

BARRIERS TO HIV/AIDS CARE IN RURAL-SPECIFIC AREAS OF PENNSYLVANIA

by

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ABSTRACT

Medical advancement in the field of HIV/AIDS related care has resulted in what used to be an epidemic with a “death sentence” to an incurable disease that is manageable with proper medical and psychosocial attention. Although deemed amendable with various prevention and treatment strategies being in full swing, HIV/AIDS diagnoses still remain stable and consistent. The highest proportion of HIV/AIDS diagnoses are reported in urban areas of the United States, which often shifts the focus away from rural communities. However, a surge in rural diagnoses requires professional attention and new research to assist in understanding and alleviating stressors specific to HIV/AIDS related care in new targeted zones. Individuals with HIV/AIDS who reside in rural areas continue to be an underserved and forgotten population. There are characteristics specific to rural areas that can become barriers and challenges to providing HIV/AIDS related care and prevention. Specific characteristics can be social, medical, environmental, economic, and/or a combination of these variables. This study identifies and researches rural characteristics that create current barriers for rural individuals living with HIV/AIDS. It then utilizes the information to develop a survey able to be utilized by HIV/AIDS service professionals to effectively tailor interventions to address both rural and urban needs.

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The Author,

Grace Morgan Edwards

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CHAPTER 1 INTRODUCTION

HIV/AIDS in Rural America

Although medical advancement in testing and treatment have been made since the first reported cases of HIV/AIDS in the United States (US) in 1981, new HIV diagnoses in the US have remained steady throughout the past decade. (McKinney, 2002; CDC, 2019; Frew et. al, 2016) Once considered a death sentence, HIV/AIDS has since transitioned into a manageable condition. (Cohn et. al, 2001; McKinney, 2002) Due to this transition, the scope of the infection has drastically changed. Originally thought to be exclusive to the men who have sex with men (MSM) population (Frew et. al, 2016), current HIV/AIDS infection rates have increased through other routes of infection. While sexual contact (MSM and heterosexual) remains the number one cause of infection for this condition, shared needles through intravenous drug use is second and infection from mother to newborn through birth is third. (Contie et. al, 2015)

According to 2017 Centers for Disease Control and Prevention (CDC) reports, an estimated 1.1 million US citizens are currently living with HIV. Approximately 15% of these individuals are oblivious to their diagnosis. (CDC, 2017) HIV infections are unequally dispersed throughout the US, the South being disproportionately affected. In fact, the highest prevalence of HIV/AIDS in the United States is in the South. (HIV.org, 2019; Kerr et. al, 2014; NHRA, 2014;) Over half (52%) of new HIV diagnoses in the US in 2017 were made in the South alone. (HIV.org, 2019) This is particularly concerning due to the South being predominantly rural, as opposed to urban. (NHRA, 2014)

Due to the chronic and persistent nature of HIV/AIDS, in order to appropriately manage the infection, it is essential for individuals to engage in consistent and comprehensive care. (Gallant et. al, 2011; Cohn et. al, 2001; Masiano, 2019) Consistent and comprehensive care (See Figure 1) (henceforth HIV/AIDS related care) includes frequent medical treatment, medication adherence, case management, prevention, education, and social service coordination and/or connection. (Gallant et. al, 2011) Engagement and retention in HIV/AIDS related care is an integral part of achieving viral suppression, longer and healthier lives for those diagnosed, and prevention of disease transmission. (Gallant et. al, 2011; Cohn et. al, 2001)

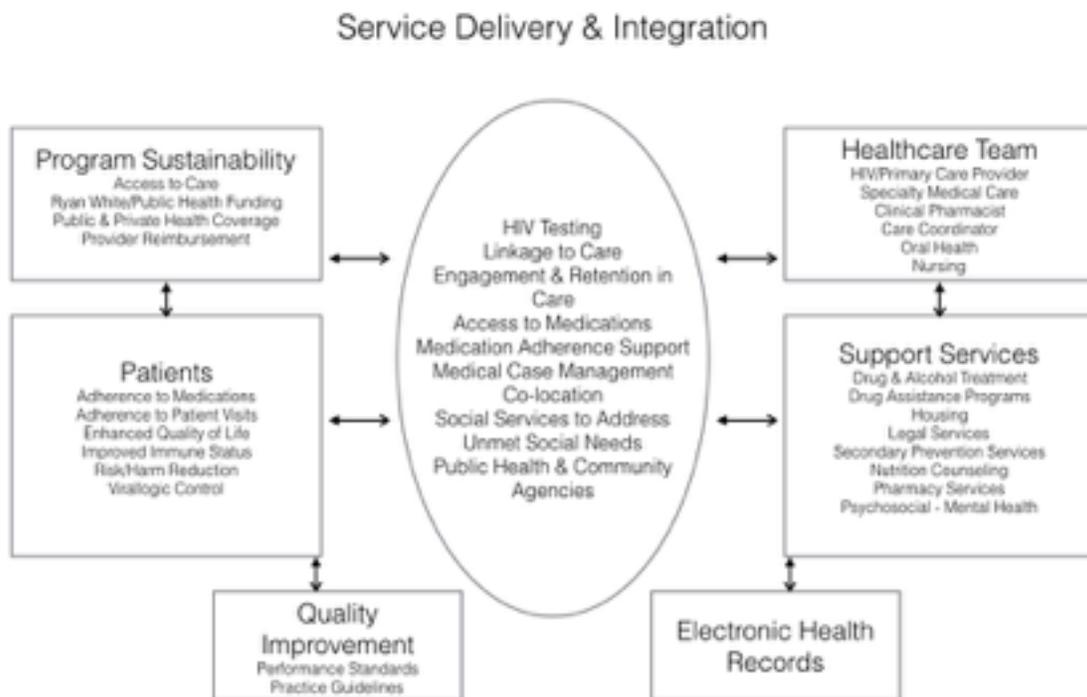


Figure 1 : Critical features of HIV comprehensive care, as adapted from *Gallant et. al, 2011*.

CHAPTER 2

Literature Review

Of individuals who were HIV positive in 2015, 63% received some HIV/AIDS related care, 49% retained in care, and 51% achieved viral suppression. (CDC, 2019) These numbers are suboptimal to achieve national standards. (CDC, 2015) Unfortunately, there are many areas within the US that do not have access to quality, extensive care to manage their diagnoses. (Gallant et. al, 2011; CDC, 2015) This is particularly true for rural areas. (Cohn et. al, 2001; Masiano, 2019) Social, environmental, economic, or a combination of these characteristics can produce barriers that interfere with HIV/AIDS related treatment and prevention for individuals who reside in rural America. Examples of these characteristics include poverty, stigma, and long distances to specialized care. (Frew et. al, 2016; NRHA, 2014; Heckman et. al, 2004;)

In order to be congruent with the national standards to mitigate the HIV epidemic and to address the complexities of the multiorgan system infection, professionals in many disciplines must work collectively to progress with these goals and to meet the physical and psychosocial needs of PLWH/A. (CDC, 2015; Gallant et. al, 2011) To accomplish this, it is vital that every region and community within the US has access to HIV/AIDS related care and other prevention efforts. Some of these services are just now reaching certain areas of the country, while others, such as antiretroviral therapy, are underutilized. (CDC, 2015)

While urban areas continue to report the highest rates of HIV/AIDS prevalence (CDC, 2019; NRHA, 2014), it is important to note that surveillance data reporting estimates of the geographic distribution of HIV/AIDS diagnoses can be deceptive. HIV/AIDS diagnoses are reported at the time of diagnosis by place of residence. Therefore, if large quantities of HIV/

AIDS positive individuals have relocated post-diagnosis, this can interfere with truly accurate data. (McKinney, 2002) Individuals who have been diagnosed with HIV/AIDS are moving from urban to rural areas in greater quantities and rising numbers of new diagnoses are responsible for higher prevalence rates in rural America. (Heckmen et. al, 2004; Cohn et. all, 2001; Varni, Miller, and Solomon 2012) In addition to this, increased survival rates and more positive prognoses due to medical advancement, such as antiretroviral therapy, (Heckmen et. all, 2004; McKinney, 2002, Durvsala and Miller, 2014; NHRA, 2014; Gallant et. al, 2011) further cements a need for the exploration of rural implications regarding HIV/AIDS-related care. A surge of HIV Diagnoses in rural Indiana in 2015 is a perfect example of the urgency to continue striving for vigilance regarding prevention, care, and screening for rural America. (“Community Outbreak”, 2015) If left unaddressed, HIV/AIDS in rural America can remain an invisible epidemic.

The purpose of this research article is to assist in bringing awareness to a buried population, aim to provide increased awareness for HIV/AIDS related care providers, attempt to bridge the gap in research for rural communities, and act in accordance with the goals of the Centers for Disease Control (CDC).

“The CDC strives to provide the evidence, guidance, and resources needed to shift the course of the HIV epidemic. Our nations success, however, depends on the actions of health departments, CBOs, and healthcare providers nationwide.” (CDC, 2015, pg. 10)

The available literature paints a partial picture of the current state of HIV/AIDS care in rural America. That is because of a lack of published research, but also because of the rapid state

of change in the epidemic, funding requirements, and cultural issues. What is needed is a contemporary snapshot of challenges currently being faced by HIV/AIDS service providers in rural areas. This study attempts to bridge that gap by creating an instrument that can be used by HIV/AIDS service providers to assess current needs in the field.

In order to accomplish this goal, the author starts with a systematic literature review of articles containing information on HIV/AIDS related care in rural communities. The author then moves to semi-structured interviews of professionals actively serving PLWH/A in rural areas of northwest Pennsylvania.

CHAPTER 3

Theoretical Orientation and Methods

Theoretical Orientation

Utilizing Bronfenbrenner's ecological model provides a solid framework for the examination of rural implications for HIV/AIDS related care on a multi-systematic level. By applying this model (Figure 2), the individual behavior and the encompassing ecological, environmental, and systematic influences can be seen. This model can assist interested parties in developing a further understanding by providing appropriate contextual framework.

On an individual level, influences such as beliefs, feelings, perceptions, and attitudes are included in risk factors for the contraction of HIV. Examples of this include risk-taking behavior and disease awareness. The next level consists of the microsystem. Within the microsystem, interpersonal dynamics are stressed. Interpersonal dynamics are considered to have a substantial effect on a person's decision-making regarding their health. Personal relationships are an example of this system. A person is often affiliated with multiple microsystems. The mesosystem is the third level. It is comprised of the connections/interactions between several microsystems. This can include Intimate Partner Violence (IPV), community social support, and sex exchange. The fourth level is the exosystem. The exosystem represents influences that are beyond a person's control, such as poverty and discrimination (sexual orientation/racial/etc). The final level is the macrosystem. This encompasses the external system. It includes policies, laws, and regulations that are a major determinant of cultural and social norms and therefore, can persuade behavior.

By applying Brofenbrenner's ecological model, a deeper understanding can be made of a rural areas specific characteristics that can directly impact HIV contraction risks, prevention, diagnosis, and treatment. It assists in identifying differences for rural populations and can open a discussion for how to tailor modalities to address these needs.

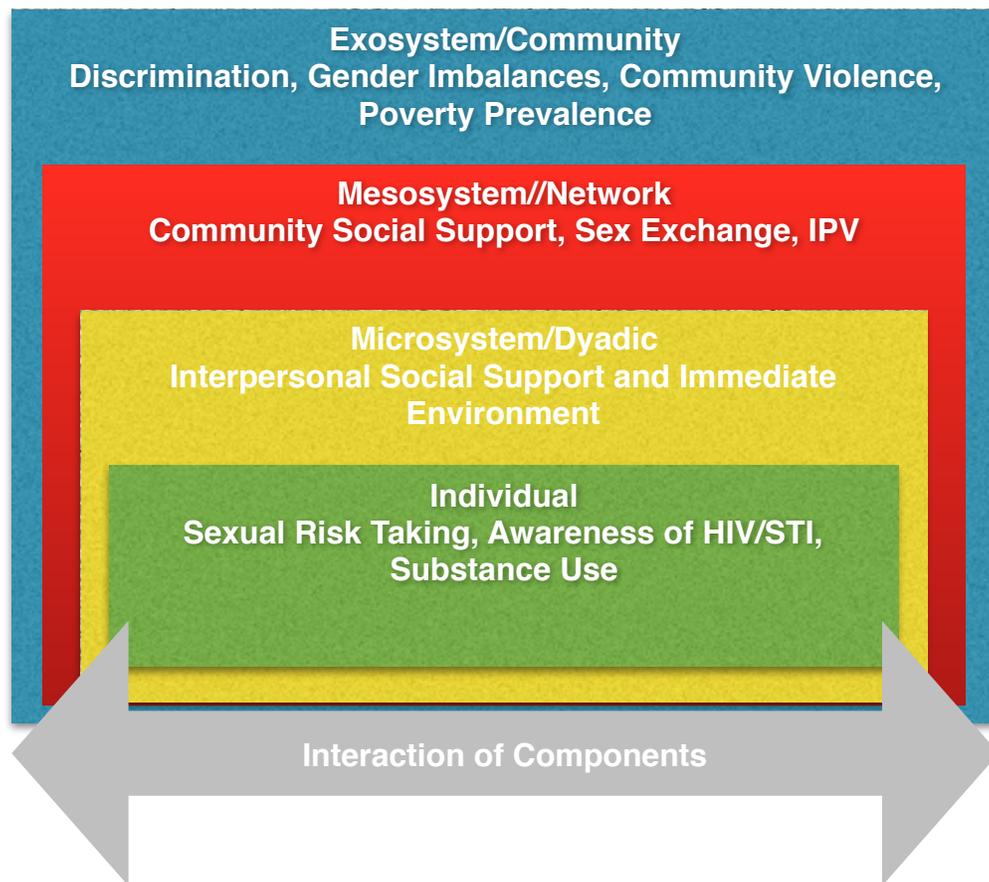


Figure 2 describes the application of Brofenbrenner's ecological model, as adapted from *Frew. et al, 2016*.

Methods

A systematic literature review of 157 studies, published in the year 2000 or later, was conducted. Articles were searched for through July 20th, 2019 in various electronic databases. To find applicable articles and publications, this author searched EBSCOHOST, as well as relevant and reliable internet websites (i.e. CDC, NIH, HIV.gov), to compile the most current and accurate research regarding HIV/AIDS related care in rural areas. Studies and statistics containing the key words, or a combination of the key words: *united states, rural, barriers, HIV, AIDS, barriers to care, and access to care* were considered. Any studies or statistics conducted outside of the US were not included. Studies reporting both urban and rural data were only used if the data was differentiated separately into urban data and rural data. Non-English studies were eliminated, in addition to studies not published as scholarly journals.

The electronic and advanced search revealed 157 possible articles (See Figure 3). Abstracts were read to detect qualification based on the aforementioned criteria: (a) administered in the United States, (b) discussed barriers and/or access to care, (c) regarded PLWHA, (d) addressed rural populations, (e) were published in the year 2000 or later. Due to variations in the definitions of rural for each study, it was determined that any study that reported rural-only sample (as defined by the study authors) would meet the qualifications for inclusion.

Of the original 157 possible articles, 46 were automatically eliminated that did not have “United States” as specifically stated in the title. 2 additional articles were discarded due to being published in years prior to 2000. This resulted in 102 total articles that were considered and thus, abstracts were read. After reviewing each abstract 48 were disposed of, 36 of which due to the study not being conducted in the United States and 12 not written in the English language. 54

applicable articles were then read in their entirety and considered. 46 of them are consequently disqualified, due to 22 articles containing only urban data, 18 articles where urban and rural data were not differentiated from each other, and 6 were not able to be read due to restricted access. 8 remaining articles qualified for the literature review and were included in this study.

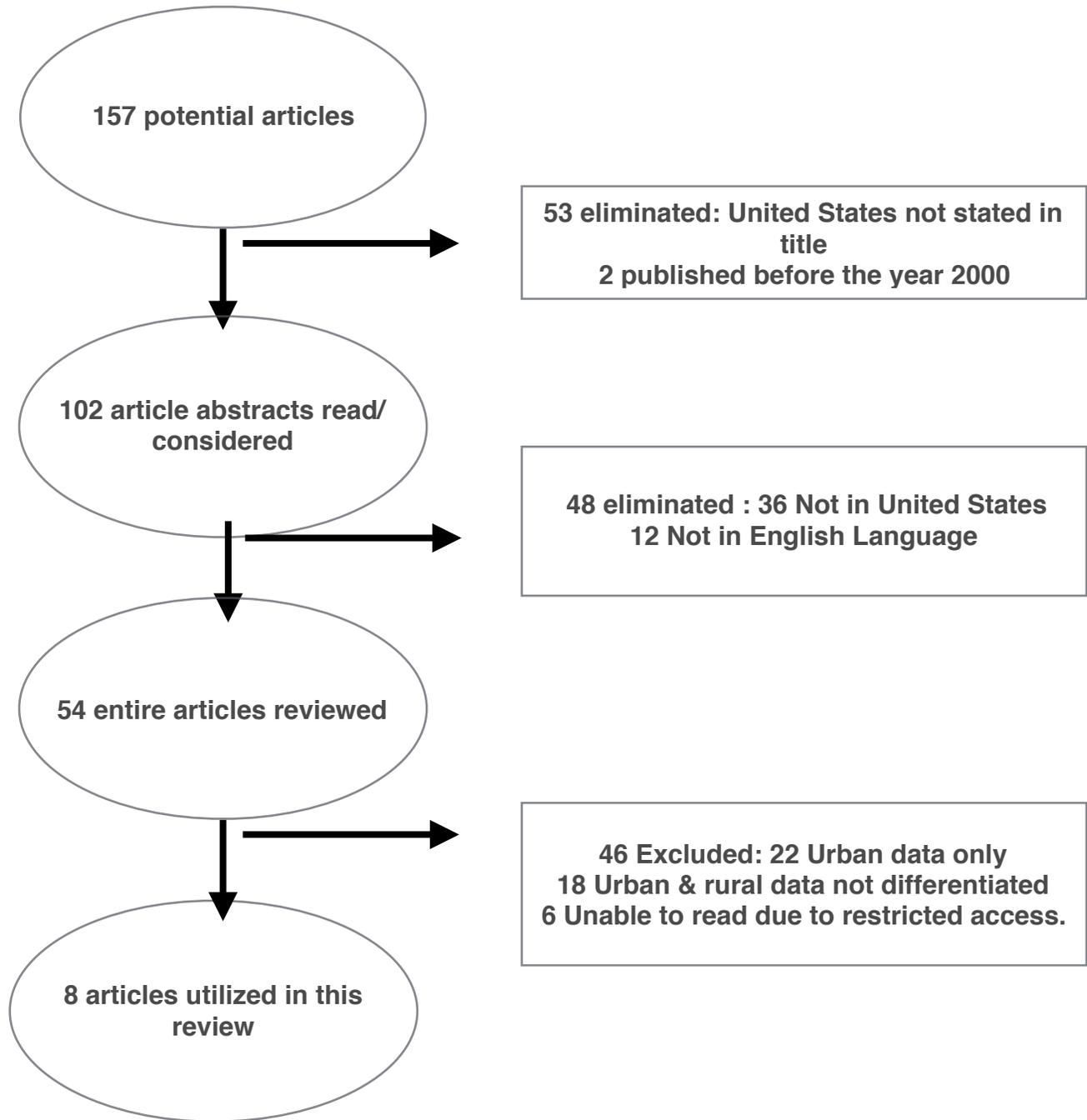


Figure 3 Describes the process utilized to identify the 8 applicable articles reviewed in this study.

Characteristics of Selected Articles

Of the 8 articles selected for review, 4 out of 8 were focused solely on rural implications associated with HIV/AIDS related care. The remaining 4 contained both rural and urban information that were differentiated accordingly. The majority of the articles were conducted in the southeast and/or northeast US, which is congruent to the recognized needs of PLWH/A in rural parts of the US. The southeast and northeast contain the highest rural prevalence rates for infection. (NHRA, 2014) Additional locations within considered studies included Alaska and Arizona. Underrepresented rural areas were the western and midwestern United States. Table 1 provides a snapshot of relevant study characteristics for easier viewing.

Author, Date	Journal	Type of Data	Sample	Recruitment Style	Location of Study
Cohn et. al, 2001	JAIDS	Interviews	367 Rural HIV+ Residents, 2806 Urban HIV+ Residents	Through Medical Providers	Not Specified
Durvasula and Miller, 2014	Behavioral Medicine	Literature Review	Publications	Academic Search Engines	N/A
Frew et. al, 2016	BMC Public Health	Interviews and Focus Groups		Enrolled in HPTN 064 Across 10 Communities	Georgia, New York, North Carolina, and Washington, D.C.
Gallant et. al, 2011	Clinical Infectious Diseases	Literature Review	Publications	Academic Search Engines	N/A

Author, Date	Journal	Type of Data	Sample	Recruitment Style	Location of Study
Heckman et. al, 2004	AIDS CARE	Surveys	329 Non-Government Organizations in Rural Areas of 12 States	Advertisements and Medical Providers	Rural Areas of 12 US states - Ohio, Pennsylvania, Virginia, Rhode Island, New York, Wisconsin, Michigan, Arizona, Indiana, West Virginia, Montana, and Alaska.
Kerr et. al, 2014	AIDS Behav	Baseline Data	1606 African American Adolescents aged 14-17	Through Medical Providers	Georgia, Rhode Island, New York, South Carolina
McKinney, 2002	The Journal of Rural Health	Literature Review	Publications	Academic Search Engines	N/A
Varni, Miller, and Solomon, 2012	AIDS Behav	Surveys	193 People, 58% Living in Rural Areas	Through Medical Providers	Vermont, New Hampshire, and New York

Table 1 provides a basic overview of the utilized studies or articles in this systematic literature review.

Following the selection of approved articles, this author reviewed each study to identify barriers discussed. A total of 15 barriers to care were identified, then placed into a table for easier visualization. (See Table 2) The most commonly discussed barriers were stigma (4), comorbidity/

polymorbidity (HIV, substance use, and/or mental health) (4), long distances to care (3), lack of qualified professionals (3), lack of support (3), and isolation (3).

Barriers	Cohn et. al, 2001	Durvasula and Miller, 2014	Frew et. al, 2016	Gallant et. al, 2011	Heckman et. al, 2004	Kerr et. al, 2014	McKinney, 2002	Varni, Miller, and Solomon, 2012
Transportation					X		X	
Long Distances to Care	X				X		X	
Insurance Issues							X	
Lack of Qualified Professionals	X						X	X
Overburdened Services	X							
Existing Services					X		X	
Lack of Social Support/ Services	X		X					X
Stigma					X	X	X	X
Confidentiality					X		X	
Comorbidity (SUD/ MH)		X	X		X		X	

Barriers	Cohn et. al, 2001	Durvasula and Miller, 2014	Frew et. al, 2016	Gallant et. al, 2011	Heckman et. al, 2004	Kerr et. al, 2014	McKinney, 2002	Varni, Miller, and Solomon, 2012
Isolation			X		X			X
Cultural Sensitivity			X				X	
Medication Adherence					X			
Housing			X					
Health Education			X					

Table 2 shows the barriers identified in each specific study or article.

Interviews of HIV/AIDS Service Providers

This author and Dr. Mark Kilwein* (See Appendix A) then conducted semi-structured interviews with various HIV/AIDS healthcare providers employed by the Northwest Pennsylvania Rural AIDS Alliance* (See Appendix A). The professions ranged from nurses, case managers, program directors, prevention specialists, and medical coordinators. The interviews consisted of open ended questions regarding commonly experienced barriers and challenges in rural HIV/AIDS service delivery. The goal of this portion of the study was to gain the perceptions of providers regarding current barriers, successes, and trends among the individuals that they serve.

Questions asked included:

- What is your job title (general)?
- What percentage of your clientele reside in rural vs urban areas?
- What is going well in your service delivery efforts?
- What is going wrong in your service delivery efforts?
- What continues to be the most commonly experienced barriers for the people you serve?
- What mental health trends are you seeing in your clients?
- How does substance use, if at all, impact the clients you serve as it relates to their treatment?
- Do you have any other pertinent issues regarding HIV/AIDS related care that we forgot to mention?

Common responses (See Table 3) to “What is going wrong in your service delivery efforts?” and “What continues to be the most commonly experienced barriers for the people you serve?” were wait times to receive mental health services, lack of or overburdened mental health

services, housing issues, transportation needs, medication adherence, stigma, and lack of knowledgeable/qualified PCPs. Other cited issues included being denied medical care (particularly by dentists), and adequate nutrition.

Future research is needed to further explore the scope of these perceived implications. Administering the Rural HIV/AIDS care survey to HIV/AIDS service providers in both rural and urban communities to identify and decipher the differences would be exceptionally beneficial. Furthermore, to develop and administer a survey that addresses the consumers perspective about their HIV/AIDS related care could peak more interests for future research opportunities.

Barriers Reported	Interview 1	Interview 2	Interview 3	Interview 4	Interview 5	Interview 6	Interview 7	Interview 8
Stigma	X	X	X			X		
Lack of Qualified Professionals	X	X						
Housing	X	X						X
Unaddressed Mental Health Needs	X	X	X	X	X	X	X	X
Nutrition/Food	X							X
Transportation	X				X	X	X	X
Lack of Social Supports / Services		X			X	X		
Denied Care Due to Positive Status		X						
Drug and Alcohol Issues	X	X	X	X			X	X

]Table 3 displays the most commonly experienced barriers for PLWH/A, as reported by service providers.

Feedback for the questions “What is going well in your service delivery efforts?” included funding, particularly through assistance programs such as Housing Opportunities for People With AIDS (HOPWA), Tenant Income Based Rental Assistance (TIBRA), and Special Pharmaceutical Benefits Program (SPBP). In addition to funding, many providers reported that medical advancement in regards to medications have improved exponentially including Antiretroviral Therapies, Pre-Exposure Prophylaxis (PrEP), and Hepatitis C treatments.

According to each provider surveyed, comorbidity and polymorbidity are very much prevalent among PLWH/A served by the agency. Substance use continues to be not only an issue in contracting HIV/AIDS (through shared needles and increases in risky behaviors), but also in treatment compliance and attendance, medication adherence, and mental health symptom exacerbation. Depression, bipolar disorder, isolation, and trauma histories continue to remain the most frequently reported mental health conditions among PLWH/A according to the professionals surveyed.

CHAPTER 4

RESULTS

To develop the Rural HIV/AIDS Care Survey, this author and Dr. Kilwein generated open ended questions by incorporating the information discovered through the literature review in addition to the responses provided by the HIV/AIDS healthcare professionals. The Rural HIV/AIDS Care Survey is a Likert-type scale survey that consists of 39 questions rated on a 7-point scale ranging from strongly agree to strongly disagree. The questions aimed to provide an encompassing survey for providers to utilize to examine, modify, and enhance their programs based on commonly reported trends.

Many significant insights into the current challenges of providing HIV care in rural environments were expressed during these interviews. Some notable quotes are provided here, in the words of the providers.

- “Drug and alcohol abuse is a big issue. The heroin epidemic through intravenous drug use has increased and shifted the focus from MSM contraction.”
- “Even though the trend is still MSM, programs like clean needle exchanges are still needed.”
- “Problems in the prevention piece are challenging, more so individuals who are engaging in risky behaviors, such as addiction.”
- “It seems like there is never enough psychiatrists or mental health providers to link individuals to.”
- “There is such a deficit in mental health interventions and professionals that can see and prescribe.”

- “Mental health is becoming few and far between for rural communities. It can take months to get someone in to see a psychiatrist.”
- “I don’t think that education spreads as quickly to rural areas as it does urban areas.”
- “A lot of people in rural communities think “Oh, this person is HIV positive, so I’m going to get it from them if they breathe on me or touch me.””
- “I would definitely say that transportation barriers are huge. Not so much vehicles, because a lot of my clients do have access to vehicles - but in regards to having to travel long distances to receive the care they need.”

The goals of this research study are to bring light to a hidden population, assist in identifying the contextual barriers for rural PLWH/A (with the ultimate goal of alleviation of said barriers), providing a voice to those service providers who struggle daily to connect clientele to necessary and beneficial services due to rurality, and to encourage interdisciplinary professionals (mental health, substance abuse, psychiatric, etc) to collaborate with HIV/AIDS service providers within their area to create mutual, lasting professional relationships.

Providing a voice for these service providers to achieve the aforementioned goals is necessary to leave a lasting impact on policy makers, other service providers, interdisciplinary professionals, and future researchers.

A copy of the finalized Rural HIV/AIDS Care Survey is included in Appendix B.

CHAPTER 5

Conclusion

Funding, although considered plentiful by the interviewed providers, continues to be an identified barrier for individuals living in rural America (McKinney, 2002), as Southern states remain to have the greatest number of residents without health insurance (NHRA, 2014; CDC, 2016), yet the highest infection and death rates in the US. (HIV.ORG; Kerr et. al, 2014; CDC, 2016) This may be due to lack of education on available funding resources, such as The Ryan White Program, Medicare, and Medicaid. (Gallant et. al, 2011) In addition to this, historic distribution of federal and state funding has benefited urban areas of the US more so than rural areas. (Masiano et. al, 2019) This necessitates greater awareness of policy makers and funding coordinators, as well as HIV prevention and education specialists to assist in directing funds to the greatest potential.

A shortage of HIV-experienced healthcare providers is another barrier to receiving care in rural areas. Many primary care physicians in rural areas lack experience and education in HIV/AIDS related-care. (NHRA, 2014; Cohn et. al, 2001; McKinney, 2002; Varni, Miller, and Solomon, 2012) Providers may not feel competent to accept and treat individuals that have a positive status. In addition to this, PLWH/A may be reluctant to accept or retain in care if there is an absence of trust and open communication. (Gallant et. al, 2011) Access to qualified and knowledgeable professionals in HIV/AIDS related care is essential to reduce lethality and transmission potentials. In areas where HIV-knowledgeable medical providers are scarce, individuals can benefit from continuous consultation with HIV experts via telecommunication or telemedicine. (Gallant et. al, 2011)

Stigma is responsible for many PLWH/A not receiving timely, quality, and frequent care. Rates of stigma, either perceived or experienced, tend to be higher in rural areas. (CDC, 2016) HIV/AIDS can be particularly stigmatizing due to its correlation with homosexuality, intravenous drug use, sex work, and other commonly marginalized groups in American society. (Varni, Miller, and Solomon, 2012; Kerr et al, 2014) In addition to this, HIV/AIDS association with contagion, fear, and death can also be responsible for high levels of stigma. Those who are stigmatized against due to their positive status have experienced prejudice and discrimination, violence and threats toward their welfare, and job loss. (Varni, Miller, and Solomon, 2012) Interventions that provide HIV/AIDS education and counter stigma are essential in reducing the impacts of stigma and enhancing the quality of HIV/AIDS related care.

Rural areas are less likely to be inclined to provide psychosocial services. (Varni, Miller, and Solomon, 2012; Cohn et. al, 2001) This includes mental health and substance use treatment. For PLWH/A, comorbidity and polymorbidity are not uncommon. In order to increase the likelihood of viral suppression, retention and engagement in care, and increase overall quality of life for PLWH/A, access to timely, knowledgeable psychosocial providers is critical. (Durvasula and Miller, 2014) Prevention, education, and treatment efforts should be geared toward mental health and substance use concerns. Strong relationships among interdisciplinary providers and organizations would be an asset.

It is no secret that travel distances are long and burdensome to PLWH/A in rural communities. (McKinney, 2002; Cohn et. al, 2001; Mariano et. al, 2019, Heckman et. al, 2004) According to one study, rural individuals must travel, on average 90 minutes, an additional 50 minutes to care compared to their urban counterparts. (Masiano et. al, 2019) Arguably the

allocation of funds to open HIV/AIDS speciality clinics in underserved, overburdened areas would be most beneficial. However, access to transportation and telehealth can alleviate the inconvenience of long travel distances to care.

Contextual factors in rural America will continue to impact the HIV/AIDS epidemic unless properly addressed. This is evidently especially true for the Southeastern US. In order to meet CDC standards and mitigate the HIV/AIDS epidemic, prevention and treatment endeavors must be tailored to address these concerns.

It is our hope that the Survey for HIV/AIDS professionals will be utilized to assist policy makers, funding coordinators, and service providers alike to better serve PLWH/A in rural communities across the United States.

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APPENDIX A

TERMS AND DEFINITIONS

Dr. Mark Kilwein is a licensed clinical psychologist, as well as a professor in Clarion University's Human Services, Rehabilitation, Health, and Sports Sciences department. He has 20 years of experience as a volunteer and former Director of Mental Health at the Northwest Pennsylvania Rural AIDS Alliance.

Antiretroviral Therapy (ART): Medication that stops the progression of HIV. (HIV.org, 2019)

AIDS: Acquired Immunodeficiency Syndrome. It is considered the late stage of HIV infection. An individual is considered to have AIDS when their CD4 count falls below 200 (A healthy individual typically has CD4 counts of 500 and 1,600). Or if an individual has acquired one or more opportunistic infections (OIs - e.g. Salmonella, Herpes Simplex Virus 1), regardless of their CD4 counts. (HIV.org, 2019)

HIV: Human Immunodeficiency Virus. It is an infection that attacks cells that assist the body in fighting infections. It can be spread by having contact with bodily fluids, such as blood or semen. (HIV.org, 2019)

HIV/AIDS Related Care: Comprehensive care including case management, medical. It is consistent and frequent.

PLWH/A: People Living With HIV/AIDS.

Rural: All populations, housing, and territories not included in an urban area. (United States Census Bureau, 2010)

The Northwest Pennsylvania Rural AIDS Alliance provides services and connection for PLWH/A and/or the Hepatitis C Virus. Their mission reads as follows: "We work in unison with

the communities of northwest Pennsylvania to improve and protect the health of those struggling against HIV/AIDS.” They provide medical case management, specialty clinics/care, patient care, and high impact prevention services in 13 counties in northwest Pennsylvania. It was established in 1991 and is a grant-funded program under Clarion University of Pennsylvania.

Website: <http://www.clarion.edu/about-clarion/offices-and-administration/centers-and-outreach/nw-pa-aids-alliance.html>

Urban Areas: Comprised of 50,000 people or more. (United States Census Bureau, 2010)

Urban Clusters: Comprised of at least 2,500 people, but less than 50,000 people. (United States Census Bureau, 2010)

Viral Suppression: When ART reduces an individual’s viral load to an undetectable level. This does not mean cured. (NIH, 2019) <https://aidsinfo.nih.gov/understanding-hiv-aids/glossary/1650/viral-suppression>

APPENDIX B

Likert Scale Survey: Rural HIV/AIDS Care Survey

Job Title (be as specific or general as you'd like): _____

Approximate percentage of rural clientele served: _____

Approximate percentage of urban clientele served: _____

Please assess the following statements regarding your own personal and professional perceptions while working in the HIV/AIDS field. Indicate your answer using a scale where 1 signifies that you **strongly disagree** with the statement; 2 signifies that you **disagree** with the statement; 3 signifies that you **slightly disagree** with the statement; 4 signifies that you **neither agree nor disagree** with the statement; 5 signifies that you **slightly agree** with the statement; 6 signifies that you **agree** with the statement; 7 signifies that you **strongly agree** with the statement.

1. Undiagnosed mental health problems are an issue in providing for PWHIV/AIDS.

1	2	3	4	5	6	7
Strongly Disagree			Neither			Strongly Agree

2. There are a full range of mental health services available for my clients.

1	2	3	4	5	6	7
Strongly Disagree			Neither			Strongly Agree

3. Long delays characterize referrals for mental health treatment.

1	2	3	4	5	6	7
Strongly Disagree			Neither			Strongly Agree

4. Mental health negatively affects medication adherence.

1	2	3	4	5	6	7
Strongly Disagree			Neither			Strongly Agree

5. Mental health negatively affects adherence to medical appointments.

1	2	3	4	5	6	7
Strongly Disagree			Neither			Strongly Agree

6. There is a mental health stigma among clients.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

7. Low health literacy is a problem for the people I serve.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

8. My clients are concerned about medical privacy.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

9. Rapid aging is an emerging concern among PWHIV/AIDS.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

10. There is a theme among my clients of childhood trauma.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

11. Many of my clients don't take responsibility for their own care.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

12. Isolation is a problem among my clients.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

13. Most of my clients exhibit signs of anxiety/depression.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

14. HIV/AIDS ignorance is a problem among medical professionals.

1	2	3	4	5	6	7
Strongly Disagree			Neither			Strongly Agree

15. Medical professionals understand the importance of PREP.

1	2	3	4	5	6	7
Strongly Disagree			Neither			Strongly Agree

16. Medical services are readily available for motivated clients.

1	2	3	4	5	6	7
Strongly Disagree			Neither			Strongly Agree

17. There is a lack of qualified psychiatric personnel to take referrals.

1	2	3	4	5	6	7
Strongly Disagree			Neither			Strongly Agree

18. Addiction is a problem for many of my clients.

1	2	3	4	5	6	7
Strongly Disagree			Neither			Strongly Agree

19. Addiction negatively affects medication adherence.

1	2	3	4	5	6	7
Strongly Disagree			Neither			Strongly Agree

20. Addiction negatively affects adherence to medical appointments.

1	2	3	4	5	6	7
Strongly Disagree				Neither		Strongly Agree

21. Injection drug use is the current greatest threat as a route of HIV/AIDS transmission.

1	2	3	4	5	6	7
Strongly Disagree			Neither			Strongly Agree

22. Transportation is a challenge serving people in rural areas.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

23. Transportation is a challenge serving people in urban areas.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

24. HIV/AIDS stigma is improving in society.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

25. I am satisfied with harm reduction, eg. needle exchange programs, efforts in Pennsylvania.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

26. In my job, I encounter individuals that show evidence of narcissistic personality traits.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

27. In my job, I encounter individuals that show evidence of antisocial personality traits.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

28. I'm confident that the availability of medical marijuana will help the people I serve.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

29. I believe that HIV/AIDS prevention services are adequate to meet our current needs.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

30. Electronic Medical Records come between me and my clients.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

31. I see evidence of the opioid epidemic in my daily duties.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

32. Treatment for hepatitis C has been a success.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

33. There is an unmet opportunity to provide services through Telehealth.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

34. I see recurring service needs across generations of the families in the communities I serve.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

35. Support programs, eg. Social Security Disability, keep up with the cost of living for my clients.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

36. HOPWA programs are a success.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

37. The ACA (Affordable Care Act) has provided significant benefits for my clients.

1 2 3 4 5 6 7
 Strongly Disagree Neither Strongly Agree

38. The Ryan White programs have been a success.

1 2 3 4 5 6 7
Strongly Disagree Neither Strongly Agree

39. Pennsylvania provides access to necessary HIV/AIDS medication.

1 2 3 4 5 6 7
Strongly Disagree Neither Strongly Agree

Open Ended Questions:

Please evaluate and answer the following open ended questions based on your personal and professional perceptions working in the HIV/AIDS field.

1. What are the most commonly seen drugs of abuse among those served in my practice?

2. What is the most common route of HIV/AIDS transmission among the people I serve?