Stigma towards HIV positive people in the El Paso community

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STIGMA TOWARDS HIV POSITIVE PEOPLE IN THE EL PASO COMMUNITY

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DEDICATION

I dedicate this thesis to my beloved family back home in Russia, and also to all those people who are my family here in El Paso. I want to thank my friend Norman for being my support during this thesis work. I want to thank my beloved father, Dr. Pavel Romanov, who is not with me anymore, but will always stay in my heart and serve as my inspiration and my mentor. Nevertheless, most of all, I want to thank the people who participated in my project; I will always remember your stories and they will motivate me to fight against inequalities in this world.
STIGMA TOWARDS HIV POSITIVE PEOPLE IN THE EL PASO COMMUNITY

By

EVDOKIA ROMANOVA

THESIS

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ABSTRACT
Stigma and discrimination towards individuals living with Human Immunodeficiency Virus (HIV) is a serious issue. The stigma experienced by people with HIV relates to how the virus has been primarily associated with so-called deviant behaviors (e.g. promiscuity and homosexuality). Stigma may isolate infected individuals from society and create barriers when accessing medical care and seeking social support. Conducted in El Paso, Texas, this study aims to better understand the issue of stigma through the life stories of individuals living with HIV and to test an exploratory model of a community-based intervention for fighting self-stigma. This research project is divided into two stages of data collection and analysis. In Stage 1 of the project, I conducted in-depth interviews (n=12) with people living with HIV in the community of El Paso. In Stage 2 of the project, I conducted and evaluated a theater intervention using workshops. Common themes in the Stage 1 interviews were stigma from primary and secondary social groups, and the way self-stigmatized attitudes influence individual’s self-perceptions, and the positive aspects of having HIV. Stage 1 analyses demonstrate that stigma, especially from friends and family members (i.e., primary groups), remains a relevant issue in the El Paso community as individuals living with HIV tended to experience stigma, which had a strong influence on their self-esteem and emotional health. The evaluation conducted in Stage 2 revealed that all participants (n=13) were satisfied with the intervention; the follow-up interviews (n=4) suggested that participants received an emotional and psychological release, open up about their personal problems, and improved their relationships within the support group. Practically, the results speak to the necessity of providing additional support, not only to individuals living with HIV, but also to their families and close friends and to the importance of educating community activists about the close connection between HIV stigma and heterosexist and homophobic values. Lastly, this thesis illustrates opportunities for theater approaches as efficient ways for working with support groups serving individuals living with HIV.
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CHAPTER 1: INTRODUCTION & LITERATURE REVIEW

1.1 Introduction

The HIV epidemic is widely acknowledged as a relevant issue in the global community. There are a variety of funds such as the United Nations Fund in Population (UNFPA) and the Global Fund to fight AIDS, Tuberculosis and Malaria, which aim to provide intervention programs to eradicate HIV. Even though stigma and discrimination towards people living with HIV has been previously illustrated and has become a part of the discourse in contemporary scientific circles, it remains an important problem, particularly in societies where sexuality remains a taboo topic. This thesis aims to understand HIV-stigma in the community of El Paso, Texas and to explore an alternative model for fighting self-stigma amongst people living with HIV using a novel theater intervention. In the Chapter 1 of this thesis, I report what has been previously known about the topic of HIV-stigma in the global community, the US as a whole, and border communities of US/Mexico like El Paso. In Chapter 2, I describe the data and methods I have applied in this research. I talk about Stage 1 and Stage 2 of my research project, touching on such topics as recruitment of participants, data collection and analysis. In Chapter 3, I report the results of Stage 1 and Stage 2 of this research project. I analyze and evaluate the interviews with the participants based on their experiences of stigma. I analyze surveys and interviews collected to understand the efficacy of theater workshops on the individuals living with HIV. Chapter 4 of this thesis focuses on connecting previous findings with the findings of my research, highlighting the findings that are unique to this research. Finally, in Chapter 5, I conclude this thesis by highlighting challenges experienced during this research and some practical implications stemming from my findings.
Chapter 1 will first outline the background and significance of the issue of HIV globally, nationwide in the US, and on the US-Mexico border. Then I explain the theoretical framework of my research for which I use stigma theory, originally from Goffman, and identity theory. With the support of these theories, I uncover the way HIV-prevention strategies can be used for the purpose of education, prevention, and empowerment. I also discuss how art and particularly theater are used as a tool for community intervention with the focus on changing societal attitudes on HIV. Lastly, I evaluate the presented material in the conclusion section, discussing the main points and limitations of previous studies.

1.2 Background and Significance of HIV Infection Worldwide, in the US, and along the US-Mexico Border

Human Immunodeficiency Virus (HIV) targets the immune system of a person by weakening it and making it vulnerable to infections and several types of cancer. The final stage of HIV infection is Acquired Immunodeficiency Syndrome (AIDS), the stage when the immune system cannot respond to any infection, which leads to death. On average, AIDS takes four to seven years to develop in the body of a person after HIV infection although the timeline for progressing to AIDS depends on the immune system of the individual and if this person takes medication and effectively responds to it (WHO, 2014). HIV was discovered in the early 1980’s, and during the thirty years of its existence, more than 39 million people have been infected globally (WHO, 2014). According to the statistics, 1.5 million people have died from HIV-related causes worldwide in the past thirty years. Sub-Saharan Africa is the most affected region as it has had about 27 million cases since the discovery of HIV and it holds 70% of the total global cases of HIV infection (WHO, 2014).
In the US in 2011, more than 1.2 million people were living with HIV, with 648,459 diagnosed with AIDS (CDC, 2011). In the US, 13,834 people who were diagnosed with AIDS died of related illnesses in 2011 (CDC, 2011). According to the Centers for Disease Control and Prevention, despite the fact that everyone is at risk for HIV, some racial/ethnic groups, genders, sexual orientations, and age categories are at greater risk, and that is why they are called “risk groups” or “key populations” (CDC, 2011). This may be because certain types of behaviors are associated with greater chances of getting HIV, such behavioral patterns may include high-risk sexual contacts, intravenous drug use, low educational resources, low socioeconomic status, and migration and mobility are among the factors that facilitate the spread of HIV in the US (Moya et al, 2012, p. 169). African Americans are the racial/ethnic group most affected by HIV and they account for 44% of the people in the US that are diagnosed with HIV, but only 12.6% of total US population. An estimated 72% of black Americans contracted the virus through men-to-men sexual (MSM) contacts. Hispanics/Latinos accounted for 21% of newly diagnosed HIV infection cases in 2010 and comprised 16% of the population in the US (CDC, 2011). Among Hispanics, 87% cases are among men and 79% of these men contracted HIV through MSM contacts. Men, and especially MSM, are disproportionately affected by HIV overall. In 2010, 72% of newly diagnosed HIV cases were men and the most common manner of transmission was through MSM.

Due to the migration and mobility of residents, the control and treatment of HIV infection is complicated on the US/Mexico border (Moya et al, 2012, p. 169). US/Mexico border communities, like El Paso-Ciudad Juarez, are characterized by high levels of mobility and migration (Moya et al, 2012, p. 169). Even though HIV prevalence in Mexican border states is lower than for US border states, the epidemic is concentrated among risk groups in the bigger cities, for example, in Tijuana and Ciudad Juarez where there is a high prevalence of intravenous
drug users, MSM, migrants and deportees, and female sex workers. The other important factor is that almost half of counties along the US-Mexico border are medically underserved and of low economic status (Moya et al, 2012, p. 170). These factors contribute to the growing epidemic in the border communities, and without the appropriate prevention programs, these communities may face an emerging epidemic of HIV.

The US/Mexico border is home to a predominately Latino population. The majority of HIV positive Latinos contracted the virus through MSM contact (CDC, 2011). In addition, HIV positive Latino MSM face greater stigma from their HIV status than they do from their sexual orientation (Wohl et al., 2012). Ayla et al. (2012), conducted research in Los Angeles County, California, New York, New York, and Philadelphia, Pennsylvania, and found that negative attitudes towards HIV positive Latino men, financial hardships, racism, and lack of social support may lead HIV positive Latinos to additional risky sexual behaviors. Such conditions create the situation of further spread of the HIV virus and strengthen the stigma towards them on the community level (Ayala et al., 2012, p. s2).

1.2 Stigma Theory

In order to analyze the experiences of stigma in lives of individuals living with HIV, I will utilize two sociological theories: stigma theory and identity theory that may be united under the theoretical tradition of symbolic interactionism. Symbolic interactionism examines the meanings behind the behaviors of individuals, which may vary depending on social context. The perspective assumes that symbols and meanings emerge through social interactions between individuals (Aksan et al., 2009). These interactions may have a strong influence on the individual’s identity. Next, I will focus on the issue of individuals’ perceptions of stigma and the difficulties that a disease like HIV may cause to infected individuals. For this, I will first explain the concept of
stigma, discuss the influence of stigma on the life of a person with HIV by using identity theory, and then focus on the literature related specifically to HIV-stigma.

Goffman (1963) described stigma as a social or physical label that is used by others as a symbol of social rejection. He identified three major types of stigma: physical deformities, blemishes of individual character (that are based on the actions that are viewed as deviant behavior) and tribal stigmas (belonging to a specific race, religion or ethnicity) (Goffman, 1963, p. 21). Based on Goffman’s theory, I may conclude that blemishing of individual character stigma can be applied to HIV. Due to the history of the virus, and the way someone with HIV was associated with deviant sexual behavior (e.g. homosexuality, many sexual partners) individuals who live with HIV will be more likely to be assigned with the features of negative behavior. According to Goffman (1963), society creates certain labels and means for categorizing individuals according to their behavior. If the individual does not fit into what is considered “normal,” then the society assigns such behavior as deviant, and the individual is more likely to be negatively stigmatized and to receive a “spoiled identity” (Goffman, 1963, p. 5). Stigma towards HIV positive people is mainly associated with the means by which one may get infected (e.g. unsafe sexual behaviors), which is why others may question the moral character of people with an illness like HIV, which creates negative attitudes about individuals affected by the virus. Goffman’s approach to stigma remains relevant in contemporary social science. My interest specifically relates to what can be done to overcome stigma and discrimination against stigmatized groups in the population. To understand this I review the work of scholars that have linked stigma to the complex structure of power and dominance.

Campbell and Deacon (2006), with the support of Goffman’s (1963) theory, discuss that stigma-related research should take into consideration such factors as social power, inequality, and
exclusion. They see stigma as a complex process that is linked to the competition for power, which is connected with existing mechanisms of dominance and exclusion (Campbell & Deacon, 2006, p. 416). The same point is stressed by Parker and Aggleton (2003) as they see that most of the stigma-related research on the topic of HIV is observing stigma for the most part in relation to beliefs and attitudes but not linking HIV stigma to more complicated concepts of culture and power.

Stigma should not be simplified to understanding it as an ignorance that can be easily overcome by education and providing society with the “facts” about the stigmatized group (Campbell and Deacon, 2006, p. 417). That is why, when we talk about stigma towards people living with HIV, there is a need to understand the layers of stigma that may include such factors as sexual orientation and gender identity, and the association of HIV with some sexual behaviors or drug addiction. All of these layers may form the negative perceptions of an individual with HIV and create the grounds for the exclusion of social minorities. Hence, stigma towards individuals living with HIV is influenced by multiple layers of discriminatory attitudes that are formed by mechanisms of social exclusion.

Stigma may play a key role in access to testing and therapy for at risk groups and HIV positive people. Oster at al. (2013) conducted a study in 21 Metropolitan Statistical Areas (MSAs) the in US states with high rates of HIV infection, including the Houston MSA in Texas: “HIV infection was associated with older age, lower household income, gay identity, and being U.S.-born or an established immigrant as compared with being a recent immigrant” (Oster et al, 2013, p. 5). The relatively low risk of immigrants may be due to a lack of full access to testing services and that is why, in many cases, infection of immigrants with HIV may remain unknown. That puts the immigrant Latino population at higher risk of exposure to the virus. Immigrant populations
may face even stronger levels of stigmatization due to the vulnerable position in society that they occupy and the fact that in many cases, they are already associated with a stigmatized group.

Investigating the ways stigma affects lives of people living with HIV (PLHIV) on the border is highly relevant for US society today. First, it is relevant due to the historical background of formation of stigma towards individuals living with HIV in the U.S., and the way social inequalities affect the lives of racial/ethnic minorities, especially Latino MSM, which are concentrated in US-Mexico border cities (Moya et al, 2012, p. 169). Second, border communities have a higher percentage of the immigrant population, both documented and undocumented, which puts them in a vulnerable position and creates obstacles in accessing health care services. Third, almost no research has been conducted on the way HIV affects lives of Latino residents of border communities. That is why investigating the role stigma plays in the lives of HIV positive people in the US-Mexico border is highly relevant.

The global AIDS response has highlighted the tremendous efforts to fight the epidemic: “No past effort to combat disease captures the promise of medicine and global health like the worldwide response to AIDS” (Messac & Prabhu, 2013, p. 111). However, two major issues facing PLHIV in the contemporary world are barriers to testing and access to antiretroviral therapy (ART) in cases of infection and a high viral load. Such barriers have been caused in part by stigma and discrimination towards PLHIV, which remains a highly relevant, but not highly visible problem (Messac & Prabhu, 2013, p. 113). Even though the stigma towards PLHIV has been acknowledged by the global health community, e.g. it was the main topic on the agenda of the 2012 International AIDS conference in Washington, DC, not enough efforts have been made in order to overcome stigma barriers, especially among at-risk groups like the Latino population in the border community.
The complexity of HIV related stigma might create additional difficulties when seeking to understand what influence it may have on the self-perception of an individual with HIV. Goffman (1963) mentioned that stigmatized individuals may internalize negative representations of their self. In this case, internalized stigma towards people living with HIV needs to be understood in reference to one’s identity. In understanding this, identity theory is useful.

1.3.1 Positive Sides of Stigma

Although stigma is, in most cases, considered to be a negative phenomenon, some studies provocatively assert that there are positive sides of stigma. For instance, Miller and Kaiser (2002) discussed stigma as a stress-causing factor, which causes individuals to understand stigmatization from society as a need for adaptation with the society and in many cases they start coping-efforts to deal with stigmatization. Miller and Kaiser (2002) call for readers to view stigmatization as a “form of stress”, in that way, potential coping mechanism for dealing with stress may be developed and applied through community work and practice (p. 73).

As a second example, Shih (2004) investigated the ways in which self-stigma may be understood as a means for empowerment. According to the author, some stigmatized individuals may develop certain strategies related to their identity, such as compensation, strategic evaluation of the social environment, and focusing on multiple identities. In the strategy of compensation, individuals tend to compensate for negative experiences by making an effort to improve themselves in other dimensions. Individuals may also strategically evaluate their social environment based on their own assumptions of acceptability, and use particular behaviors with specific groups of the population. This explains the strategy of multiple identities, where the individual is able to separate the stigmatized identity from other identities, which existed before experiences of discrimination happened. These strategies help stigmatized individuals to handle
stigma in their lives. By doing so, stigmatized individuals may develop an alternative model for coping with stigma, what Shih (2004) called the “empowerment model”, which helps them to overcome stigmatization and inspire them for action against stigmatized values (Shih, 2004, p. 178). Further in the literature review, I will review some of the potential intervention approaches for dealing with stigma that can help stigmatized individuals use their experiences to become empowered.

1.4 Identity Theory

Identity theory takes its roots from the writings of G.H. Mead, an early symbolic interactionist thinker, and sees the identity of a person as connected to various networks and relationships in which they may have a particular role (Stryker and Burke, 2000). In the center of identity theory is the concept of “self” and the way the “self” is interacting with various social institutions and social networks. The theory is stating that the person has as many identities as social networks “in which they occupy positions and play roles” (Stryker and Burke, p. 287, 2000). Brown (2000) states that our social identity is determined by the connection to membership in particular groups and individuals strive to achieve and maintain a positive identity. In case of becoming HIV positive, individuals gain a negative, or as Goffman (1963) states, “spoiled” social identity, as people are associated with groups that are suspected of deviant behavior. According to Brown (2000), connection to a particular group may also influence the way society perceives the group members. As he stresses, society is more likely to identify group members “as possessing various common attributes- in other words, being seen more similar to each other then they are to the members of another category” (Brown, 2000, p. 750).

The most important point about identity theory is the way the individual self-identifies herself/himself with a particular group, the way individuals that are assigned with the certain group
are thinking about the self and how these assignments may contribute to the formation of the stigmatized attitudes about self. Brown (2000) discusses a strong connection between positive group identity and higher self-esteem of the group members. The individual is motivated to see his/her group in a positive way; that is why, in cases where the group is seen by the society in a negative way, it has a strong connection with lower self-esteem of the group members. This helps us to understand why people living with HIV are more likely to acquire negative identities and hence have lower self-esteem, which is influenced by the negative perception of their group in the society.

As is the case with positive identities, negative identities may be formed in a particular group of individuals due to stigma and discrimination. Some researchers call this concept “disruption” (DeGarmo et al, 1996), revealing the stress factors that influence the formation of a person’s negative identity. Burke (1991) proposes a relationship between stress and identity, pointing out that a variety of situations that produce stress may result in the process of identity disruption, which may cause long lasting stress and result in depression. One example of this situation, according to Burke (1991), is negative evaluations of a person by others. This negative evaluation may contribute to the process of identity disruption, which may result in anxiety and distress (p. 843). Stigma experienced by individuals living with HIV in this case may appear as one of the factors that may cause identity disruption.

Identity theory is important to be understood together with the important points that are discussed by Campbell and Deacon (2006). The group identity of HIV positive individuals puts them in the position of outsiders compared to the groups who hold cultural and political dominance (e.g. heterosexual individuals). As previously discussed, in many cases HIV is seen as a disease of marginalized groups of society, those who do not “fit in” the frames of normality. This has a strong
influence on identity and self-identification of a person infected with HIV, which is why it influences a person’s self-esteem by placing an individual in the position of an outsider.

1.5 HIV-related Stigma

Historical context played a key role in the rise of stigma towards HIV positive individuals, as the virus was mostly spread among marginalized groups that were characterized by their “deviant” behavior. Parker and Aggleton (2003) connect the history of the HIV epidemic to the notions of culture, power, and difference and call HIV-related stigma a “part of the political economy of social exclusion” (p. 19). Even after reproductive health education became an essential part of the curriculum in many schools in the US, the level of stigma towards HIV positive people remained a relevant issue in contemporary society. Herec (1999) devoted a significant amount of his research efforts to studying AIDS-related stigma. He described stigma as: “a term that refers to prejudice, discounting, decrepitating and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups and communities with which they are associated” (Herec, 1999, p. 1106). According to Herec (1999, p. 1108), over 21% of HIV positive people in the US have experienced violence in their communities because of their HIV status. The recent statistics on stigma towards HIV positive people indicates that it remains a relevant issue for the US society: as estimated 21% of women and 12% of MSM experienced physical and psychological violence since learning of their diagnosis (Vanable et al., 2006, p. 474).

Most of the evidence related to stigma towards HIV positive people was collected with the goal to examine the way society reacts to the individuals with the virus. However, taking into consideration that PLHIV can be stigmatized for different reasons (e.g. low level of knowledge about the way the virus may be transmitted, or assumptions about possessing characteristics
deemed deviant in broader society), it is important to examine what factors can cause more stigmatization. Traditional psychological approaches to HIV related stigma argue that the core of the issue is people’s ignorance about how HIV is transmitted from one person to another (Deacon et al, 2005, p. 9). For example, some believe that it can be transferred via handshakes or shared drinks. That is why many prevention programs are focusing their attention on providing education about the virus. However, there is a need to understand that simplifying the issue of HIV-stigma to the low level of knowledge about the infection in society will not eradicate the core causes of HIV-stigma. As argued by Parker and Aggleton (2003), such understanding of the core issue of HIV-stigma needs rethinking and understanding how stigma is influenced by social, cultural, and political factors (p. 20).

Some research demonstrates that stigma is experienced differently amongst various social groups. For instance, Rankin et al (2005) reported that stigma towards HIV positive people in many parts of Africa is driven by the historical past of the continent when influential Western missionaries presumed the superiority of certain lifestyles and sets of values. This specifically affected women and the way society expected them to behave according to the norms of morality. Hence HIV positive women are seen as individuals who is acting against the social norms and expectations, which strengthens the stigma towards HIV positive women in Africa.

Rankin et al (2005) state that the historical past of the African continent created the perfect ground for the “flourishing” of stigma towards people living with HIV. Besides that, pervasive gender inequality has strengthened discrimination and violence towards women living with HIV; for example, some women have been beaten or abandoned by their husbands because they have HIV, despite the fact that many women contracted the virus from their husbands (Rankin et al, 2005, p. 704).
One focus in the literature on HIV-related stigma in the US has been comparing HIV stigma among different racial/ethnic groups. For example, Wohl et al (2012) provided a comparative analysis of stigma among Latino and African American MSM at five clinics in Los Angeles County, California. Both Latino and African American men have the highest rates of HIV in the US and members of both groups tend to live in communities with restrictive gender and sexuality norms, where HIV and deviant sexual behavior are highly stigmatized (Wohl et al, 2012, p. 1455). This links to Campbell and Deacon’s (2006) idea that stigma is influenced by power, in this case the power of heterosexist values. According to the results, Latino men experience more stigma associated with their HIV status compared to African American men, although African American men experience more stigma towards their sexual orientation than do the Latino men (Wohl et al, 2012, p. 1464). However, both of these groups experience a strong level of self-stigma that is formed by being associated with other HIV positive people.

Experiencing stigma can have negative psychological consequences for the individual. Herec et al (2013) state that “stigmatized individuals can react to society’s devaluation of them with righteous anger, indifference, or internalization of the stigma and acceptance of its validity. The last of these responses is labeled self-stigma and is manifested in negative affect toward and beliefs about the self” (Herec at al, 2013, p. 42). High levels of self-stigmatization may lead to social isolation and rejection in taking antiretroviral therapy (ART), for the reason that some individuals may start thinking that they “deserve” a disease like HIV, for example that HIV is a punishment for their behavior in the past. That is why self-stigma has a primary connection with not accessing health services and controlling the viral load (Herec at al., 2013, p. 44).

Self-stigma, which is formed through an association with a broader group of HIV positive individuals, decreases the likelihood of HIV disclosure especially to sexual partners, which has a
primary connection with the spread of HIV infection (Bird & Voisin, 2013, p. 2193). Bird and Voisin (2013) describe the way self-stigma may affect sexual behavior of HIV positive MSM. Almost all of the 20 participants in their study expressed awareness about HIV related stigma and concerns of being stigmatized (Bird & Voisin, 2013, p. 2193). The authors highlighted that stigma from family, friends, and society may influence self-stigmatization (Bird & Voisin, 2013, p. 2194). In most of the cases, the perception of the way respondents would be treated by others, because of their HIV status, was intensified by their past and “preinfection” beliefs about HIV positive individuals. For example, most informants associated HIV status with homosexuality (Bird & Voisin, 2013, p. 2195). These “preinfectious” beliefs affected the way newly diagnosed HIV positive individuals were treating the virus in their own bodies and they were not able to become more aware about their infection.

Simbaye et al (2007) investigated the effects of internalized stigma in South Africa, which is one of the regions the most affected with the HIV epidemic. According to Simbayi et al (2007), internalized stigma is correlated with the symptoms of depression and anxiety. The authors identified internalized stigma as an outcome of broader views on AIDS that are assimilated and internalized by infected persons (Simbaye et al, 2007, p. 1824). A survey of 420 HIV-positive men and 643 HIV-positive women conducted by Simbaye et al (2007), found that internalized AIDS stigma scores were higher for men than for women, however women reported higher depression scores and greater social support scores. More than one in three men and women endorsed stigmatizing views towards self; almost a half of the participants also reported being ashamed of their disease, feeling that they deserve to have HIV, and feelings of guilt because of their status (Simbaye et al, p. 1829).
To understand the nature of HIV stigma, it is important to consider the social context in which attitudes about the virus were formed with the influence of power and a culture of dominance. Stigma towards HIV positive individuals should be understood as a complex structure formed not only by ignorance and the low levels of correct information about the virus in society but more importantly by hegemonic group dominance and societal perceptions of an individual with HIV as an outsider or marginalized other.

1.6 Addressing Stigma

1.6.1 Traditional approaches in addressing HIV-related stigma

Community-based interventions could become an important response to the issue of stigma towards PLHIV and self-stigma. However, most of the actions of community projects are targeting prevention of transmission of the virus; they focus less on such issues as self-stigma and barriers to accessing health care programs. Academic circles are outlining such issues as self-stigma based on sexual identity among PLHIV (Bird & Voisin, 2013; Herec at al., 2013; Wohl et al, 2012), but they do not provide an efficient response to these issues compared to community-based interventions, but those tend to focus on providing educational materials, rather than the creation

I believe that it is important to understand the efficacy of community-based projects, so that best practices can be distilled and used as part of established community practices. Creation and evaluation of a community-based project is one of the goals of this thesis research. In order to evaluate the efficacy of community-based interventions, I consider it important to review projects related to the prevention of stigma towards HIV positive individuals in the US and other parts of the world. In recent years, a huge step has been made in addressing the issue of HIV-related stigma in and outside of the scientific community (Grossman & Stangl, 2013, p. 2). Most of the research related to stigma interventions has been done by health care providers, and most of the programs have been focused on community knowledge
interventions and development of stigma-free healthcare services. These studies suggest that stigma and discrimination reduction does lead to better HIV outcomes, fewer cases of HIV in society, as well as the proven cost-effectiveness of these approaches (Grossman & Stangl, 2013, p. 8). Still, despite the efforts of community-based programs, the issue of stigma creates barriers to PLHIV in access to testing, retention in care, and adherence to antiretroviral therapy (Grossman & Stangl, 2013, p. 4). In order to reduce stigma towards PLHIV, interventions are needed on several levels such as: individual, interpersonal, organizational, community, and public policy (Grossman & Stangl, 2013, p. 3). Grossman and Stangl (2013) are calling for a global response to HIV-related stigma, however, they stress the point that most of the action should be done at the local levels because PLHIV experience prejudice and discrimination at the individual level, during face-to-face interactions. HIV and stigma towards individuals with HIV should be understood as an issue within the global community, but to provide an efficient response to this issue, communities should be empowered for action on the national and local levels.

The evaluation of the community-based projects related to eradication of stigma and discrimination is very important in order to understand the efficiency of community-based interventions in response to HIV. One example of these types of projects has been done in Thailand in order to evaluate the efficiency of HIV educational programs (Jain et al., 2013). The evaluation program of Jain et al. (2013) contained four major activities: educational activities about HIV, e.g. inviting a person with HIV to share her/his story, HIV campaigns, information and education materials, and “funfairs” (Jain et al., 2013, p.1). According to the results of the community-based project, participants who were exposed to project activities were more likely to have a reduction in the fear of HIV infection, (Jain et al., 2013, p. 7).

Another example of an educational project to address stigma is the Barbershop Talk With Brothers (BTWB) program, a community-based intervention that seeks to reduce sexual risks
among heterosexual black men in the New York (Wilson et al, 2014). The BTWB program is an alternative to health institution-based programs in that they are using the barbershop as a vehicle for communication with an at-risk community in New York. In-depth talks with participants of the project include such topics as masculinity, partner selection, HIV testing and prevention, and myths and stigma surrounding HIV. The main purposes of the program were to provide education to black men and to build positive perceptions about HIV positive people and homosexual individuals (Wilson et al, 2014, p. 393). Based on the results of the BTWB program, authors suggest that this type of project may be effective in terms of providing education related to safe sexual behavior, however it may not be as effective in shifting men’s stigma toward PLHIV. This means that despite the fact that individuals are learning more about virus transmission, they still have stigmatized attitudes about HIV, due to its complexity as it is formed by various layers of stigmatized attitudes but also because of the linkage to hegemonic power and culture (Wilson et al, 2014, p. 394).

Despite the fact that some education-related interventions can lower the level of stigma towards PLHIV, this effort may not be enough. Stigma towards HIV positive individuals has a complex structure, as it is associated with deviant behavior and nontraditional sexuality. Education about the way of transmission of the virus may serve to lower the stereotypes and myths related to the way a person might become infected, but it will not be as effective in dealing with the issue of stigma for the reasoning behind the judgment of one’s behavior. For that reason, additional approaches to addressing sigma are needed. Parker and Aggleton (2003) stress that the most efficient stigma prevention programs are those that are designed “with the goal of unleashing the power of resistance on the part of stigmatized population and communities” hence they recommend prevention programs to focus on such issues as community mobilization and
empowerment (p. 21). Community mobilization and empowerment should be primary targeting stigmatized populations, in this case HIV positive individuals, which is why they need to be seen as the main agents in the stigma prevention programs.

1.6.2 Art responses to stigma

I consider it important to uncover nontraditional ways of HIV-stigma prevention through the tools of art and community art projects. The use of art techniques in response to stigma and discrimination have appeared recently as effective methods for stigma prevention, and have been gaining momentum in the recent decade. Some examples have started to appear in academic journals, which reflects the growing acknowledgment of this tool within academic circles. For instance, Storey, a social worker, has represented stigma towards HIV positive people in acrylic painting (Fee, 2013). According to Fee “Storey’s primary goals were to counsel clients who tested HIV positive people about how to deal with the social stigma of AIDS, how to advocate for themselves with others, and allow for creative solutions in dealing with the oppressive constraints of stigma” (p. 1747).

In some cases social art projects are done to increase the level of awareness in the community in response to a particular issue. Moya and Nunez (2013) mobilized the project Nuestra Casa (Our Home, in English), which was created in order to increase the level of awareness about tuberculosis (TB) in border communities. One of the most important outcomes from the project was dispelling social stigmas that were associated with TB. This was done by presenting the personal stories of people infected with TB to the visitors of the exhibit. As noted by one of the visitors: “I have opened my eyes and my heart to understanding them and to comprehend what a person has to go through when diagnosed with tuberculosis” (Moya & Nunez, 2013, p. 131). This type of project focused not only on prevention of a disease, but also on reducing the negative
connotations towards someone with the infection. In the case of HIV, this approach can be effective, as it will help to acknowledge the suffering of a person who has been diagnosed with the virus and to bring sympathy through the messages of art.

Another form for bringing awareness to social issues is through theater. Although theater is still considered to be an innovative approach of working with the community, I consider it important to uncover its potential and explain the way it can be used with vulnerable groups as a mean for empowerment and as a tool for advocacy. Theater is one of the innovative techniques that can be used to create a social response to a particular issue (e.g., stigma) and to promote the rights of oppressed groups. According to Hooks: “Often when the radical voice speaks about domination, we are speaking about those who dominate” (Prentki & Preston, 1990, p. 80). The end of the 20th century characterized the rise of artists who were demonstrating their personal story as a social issue, arguing the importance of the individual's problems as political. Hooks (1990) was one of those artists. He was involved in these practices by the means of art, literature, and theater.

1.6.3. Theater as a tool for empowerment

Using theater as a practice for resistance took its tradition from two mainstream strands of pedagogy: Brazilian educator Freire, and European models of informal education (Nicholson, 2005, p. 9). Freire was mostly preoccupied with the issues of adult literacy in Brazil. He saw the solution to this problem in the use of improvisation and dramatic play. Singhal et al (2004) evaluated how Freire was establishing adult literacy programs, stating that he was in charge of creating a theater-based approach for empowerment of underserved communities. For instance, Freire developed theater methodology for education of the illiterate adult population in Brazil about their rights and freedoms. Singhal et al (2004) created a manual in support for community activists who are using theater for participatory theater engagement in the community. They
describe and evaluate such topics as using entertainment as an educational tool for empowerment. Besides, theater is possible to use in order to build better perceptions of self amongst marginalized groups of population (pp.41-43).

Freire’s tradition to implement theater in the community became a major influence for one of the leading figures in the field of applied theater, Augusto Boal, who created the “Theatre of the oppressed” (Boal, 1974, p. 1). For Boal (1974), theater and politics were two components of one body: “Those who try to separate theater from politics try to lead us into error – and this is a political attitude” (Boal, 1974, p. 1). He created a whole generation of advocates that were using theater to promote political statements to the authorities. Boal (1974) was influenced by Marx's ideas, however, he believed in a peaceful way of dealing with oppression. The main instrument he proposed for peaceful conflict resolution was theater: “Maybe the theater in itself is not revolutionary, but it is without a doubt a rehearsal of revolution” (Boal, 1974, p. 141). For revolution, Boal (1974) proposes forum theater, where the audience is actively engaged in the performance and they might discover their ideas on their own (p. 139).

Boal (1974) emphasized that forum theater (or the theater of the oppressed) is a tool for the proletariat, because bourgeoisie theater (he was talking about the classical type of performance, the mainstream theater) is a “finished theater” (Boal, 1974, p. 143). By this, he meant that the bourgeoisie presented the images of certain groups of people (i.e., the wealthy), that are the minority in a quantitative sense, in the theater performances as if they were representative of all people. For Boal (1974), bourgeoisie theater lost its importance, because it did not present the actual issues outside of bourgeoisie circles. In contrast, proletariat theater can represent the ideas of a majority of oppressed groups, for example, the periphery of the working class in a particular country. This makes the forum theater of Boal (1974) a tool to work with the groups of oppressed
individuals that might face stigma and domination more than others might. For example, this includes people who live with HIV and exposed to stigma and discrimination in their daily interactions.

Based on the theory of Boal (1974), using theater in the practices of education and empowerment is becoming a popular practice amongst community activists. For instance, Wernick et al (2014) demonstrate it by applying the theater approach for the support of LGBTIQ youth in the unfriendly school environment. Experiences of bullying and discrimination and a hostile school environment may negatively affect the psychological well-being of LGBTIQ young people. The goal of the research presented by Wernick et al. (2014) was to test the hypothesis that through theater, marginalized youth may develop the sense of belonging, develop a productive outlet for feelings like anger and frustration, and contribute to increasing their civic engagement (p. 840). Wernick et al (2014) provided a series of workshops over six months with the final result being a theater project that integrated LGBTIQ youth. According to the results of their research, theater may be a powerful strategy for empowerment. For example, personal storytelling through theater exercises helps to reduce personal isolation and builds community through sharing experiences of discrimination and harassment. In this study, theater helped to LGBTIG youth to build the sense of belonging with others and “connect them with others through the collective struggle” which means to get united with the other students against an unfriendly environment. Theater also allowed participants to politicize their experience and to build a critical consciousness about certain topics through the process of hearing others and the process of engaging in a critical analysis of oppression (Wernick et al., 2014). Besides that, theater and storytelling provide opportunities for participants to act as “changed agents”, which means to talk from their personal experiences but by using the names of others (pp. 842-846). Wernick et al.’s (2014) study suggests
that I may find similar patterns among people living with HIV, many of whom represent the LGBTIQ community.

Besides the theoretical ideas that theater may be used as a tool for community work to uncover the issues that are faced by oppressed groups of population, I want to bring an example from the practices of social work acknowledged by Boehm and Boehm (2003). The authors argue that theater in combination with social work can be a powerful manual for empowerment especially in terms of self-esteem, mastery, and critical awareness (Beohm and Boehm, 2003, p. 285). They see community theater, or theater-based interventions, as a type of theater that is critical about political issues and based on participatory approaches (when the community group is engaged in the theater production during all stages of the project) (Beohm and Boehm, 2003, p. 285). Boehm and Boehm (2003) consider community theater in social work as a powerful tool and argue that it has the possibility “to assist the oppressed group who experienced a loss of power to better understand and address the role that powerlessness plays in perpetrating personal and social problems” (pp. 285-286). By using the example of a community theater project with migrant women of Jaffa (town near Tel Aviv), the authors described the positive effects of the project, such as the rise of self-esteem, sense of confidence, and pride in the abilities and talents of the participating women (Beohm and Boehm, 2003, p. 294). This study suggests that theater can be one of the ways to assist in this process of social mobilization.

1.6.4 Theater for addressing HIV-related stigma

Theater projects related to HIV prevention are usually used with the purpose of education about safe sexual behavior and HIV transmission. For example, one project, called the PALMS, sought to prevent AIDS in the juvenile detention system through live movement and sound (Lauby
et al, 2010, p. 402). The six month long PALMS project targeted African American juveniles with the goal of educating them about safe sexual behavior and changing their attitudes towards HIV testing. The program has proven its efficiency, as the participants were more likely to start using condoms because of this educational practice (Lauby et al, 2010, p. 408). Programs such as PALMS, which include a theater component, could be a potential resource for education and changing attitudes towards HIV infection and the ways of its transmission, which has the potential for lowering the stigma to HIV as a contagious infection.

In the case of prevention of HIV and stigma towards PLHIV, theater interventions were applied in the rural areas of sub-Saharan Africa. One example is the Ola Johansson’s project in Tanzania. Johansson (2011) was arguing that using theater is crucial in educating young people: “Urbanized young spectators may openly mock shows that appear absolute, while people from older rural communities might do the same at progressive performances. That is the first auspicious premise of community-based theater: it is a highly mobile and challenging phenomenon, which cuts through cultural layers of time and space as well as democratic, and generation differences” (pp. 4-5). This type of theater is very effective in preventing stigma towards HIV positive people, as community members organize theatrical performance themselves and face the reality of someone who lives with HIV.

Auger and Heather (2005) described the way in which theater was used in mobilizing rural aboriginal population around issues of HIV in Canada through the performance My people’s Blood. The project was planned by one of the authors in order to begin a public discussion about the problems of sexuality and further actions for prevention of HIV (Auger & Heather, 2005, p.281). The main goal of the project was to create drama that would provide visibility to the issue of HIV, and would break the barriers that stop adults from discussing topics related to sexuality with their
children. The first step of the project was to recruit young indigenous people to form a group of co-researchers and actors. The second step was to create three short theater performances that were presented to over two hundred community members in a third step. The main point of My people's Blood project was to lower the level of negative prejudice towards people living with HIV in small rural areas of Alberta. The main difficulties faced by the author were the troubles of working with community members in creating the project, as most of the participants feared talking about such issues: “each participant wanted to take that power, but each was weighted down by fear” (Auger & Heather, 2005, p.289). The fear of talking about HIV is likely one of the barriers in doing socially oriented theater performances and any theater-based intervention.

1.7 Conclusion to the Literature Review

The epidemic of HIV infection has been widely acknowledged and researched in the past thirty years of the existence of the infection. Such important topics as access to Antiretroviral Therapy (ART), health services, stigma and discrimination towards individuals with HIV, and stigma towards at risk groups have been examined. Most of the research related to understanding HIV-stigma is using the theory of Goffman (1963) however some of the articles examine the need to understand the deeper cause of stigma and the way it relates to power and culture (Parker & Aggleton, 2003). Although prevention strategies are usually shifted towards testing and basic education on the issue on HIV, they do not focus on approaches for lowering self-stigma amongst PLHIV. Using art remains an innovative and nontraditional response to the issue of stigma towards HIV positive people, however, we may find growing interest in such techniques, for example, in the works of Fee (2013) and Moya & Nunez, (2013). Theater, as a form of art, becomes a powerful tool to use in educational projects related to HIV transmission as argued by Lauby et al, (2010); Johansson, (2011); and Auger & Heather (2005). Besides that the opportunities of using theater as
a mean for empowerment has been discussed in the practice of social work (Boehm & Boehm, 2003; Wernick et al, 2014).

However, a critical limitation of these studies of previous theater projects is that they do not systematically evaluate the impact of the social theater on the participants. One of the exceptions to this is PALMS project (Lauby et al, 2010). However, the PALMS project was evaluating the educational impact of theater, not how effective theater is for lowering the level of self-stigma and empowerment of the community of PLHIV. There is almost no research on the way theater can be used as a tool for lowering self-stigma and increasing empowerment in the predominately Latino PLHIV community on the border. Another weakness of previous theater studies is that they do not have systematic data collection before been done, to inform its design. In addition, most of the community intervention projects simplify the issue of stigma and the leaders design their projects with the purpose of education instead of concentrating on reducing hegemony of powerful groups while empowering stigmatized individuals. This research seeks to rectify these gaps and proposes the use of theater as a tool for lowering the level of self-stigma among PLHIV on the border communities.
CHAPTER 2: DATA & METHODS

I conducted this research project in two stages of data collection and analysis. First, I examined how stigma affects lives of people living with HIV in the city of El Paso through a series of twelve qualitative interviews. Second, through ongoing community engagement, I conducted a series of four community theater workshops with people living with HIV and evaluated the effects of these workshops on the participants using quantitative and qualitative methods. I will next describe the study area, before describing the data and methods for each stage of the project.

This chapter aims to explain the stages of data collection and analysis. First, I will discuss the study area, and then the way I recruited the participants, collected interviews, and analyzed the data from the interviews for Stage 1 of this study. Second, I will describe the applied part of this project (i.e., Stage 2), which is the theater intervention with HIV positive individuals. I will explain how I recruited the participants for this part of the research project and how I conducted theater workshops with them. It will also include the type of evaluation data that I collected and how I analyzed it.

2.1 Study Area

The city of El Paso represents the sixth largest city in the state of Texas and twenty second largest city in the US. El Paso is located on the border between the US and Mexico and its residents suffer barriers to accessing education and health care. Additionally, the prevalence of many health conditions is higher in the border region than compared to the other regions of the US (cites?). The County of El Paso has a predominantly Latino/a population, as 82% of the population is of Hispanic origin (US Bureau of the Census, 2010).

El Paso County remains one of the poorest in the state of Texas; in 2010 25.5% of the population was living in poverty (US Bureau of the Census, 2010). In 2010, the median household
income was $36,519 and almost 14% of the population had a median household income of $10,000 or below. Almost 20% of adults in El Paso have achieved an academic level of less than the ninth grade and 11.9% of adults had dropped out of from high school (US Bureau of the Census, 2010).

El Paso ranked as the fifth county in the state of Texas in terms of the number of HIV newly diagnosed cases, AIDS cases, and people living with HIV (Texas HIV Surveillance Report, 2013). HIV is a serious issue in the community of El Paso represented by 2,482 cumulative HIV cases (Texas HIV Surveillance Report, 2013). However, very little research has been conducted to understand the issues that are faced by people living with HIV in this area.

2.2 Stage 1 (Understandings Stigma): Data Collection

Stage 1 of the project relied on in-depth interviews with people living with HIV. Interviews were collected through my preexisting connections with the local chapter of International AIDS Empowerment (IAE). I first connected with IAE when I started attending the meetings of the HIV Community Mobilization Program. This local initiative was created to rectify gaps in HIV support and health care coverage in the area of El Paso. During these meetings, I got to know community workers and HIV activists, including the director of IAE. I asked him to assist me in recruiting the participants for my research and he agreed. IAE is a local nonprofit, nongovernmental organization, which has provided HIV-related services for almost 20 years to El Paso and southern New Mexico. IAE is a peer-based organization that is mostly operated by people living with HIV for people living with HIV and targets individuals infected and affected by HIV. IAE’s main aims are to improve the quality of life for people living with HIV/AIDS regionally, nationally and internationally and to reduce the incidence of new infections through education, outreach, and testing. It provides such services as: HIV testing, HIV education, support groups for people living with HIV, support for local LGBTIQ youth, housing for people living with HIV, and a pet shelter.
For the recruitment of the participants, I created a flyer (Appendix A) in English that included information about the research and my contact information. The flyers were distributed among the clients of IAE. If the person was interested in participating in the study, she/he filled in the flyer and left it with one of the staff members (e.g. his/her counselor). After that, I called each interested participant to arrange the meeting for the interview. The participants chose a convenient day, time, and location. In total, I contacted twenty individuals but only twelve participated in the study. The reason why contacted individuals were not interviewed was because they did not show up for their scheduled interview. Most (n=10) of the interviews were conducted in a private library room at the office of IAE. Some (n=2) of the participants were not interviewed at the office of IAE due to transportation issues or concern for privacy.

The interviews lasted from fifty-five minutes to two hours. Overall, participants mentioned that being interviewed was a positive experience for them, because it helped them to release the extra stress and pressure from being closed about the topic of HIV in their lives. A short demographic survey (Appendix B) and interview guide (Appendix C) were used with each person. At the end of the interview, I asked each participant individually if he/she was interested in participating in the theater workshops. Most of the participants expressed an interest at the time of the interview, however, some were hard to reach a couple months later when the actual workshops took place.

In terms of my participants’ characteristics, there were ten men and two women. Eleven participants self-identified as Hispanic, and one participant who self-identified as non-Hispanic white. All of the participants were born in the US, and some of the participants mentioned crossing the border to Ciudad Juarez in the past, however they had stopped due to safety concern reasons. Seven out of the twelve participants were unemployed and two participants were self-employed.
Half of the participants reported their income as less than $1,999 annual (n=6). Only three out of twelve participants self-identified as heterosexual; nine participants self-identified as gay. The youngest participant was age 23 and the oldest participant was age 57. The majority of the participants had been living with HIV for over ten years, but three of them had been diagnosed with HIV for only a year. Table 2.1 shows the characteristics of each participant.
Table 2.1. Stage 1 Demographic information about the 12 interviewees.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Sex</th>
<th>Sexual Orientation</th>
<th>Marital Status</th>
<th>Years Living with HIV</th>
<th>Ethnicity</th>
<th>Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antonio</td>
<td>46</td>
<td>Male</td>
<td>Homosexual</td>
<td>Single</td>
<td>19</td>
<td>Mexican American</td>
<td>Employed</td>
</tr>
<tr>
<td>Jernando</td>
<td>54</td>
<td>Male</td>
<td>Homosexual</td>
<td>Partner</td>
<td>15</td>
<td>Mexican American</td>
<td>Employed</td>
</tr>
<tr>
<td>Roberto</td>
<td>38</td>
<td>Male</td>
<td>Homosexual</td>
<td>Partner</td>
<td>3</td>
<td>Mexican American</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Tom</td>
<td>50</td>
<td>Male</td>
<td>Homosexual</td>
<td>Single</td>
<td>14</td>
<td>White American</td>
<td>Employed</td>
</tr>
<tr>
<td>Laura</td>
<td>55</td>
<td>Female</td>
<td>Heterosexual</td>
<td>Partner</td>
<td>15</td>
<td>Mexican American</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Diego</td>
<td>23</td>
<td>Male</td>
<td>Homosexual</td>
<td>Single</td>
<td>1</td>
<td>Spanish American</td>
<td>Employed</td>
</tr>
<tr>
<td>Carlos</td>
<td>64</td>
<td>Male</td>
<td>Homosexual</td>
<td>Single</td>
<td>15</td>
<td>Mexican American</td>
<td>Employed</td>
</tr>
<tr>
<td>Fernando</td>
<td>24</td>
<td>Male</td>
<td>Homosexual</td>
<td>Married</td>
<td>4</td>
<td>Mexican American</td>
<td>Employed</td>
</tr>
<tr>
<td>Alejandro</td>
<td>25</td>
<td>Male</td>
<td>Homosexual</td>
<td>Single</td>
<td>1</td>
<td>Mexican American</td>
<td>Self-Employed</td>
</tr>
<tr>
<td>Luna</td>
<td>36</td>
<td>Female</td>
<td>Heterosexual</td>
<td>Partner</td>
<td>1.5</td>
<td>Mexican American</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Emmanuel</td>
<td>56</td>
<td>Male</td>
<td>Homosexual</td>
<td>Single</td>
<td>16</td>
<td>Mexican American</td>
<td>Self-Employed</td>
</tr>
<tr>
<td>Christopher</td>
<td>57</td>
<td>Male</td>
<td>Heterosexual</td>
<td>Married</td>
<td>11</td>
<td>Chicano</td>
<td>Unemployed</td>
</tr>
</tbody>
</table>
2.3 Stage 1: Data Analysis

After the interviews were recorded, they were transcribed and analyzed for common themes using NVivo 10 qualitative software. Through the analysis of the interviews, I identified three common themes in the experiences of stigma among people living with HIV. These categories are: stigma from secondary groups (medical institutions, places of employment, church community), stigma from primary groups (family members, close friends, sexual partners), and impact of HIV on the self-perception of the participants. I draw on Simmel’s (1907) categories of primary and secondary social groups to organize the data. Individuals are more closely tied to their primary groups. Primary groups have a stronger influence on a person’s identity. Such groups in my analysis included close friends, family members, and sexual partners. Members of secondary social groups interact with each other on a less personal level and their relationships may be less lasting compared to primary social groups. In my research, secondary groups are co-workers, church community members, and medical professionals. The influence of HIV on the participants’ self-perception, my third theme, relates to negative perceptions of self because of the person’s HIV positive status with the subthemes: influence of HIV on a daily lifestyle and emotional health, feeling of “being unwanted” in the society, and feeling that “having HIV was a punishment.” In addition to the mentioned themes, I identified fourth theme, which was focused on positive sides of having HIV. In terms of the positive sides of having HIV theme, I identified the subthemes of: healthier lifestyle, interest in the community involvement, or quitting negative habits such as alcohol or drug addiction).

2.4 Stage 2 (Theater Workshops): Data Collection

The goal of Stage 2 is to understand the influence of theater workshops on an individual’s self-perception. Persons living with HIV may experience anxiety and depression because of their
acquired HIV positive status. Negative perceptions about individuals living with HIV may also adversely influence an HIV positive person’s daily activities, social life, and sexual life. During stage 2 of the project I was interested in finding out what changes such participation in theater workshops could bring into the lives of a person living with HIV.

With the permission of the support group leaders, I attended a regular meeting of both the men’s and women’s support groups and presented the idea of conducting theater workshops to the participants. A series of a workshops (n=4) were organized for participants from the support groups held at IAE and one woman from the interview phase who was also a member of the support group. The themes of the workshops were related to acting techniques and improvisation methodologies. The workshops were organized in the office of IAE and were open to all respondents who participated in the study and for participants of the support groups. I decided to conduct the workshops with the support groups serving local people living with HIV after the conclusion that arranging meetings with the interview participants was untenable. I was experiencing challenges finding a time of day to meet that would suit all the participants, besides that, some participants would agree to come at a certain time for the workshops, but then not show up. These challenges can be explained by the voluntary nature of participation in this study; the fact that no incentives were offered; and, most importantly, the myriad challenges faced by participants such as no transportation, family duties, or an unhealthy state that prevented interview participants from attending the theater workshops. That is why I decided, in consultation with IAE, that it would be much more practical to arrange the meeting time for the workshops during the meeting time of the support groups and the organization was supportive and excited about this plan.

For conducting the workshops, I used the Y-Peer training manual (Theater Based Techniques for Youth Peer Education and Training Manual, 2005) and some of the theater
techniques of the Theater of the Oppressed methodology (Boal, 2002). Workshops contained exercises which were designed to help the participants develop improvisational skills, build character creation techniques, and create small scene-performances.
### Table 2.2 Workshop 1. Getting to Know each other. Getting to know theater techniques.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Time spent on the topic</th>
<th>Description of Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Introduction of the</td>
<td>20 minutes</td>
<td>- Participants introduce each other in a creative way by speaking their name loudly and applying a body gesture to their name.</td>
</tr>
<tr>
<td>Participants</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Stating goal and objectives</td>
<td></td>
<td>- Participants discuss their expectations of the workshop (the process is facilitated by the instructor).</td>
</tr>
<tr>
<td>of the workshop</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ice-Braking Exercises</td>
<td></td>
<td>- Each participant imagines that they have any type of play ball in their possession. The participants are given a few minutes to establish the nature of their ball (e.g., what it feels like, what kind of ball it is, how it is played with) and decide on a repetitive rhythmic action and sound that they will practice during this exercise. When they have decided on what they are doing, the instructor instructs the participants to walk around the space holding their imaginary ball. After a few minutes the instructor says, ‘Find a partner’. When the participants are paired up, they must continue playing with their ball using their repetitive rhythmic action and sound, but simultaneously should each observe their partners every movement.</td>
</tr>
<tr>
<td>The “Peruvian ball exercise”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- The actor as “subject”</td>
<td>30 minutes</td>
<td>- One person stands in the middle of the circle, while the other people stand around her/him. The person starts the movement, and the other people in the circle should repeat the movements after the person.</td>
</tr>
<tr>
<td>- Dissociate coordinated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>movements</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Participants walk around the space. The instructor touches the shoulder of one of the participants and the participant should start making dissociating sound and movement. Everyone else in the room should repeat after the participant. Each time instructor touches the shoulder of a different participant, the others in the room should repeat the sound and the movement after the person who makes the sound.

<table>
<thead>
<tr>
<th>Rhythm exercises (Zip Zap Zop)</th>
<th>20 minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Everyone stands in a circle. The group repeats the words “Zip, Zap, Zop” three or four times, all together. To start the game, a bolt of energy is sent with a strong forward motion straight to someone else in the circle (using hands, body, eyes, and voice) saying “Zip.” One of the participants receive it with their whole body and pass it immediately to someone else saying “Zap.” That person passes it on with a “Zop.” The exercise continues “Zip, Zap, Zop.”</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Improvisational Exercises (Who? Where? What?)</th>
<th>10 minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants stand in 2 lines, one in front of another. Participants imagine a small scene (but do not communicate the context of the scene with the person in front). When the instructor claps her hand participants present the scene in three sentences, highlighting three main points of the scene (who is in the scene, where the scene is taking place, and what is happening in the moment).</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mirror exercise, working with the partner on the stage</th>
<th>10 minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants form two lines that are parallel to each other, the participants in Line A are the ‘subjects’ and those in Line B are the ‘images’. Each ‘subject’ must complete a series of movements and expressions by which the ‘image’ in Line B must copy. The exercises objective is to produce a synchronization of movements between the ‘subjects’ and their ‘images’.</td>
<td></td>
</tr>
<tr>
<td>Closing circle</td>
<td>10 minutes</td>
</tr>
</tbody>
</table>

**Note:** Conducted on the 28th of April 2015 with the Women’s Support Group and the 4th of October 2015 with the Men’s Support Group.
Table 2.3 Workshop 2. Improvisation techniques & Stating the issue.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Time spent on the topic</th>
<th>Description of Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>-Opening of the workshop</td>
<td>15 minutes</td>
<td>-Participants discuss their expectations of the workshop.</td>
</tr>
<tr>
<td>-Team Building exercises</td>
<td></td>
<td>-Participants find a partner and share the stories behind their physical scars (how did they get them, what was the story behind their physical scars).</td>
</tr>
<tr>
<td>Work on the development of the topic</td>
<td>45 minutes</td>
<td>-Participants use sticker notes to write about the topic of HIV in their lives and what they think is important to visualize about this topic. Sticker notes are shared with the instructor and the instructor facilitates the process of discussion.</td>
</tr>
<tr>
<td>-What do you want to say about the HIV problem?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-What attitudes do you want to change?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-No dialogue line</td>
<td>20 minutes</td>
<td>-Participants divide into pairs and create scenes without dialogue. Participants present the scenes to the audience. The task of the audience is to guess what the scene is about.</td>
</tr>
<tr>
<td>-Forum theater exercise</td>
<td></td>
<td>-Two participants go in front of the group and start improvising a theater scene. Anybody from the group may clap their hands, stop the scene, and replace one of the participants on the stage. The person has the choice to go with the previous improvisation line or start her/his own.</td>
</tr>
</tbody>
</table>
The support groups at IAE are divided by gender and meet at different times. Participants of both the men’s and women’s support groups expressed their interest in the workshops, which allowed me to arrange workshops during the meeting time of the support groups (Tuesday 11:00 am for women during April-May and Tuesday 10:30 am for men during October). Each workshop lasted approximately 1 hour and 30 minutes. I conducted a total of four workshops, two with the members of women’s support group and two with the members of men’s support group. Thirteen people participated in the theater workshops (with n=8 for the first women’s workshop and n=6 for the second women’s workshop; n=5 for both men’s workshops with the same people for both workshops); information about these individuals is included in Table 2.4.

After each workshop, each participant filled out a short survey that asked him/her evaluate the quality of the workshop, what he/she liked or did not like about the workshop, and his/her interest in creating a theater performance at a later date. A copy of this instrument can be found in Appendix D. In addition, I conducted evaluation follow-up interviews with a subset of participants who expressed their willingness and were available to participate in the interviews. The interviews relate to the person’s experiences during the workshops, including the overall quality of the experience, and any emotional changes that occurred after the workshops. There was a time gap of one week in between the workshops with the participants and the interview. I also asked the participants about their interest to participate in the creation of a theater performance that may
come out as a result of the workshops, which has not yet been planned or conducted (December 2015). The post-workshop interview guide is located in Appendix E.

Specifically, I have collected two interviews (n=2) with women participants and one interview (n=1) with a man. Furthermore, I collected one interview (n=1) with the leader of the women support group, who has over four years of experience of leading a support group in IAE and who also participated in the theater workshops. I consider it important to present the opinion of the leader of the support group in this research. First, this will demonstrate the opinion of the professional who has experience working with HIV positive individuals. Second, coincidentally, the leader of the support group has a professional theater education, and has previous experience in applying theater interventions with socially marginalized populations. I will discuss the interview with the leader of the support group separately from the interview with the participants.
## Table 2.4 Stage 2 Demographic information about the 13 workshop participants

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Year living with HIV</th>
<th>Age</th>
<th>Sex</th>
<th>Ethnicity</th>
<th>Marital Status</th>
<th>Surveyed</th>
<th>Interviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marina</td>
<td>8</td>
<td>55</td>
<td>Female</td>
<td>Mexican American</td>
<td>Married</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Paula</td>
<td>11</td>
<td>46</td>
<td>Female</td>
<td>Mexican American</td>
<td>Partner</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Andrea</td>
<td>11</td>
<td>48</td>
<td>Female</td>
<td>Mexican American</td>
<td>Partner</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Angela</td>
<td>6</td>
<td>54</td>
<td>Female</td>
<td>Mexican American</td>
<td>Single</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Laura</td>
<td>15</td>
<td>55</td>
<td>Female</td>
<td>Mexican American</td>
<td>Partner</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Sinthia</td>
<td>8</td>
<td>53</td>
<td>Female</td>
<td>Mexican American</td>
<td>Married</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Monica</td>
<td>10</td>
<td>61</td>
<td>Female</td>
<td>Mexican American</td>
<td>Single</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Lizabeth</td>
<td>7</td>
<td>58</td>
<td>Female</td>
<td>Mexican American</td>
<td>Married</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Eduardo</td>
<td>5</td>
<td>51</td>
<td>Male</td>
<td>Mexican American</td>
<td>Partner</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Bertran</td>
<td>28</td>
<td>68</td>
<td>Male</td>
<td>Mexican American</td>
<td>Divorced</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Alexandro</td>
<td>6</td>
<td>60</td>
<td>Male</td>
<td>Mexican American</td>
<td>Single</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Santiago</td>
<td>11</td>
<td>50</td>
<td>Male</td>
<td>Mexican American</td>
<td>Single</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Luis</td>
<td>3</td>
<td>48</td>
<td>Male</td>
<td>Mexican</td>
<td>Partner</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
2.5 Stage 2: Data Analysis

Post-workshop surveys were analyzed using Microsoft Excel spreadsheets. I calculated the mean scores for each survey item for each workshop. I also used write-in comments mentioned by the participants in the surveys to support the analysis of the surveys.

In terms of the qualitative evaluation, after the interviews were recorded, they were transcribed and analyzed for common themes. Through the analysis of the interviews, I identified common themes in the experiences of the participants from their participation in the workshops. The themes were the effects of the theater workshops on the emotional condition of the participants, evaluation of the theater workshops, and the suggestions for the improvement of the workshops.
CHAPTER 3: RESULTS

In the Chapter 3 of this thesis, I will report results of the interviews conducted with the participants during Stage 1 and evaluation of the theater intervention surveys and interviews conducted with the participants during Stage 2. For Stage 1, I will start be introducing the profile of the participants followed by analysis of interviews divided by four main themes: stigma from secondary social groups, stigma from primary social groups, impact of stigmatized attitudes on individual’s self-perception, and positive sides of having HIV.

Results of the analysis of the in-depth interviews that I conducted with 12 people living with HIV (PLHIV) are presented in this chapter first, before Stage 2 results. Most of the participants (n=10) have been infected with HIV through consensual sexual contact. One of the participants reported getting infected through intravenous drug use and another through rape. All of the participants have experienced stigma in their lives due to their HIV positive status, but the source of this stigma varies depending on how open the person is about her/his HIV status. Such factors as how many years the person has lived with HIV, or whom the person chooses to disclose the information to about her/his HIV, influences experiences with stigma from society. Amongst the participants in the study, only three out of the twelve are completely open about their HIV status. This includes at their place of employment, and to family members and close friends. Even though most of the participants reported disclosing their HIV positive status to their sexual partners, they mentioned that they prefer not to disclose in case of protected sexual contact, but they do disclose in case of unprotected sexual contact (e.g., when not using condoms). Ten out of twelve participants are open about their HIV in their closest relationships, for example to their best friends or to their family members. Two participants live with a closed status, which means they
do not disclose the information about their HIV to anybody who is not their counselor or medical professional.

It was notable that my interviews revealed some positive sides of having HIV, with two participants mentioned that becoming HIV positive was a “life changing experience.” For example, the way HIV influences opportunities for increased community engagement, becoming closer to family, and prompting changes negative habits (e.g. alcohol, drugs, unhealthy eating). Most of the participants noticed the positive changes in their behavior.

In what follows, I will present the analysis of stigma under three main themes, which emerged during the coding of the data. These themes are 1) stigma from secondary social groups (e.g. medical professionals, place of employment, church community), 2) stigma from primary social groups (e.g. family, close friends, and sexual partners), 3) impacts of stigma on participants’ self-perception. I will also acknowledge 4) positive sides of having HIV and HIV-related stigma and discuss it in my thesis.

3.1 Stage 1: Stigma from Secondary Social Groups

3.1.1 Place of employment

Stigma experienced by the participants from their secondary social groups remains a difficult issue for PLHIV in El Paso. For example, four participants reported experiencing stigma from their coworkers or employers, and in only one of these cases was it the choice of the participant to openly disclose her HIV status to co-workers. In the other three cases the status of an individual was disclosed without consent by his employers. For the most part, these experiences of stigma were related to the false perceptions of how HIV can be transmitted from one person to another. This was the case for Laura, a fifty five year old woman who has lived with HIV for over
fifteen years and has been open about her status to her coworkers and employers. Laura decided to live with an open status as a statement to destroy negative perceptions about HIV in society, and to prevent young people from getting the virus. Because of this, Laura had troubles in the main office of the Goodwill thrift store where she used to be employed. She said: “And the main office knew that I am HIV positive, but they did not know that the manager will put me out there where you can get poked [get pricked by a sharp needle (what do people do with needles at Goodwill? Explain)]. So the girl [co-worker] was worried that she can get HIV from me. So they called me to the main office and I had to talk to them.” Laura did not lose her job at Goodwill at that time; however, the manager of the store did not want Laura to take job responsibilities where she could “potentially infect other employees.” This demonstrates the low level of knowledge on how a person can transmit HIV to others. The co-worker of Laura was assuming that she could get HIV from her if she will get in contact with Laura’s blood. In addition, the fact that Laura was open about her HIV status at her place of employment created a situation where some of her coworkers tried to avoid working with her. This creates uncomfortable working conditions for a person who is HIV positive. For instance, Emmanuel, a fifty six year old gay man who never disclosed his status to employers but suspected that they knew about his disease because of the insurance bills, experienced discomfort at the factory where he used to work. He stated, “I was at the factory I got cut at the machine. I was [in] quality control and they rushed me, bandaged me. I went to the cafeteria, took my coffee and came to the window…they [co-workers] were washing the whole place and they had the masks over their faces. I was like ‘Oh my gosh’…I told know about me.” This incident was very stigmatizing to Emmanuel and it influenced his decision to leave his place of employment.
3.1.2 Church Community

People at church are another secondary group from which PLHIV may experience stigma. This is unfortunate since religion could become an important source of support and comfort for individuals with HIV. Even though nine out of twelve participants reported being religious, with eight people being Christian and one person being Jewish, only five participants reported attending church regularly. Only three individuals were open with their church community or with their religious leader about their HIV status by openly talking about it. One of these participants reported being a part of a very small church community, which became a strong source of emotional support when dealing with her HIV. The most common response from participants who do attend church services but are not open about their HIV is that there is “no need” to let the church community know about it and that they do not want people to “worry about them”.

Of the three participants who were open about their status at church, one participant reported experiencing stigma from the religious leader in his church. Christopher, a fifty seven year old Chicano man, has been living with HIV for eleven years. He self-identified as a Catholic Christian, and he talked about his HIV with the Priest at the church where he goes every Sunday with his wife. He explained, “I told, one time to the Priest who got us married at St. Patrick’s, and he kind of…he was kind of…not very…because he…because when he was giving the communion, he would not let me drink out of the wine. And I knew why….oh it hurt me a lot, a lot.” Experiences of stigma from such social institutions as a church can lead to emotional traumas, as was the case for Christopher who was very hurt by the Priest’s action. It can also contribute to avoiding meetings with the church members or to changing the church where the participant used to go, as mentioned by Christopher during the interview. After this case, Christopher continued to attend
services at the same church, but he tried to avoid meeting with the Priest and lost some trust in the church community members.

3.1.3 Medical institutions

Stigma from medical professionals remains an obstacle in accessing timely medical services and building trustworthy relationships with medical professionals. Although most of the participants reported never experiencing stigma from medical professionals, some of them reported being told incorrect information about the way they can transmit HIV to people around them. Besides the incorrect information, participants experienced negative judgments of their behavior both in verbal (e.g., through negative comments) and nonverbal (e.g., facial expressions, tone of voice) ways.

Christopher, previously introduced, reported that his doctor prohibited him from having a sexual relationship with his wife because of his HIV. Christopher recounted this conversation with the doctor from the emergency room: “And then he asked me: ‘Are you having sexual intercourse with your wife?’ I said ‘Yes, but I am using protection’, and he says: ‘Don’t you know that you can kill your wife?’ And when he said that, it hurt me.” Christopher never returned to the clinic where he had this talk with the doctor. He started having a fear of disclosure to medical professionals who are supposed to provide individuals living with HIV with correct information and stigma free services. Christopher mentioned that after this happened, he had to change his clinic and find a new physician.

False information provided by medical professionals may influence a person’s attitudes on what is allowed for someone who has HIV and what is not, for instance when applying for specific jobs. This false information may be caused by stigmatized attitudes of medical professionals or by
the low level of information they receive about the way infection may be transmitted from one person to another. To illustrate this I will use the story of Diego, a twenty three year old gay man who has lived with HIV for only one year. He mentioned that his newly discovered HIV stopped him from applying for a position in the police and security sector: “When I went to Roswell [a small city in NM, USA], the nurses did not know anything. This was their first HIV case. I know for sure that in their heads they were judging, even though they are not supposed to because of the medical profession. They told me I could not get into protective services, because it is a lot of grappling and a lot of sweat. I was not so sure at that moment of time if it is true or not.” Such cases may strongly affect the level of trust to the medical professionals from their clients. Even if the medical professional is not openly stigmatizing HIV positive individuals, the way they behave with their client and talk to them about their HIV status remains important. Diego received false information about his career opportunities and he did not apply for that job. Besides that, he had feelings of emotional discomfort when talking to the nurse and was left unsure as to if he should trust her advice or not.

3.2 Stage 1: Stigma from Primary Social Groups

3.2.1 Family members

Most of the participants reported that their family was an important source of social support when dealing with their HIV status. In the study, ten participants reported disclosing their status to their family members eventually, but only two participants reported disclosing their status as soon as they found out about it. For others it took a longer time to talk to their families. Two participants reporting not disclosing their status to their family because “they do not need to know” or “they do not need this extra pressure.” Five participants reported experiencing stigma from their family mostly in the form of not sharing dishes or a bathroom with them. For example, Emmanuel,
previously introduced, reported that his family did not want to eat from the same dishes as him anymore, and that his family excluded him from helping with the food preparation. For example, he stated, “My sister would first wash everything after me all the time, and she would not let me touch the food. She would be like: “No, no, I’ll cut the lettuce.” These actions were stigmatizing for Emmanuel because it affected his self-esteem and made meetings with his sister less frequent as mentioned during the interview.

The two most common reactions of the family members after they were told about the HIV positive status of the participant was the fear that they would get HIV from the infected family member and the fear of losing the interview participant to her/his HIV positive status. Both of these patterns appeared during the interview with Fernando when he described telling his family. Fernando is a twenty five year old Latino, gay man who lived with HIV for the past three years. According to Fernando, “My mom got really bad…For eight months she was in denial that I have HIV. My dad accepted that I have HIV, but he thought that I am going to die that way. My brother was more afraid that I will infect my family.” The fear that the infected family member may pass HIV to the other family members is a clear example of how stigma may affect distancing from family members of HIV infected individuals. As mentioned by Fernando, after he disclosed his HIV positive status and his homosexuality, he had to leave his family and his house immediately:

He recalled, “And I left the home and it was very cold. I did not have my passport and my contact case, something like that, I was wearing a T-shirt and jeans, that was how I left”.

Disclosing HIV positive status to a family member can be more complicated when someone self-identifies as homosexual and has never disclosed this fact to their family members. This also has a strong influence on the decision to disclose to the family as an individual with HIV may decide that disclosure of HIV status will lead to the disclosure of the sexual orientation. This
is because some of the participants felt that the need to disclose their HIV status meant that they also had to disclose their sexual orientation. In some cases, participants who were open about their homosexuality had already been receiving negative comments from the family members, which made disclosing the fact of their HIV more challenging. This is illustrated in the story of Alejandro, a twenty-five-year-old gay man who lived with HIV for the past two years and was open about his sexual orientation with his family members. He chose to disclose his status to his family the same date he found out about his HIV. He stated, “It was just hard for me to let them accept it the way it is. My family is very…we say a lot of things. A lot of hurtful things. My grandpa was like ‘If you would not have done this [having sexual relationships with men] you would not have gotten this [HIV]’.” The choice not to tell one’s family, because of the fear of stigma, can be very painful for PLHIV. Diego, previously introduced, has disclosed his sexual orientation and his HIV to some of his family members, but not to other relatives, including his mother. He tends to disclose his HIV status to the family members who are already familiar with the fact that he is homosexual. Diego feels that not all of his family members “will understand him” hence will be blaming him for becoming HIV positive and that some of his family members “are not educated enough” to understand that he is not a threat to others. He said: “I still need to tell my mom…But I will tell her very soon. I would prefer my aunt to talk to her first, hopefully she can give her more knowledge before, because my mom is not….smart.” Not having told his mother and fearing her rejection has caused emotional discomfort and stress for Diego.

### 3.2.2 Close Friends

Most of the participants who are open about their HIV with their family members also disclose their status to their friends, however, only to those close friends with whom they have a trustworthy relationship. Many participants mentioned that having HIV helped them to identify
who were their “true friends.” So called “true friends” were described as people who want to continue communication with the participants despite their HIV status. Roberto, a thirty six year old man who has lived with HIV for the past three years, is open about his HIV status in most settings. Roberto is actively engaged in community activism with the main mission to eradicate stigma towards people living with HIV. He speaks to some of his friends about his HIV positive status; however, it makes him vulnerable to experiencing stigma from some of his friends. He remarked, “I noticed the difference…as far as not wanting to get together as much, I guess. It was at the beginning, when they were not educated. But the more I learned, the more I shared. At the beginning, I mentioned stepping back from some of my friends.” Roberto faced distancing from some of his friends with whom he was open about his HIV. In his opinion the more educated people are about the way HIV can be transmitted from one person to another, the less stigma towards PLHIV will exist in the society. Roberto mentioned that he also works as an HIV educator for young gay men, which helps him to educate other people about an issue of HIV. However, he does not disclose his status during education sessions as he has a fear of experiencing stigma. This shows that even despite the fact of Roberto considers himself to be “open” about his HIV, he is still fears rejection due to his status, as he stated: “I think I have never felt discrimination per se, but I have never put myself in that situation. Going public. I am gay and I am HIV positive, I don’t throw it into people’s faces. Because if you did, they might throw something at you.”

True friends can shelter PLHIV from stigma and even help them overcome self-stigma. This is the case for Luna, a thirty six year old mother of four children, who has lived with HIV for the past two years. Luna mentioned that she has the fear of transferring HIV to other people, which makes her avoiding physical contact (e.g. hugs, kisses) with her friends. She explained, “I have told several people that I have HIV. I have told people that it is all right if they don’t want to be
my friend anymore, or if they are scared to touch me. That I understand. And if anything, it was a complete opposite, people would say: ‘Come and give me a hug, my poor thing, you’ll get through this’. So, I get a lot of positive feedback.’’ Luna is stigmatizing herself for having HIV, but the support she is getting from her friends does help her to feel better, as she mentioned during the interview.

3.2.3 Sexual Partners

Nine out of twelve participants reported disclosing their HIV positive status to their sexual partners when they practice unprotected sex. When they use protection (e.g. condoms), they sometimes disclose their status but sometimes do not. The other three participants reported that they prefer not to disclose their status to their partners but that they always use protection or do not practice anal sex. Out of nine participants who disclose their status to the sexual partners, only two reported very negative reactions from their partners like anger or violence. Roberto, previously introduced, reported “rejection in the future communication” as the most negative reaction he ever received. This “rejection in the future communication” may be experienced in the form of anger from others when he is disclosing his status or from some people stopping future communication with him. He elaborated: “The worst part is that they stop communication. You tell them, and then they tell you: ‘O.K., thank you for telling me’ and then they say bye, and you never see this person again. It is negative in the point that it is a little bit hurtful. You think: ‘Oh wow, he is such a good person and he does not want to talk to me because I have HIV’”.

Participants reported responding in several ways to the challenge of negotiating sexual relationships. They do not disclose their status and practice safe sex; avoid romantic relationships with HIV negative partners; seek out HIV positive partners; or delay telling long-term partners. First, participants who do not disclose their status to sexual partners explain that they have made
this decision due to the fear of facing stigma and rejection. Thomas, a fifty-year-old gay man, reported not experiencing stigma, according to his opinion. However he also reported that does not disclose his status to anyone besides medical professionals or sexual partners in case of unprotected sex. This suggests that he is seeking to avoid a spoiled identity by concealing his status. He remarked: “I…it is very interesting to me. I tend to always allow the person first to ask, and if they ask, I disclose. If they do not ask and I know that we are not going to be practicing unsafe sex, I do not disclose.” The same pattern may be discovered in most of the stories, for instance Alejandro, previously introduced, stated: “Yes I have and it is not very comfortable. I usually tell them before. There are some times when you think that as long as they don’t ask, you can just put the condom on and it will be safe. I am undetectable, so if you put on condom, it is even ten times better.” The fear of disclosure of HIV positive status may be caused by stigmatized attitudes about HIV. Carlos, a sixty four year old gay man who lived with HIV positive status for the past fifteen years too reported always disclosing his HIV positive status in cases where he is going to practice unprotected sex. He reported being rejected because of his HIV in a case where he had disclosed his status. He described, “OK, there was one situation in Las Vegas, where this one guy wanted for us to have sex, and he was very attractive and we’d been out before, you can call it dating. And then I told him. And he got so angry. So, he was upset…” Carlos also mentioned that being rejected because of HIV is inevitable, but not disclosing one’s status to a sexual partner is “illegal” and this should be the main reason for disclosure for people living with HIV. Although, personally, he prefers not to disclose his status in case of protected sexual contact. Despite the fact that disclosure of HIV positive status to sexual partners is obligatory by the law, stigma stops individuals with HIV from disclosure and they try to compensate by practicing safe sex.
Second, others have avoided or terminated serious romantic relationships with HIV-negative partners due to the stigma attached to HIV. For instance, Alejandro decided to leave his HIV-negative boyfriend after he found out about his virus. Alejandro said: “He did not have HIV and we had a lot of unprotected sex. He did not want to leave me, he told me that he still loves me. He did not change…but…I don’t know…I kind of went on the wrong page after. I told him that I don’t want to bring him down.” In this way, Alejandro felt stigmatized and that he had a spoiled identity due to his HIV positive status, even though his boyfriend still loved him, and therefore he decided to leave him. Feeling as though he would “bring down” his boyfriend due to his status reflects the stigma associated with being HIV positive that Alejandro felt.

In terms of the third response to the challenge of sexual partners Jernando, a fifty four year old gay man, explained, “I only go out with those who have HIV. That’s what makes it easy. Because I don’t want to have guilt.” For instance, the “feeling of guilt” is another common pattern in many stories. Most of the participants in other way or another have experienced the “feeling of guilt” mostly when they had to report their HIV status to their sexual partners or family members.

Fourth, fear of losing the relationship may create delays in disclosing HIV positive status to a long-term sexual partner. This may be observed in the story of Laura, previously introduced. Laura disclosed her status to her partner, who does not have HIV, after a year of unprotected sexual contact, as she stated during the interview: “I told him about my HIV after a year of being together. It was very hard, because I was getting serious with him. I did not know how to tell him because he is a person who starts judging…you know what I mean? Right away…he is a strange person, so it was hard to let him know”. She reported disclosure of her status as a very complicated step, as her partner “was not educated about HIV.” After Laura informed him about her HIV status, she told me that he emotionally abused her because of her HIV, “He made me feel bad…we had a fight
and he told me that I am SIDOSA [Spanish translation – a person with AIDS], and that I was podrida [Spanish translation - Rotten]. And that kind of hurt me, because I did not expect him to tell me that, knowing that I already told him and explained it to him…”

3.3 Stage 1: Impact of Stigmatized Attitudes on an Individual’s Self-Perception

Being infected with HIV can cause significant changes in an individual’s self-perception. Only one out of twelve participants reported no changes in self-esteem or in mood after being diagnosed with HIV. However, most of the participants reported significant changes such as: feeling depressed, feeling isolated, not wanting to interact with others, feeling dirty or unwanted, feeling that they lost their chance to have romantic relationships or feeling that they will never be able to have children. Most of these feelings seem to have been formed because of the pre-infection information that the participants had about HIV. Due to the negative perceptions attached to the disease like HIV in broader society, individuals may form negative attitudes about self, as they start blaming themselves for contracting HIV, stating that they “deserve to have HIV”, or “it was their fault so they have to pay for it.”

Accepting an HIV positive status was more difficult for some of the participants. Two participants reported not accepting their HIV positive status for a long period of time, which negatively affected their health, such as delaying the decision to get tested for the virus. For example, Antonio, a forty six year old Latino gay man, who found out about his HIV nineteen years ago, reported not accepting his status until he was on the way to getting AIDS. Antonio reported, “I was in denial for almost ten years, half of the life that I had with HIV. I started getting a lot better. I started getting into the point when you would see me and you would not know that I have AIDS.” Antonio finally accepted his HIV status when he almost died from AIDS. He
mentioned that only the fear of death made him realize that he had to deal with his illness and take care of himself.

Stigma attached to HIV influences daily lifestyle and emotional health of individuals with HIV, mostly due to the fear of disclosing the virus. For instance, Jernando, previously introduced, reported significant changes in his life after being diagnosed with HIV fifteen years ago. He did not leave his house for almost four years. He left his job because of the fear that people may find out of his HIV. He stated, “I wanted to find a job with the safer environment. I wanted a job where I would not know anyone and people would not know me, so I can start with the clear reputation. Sometimes I think that, that was the punishment I needed for contracting the disease. Why did I have to jump in the relationship with that person, when all this happened?” Jernando saw HIV infection as his “punishment” for certain decisions in his life, he blamed himself for becoming HIV positive, which explains why he had a fear of leaving his house.

Another common response in the stories of the participants is the feeling of “being dirty” or being “unwanted” in society. It may also affect individual’s self-perception. Interviewees describe self-perception in terms of experiencing anger or being mad at themselves. Alejandro, previously introduced, reports that his self-perception has changed significantly after he was infected as he explained: “You don’t feel pretty anymore. You don’t feel clean. It is like a stain you cannot get out. Hmm, it is changing you because the way the world taught it to me, the way people talk about it, the way it is advertised. Because you see people publically say that it is bad, it is bad.” Public attitudes about the disease like HIV may influence an individual’s negative perception about it prior to getting infected with the virus as several participants mentioned their fear of disclosing their status because of the way PLHIV are treated in the society. This may affect a person’s self-perception and emotional condition when being diagnosed with HIV.
3.4 Stage 1: Positive Sides of having HIV and HIV-related stigma

In this section I want to discuss the findings related to positive sides of being infected with HIV from the perception of participants. Ten out of twelve participants reported significant positive changes in their lives. One participant reported no changes at all to occur and other participant reported only strongly negative changes from being infected with HIV. Yet, most of the participants reported that HIV was not only a negative experience as it helped them to “change their lifestyle”, get rid of negative habits, and reconnect with distant friends or family members. This is strongly illustrated in the story of Christopher, previously introduced: “At first I was mad at myself. But in a way, thank God it opened my eyes, because it showed me what I was doing to myself and what I can lose. I am just, I guess, in a ways….this is the only way I can put it. I am grateful I got it. It stopped me from doing things I should not have done.” According to Christopher getting HIV strongly affected his behavior as he stopped using the services of sex workers and reconnected with his wife.

The other common pattern that was mentioned by almost every participant was “getting healthier” because of HIV as it makes individuals more aware of their health and contributes to the healthier food choices or rejection of alcohol or drug consumption. For example, Roberto, previously introduced, mentioned positive changes in his health: “Now I feel like the healthiest I have ever been, because, knowing, having the mentality that I have something that is immune surprising virus. I am more conscious of what I eat, I am more conscious of how I dress in a cold weather. So, in my opinion, my life with HIV is now healthier than before.” For Roberto, becoming HIV positive had a strong correlation with the improvement of his health. The same is visible in the story of Laura, previously introduced: “All that drinking, partying, all of that had to stop. It was hard, because I had to stop it one day to another... So, I had the choice to make, either continue
on partying and drinking or change my lifestyle and have a “me” lifestyle again.” In case of Laura, becoming HIV positive helped her to start a healthier lifestyle and motivated her to quit negative habits she had.

Another common idea in the stories of some participants is that becoming HIV positive helps individuals to “reconnect” with the closer friends and become more distant with those who were not a “true friend.” A couple of the participants mentioned that HIV helped them to understand who is their “true friend” is and who is not a “true friend” were those who accepted them with their status. Disclosing to the close friends may also be a strong support factor to an individual with HIV, as I mentioned previously. For example, Alejandro, previously introduced stated “Oh, yeah. I reconnected with the friends I should have stayed connected with. I don’t take the compassion in love I get from my friends for granted anymore. They make you forget about everyday fact that you always remember.”

Aside from that, HIV-stigma may have an empowering effect on individuals living with HIV. For instance, half of the participants (n= 6) who agreed to be interviewed were either volunteers or staff members of IAE. Given the levels of stigma experienced by these individuals, it suggests that their negative experiences may have led them to be involved with an organization working to improve the lives of PLHIV. These individuals may have realized that the HIV-related stigma they experienced may create the need for community interventions. After being infected with HIV and experiencing stigma, some HIV positive individuals want to fight against the social inequalities they experience and get more involved in the life of civil society. As mentioned by Diego, previously introduced: “I want to do a lot of stuff, I plan to. Ironically, getting this disease actually put me into the path to open many doors. I want to go to different places, I want to speak publically and I know that it will not be easy, but I still want to do that. I am sure in that.”
3.5 Stage 1: Stigma Results Conclusion

Based on the findings, I can conclude that stigma and discrimination remain relevant issues in El Paso. Stigma experienced from the place of employment and religious institutions may bring emotional trauma and have a strong influence on someone’s choice to continue to be a part of that community. Stigma experienced from medical institutions and medical professionals, while a minor factor among these interviewees, may strongly affect individual decisions on whether or not to continue using medical services, besides that, it may affect person’s decisions on career expectations (which job may be allowed or not) and sexual behavior (whether or not a sexual lifestyle is allowed).

Getting a disease like HIV influences a person’s decisions on whether or not to remain close with friends and family members. Individuals with HIV are more likely to isolate themselves from friends or family members who they fear will not accept them with their status. Family can become a strong source of support for an individual with HIV; although, the fear of disclosure may be complicated due to stigmatizing attitudes about the virus and homosexuality. Disclosing HIV status to the family members was harder for individuals who self-identify as homosexuals and had not previously disclosed their sexual orientation to the family.

Stigma attached to HIV has a strong influence on the sexual behaviors of PLHIV and disclosure to the sexual partners. For instance, most of the participants in the study tended to avoid disclosure in case of protected sexual contact. They also fear disclosing their status to long-term sexual partners, as they are afraid to “lose them” because of their status. Common responses to concerns about sexual partners included: not disclosing their status and practicing safe sex; avoiding romantic relationships with HIV negative partners, and/or seeking out HIV positive
partners. Rejected by a sexual partner had happened to most of the participants who tend to disclose their status to the sexual partners.

Diseases like HIV may have a strong influence on the emotional health of an individual with the virus. I noticed that individuals who found out about their HIV in recent years tended to accept it more easily and more quickly than the participants who found out about their status more than ten years ago. This shift may be explained by a higher level of visibility of a disease like HIV in the community today. Most of the participants reported feeling of “deserving” the infection for their deviant lifestyle, feelings of “punishment”, and feelings of “being dirty” with the virus. Almost all of the participants reported a strong fear of disclosure of their status to anyone mostly due to stigma attached to the virus.

3.6 Stage 2: Evaluation of the Theater Workshops with the Support Group of People Living with HIV

For the analyses of Stage 2 of the research project, I will talk about the influence of theater intervention on the emotional state of the participants and talk about the possibility of using such a tool for work with the support groups of individuals living with HIV.

3.7 Stage 2: Survey Results

In this section, I present an evaluation of the workshops using the surveys collected with the participants after each of the workshops. I will analyze each workshop separately before providing an overall assessment of the workshops. Table 3.1 includes a numerical summary of the survey findings.
Table 3.1: Mean Scores on Evaluation Surveys

<table>
<thead>
<tr>
<th></th>
<th>Workshop 1: Women (n=8)</th>
<th>Workshop 2: Women (n=6)</th>
<th>Workshop 3: Men (n=5)</th>
<th>Workshop 4: Men (n=5)</th>
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</thead>
<tbody>
<tr>
<td>Was the participation in this</td>
<td>5.0</td>
<td>5</td>
<td>5</td>
<td>5</td>
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<tr>
<td>workshop interesting to you?</td>
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<tr>
<td>Did you gain any new information?</td>
<td>4.6</td>
<td>5</td>
<td>4.8</td>
<td>5</td>
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<tr>
<td>Were your expectations from</td>
<td>4.7</td>
<td>5</td>
<td>4.6</td>
<td>5</td>
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<tr>
<td>the participation in the</td>
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<td>theater workshop fulfilled?</td>
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<tr>
<td>Do you think theater workshops</td>
<td>4.8</td>
<td>5</td>
<td>5</td>
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<td>can be useful as a tool for</td>
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<td>empowerment of people living</td>
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<td>with HIV?</td>
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Note: Scores range from 1-5 with 5 being “Strongly agree” and 1 being “Strongly disagree”

Based on the analysis of the surveys, the theater workshops were positively evaluated by the participants. All of the participants evaluated workshops as being interesting and unusual experiences in their lives, besides that participation in the workshops helped the participants to release stress and tension.

3.7.1 Workshop 1. Women’s Support Group.

The first workshop was attended by the highest number of participants (n=8). Overall, the results of the surveys showed a high level of satisfaction with the workshop. All of the participants marked that the workshop was interesting to them (the mean was 5 out of 5) and they agreed that it was a good tool to work with HIV positive individuals (mean of 4.8 out of 5). In the comments section of the survey, participants said the following: “Made us more open”, “It is a good tool to work with HIV positive individuals”, “All the things you made us do were very interesting, I feel different after the workshop”, and “I liked it a lot.”
3.7.2 Workshop 2. Women’s Support Group.

The second workshop (n=6) was attended by fewer participants compared to the first one. The second workshop with the women’s support group was characterized by the highest level of positive evaluations of the four I conducted. That particular workshop was concentrated on the role-playing exercises and improvisation. All the five questions in the survey were marked as excellent by all participants (with the total mean of 5 out of 5 for all responses). Participants did not include much in the comments section, but some of them included such phrases as: “empowering” and “I liked being silly.”


Workshops with the men’s support group were characterized by lower levels of attendance (with a total of n=5 participants) as compared to the women’s groups. All of the participants in the workshop marked it as being interesting to them (with the total mean being 5 out of 5). Although, in the response to the question “Were your expectations fulfilled?” not everyone responded positively (with the total mean of 4.5 out of 5, for instance one participant left the comment “it would be better if more people would attend.”). Participants from the men’s support group were more explicit in their comments than were the women. Some of the comments included such responses as: “I learned how to expand my mind to other participants and it was interesting to do the things I normally do not do”, “It made me relaxed”, and “I really liked the workshop, I think it helped me in many ways.”

3.7.4 Workshop 4. Men’s Support Group

The second workshop with the men’s support group was characterized by a high level of positive responses and the same level of attendance as the first workshop (n=5). Most of the
questions included an excellent response from everyone (with the total mean being 5 out of 5). Some of the comments included such responses as “very good, I liked the role-playing exercises” and “excellent, everything was excellent.” As a note, the comments presented were selected because they were representative examples of what was provided.

3.8 Stage 2: Interview Findings

In addition to the positive numeric evaluation of the workshops as presented above, participants mentioned positive changes in mood and self-esteem during follow-up qualitative interviews (to be discussed next). To evaluate the interviews, I have organized them based on three main themes: effect of the theater workshops on the emotional condition of participants, evaluation of a theater intervention in a community support group for individuals living with HIV, and the suggestions for the improvement of the workshops based on the opinion of the participants and the support group leader. The analysis of these sections is presented outlined below.

3.8.1 Effect of the theater workshops on the emotional condition of participants

Based on the three interviews conducted with the participants of the workshops I may evaluate that theater workshop resulted in certain emotional changes. Such changes include effects like: laughter, opportunity to be someone else during the workshop, putting one’s problems in perspective by learning about other’s problems, and stress release. Laura, previously introduced in the stigma results section, was the only person to take part in an interview and the workshops, and she mentioned a strong positive effect from her participation in the theater workshops. After responding affirmatively to a question about whether the workshops were a positive experience in her life, she explained: “Oh yes, because I tried doing it [theater exercises] in my house. I feel better, my body feels better, my mental feel better, I feel very good. I tried doing also different
exercises and when I do them, I feel different. More light. I don’t have as much stress in my head anymore, I feel released.” Laura mentioned that the workshops were a positive experience to her because they helped her to forget about her daily routine and distracted her from negative thoughts and emotions. Doing such an “unusual [theater] exercise” helps her to forget about stressful situations in her life (like coping with the virus) and to “let go” of negative thoughts. For instance, she mentioned: “They [theater workshop exercises] help you to forget about the problems that are at your head, they help you to relax and influence your mental health, and they also help you to release the stress and to forget about your problems.”

Andrea, a forty-eight year old women who has lived with HIV for eleven years, illustrates another positive emotional effect of participation in the workshops. Andrea mentioned that being engaged in the workshops helped her to feel like she was “somebody else” and, like Laura, forget about the usual social roles that she is committed to in her daily interactions. She stated, when asked about her experiences with the workshops, “it was exciting, new…it was like…very different. I have never done anything like this before and they helped me, they open me up, let me be not myself, but be somebody else.” Andrea is referring here not to a particular exercise but to the overall effect from participation in the workshops. The idea that person with HIV may leave his/her usual environment and feel “as somebody else” may have a valuable implication. Acting out the roles of other people helped the participants to share their own problems, but at the same time from the perspective of somebody else. The ability to share your own problem from the perspective of somebody else is highly valuable as it may become a way to elaborate on personal experiences and open up about which will help to release a tension and stress from a burden of having a stigmatized disease like HIV.
Eduardo, a fifty year old man who has lived with HIV for the past five years, mentions that theater workshops helped him deal with the issues of depression and anxiety, as he mentions: “I suffer from depression but since we did these workshops I have been thinking a lot about what one of the clients have been going through, and I went through the similar experience and it made me feel a lot better. And I don’t get down as often…it did work on me, I noticed some changes.” Listening to the other personal stories and voices of the other participants may be a helpful tool for dealing with stress from living with an HIV positive status.

The leader of the women’s support group shared the point of view that theater intervention was a powerful tool for improvement of the emotional conditions of the participants because it encouraged them to laugh. She reflected: “Now one of the things that I noticed when I was observing these women, with the workshops that you were initiating, was their laughter. And I believe that through this laughter, they shared a lot. That moment of spontaneity of laughter was fabulous for them. I think that workshops for improvisation helps to promote the openness of who we are and what we are thinking and helps to build these informal dialogues with ourselves and break the barriers. It was in that laughter that I most saw these barriers begin to fall away.” Strong positive emotions, reflected in the laughter of the participants, may be a powerful tool for helping them to cope with stress and negative emotions from the daily lifestyle.

3.8.2 Evaluation of a theater intervention in a community support group for individuals living with HIV

One critical benefit of the theater workshops that Andrea recognized was the anonymity that accompanies role-playing in a theater exercise: “Because you can actually be somebody else at that moment and be expressing a lot at that moment. There are some things that you don’t want anybody to know, but they are happening inside you. In the performance you can actually say it
without them knowing if you are talking about yourself or you are talking about somebody else.” Like Andrea, Laura also enjoyed the role-playing exercise. In the role playing exercise (Note: the role playing exercise includes playing the short theater scenes that are discussed and created by the participants; participants discuss the stories they are going to present and based on the discussions they improvise the scenes from and interact with each other on the stage in the improvised roles). Both mentioned that during this exercise they experienced the most openness and the joy from the planning and developing of their role.

Both Andrea and Laura shared the common idea that the workshops were good for improving their communication within the group and helped them to “open up” more for the other members of the support group. They also mentioned that such intervention may be a powerful tool for community support of individuals living with HIV. Eduardo, who states that theater workshops helped him and other participants to become more united with the participants of the support group and to “open up” more about their personal problems within the group, shares the same attitude. Eduardo states: “We have one, one participant who is gay, and he did enjoy it, because he told me that it helped him more. It helped him to be more open with us, because he used to be very quiet but now he is more open.” It is important to mention that speaking up about personal issues in the support group is voluntary and not all participants feel comfortable opening up to the others. Just because they regularly attend a support group does not mean that they regularly share their feelings with the other members. Participation in the theater workshops helped some of the individuals feel more comfortable with each other and to become united hence more open about their HIV with the others. As mentioned by Eduardo, “For me it was a good idea, because I wanted to be open more about life. It helped me cope with life and I noticed that it helped others who participate. They are more open now than when they used to be at the beginning.”
Theater workshops may have an effect of opening up individuals with HIV hence help them in accepting their status. This kind of intervention may be an efficient tool to provide community support for those who are struggling in accepting their status. For instance, in the interview with the support group leader she elaborates on this matter. According to the support group leader, strong positive emotions like those elicited during the workshops, are key to becoming more open about the disease like HIV and accepting the acquired status, as she mentions, “When we do theater workshops exercises we start to open up and we start to discover- IT IS OK. Whatever comes to your mind, whatever in your heart at this moment, IT IS OK. In the long run that will help to facilitate these women to be more open with their families and on public, which is empowering, just to say I own who I am. And it is OK.”

In sum, the theater workshop intervention appears to be a strong tool for community-based interventions for individuals living with HIV. First, it provides participants with the opportunity to “open up” about their personal experiences in a safe environment, sometimes while feeling anonymous due to role-playing exercises. Openness about one’s personal problems does not come easily to most of the individuals with HIV that I encountered through this project. Support groups provide them with such opportunity, and theater intervention may be an effective tool for support group members to become more open about such personal issues as HIV and HIV-related sigma. Second, it helps to participants to accept their own status, by listening to the stories of others and sharing their own story. Lastly, it may appear as a tool for building personal connections within the group of individuals living with HIV, which helps them to benefit to a greater degree from the supportive and comforting environment of the support group.
3.8.3. Suggestions for improvement

Despite the fact that most of the participants evaluated the workshops as a very positive experience in their lives (e.g., many surveys stated “excellent” in the comments), participants also offered suggestions for improvement of the workshops. One participant, Eduardo, felt that the workshops should be more focused on the topic of HIV in the lives of the participants. Eduardo stated: “I think we should talk more about our HIV during the workshops. I know that what we did was just the introduction to the exercises, but if we will be working more on this we should talk more about HIV in our lives through the theater.” Unfortunately, due to a short time frame of the project, I was unable to have a strong focus on the topic of HIV in the life stories of the participants during the workshop intervention. Only some participants were able to speak up of their experiences to the other members of the support group. However, this suggestion will be very valuable for the future work with individuals living with HIV. Theater intervention should be more focused on their experiences of life of an individual with the virus.

The leader of the support group felt that the theater intervention presented in this research would have been more effective if the theater workshops would have been conducted regularly with the participants for a longer period of time (for at least one year). She also mentioned that theater intervention requires time and commitment of both the person who leads the workshops and the members of the workshops in order to achieve meaningful impacts on the participants. As she stated during the interview “But getting them down the road when they can actually start being more open about their intimate stories and making theater a piece of it, that’s a bit off in distance. But, just given into consideration that we are not a predictable group and there are people who can come late and miss the sessions, but also to move the women who have been here every week, on through the process.” Using theater as community support tool for individuals living with HIV
most effectively would require a meaningful commitment for a longer time. Besides that, the main
task of the facilitator should be navigating the group to help them to focus more on the experiences
of the participants related to their HIV positive status.

3.9. Stage 2: Workshop Results Conclusion

Based on the analysis of the survey results, the interviews with the participants of the
workshops, and the interview with the women’s group leader, I found that theater interventions
with HIV positive individuals can be a powerful tool. This tool can help PLHIV deal with stress,
anxiety, or the challenge of opening up about personal problems or one’s HIV positive status, as
mentioned by the participants. All of the participants of the workshops reported that the theater
intervention was a positive experience. Another important finding is that theater workshops were
a team building activity within the group and help the participants to learn about the experiences
of others and compare it to experiences in their lives, which will in the future help them to accept
their acquired status.
CHAPTER 4: DISCUSSION

In Chapter 4 of this thesis work, I will apply the research findings and connect them with the literature evaluated in Chapter 1. I will start by talking about general implications and discuss in details such sections as stigma experienced by individuals from their secondary social groups, from their primary social groups, self-stigma, and positive sides of having HIV. I will also discuss the connections of the findings from the Stage 2 of the project and its connection to the literature.

Interviews that I have conducted with the individuals living with HIV in El Paso were an effective way to understand the difficulties faced by PLHIV in this border community. I reported on the stories of individuals with HIV in the analyses that are presented in Chapter 3. Narrative material on the topic of stigma related primary to four themes: stigma from secondary social groups, stigma from primary social group, the impact of stigmatized attitudes on self-perceptions, and positive sides of having HIV. In Chapter 3, I aimed to understand the process that leads individuals with HIV to experience stigma and how stigmatized attitudes may be formed in response to the perceptions of powerful social groups and institutions. Parker and Aggleton (2003) insisted that HIV-related stigma should be understood and acknowledged not only from a psychological dimension, but also in the ways social, cultural, political, and economical power stand behind the stigmatization processes. That is why in my analysis I link stigmatizing processes to the influence of hegemonic groups in the community. I analyzed collected interviews with the support of stigma theory of Goffman (1963), while also considering more contemporary approaches to understanding stigma, and identity theory, which helps me to explain why HIV infected individuals still experience stigma in the contemporary society. In what follows, I discuss the key implications and the significance of my findings related to each of the four Stage 1 themes after first reviewing some general implications that crosscut the four themes.
4.1 Stage 1: General Implications

In terms of general implication, compared to the previous research related to HIV stigma, I may conclude that the issue of stigma and discrimination towards people living with HIV remain relevant problems in the community of El Paso. Even though, it seems that there is also a generational difference in experiences of stigma, as younger, newly diagnosed participants tend to experience less stigma and be more open about their status than older participants. This may be explained by both the change of values in the society since the discovery of the virus and by more accurate information about the virus available for the medical professionals and in the mass media. Although, based on my research findings, stigma experienced from secondary social groups tends to be much stronger compared to stigma from primary social group. In addition, the issue of self-stigma remains highly relevant and was present in most of the interviews collected for this research.

Among the most well-known researchers examining stigma and violence towards people living with HIV in the US society is Herec (1999). Although Herec collated a significant amount of statistical data related to HIV stigma, he did not take into consideration that individuals living with HIV come from different social, gender, racial, and sexual identity backgrounds. Each of these social categories may influence the level of stigma experienced by PLHIV. In my research, I found that some groups experience more stigma due to their HIV status than do others. Specifically, I learned that sexual identity and gender were the most important attributes shaping one’s experiences with HIV-related stigma. The woman participant in my study was the only one to report experiencing violence from her sexual partner. Also, homosexual participants were more likely to experience more HIV-related stigma than heterosexual participants. In addition, the
interconnectedness of HIV-related stigma with gender and sexual identity also seemed related to their willingness to disclose HIV to other people.

Homosexuality is still stigmatized nationwide, and it may be stigmatized even more in the El Paso community, given patriarchal and heterosexist values. The MSM population has the higher risk to be exposed to double stigma based on HIV status and sexuality. However, the heterosexual participants were sometimes accused of engaging in homosexual behavior given the misconception that most people living with HIV are homosexuals. From the perspective of identity theory (Brown, 2000), being associated with a certain group or community creates the assumptions that all individuals share the common attributes of this group. This explains why heterosexual individuals who live with HIV may fear experiencing accusations of deviant sexual behavior.

4.2 Stage 1: Stigma From Secondary Social Groups

Stigma experienced by individuals living with HIV from interactions with secondary groups in the society was not as serious as it could have been. Most of the participants mentioned that they feel comfortable using the services of the medical professionals and receiving medical treatments. Some of the participants who lived with the acquired status for longer periods of time mentioned that now the level of the awareness in the society about HIV is higher, and individuals who contract HIV in the contemporary world will be less likely to face stigma from the medical institutions. However, the only secondary group where HIV positive individuals feel comfort in disclosing their status was among medical professionals. Only some participants were able to talk openly about their status with their co-workers and employers, others experienced fear that their employers may find out about their HIV from the insurance bill they are receiving.
HIV-related stigma from such secondary and primary social groups as medical professionals, places of employment and co-workers, friends, and family members was widely researched among such scientists as Herec, (1999); Deacon et al, (2005); Wohl et al, (2012); Herec et al, (2013). Stigma experienced from medical professionals may influence the decision of the participant to not continue receiving the services from that clinic or hospital as noted by Deacon et al (2005). Although this was not exactly the case in my findings, as most of the participants mentioned that they did not experience stigma from medical professionals. Stigma experienced from co-workers may influence the decisions of the participant to quit his/her job, which was identified by Herec (1999). This was evident in my research, as two out of twelve participants quit their place of employment fearing stigma due to their HIV status and only three were formally employed at the time of the interview. The lack of formal employment among my interviewees may relate to HIV-related challenges or stigma, but this was not directly mentioned by my participants during the interviews. Related to stigma from co-workers, homosexual participants tended to have a double fear of disclosure of their HIV as they believed disclosing their status would also reveal their sexual orientation in their place of employment, which was not desirable to them. This is a new finding in a context of HIV-related stigma to my knowledge.

According to my findings, discrimination from medical professionals is still a relevant subject, however PLHIV reported experiencing little discrimination when accessing health services. This can partly be because contemporary society is more aware about the issue of HIV, compare to the time how it used to be when it was newly discovered disease. According to the participants, their medical professionals were likely to have correct information about HIV transmission but one out of twelve participants mentioned experiencing offensive comments in regards to participant’s sexual lifestyle. It is important to understand that despite accurate
knowledge about the virus, medical professionals may still project their own values and judgements onto infected individuals for personal reasons that are not related to fear of getting infected from a person living with HIV, as it was defined by Deacon and Boulle (2006).

Overall, the experiences of stigma from the secondary social groups by people living with HIV interviewed in this study seems to be much less than anticipated, given what I read in the HIV-stigma related studies. Although, it is important to consider that participants tend to avoid disclosure of their status to anyone other than medical professional, who seem to be less stigmatizing today as compare to the time when HIV was a newly discovered disease.

4.3 Stage 1: Stigma From Primary Social Groups

The experiences of stigma towards people living with HIV from their primary groups (e.g., family, close friends, and sexual partners) appeared to be a serious problem, which is an important finding in my research. One of the key findings of my research is that the experiences of stigma can be intensified by sexist and homophobic values. Women are more likely to experience discrimination from a sexual partner and gay men are more likely to hide their HIV positive status, as they fear that this will uncover their sexual orientation to close friends and family.

Women participants tended to have more fear of experiencing negative attitudes or violence from sexual partners upon disclosing their HIV positive status than did men, which may relate to patriarchal values in the community. Such findings have been previously introduced by Rankin et al. (2005). This is evident from the fact that two women presented in my study tend to avoid any talk related to their HIV status with their permanent boyfriend or husband. For example, one woman participant was quite open about her HIV status, telling about it to her friends and
employers, and even giving an interview to the local newspaper about the way HIV changed her life. However, she did not tell her sexual partner for fear of his response, but she eventually opened up for him after one year of being together. When she finally disclosed her status to him, she faced emotional abuse and physical violence. Sandelowski et al (2004) have previously mentioned that women may experience more stigma in relation to their HIV positive status, and such phenomenon has been widely researched in African continent; however, nothing was said about the influence of stigma and discrimination on women’s self-perception and disclosure of their status to the community where they live.

The homosexual participants who were open with their family about their sexual orientation tended to also be more open about their HIV with their family members. For most of the participants, finding acceptance in their close social circles served as a very important source of social support. In contrast, rejection or experiences of stigma and discrimination in those circles had a strong negative effect on their self-perception. Gender and sexual orientation seemed to be important influences on participants’ decisions related to disclosure of their status among friends and family members.

4.4 Stage 1: Similarities Across the Primary and Secondary Social Groups

An important finding to acknowledge is the similarities across the sources of stigma in primary and secondary social groups. All of the data analyzed in Chapter 3 may be categorized by having three common patterns. First, many of the experiences of stigma both from primary and secondary social groups have a connection with uneducated assumptions about HIV transmission. PLHIV face stigmatization because of a lack of knowledge among those they interact with, in both their primary and secondary groups. Stigma in many cases is driven by prejudice and judgment about the ways in which individuals have contracted the virus, which may be due to the low level
of knowledge about the way the virus may be transmitted from one person to another. Second, homophobia is behind much of the stigma that men experience. Most of the men who experience HIV stigma also experience stigma based on their presumed sexual orientation. Even the male participant who self-identified as heterosexual mentioned that he feared disclosure based on the tight connection between the disease and homosexuality. Third, while I am limited by only two women participants, it seems the patriarchal assumption that HIV positive women are promiscuous women leads women to experience more stigma than men, particularly from their sexual partners. Here I want to refer back to the findings of Rankin et al. (2005) and Sandelowski et al (2004) who mentioned that social minority groups may experience a stronger level of stigma. My research suggests that female participants and homosexual participants experience a greater level of stigma compared to men and heterosexual participant. This finding applies both across primary and secondary groups. Gender and sexual orientation are an important factors that affect the strength of stigma experienced by individuals living with HIV. This may be tightly linked with the strength of homophobic and heterosexist values in the particular society, as it was mentioned by Parker and Aggleton (2003).

4.5 Stage 1: Self-Stigma

Based on the findings from my research, experiences of self-stigma amongst people living with HIV are very common and they have a strong effect on the social and sexual lives of the participants. Even when a participant did not acknowledge that HIV has a strong impact on her/his social life, I evaluated that many of the participants tended to avoid such social interactions as hugs or handshakes with friends, living the previous active social lifestyle, or getting engaged in sexual relationships with HIV negative people. Some of the participants mentioned that HIV makes them feel “dirty” or “unwanted.” However, participants who experience more support from the
community tend to lead a more active social lifestyle. Community centers and support groups became a greatest support factor for the individuals living with the virus.

Another important finding that has been underemphasized in the literature is that most of the participants experienced such emotions as “self-blame” or they felt that they “deserved” to have the virus because of mistakes they made in the past; this was mentioned by Simbaye et al (2007). These feelings led some respondents to isolate themselves within a closed group of other people living with HIV. In this closed circle, they felt that they could build the trustworthy relationships and feel “safe,” as some participants mentioned that they would prefer to engage in sexual relationships with only “positive” individuals. This relates to identity theory (Brown, 2000) which suggests that by receiving a certain identity, individuals tend to avoid connections with individuals outside of their identity group. These feelings of self-blame may create a disrupted identity and increase the stress and anxiety of an individual with HIV (Burke, 1991). Disrupted identity theory proposes that PLHIV would then seek to avoid situations where stigma may happen, however in case of HIV stigma, such situations may be unavoidable. To overcome disrupted identity, empowerment strategies and interventions, as mentioned by Parker and Aggleton (2003), are useful; this may include a theater intervention like the one I used here.

The consequences of self-stigmatizing attitudes are serious for PLHIV and the border community. Bird & Voisin (2013) acknowledge the fact that self-stigma experienced by individuals living with HIV decreases the likelihood of HIV disclosure especially to sexual partners, which has a primary connection with the spread of HIV infection. Their research has important implications; however, it does not take into consideration the other negative sides of self-stigma or the actual influences of stigma on the emotional and psychological health of an individual living with the virus. Self-stigma may cause strong emotional suffering, separate an
individual from close surrounding, and even separate an individual from the community where she/he lives. For instance, one of the participants in my study did not leave the house for over three years after he found out about HIV status.

4.6 Stage 1: Positive Sides of having HIV and Experiencing HIV-related stigma

The positive sides of getting a disease like HIV have been hardly discussed in the HIV-literature. Some authors touch upon the topics of how self-stigma may become the basis for formation of empowerment of stigmatized individuals (e.g., Shih, 2004). According to my findings, despite all the negative consequences of becoming HIV positive, some participants saw HIV as a life-changing event that helped them to stop negative habits or dramatically change their lifestyle. Something similar was noted by Forero (2010) among El Paso residents with tuberculosis. In my study, two out of twelve participants mentioned that HIV “saved their lives.”

Another positive aspect was that HIV helped some participants to become more socially engaged in the life of the community by becoming involved in community-based projects related to HIV prevention or sexuality education. Although, it is important to understand that seeing positive sides of having HIV were more common amongst participants who were open about their status, accepting of their status, and supported by other community members. That suggests that supporting individuals living with HIV and helping them to accept a newly acquired status can have far-reaching consequences for their quality of life and moving forward.

4.7 Stage 2: Theater Intervention Discussion

The significance of community-based projects for providing support and empowerment of marginalized groups of population have been widely acknowledged in the contemporary scientific literature. For instance, it was mentioned in the work of Grossman & Stangl (2013); Jain et al.,
(2013); and Wilson et al., (2014). However, a very few of the above-mentioned authors talked about approaches that would target specifically strategies of empowerment for marginalized groups of population. The work of Singhal et al (2004), who presented a manual for activists who want to use theater for participatory engagement and empowerment, is an exception. While an important tool, Singhal et al. (2004) did not evaluate a specific project related to the experiences of marginalized group, rather the manual provided suggestions and methodological tools for activist engagement through theater.

As also argued by Parker and Aggleton (2003), the only way to eradicate HIV-stigma is through the means of empowerment strategies because HIV-stigma was created by hegemonic values of cultural dominance. That should be understood by individuals living with HIV and theater intervention may become one of the intervention strategies for uniting the HIV-positive individuals, giving them the possibility to open up, raise their self-esteem and improve their emotional states.

The use of art and theater with socially marginalized groups is becoming an acknowledged tool among social science researchers and community workers (Fee, 2013; Moya & Nunez, 2013). Usually, the art and theater strategies are primary targeting the goal of providing more visibility to the issues experienced by social minorities. This project sheds light on another, less examined benefit: the efficacy of theater interventions for improving the psychological state and group unity within groups of individuals living with HIV. Identity theory can help us understand why this happens. Brown (2000) discusses a strong connection between positive group identity and higher self-esteem of the group members. As was demonstrated here, a theater intervention had the power to bring people together in a positive way, which may relate to the positive feelings experienced by participants post-intervention. That is why it is important to work with groups of individuals
living with HIV and apply theater strategies for the empowerment of the group as a whole. Theater interventions have been previously discussed more as a means of education of an underserved group on the particular topic. For example, as a tool for education for young people, or youth offenders (Lauby et al, 2010; Auger & Heather, 2005). Nevertheless, none of the studies specifically discusses theater as practices for providing support with self-acceptance and empowerment as presented in this project. Very few of these educational initiatives specifically focus on the individuals living with HIV as a target group of participants. Instead, they have a focus mostly on support of youth or refugee populations.

An HIV-theater project was implemented by Johansson (2011) in sub-Saharan Africa, but her project was focusing more on evaluating the effect of theater as a tool for education about HIV of the general public. Comparing Johansson’s (2011) project to mine, I focus more on exploring the effect of theater as a practice for providing psychological and emotional release and acceptance of the individuals with the virus. In the next section, I will provide a closer look at the connections between my research and previous research.

4.8 Stage 2: Effect of Theater Intervention on the Individuals Living With HIV

Very few previous studies have examined how a theater intervention affects the emotional condition of the particular group under study. While not focused on HIV, community workers and researchers from Israel evaluated the changes in the emotional condition of migrant women of Jaffa after implementing a theater intervention (Beohm and Boehm, 2003). The project of Boehm and Boehm (2003) lasted for over six months of regular meetings with the community members. They concluded that theater provides empowerment in terms of self-esteem, mastery, and critical awareness. My project is different in terms of the target group and the emotional challenges that may be experienced by that target group, however I too saw benefits of the theater workshop even
though I was working on a much shorter timescale. Boehm and Boehm (2003) found that theater interventions are meaningful in assisting groups who have experienced the loss of power, as have the participants in my research project. My study adds another previously underemphasized benefit in that theater helps individuals to talk about their personal issues from the perspective of somebody else, which is helpful in terms of self-acceptance and self-esteem.

Apart from Boehm and Boehm (2003), one other study in particular is relevant to my findings related to the theater intervention. This study focused on understanding the effects of a theater intervention for marginalized LGBTIQ youth in the school environment (Wernick et al, 2014). According to Wernick et al (2014), through the theater intervention, marginalized youth developed a sense of belonging, developed a productive outlet for feelings like anger and frustration, and increased their civic engagement. I noted similar benefits in this study of individuals living with HIV. According to my research findings, PLHIV feel comfortable “opening up” about their status and experiences through the tool of theater as it helps them to act on behalf of the other. This phenomenon was also noted by Wernich et al (2014), who explain that theater allows participants to act as a “changed agent”, which means to talk about their personal experiences on behalf of others.
CHAPTER 5: CONCLUSION

5.1 Relevance of HIV/AIDS Stigma in the Border Community

The topic of HIV/AIDS remains a highly relevant issue in the community of El Paso and in the US as a whole. Stigma and discrimination faced by people living with HIV are not widely acknowledged, especially in this border community of El Paso. It is a matter of high importance to recognize and visualize the struggles faced by individuals living with HIV and to understand what role stigma plays in their lives.

Much HIV-stigma research examines the factors that may form stigmatized settings (for example Herec, 1999). Some of the studies stress the importance of knowledge about HIV and the way that a lack of knowledge can form negative perceptions about the virus and those infected with it in the society (Herec et al., 2013). However very few studies reflect on the way HIV-stigma is formed under the influence of powerful groups in the society (for exceptions, see Bird & Voicin, 2013 and Wohl et al., 2012). Very few of the studies (for instance it was mentioned by Simbaye et al., 2007 and Rankin et al., 2005) examines specifically how gender and sexual orientation contribute to negative perception of an individual with HIV and how it affects self-esteem of a person with the virus.

Many studies use statistical analysis to quantify violence and discrimination against individuals with HIV and the negative perceptions of self that are experienced by PLHIV (see statistical research made by Herec et al., 2013), and they do not propose any specific policy interventions or community-based projects that can be implemented with PLHIV to reduce this discrimination. Quantitative approaches to measuring stigma faced by people living with HIV neglects the personal voices of individuals who have to pass through this experience. In contrast to these studies, my research project sought to understand, through a qualitative perspective, the
way stigma affects the daily lifestyle of PLHIV and influences their self-perception. I also uncovered the potential for community implications, such as social theater, that can be implemented with the infected individuals.

Related to how HIV-stigma is formed under the influence of powerful groups in the society is how closely related HIV stigma was with the hegemonic heterosexist and patriarchal values in the El-Paso community. Based on the narratives shared by the interview participants and my own experiences as an activist, the El Paso community remains a society where these values are predominant, which creates stronger circles of oppression and discrimination. Even though sex education classes have become a part of school curriculum, such topics as homosexuality and gender orientation are rarely discussed and remain stigmatized. This creates unfriendly environment for people living with HIV, in which they have to deal with the issues of self-stigma and self-discrimination.

5.2 Results Summary

One of the main goals of my study was to visualize the life struggle of people living with HIV on the border community and to test an intervention that had the potential for improving lives of the participants in my study. I used the tool of the interview to understand and recognize the issues faced by individuals living with HIV, and I used theater workshops to understand the effect that this intervention may have on the psychological and emotional state of the participants.

As a results of my Stage 1 interviews I analyzed the way stigma affects lives of my participants in their primary and secondary social groups, also how self-stigma affects their behavior. I also took into consideration the positive sides of having HIV and positive sides of HIV-stigma. I uncovered similarities between stigma in primary and secondary social groups in terms of the causes of stigma, which may be summarized as stemming from homophobia, patriarchal
assumptions about women, and uneducated perceptions about HIV virus. I discovered that female participants are more likely to face stigma and discrimination from their sexual partners. Another important discovery was that homosexual participants are less likely to disclose their HIV positive status to their family and to their close surroundings, which creates a stronger burden of self-stigma. In contrast, stigma from medical professionals seems to be a less issue rather than it used to be in the past. I made this assumption based on the literature that I reviewed for this study. Besides that findings, I came to conclusion that individuals who were infected with HIV for a longer time (at the beginning of the times when AIDS was a newly discovered disease) are more likely to have self-stigmatized attitudes.

Many of the participants in this study mentioned some positive sides of having a disease like HIV. For instance, change of behavior, such as healthier diet or quitting negative habits. Participants tend to become more aware of their health and try to improve their health condition. Some participants mentioned healthier eating habits. I would like to mention here, that most of the participants in my study come from a low social-economic background, which may create a wide range of challenges when accessing antiretroviral therapy or healthier foods.

As an applied part of this research, I have conducted theater workshops with the participants in Stage 2 of this project. My goal was to understand what effect theater intervention might have on participant’s emotional and psychological wellbeing. The workshops were conducted separately with the men and women support group. There were more participants during the meetings of the women support group, rather than the men support group.

Based on the survey results and the interviews conducted with the participants for the workshops I evaluate that theater intervention was an efficient method to provoke changes in emotional well-being of individuals living with HIV. Most of the participants provided a high
grade of evaluation for the workshops and mentioned positive emotional changes in their mood. One of the findings after the workshop suggests that theater intervention supports positive emotions and helps participants to become more open about their personal problems while being in the role. It helps participants to speak up about topics they are usually not talking about during the regular support group meetings. Improved relationships within the support group was another finding of Stage 2 of this project. After the workshops, participants mentioned the improved knowledge of other participants and their personal problems. Theater intervention allows individuals living with HIV to understand better the problems faced by others with the same issue.

5.3 Practical Recommendations

One of the main conclusions coming out of my research is that HIV-stigma should not be seen separately from the hegemonic values held by the privileged and power groups in the society. This creates an uneasy task for the community activist as such changes in society do not come easily and require a lot of time and commitment. That is why, as a first practical implication, I want to point out that HIV stigma has to be acknowledged as having tight connections with heterosexist and homophobic values. Activists who are working on eradication of HIV-related stigma must practice self-reflection to be sure they are free from such values themselves and to understand the way in which these values affect society and create discrimination and oppression of HIV positive people.

Analyzing the life stories of the people who participated in Stage 1 of my research, I saw that acceptance by family members and close circles, such as friends or community groups, is strong support factor for a person living with HIV; however, many individuals who live with HIV have a fear of disclosure of their status years even years after they were diagnosed with the virus. For the second practical implication then, it is important to cultivate a safe environment in the
community that will allow individuals living with the virus to live their lives free from fear of discrimination. Additional support must be provided to the family members and friends of people living with HIV, so these social groups may be used as sources of social support for a person coping with the virus. Therefore, the emphasis of policy work and counseling must be shifted towards organizing support, not only for individuals with HIV, but to the society surrounding them.

Third, we must implement empowerment strategies through education, counseling, and such interventions as art (including theater), which will allow people living with HIV to accept themselves the way they are and lower the self-stigma that may be experienced by an individual with the virus. Case workers and service providers should understand the way stigma is formed towards people living with HIV and provide the support that will include empowerment strategies. Besides that, understanding that stigma towards people living with HIV has a strong connection to the values of the powerful groups in the society (e.g., heterosexual men) and awareness of this should be acknowledged by services that provide support to individuals living with HIV and included in the future publications or counseling materials. Specific education strategies should be provided for community workers to stress this point of importance.

An important point to consider is that all activist strategies should be done together with the people living with HIV, with their full inclusion into advocacy work. While my experiences trying to engage this population through this project illustrates some of the challenges likely to accompany this, all efforts must be taken to include everyone. Something that could be done would be to offer free transportation (e.g., bus passes or carpools). The governmental institutions should provide grants and sponsorship opportunities for community interventions, such as theater approaches for education and empowerment that specifically target people living with HIV and are implemented by people with HIV.
5.4 Challenges and Limitations

In this section, I want to mention some of the challenges that I faced while conducting this research and its limitations. The study is limited by several recruitment challenges that I faced. Individuals living with HIV face many obstacles and life struggles; that is why even if they expressed their interest in participation in this research it was difficult for them to appear for the interviews and planned workshops. Some would cancel the meeting on the day of the interview. That is why out of twenty interested participants who provided their contact information for the study, I was able to collect only twelve interviews. Unavailability of transportation, effect of antiretroviral therapy, family problems, or mood swings (some of the participants also mentioned suffering from bipolar disorder) made it difficult for some potential respondents to participate. In order to recruit more participants for the interviews, I was attending volunteer events and social events for the IAE clients with HIV. At those events, I talked about my research in attempt to recruit more individuals to participate in the interviews and theater workshops. Throughout this process, I have listened to many stories of PLHIV that have revealed cases of stigma and have come to understand more about the lives of the clients of the organization and what issues they may face while accessing services of the organization.

Other limitations to the research included lack of women participants in the initial Stage 1 of interviews. Such limitation may be explained by the primary focus of the services of IAE on MSM participants. Recruitment of women interview participants appeared to be a more complicated task. However, there were more women participants present at the meetings of the support group. I conducted the workshops with the women support group before the turmoil of IAE (see below), which may explain this factor. I had few Spanish speaking participants (n=2).
included in this study partly due to the fact that all information materials about the research were presented in the English language.

Recruitment challenges also plagued the initial stages of recruitment for the theater workshops. I faced the reality that many PLHIV were unable to come to participate in the workshops even if they are interested in participating. That is why I decided to conduct the theater workshops with the support groups in the organization, which was ultimately a good choice since they proved effective and beneficial for participants. This delayed the start of the workshops and resulted in a significant limitation of this research study: the small number of workshops with the support groups during Stage 2 of the research project. Ideally, 25 workshops would have been conducted with each support group over the time frame of six months. The lack of time complicated the process of theater workshops.

Turmoil at IAE also complicated this project; during the time of my research, International AIDS Empowerment was going through a transition period. The director of the organization left his position along with many staff members. The new rules and regulations established with the new director have significantly reduced the flow of the clients. All of this influenced the participants of the support groups. Many individuals decided to stop using the services of the organization or to stop attending the meetings of the support group. This turmoil happened over a period of four months (May through October 2015) and affected the workshops I conducted with the men support group in October by lowering the level of participation in the support group.

Another complicating factor was the internal dynamics within IAE and its clients related to gender and sexuality, which played a role in my sample, which was predominantly MSM participants. These dynamics likely influenced who felt comfortable attending support groups at IAE and who did not. I noticed stigmatizing attitudes against homosexual, transgender and women
participants within the organization. As I understood from the opinion of some of the volunteers in the organization that affected participation of transgender people in the support groups. For instance, the support groups were only for “male” and “female” participants, which may be confusing for transgender persons and exclude their participation in the support group meeting. In addition, women participants faced such issues as trouble accessing resources for their projects or requesting more funding for their activities. For example, each support group was promoting civic engagement by involving HIV-positive individuals in the local projects and initiatives. Although, as I understood from the discussions within the support groups, women are always excluded from requesting funding for the activities they are willing to implement and priority is given to the men’s support group. Following the discussions within the women’s support group while I was present, some individuals consider this to be an issue due to sexist attitudes within the organization and IAE’s focus on the needs of MSM and homosexual clientele.

5.5 Future Directions

In my recommendations to the future studies related to HIV stigma, I would suggest focusing the research on marginalized groups and the way HIV stigma affects them on the US/Mexico border. The border creates interesting opportunities to research both sides; my suggestion for the future researchers is to use Ciudad Juarez as a source for participants. Another important point is to keep in mind the generation gap within participants who are HIV positive. Through my research, found that younger participants tended to be more optimistic about their HIV, hence, more open with society and in many cases experienced less stigma and a higher level of psychological support in informal settings. This phenomenon will be interesting to research and analyze in the future studies.
To conclude the thesis, I want to stress the importance of advocacy strategies and their importance in the El Paso community to raise awareness about the issue of HIV-stigma. Future advocacy research should target a larger audience, and not only people living with HIV. This may be achieved by conducting a theater performance about stigma together with the individuals living with HIV and then evaluating its effects on participants and audience members. Due to the specifics of the region, the performance should be conducted in both English and Spanish and presented to the general audiences and to the decision makers. This will help to open up the dialog about certain taboo topics in the community and create the positive attitudes about persons living with HIV.
REFERENCES


Prevention Intervention Delivered To High-Risk Male Adolescents In Juvenile Justice Settings.


APPENDIX

APPENDIX A: ‘Flyer for recruitment of the participants

Share Your Personal Story
About HIV

Are you a person who lives with HIV? If so, I would like to invite you to talk about your experiences. My name is Dunia Romanova and I am a Master’s student in the Sociology Department at the University of Texas at El Paso working under the direction of Dr. Sara Crincoli. I am investigating the experiences of people living with HIV in order to design a social theater performance about the community of people living with HIV in El Paso. How has your life changed since you found out about your HIV status? Did you ever face stigma because of your HIV status?

Why:
People living with HIV that are 18 years and older

What:
Be interviewed by me about your experiences as a person who lives with HIV.

Where:
In a private space at the International AIDS Empowerment office or another place that is convenient for you.

When:
At a date and time that works for you (days, evenings, mornings, and afternoons)

How long:
The interview can last from one hour to an hour and a half

Why participate?
1. The project allows the participants to share their experiences as people who live with HIV.
2. The project will find out about challenges that are facing people living with HIV and strategies that individuals use to cope with them. Ultimately, I will share them with health care providers, policymakers, and the El Paso community through reports and a social theater performance.
3. While not a requirement of the project, participants will be invited to be involved in the creation of the social theater performance about the experiences of people living with HIV, which will be based on life stories collected through this project.

Thank you, Dunia Romanova

If you are interested in participating, please return this contact card to the project manager of International AIDS Empowerment.

***IMPORTANT INFORMATION***
All information shared during the interviews will be kept confidential and private. Names and other identifying information will be removed when the project is shared with others. You may withdraw from the study at any time without penalty.

☐ Yes, I am interested in participating in this study, and I will like to be contacted to receive more information about the UTEP HIV study (Please fill in the form)

Your Name: ____________________________

Cell Phone: ____________________________

A good time to call me is: ____________________________
APPENDIX B: Survey (Stage 1)

Your participation in this survey is voluntarily, and you can skip any question you do not want to answer.

1. Identify your sex
   □ Male
   □ Female
   □ Other, please describe: __________

2. What is your age? ______________

3. Identify your current marital status
   □ Single
   □ Married
   □ Divorced
   □ Civil Union
   □ Widowed/Widower
   □ Other, please describe: __________

4. What was your country of birth?
   □ US
   □ Mexico
   □ Other, Please list: __________

5. Are you of Hispanic, Latino, or Spanish origin? Please mark only one.
   □ No, not of Hispanic, Latino, or Spanish origin
   □ Yes, Mexican, Mexican American, Chicano
   □ Yes, another Hispanic, Latino, or Spanish origin – Please specify: ______________

6. What is your race/ethnicity? Mark one or more boxes.
   □ White
   □ American Indian
   □ Pacific Islander
   □ Black or African American
   □ Asian
   □ Some other race, please specify: __________

7. Which of the following best describes your total household income before taxes? Please include your income and income from anyone else in your household from jobs, investments, public assistance, unemployment insurance, social security, disability/pension funds, and all other sources. Your best estimate is fine. Please mark only one.
   □ Less than $1,999 (Less than $166/month)
   □ $2,000 - $4,999 ($167 - $416/month)
   □ $5,000 - $9,999 ($417 – $833/month)
   □ $10,000 - $14,999 ($834 – $1249/month)
   □ $15,000 – $19,999 ($1250 – $1666/month)
8. Are you currently employed?
   ☐ Yes – Please specify your job title:____________
   ☐ No

9. How long have you lived with knowledge of your positive HIV status?

   ________________________________________________________

10. How did you hear about services of International AIDS Empowerment?

   ________________________________________________________

11. How long have you been accessing the services of International AIDS Empowerment?

   ________________________________________________________
APPENDIX  C: Interview Guide (Stage 1)

General Questions

1. Tell me about your life before you found out about your HIV positive status.
   a. Tell me about your family
   b. Tell me about your friends or people who were close to you
   c. How was your lifestyle like?
   d. What was your livelihood?

2. How did you found out about your HIV status?
   a. When did it happen?
   b. Where did it happen?
   c. How do you think you got HIV?
   d. What were your emotions like at that moment?

3. Why did you decide to take the test for HIV infection?
   a. Was it your decision to take the test for HIV?
   b. Where did you test? Describe the circumstances surrounding the test.
   c. Did you expect the results to be positive?
   d. Did you have any initial symptoms?

4. Tell me about your life after you found out about your HIV positive status.
   a. Did any changes happen?
b. How has your daily activities changed since you got HIV?

c. Did any changes happen at your work, or to your daily lifestyle?

d. Did you start ART after being diagnosed?

i. If yes, was it hard to get an access to ART? Did you experience any side effects?

**Stigma-focused questions:**

5. Did you ever face discrimination or stigma because of your HIV status?

6. Did you tell your family about your HIV status?

   a. If yes, how did it happen?

      i. How did you do it?

      ii. When did you do it?

      iii. Why did you do it then?

      iv. What was the reaction of your family on your status?

   b. If no, why? What has stopped you?

7.6. Are you a religious person? Do you attend church meetings regularly?

   a. If yes, do people in your church know about your HIV status?

      i. If not, why?

   b. If yes, what was the reaction of the church community (or separate individuals) when you told them that you are HIV positive?

      i. How did it happen?
ii. Was this a difficult moment for you?

iii. Has your church (or faith community) been a resource for you in coping with HIV? Please describe.

7. Does anyone from your place of employment know about your HIV status?

   a. If yes:

      i. Who?

      ii. Was it your choice to tell them?

      iii. How did it happen?

      iv. If applicable, what was the reaction of your administration on this fact?

      v. Did you ever face stigma or discrimination from your employer? Please describe the case.

      vi. Did you ever face stigma or discrimination from your co-workers? Please describe the case.

   b. If no, has this caused any complications for you? Why or why not?

8. Did you ever have an experience of telling your sexual partner (if any) about your HIV positive status?

   a. If yes:

      .i. When did it happen? Who was the partner? Describe the reaction of the partner? Do you know the partner’s status?
ii. Was this a partner that you had before you learned you were positive?

i. If yes, has the relationship changed since you disclosed your status? Why or why not?

ii. If no and the person started a new relationship since becoming HIV positive: how did your positive status influence the formation of the new relationship?

iii. How do you feel about people who choose not to disclose their status to their partners? Why do you think they do that?

b. If no… (to question 9)

i. What has stopped you?

ii. What are the challenges in keeping your status hidden?

iii. Given that you have not told your partner, how do you feel about people that are open about their status? What do you think about that choice?

Note: If the person has had more than one partner, we will discuss each case separately

9. Have you ever had an experience of being told by a partner that he/she has HIV? If so, describe what happened.

10. Did you ever have the experience of telling to a friend that you are HIV positive?

a. If yes:

i. How did it happen?

ii. Why did you decide to share with your friend?
iii. Was it hard for you to make this step?

iv. Have you told all of your close friends?

v. How do you decide which friends or acquaintances to tell?

vi. Did you ever lose a friend because of your HIV status? If so, please tell me about that.

b. If no:

i. Why not? Have you considered telling a friend?

ii. What are the circumstances under which you would tell a friend?

11. What are some of the changes you noticed in yourself that have happened ever since you found out you had HIV?

   a. How has your self-esteem changed? How was it before? What about now?

   b. Why do you think it changed (if it did) and why do you think it did not (if it did not)?

   c. If it lowered, are there ways you have tried to raise it?

12. What are some of the emotional effects of being a person with HIV?

   a. Have you felt depressed because of HIV? How would you describe how you felt at that time?

   b. If applicable, Have you received treatment for depression?

**Border questions**
13. Have you lived on both sides of the border Mexico-USA? If so, please describe.

14. How often do you cross the border?

15. Do you have family living on both sides of the border? If so, please describe.

16. If applicable, are your experiences of stigma and discrimination different in the US and in Mexico?
   
   a. If so, how?
      
      i. Describe the cases of discrimination and/or stigma.
      
      ii. Why do you think you have a different experiences in US and in Mexico?

**Positive sides of stigma**

17. In your experience as someone with HIV, do you think there are positive ways in which stigma and discrimination can be overcome?

18. Have you had any experiences of involvement in community projects related to HIV? If so, please describe.

19. If you would have the chance to organize a project related to prevention of stigma towards HIV positive people, what would it be?

20. Do you think there is anything positive that can come out of having HIV? What might those things be?
   
   a. A change of behavior?
   
   b. Did you find any new friends
APPENDIX D: Post Workshop Survey (Stage 2)

Date of the Workshop: ___/ ___/ ______
Workshop Name or Number _____________________

Your participation in this survey is voluntary, and you can skip any question you do not want to answer.

INSTRUCTIONS
Please circle your response to the items. Rate workshop on a 1 to 5 scale:
1 - “Strongly disagree”, or the lowest, most negative impression
3 – “Neither agree, nor disagree”, or an adequate impression
5 – “Strongly agree”, or the highest most positive impression

1. Was the participation in this workshop interesting to you?

   | 1 | 2 | 3 | 4 | 5 |
---|---|---|---|---|---|

Comments__________________________________________________________________

2. Did you gain any new information?

   | 1 | 2 | 3 | 4 | 5 |
---|---|---|---|---|---|

Comments__________________________________________________________________

3. Were your expectations from the participation in the theater workshop fulfilled?

   | 1 | 2 | 3 | 4 | 5 |
---|---|---|---|---|---|
4. Do you think theater workshops can be used as a tool for empowerment for people living with HIV?

1  2  3  4  5

5. What are the chances that you will attend another theater workshop that I will hold next week?

1  2  3  4  5

6. Would you like to present the final outcome of this workshop (the theater performance) to the audience in El Paso?

1  2  3  4  5

7. What you did not like about the workshop?

8. How this workshop can be improved?

Thank You!
Hope to see you for the next theater workshop!
APPENDIX  E: Interview Guide (Stage 2)

ID Number: ________________

Date of Interview: __/ __/ ______

Interview Questions:

1. Tell me about your experience with the theater project.
   a. Was it a positive experience in your life?
   b. Was there something you did not like about the project?
   c. What would you change about the project?
   d. What are your overall emotions about the theater project?

2. Do you think the theater project provoked any changes in your life?
   If yes:
   a. If yes what are the changes?
   b. In your opinion, are these changes positive?

3. Why did you make the decision to participate in the theater project?
   a. For personal reasons?
   b. For social activist reasons? To bring changes in the community?
   c. What did you expect to receive from your participation in the theater project?
   d. Do you think the results of the project met your expectations?
4. Do you think the theater project brought any changes in perception of stigma towards PLHIV in El Paso?

5. Did you inform your family about your participation in the theater project?
   a. If yes, what was their opinion about it?
      i. Did they attend a performance? (If yes) What was their reaction on the performance?
      ii. Did they support you in this initiative?
   b. If not, why not?

6. Does anyone from your place of employment know about your participation in the project?
   a. If yes:
      i. What do they think about your participation in the project?
      ii. Would you show the outcome theater performance to your coworkers and employers?
   b. If not, why not?

7. Did you tell to any of your friends about your participation in the theater project?
   a. If yes:
      i. Did they attend a performance? (If yes) What was their reaction to the performance?
ii. Did they support you in this initiative?

b. If not, why not?

8. Did you notice any changes in your emotional condition after the participation in the project?

   a. How has your self-esteem changed? How was it before? How is it now?

9. In your experience, as a theater project participant, do you think this can be a way to overcome stigma and discrimination towards someone with HIV?

10. Do you think the theater project brought any emotional changes in your life?

11. If you would have the chance to organize a theater project yourself, would you do so?

   a. If yes, what would be the topic that you would choose?

   b. If no, explain why?

      i. Challenges of the organization process?

      ii. Lack of time?

12. Would you like to continue your participation in the theater show?

   a. If yes, what platforms (locations, audiences, etc) would you choose to present the performance?

   b. If no, explain why?
VITA

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