fentress, Franklin, Grainger, Greene, Grundy, Hamblen, Hamilton, Hancock, Hawkins, Jackson, Jefferson, Johnson, Knox, Lawrence, Lewis, Loudon, McMinn, Macon, Marion, Meigs, Monroe, Morgan, Overton, Pickett, Polk, Putnam, Rhea, Roane, Van Buren, Warren, Washington and White counties.

Number and rate of PLWH, defined as adults diagnosed with HIV on or before December 31, 2018 by region in TN, are shown below in Table 3. The overall rate of PLWH in TN was 269 per 100,000 as of year 2018. The highest rate was seen in the West region (495.9 per 100,000) followed by Middle (237.2 per 100,000), Appalachian (169.5 per 100,000) and East (158.7 per 100,000) regions. The majority of PLWH were between ages 35-54 (513.8 per 100,000) followed by ≥55 (269.5 per 100,000), adults 18-34 (259.1 per 100,000) and adolescents 0-17 (8.4 per 100,000). Most PLWH were between the ages of 35-54 in East (313.4 per 100,000), Middle (437.4 per 100,000), West (961.9 per 100,000) and Appalachian regions (513.8 per 100,000).

A total of 215 PLWH identified as transgender, and a rate was not calculated due to this small sample size. Among those identifying as transgender, 32 lived in in East TN, 33 in the Appalachian region, 76 in Middle TN, while the majority resided in West TN (107). The most common mode of transmission was any sexual contact for transgender persons (178), heterosexual sexual contact among cisgender females (3230), and MMS among cisgender males (8913). By race, Non-Hispanic Black PLWH made up the greatest proportion of PLWH (903.4

per 100,000) followed by Hispanic (231.6 per 100,000), Other races (199.3 per 100,000) and Non-Hispanic White (131.5 per 100,000).

Table 1.3.

Persons living with diagnosed HIV by region, Tennessee, 2018

	East		Middle		West		Appalachia		Tennessee	
	No.	Rate	No.	Rate	No.	Rate	No.	Rate	No.	Rate
Gender										
Cisgender male	3000	253.4	5034	375.4	5343	711.5	3377	270.9	13378	408.4
Cisgender female	810	65.5	1374	98.6	2292	282.8	904	69.6	4476	130.1
Transgender person	32	—	76	—	107	—	33	—	215	—
Age group (years)										
0–17	28	5.6	40	6.4	58	15.4	28	5.3	126	8.4
18–34	653	127.7	1352	210.0	1911	535.4	727	134.1	3917	259.1
35–54	1935	313.4	3119	437.4	3827	961.9	2181	338.1	8881	513.8
≥55	1226	157.8	1973	282.1	1946	449.4	1378	170.5	5145	269.5
Race/ethnicity										
Non-Hispanic black	1026	687.0	2926	830.1	6227	996.6	1086	703.7	10179	903.4
Non-Hispanic white	2541	121.3	2928	141.7	1055	131.4	2901	131.7	6525	131.5
Hispanic	197	198.0	433	230.5	219	276.6	237	218.7	849	231.6
Other	78	101.6	197	154.5	241	441.0	90	111.8	516	199.3
Transmission risk										
Cisgender male										
Male-to-male sexual contact (MMS)	2102	—	3502	—	3309	—	2337	—	8913	—
Injection drug use (IDU)	169	—	309	—	148	—	201	—	626	—
MMS and IDU	169	—	248	—	139	—	200	—	556	—
Heterosexual sexual contact	327	—	451	—	929	—	374	—	1707	—
Perinatal exposure	18	—	22	—	35	—	20	—	75	—
Other	12	—	18	—	16	—	13	—	46	—
Unknown	203	—	484	—	767	—	232	—	1455	—
Cisgender female										
Heterosexual sexual contact	555	—	940	—	1735	—	616	—	3230	—
Injection drug use (IDU)	115	—	201	—	105	—	132	—	421	—
Perinatal exposure	15	—	29	—	57	—	17	—	101	—
Other	3	—	8	—	4	—	5	—	15	—
Unknown	122	—	196	—	391	—	134	—	709	—
Transgender person										
Any sexual contact	28	—	63	—	87	—	29	—	178	—
Injection drug use (IDU)	0	—	1	—	0	—	0	—	1	—
Any sexual contact and IDU	3	—	5	—	1	—	3	—	9	—

Perinatal exposure	0	—	1	—	0	—	0	—	1	—
Other	0	—	0	—	0	—	0	—	0	—
Unknown	1	—	6	—	19	—	1	—	26	—
Overall	**3842**	**158.7**	**6484**	**237.2**	**7742**	**495.9**	**4314**	**169.5**	**18069**	**269.0**

Source: Tennessee enhanced HIV/AIDS Reporting System (eHARS), accessed August 1, 2019.
Living with diagnosed HIV: persons diagnosed with HIV on or before December 31 and resided in Tennessee on December 31, 2018
For persons living with diagnosed HIV, age group refers to age as of December 31, 2018.
Hispanics can be of any race.
Transmission risk categories are mutually exclusive; heterosexual sexual contact includes high risk heterosexuals and persons who had sexual contact with someone of the opposite sex and said no to injecting drugs; other includes blood transfusion and hemophilia; unknown indicates no identified risk (NIR) and no reportable risk (NRR).
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Appalachia: Anderson, Bledsoe, Blount, Bradley, Campbell, Cannon, Carter, Claiborne, Clay, Cocke, Coffee, Cumberland, DeKalb, Fentress, Franklin, Grainger, Greene, Grundy, Hamblen, Hamilton, Hancock, Hawkins, Jackson, Jefferson, Johnson, Knox, Lawrence, Lewis, Loudon, McMinn, Macon, Marion, Meigs, Monroe, Morgan, Overton, Pickett, Polk, Putnam, Rhea, Roane, Van Buren, Warren, Washington and White counties.

Varying percentages of PWLH engaged in the HCC exist across the state of TN (presented in Table 4). In East, Middle, West, and Appalachian regions of TN, 100% persons infected with HIV were diagnosed with HIV as of 2016. Of those newly diagnosed in 2017, only 49% were linked to care within 30 days. The greatest proportion of adults linked to care within 30 days resided in the Appalachian region (53%) followed by the East and West, 50%, then Middle, 47% regions. Of the PLWH who were diagnosed as of December 31, 2016 and believed to be alive and living in TN, only 57% were retained in care. A greater proportion of adults were retained in care in West TN, 60%, followed by the East and Appalachian (57%) then Middle (52%) regions. Similarly, virologic suppression was higher in the Appalachian region of TN (62%; East TN is a part of the Appalachian region) and lowest in Middle TN (46%). Of PLWH diagnosed as of December 31, 2016 with at least one measured viral load and believed to be alive, only 56% were virologically suppressed in 2017. The region with the most adults virologically suppressed was East TN, 63%, followed by the Appalachian (62%), West (60%), and Middle (46%) regions.

Table 1.4.

HIV Continuum of Care by region, Tennessee, 2017

	Diagnosed	Linked to care (in 30 days)	Retained in Care	Virologically Suppressed
Region				
East region	100%	50%	57%	63%
Middle region	100%	47%	52%	46%
West region	100%	50%	60%	60%
Appalachian region	100%	53%	57%	62%
Overall	**100%**	**49%**	**57%**	**56%**

Linked to Care: >= 1 CD4 or VL result reported <= 30 days after the diagnosis date for those newly diagnosed with HIV in 2017 in the jurisdiction.
Retained in Care: >= 2 CD4 and/or VL results reported >= 3 months apart in 2017. For all individuals diagnosed with HIV on or before December 31, 2016 and believed to be alive and residing in the jurisdiction as of December 31, 2017.
Virologically Suppressed: HIV diagnosed individuals who had >= 1 VL measurement in 2016 and whose last VL measure in 2017 <= 200 copies/mL. For all individuals diagnosed with HIV on or before December 31, 2016 and believed to be alive and residing in the jurisdiction as of December 31, 2017.

Health Disparities among PLWH in TN

In the Appalachian region of the US, HIV prevalence is 57% lower than the national rate (Appalachian Regional Commission, 2017). However, Southern Appalachia, encompassing the Northeast region of the state of TN, has the highest rate among its sub-regions, although still 41% lower than the national rate for PLWH (Appalachian Regional Commission, 2017). The below figure highlights areas in dark blue that have the highest prevalence of HIV in the Appalachian region of the US, including TN, from the year 2013 (Appalachian Regional Commission, 2017). Based on literature findings of mental health and HIV adherence, it is hypothesized that PLWH in rural regions of the South Central region of Appalachia and Washington County who have fallen out of HIV care and are less adherent to HIV treatment regimen suffer from life trauma and mental health conditions (S. C. Kalichman & Grebler, 2010; Maulsby et al., 2017). Furthermore, the average number of mentally unhealthy days is 25% higher than the national average (Appalachian Regional Commission, 2017). The below figures, 1 and 2, display the number of mentally unhealthy days and prevalence of HIV across the

Appalachian region of the US and TN. Areas in dark blue illustrate the highest averages of mentally unhealthy days per month per person from the year 2014 (Appalachian Regional Commission, 2017).

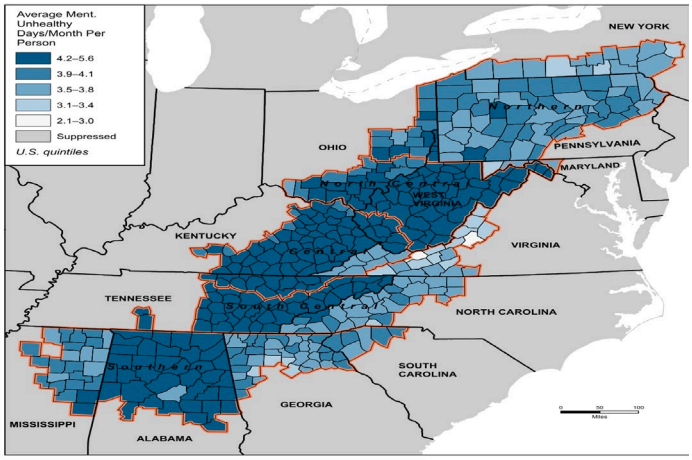

Figure 1.1. Mentally unhealthy days in Appalachia

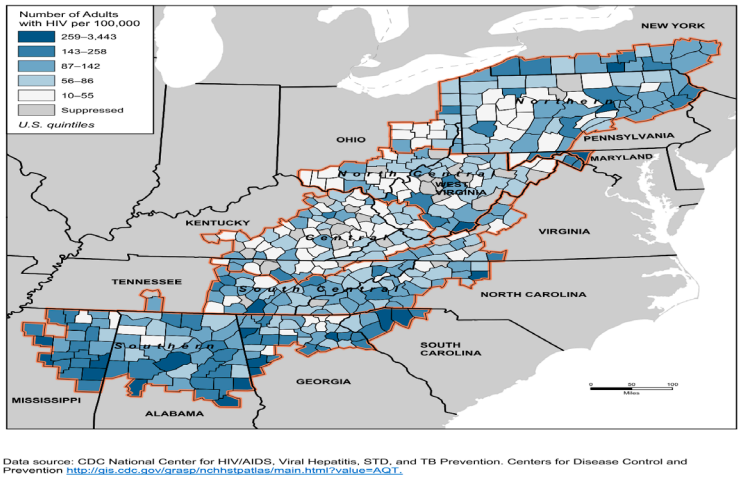

Figure 1.2. Prevalence of HIV in Appalachia

While ACEs remain anecdotal among PLWH in the state of TN, the number of mentally unhealthy days are known to be more common compared to the average American (Appalachian Regional Commission, 2017). In fact, Appalachian residents report 0.5 more mentally unhealthy days compared to the rest of America averaging out around 6 more days per person annually

(Appalachian Regional Commission, 2017). Trauma, mentally unhealthy days, and living with HIV/AIDS are suspected to be a challenge providers face in retaining PLWH in HIV care.

Little evidence has linked PLWH in TN with ACEs. Existing evidence is primarily from the TDH reports. Specifically, in TN, the latest data from 2015 describes adults with four or more ACEs were eight times as likely to have HIV risk factors compared to adults with less than four ACEs (TDH, 2015). Evidence for HIV risk factors and ACEs among PLWH have yet to be described scientifically through peer-reviewed publications beyond the calculation of relative risks from the TDH or regarding regions within Appalachia (VanderEnde et al., 2018; Wisconsin Children's Trust Fund, 2012).

Barriers and Facilitators for HIV care in TN

According to responses to a survey conducted by the TDH in 2015, barriers to HIV testing included fear of diagnosis, stigma, low perceived risk, substance abuse, mental health disorder, absence of routine tests, lack of access to care (TDH, 2016). This same survey asked about barriers positive prevention services among PLWH. Responses were similar including stigma, lack of social support, housing instability, mental health issues, substance abuse, denial of HIV risk, transportation, lack of insurance/access, and cost of services (TDH, 2016). Similar responses were seen for reasons why linking to care may be unsuccessful (TDH, 2016). To improve the HCC, the TDH provides most of its care through Centers of Excellence for HIV/AIDS (COE) across the state of TN (TDH, 2016).

There are fourteen COEs in the state of TN (TDH, 2016) assisting in providing HIV testing to at risk individuals, PrEP, post exposure prophylaxis (PEP), and treatment for PLWH. Medical services offered include primary, infectious disease, and internal medicine with support from nurse practitioners, registered nurses, and physician assistants (TDH, 2016). In 2015, the

Ryan White Program provided HIV care to approximately 4,500 patients across the state of TN specifically at COE sites (TDH, 2016). That same year, over 100,000 HIV tests were administered identifying 462 new positive cases with nearly 75% linked to care. Washington County is of interest primarily because it is home to the only COE in the county and from which part of this dissertation work was completed.

In 1998, East Tennessee State University (ETSU) applied and received designation for developing the COE. Annually, the COE receives designation from the TDH to provide comprehensive medical care to PLWH. Services include outpatient/ambulatory medical care, medical case management, case management/social work, clinical pharmacology, psychotherapy, in-house specialty pharmacy, in addition to nutrition and dental services as well as prevention and outreach (PrEP, testing and linkage to care, and syringe exchange program).

The mission of the local COE in Johnson City, TN is to provide quality comprehensive medical care to persons living with HIV. Achieving this is measured by satisfactory clinical performance on TDH and Health Resources and Services Administration guidelines. Values are centered around ensuring PLWH can attend their appointments, receive needed food, housing, and transportation assistance along with providing care to uninsured, insured, and Ryan White recipients. Approximately 600 patients are seen annually at the COE in Washington County. The current burden of ACEs, IPV, or domestic violence has yet to be characterized in the COE using a questionnaire but has been reported to clinic providers through patient intake and regular appointments.

Research Aims

The burden of traumatic experiences in TN and specifically in Johnson City, TN have not yet been characterized in the published literature with respect to correlates associated to the

HCC. This dissertation examines several potential correlates that either facilitate or act as a barrier to the HCC specifically related to sociodemographic characteristics, life traumas experienced before the age of 18, sexual minority groups, and mental health among adults living in the state of TN. TN surveillance data specifically examined ACEs, sociodemographic characteristics, and sexual minority groups, minority groups as they relate to being at risk for HIV and being tested for HIV (research aims 1 and 2). Locally, perspectives from PLWH were ascertained from a COE in Johnson City, TN, to seek opinions to develop an appropriate questionnaire to investigate the role life traumas and barriers to HIV care among PLWH have on the motivation to adhere to HIV care (research aim 3). Findings inform additional research and interventions geared towards TN achieving 90% of residents aware of their HIV status, 90% linked and retained in HIV care, and 90% virally suppressed.

Research Aim #1: Determine the prevalence and the odds of HIV risk behaviors and HIV testing among LGBT adults living in TN.

Research Aim #2: Investigate the impact of adverse childhood experiences on HIV risk behaviors and HIV testing with a specific focus on low-income populations in the state of TN.

Research Aim #3: Develop a questionnaire for the COE in Johnson City, TN to assess ACEs, mental health issues, perceived barriers to treatment, and readiness to adhere to treatment regimen.

Hypotheses

Studies examining life traumas with a variety of barriers and facilitators to care are necessary to assess readiness to adhere to HIV care in the US to improve health disparities among minority groups of PLWH in addition to achieving NHAS and UNAIDS goals for ending the HIV epidemic. A modified socioecological model was applied to the present study to

describe the multifaceted and complex relationships associated with the HCC in TN specifically among adults in TN at risk, ever tested, or PLWH.

The present model (shown below in Figure 3) was modified to reflect the variables explored in TN for the purposes of this dissertation (bolded) along with other correlates pertaining to the HCC in the US. Development was influenced by socioecological models constructed by researchers in 2013 to characterize the multi-layered factors connected with HIV risk in the US (Baral, Logie, Grosso, Wirtz, & Beyrer, 2013). At the individual level, HIV risk behaviors are among the most significant aspect of HIV transmission in TN aligning with risk perception for and knowledge of HIV transmission and treatment. Thus, sexual risk behaviors are a paramount component related to the HCC. Additionally, HIV risk and ever tested for HIV were analyzed as a part of this dissertation research along with other variables specific to sexual orientation, age, income, and ACEs. Other factors known to play a role in HIV risk and transmission as previously discussed involve substance use, history of substance abuse, domestic violence, engagement in HIV care if HIV positive, and adherence to HIV care.

Interpersonal relationships are also considered to play a role through social support (peer or family) and intimate relationships. The community level is necessary in attributing regional findings with determinants associated with HIV, such as community norms that may increase stigma among sexual minority groups and/or PLWH. The most influential level impacting HIV/AIDS transmission is with respect to the public policy level by which NHAS, Division of HIV/AIDS Prevention Strategic Plan, and TN laws help with providing human rights to PLWH along with other marginalized groups, preventing the spread of transmission through effective treatment and educational programs, and implementation of testing sites across the state (Baral et al., 2013; CDC, 2017a; HIVgov, 2017; The Center for HIV Law and Policy, 2019). Through

incorporation of structural and societal factors contributing to the HCC, public health and medical practitioners can unite to combat the transmission of HIV at the HIV epidemic stage (Baral et al., 2013; Frieden, Foti, & Mermin, 2015)

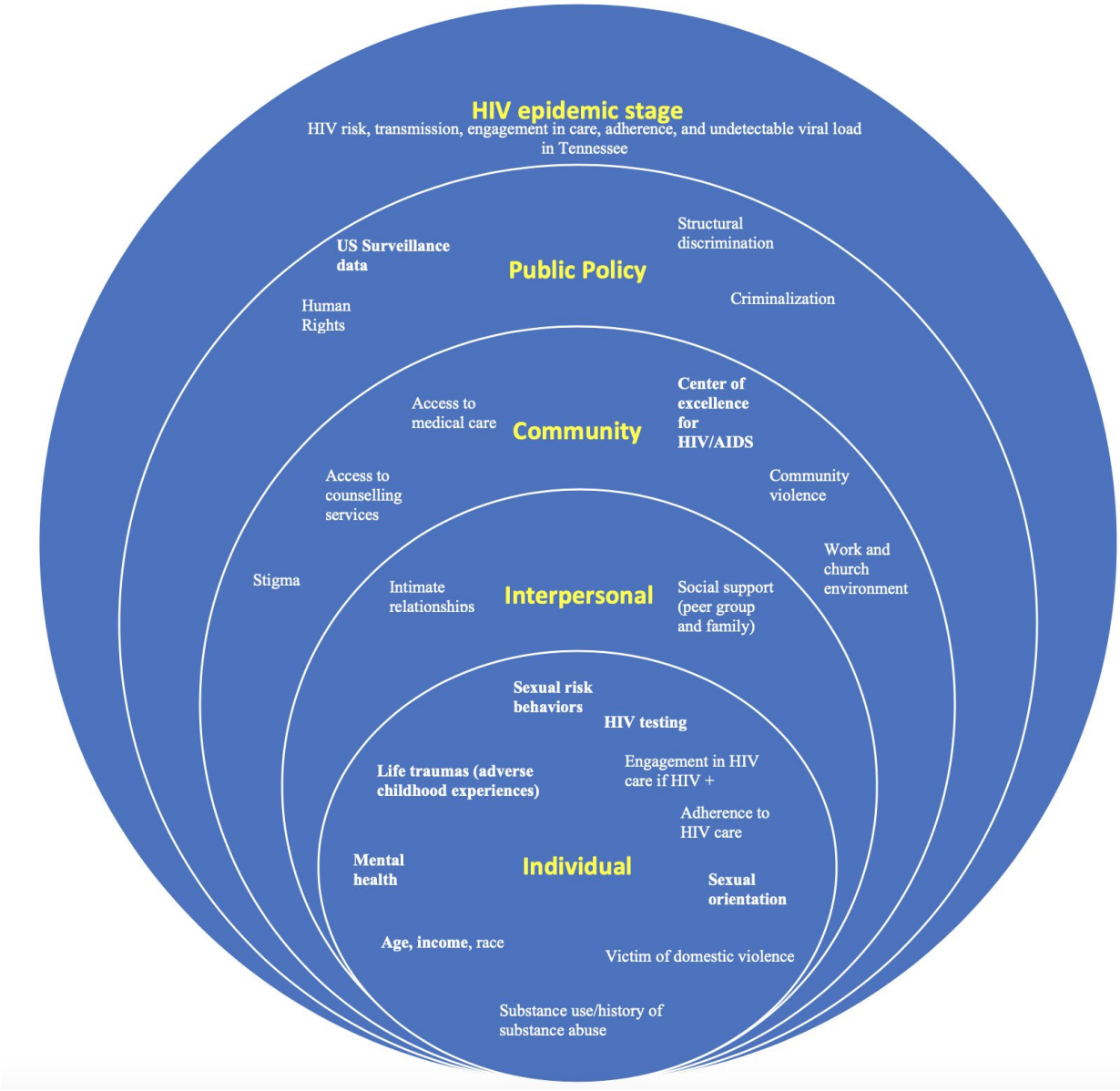

Figure 1.3. Modified Socioecological Model for the HIV Continuum of Care in Tennessee (bolded variables were the only ones analyzed in this research)

Research aim 1 addresses the individual, interpersonal, and community level using the most recent TN data available to explore the prevalence of being at risk for HIV and HIV testing among LGBT adults. Moreover, the odds of testing for HIV were explored with HIV risk behaviors and/or self-reported mental health diagnosis controlling for sociodemographic characteristics (see Figure 4).

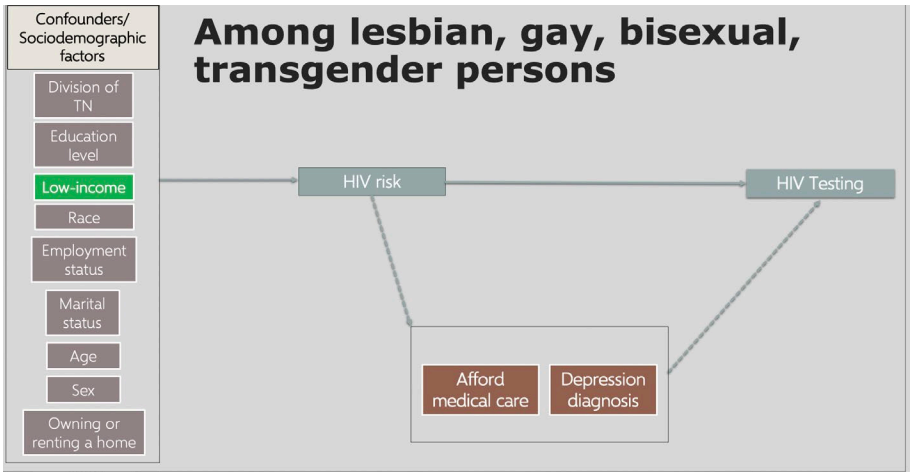

Figure 1.4. Conceptual Framework for Research Aim 1

Research aim 2 incorporates individual, interpersonal, and community factors by again using the most recent data available in the state of TN among adults with ACEs. The role ACEs with being at risk for HIV and HIV testing was examined while controlling for mental health and sociodemographic characteristics (see Figure 5).

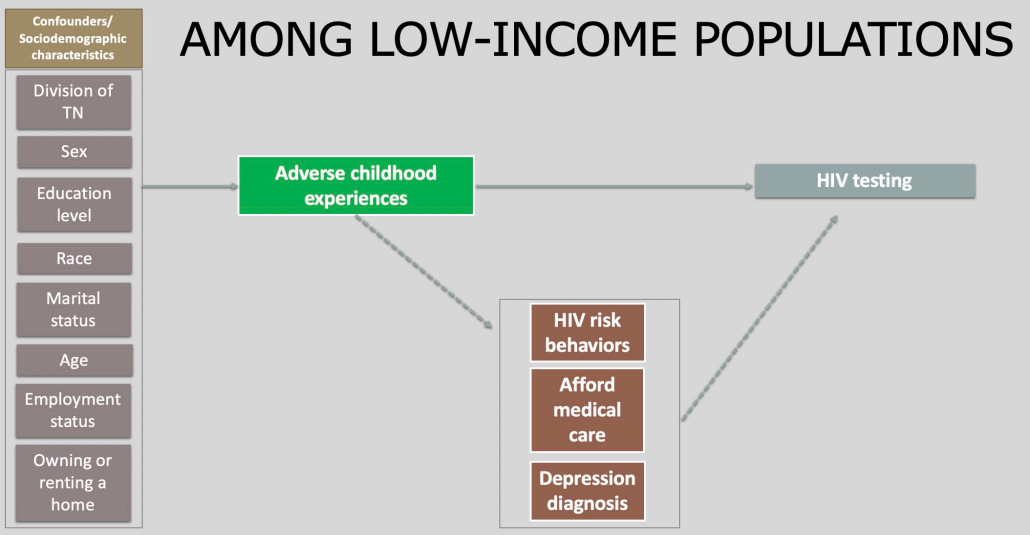

Figure 1.5. Conceptual Framework for Research Aim 2

The third hypothesis involved modifying surveillance questions through interviewing PLWH at a local COE. The current phrasing of questions was assumed to be inappropriate, potentially offensive, and thus warranted opinions to create a culturally competent survey for utility at the specific COE. Furthermore, a life traumas survey, including ACEs, had never been studied nor implemented to the best of our knowledge among a HIV positive population in a clinical setting. Thus, research aim 3 involved development of a culturally competent survey through the evaluation of questions related to life traumas and adherence to HIV care.

Chapter 2. Examining Risk and Testing for HIV among Lesbian, Gay, Bisexual, Transgender Adults and Low-income Populations in Tennessee

[1]Elaine Loudermilk, [1]Shimin Zheng, [1]Melissa White, [2]Emmitt Turner, [3,4]Robert Pack, [2,5]Jonathan Moorman, [1]Megan Quinn

[1]Department of Biostatistics and Epidemiology, College of Public Health, East Tennessee State University, Johnson City, Tennessee 37604

[2]Quillen College of Medicine, East Tennessee State University, Johnson City, Tennessee 37604

[3]Department of Community and Behavioral Health, College of Public Health, East Tennessee State University, Johnson City, Tennessee 37604

[4]Center for Prescription Drug Abuse, Prevention, and Treatment, College of Public Health, East Tennessee State University, Johnson City, Tennessee 37604

[5]Center of Excellence for Inflammation, Infectious Disease and Immunity, Quillen College of Medicine, East Tennessee State University, Johnson City, Tennessee 37604

Abstract

Introduction

In Tennessee (TN), little research exists on the risk for HIV and uptake of HIV testing among sexual minority groups, specifically lesbian, gay, bisexual, transgender (LGBT) adults.

Methods

TN Department of Health Behavioral Risk Factor Surveillance data, year 2018, were obtained. Descriptive statistics for the overall sample were completed followed by subpopulation analysis among LGBT stratified by TN grand division (East, Middle, and West) and regression analysis with outcomes, at risk for HIV and ever tested for HIV.

Results

Among LGBT adults living in TN (N=262), 45.53% were at risk for HIV and 58.32% had ever tested in East TN; 25.95% were at risk for HIV and 50.57% had ever tested for HIV in Middle TN; and 17.82% were at risk for HIV and 39.56% had ever tested for HIV in West TN. Depression increased the odds of being at risk for HIV across all TN divisions (East TN, aOR: 5.07, 95% CI: 4.90-5.25; Middle TN, aOR: 4.46, 95% CI: 4.40-4.72); West TN, aOR: 2.53; 95% CI: 2.43-2.62). Being at risk for HIV increased the odds of HIV testing (East TN, aOR: 1.04, 95% CI: 1.00-1.07; Middle TN, aOR: 4.41, 95% CI: 4.25-4.58); West TN, aOR: 33.59; 95% CI: 31.97-35.96). In Middle TN, an annual income of <$25,000 decreased the odds of HIV testing by 87% (aOR: 0.13, 95% CI: 0.13-0.14).

Discussion

Regional disparities are evident among LGBT with depression and risk for HIV in TN. Future longitudinal and qualitative studies are needed to further understand differences within and between TN divisions among LGBT.

Keywords: Sexual minority groups, low income, regional disparities, HIV testing

Introduction

Incidence of HIV diagnoses in TN has decreased by 9% with PLWH decreasing by 3% from 2013-2017 (Tennessee Department of Health (TDH), 2019). However, health disparities exist by region, sex, and age group. By TN region at time of diagnosis, the mid-Cumberland region carried the majority of new HIV cases with West TN, specifically Shelby County, following in second between 2005 to 2015 (Plan, 2016). In 2015, the highest prevalence of persons living with HIV (PLWH) were males, who were three times higher than females (Plan, 2016). Among persons living with HIV/AIDS (PLWH), the majority of adults were aged 44-54 years (Plan, 2016). By race, the prevalence of HIV was 13.5 times higher among Blacks/African American females compared Whites; for males, the rate among Blacks/African Americans was 5.9 times as high compared to Whites (Plan, 2016).

As of 2017, majority of new cases were among males and self-reported to be most frequently due to male to male sexual contact (MSM); comparatively, heterosexual sexual contact was the most common among cisgender females (TDH, 2019). This information was obtained from the TDH HIV Surveillance and Epidemiology program report, TN HIV Epidemiologic Profile 2017, but was limited in the representation of LGBT minority groups, specifically for adults identifying as transgender (TDH, 2019). Data are collected annually by TDH to provide statistics of adults who were newly diagnosed and along the HIV Continuum of Care (HCC), however reports are limited in examining additional associations related to mental health, affordability of medical care, and the odds of being at risk and testing for HIV by TN Grand Division, which is the East, Middle, and West regions of TN, among sexual minority groups (TDH, 2016).

Sexual minority groups were reportedly at higher risk for chronic diseases, binge drinking and smoking, HIV, and worse health care experiences (Austin, Herrick, & Proescholdbell, 2016; Elliott et al., 2015; Fredriksen-Goldsen et al., 2013; Gonzales & Henning-Smith, 2017). Furthermore, HIV infection risk and mental health are potentially higher among this population compared to heterosexual adults in part due to stigma and discrimination experienced from healthcare providers and society (Clark, Babu, Wiewel, Opoku, & Crepaz, 2017; Legal, 2010; Mayer et al., 2008; Owens, Riggle, & Rostosky, 2007). Possible reasons for being at higher risk for HIV may be due to intimate partner violence, childhood trauma, substance abuse, and fear of receiving medical care from providers who may not support LGBT lifestyle (Owens et al., 2007; Relf et al., 2019; Sustance Abuse and Mental Services Administration, 2012).

In the present study, we examined the odds of being at risk for and ever testing for HIV among a LGBT adult population in TN. This study is, to the best of our knowledge, among the first to examine regional differences among LGBT adults in TN relating to the HCC.

Methods

This research was determined to be exempt by the East Tennessee State Institutional Review Board. Data were obtained from the TDH to (1) determine prevalence of being at risk for and testing of HIV testing among adults who identify as lesbian, gay, bisexual, or transgender (LGBT) and (2) the odds of being at risk for and testing of HIV among LGBT with a specific focus on adults making <$25,000 annually defined throughout this paper as “low-income.” The current study is limited to only the year 2018; prior to 2018, data were not collected for adults who identified as transgender through the Behavioral Risk Factor Surveillance System (BRFSS)

(Centers for Disease Control and Prevention (CDC), 2018). All data analysis was completed in SAS 9.4 (Version 9.4. SAS Institute Inc., Cary, NC, USA).

Subpopulation

Sexual orientation was defined as adults responding to being either straight, lesbian or gay, bisexual, or other. An additional question was asked to adults if they considered themselves to be transgender. Responses were the following: yes, transgender, male-to-female; yes, transgender, female to male; yes, transgender, gender nonconforming; or not transgender. LGBT variables were combined into one variable to increase the sample size since there were not enough responses individually to stratify by sexual orientation for the purposes of this analysis. A new variable was created and defined as any adult, aged 18 or older, who responded to being LGBT or other than heterosexual (N=262).

Covariates

Demographics included sex (male or female), education (high school or less and some college or above), race (White, Black, Other), employment status (employed for wages, self-employed, other, retired), home ownership (rent or own), marital status (married/widowed or other), age (18-34, 35-54, and 55+), TN Grand Division (East, Middle or West), diagnosis of depression (ever told you have a depressive disorder including depression, major depression, dysthymia, or minor depression), and affordability of medical care (there was a time in the past 12 months when you needed to see a doctor but could not because of cost). Income level was defined into two categories, adults who made <$25,000 annually compared to adults making ≥$25,000 annually, to attempt to align as closely as possible with the federal poverty line in the US and more specifically TN (U.S. Department of Health & Human Services, 2014; US Census Bureau, 2016).

Dependent variables

There were two outcome variables in the current study: (1) risk for HIV and (2) tested for HIV. HIV risk was examined as an outcome and was also used as a predictor of interest with HIV testing as the outcome. The variable at risk for HIV was dichotomous and defined as responding "yes" or "no" to the following survey question:

> "I am going to read you a list. When I am done, please tell me if any of the situations apply to you. You do not need to tell me which one. You have injected any drug other than those prescribed for you in the past year. You have been treated for a sexually transmitted disease or STD in the past year. You have given or received money or drugs in exchange for sex in the past year."

For the second outcome, respondents answered "yes" or "no" when asked, "Have you ever been tested for HIV? Do not count tests you may have had as a part of a blood donation. Include testing fluid from our mouth (CDC, 2018)."

Descriptive statistics

Descriptive statistics including unweighted and weighted frequencies first calculated among the entire adult population for year 2018 (N=5,160). The sample was then limited to only adults who identified as LGBT or other than heterosexual with a final unweighted sample size of 262 (weighted N=3,523). Unweighted and weighted frequencies and Pearson's χ^2 tests of differences in proportions with HIV risk and HIV testing among the subpopulation were stratified by TN Grand Division (East, Middle, and West). Within-group simple and multiple logistic regression (MLR) analysis were then conducted for each strata (East, Middle, and West divisions of TN).

Within group regression analysis for at risk for HIV

First, simple logistic regression (SLR) analysis was performed with being at risk for HIV as an outcome predicted by diagnosed with depression, ability to afford medical care, sex, income status, marriage status, age, race, home ownership, employment status, and education level stratified by TN Grand Division. MLR was then estimated by which interaction, multicollinearity and confounding were controlled for. The following explanatory variables were not included due to large confounding effects: age, sex, and race. Multicollinearity was present between affordability of medical care, marriage status, home ownership, employment status, and education level with income status. Therefore, the final model only included two explanatory variables, depression and income status, and MLR was completed for each TN grand division strata (East, Middle, and West).

Within group analysis for ever tested for HIV

SLR analysis was conducted with ever tested for HIV as an outcome predicted by being at risk for HIV, diagnosed with depression, ability to afford medical care, sex, income status, marriage status, age, race, home ownership, employment status, and education level stratified by TN Grand Division. Interaction, multicollinearity and confounding were controlled for, and a final MLR model was estimated. Interaction was revealed between depression and HIV risk with ever tested for HIV as the outcome. Age, sex, and race were excluded from the final model due to large confounding effects. Multicollinearity was present with income status between the following explanatory variables and were therefore not included in the final model: affordability of medical care, marriage status, home ownership, employment status, and education level. Thus, the final model included only two explanatory variables, being at risk for HIV and income status. MLR was completed for each TN grand division strata.

Results

Descriptive statistics

Descriptive statistics presented in Table 1 indicate less than half (37.33%) of the total adult population (N=5,160) ever tested for HIV and less than a quarter (7.55%) were at risk for HIV in 2018. Similar proportions were seen among adults identifying as heterosexual orientation with 36.50% ever tested for HIV and 6.22% at risk for HIV. A very small proportion, 5% to be exact, of the population identified as LGBT (N=262); approximately half of this subpopulation (49.25%) ever tested for HIV and just over a quarter (28.98%) were at risk for HIV.

Table 5.1.

Descriptive statistics: HIV risk, HIV testing, and socioeconomic status of adults living in Tennessee, year 2018 (N=5,160)

	Total Sample		**Heterosexual (N=4898)**		**Other sexual orientation (N=262)**	
Variables	A, N (%)	B %	A, N (%)	B %	A, N (%)	B %
HIV Testing						
Yes	1519 (33.61)	37.33	1396 (32.74)	36.50	123 (48.24)	49.25
No	3000 (66.39)	62.67	2868 (67.26)	63.50	132 (51.76)	50.75
HIV risk behaviors						
Yes	239 (5.10)	7.55	190 (4.29)	6.22	49 (18.77)	28.98
No	4447 (94.90)	92.34	4235 (95.71)	93.78	212 (81.23)	71.02
LGBT						
Yes	262 (5.08)	5.76	NA^	NA	NA	NA
No	4898 (94.92)	94.24	NA	NA	NA	NA
Age						
18-34	1073 (20.79)	32.21	987 (20.15)	31.54	86 (32.82)	43.31
35-54	1385 (26.84)	29.68	1315 (26.85)	29.76	70 (26.72)	28.37
55+	2702 (52.36)	38.11	2596 (53.00)	38.71	106 (40.46)	28.33
Marriage						
Married/Widowed	3188 (63.89)	61.63	3075 (64.71)	62.87	113 (47.48)	39.5
Other	1802 (36.11)	38.37	1677 (35.29)	37.13	125 (52.52)	60.5
Sex						
Male	2322 (45.10)	48.09	2208 (45.17)	48.56	114 (43.68)	40.34
Female	2827 (54.90)	51.91	2680 (54.83)	51.44	147 (56.32)	59.66
Education						
High school or less	2093 (40.72)	46.8	1965 (40.27)	46.13	128 (49.04)	57.65
Some college or above	3047 (59.28)	53.2	2914 (59.73)	53.87	133 (50.96)	42.35
Race						
White	4196 (81.32)	76.33	3995 (81.56)	76.66	201 (76.72)	70.98
Black	599 (11.61)	15.71	569 (11.62)	15.55	30 (11.45)	18.33
Other	365 (7.07)	7.96	334 (6.82)	7.79	31 (11.83)	10.69
Ownership						
Own	3607 (74.59)	73.7	3462 (75.33)	74.29	145 (60.42)	63.38

Rent	1229 (25.41)	26.3	1134 (24.67)	25.71	95 (39.58	36.62
Employment						
Employed for wages	2057 (40.39)	45.85	1952 (40.41)	46.01	105 (40.08)	43.35
Self-employed	408 (8.01)	8.37	395 (8.18)	8.67	13 (4.96)	3.68
Other	1260 (24.74)	27.21	1178 (24.38)	26.58	82 (31.30)	37.32
Retired	1368 (26.86)	18.56	1306 (27.03)	18.74	62 (23.66)	15.64
TN Grand Division						
East	1245 (24.13)	22.5	1183 (24.15)	22.02	62 (23.66)	30.22
Middle	1678 (32.52)	40.67	1584 (32.34)	40.91	94 (35.88)	36.65
West	2237 (43.35)	36.83	2131 (43.51)	37.06	106 (40.46)	33.13
Low income						
<$25,000	1386 (32.38)	31.49	1281 (31.58)	30.35	105 (47.09)	50.65
≥$25,000	2894 (67.62)	68.51	2776 (68.42)	69.95	118 (52.91)	49.35
Depression diagnosis						
Yes	1343 (26.14)	25.24	1234 (25.30)	24.13	109 (41.92)	43.38
No	3795 (73.86)	74.76	3644 (74.70)	75.87	151 (58.08)	56.62
Affordability (medical care)						
Yes	727 (14.13)	15.81	658 (13.48)	14.90	69 (26.44)	30.78
No	4417 (85.87)	84.19	4225 (86.52)	85.10	192 (73.56)	69.22

^ *not applicable; A. Unweighted; B. Weighted.*

Table 2 displays descriptive statistics further limited to only adults identifying as LGBT by TN grand division strata. Of adults identifying as LGBT (East, N=62; Middle, N=94; West, N=106), the greatest proportion were between the ages of 18-34 (East, 50.77%; Middle, 43.82%; West, 35.93%). In East TN, 45.53% were at risk for HIV and 58.32% had ever tested for HIV. In Middle TN, 25.95% were at risk for HIV and 50.57% had ever tested for HIV. In West TN, 17.82% were at risk for HIV and 39.56% had ever tested for HIV.

The greatest proportion of LGBT adults were female (East TN, 69.28%; Middle, TN 55.96%; West TN, 54.91%) compared to male (East TN, 30.72%; Middle TN, 44.04%; West TN, 45.09%) and were between the ages of 18-34 (East, 50.77%; Middle, 43.82%; West, 35.93%). Among those aged 18-34, East TN had the highest proportion at risk for HIV (71.54%), whereas half were at risk in Middle TN (50.02%), and over a quarter at risk in West TN (39.01%). Over half of adults 18-34 in all regions had ever tested for HIV (East, 73.17%; Middle, 62.22%; West, 59.10%). LGBT adults with an annual income of <$25,000 living in East TN carried the highest burden of at-risk adults for HIV (50.83%) whereas Middle TN had the smallest proportion who ever tested for HIV (30.75%).

Table 6.2.

Descriptive statistics by TN Grand Division among adults who identify as LGBT or other than straight in sexual orientation, HIV risk, HIV testing and socioeconomic status in TN, 2018 (N=262; weighted N=3523)

	East Tennessee Region, N=62				**Middle Tennessee Region, N=94**				**West Tennessee Region, N=106**			
Variables	A, N (%)	B (%)	C (%)	D (%)	A, N (%)	B (%)	C (%)	D (%)	A, N (%)	B (%)	C (%)	D (%)
HIV Testing			NA^	NA			NA	NA			NA	NA
Yes	33 (55.00)	58.32	NA	NA	48 (53.33)	50.57	NA	NA	42 (40.00)	39.56	NA	NA
No	27 (45.00)	41.68	NA	NA	42 (46.67)	49.43	NA	NA	63 (60.00)	60.44	NA	NA
HIV risk behaviors			NA	***			NA	***			NA	***
Yes	17 (27.87)	45.53	NA	67.75	20 (21.28)	25.95	NA	69.42	12 (11.32)	17.82	NA	94.67
No	44 (72.13)	54.47	NA	47.23	74 (78.72)	74.05	NA	43.74	94 (88.68)	82.18	NA	27.50
Age			***	***			***	***			***	***
18-34	19 (30.65)	50.77	71.54	73.17	37 (39.36)	43.82	50.02	62.22	30 (28.30)	35.93	39.01	59.10
35-54	20 (32.26)	29.49	29.85	54.94	24 (25.53)	27.75	14.52	70.94	26 (24.53)	28.03	13.57	50.07
55+	23 (37.10)	19.75	7.14	24.94	33 (35.11)	28.43	0.00	9.35	50 (47.17)	36.04	0.00	12.28
Marriage			***	***			***	***			***	***
Married/Widowed	21 (36.84)	18.01	5.05	29.49	42 (50.60)	46.83	2.94	36.68	50 (51.02)	50.10	0.00	13.06
Other	36 (63.16)	81.99	63.20	67.45	41 (49.40)	53.17	41.99	62.24	48 (48.98)	49.90	33.93	57.75
Sex			***	***			***	***			***	***
Male	26 (41.94)	30.72	37.94	48.68	41 (44.09)	44.04	27.90	39.93	47 (44.34)	45.09	13.89	38.06
Female	36 (58.06)	69.28	48.48	62.51	52 (55.91)	55.96	25.07	57.59	59 (55.66)	54.91	21.04	40.77
Education			***	*			***	***			***	***
Highschool or less	36 (58.06)	67.03	55.24	58.63	39 (41.94)	54.59	38.28	35.81	53 (50.00)	52.46	18.48	38.27
Some college or above	26 (41.94)	32.97	23.20	57.71	54 (58.06)	45.41	11.31	68.63	53 (50.00)	47.54	17.09	40.95
Race			***	***			***	***			***	***
White	40 (64.52)	51.95	37.54	49.90	75 (79.79)	75.27	23.28	54.44	86 (81.13)	83.59	15.53	35.49
Black	17 (27.42)	41.41	49.28	77.13	8 (8.51)	12.13	0.00	51.48	5 (4.72)	4.14	81.99	87.39
Other	5 (8.06)	6.64	86.94	6.38	11 (11.70)	12.60	66.92	26.21	15 (14.15)	12.28	11.79	50.85
Ownership			***	***			***	***			***	***
Own	32 (59.26)	59.46	37.12	57.48	45 (52.33)	55.11	6.77	42.50	68 (68.00)	75.01	7.85	35.39
Rent	22 (40.74)	40.54	63.93	60.08	41 (47.67)	44.89	40.06	64.74	32 (32.00)	24.99	16.40	44.60
Employment			***	***			***	***			***	***

Employed for wages	30 (48.39)	45.21	35.03	57.05	45 (47.87)	52.22	27.44	71.53	30 (28.30)	31.84	30.23	48.83
Self-employed	2 (3.23)	3.76	39.78	100.00	4 (4.26)	2.34	42.56	72.35	7 (6.60)	5.10	0.00	90.09
Other	18 (29.03)	42.46	64.79	60.95	26 (27.66)	29.20	36.39	34.38	38 (35.85)	41.62	19.69	42.34
Retired	12 (19.35)	8.57	3.40	33.39	19 (20.21)	16.24	0.00	6.28	31 (29.25)	21.44	0.00	8.46
Low income			***	***			***	***			***	***
<$25,000	29 (51.79)	60.70	50.83	59.33	34 (45.33)	45.79	37.62	30.75	42 (45.65)	47.13	30.65	50.86
≥$25,000	27 (48.21)	39.30	22.72	58.04	41 (54.67)	54.21	20.25	68.53	50 (54.35)	52.87	9.11	37.85
Depression			***	**			***	***			***	***
Yes	21 (33.87)	33.03	65.96	60.74	48 (51.61)	54.19	39.73	52.46	40 (38.10)	40.89	28.87	59.53
No	41 (66.13)	66.97	34.85	57.12	45 (48.39)	45.81	9.89	45.61	65 (61.90)	59.11	10.34	25.40
Affordability (medical care)			***	***			***	***			***	***
Yes	18 (29.51)	38.31	69.47	67.97	27 (28.72)	32.37	28.72	52.49	24 (22.64)	22.17	28.05	50.67
No	43 (70.49)	61.69	30.03	52.86	67 (71.28)	67.63	24.63	49.64	82 (77.36)	77.83	14.91	36.36

*^NA, Not applicable; Pearson $\chi 2$, *P<0.01 **P<0.001 ***P<0.0001*
A. Unweighted; B. Weighted; C. At risk for HIV, weighted %; D. Tested for HIV, weighted %

Within group analysis with being at risk for HIV

SLR and MLR analysis with HIV risk as the outcome are shown in Tables 3 and 4. MLR analysis uncovered significant findings with LGBT adults who reported being diagnosed with depression across all TN strata. For example, in East TN, LGBT adults with a depression diagnosis were 5 times more likely to be at risk for HIV compared to LGBT adults who did not report depression (aOR: 5.07, 95% CI: 4.90-5.25). Similarly, LGBT adults living in Middle TN and diagnosed with depression were 4.5 times more likely to be at risk for HIV compared to LGBT adults who did not report depression (aOR: 4.56, 95% CI: 4.40-4.72). In West TN, LGBT adults with depression were 2.5 times more likely to be at risk for HIV compared to LGBT adults who did not report a depression diagnosis (aOR: 2.53, 95% CI: 2.43-2.62).

LGBT adults with a low-income (<$25,000 annually) were also at increased risk for HIV within the state of TN. Among those living in West TN who were low-income, the odds of being

at risk for HIV were 3.3 times compared to adults with a higher annual income (aOR: 3.36, 95% CI: 3.23-3.50). Nearly identical odds were seen in East and Middle TN regions where LGBT adults with low income were over two times more likely to be at risk for HIV compared to LGBT adults with higher income (East, aOR: 2.64, 95% CI: 2.53-2.73; West, aOR: 2.08, 2.01-2.14 respectively).

Table 7.3.

Region disparities - simple logistic regression analysis of the association between mental health, socioeconomic status, and having HIV risk behaviors among LGBT adults in TN, year 2018 (N=260)

Predictors	**OR (95% CI)**		
	East TN (N=61)	Middle TN (N=93)	West TN (N=106)
Depression	3.62 (3.52-3.73)***	6.00 (5.81-6.21)***	3.52 (3.40-3.64)***
Affordability (medical care)	5.30 (5.15-5.46)***	1.23 (1.20-1.27)***	2.23 (2.15-2.31)***
Sex (M vs F)	0.65 (0.63-0.67)***	1.16 (1.13-1.19)***	0.61 (0.59-0.63)***
Low income (<$25,000 vs other)	3.52 (3.40-3.64)***	2.38 (2.31-2.45)***	4.41 (4.24-4.58)***
Marriage			
Other vs married/widowed	32.27 (29.88-34.85)***	23.93 (22.62-25.31)***	†
Age			
18-34	Reference	Reference	Reference
35-54	0.17 (0.16-0.18)***	0.17 (0.16-0.18)*	0.25 (0.24-0.26)***
55+	0.03 (0.029-0.032)***	†	†
Race			
White	Reference	Reference	Reference
Black	1.62 (1.57-1.66)***	†	24.76 (22.83-26.86)***
Other	11.07 (10.25-11.95)***	6.67 (6.41-6.93)***	0.73 (0.69-0.77)***
Rent home vs own home	3.00 (2.91-3.10)***	9.21 (8.86-9.57)***	0.43 (0.41-0.46)***
Employment			
Employed for wages	Reference	Reference	Reference
Self-employed	1.23 (1.14-1.32)***	1.96 (1.81-2.12)***	†
Other	3.41 (3.31-3.52)***	1.51 (1.47-1.56)***	0.57 (0.55-0.59)***
Retired	0.07 (0.06-0.07)***	†	†
School (Some college or more vs high school or less)	0.25 (0.24-0.25)***	0.21 (0.20-0.21)***	0.91 (0.88-0.94)***

†Note: Not enough observations in the 2 by 2 table to calculate odds ratio
**P<0.01 **P<0.001 ***P<0.0001*

Table 8.4.

Region disparities - multiple logistic regression analysis of the association between a diagnosis with depression, lower income level, and being at risk for HIV among LGBT adults in TN, year 2018 (N=227)

Predictors	**OR (95% CI)**		
	East TN (N=61)	Middle TN (N=75)	West TN (N=91)
Depression	5.07 (4.90-5.25)***	4.56 (4.40-4.72)***	2.53 (2.43-2.62)***
Low income (<$25,000 vs other)	2.63 (2.53-2.73)***	2.08 (2.01-2.14)***	3.36 (3.23-3.50)***
**P<0.05 **P<0.0001*			

Within group analysis with ever tested for HIV

SLR analysis and MLR analysis with HIV testing as the outcome are shown in Tables 5 and 6. MLR revealed substantial regional differences among LGBT adults and risk for HIV. Among LGBT adults in Middle TN, the odds of testing for HIV increased by 4.4 times among those at risk for HIV (aOR: 4.41, 95% CI: 4.25-4.58) compared to adults not at risk for HIV. The greatest disparity within division strata was seen in West TN where the odds of HIV testing increased by 33 times among adults who reported HIV risk behaviors (aOR: 33.59; 95% CI: 31.97-35.96) compared to those not at risk. East TN hardly saw any association with only a 4% increase in the odds of HIV testing for those at risk (aOR: 1.04; 95% CI: 1.00-1.07) while holding income constant.

The opposite regional differences were seen among LGBT adults with an annual income of <$25,000 (low-income). For example, in East TN, the odds of HIV testing were 1.3 times higher for those with low-income (aOR: 1.33, 95% CI: 1.28-1.37) compared to LGBT adults with higher income. A notable difference was seen in Middle TN; LGBT adults with low-income were 87% less likely to test for HIV compared to adults making $25,000 or more (aOR: 0.13,

95% CI: 0.13-0.14). No significant association was found in West TN (aOR: 0.99, 95% CI: 0.95-1.02).

Table 9.5.

Region disparities - simple logistic regression analysis of the association between HIV risk behavior, mental health, socioeconomic status, and testing for HIV among LGBT adults in TN, year 2018 (N=218)

Predictors	**OR (95% CI)**		
	East TN (N=54)	Middle TN (N=73)	West TN (N=91)
HIV risk behaviors	2.35 (2.28-2.41)***	2.92 (2.84-3.01)***	46.76 (43.74-49.99)***
Depression	1.16 (1.13-1.94)***	1.14 (1.38-1.45)***	4.32 (4.21-4.44)***
Affordability (medical care)	1.89 (1.84-1.95)***	1.12 (1.09-1.15)***	1.80 (1.74-1.85)***
Sex (M vs F)	0.57 (0.55-0.59)***	0.49 (0.48-0.50)***	0.89 (0.87-0.92)
Low income (<$25,000 vs other)	1.06 (1.02-1.09)**	0.20 (0.19-0.21)***	1.70 (1.65-1.75)***
Marriage			
Other vs married/widowed	4.95 (4.76-5.15)***	2.85 (2.77-2.92)***	9.10 (8.80-9.40)***
Age			
18-34	Reference	Reference	Reference
35-54	0.45 (0.43-0.46)***	1.48 (1.44-1.53)***	0.69 (0.67-0.72)***
55+	0.12 (0.12-0.13)***	0.06 (0.060-0.065)***	0.10 (0.093-0.101)***
Race			
White	Reference	Reference	Reference
Black	3.39 (3.29-3.49)***	0.89 (0.86-0.92)***	12.59 (11.48-13.81)***
Other	0.07 (0.06-0.08)***	0.30 (0.29-0.31)***	1.88 (1.81-1.95)***
Rent home vs own home	1.11 (1.08-1.15)***	2.48 (2.42-2.55)***	1.47 (1.43-1.52)***
Employment			
Employed for wages	Reference	Reference	Reference
Self-employed	†	1.04 (0.95-1.14)	9.53 (8.67-10.47)***
Other	1.18 (1.14-1.21)***	0.21 (0.203-0.215)***	0.77 (0.75-0.79)***
Retired	0.38 (0.36-0.40)***	0.027 (0.025-0.028)***	0.10 (0.092-0.102)***
School (Some college or more vs high school or less)	0.96 (0.94-0.99)*	3.92 (3.82-4.02)***	1.12 (1.09-1.15)***

†Note: Not enough observations in the 2 by 2 table to calculate OR
**P<0.01 **P<0.001 ***P<0.0001*

Table 10.6.

Region disparities - multiple logistic regression analysis of the association between HIV risk behavior, lower income level, and testing for HIV among LGBT adults in TN, year 2018 (N=218)

Predictors	**OR (95% CI)**		
	East TN (N=54)	Middle TN (N=73)	West TN (N=91)
HIV risk behaviors	1.04 (1.00-1.07)*	4.41 (4.25-4.58)**	33.59 (31.97-35.96)**
Low income (<$25,000 vs other)	1.33 (1.28-1.37)**	0.13 (0.13-0.14)**	0.99 (0.95-1.02)
**P<0.05 **P<0.0001*			

Discussion

The goal of this study was accomplished through the identification of regional disparities among LGBT with the odds of being at risk for and having ever tested for HIV in TN. Depression increased the odds of being at risk for HIV across all TN grand divisions compared to LGBT adults who did not report depression. However, the odds were the highest in East TN when comparing the odds ratios from within group analysis. Additionally, LGBT with lower annual income (<$25,000) were also at increased risk fairly consistently across the TN. When comparing odds from within-group analysis across all strata, the odds were highest in West TN. Among LGBT at risk for HIV, the most notable regional difference seen in West TN where adults were more 30 times more likely to have ever tested for HIV. While being at risk for HIV increased the odds of HIV testing in Middle TN, being at risk for HIV in East TN did not increase the odds by the same impact. Furthermore, LGBT with lower income in Middle TN were less likely to have ever tested for HIV compared to LGBT with higher annual income.

Awareness of HIV is accomplished through testing for HIV, and because HIV risk was found to increase the odds for HIV testing, resources could be allocated specifically to LGBT adults who have lower income, specifically in Middle TN to combat the spread of HIV. More

specifically, in Middle TN, health promotion campaigns for HIV testing could be targeted at LGBT individuals who make less than $25,000. Additional findings suggest depression and low income are factors that increase risk of HIV among LGBT within all TN grand divisions. While this is a novel finding, future research is warranted to study in more depth how depression and income impact access to care among LGBT adults in TN. Additionally, this study examined individual regions via within-group analysis. To compare regions, a between group analysis should be conducted preferable via longitudinal study design to provide a temporal relationship with risk for and testing for HIV.

Strengths and limitations

The current study findings build on a nationally representative study conducted in 2017 with respect to transgender adolescents and adults diagnosed with HIV using the National HIV Surveillance data between years 2006-2014 (Clark et al., 2017). The largest proportions of transgender women and transgender men in this same study were examined in the Southern region of the US and had a transmission risk attributable to sex (Clark et al., 2017). The present study provides additional information in TN, in the Southern US, related to HIV risk, involving sexual risk taking, as well as other potential correlates such as depression and low-income with the impact on the odds of HIV testing.

Furthermore, this study is innovative in discussing regional disparities of HIV risk and HIV testing among sexual minority groups living in TN. Among LGBT individuals, the rate of individuals identifying as transgender who tested for HIV or were newly diagnosed with HIV in TN could not be calculated between the years 2013-2017 due to unavailable data (TDH, 2019). Thus, this study provides additional information on correlates along the HCC in the state of TN.

Limitations of this study exist. This study focused on one year of data since this was the only year TN had responses to analyze LGBT populations. Sexual orientation responses were combined to reach a sample size that could provide enough statistical power due to the few responses for sexual orientation other than heterosexual. Thus, analysis among individual orientations should be conducted in the future with a larger sample and additional years of data.

Another limitation is with regard to causality; a temporal relationship is lacking. Therefore a causative relationship cannot be inferred from any associations due to the cross-sectional nature of BRFSS data. However, these associations provide the foundation for developing hypotheses to carry out future studies focusing on improving access to HIV testing and HIV care across the three regions of TN.

Furthermore, the HIV testing outcome question was phrased "ever tested" meaning that the frequency of testing or the last testing date is unknown. The CDC recommends all adolescents and adults, with a specific focus on gay and bisexual men, be screened for HIV annually as a part of routine medical care (CDC, 2016). Furthermore, increasing HIV testing among adolescents and adults in the past year is a Healthy People 2020 (HP 2020) goal (ODPHP, 2020). Since TN BRFSS data does not currently have a surveillance question that states, "have you been tested for HIV this past year,", future considerations should focus on including more specific questions to know if adults were tested in the past year. This will provide a better measure for knowing if TN is close or has achieved goals for the CDC and HP 2020 focused on prevention of HIV. Moreover, inclusion of this question will aid TN epidemiologists and providers in utilizing surveillance data to determine types of correlates that interfere or facilitate LGBT testing for HIV in TN in general, and by grand division. As mentioned previously, the current study examined divisions of TN within-group instead of between-group.

Thus, to compare divisions and develop a better strategy for improving risk behaviors for HIV and increase testing for HIV equally across all TN regions, between-group analysis should be completed for East, Middle and West TN divisions.

Another consideration for future research as well as a limitation involves the use of lower income level used as a predictor for this study. This variable was a proxy for federal poverty level, however inclusion of health insurance and federal poverty level data would provide a better understanding of what healthcare resources LGBT adults may be eligible for in the state of TN with respect to HIV. Other variables that should be included upon further analysis should be alcohol consumption, poor mental health, and physical health since the present study was limited in utilizing these variables from BRFSS due to greater than 50% missingness. Finally, future studies should consider inclusion of adverse childhood experiences (ACEs) since previous research has established a relationship with HIV risk behaviors in the state of TN and in the US (Anda et al., 2006; TDH, 2015).

Conclusion

This study uncovered regional disparities in TN among low-income sexual minority groups. Identifying health disparities are paramount in moving the National HIV/AIDS Strategy goal forward in a direction that can prevent new HIV diagnoses and increase HIV serostatus awareness in underserved and minority groups (CDC, 2019). Future epidemiologic studies should build upon the current design via longitudinal study design to better assist public health practitioners, medical providers, and health departments in understanding the most impactful ways to improve HIV prevention and care among sexual minority groups.

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Chapter 3. Investigation of the Role Adverse Childhood Experiences Have in HIV Risk and Testing Among Low Income Populations in Tennessee

[1]Elaine Loudermilk, [1]Shimin Zheng, [1]Melissa White, [2]Emmitt Turner, [3,4]Robert Pack, [2,5]Jonathan Moorman, [1]Megan Quinn

[1]Department of Biostatistics and Epidemiology, College of Public Health, East Tennessee State University, Johnson City, Tennessee 37604

[2]Quillen College of Medicine, East Tennessee State University, Johnson City, Tennessee 37604

[3]Department of Community and Behavioral Health, College of Public Health, East Tennessee State University, Johnson City, Tennessee 37604

[4]Center for Prescription Drug Abuse, Prevention, and Treatment, College of Public Health, East Tennessee State University, Johnson City, Tennessee 37604

[5]Center of Excellence for Inflammation, Infectious Disease and Immunity, Quillen College of Medicine, East Tennessee State University, Johnson City, Tennessee 37604

Abstract

Objectives

Determine regional disparities among adults with Adverse Childhood Experiences (ACEs) and the relationship between being at risk for HIV and HIV testing among low-income groups in TN.

Methods

Data for years 2016 and 2017 were obtained from the Tennessee Department of Health Behavioral Risk Factor Surveillance System to study the association between ACEs and two outcomes, at risk for HIV and ever tested for HIV. Descriptive statistics with the entire sample further analyzed among a subpopulation of adults with an annual income of <$25,000 stratified by TN grand division (East, Middle and West) was conducted followed by stratified subpopulation regression analysis.

Results

Among adults with an annual income of <$25,000 (N=3258), over half had never been tested for HIV (58.12%), and only 7.13% were at risk for HIV. Adults in East TN with 1-3 ACEs were 46% less likely to be at risk for HIV compared to adults with no ACEs (aOR: 0.54, 95% CI: 0.52-0.56). In Middle TN, adults with 4+ ACEs were 32 times more likely to be at risk for HIV (aOR: 31.86, 95% CI: 29.83-34.02); adults ever tested for HIV increased by two-fold (East TN aOR: 2.81, 95% CI: 2.76-2.81; Middle TN aOR: 2.19, 95% CI: 2.16-2.22; West TN aOR: 2.85, 95% CI: 2.81-2.89).

Conclusion

Regional disparities were revealed among adults with ACEs within TN grand divisions. Future studies should focus on longitudinal study designs and between group analysis by TN grand division to develop appropriate HIV prevention programs for adults with low income and ACEs in TN.

Keywords: Adverse childhood experiences; HIV; regional disparities

Summary box

1) What is the current understanding of this subject?

ACEs have been linked to adult HIV risk behaviors among adults in TN.

2) What does this report add to the literature?

This report provides statistical evidence of regional disparities in the state of TN for low-income adults with ACEs and their HIV risk and if they ever tested for HIV.

3) What are the implications for public health practice?

Public health and medical practitioners can work together to improve access to care for adults who are considered high risk across the state of TN.

Introduction

Tennessee (TN), located in the southern region of the US, ranked 16th among the 50 states in the number of HIV diagnoses in year 2015.[1,2] By region, the highest rate of persons living with HIV (PLWH) in TN reside in Davidson and Shelby County.[1] Known social and behavioral determinants related to HIV transmission may include low perceived risk, socioeconomic status, and life trauma among minority groups, specifically lesbian, gay, bisexual, transgender (LGBT).[3–6] Moreover, previous research has uncovered a graded relationship with Adverse Childhood Experiences (ACEs), specific life traumas experienced before the age of 18, and HIV risk behaviors.[7] ACEs consist of sexual/physical/emotional trauma and/or growing up with household dysfunction.

In year 2015, more than half of adults in TN had experienced at least one ACE; approximately 20% having had at least three.[8] Findings from a descriptive study conducted by the Tennessee Department of Health (TDH) discovered having four or more ACEs increased the risk for chronic diseases, unemployment, depression and HIV risk behavior.[8] Long term health effects of ACEs have notably been reported to decrease quality of life into adulthood as a result from high stress responses causing chronic diseases and uptake of risky behaviors including substance abuse later in life.[7,9–13]

Regional disparities among adults with ACEs and the relationship between being at risk for HIV and HIV testing among low-income groups is still largely unknown in TN. The current study aids in addressing literature gaps by focusing on regional health disparities in TN among adults with ACEs to better examine how trauma plays a role in HIV risk and testing behaviors.

Methods

The East Tennessee State University Institutional Review Board (IRB) and TDH IRB deemed the current study exempt since de-identified, secondary data were used. This study sought to (1) determine the prevalence of ACEs affecting TN adults who were and were not (a) at risk for HIV and (b) tested for HIV in TN and (2) to calculate the odds of being at risk for HIV and tested for HIV as predicted by ACEs among low income groups in TN.

Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance System (BRFSS) is a nationwide telephone survey collecting data from adults living in the US along with the District of Columbia and three U.S. territories.[14] BRFSS is sponsored by the National Center for Chronic Disease Prevention

and Health Promotion, Centers for Disease Control and Prevention (CDC), along with other federal agencies to assess health-risk behaviors, chronic diseases, and the use of preventive services.[14] Data for years 2016-2017 were obtained from the TDH Division of Population Health Assessment. TDH did not collect ACE data for year 2018 thus only two years, 2016 and 2017, of data were analyzed for the current study.

Outcome

The first outcome of interest was HIV risk defined as having done any of the following in the past year: injected any drug other than those prescribed, been treated for a sexually transmitted disease or STD, given or received money or drugs in exchange for sex, had anal sex without a condom in the past year, and/or had four or more sex partners. The second outcome of interest was HIV testing (ever been tested for HIV, not counting tests that may have been a part of a blood donation and including testing fluid in the mouth).[15]

Adverse Childhood Experiences

The ACE questionnaire is a voluntarily module for which states may choose to complete and submit to CDC with their BRFSS data.[16] There were a total of 11 ACEs in the module with questions about experiences before the age of 18 encompassing child emotional/physical/sexual abuse. ACEs were analyzed as having 0, 1-3, or 4 or more.[8]

Covariates

HIV risk behavior was used as a predictive factor with having ever tested for HIV as the outcome. Depression diagnosis was defined as having been diagnosed or told he/she had a depressive disorder (including depression, major depression, dysthymia, or minor depression). Affordability of medical cost was defined as needing to see a doctor in the past 12 months when needing to but could not afford it due to cost.

Sociodemographic variables included age (18-34, 35-54, and 55+) , sex (male or female), race, marital status (married/widowed or divorced/separated/never married), and education level (high school or less and some college or above) race (White, Black, or Other), employment status (employed for wages, self-employed, other, retired), home ownership (rent or own a home), and TN grand division (East, Middle, West). Income was categorized as adults who make <$25,000 or ≥$25,000 as an estimate for an income near federal poverty limits in TN.[17,18]

Statistical analysis

Descriptive statistics in the form of frequencies and proportions were reported with entire adult population for years 2016 and 2017 combined. The sample was then limited to only individuals making <$25,000 annually and descriptive and regression analysis were subsequently competed. Chi-square test was conducted to evaluate differences among ACEs and sociodemographic variables among adults for HIV risk and HIV test stratified by TN grand division. Finally, simple and multiple logistic regression analysis (MLR) was performed to estimate the odds ratios and 95% confidence intervals between ACEs, HIV risk, and HIV testing among adults with an annual income of <$25,000 annually stratified by TN grand division.

Multicollinearity was detected between employment status, affordability of medical care, home ownership, marital status, and education with both outcomes (at risk for HIV and ever tested for HIV) and large confounding effects were revealed with sex and race and thus both variables were omitted from MLR models. Interaction existed between depression and ACEs with being at risk for HIV, thus depression was removed from the MLR model specifically with the outcome of HIV risk. All statistical analysis was performed in SAS 9.4 (SAS Institute Inc., Cary, NC, USA).

Results

Demographic characteristics

Descriptive statistics are shown in Table 1. Only 6.25% reported being at risk for HIV. Over half of the sample had not been tested for HIV (62.70%), 61.79% married or widowed, 51.86% female, 76.53% white, owned a home (74.16%), and employed for wages (46.42%). Majority of the population could not afford medical costs (86.30%), had never been diagnosed with depression or similar mental health problem (78.02%), had an income of ≥$25,000 (68.49%), and resided in middle TN (40.22%).

Among adults with an annual income of <$25,000, over half had never been tested for HIV (58.12%), and only 7.13% were at risk for HIV. Majority of the sample were aged 55 and older (40.90%), were not married/widowed (56.51%), male (56.51%), White (66.07%), owned a home (55.85%), had “other” employment (47.33%), resided in West TN (38.68%), and could not afford medical costs (75.11%). A larger proportion reported having a depression diagnosis (33.28%) compared to adults with an annual income of ≥$25,000 (17.01%).

Majority of adults in the entire adult population experienced 1-3 ACEs (40.67%); less than a quarter had reported having 4+ ACEs (19.96%).

By income category, a greater proportion of adults with an annual income of <$25,000 reported 1-3 ACEs (39.43%) and approximately one quarter had 4+ ACEs (26.63%). Similarly, adults making ≥$25,000 annually had a higher proportion of adults with at least one to three ACEs (40.05%) and less than a quarter had 4+ ACEs (22.99%).

Table 11.1.

Descriptive statistics for HIV risk, HIV testing, Adverse Childhood Experiences (ACEs) and socioeconomic status -2016-2017, N=12,010

		Total Sample		**≥$25,000, N=6,564**		**<$25,000, N=3,258**	
		A, N (%)	B (%)	A, N (%)	B (%)	A, N (%)	B (%)
Variables							
HIV Testing	Yes	3,292 (32.03)	37.30	1,902 (32.63)	38.01	998 (36.03)	41.88
	No	6,986 (67.97)	62.70	3,927 (67.37)	61.99	1,772 (63.97)	58.12
HIV risk behaviors	Yes	437 (4.09)	6.25	250 (4.14)	6.31	139 (4.83)	7.13
	No	10,239 (95.91)	93.75	5,786 (95.86)	93.69	2,741 (95.17)	92.87
Number of ACEs							
	0	4,052 (43.89)	39.37	2,314 (44.57)	39.91	934 (36.96)	33.94
	1-3	3,635 (39.37)	40.67	2,117 (40.77)	42.33	1,012 (40.05)	39.43
	4+	1,546 (16.74)	19.96	761 (14.66)	17.76	581 (22.99)	26.63
Age							
18-34		2,326 (19.37)	32.37	1,265 (19.27)	31.31	579 (17.77)	32.14
35-54		3,218 (26.79)	30.36	2,092 (31.87)	35.24	771 (23.66)	26.96
55+		6,466 (53.84)	37.27	3,207 (48.86)	33.45	1,908 (58.56)	40.90
Marital status							
Married/Widowed		7,742 (66.42)	61.79	4,756 (74.29)	70.19	1,537 (48.56)	43.49
Divorced/Separated/Never Married		3,915 (33.58)	38.21	1,646 (25.71)	29.81	1,628 (51.44)	56.51
Sex							
Male		5,149 (42.89)	48.14	3,242 (49.40)	54.35	1,141 (35.02)	56.51
Female		6,857 (57.11)	51.86	3,321 (50.60)	45.65	2,117 (64.98)	43.49
Education							
High school or less		5,112 (42.71)	47.68	1,929 (29.40)	35.16	2,066 (63.55)	68.48
Some college or above		6,857 (57.29)	52.32	4,632 (70.60)	64.84	1,185 (36.45)	31.52
Race							
White		9,887 (82.32)	76.53	5,634 (85.83)	80.78	2,426 (74.46)	66.07
Black		1,414 (11.77)	15.74	623 (9.49)	13.03	556 (17.07)	23.23
Other		709 (5.90)	7.73	307 (4.68)	6.18	276 (8.47)	10.69
Home ownership							
Own		8,565 (75.90)	74.16	5,365 (84.21)	82.15	1,716 (57.43)	55.85
Rent		2,720 (24.10)	25.84	1,006 (15.79)	17.85	1,272 (42.57)	44.15
Employment							
Employed for wages		4,687 (39.28)	46.42	3,490 (53.32)	60.01	642 (19.78)	25.97
Self-employed		912 (7.64)	8.42	583 (8.91)	9.39	190 (5.85)	7.08
Other		3,021 (25.32)	27.04	883 (13.49)	15.31	1,469 (45.26)	47.33
Retired		3,312 (27.76)	18.11	1,589 (24.28)	15.30	945 (29.11)	19.62
TN Grand Division							
East		3,151 (26.24)	22.85	1,607 (24.48)	20.36	962 (29.53)	28.27
Middle		3,721 (30.98)	40.22	2,184 (33.27)	43.69	879 (26.98)	33.05
West		5,138 (42.78)	36.93	2,773 (42.25)	35.94	1,417 (43.49)	38.68
Low income							
Yes (<$25,000)		3,258 (33.17)	31.51	^NA	NA	^NA	NA

No (≥$25,000)	6,564 (66.83)	68.49	NA	NA	NA	NA
Depression						
Yes	2,779 (23.26)	21.98	1,138 (17.38)	17.01	1,178 (36.39)	33.28
No	9,167 (76.74)	78.02	5,409 (82.62)	82.99	2,059 (63.61)	66.72
Afford medical costs						
Yes	1,473 (12.31)	13.70	518 (7.91)	9.26	733 (22.61)	24.89
No	10,490 (87.69)	86.30	6,031 (92.09)	90.74	2,509 (77.39)	75.11

^ *not applicable; A. Unweighted; B. Weighted.*

Regional descriptive statistics

Subpopulation analysis was completed among adults who made <$25,000 and stratified by TN grand division (N=3,258) shown in Table 2. East TN (N=962) contained a higher proportion of adults who were at risk for HIV (8.14%) and tested for HIV (52.05%) compared to Middle TN (N=879, 5.96% at risk; 38.86% ever tested) and West TN (N=1417, 7.43% at risk; 37.44% ever tested). Of those at risk for HIV, Middle TN had the highest proportion who tested for HIV (80.44%) compared to East TN (76.51%) followed by West TN (74.96%).

Table 12.2.

Descriptive statistics by TN Grand Division among adults living with an income of <$25,000, HIV risk, HIV testing, and socioeconomic status in TN, 2016-2017,N=3,258

	East (N=962)				**Middle (N=879)**				**West (N=1,417)**			
Variables	A, N(%)	B %	C (%)	D (%)	A, N(%)	B %	C (%)	D (%)	A, N(%)	B %	C (%)	D (%)
HIV Testing												
Yes	308 (38.55)	52.05	^NA	NA	248 (33.88)	38.86	NA	NA	442 (35.67)	37.44	NA	NA
No	491 (61.45)	47.95	NA	NA	484 (66.12)	61.14	NA	NA	797 (64.33)	62.56	NA	NA
HIV risk				***				***				***
Yes	39 (4.73)	8.14	NA	76.51	33 (4.29)	5.96	NA	80.44	67 (5.21)	7.43	NA	74.96
No	785 (95.27)	91.86	NA	50.13	736 (95.71)	94.04	NA	35.64	1,220 (94.79)	92.57	NA	34.18
ACEs			***	***			***	***			***	***
0	285 (39.58)	33.44	4.87	32.18	234 (35.14)	35.83	0.41	25.00	415 (36.37)	32.79	0.57	21.80
1-3	305 (42.36)	45.42	3.61	58.33	264 (39.64)	34.79	3.73	36.59	443 (38.83)	39.46	6.29	30.58
4+	130 (18.06)	21.14	13.75	68.47	168 (25.23)	29.37	15.08	56.99	283 (24.80)	27.75	16.72	59.42
Age			***	***			***	***			***	***
18-34	195 (20.27)	39.38	14.77	68.39	157 (17.86)	29.67	13.68	51.35	227 (16.02)	28.95	18.67	46.07
35-54	200 (20.79)	24.12	7.88	63.57	212 (24.12)	26.65	4.73	47.36	359 (25.34)	29.30	4.31	50.95
55+	567 (58.94)	36.51	1.88	27.26	510 (58.02)	43.68	1.32	24.69	831 (58.65)	41.74	1.89	21.81
Marital status			***	***			***	***			***	***

Married/Widowed	443 (47.53)	36.06	4.45	59.02	397 (46.71)	42.12	3.05	21.97	686 (49.60)	49.87	4.73	25.85
Divorced/Separated/ Never Married	489 (52.57)	63.94	11.15	34.51	453 (53.29)	57.88	6.89	49.79	697 (50.40)	50.13	10.13	47.85
Sex			***	***			***	***			***	***
Male	306 (31.81)	38.18	10.00	53.92	310 (35.27)	39.06	4.91	46.87	525 (37.05)	40.36	10.14	38.17
Female	656 (68.19)	61.82	6.94	50.80	569 (64.73)	60.94	6.62	33.55	892 (62.95)	59.64	5.65	36.95
Education			*	***			***	***			***	***
Highschool or less	638 (66.67)	71.82	8.10	54.02	566 (64.39)	67.02	5.71	34.12	862 (60.92)	67.30	7.27	33.68
Some college or above	319 (33.33)	28.18	8.31	46.90	313 (35.61)	32.98	6.43	47.74	553 (39.08)	32.70	7.6	45.46
Race			***	***			***	***			***	***
White	531 (55.20)	36.38	2.42	33.31	703 (79.98)	71.55	4.79	31.85	1,192 (84.12)	83.10	7.29	34.04
Black	347 (36.07)	52.76	11.58	63.29	103 (11.72)	15.96	5.54	59.44	106 (7.48)	7.87	2.69	63.28
Other	84 (8.73)	10.86	12.77	64.78	73 (8.30)	12.49	12.44	51.19	119 (8.40)	9.03	13.02	49.09
Home ownership			***	***			***	***			***	***
Own	495 (55.25)	51.75	4.59	39.77	442 (54.77)	52.70	2.87	27.36	779 (60.62)	61.66	6.28	30.94
Rent	401 (44.75)	48.25	12.11	61.78	365 (45.23)	47.30	9.66	51.25	506 (39.38)	38.34	9.56	49.11
Employment			***	***			***	***			***	***
Employed for wages	181 (18.99)	27.07	14.08	62.38	190 (21.64)	26.94	7.41	41.76	271 (19.15)	24.35	13.54	43.99
Self-employed	60 (6.30)	9.30	5.03	71.27	60 (6.83)	6.50	6.78	37.43	70 (4.95)	5.96	15.56	44.32
Other	423 (44.39)	44.93	8.44	54.70	381 (43.39)	46.45	7.45	47.20	665 (47.00)	49.84	6.54	42.68
Retired	289 (30.33)	18.70	1.52	21.98	247 (28.13)	20.11	0.58	16.61	409 (28.90)	19.85	0.47	14.84
Depression			***	***			***	***			***	***
Yes	296 (30.90)	26.02	9.93	58.49	324 (37.11)	34.90	7.13	47.64	558 (39.69)	37.22	11.83	52.72
No	662 (69.10)	73.98	7.54	49.78	549 (62.89)	65.10	5.32	34.20	848 (60.31)	62.78	4.72	27.98
Afford medical costs			***	***			***	***			***	***
Yes	200 (20.83)	22.77	15.93	57.07	215 (24.66)	27.41	10.45	47.14	318 (22.55)	24.30	12.82	52.53
No	760 (79.17)	77.23	5.73	50.52	657 (75.34)	72.59	4.28	35.81	1,092 (77.45)	75.70	5.71	32.49

*Pearson $\chi 2$, *P<0.01 **P<0.001 ***P<0.0001; A. Unweighted; B. Weighted; C. At risk for HIV, weighted %; D. Tested for HIV, weighted %*
^ not applicable

Within group relationship between ACEs and being at risk for HIV by TN grand division

Table 3 displays simple logistic regression results; MLR results displayed in Table 4 revealed regional disparities in ACEs, age groups, and being at risk for HIV among adults making <$25,000 annually (N=2521; East TN, N=716; Middle TN, N=664; West TN, N=1141).

ACEs were examined as having 1-3, or 4+ ACEs compared to adults with no ACEs with HIV risk behaviors by TN grand division (East, Middle and West).

Table 13.3.

Regional disparities: simple logistic regression analysis of the association between ACEs, being at risk for HIV and ever tested for HIV among adults making <$25,000 annually, years 2016-2017 (N= 3258)

	OR (95% CI)					
	At risk for HIV			Ever tested for HIV		
Predictors	East (N=962)	Middle (N=879)	West (N=1417)	East (N=962)	West (N=879)	West (N=1417)
At risk for HIV	^NA	NA	NA	3.24 (3.17-3.31)***	7.43 (7.25-7.61)***	5.77 (5.66-5.87)***
Depression	1.35 (1.33-1.38)***	1.37 (1.34-1.39)***	2.71 (2.67-2.75)***	1.42 (1.41-1.44)***	1.75 (1.73-1.77)***	2.87 (2.85-2.90)***
Afford medical costs	3.12 (3.06-3.18)***	2.61 (2.56-2.66)***	2.43 (2.39-2.47)***	1.30 (1.29-1.32)***	1.60 (1.58-1.62)***	2.30 (2.28-2.32)***
Age						
18-34		Reference			Reference	
35-54	0.49 (0.48-0.50)***	0.31 (0.31-0.32)***	0.20 (0.19-0.20)***	0.81 (0.80-0.82)***	0.85 (0.84-0.86)***	1.22 (1.20-1.23)***
55+	0.11 (0.10-0.11)***	0.08 (0.082-0.087)***	0.08 (0.08-0.09)***	0.17 (0.171-0.175)***	0.31 (0.307-0.314)***	0.33 (0.32-0.33)***
Marital status						
Other vs married/widowed	2.69 (2.63-2.75)***	2.35 (2.29-2.41)***	2.27 (2.23-2.31)***	2.73 (2.70-2.76)***	3.52 (3.49-3.56)***	2.63 (2.61-2.66)***
Sex (M vs F)	1.49 (1.46-1.52)***	0.73 (0.71-0.74)***	1.89 (1.86-1.91)***	1.13 (1.12-1.15)***	1.75 (1.73-1.76)***	1.05 (1.04-1.06)***
Education						
Some college or more vs high school or less	1.03 (1.01-1.05)**	1.14 (1.11-1.16)***	1.05 (1.03-1.07)***	0.75 (0.74-0.76)***	1.76 (1.75-1.78)***	1.64 (1.63-1.66)***
Race						
White		Reference			Reference	
Black	5.27 (5.13-5.42)***	1.17 (1.13-1.20)***	0.35 (0.34-0.37)***	3.45 (3.41-3.49)***	3.14 (3.10-3.18)***	3.34 (3.28-3.39)***
Other	5.90 (5.70-6.10)***	2.82 (2.76-2.88)***	1.90 (1.86-1.95)***	3.68 (3.62-3.75)***	2.24 (2.21-2.27)***	1.87 (1.84-1.90)***
Home ownership						
Rent vs own	2.86 (2.80-2.92)***	3.62 (3.54-3.71)***	1.58 (1.55-1.60)***	2.45 (2.42-2.47)***	2.79 (2.76-2.82)***	2.15 (2.13-2.17)***
Employment						
Employed for wages		Reference			Reference	
Self-employed	0.32 (0.31-0.34)***	0.91 (0.87-0.95)***	1.18 (1.15-1.21)***	1.50 (1.47-1.53)***	0.83 (0.82-0.85)***	1.01 (0.99-1.03)
Other	0.56 (0.55-0.57)***	1.01 (0.99-1.03)***	0.45 (0.44-0.45)***	0.73 (0.72-0.74)***	1.25 (1.23-1.26)***	0.95 (0.94-0.96)***
Retired	0.09 (0.09-0.10)***	0.07 (0.06-0.08)***	0.03 (0.028-0.032)***	0.17 (0.167-0.173)***	0.28 (0.27-0.28)***	0.22 (0.22-0.23)***
Number of ACEs						
0		Reference			Reference	
1-3	0.73 (0.71-0.76)***	9.40 (8.78-10.05)***	11.80 (11.20-12.43)***	2.95 (2.91-2.99)***	1.73 (1.71-1.75)***	1.58 (1.56-1.60)***

4+	3.12 (3.03-3.21)***	43.04 (40.33-45.94)***	35.31 (33.54-37.17)***	4.58 (4.50-4.65)***	3.98 (3.92-4.03)***	5.25 (5.19-5.32)***

**P<0.01, **P<0.001 ***P<0.0001*

The odds of being at risk for HIV were notably different in East TN compared to odds within other strata (See Table 4). In East TN, adults with 1-3 ACEs were 46% less likely to be at risk for HIV compared to adults with no ACEs [adjusted odds ratio (aOR): 0.54, 95% CI: 0.52-0.56]. In Middle TN, adults with 1-3 ACEs were 8.83 times more likely to be at risk for HIV (aOR: 8.83 95% CI: 8.25-9.45). Similarly, adults reporting 1-3 ACEs in West TN were 7.92 times more likely to be at risk for HIV compared to adults with no ACEs by 7.92 times (aOR: 7.92, 95% CI: 7.51-8.34).

Adults with 4+ ACEs were more likely to be at risk for HIV across all divisions. However, in Middle TN, the highest odds ratio was seen among adults with 4+ ACEs; among those with <$25,000 annually, there was an increased odds of being at risk for HIV by nearly 32 times (aOR: 31.86, 95% CI: 29.83-34.02). The second highest odds ratio was seen in West TN where the odds of being at risk for HIV were nearly 20 times compared to adults with no ACEs (aOR: 18.98, 95% CI: 18.02-19.99). The lowest odds were in East TN where adults with 4+ ACEs were two times more likely to be at risk for HIV compared to adults with 0 ACEs (aOR: 2.00; 95% CI: 1.94-2.06).

Within group relationship between ACEs and ever tested for HIV by TN grand division

MLR analysis examining the relationship between ACEs and HIV testing among adults making <$25,000 annually are also displayed in Table 4. ACEs and HIV testing were mediated by being at risk for HIV and diagnosis of depression (N=2389). Within group analysis by TN grand division (East TN, N=680; Middle TN, N=622; West TN, N=1087) revealed notable regional differences.

In East TN, adults with 1-3 ACEs were 2.54 times more likely to have ever tested for HIV compared to adults who reported no ACEs (aOR: 2.54, 95% CI: 2.50-2.57). In Middle TN, adults with 1-3 ACEs were 1.38 times more likely to ever test for HIV compared to adults who reported no ACEs (aOR: 1.38, 95% CI: 1.36-1.39). Similarly, adults with 1-3 ACEs in West TN were 1.2 times more likely to ever test for HIV (aOR: 1.20, 95% CI: 1.18-1.21).

Adults with 4+ ACEs increased the odds of ever testing for HIV by over two times compared to adults with no ACEs across all TN divisions. Similar odds ratios were seen with the East and West TN strata. More specifically, adults in East and West TN with 4+ ACEs were 2.8

times more likely to ever test for HIV compared to adults with no ACEs (East – aOR: 2.81, 95% CI: 2.76-2.81; West – aOR: 2.85, 95% CI: 2.81-2.89). Adults in Middle TN with 4+ ACEs were 2.2 times more likely to ever test for HIV compared to adults with no ACEs (aOR: 2.19, 95% CI: 2.16-2.22).

Among adults at risk for HIV, odds of testing for HIV again increased across all TN divisions. In East TN, adults at risk for HIV were 5 times more likely to test for HIV compared to adults not at risk for HIV (aOR: 5.14, 95% CI: 4.95-5.34). Adults in Middle TN were 3.7 times more likely to test for HIV among those at risk compared to those not at risk (aOR: 3.71, 95% CI: 3.61-3.82). Adults in West TN were 3 times more likely to test for HIV if they were at risk for HIV compared to those not at risk (aOR: 3.00, 95% CI: 2.94-3.06).

Similarly, depression also increased the odds of testing for HIV in all TN divisions. In East TN, adults with a depression diagnosis were 1.3 times more likely to ever test for HIV compared to those without a depression diagnosis (aOR: 1.32, 95% CI: 1.30-1.34). Adults diagnosed with depression in Middle TN were 1.6 times more likely to ever test for HIV compared to those without depression (aOR: 1.65, 95% CI: 1.63-1.67). In West TN, adults with depression were two times more likely to ever test for HIV compared to adults without depression (aOR: 2.05, 95% CI: 2.03-2.07).

Table 14.4.

Region disparities - Multiple logistic regression between number of ACEs (categorized as 0, 1-3, or 4+), at risk for HIV, diagnosed with depression, age group, and HIV testing among adults making <$25,000 annually, years 2016-2017

	OR (95% CI)					
	At risk for HIV (N=2521)			Ever tested for HIV (N=2389)		
	East (N=716)	Middle (N=664)	West (N=1141)	East (N=680)	Middle (N=622)	West (N=1087)
Predictors						
ACEs						
0	Reference			Reference		
1-3	0.54 (0.52-0.56)***	8.83 (8.25-9.45)***	7.92 (7.51-8.34)***	2.54 (2.50-2.57)***	1.38 (1.36-1.39)***	1.20 (1.18-1.21)***
4+	2.00 (1.94-2.06)***	31.86 (29.83-34.02)***	18.98 (18.02-19.99)***	2.81 (2.76-2.87)***	2.19 (2.16-2.22)***	2.85 (2.81-2.89)***
At risk for HIV	^NA	NA	NA	5.14 (4.95-5.34)***	3.71 (3.61-3.82)***	3.00 (2.94-3.06)***
Depression	NA	NA	NA	1.32 (1.30-1.34)***	1.65 (1.63-1.67)***	2.05 (2.03-2.07)***
Age						
18-34	Reference			Reference		
35-54	0.28 (0.27-0.29)***	0.28 (0.27-0.29)***	0.24 (0.23-0.24)***	0.56 (0.55-0.57)***	0.75 (0.74-0.76)***	1.52 (1.50-1.54)***

55+	0.18 (0.17-0.19)***	0.14 (0.14-0.15)***	0.12 (0.11-0.12)***	0.13 (0.130-0.134)***	0.36 (0.35-0.36)***	0.57 (0.56-0.58)***

****P<0.0001; ^NA, not applicable*

Discussion

The current study built off of the 2015 TN epidemiologic report and prior studies linking ACEs with HIV risk.[7–10,12,13] The proportion of adults with at least one ACE was more than half of the study sample consistent with 2015 findings from the TDH.[8] However, 15-25% of adults in the total population were found to have experienced at least 4 ACEs across all regions and all income levels, a finding that is slightly higher than the 2015 report.[8]

Among adults with an annual income of <$25,000, ACEs were noted to have a significant impact on the odds of being at risk for HIV and having ever tested for HIV. Adults with any ACEs across all regions of TN were more likely to be at risk for HIV with the exception of East TN. Adults in East TN with 1-3 ACEs were actually less likely to be at risk for HIV compared to those with zero ACEs. The most severe impact of being at risk for HIV was among adults with greater than 4 ACEs living in West TN. Among adults with an annual income of <$25,000, 4+ ACEs, depression, and being at risk for HIV increased the odds of testing for HIV.

Age was protective against HIV risk and testing for HIV. Older adults appeared to be less likely to be at risk for HIV and to have ever tested for HIV compared to adults 18-34. These findings are similar with the CDC statistics on HIV; older adults, specifically 50 years+, were more likely than younger people to have late-stage HIV infection.[19] This could likely be due to lower HIV testing and decreased perception of risk for HIV as age increases.[19,20] However, West TN was the exception with adults aged 35-44 who were actually more likely to test for HIV compared to adults aged 18-34.

Strengths and limitations

This study is limited in the ability to infer a causal relationship, because all information was obtained through self-reported survey responses from years 2016 and 2017. However, it is worth considering the existing time difference between the occurrence of ACEs, HIV risk behaviors, and HIV testing. Since ACEs occurred before the age of 18, and HIV risk behaviors and HIV testing occurred as an adult, 18 years of age or older, this study provides some temporal relationship. An additional strength of this study is the large statewide representative sample. However, findings can only be extrapolated to the TN grand divisions. Moreover, this was a

within-group analysis where divisions of TN were not compared to each other. Thus, future studies could examine TN divisions via between-group analysis.

Public Health Implications

Study findings aid in assisting health practitioners in providing information on correlates that could act as a facilitator to HIV risk and as a barrier to HIV testing in TN. It should be noted that "ever tested for HIV" as an outcome is not specific temporally whereas HIV risk behaviors was specific in having occurred in the past year. To better understand possible links between ACEs, depression, and risk for HIV with HIV testing along the HIV continuum of care (HCC), a question should be developed for the TN BRFSS that is more specific in terms of when HIV testing occurred.

Future studies are warranted to provide more information on regional disparities. Furthermore, gender and sexual minority differences among adults with ACEs across TN grand divisions could aid in gaining insight related to adults known to be at higher risk for HIV.[21] Inclusion of lifestyle variables related to current substance abuse (such as street drug use and alcohol abuse), health insurance, individuals with adult trauma (for example, intimate partner violence), and high risk groups specifically among sexual minority groups LGBT will aid in designing relevant prevention strategies specific to the needs of adults living in TN to limit the spread of HIV and be most impactful to the HCC.

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Chapter 4. Development of a Culturally Appropriate Screener for Assessing Life Traumas and Barriers to HIV Care in a Center of Excellence for HIV/AIDS in Northeast Tennessee

[1]Elaine Loudermilk, [1]Melissa White, [2]Emmitt Turner, [3]Morgan Jones, [4]Hadii Mamudu, [5]Lisa Bynum, [5]Roxanne Underwood, [5]L. Susan Dotson, [5]James Adkins, [5]Joy Bohannon, [6]Stephanie Mathis, [3]Kelly Foster, [6,7]Robert Pack, [2,5]Jonathan Moorman, [1]Shimin Zheng, [1]Megan Quinn

[1]Department of Biostatistics and Epidemiology, College of Public Health, East Tennessee State University, Johnson City, Tennessee 37604

[2]Quillen College of Medicine, East Tennessee State University, Johnson City, Tennessee 37604

[3]Department of Sociology and Anthropology, College of Arts and Sciences, East Tennessee State University, Johnson City, Tennessee 37604

[4]Department of Health Services, Management, and Policy, College of Public Health, East Tennessee State University 37604

[5]Center of Excellence for Inflammation, Infectious Disease, and Immunity, Quillen College of Medicine, East Tennessee State University, Johnson City, Tennessee 37604

[6]Center for Prescription Drug Abuse, Prevention, and Treatment, College of Public Health, East Tennessee State University 37604

[7]Department of Community and Behavioral Health, College of Public Health, East Tennessee State University, Johnson City, Tennessee 37604

Abstract

Introduction

A culturally competent survey currently does not exist to characterize the burden of Adverse Childhood Experiences (ACEs) among a HIV positive population receiving care at a local Center of Excellence (COE).

Methods

A qualitative study was conducted and included 11 interviews that obtained opinions (keep, modify, or remove) on national surveillance questions to develop a culturally competent survey. Interrater reliability and % agreement between two coders was completed to determine the questions and their wording for the final survey.

Results

The final 55-question survey contained more generalized ACE questions, topics pertaining to barriers to HIV care, along with the opportunity for patients to list what they need help with to improve HIV care.

Conclusion

The final survey allows for characterizing the burden of ACEs at the COE. Future directions involve piloting the survey as a quality improvement tool with the goal of increasing retention rates through individualized HIV care.

Key words: HIV care, barriers to care, adverse childhood experiences, retention in care

Introduction

In the state of Tennessee (TN), across the United States (US), and abroad, Adverse Childhood Experiences (ACEs) have been linked to poor mental health, substance abuse, and HIV risk behaviors.[1–10] ACEs were originally studied by the Centers for Disease Control and Prevention (CDC) in corroboration with Kaiser Permanente in the mid to late 1990s.[11] These potentially traumatizing events involve growing up in a dysfunctional household, witnessing or experiencing abuse. More specifically, ACEs involve physical, emotional, verbal, and or sexual maltreatment along with growing up with living with a parent who was imprisoned, abused substances, was mentally ill or suicidal, and/or witnessing parents abuse each other; all of these experiences were before the age of 18.[12]

Long term health consequences of the high stress levels associated with ACEs include chronic disease, mental health issues, and poor coping skills involving injection drug use and other substance abuse like alcoholism, as well as partaking in risky sexual behaviors potentially leading to a diagnosis with HIV and other blood-borne pathogens.[6,10,13–16] Among adults residing in the Appalachian region of TN, persons living with HIV (PLWH) have reported ACEs and substance abuse as barriers for nonadherence to HIV treatment regimen. However, these specific reasons for nonadherence are primarily anecdotal with little published evidence to confirm what is being seen specifically in the Northeast TN region.

Providers and case managers working with PLWH at the Center of Excellence (COE) for HIV/AIDS in Johnson City, TN have seen trends similar to the present research with regard to ACEs having an impact on adult behaviors and mental health. The Southern region of Appalachia, which includes Northeast TN, has the highest HIV prevalence compared to other parts of Appalachia.[17,18] Southern Appalachia also has the highest burden of mentally unhealthy

days, which is 25% higher than the national average.[17] Mentally unhealthy days are the number of days in a month that an individual feels unhealthy and is very similar to feeling depressed.[17] Depression has long been known as a correlate for HIV treatment nonadherence and as a result from ACEs in both the US and abroad.[17,19–21] Furthermore, ACEs have also been linked to intimate partner violence (IPV) among adults, which has been associated to an increased risk for HIV diagnosis and also a contributing factor to nonadherence for HIV treatment among PLWH.[22,23] Moreover, a study analyzing data for the Southern region of the US determined that internalized HIV stigma and depression decreased engagement in HIV care.[19] Thus, retention in HIV care among PLWH in rural Appalachia, specifically TN, are hypothesized to be affected by mental health, ACEs, stigma, and substance use in the motivation to adhere to HIV care.

The current research study sought to develop a survey informed by the patient population at the COE to better understand what factors are believed to play a role in HIV treatment adherence or nonadherence as well as characterizing the burden of trauma among this population of PLWH at the COE. To date, a survey assessing life traumas, specifically ACEs, domestic violence, mental health, barriers to HIV/AIDS care, stigma and discrimination, HIV risk behaviors, and attitudes/knowledge/beliefs about HIV/AIDS with factors along the HIV Continuum of Care (HCC), specifically adherence and motivation to adhere, regarding HIV treatment regimen has not yet been published for use in a clinical setting specifically for PLWH. From now on, the topics mentioned in this list will be referred to as life traumas and factors related to the HCC.

The present study is unique in that it sought to formatively evaluate surveillance questions used in the US, and some internationally specific to WHO ACE-IQ, pertaining to the aforementioned topics. Furthermore, this study aimed to provide an opportunity for PLWH

receiving care at the COE in Northeast, TN to voice their opinions and discuss their perspectives regarding the phrasing and relevance of questions and the role life traumas have on adherence to and retention in their HIV care at the COE.

Methods

Study design

This was a qualitative study completed through interviews involving the formative evaluation of a pretesting survey. The survey was comprised of questions developed from local providers for HIV/AIDS and taken from surveys used across the United States (US) and internationally. Survey questions evaluated by participants were obtained from the following sources: (1) anecdotal from clinic providers and retention care specialists in Northeast Tennessee's Health Department and COE (specifically time it takes to get to the COE, length of time being aware of HIV diagnosis, and use of hook-up applications as a risk factor for HIV transmission), (2) the CDC Medical Monitoring Project,[24] (3) CDC Behavioral Risk Factor Surveillance System (BRFSS) Adverse Childhood Experiences Questionnaire,[25] (4) a BRFSS knowledge, attitudes, and beliefs about HIV/AIDS questionnaire,[26] and (5) the World Health Organization Adverse Childhood Experience International Questionnaire (ACE-IQ).[27]

The pretesting survey participants evaluated consisted of ten sections comprised of a total of 83 questions and an additional task where participants were asked to star which ACEs pertained to them and then to rank only those that were starred to determine those that had the worst possible impact in terms of living a healthy life as an adult. Questions were studied in depth and discussed with medical providers, sociologists, and childhood trauma experts before conducting interviews at the COE, and probes were prepared to ask participants where questions might pose problems. The evaluation of the pretesting survey involved participants providing

personal opinions about whether to keep, remove, modify, or add questions regarding life traumas and demographic information. Demographic questions were also evaluated, obtained, and included the following: sex at birth, sexual identity, sexual orientation, race/ethnicity, education level, work status over the last 12 months, current legal marriage status, religiosity, income, place of residence (rural, suburban, or urban), and the length of time in months and years known to be HIV positive. This information was obtained through in-depth interviews with PLWH conducted between 2019-December and 2020-March.

Study setting

All interviews were conducted at the Quillen College of Medicine, East Tennessee State University (ETSU) Physicians: Infectious Diseases Clinic; this site serves the Northeast TN region as the only COE located in Johnson City, TN. ETSU became a designated COE by the Tennessee Department of Health (TDH) in 1998. The COE provides medical case management, social work, treatment assistance, as well as food and transportation assistance to patients. Their mission is to provide the best comprehensive and cost- effective medical care through utilizing a multidisciplinary team approach for PLWH. Moreover, services include outpatient and ambulatory medical care, medical case management through Ryan White Services, case management via social work, clinical pharmacology, psychotherapy, in-house specialty pharmacy in addition to prevention and outreach services (pre-exposure prophylaxis (PrEP), testing and linkage to care, and syringe exchange).

Recruitment

We used purposive sampling for clinic staff to identify and recruit eligible patients to participate in the study. Eligibility was based on the following criteria: patients who were mentally stable (participation posed minimal risk to their mental health and existing mental

health conditions were under control through treatment regimen), were existing patients (not new), were 18 years of age or older, and were able to speak English since funding was unavailable to pay for a translator. Additionally, recruitment focused on a representative demographic characteristic of the HIV positive population at the COE. All participants who agreed to the study were informed of the study by the principal investigator, consented, and compensated in the form of a Walmart gift card (10 USD) once the interview was completed.

Ethics Approval

Approval of the study protocol was obtained from the ETSU Institutional Review Board. Privacy and confidentiality were maintained by not collecting identifiable information from participants and conducting interviews in a room at the COE in compliance with the Health Insurance Portability and Accountability Act. All audio recorded interviews were transcribed followed by destruction of the audio file.

Data Collection

One trained female investigator conducted the interviews while a second trained female took notes. The pretesting survey was administered at a literacy level of less than high school education to be consistent with best practices and clinic provider request.[28] Interviews involved the participant providing their opinion about the questions, without answering them, and taking notes on a paper copy of the pretesting survey to modify phrasing of questions and/or responses, using similar methodology for modifying an ACE questionnaire for cultural competence as a previous study.[29] Each interview was labeled with a unique identifier and no identifying information was collected during the interviews.

Participants went through each section, one by one, reading each question aloud, and 1) starring questions considered to be important, 2) marking out questions that were considered to

be offensive or irrelevant, 3) modifying questions and/or responses to make them more relevant to their experiences, and 4) adding questions/responses as needed based on their life experiences. Participants were also asked to determine from a list of ACEs which were the most important to them based on their own experience; then, they were asked to rank them in terms of worst to least impact with a score of one have the greatest negative impact on their ability to live their best life. Participants then reviewed the demographic questions to select their preferred style. Participants answered the demographic questions. Reactive probing was applied as needed during the interviews; this technique is a non-standardized methodology implemented to allow for flexibility and adaptability of the interviewing process.[30–33] Sampling ended after reaching saturation.[34]

Prior to the conclusion of the interview, participants were asked if they wished to provide any additional comments. Support resources for mental health providers in the region were provided in case participants experienced any distress from the interview. A total of 11 interviews, with each interview lasting 3-4 hours were completed.

Data Analysis

Data were transcribed verbatim and imported into NVivo (Nvivo 12 Mac, QSR International 2020) for coding and analysis by two researchers using a structured coding scheme reflecting questions that should be kept, removed, modified, or if additional questions should be added. The researchers developed a protocol to specifically code questions and justifications using the transcription of interviews. However, the note taking tool, interview tool, and the participant survey were studied heavily to aid in making the final determination between which questions were going to be kept, removed, or modified in order to be relevant for the final survey.

To check that the coding was appropriate and assess the level of agreement between both researchers,[35] overall Cohen's Kappa inter-rater reliability[36] and percent agreement for each individual question were calculated.

ACEs ranked by participants were qualitatively analyzed to determine if a weight for ACEs could be developed. Results were shown tabularly to depict which ACEs were most frequently ranked along with justifications where applicable.

Results

Demographic characteristics

Demographic characteristics of the 11 HIV positive participants who completed the interviews are shown in Table 1. The participant population was primarily males (ten). All ten males reported being male at birth and male currently. Similarly, the female participant reported being female at birth and female currently.

One male identified himself to be Black whereas another male identified himself as "other" race. All other participants identified their race as White. Regarding sexual orientation, the female participant identified herself as straight and married. Among male participants, eight identified as gay. Of the three males currently married, one male was currently married to a woman and identified himself as bisexual. The other two males currently married identified themselves as gay. Two other male participants, who identified as gay, were widowed with one having been married to a woman. Other relationship statuses were reported as follows: two males identified themselves as "single," one as "never married," one "divorced," and one in a "civil union or domestic partnership."

Education level varied from high school to a college degree. For employment status, all worked except for three who were unable to, one due to a medical complication and was waiting

to be cleared by his physician, and the other two were on disability. One of the two who reported disability and unable to work also reported being self-employed some of the time with his spouse.

Three participants stated they were spiritual while one male and female stated they were religious. Among the remaining participants, religion and spirituality were either not very or not important at all.

Table 15.1.

Demographics of participant population (N=11)

Sex at birth	
Male	10
Female	1
Sex now	
Male	10
Female	1
Sexual orientation	
Lesbian or gay	8
Straight (heterosexual)	2
Bisexual	1
Race/Ethnicity	
White	9
Black	1
Hispanic	0
Other	1
Age (years)	Mean = 55
Highest level of education	
Less than high school education	0
High school education or GED	2
Some college/associate's/Technical degree	5
Bachelor's degree	4
Any post-graduate studies	0
Main work status	
Government employee	1
Non-government employee	4
Self-employed	2
Non-paid	0
Student	0
Homemaker	0
Retired	1
Unemployed (able to work)	0
Unemployed (unable to work)	3
Current legal marriage status	
Married	4
Civil union/domestic partnership	1

Divorced	1
Widowed	2
Separated	0
Never married	1
Single	2
Income ($)	
0-12,999 per year	0
13,000-14,999 per year	1
15,000-16,999 per year	2
17,000-19,999 per year	0
20,000-24,999 per year	1
25,000-29,999 per year	1
30,000-39,999 per year	1
40,000-49,999 per year	2
50,000-74,999 per year	2
75,000 or more	0
Missing	1
Religion/Spirituality importance	
Very important	5
Somewhat important	0
Not very important at all	2
Not important at all	3
Missing	1
Region of Northeast TN	
Rural/County	3
Suburban/City	6
Urban/City	0
Missing	2
Length of time known for HIV positive	
Mean time (years)	24

Main findings from ranking ACEs

Participants were given an additional task relating to all ACEs listed with the goal of collecting data to apply a weight, if possible, to individual ACEs (Table 2). First participants were asked to star all ACEs considered to be important to them. Then, participants were asked to rank only those starred with one being the most severe in terms of negatively affecting their adult life. Table 2 displays the ACEs starred by all participants; results of the additional task are described in further detail with regard to rank below.

Table 16.2.
Results of ACEs starred from the additional task

	Participant											
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**Total**
ACEs												
Parents/guardians did not understand your problems and worries	*	*		*	n/a		*	*	*			**6**
Parents/guardians did not know what you were doing with your free time when you were not at school or work	*	*		*	n/a			*	*		*	**6**
Parents/guardians did not give enough food when could have easily done so	*				n/a	*		*				**3**
Parents/guardians were too drunk/intoxicated by drugs to take care of you	*			*	n/a	*	*	*		*		**6**
Parents/guardians did not send you to school when it was available	*				n/a	*	*	*				**4**
Lived with anyone depressed, mentally ill, or suicidal	*		*	*	n/a	*	*	*		*		**7**
Live with anyone who used illegal drugs or abused prescription medication	*			*	n/a	*	*	*				**5**
Lived with anyone who was a problem drinker or alcoholic	*			*	n/a			*			*	**4**
Lived with anyone who was sentenced or served time in prison	*			*	n/a		*	*				**4**
Parent/guardian died	*		*	*	n/a		*	*				**5**
Parents/guardians separated or divorced	*			*	n/a		*	*	*		*	**6**
Witnessed parents/guardians hitting, kicking, punching, or beating each other up	*		*		n/a	*	*	*	*		*	**7**
Witnessed or heard parents/guardians being yelled at, screamed at, sworn at, insulted, or humiliated	*	*			n/a		*		*		*	**5**
Witnessed or heard parents/guardians being hit or cut with an object	*				n/a		*					**2**
Was hit, beaten, kicked, or physically hurt in anyway by a parent/guardian	*				n/a		*		*			**3**
Was hit or cut with an object by a parent/guardian	*				n/a		*					**2**
Was sworn at, screamed at, insulted, or put down by a parent/guardian	*	*	*		n/a			*	*			**5**
Was threatened to or actually abandoned by parent/guardian OR parent/guardian threw you out of the house	*				n/a	*	*			*	*	**5**
Was touched sexually when you did not want them to by a parent/guardian/adult	*		*		n/a		*	*		*	*	**6**
Was forced to touch parent/guardian/adult sexually when you did not want to	*				n/a	*	*					**3**
Was forced to have sex with parent/guardian/adult when you did not want to	*		*		n/a		*			*		**4**
Bullied or teased in an unpleasant way by peers	*	*	*		n/a		*	*				**5**
Involved in physical fighting (occurs when two people of about the same age, strength or power choose to fight each other)	*	*			n/a		*				*	**4**

Saw or heard someone being threatened with a knife or gun, being beaten up, stabbed, or shot in real life	*				n/a							**1**
Exposed to collective violence (wars, terrorism, political or ethnic conflicts, genocide, repression, disappearances, torture and organized violent crime such as banditry and gang warfare)	*				n/a							**1**
Was beaten up by soldiers, police, militia or gangs	*				n/a		*					**2**
Witnessed family or friend get killed or beaten up by soldiers, police, militia, or gangs	*				n/a	*	*					**3**

Ranking of ACEs were overall inconsistent and subjective based on the experiences or beliefs of the participant even if they had not personally experienced them. Still, some ACEs were identified consistently as having a lasting negative impact into adulthood either by personal experiences or perceptions and are shown in Table 2 under the "total" column. ACEs starred the least frequently were considered to be culturally irrelevant to the population receiving treatment at the clinic.

Ultimately, this task was not included in the final survey due to feedback from participants with one specifically saying, "I'm getting frustrated, because it's boggling my brain…This is a little overwhelming." A different participant found the task so overwhelming and frustrating that he declined to do the additional task stating, "I would look at this and say, 'What the hell? I gave you my answers already...why?'"

Main findings from pretesting survey evaluation analysis

The overall Kappa score was 0.72 with 100% agreement for each individual question between the two coders. Majority of participants thought the barriers to HIV care, motivation to adhere to HIV treatment regimen, and mental health questions were relevant to ask. Modifications in these sections involved the removal of "don't know" in the answer responses

where inappropriate, the addition of "not applicable" as an answer response, the addition of an option to explain, and the combination of questions where applicable.

Most participants were uncomfortable with having "HIV/AIDS" and preferred only "HIV." One participant justified this further by saying, "I feel better with HIV. You know, you don't have AIDS. You have HIV, not AIDS. Or not yet, anyway." However, other participants thought AIDS needed to be there since they initially were diagnosed with AIDS. Therefore, the language was changed to "HIV or AIDS" reflecting how all participants read "HIV/AIDS" aloud during the interviews and removed in places where having both HIV/AIDS was not necessary.

Adverse childhood experiences

Majority of the questions in the ACEs section were considered relevant, however some participants requested that more general questions be asked so as not to trigger anyone who had experienced the events. The phrasing of nearly all questions was updated to be, "growing up before the age of 18, did…" since "how often" was thought to be accusatory. One participant stated more specifically, "I think the phrasing, 'how often' is more open ended whereas 'did a parent' or 'growing up,' that is more specific… I would probably do 'growing up.' I think the wording would be more comfortable."

Neglect

Question one and two relating to if parents/guardians understood your problems worries/knew what you were doing in your free time were determined to be kept. One participant relayed information about what their peers had experienced to justify why these questions were important,

> "The same people that I've seen rejected when they came out to their parents, were put out of home, were still-they had to start sneaking around to have that, ya know they

couldn't bring their boyfriend/girlfriend home to meet the parents. So, they were out sneaking around, taking a lot of unnecessary risk."

Another participant thought these questions were important by relating a similar story stating,

> "I've been/had friends who went through and sat there with them and said listen, 'Just because you have parents that said, "I won't have a gay child. I won't have a lesbian child, then you're out of my house." doesn't mean you're wrong; it means them wrong.' And I've seen them in their 20s and into their 30s still struggling with the fact, ya know, they felt like there was something wrong with them, because when they told their parents, ya know, rejected, ya know, they didn't understand what they were going through. And, just, fortunately, we're in a time where we are a little better educated. Ya know, having a child come out to you. But, ya know, like I said, I still see a lot of people in their 30s especially, seems like, that are trying to cope with, ya know, what happened when they came out with their parents. They're still very withdrawn about being open about it and talking about it. Ya know, I have a friend that [I] talked her down often off that ledge, 'I'm just going to end it all,' more than once, ya know, just because of what she went through as a teenager with her parents. It's really rough on a lot of them."

A third participant discussed their own personal experience to justify why this question should be kept,

> "You need to be a parent, but at the same time you need to have a relationship with your children to the point where they feel like they can discuss things with you that are going on with them. Because like I said, I was molested. And I kept that a secret until 1996 until I was diagnosed…other than the person that knew it."

Some questions were requested to be combined into one over-arching question. For example, questions about childhood neglect (having enough food and going to school) seemed to make participants confused and uncomfortable. One participant specifically stated, “I don’t know what you’re trying to get from it. I mean, it’s an okay question. It doesn’t make me feel weird, but it’s kind of odd.” Another participant stated, “So as an adult, you would get people, and they’re gonna say, ‘well [why] the hell are you asking me about this?’” Therefore, neglect related questions were combined to a general question about having experienced childhood neglect as one participant had suggested stating, “You could have people shut down. So, if you can shorten and put it into just the one question, great.”

Household dysfunction

Growing up with a parent/guardian who was mentally ill, suicidal, or had depression was a question that one participant wanted the option to explain who had died based on the following statement,

> “I would like to be able to give you an answer as to what-were they depressed, were they mentally ill, or were they suicidal…I guess that's due to the fact my mother had extreme problems with depression. She wasn't mentally ill and was never suicidal. The person wanting information from you [needs] to know…who was the adult you were having to deal with.”

Additionally, a different participant gave a personal experience for why this question was relevant,

> “That's a good question. Well, I didn't have it…but I think it's a good question, because it opens the door to… well what if you grow up in a situation and you see it all the time? … my best friend's father took his life on mother's day when we were 16. I think it's a very

valid question, … because it kind of opens the possibility of … is this someone you need to refer to mental health or is it [a] possibility they may want to hurt themselves?..."

Therefore, this question was kept and modified to reflect information provided by the participants.

For the question which asked about whether a parent/guardian died, a participant wanted the option to explain who stating, "I would like to see an option that somehow would allow me to say it was my mother, or my father, or, of course it could be a sibling. It's entirely possible. So, mother or father or sibling." Living with a problem drinker, alcoholic, or someone who used drugs was requested to be kept in a table format but to add the option of "not applicable." For asking about parental divorce or separation, one participant recommended changing this to the following, "What kind of household? Word choice again-use like, single parent household, parents of the same gender, people live with their grandparents." For growing up with someone who went to prison, wording was changed to reflect one participant's proposed modification of, "Jail or other correctional facilities is better wording…get rid of 'sent.'"

Abuse

The phrasing of abuse questions as they existed in the original ACE and ACE-IQ were considered to be triggering where one participant said, "Triggering, but still need to have enough of a description where the patient doesn't shut down by trying to remember if abused." Another participant opened up about a memory they had during the interview of having an abusive father who was violent,

"A few times. My dad, if he couldn't get to you one way, he would another if you done anything…a few times. And that's pretty clear. Daddy had a habit, if he couldn't reach

you or slap you, then he'd do his hands like that and peck you. Tell us to shut up or do something different."

Another participant provided a modification proposal, "'abused' instead of all of that. I am getting the visual now … picturing violence in your head. I would say if the key is not to trigger anyone, then for me personally, then just say "beaten with an object" or "abused" instead of getting so specific-so you don't get the visual." Another participant suggested the following, "I think they could kind of be brought into like physically or emotionally or physical, emotional, or mental abuse- a consolidated question, with an option to explain if they wanted to…"

For witnessing abuse, a different participant provided a modification based on a personal experience, "My father was very abusive. Had to be divorced. I think maybe instead of how often, [did you witness your parents abusing each other]. Because it's one of those, either that or I would make not applicable a selection on there."

Thus, the phrasing of abuse questions, either witnessing or having experienced, was modified to be more general to avoid triggering individuals from having to relive the event.

Sexual abuse was another section of questions that was very sensitive and recommended to be direct and less triggering. Two of the eleven participants revealed that they had been molested or sexually abused as a child. Thus, this section of questions was modified to reflect participant suggestions such as, "With these type of these situations, you want the question to be direct as possible. Because this is relevant to me. You want to try and get that information as quickly as possible, because they're going to be uncomfortable."

Another common concern with the sexual abuse questions was the phrasing regarding someone being five years older to cause the sexual abuse. One participant stated, "…I have a problem…I question "at least 5 years older" while another stated,

> "…cross out the five years. Because I think age doesn't play a role in how awful it is… that is almost a little too graphic. If it happened, it happened. If you're not in a therapy session to try and fix it, you just want to know did it or not…so that you'll learn there was a trauma in the past that may relate to the future."

Being threatened or actually kicked out of the house or abandoned was suggested to be left in a tabular format, however the option of not applicable was added. Bullying was also deemed important and a modification was made by adding an option to explain while also being able to check all that applied. Physical fighting was deemed important with the modification of adding an option to explain.

Community and collective violence

Questions pertaining to community violence and collective violence were generalized with the option of individuals to explain based on the below participant suggestion, "Did you witness community violence and just let someone explain…Because community violence…it's broad spectrum…community violence would be a better wording and that would cover all three of the questions." Other questions in this section regarded being beaten up by police or gangs and were updated by removing "militia" and "soldiers" to make them more culturally appropriate for the clinic population based on the following suggested modification, "I probably wouldn't keep soldiers or militia, but police or gangs are good questions."

Additionally, although some participants could not relate to the questions about witnessing or experiencing community or collective violence, one participant could and shared his story:

> "Okay, I think experiences like this could be relevant for a provider…because again back to my partner, part of his issue, in a sense, is being profiled. Just simply, he didn't

experience any physical violence from it. But there was some obscenities yelled from the folks in the big fancy houses. Basically, telling him to take his, ya know, back to his side of the town. And it added to his situation, the depression. And I'm sure it could easily escalate to violence, ya know, being beaten up."

The final question in the ACE section involved a modified ranking ACEs question where someone could discuss any ACEs that still have an impact on an individual today. This is due to the ranking of ACEs being overwhelming in addition to the questions as well as feedback from one participant who had been sexually abused stating it still affected them to this day.

Domestic violence

A definition was applied to the domestic violence section to help participants understand the definition of domestic assault. "Domestic assault in Tennessee is when it's committed against someone who is current or former spouse; cohabitant; dating or sexual partner; blood or adoptive relative; current or former relative by marriage; or adult or minor child of any of the above individuals."[37] Questions in this section were modified to be less triggering as one general question through combining questions.

One participant stated this was relevant due to his experience, but that having resources was more useful than having the general question stating, "…my answer would have been no…even with the fact that his bottom was the night that he threatened to kill me…98% chance that I would pull a tab, where I wouldn't admit to anything here…the man I married in 2015 is the person that I always knew was inside…" The same participant also made the following suggestion, "has…my partner abused me period…" Thus, if someone says yes to having been abused recently by a partner or spouse, then they will be prompted to answer another question on if they received domestic violence services.

Some participants indicated that if you have experienced abuse then that is the same as needing domestic violence services. Modifications were made based on participant feedback such as,

> "I feel like it's very important to be asked, because I actually know someone that comes here who has been threatened at one point. If this were a question here, I know the ones here are going to say, 'Hey, well we've got resources.' And you're going to have a room full in about two minutes getting you everything you need."

Moreover, another participant made a suggestion for an additional sub question, "…I would put in there do you know there are services available…Or do you know that there is a safe house."

Stigma & Discrimination

Stigma and discrimination questions were suggested to be modified to one general question rather than asking specific questions where someone could answer yes, no, or prefer not to answer. Specific questions made some participants uncomfortable with one specifically saying, "Wooo, that is a harsh question," while others could relate to the experiences saying, "…they'll find out you have HIV, and…they were shaking your hand a few minutes ago. And they won't want to touch you. They won't want to talk to you. There are still ignorant people out there."

A definition was also added to specifically define related experiences since some participants who said they had never experienced it had described events that were examples of stigma and discrimination.

> "HIV stigma is negative attitudes and beliefs about people living with HIV. It is the prejudice that comes with labeling an individual as part of a group that is believed to be socially unacceptable. HIV discrimination refers to the unfair and unjust treatment of

someone based on their real or perceived HIV status. Discrimination can also affect family and friends, and those who care for people with HIV. HIV discrimination is often fueled by myths of casual transmission of HIV and pre-existing biases against certain groups, certain sexual behaviors, drug use, and fear of illness and death. Discrimination can be institutionalized through laws, policies, and practices."[38]

HIV related risk behaviors

Questions related to HIV risk were thought to be relevant. One question asking about which drugs were most used in the Appalachian region was modified to include examples in parentheses and an added section to the question stem regarding drug interactions. Most participants could justify having the question included in the survey since street drugs and alcohol could interact with HIV medications, "I'm just kinda trying to figure out, a doctor asking you, 'well what do you think the biggest drug problem is in this area,' well why would they ask that unless it was for drug interactions." Initially, two options were provided for a question asking about specific HIV risk situations individuals had partaken in, such as using a condom or not, having anal sex, getting paid for sex, injecting drugs. The modification was made to leave the question more general due to statements such as this:

> "I think if you give someone the option to explain, I honestly think they're not going to go into the details. If there is that concern, that people will not respond, then maybe you need to do the generic... I don't have to specify how dirty I am. General question is the way to go."

Participants who were willing were also given the option of explaining which one if they would like based on responses such as, "If you're going to remain anonymous on the paper, then I think this is good as well..." Other questions related to substance and alcohol use were combined and

modified, based on participant feedback, to be less offensive or judgmental so that participants could answer if they were relevant or prefer not to answer.

Mental Health

Some questions were considered to be repetitive in this section and were therefore combined be more clearly understood and reduce the number of questions overall. Additionally, participant feedback indicated it would be good to ask if those who did struggle with mental health would like counseling services. Similarly, for those who respond as not having good social support outside of the clinic, the option of receiving information at the clinic to find social support can then be offered at the COE if they would like it.

Knowledge, Attitudes & Beliefs about HIV or AIDS

This section of questions regarding knowledge, attitudes, and beliefs about HIV or AIDS, was found to be relevant by majority of participants. Some questions were modified, based on participant feedback, to be less offensive by removing the word, "AIDS," from most question stems. One question was added asking if participants knew the difference between a HIV infection and an AIDS diagnosis.

Additionally, some participants did not know that if you had an undetectable viral load that the virus was not transmittable, "If me or anybody says yes to that, then some people need some to be educated" whereas another participant stated, "That's actually a good question because most people don't know that when you're undetectable, you can't get…you can't get it transmitted." This question was thus modified to also include a box of information about a recent campaign from the Centers of Disease Control and Prevention called, U=U,[39] based on one participant's feedback, "Basically my understanding from this question is that well it's okay it's okay to have unprotected sex then… if you could have a box of an explanation." A couple of

participants specifically mentioned the U=U campaign with one specifically saying, “That’s a very relevant question, especially today. Now a days, it’s more, you = you… There is something-some kind of term now where undetectable equals untransmittable, U=U, that’s what it is…”

An additional question was added to assess the belief about HIV treatment regimen lengthening and improving a PLWH’s quality of life. Questions from an outdated BRFSS questionnaire assessing knowledge and awareness about HIV from the 1990s were still considered important today (“Do you think a person who is infected with the AIDS virus can look and feel well”);[26] the question was updated from “AIDS virus” to HIV. The other question from this survey, “To your knowledge, are there drugs available which can lengthen the life of a person with the AIDS virus,” was thought to be offensive and not considered relevant since participants in this study were adherent to their HIV treatment regimen and were therefore aware of this.

Barriers to HIV care

Questions in the barriers to HIV care section were considered relevant. Modifications were made to six months instead of the past year based on participant feedback that a year was too far back to remember. An additional question was added about being hospitalized and if it affected HIV treatment regimen. Travel related questions to getting HIV treatment were updated so that a response to one question would lead to another. This way, participants who don’t have certain barriers will not be prompted to answer all questions in the section. Additionally, if participants answered yes to having things going on in their life that made it difficult to adhere to HIV care, they would then be prompted to explain if they wanted to and list anything that clinic providers could possibility assist in providing to improve care for that individual specifically.

Adherence

Participants thought having a definition for adherence could be helpful, so the following was added, "These questions are about your adherence to HIV care: starting HIV treatment; keeping all medical appointments; taking HIV medicines every day and exactly as prescribed (also called medication adherence)."[40] Questions pertaining to motivation to adhere were updated to include, "for the benefit of your health," and combined due to feedback on the redundancy.

Participants preferred "drug vacation" as opposed to "choosing not to take HIV medicine." Additionally, it was shocking to most participants but considered relevant to include the question, "Do you ever spend money on substances instead of your HIV care?" Finally, When asking about if medication was missed, participants preferred "doses" instead of "days" and a timeline of the past 30 days instead of a year. Answering yes to "In the past 30 days, did you miss doses of your HIV medicine?" prompted the next question, "how many doses?" and "why?"

Demographic information

Demographic information was updated to include all modifications except for one suggestion, including the term "hermaphrodite" for the question, "What was the sex assigned to you at birth?" The participant who suggested using this terminology was not someone who was born with both genitals so was most likely unaware of the stigmatizing and culturally inappropriate terminology for someone who was assigned, "intersex," at birth. And since the final survey is meant to build the relationship between patient and provider, the decision to not incorporate this terminology was determined by a recent article where Professor Alice Domurat from Northwestern University was quoted, "The medical profession came to a consensus about

three years ago to get rid of all terms based on the root 'hermaphrodite' (including 'pseudo-hermaphrodite') because they are stigmatizing and confusing."[41]

The question pertaining to religion was modified to include spirituality since only two of the eleven were religious while several others stated they were spiritual. Income level was modified to include an option for participants to write what their annual earnings were; however, the options to select were left since some preferred having categories to choose from. Living in a rural, suburban, or urban area was considered to be confusing and updated to be city or county based on participant feedback. Current legal marital status was also updated to include options of "single" and "cohabitating." Employment status was updated to be a "check all that apply" with added answer options of "on disability" and "other."

Overall summary of results

The final survey consisted of 55 questions. The survey did not include the additional task to rank ACEs due to the overwhelming nature and feedback provided based on that section. Sections within the survey noted to need definitions either by participants stating specifically that they did not understand or by rereading several times were provided for stigma and discrimination, adherence, and domestic violence. Additionally, sections were rearranged to flow in an intuitive order. Motivation to adhere and adherence were combined since both related to adherence.

Discussion

The current study achieved its goal of developing a culturally competent survey for use with a population of PLWH with a reduced number of questions from the original. This was a strength in that participants are more likely to answer this survey compared to the original lengthy survey. The goal of the study was not to conduct thematic analysis and therefore did not

attempt to pull out themes. Rather, it focused solely on the development of a final survey to be implemented at the COE.

Findings suggest that asking questions very detailed in experiences can be triggering to patients and potentially disrupt the patient-provider relationship. Thus, asking general questions about whether or not abuse or trauma occurred may be more appropriate and allow the physician an opportunity to gain more information should the patient be willing to explain in more detail. Moreover, participants alluded to the fact that any kind of abuse is bad, and thus a question about counseling should be added to ensure those with that experience are able to seek and have access to help from trained professionals in addition to their provider.

ACEs deemed inappropriate by the majority of participants were those obtained from the WHO ACE-IQ involving community violence, destruction of home, or being beaten up or killed by militia. Questions in other sections deemed inappropriate were those obtained from the CDC asking about specific instances of stigma and discrimination; these were ultimately combined into one question and an option to explain was provided.

Other sections of the survey were overall considered relevant although required modification to be more applicable to the current needs of the patients. Overall feedback aided in strengthening the final survey to potentially allow providers at this COE to allocate clinic resources based on the responses of certain questions pertaining to the needs of the patients. For example, participants may indicate they need domestic violence and/or counseling services, do not understand the difference between HIV or AIDS, would like to have a social support team outside of the clinic, and/or have needs the clinic resources could help in supplying. Furthermore, the current survey measures motivation to adherence. Therefore, this allows for

future analysis in determining if associations exist between ACEs, risk factors related to HIV, and barriers to HIV care affecting adherence and/or the motivation to adhere.

Strengths and limitations

Strengths of the methodology used in this study are worth noting. Saturation was met with interviews, specifically meaning that no new information was obtained to indicate the need to continue to interview additional patients at the COE.[34] Additionally, this is the first time a culturally competent life traumas and factors related to the HCC survey has been created for utility among PLWH.

Despite the strengths in methodology and successful development of a culturally competent survey, several limitations exist. Weaknesses involve an inability to extrapolate findings to clinic settings outside of the COE. Moreover, the clinic demographics for HIV positive adults who participated in this study do not reflect the entire HIV positive COE clinic population. Specific to females, of four women who were consented and informed of the study, only one of completed an interview. Furthermore, it should be noted that the population is a convenience sample and does not represent all PLWH opinions in the Northeast TN region.

The final survey did not include the ranking of ACEs due to the feedback provided from participants describing the overwhelming nature of having to rank them after answering questions about them. Thus, it is recommended that the ranking of ACEs be a separate qualitative study in the future in order to better understand how to develop a weight for these specific questions. Specific ACEs were, however, noted to be considered long lasting and likely to have a negative impact into adulthood. These included child sexual abuse, witnessing parent IPV, living with a parent or guardian with mental health issues, who abused alcohol, who didn't

understand problems or worries, who didn't know what their child was doing in their free time, and/or who abused their child verbally, physically, or emotionally.

Conclusion

The short-term goal of this research was to create a culturally appropriate survey to characterize the burden of ACEs among PLWH while also assessing life traumas for each patient who receives care from the COE. A second goal was to obtain feedback that would allow for the development of a weight to be applied to ACEs. This would aid in determining the impact of ACEs into adulthood without assuming all ACEs contribute equally to adult health outcomes.

Furthermore, the final survey will be utilized as a quality improvement instrument to aid providers at the COE in measuring the burden of ACEs among PLWH while also gaining insight into individualized barriers to HIV care. Long term goals include using the survey to predict patients at risk for falling out of care, individualizing care to patients based on responses, and increase retention of care and adherence of the patient to treatment regimen to greater than 90%.

To achieve long term goals, future research should include piloting of this survey at the COE to further understand the best way to ask questions based on feedback and validate the questions. When piloting the current survey, considerations should also be given to testing the survey at the other 13 COE's across the state of TN to further characterize the burden of trauma and determine if there is a link with nonadherence to HIV treatment regimen as well as gain a better understanding into the current barriers to care their PLWH patient population is experiencing. Additionally, future studies should seek to validate the present questions and develop methods enabling the ability for predictive modeling to identify PLWH patients who may be at high risk for falling out of HIV care based on survey responses.

Weighting of ACEs and utility of the entire survey should plan to be explored via piloting the survey and subsequently planning additional qualitative studies as needed. It is recommended to have a licensed psychologist and social worker on the team while the ranking is completed so that participants who become traumatized are in an environment where a therapy session may be conducive; clinic resources may need to be utilized, specifically the licensed psychotherapist and social worker onsite at the COE, since rapport is likely already developed.

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Chapter 5. Discussion and Conclusion

In TN, the HCC is influenced by several factors that differ not only by minority and low-income populations, but also by grand division. Among PLWH, structural barriers such as income and access to medical care, mental health, and life trauma are important factors providers should examine with HIV care.

Research Aim 1

The LGBT community are considered a high risk population by the CDC (CDC, 2017, 2019). Study findings corroborate the CDC's statistics showing an increased odds of HIV risk with LGBT, specifically among those who make <$25,000 annually or were diagnosed with depression across all TN divisions. Regional disparities became apparent with LGBT at risk for HIV and their odds for HIV testing. LGBT adults living in West TN were over 30 times more likely to test for HIV compared to LGBT not at risk. The odds were significantly different with East TN LGBT at risk being only 1.04 times more likely to test for HIV. Among LGBT adults with <$25,000, those living in Middle TN were less likely to test for HIV whereas more likely to test for HIV in East TN when comparing to LGBT with ≥$25,000 annually (see Figure 5.1).

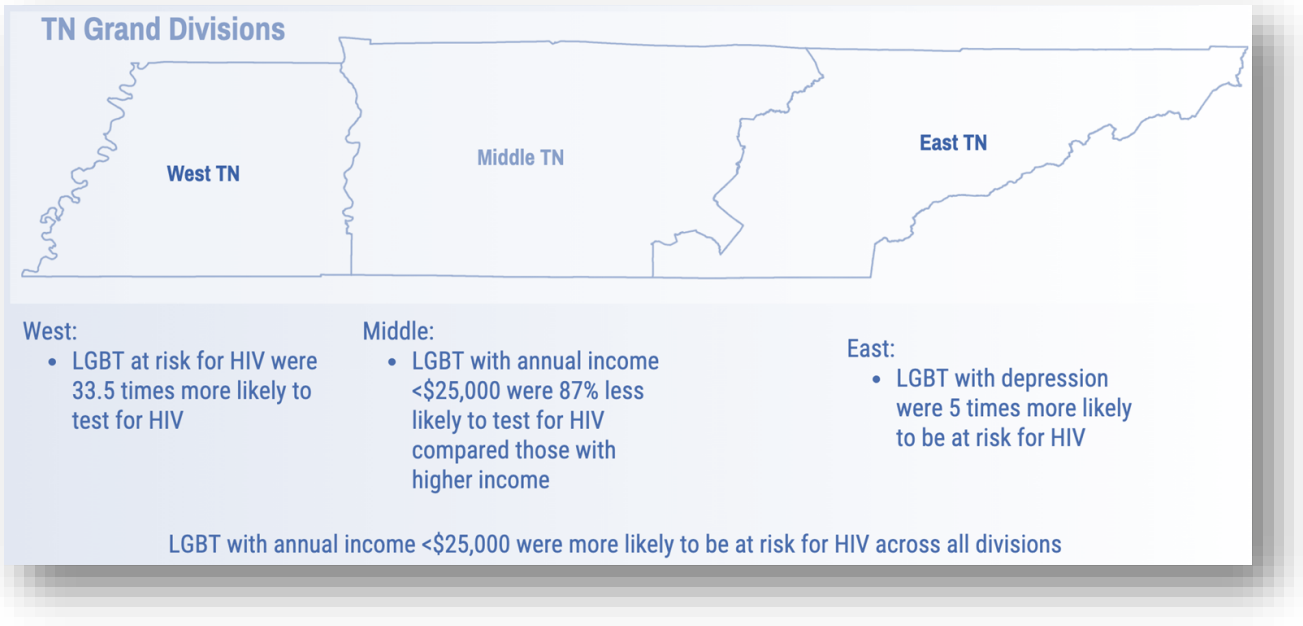

Figure 1.1. Summarized findings for Research Aim 1

Because LGBT with ACEs could not be examined with outcomes, at risk for HIV and ever tested for HIV, future studies should consider qualitative focus groups by region to build off the present study. Furthermore, since BRFSS did not begin collecting data for transgendered individuals until 2018, the LGBT findings from the present study are novel in TN and in the US. Therefore, future studies should try to incorporate data where LGBT and ACEs data are both available to represent the traumatic experiences potentially impacting the HCC as a causal component of risk for HIV and odds of HIV testing among LGBT adults with ACEs. Finally, the analysis was a within group study and therefore cannot compare TN regions to each other.

Research Aim 2

Aim 2 data analysis incorporated ACE data and suggest a strong association with being at risk for HIV in all divisions of TN among adults with low annual income in all regions of TN. More specifically, ACEs decreased risk in East TN whereas increased the risk in West and

Middle TN. Furthermore, ACEs drastically increased the odds of HIV testing among adults with low income at risk for HIV in Middle and West TN.

By age, across TN divisions, an inverse relationship was revealed with risk for HIV among adults with low-income. As adults aged, the odds of being at risk for HIV decreased within TN divisions. Varying associations were seen with HIV testing by region. For example, adults between the ages of 35-54 years were more likely to test for HIV in West TN, whereas less likely in Middle and East TN. Additionally, adults 55+ were less likely to test for HIV across all regions. Limitations exist with respect to HIV testing since the question from BRFSS was phrased "ever tested" instead of providing a timeline for how recent testing occurred.

The CDC recommendations for HIV testing include testing at least once for all people between the ages of 13 and 64 but annually for high risk groups such as gay, bisexual, and other men who have sex with men (CDC, 2016; DiNenno et al., 2017). However, the findings from this study suggest adults with low-income and ACEs are also a high-risk population. Therefore, TN recommendations could include annual testing for adults who fall into these categories although again, this study design can only discuss correlation and not causation. Additional research is needed to understand the link between depression, risk HIV risk behavior, and ACEs among low-income adults with HIV testing. Additionally, adults at risk for HIV and diagnosed with depression among low-income groups were also more likely to test for HIV (see Figure 5.2).

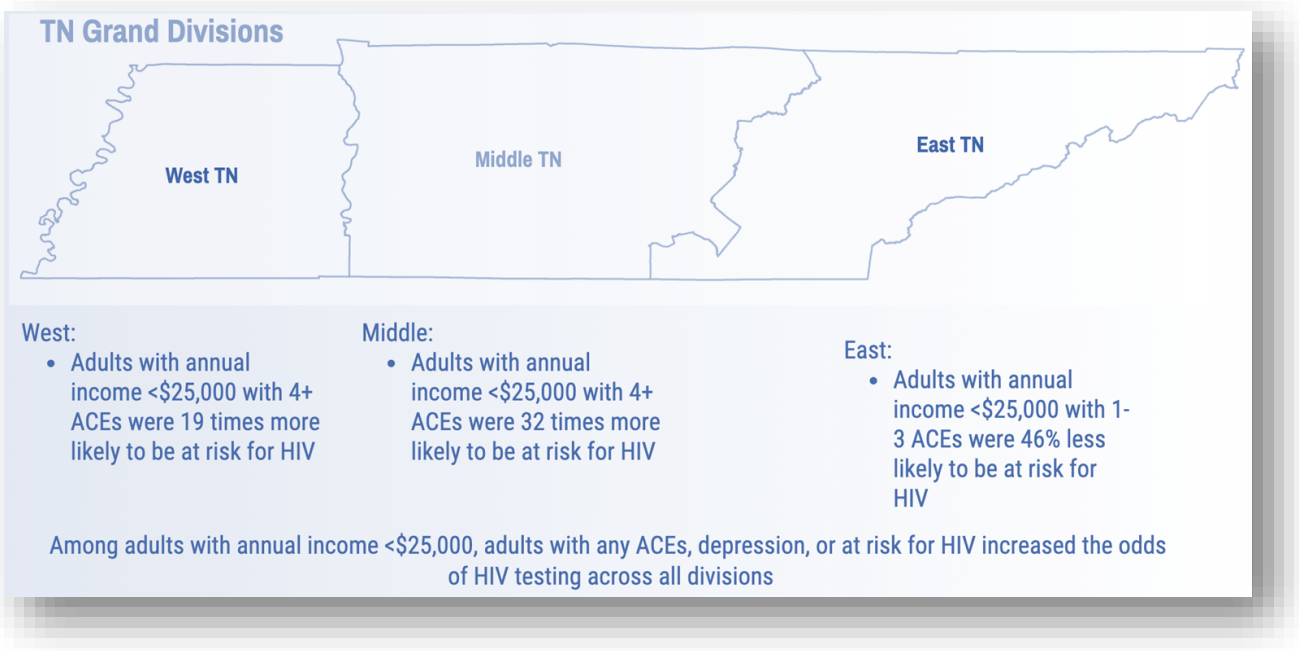

Figure 2.2. Summarized findings for Research Aim 2

Because ACEs and depression were not included in the same model due to interaction, qualitative research would be beneficial to better understand the link between adults in TN, specific to grand division, who live with depression, have an annual income of <$25,000, and are at risk for or had ever tested for HIV. This kind of study will aid medical and public health professionals in developing tailored resources to ensure regional disparities are diminished. Furthermore, depression, mental health, and ACE related questions were deemed to be relevant among PLWH who provided opinions on the development of a culturally appropriate survey at the local COE. Therefore, mental health is expected to play a significant role in the HCC, however future studies are paramount in exploring where in the HCC it has the most impact.

It is worth noting that the significant relationship between ACEs, risk for HIV and ever tested for HIV may be due to educational campaigns targeting high risk groups more than educating the general population of adults living in TN. Risk perceptions of HIV are important to

gauge for next steps in different regions to again aid practitioners in understanding where best to allocate resources aimed at preventing the spread of HIV.

Research Aim 3

Among adults living with HIV, engagement and retention in HIV care are a vital component of the HCC with the goal of achieving viral suppression. One such barrier previous research uncovered was medical mistrust interfering with not only HIV care but also receiving mental health care due to stigma and discrimination (Elliott et al., 2015; Owens et al., 2007; Relf et al., 2019). Qualitative interviews from the present study regarding stigma and discrimination questions determined several participants thought it was an important topic and related to their personal experiences, but not relevant specifically to their care at the local COE. Participants instead expressed that their providers should know about structural barriers related to transportation, living conditions (such as homelessness or domestic violence), and access to medical care even when life events (such as taking care of an elderly family member) interfered with their care.

Some participants indicated that families were supportive by not talking about their HIV care or know of some individuals who no longer communicate with family that shut them out because of their HIV status. Thus, having a clinic facilitated support group may be beneficial to those without an accepting and loving environment external to the COE would help improve their quality of life. This finding is similar to a study conducted by Earnshaw et al which found having instrumental social support (such as transportation assistance to a doctor appointment) and a perceived community support system were helpful in reducing HIV physical symptoms and stress levels (Earnshaw, Lang, Lippitt, Jin, & Chaudoir, 2014). Having access to social support or counseling services were also noted throughout nearly all interviews indicating having

a sense of community may help improve quality of life. Thus, having a Community Based Organization (CBO) that facilitates healthy support groups within the community, specifically at the local COE, may be a significant resource among PLWH with improving health and well-being, even if familial support is lacking. Therefore, another area for future research would be to examine the role family dynamics have in quality of life among PLWH to understand the impact on HIV retention in care and mental health.

With the goal of the survey aimed at improving PLWH adherence to HIV care, participants suggested including questions that would make receiving HIV care easier. Thus, in the case there were things going on in a PLWH's life that interfered with care, clinic resources may be able to be tailored to assist in improving care for that specific patient. Moreover, information provided in the survey by PLWH receiving care at the clinic may be able to predict those at high risk for falling out of care in the future. However, piloting of the survey must be done first with subsequent efforts to validate and test for predictive modeling capabilities.

Several participants reported staying engaged in care and in part this was due to medication refill reminders from the local COE. However, current depression and mental health were mentioned by a few participants to interfere with adherence. Despite this, all participants agreed that adherence was necessary if they wanted to live a longer life. Majority did not feel that ACEs had an impact on their HIV care currently, but rather had an impact in another way, such as depression or substance abuse. Thus, ACEs were still considered to be important questions to ask due to the nature of potential effects on quality of life into adulthood. ACEs are still able to be characterized at the COE to compare with CDC BRFSS's ACE module, however wording of the questions were modified to be less triggering and yet still allow providers at the COE a way to note what potential services may be needed for that specific patient.

Conclusion

Adults living in TN are not close to achieving the 90-90-90 goal according to the BRFSS self-reported responses and the HCC data shown in Chapter 1 provided by the TDH. HIV risk and HIV testing in TN among adults 18 and did not change between 2016 and 2017 compared to 2018 with the proportion of adults who had ever tested for HIV remaining unchanged at 37% and the proportion of adults at risk for HIV increasing by nearly 1%. Results further demonstrate that regional differences will require tailored interventions to include increased awareness, decreased stigma, and improved access to HIV testing and treatment sites throughout all of TN.

Stigma still remains a reported barrier along the HCC in TN (Plan, 2016; TDH, 2019). While this dissertation was being written, sexual minority groups, who have been disproportionately affected by HIV, are now protected against stigma and discrimination in employment as of June 15, 2020 through Supreme Court ruling (Supreme Court of the United States, 2020). This change in policy going into effect in 2020 still does not change the perceived stigma and discrimination among LGBT or PLWH from their communities throughout TN. To better understand the degree to which stigma and discrimination impact the HCC, further studies are necessary to determine how to mitigate this issue through appropriate interventions and community awareness campaigns.

In relation to life traumas, the effect of ACEs into adulthood, specifically as it pertains to HIV, requires further research. Nevertheless, findings from this dissertation suggest childhood trauma is associated with being at risk for HIV, ever tested for HIV, staying retained in HIV care, and depending on the individual, can affect adherence to achieve virologic suppression. Future research should include piloting the final survey at the local COE and then at other COEs in TN to gain insight into barriers and facilitators to HIV care among PLWH. With respect to

sexual minority groups at risk for HIV, longitudinal studies should be pursued to follow individuals over time to assess risk and uptake of local resources in the community, specifically TDH CBOs. Finally, the present research is limited in discussing linkage to care and virologic suppression due to lack of available data sources with the correlates aforementioned. Because this dissertation could not study all factors related to the HCC based on available data sources with the predictors of interest, future TN HCC surveillance sources should attempt to collect data on all factors related to the HCC as well as HIV risk to aid in discovering how best to prevent the spread of HIV in TN.

In conclusion, future research is warranted to understand the correlations uncovered in this dissertation since a multifaceted approach to improving access to and uptake of resources for the TN HCC. Surveillance questions should be modified to be less triggering, more open-ended, and geared more towards examining all factors related to the HCC in a public surveillance source. Moreover, to combat HCC, tailoring of interventions by TN region are necessary since disparities existed among those at risk, sexual minority groups, those with low-income, and PLWH. Overall, findings from this dissertation build upon previous research and provide information for future steps to assist TN in achieving the 90-90-90 goal as well as improve life quality among PLWH.

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APPENDIX: Final Survey for Research Aim 3

Title of Survey: Improving HIV Quality of Care Assessment Tool

Instructions

The current survey is being piloted for the first time here at the Center of Excellence.

The clinic providers and staff would like to be aware of what challenges you face in your home environment and have faced in your life with the goal of providing you with the best possible quality care for your treatment related to HIV.

All answers obtained will be anonymous and will not linked back to you, so please answer honestly.

At the end of the survey, you will be asked to provide your opinion for what you thought about the questions as well as how your providers and clinic staff being aware of this kind of information could best serve you.

Thank you for your time and participation in this survey.

Section I: Adverse Childhood Experiences (ACEs)

These questions are about childhood abuse and household dysfunction that occurred before the age of 18.

Reminder: <u>You are being asked to answer these questions anonymously. Please answer honestly.</u>

1. Growing up, before the age of 18, did your parents/guardians understand your problems and worries?

- o Always
- o Most of the time
- o Sometimes
- o Rarely → Q1a. If you marked rarely, would you like to explain? _____
- o Not applicable
- o Prefer not to answer

2. Growing up, before the age of 18, did your parents/guardians really know what you were doing with your free time when you were not at school or work?

- ○ Always
- ○ Most of the time
- ○ Sometimes
- ○ Rarely → Q2a. If you marked rarely, would you like to explain? _____
- ○ Not applicable
- ○ Prefer not to answer

3. Growing up, before the age of 18, did your parents ever neglect you?

- ○ Yes → Q3a. If you answered yes, would you like to explain? _____
- ○ No
- ○ Not applicable
- ○ Prefer not to answer

4. Growing up, before the age of 18, did you live with anyone who had mental health issues (for example, depression, was suicidal, other)?

- ○ Yes → Q4a. If you answered yes, would you like to explain? _____
- ○ No
- ○ Not applicable
- ○ Prefer not to answer

5.

Growing up, before the age of 18, did you live with a household member who was:				
	Yes	No	Not applicable	Prefer not to answer
A problem drinker	○	○	○	○
Misused street drugs	○	○	○	○
Misused prescription drugs	○	○	○	○
5a. If you answered yes to any of these, would you like to explain? _____				

6. Growing up, before the age of 18, did you live with a household member who was ever in jail, prison or a correctional facility?

- ○ Yes → Q6a. If you answered yes, would you like to explain? _____
- ○ No
- ○ Not applicable
- ○ Prefer not to answer

7. Growing up, before the age of 18, did an important family member pass away?

- Yes → Q7a. If you answered yes, would you like to explain? _____
- No
- Not applicable
- Prefer not to answer

8. Growing up, before the age of 18, what kind of household did you grow up in (for example: lived with grandparents, lived with parents of the same gender, parents were separated or divorced but still lived together, single parent household)?

_____

9. Growing up before the age of 18, did you see or hear a parent/guardian in your home being physically (hit or cut), verbally (yelled or screamed at), emotionally or mentally abused?

- Many times
- A few times
- Once

→ Q9a. If you answered many times, a few times, or once, would you like to explain? _____

- Never
- Not applicable
- Prefer not to answer

10. Growing up before the age of 18, were you ever physically (hit or cut), verbally (yelled or screamed at), emotionally or mentally abused by a parent/guardian?

- Many times
- A few times
- Once

→ Q10a. If you answered many times, a few times, or once, would you like to explain? _____

- Never
- Not applicable
- Prefer not to answer

11.

Growing up, before the age of 18, how often did a parent, guardian or other household member:						
	Many times	A few times	Once	Never	Not applicable	Prefer not to answer
Threaten to abandon you	○		○	○	○	○
Threaten to throw you out of the house	○	○	○	○	○	○
Actually abandon you	○	○	○	○	○	○
Actually throw you out of the house	○	○	○	○	○	○

12. Growing up, before the age of 18, were you ever sexually abused/molested?

- ○ Many times
- ○ A few times
- ○ Once
- ○ Never
- ○ Not applicable
- ○ Prefer not to answer

→ Q12a. If you answered many times, a few times, or once, would you like to explain?

_____

13. Growing up, before the age of 18, were you bullied?

- ○ Yes → Q13a. How were you bullied most often?
  - ○ I was hit, kicked, pushed, shoved around, or locked indoors
  - ○ I was made fun of because of my race, nationality or colour
  - ○ I was made fun of because of my religion
  - ○ I was made fun of with sexual jokes, comments, or gestures
  - ○ I was left out of activities on purpose or completely ignored
  - ○ I was made fun of because of how my body or face looked
  - ○ I was cyber bullied
  - ○ Other _____
  - ○ Prefer not to answer
- ○ No
- ○ Not applicable
- ○ Prefer not to answer

14. Growing up, before the age of 18, how often were you in a physical fight?

- Many times
- A few times
- Once

→ Q14a. If you answered many times, a few times, or once, would you like to explain? _____

- Never
- Not applicable
- Prefer not to answer

15. Growing up, before the age of 18, did you ever witness community violence (for example: see or hear someone being beaten up, stabbed or shot, or threatened with a gun or knife)?

- Yes → Q15a. If you answered yes, would you like to explain? _____
- No
- Not applicable
- Prefer not to answer

16. Growing up, before the age of 18, were you forced to go and live in another place due to collective violence (examples include wars, terrorism, political or ethnic conflicts, genocide, repression, disappearances, torture and organized violent crime such as banditry and gang violence)?

- Yes → Q16a. If you answered yes, would you like to explain? _____
- No
- Not applicable
- Prefer not to answer

17. Growing up, before the age of 18, were you beaten up, or was a family member or friend beaten up or killed, by police or gangs?

- Yes → Q17a. If you answered yes, would you like to explain? _____
- No
- Not applicable
- Prefer not to answer

18. Of the previous adverse childhood experiences, do any you have personally experienced still affect you today?

- Yes → Q18a. If you answered yes, would you like to explain? _____
- No
- Not applicable
- Prefer not to answer

End of section I.

Section II: Mental Health

These questions are about your mental health.

Reminder: <u>You are being asked to answer these questions anonymously. Please answer honestly.</u>

19. During the <u>past 12 months</u>, has depression or mental health problems made it difficult for you to get HIV care?

- Yes → Q19a. If you answered yes, have you received counselling?
  - Yes
  - No
  - Not applicable
  - Prefer not to answer
- No
- Not applicable
- Prefer not to answer

Q19b. (If answer to Q19a is no) Would you like counselling?

- Yes
- No

20. Do you feel you have a good social support team outside of the clinic to be there for you?

- Yes
- No → Q20a. If you answered no, would you like to have a social support team outside of the clinic?
  - Yes
  - No
  - Not applicable
  - Prefer not to answer
- Prefer not to answer

Q20b. (If answer to Q20a is no), would you like information for social support groups in the area?

- Yes
- No

End of section II.

Section III: Stigma & Discrimination

These questions are experiencing stigma and/or discrimination.

"*HIV stigma* is negative attitudes and beliefs about people living with **HIV**. It is the prejudice that comes with labeling an individual as part **of** a group that is believed to be socially unacceptable. *HIV discrimination* refers to the unfair and unjust treatment of someone based on their real or perceived HIV status. Discrimination can also affect family and friends, and those who care for people with HIV. HIV discrimination is often fueled by myths of casual transmission of HIV and pre-existing biases against certain groups, certain sexual behaviors, drug use, and fear of illness and death. Discrimination can be institutionalized through laws, policies, and practices." (Source: Centers for Disease Control and Prevention)

Reminder: You are being asked to answer these questions anonymously. Please answer honestly.

21. Have you experienced stigma or discrimination due to your HIV or AIDS diagnosis?
    - Yes → Q21a. If you answered yes, would you like to explain (where it occurred)? _____
    - No
    - Not applicable
    - Prefer not to answer

End of section III.

Section IV: Attitudes, Knowledge, and Beliefs about HIV or AIDS

These questions are about your attitude, knowledge, and beliefs about HIV or AIDS.

Reminder: You are being asked to answer these questions anonymously. Please answer honestly.

22. Do you believe hook-up applications (Example, Grindr) that can be downloaded on a computer or personal electronic device (such as a smart phone or tablet) are a risk factor for HIV?
    - Yes
    - No
    - Don't know
    - Prefer not to answer

23. To your knowledge, are you aware of the differences between having a HIV infection compared to having an AIDS diagnosis?

- Yes
- No
- Don't know
- Prefer not to answer

24. Do you believe a person who is infected with HIV can look and feel well and healthy?

- Yes
- No
- Don't know
- Prefer not to answer

25. Are you aware that if you have an undetectable viral load, you will not be able to transmit HIV?

- Yes
- No
- Don't know
- Prefer not to answer

→ U=U, Undetectable=Untransmittable! You can live without the fear of transmitting HIV to someone if you know you have an undetectable viral load (Source: UNAIDS).

26. After being diagnosed with HIV, do you believe that taking your HIV treatment regimen lengthens and improves your quality of life?

- Yes
- No
- Don't know
- Prefer not to answer

End of section IV.

Section V: Risk Behaviors related to HIV

These questions are about your experiences of risk behaviors related to HIV.

Reminder: You are being asked to answer these questions anonymously. Please answer honestly.

Please tell me if any of the situations apply to you. You do not need to tell me which one.

- You have injected any drug other than those prescribed for you in the past year.
- You have been treated for a sexually transmitted disease (STD) in the past year.
- You have given or received money or drugs in exchange for sex in the past year.
- You had anal sex without a condom in the past year.
- You had four or more sex partners in the past year.

27. Do any of these situations apply to you?

- ○ Yes → Q27a. If you answered yes, check all that apply
- ○ No
- ○ Not applicable
- ○ Prefer not to answer

You have injected any drug other than those prescribed for you in the past year.	○
You have been treated for a sexually transmitted disease (STD) in the past year.	○
You have given or received money or drugs in exchange for sex in the past year.	○
You had anal sex without a condom in the past year.	○
You had four or more sex partners in the past year.	○

28. Do you know of any street drugs/substances abused in the Appalachian region providers here should know about to inform patients of interactions with HIV treatment regimen (for example, Viagra and poppers; moonshine; cocaine; methamphetamine; opioids)?

- ○ _____
- ○ Don't know

29. On average, during the <u>past 6 months</u>, how much alcohol (wine and/or liquor) did you have on one occasion?

- ○ I do not drink alcohol
- ○ 1
- ○ 2-3
- ○ 4
- ○ 5 or more
- ○ Other _____
- ○ Prefer not to answer

→ Q29a. How often do you consume alcohol (for example, daily, monthly, etc.)? _____

30. Do you have a history of abusing drugs/alcohol [for example: injection drug use, binge drinking (4 or more drinks on one occasion), popping/crushing/inhaling/snorting pills)?

- ○ Yes → Q30a. If yes, do you currently abuse drugs/alcohol?
  - ○ Yes
  - ○ No
  - ○ Prefer not to answer
- ○ No
- ○ Prefer not to answer

Q30c. Have you ever gone to a treatment program for substance misuse (drug or alcohol)?

- ○ Yes → Q30d. If yes, are you currently in a treatment program specifically related to substance misuse?
  - ○ Yes
  - ○ No
  - ○ Prefer not to answer
- ○ No
- ○ Prefer not to answer

End of section V.

Section VI: Adherence

Adherence to treatment is a key part of staying healthy with HIV.

These questions are about your adherence to HIV care:

- Starting HIV treatment
- Keeping all medical appointments
- Taking HIV medicines every day and exactly as prescribed (also called medication adherence)

(Source: National Institutes of Health)

Reminder: You are being asked to answer these questions anonymously. Please answer honestly.

31. On a scale of 1 to 7 how motivated are you to adhere to your HIV treatment for the benefit of your health **currently** (1 being unmotivated and 7 being motivated)? Circle the number that best describes your motivation level.

Unmotivated -1-----2-----3-----4-----5-----6-----7-Motivated

Q31a. Would you like to explain? _____

32. Have you decided to take a drug vacation?

- ○ Yes → Q32a. If yes, why? _____

- No
- Prefer not to answer

33. Do you ever spend money on substances (for example, street drugs/alcohol) instead of HIV care?
- Sometimes
- Often
- Rarely
- Never
- Prefer not to answer

34. Was your viral load detectable at your last office visit?
- Yes
- No
- Don't know
- Prefer not to answer

35. In the past 30 days, did you miss doses of your HIV medicines?
- Yes → Q35a. How many doses?
  Q35b. Why? _____
- No
- Prefer not to answer

End of section VI.

Section VII: Barriers to HIV care

This section is about barriers to your HIV care.

Reminder: <u>You are being asked to answer these questions anonymously. Please answer honestly.</u>

36. During the <u>past 6 months</u>, have you been homeless?
- Yes
- No
- Prefer not to answer

37. During the <u>past 6 months</u>, were you been imprisoned?
- Yes → Q37a. If yes, did it interfere with your HIV treatment regimen?
  - Yes
  - No
- No
- Prefer not to answer

38. During the <u>past 6 months</u>, were you been hospitalized?
- Yes → Q38a. If yes, did it interfere with your HIV treatment regimen?
  - Yes
  - No

- No
- Prefer not to answer

39. During the <u>past 6 months</u>, have problems with money or health insurance made it difficult for you to get HIV care?
- Yes
- No
- Prefer not to answer

40. Do you consider travel time to be a barrier to HIV care?
- Yes → Q40a. If yes, did you get transportation assistance (for example bus or gas card for gas money)?

  Q40b. If response to Qa1 was no, do you need transportation assistance (for example bus or gas card for gas money)? _____

  Q40c. What is the distance in miles you travelled to receive care?
  - _____
  - Don't know
- No
- Prefer not to answer

41. Are there things going on in your life you would like your provider to know that make it difficult to attend appointments for HIV care?
- Yes → Q41a. If yes, what challenges specifically get in the way of attending appointments? _____
- No
- Prefer not to answer

42. Are there things going on in your life you would like your provider to know that make it difficult to take your HIV medication as prescribed?
- Yes → Q42a. If yes, what challenges specifically get in the way of taking your medication as prescribed? _____

  Q42b. Is there anything the clinic can help with to get what you need? _____
- No
- Prefer not to answer

End of section VII.

Section VIII: Domestic violence

This section is about domestic violence as it relates to your experiences.

Domestic assault in Tennessee is when it's committed against someone who is a:

- Current or former spouse;
- Cohabitant;
- Dating or sexual partner;
- Blood or adoptive relative;
- Current or former relative by marriage; or
- Adult or minor child of any of the above individuals.

Source: Tennessee Domestic Violence Laws

Reminder: You are being asked to answer these questions anonymously. Please answer honestly.

43. Have you been physically and/or sexually abused recently (for example, by your spouse, partner, or someone you live with)?

- ○ Yes → Q43a. If you answered yes, did you receive domestic violence services? _____

  Q43b. If you answered yes, are you safe now/out of the abusive relationship? _____

  Q43c. If you answered no, are you aware of safe houses/resources in the area you reside? _____
- ○ No
- ○ Not applicable
- ○ Prefer not to answer

End of section VIII.

Section IX: Demographic Information

This section asks you about your demographic information.

Reminder: You are being asked to answer these questions anonymously. Please answer honestly.

44. How old are you(years)? _____

45. What was your sex at birth?
    - Male
    - Female
    - Intersex/ambiguous

46. Do you consider yourself to be:
    - Male
    - Female
    - Transgender
    - I identify as _____

47. Do you think of yourself as:
    - Lesbian or gay
    - Straight, heterosexual
    - Bisexual
    - I identify as _____

48. What is your race/ethnicity?
    - White/Caucasian
    - Black/African American
    - Hispanic/Latino(a)
    - Other _____
    - Prefer not to answer

49. What is the highest level of education you have completed?
    - Never attended school
    - Grades 1 through 8
    - Grades 9 through 11
    - Grade 12 or GED
    - Some college, associate degree, or technical degree
    - Bachelor's degree
    - Any post-graduate studies
    - Don't know
    - Prefer not to answer

50. Which of the following describes your employment status over the last 12 months (check all that apply)?

- o Government employee
- o Non-government employee
- o Self-employed
- o Non-paid
- o Student
- o Homemaker
- o Retired
- o Unemployed (able to work)
- o Unemployed (unable to work)
- o On disability
- o Other _____

51. What is your current legal marriage status?

- o Married
- o In a civil union or domestic partnership
- o Cohabitating
- o Divorced
- o Widowed
- o Separated
- o Single
- o Never married

52. Is spirituality and/or religion important to you?

- o Very important
- o Somewhat important
- o Not very important
- o Not important at all
- o Not applicable

→ Q52a. Would you like to explain how you practice? _____

53. What is your monthly or annual income?
- $0 to $416 per month of $0 to $4,999 per year
- $417 to $749 per month or $5,000 to $8,999 per year
- $750 to $916 per month or $9,000 to $10,999 per year
- $917 to $1,083 per month or $11,000 to $12,999 per year
- $1,084 to $1,249 per month or $13,000 to $14,999 per year
- $1,250 to $1,416 per month or $15,000 to $16,999 per year
- $1,417 to $1,666 per month or $17,000 to $19,999 per year
- $1,667 to $2,083 per month or $20,000 to $24,999 per year
- $2,084 to $2,499 per month or $25,000 to $29,999 per year
- $2,500 to $3,333 per month or $30,000 to $39,999 per year
- $3,334 to $4,166 per month or $40,000 to $49,999 per year
- $4,167 to $6,249 per month or $50,000 to $74,999 per year
- $6,250 or more per month or $75,000 or more per year
- Prefer to write in response _____

54. Do you consider yourself to live in the following:
- City
- County

55. What is the length of time you have known you were HIV positive? _____ years

End of section IX.

Comments are encouraged regarding the questions asked, relevance of questions in the survey, and considerations you have for using this survey at the clinic (when it should be administered and how a multidisciplinary team could utilize it):

_____

_____

_____

_____

VITA

ELAINE LOUDERMILK

Education:	Dr.P.H., Epidemiology, East Tennessee State University, Johnson City, Tennessee, 2020
	M.P.H., Epidemiology, East Tennessee State University, Johnson City, Tennessee, 2017
	B.S., Health Sciences, Microbiology, East Tennessee State University, Johnson City, Tennessee, 2015
	Biochemistry Major, Pre-medicine, Tennessee Technological University, Cookeville, Tennessee, 2011-2012
	Brentwood High School, Brentwood, Tennessee, 2011
Professional Experience:	Graduate Research Assistant, Department of Biostatistics & Epidemiology, College of Public Health, East Tennessee State University, 2017-2020
	Graduate Assistant, Sherrod Library, East Tennessee State University, 2015-2017
Publications:	Loudermilk E, Loudermilk K, Obenauer J, Quinn M. "Impact of Adverse Childhood Experiences (ACEs) on Adult Alcohol Consumption Behaviors. (2018). Child Abuse and Neglect. pp. 368-374.
	Quinn M, Caldara G, Collins K, Owens H, Ozodiegwu I, Loudermilk E, Stinson J. (2017). "Methods for

Understanding Childhood Trauma: Modifying the Adverse Childhood Experiences International Questionnaire for Cultural Competency." International Journal of Public Health. pp. 149-151.

Honors and Awards:

Thesis and Dissertation Scholarship, East Tennessee State University, 2020

Dr. T. J. Wu Memorial Student Research Award, College of Public Health, East Tennessee State University, 2020

Outstanding DrPH Student Award, Department of Biostatistics & Epidemiology, East Tennessee State University, 2020

Chair's Award for Scholarship, Department of Biostatistics & Epidemiology, East Tennessee State University, 2019

Outstanding DrPH Student Award, Department of Biostatistics & Epidemiology, East Tennessee State University, 2019

Certificate of Recognition for service to students and faculty by students in the College of Public Health and Department of Biostatistics & Epidemiology, College of Public Health Student Council, East Tennessee State University, 2018

General Chemistry Scholarship, Tennessee Technological University, 2012