

Exploring Researcher Perceptions on Current HIV Care and Stigma Among HIV-infected Individuals in New York City

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Abstract

Background: Several studies emphasize barriers and facilitators to HIV care; however, this article emphasizes the perspective of HIV researchers working in New York City with a focus on the shift in HIV stigma since 1980s.

Purpose: The purpose of the study was to speak with researchers about the shift in the HIV care continuum and to discover differences between researcher and provider perspectives; particularly emphasizing the shift in stigma since the 1980s and the current barriers to HIV treatment in New York City.

Methods: In this qualitative study, ten New York City researchers participated in semi structured in-depth interviews.

Results: The main themes were the shift of HIV stigma since 1980, patient barriers to HIV care and facilitators to care. Since the 1980s, stigma has shifted from HIV/AIDS transmission to structural stigma around racial and economic barriers; once treatment options were discovered.

Conclusions: Researchers work to gain greater knowledge about HIV treatment and their input is vital in articulating the needs of an HIV-infected individual. It is crucial to apply this finding to clinical practice to enhance the collaboration of researchers and providers.

Introduction

HIV remains a significant public health concern in New York City. Approximately 125,000 residents were living with HIV in 2017, and 20% of them did not know their diagnosis [1]. There are medications available for HIV prevention (i.e., pre-exposure prophylaxis) and HIV treatment (i.e., antiretroviral therapies). Access to these medication options is vital for individuals who are HIV-positive or at high-risk of an HIV infection. Although care is available, not all individuals have equal access to it. HIV research is essential to decrease barriers to care. HIV researchers help expand the knowledge of this disease and through varying approaches aid in the understanding of barriers by working with vulnerable populations. Researchers are vital in developing new responses and controlling the HIV epidemic through their use of harm reduction methods for HIV-infected individuals. Epidemiologists have studied the incidence of HIV infections and discovered its relationship to substance use. Researchers are crucial in the progress of curbing HIV transmission and promoting new methods of effective treatment. However, we never hear from researchers directly, it is only through their work that we learn from them.

There are several barriers to receiving proper care including: racial (e.g. differences in likelihood of receiving care due to race),

structural (e.g. transportation, access to HIV clinics) and economic (e.g. health insurance/treatment cost) [2-4]. This research highlights patient barriers identified by HIV researchers with a specific focus on stigma as approximately 1 in 8 HIV positive individuals are not offered necessary health services for treatment due to stigmatization and marginalization of their HIV diagnosis [5]. Stigma has changed over time and the interviewees discuss why this shift has occurred, and its relationship to patient barriers.

Facilitators to HIV care (i.e. education and dignity/respect for the whole person) are also mentioned by the respondents with the example of a mHealth tool to support HIV positive individuals and those at high-risk to improve patient adherence to treatment. From the interviews, it is learned that mHealth is beneficial in an age of technological advancement, and it may be helpful to eliminate barriers due to stigma to HIV care [6, 7].

The purpose of the study was to speak with researchers about the shift in the HIV care continuum; particularly emphasizing the shift in stigma since the 1980s and the current barriers to HIV treatment in New York City. The hypothesis was that the primary reason that stigma shifted in the 1980s was due to greater access to education about HIV transmission. This study focused on HIV researchers

rather than practitioners because although researchers do not specialize in individualized care translational research is crucial in the development of effective HIV treatment. The researchers discuss how stigma has shifted once treatment became available for HIV-positive individuals. Researchers also discussed the benefits of harm reduction centers and some of the interviewees had first-hand experience working in these programs. New knowledge is gained from speaking directly with researchers and providers rely on their findings to guide patient interactions.

Methods

Study Design, Data Collection and Participants

The study was designed as a qualitative study following a semi-structured topic guide. A phenomenological approach was used to describe the barriers and facilitators to HIV care by exploring it from a researcher perspective to better understand current HIV care in NYC. Study recruitment lasted approximately two weeks from March 10th, 2019 to March 22nd, 2019. Inclusion criteria included: HIV researcher, adults (18+ years), English speaking and employed in NYC. Snowball sampling was used to recruit NYC HIV researchers. The strategy used for researcher recruitment was communication via email with faculty at hospitals, research centers, health departments, nonprofits and academia in New York City.

The interviews were conducted for about 2 weeks in March 2019 by the primary author. The place of interview was chosen by primary author. The interviews took place at the respondent's office (n=8), on the phone (n=1), and in a conference room (n=1) at a university. The interviews lasted about 30-45 minutes and followed a semi-structured topic guide, which was divided into 3 primary sections: a) introductory questions, b) facilitators to HIV care, c) barriers/challenges to HIV care. The topic guide was edited after three interviews were completed.

Data Analysis

Before starting each interview, the primary author explained to each participant that he/she would be committing to taking part in an interview, which is investigating current HIV care and stigma in NYC. A demographic survey was also emailed to each participant after the interview regarding age, gender, race, and education. It was explained that the interviews would be audiotaped and the participant had access to review the tapes and request all or any portion of the tapes to be destroyed. There were no known risks associated with participation in this study beyond those of everyday life. There were no direct benefits to the participant, however participants were told that this research would be helpful in understanding HIV care in NYC and the effective transitions made since 1980. Confidentiality of research records was strictly maintained by assigning only initials to each participant so that the data is never directly linked to the individual's identity. The ten interviews were analyzed in the software program ATLAS.ti to identify relevant themes and to create a coding scheme. There was a total of fifteen codes developed from the ten interviews. This study has IRB approval from the NYU IRB/University Committee on Activities Involving Human Subjects.

The primary author who has a Master's in Public Health degree conducted the 10 interviews. Qualitative studies have focused on the barriers and facilitators to HIV care in the United States; however, these have not focused solely on New York City researchers [8].

Ethical Clearance

This study was approved by the NYU IRB/University Committee on

Activities Involving Human Subjects. All procedures performed in the study were in accordance with the ethical standards of the 1964 Helsinki Declaration and its later amendments. Written informed consent was obtained from all individual participants included in the study.

Results

This study resulted in the recruitment of ten participants. Approximately fifteen individuals did not reply to the initial email invitation to take part in an interview. The participants came from academia, research centers, hospitals, health departments and nonprofit organizations in New York City. Each participant has been involved with HIV research for up to thirty years. Interviews revealed that progress has been made surrounding HIV itself and transmission of this disease; however, there is still much more that needs to be done, especially for this high-risk vulnerable population.

Demographic Characteristics

Ten individual HIV researchers were interviewed in New York City. Of the ten, 60% were female, 80% identified as White, 50% were between the ages 65-84, and 90% of the interviewees obtained a doctorate degree (e.g. PhD, DrPH, MD).

Themes

Several themes arose from these interviews and this article will focus on three prominent ones that address the research question exploring how HIV stigma has shifted since the 1980s: 1) HIV social stigma; 2) patient barriers to HIV care; and 3) facilitators to care. The themes were divided into subsections throughout the interview process.

HIV Social Stigma

From 2013-2017, almost 80% of these individuals newly diagnosed with HIV were Black or Latino. The estimated HIV prevalence is higher for Black and Hispanic males and females compared to their White counterparts [9]. HIV stigma certainly plays a role in this discrepancy. Research shows that HIV stigma is correlated with increased depression, reduction in patient adherence to antiretroviral therapy, and decreased social support and use of healthcare services [10]. Stigma plays a role, as patients do not have access to the HIV care needed such as syringe exchange programs or other harm reduction methods. Stigma and its impact were emphasized among interviewees and aided in the understanding of barriers to HIV care.

Stigma on disease transmission HIV

HIV stigma about transmission is oftentimes based on lack of knowledge and education on the disease [11]. The Research Triangle Institute conducted a study from August-September 2000, through a household survey that sampled 7,493 adults in the United States. These participants were selected from a larger pool of households (45,000). The larger scope of the survey was about aging and health; however, there was a question on the survey based on HIV stigma and education on how HIV is transmitted. About 75% of the participants answered this question on the survey. Approximately 40% of the 5641 participants who responded said that HIV can be transmitted through sharing a glass, and about 41% believed that one could get HIV by being sneezed or coughed on by an HIV-positive person. Almost 19% of respondents claimed that those who got AIDS from substance use or sexual intercourse deserved to get AIDS. There was significant stigma associated with the survey results and negative perceptions of HIV were more frequent among

men (22%), individuals greater than the age of 55 (30%), individuals who only have received a high school degree (22%), individuals who made less than \$30,000 (23%), Whites (21%), and about 24% across individuals who were in poorer health [12]. This study shows that there is a lack of understanding about HIV transmission and there are negative perceptions of those who acquire HIV/AIDs. The interviewees in this article spoke about lack of education and knowledge on HIV transmission and the general fear of contracting this disease [12]. In addition, in a recent survey 20% of Americans thought that an individual could get HIV from a drinking glass [13]. This study included 4-5 focus groups from New York, Westchester, Los Angeles, California, Des Moines Iowa, and Birmingham Alabama. Individuals from Los Angeles believed that sweat could transmit HIV. All these groups thought that HIV could be transmitted through cuts or open wounds. Some of the individuals were afraid to be around HIV- infected individuals who they knew. Doctors and dentists were also feared and people were uneasy about not knowing the HIV status of their healthcare providers [13].

Stigma on the disease (HIV itself) - How HIV has changed over time

At the start of the HIV/AIDs epidemic, individuals who were White, lived in urban areas, and men who have sex with men or men who use drugs were at higher risk for HIV infections compared to other groups. However, this has shifted over time and today in the United States new HIV infections are most prevalent among women, ethnic/racial minorities [14]. HIV stigma is detrimental as it targets vulnerable populations and marginalizes racial/ethnic minority groups. Individuals are treated in a different manner once their HIV status is disclosed. Negative attitudes about HIV and the idea that a person who gets HIV/AIDs deserves it impacts HIV-positive individuals through internalized stigma, the feeling of loneliness, shame and rejection. The stigma that is associated with HIV is grounded in both lack of education/knowledge on HIV transmission and fear of contracting HIV from another individual [15].

HIV stigma may prevent individuals from being tested and treated due to despair, embarrassment and shame. Some HIV-infected individuals have been rejected by their families or friends, and have been denied proper care and employment due to their HIV status. This stigma has a trickle-down effect and can influence a person’s interpersonal and professional relationships with others. If an individual is infected with HIV and uses drugs this creates an additional layer of stigma and negative perceptions of the individual [16].

Stigma shift once treatment becomes available

The main treatment available for HIV is antiretroviral therapy (ART). ART is not a magic bullet for HIV, but it decreases the risk of HIV transmission. ART decreases an HIV infected individual’s viral load (reduction of HIV in body) to an undetectable viral load, which decreases transmission risk to an individual who does not have HIV [17]. In the 1990s, ART was discovered and this changed the course of treatment-as HIV was known as a “death sentence” and became a disease that can be mitigated through ART [18]. The discovery of treatment is very important in helping prolong the lives of people who have HIV [19].

Stigma on people who use drugs

In the United States, injection drug use is correlated with an estimate of 33% of AIDs cases [20]. Individuals who use drugs are 22 times more likely to be at risk for HIV compared to those who do not

use drugs. This large difference is due to sharing needles and paraphernalia [21]. Approximately 10% of new HIV diagnoses are caused through needle sharing [22]. Oftentimes people who use drugs are looked at from a negative light. There is stigma associated with substance use through stereotyping, discrimination and rejection (as a moral failing). Stigma plays a role as patients do not have access to the proper care needed such as syringe exchange programs or other harm reduction methods. Language used towards people who use drugs is also stigmatizing such as “junkie [23].”

Perceptions of HIV-infected individuals

In a qualitative study, Moneyham et al. focused on HIV-infected women and several different themes emerged including: societal distance from those who were HIV positive, lack of comfort among HIV positive women, stereotyping, and pity for these women [24]. Negative perceptions towards both HIV and drug use are barriers to receiving treatment. Due to societal judgements and stereotyping people who use drugs are often discouraged and do not seek treatment or disclose their HIV status [25, 26]. The interviewees spoke about how stigma has changed overtime and how it is not eradicated, but rather has been shifted focus to racial, structural and economic inequities instead of on disease transmission.

Table I: HIV Stigma Breakdown

<p>1. Stigma on Disease Transmission HIV - HIV stigma, I remember the time early in my having this job where I came from work and went to a party... and somebody asks me my job and I told him, and I didn't necessarily recognize it at first, but Joanne[wife] told me about it later. People stayed away from me because I was researching people who had AIDS.</p>
<p>2. Stigma on the disease (HIV) itself - People in school, they never got HIV education and HIV was a taboo topic. And so, to them that sort of perpetuated stigma and continued stigma. Even though everyone knew someone in their world who had HIV, they are sort of getting these messages from school that, HIV is not something that we talk about. That is something that could be changed when they have mandatory HIV education in schools.</p>
<p>3. Stigma shift once treatment becomes available - At that time, there were no effective treatments. It was indeed a death sentence when we told them. They used to call it a “monster,” if people got infected. And, there were discussions about should we even tell people that they’re HIV positive because there were no treatments and there was so much stigma and that has continued. [And] so we’ve come a long way since then in around 1995 when the combination treatments became available- HIV became really a chronic disease.</p>
<p>4. Stigma on people who use drugs - We’ve changed a lot of the terms when I started within the year... HIV risk was “intravenous substance abuser” [to] “a person who injects drugs.” And in between that it was “injection drug user,” you know, like all that terminology ends up being stigmatized too.</p>

Barriers to HIV Care

Each barrier plays a role in how patients are treated for HIV and the interviewees discussed the shift from 1980s when the epidemic first began to the current day. In addition, Levy et al. discussed several barriers to HIV treatment such as lack of education, discrimination and racism [27]. While stigma around HIV has decreased, there are still barriers around race which have not gone away. There has been a shift from HIV stigma to racial stigma around HIV which is even more durable.

One interviewee commented on the lack of access to HIV care and the importance of groundbreaking HIV research along with differences between researchers and clinicians. “One thing researchers bring is that we see the persons living with HIV (PLWH) that providers don’t see. 40% of are not well engaged in HIV care. Providers typically see people who are able to overcome barriers to care and medication. People with fears, distrust, substance use, mental health problems, etc. often are read as non-compliant and get pushed out of care. All the HIV clinics have 90% viral suppression rates but the national and city-wide rate is less than that.”

Racial Barriers

Race plays a large role in HIV treatment. For instance, Heslin et al. shows that minority groups have a higher likelihood of dying, and lower likelihood of receiving proper HIV care (antiretroviral therapy) [2]. One interviewee discussed how people of color have high rates of HIV and do not have access to treatment such as PrEP. “Racial disparities are not separate or distinct from SES. If you look at racial disparities... young men of color are the fastest growing part of the epidemic right now, but they’re also the group that may be hardest to get on to PrEP. So that’s best to be further explored. They’re not actually buying into it as fast as White(s)”.

In the United States, minority populations (i.e. Latinos and Blacks) are slower to using PrEP even though their rates of HIV are higher than Whites. A study that took place in California showed that the likelihood of black Medi-Cal enrollees in 2017 was 4 times the likelihood of contracting HIV compared to their White counterparts. Latinos rate of PrEP use was the lowest of the Medi-Cal enrollees and the rate of contracting HIV was 1.5 times that of Whites.

In 2015, close to 45% of individuals who could have used PrEP to help with HIV prevention were African-American. Under 2% of these individuals had a PrEP prescription. 25% of people who could have used PrEP were Latino, and only 3% of them had a prescription for PrEP compared to 14% among white individuals. This racial disparity is due to stigma with using PrEP, lack of education and knowledge on the benefit of PrEP, and lack of trust in doctors. PrEP was also known to be used by individuals ages 25 and older. This report looked at data from the California Department of Health from 2012-2016. Medicaid patients are also at a higher risk of contracting HIV [27].

Stigma has also created a false relationship between promiscuity and using PrEP. This negative belief has discouraged the overall interest in PrEP. Eaton et al. demonstrates that stigma has impacted minority populations including: Black men and transgender women who have sex with men. Due to this negative association with promiscuity, minority populations are avoiding PrEP uptake. It is important to destigmatize PrEP use through screening for all sexually active individuals rather than those with high-risk sexual behaviors or multiple partners [28].

Furthermore, some people who are on PrEP are stigmatized and rejected by their partners for taking the medication and are often mislabeled as “promiscuous [29].” In addition, stigma towards sexuality (specifically gay sexuality) contributed to access and education around PrEP and was considered a structural barrier to care. There is also a level of discomfort among patients and clinicians when discussing gay sexuality and sexual risk taking. Judgment from a clinician is also another barrier to receiving PrEP among minority populations [30]. One interviewee discussed the benefit of PrEP and

the need for education on this medication:

People who are on PrEP getting HIV is very minimal. That awareness is also going to help people take their PrEP more because of they know that it actually works. PrEP helps destigmatize the idea of sex with an HIV positive person and a negative person. Public education is really crucial to just getting the right information out there and changing behavior and discourse on a larger scale.

Minorities have a higher likelihood of hospitalizations compared to Whites, and this may be due to lack of available HIV treatment for them due to racial disparities present in the healthcare system [2]. The media has racialized both HIV/AIDs and the opioid epidemic. Stevens et al discusses media coverage on how AIDs has decreased with the discovery of HIV treatment for African Americans. However, enough though there was a decrease in deaths, African Americans Stevens et al. were displayed negatively. Even though life expectancy and quality of life rose for African American HIV positive individuals, society viewed them as a threat for HIV/AIDs transmission [31]. Another interviewee discussed the racial disparities present in the opioid epidemic with regard to media coverage: “I’d only seen like people who inject drugs on TV and so, and mostly in the news and they’re demonized by popular culture.”

Another study, Stevens et al further demonstrates the racial disparity present in the media. As newspapers broadcasted HIV/AIDs and Stevens et al. testing, there was a decrease in African Americans getting tested for HIV compared to their White counterparts [31]. The proposed reasoning for this difference is due to stigma and distress among African Americans, which may contribute to decreased HIV testing along with greater concern among those at higher risk. Cultural concerns come into play and stigma around HIV transmission. One interviewee explained:

There’s still some cultural concerns about, you know, admitting HIV status, certain communities where people may go outside of their immediate community to a neighboring community to get care if they’re concerned inadvertent disclosure.

Another reason for lack of testing among African Americans may be due to social vicinity to HIV/AIDs or knowing others who have been impacted by the disease [32]. There is also a general mistrust of providers among African Americans that another participant discussed:

Right now most people would agree we have structural racism... but you know, like African American population in particular are very sensitive of the fact that they’ve been exploited in medical research, exploited in medical settings. And there’s mistrust. It doesn’t mean that there’s not all willingness, but there is mistrust and there is fear, maybe norms about trying alternative treatments before medications.

Drug use is also portrayed negatively in the media. In the 1980s, Blacks and Latinos were often displayed as criminals or drug addicts in urban areas compared to Whites who were shown as victims. In displaying the opioid epidemic, Whites were portrayed as victims and shown as people who fell into addiction by some external factors. Whereas for minority groups arrests and criminalization were displayed and drug use was a neurobiological disorder or a moral failing on their part [33]. One interviewee discussed the impact of racial disparities:

Like you didn't really care about the opioid epidemic until White people were dying. I've been working with people who use heroin for years and no one really paid attention because, you know, they were mostly Black and Hispanic and now suddenly, it's like a crisis because some were White people died. It is a crisis, but it was a crisis before, right? I think that the conversation around the opioid epidemic is really racialized".

Overall, racial disparities are more prevalent among Blacks and Latinos compared to their White counterparts. Approximately 14% of African Americans and 17% of Latinos who are HIV positive, are unaware of their HIV status. African communities also have larger rates of transferring sexual transmitted diseases compared to other groups. Fear of seeking HIV care may contribute to increased risk of HIV among Blacks and Latinos [34]. One participant demonstrated the racial stigma and discrimination. "The areas you find with the poorest health generally are minority areas, Black and Latino, and you know, generally poor health. So, it has, it has a major impact. Stigma is an issue because some of them are uncomfortable going to healthcare settings. And a lot of that is driven by the source of economic factors".

The interviewee highlights the health disparities among minority groups. Additionally, people who inject drugs in New York City are more likely to get HIV compared to those who do not inject drugs. Over the course of 30 years, dramatic HIV incidences have been found across people who inject drugs [35]. The opioid epidemic has contributed to greater injection drug use, which contributes to greater risk for acquiring HIV. Rural areas have been severely hit by the opioid epidemic and the HIV rates are lower in these areas. However, with increased injection drug use this is problematic as rural areas have sparse access to HIV and substance use treatment facilities [33]. One respondent addressed access to harm reduction services for people who use drugs and/or have HIV:

We have a lot of powerful tools in our toolbox, but they're not really scaled up and the way they need to be in the places where they need to be scaled up. I also think just throw the drug war out the window, like we need to stop incarcerating people. I think the drug war is, the sending people today to jail for using drugs is a really good way to undermine any efforts that we're doing.

The interviewee discussed the need for better access to HIV services and harm reduction centers and also mentions the importance of medicalization over incarceration among people who use drugs.

Structural Barriers

There are also several structural barriers to receiving HIV treatment including: incarceration [36]. Incarceration is not only a barrier to HIV care, but impacts adherence to substance use treatment due to inability to see a provider for weekly appointments. Even for those who are not incarcerated it still may be an issue for them to get to an HIV clinic [36]. One interviewee discussed the barrier of traveling to an HIV clinic, which is also a geographic barrier.

Medical care is more readily available in an urban setting regardless of where you are [compared to] rural settings because you know, just demographically people are further apart, you may have to travel a lot further [to get to an HIV clinic].

Not only is transportation to clinic an issue, but a person's circumstances can also be a barrier to receiving HIV treatment. For instance, another respondent discussed: Do you remember Maslow's hierarchy of needs from psychology? So, at the bottom it's like a pyramid. At the bottom is housing and shelter and food-basic needs and then you know, you kind of move up from there. People are worried about where they're going to live or what they're going to eat. This quote displays that HIV treatment may not always be a patient's priority and life circumstances and health inequities can get in the way.

Economic Barriers

Economic barriers to care include lack of health insurance and high cost of care [4]. The participants also addressed economic barriers to receiving HIV care and did not only focus on health insurance but the plethora of factors hindering positive-infected individuals from receiving care. One respondent stated:

Economic barriers are not just about like having health insurance, right? Economic barriers are about having childcare so that you can go to your doctor's appointment. It's about having/ being able to afford transport to get to your doctor's appointment. It's about being able to access your medications. If you're on methadone, you have to go every day to get your methadone, right? I mean, there's a lot more to it than that. And so, I do think that it's a barrier. Economic barriers are multi-faceted and certainly make access to HIV care much more difficult.

Facilitators to Care

There is much to learn from HIV researchers about facilitators to HIV care including the importance of education and knowledge about HIV, and treating patients with utmost dignity and respect through the harm reduction approach.

Education

Education is crucial in increasing patient adherence to treatment [37]. One of the respondents demonstrated the importance of being educated about available HIV medication. "I think it's an extremely important part, mainly because at this point the science has been developed to the point where we have medications to treat HIV effectively and essentially, you... [have] a relatively normal life in terms of length and quality." Education is key to teach and empower patients about HIV diagnosis, transmission, and ways to prevent it from spreading [38, 39]. With this education comes patient engagement in prevention and treatment and this was emphasized by a participant: "I think, you know, [it plays a] significant role. The more people know that if they're engaged in treatment, they can treat it like a chronic condition that you know, they're not necessarily going to be cured, but they can treat it like diabetes or something else where they're just on medication. They're likely to die of something other than HIV. So, the more people understand about the state of treatment, the more likely perhaps that people will get into treatment." Having a deeper understanding of HIV treatment may contribute to greater patient engagement in HIV care.

Treatment with Dignity and Respect

Harm reduction methods such as condom use, pre-exposure prophylaxis (PrEP), and clean needle exchanges all prevent the transmission of HIV [40]. The harm reduction approach is also about "meeting people where they are at [41]." This approach was touched on by several interviewees and one spoke about respect and compassion for HIV-infected individuals and people who use drugs.

I've really learned to try to meet people where they're at to treat everybody with respect- everybody was sir and ma'am. And basically, to treat them like I would treat family. So that they feel like whatever kind of work that I'm doing, it's a safe place to come.

A harm reduction approach to this high-risk vulnerable population is essential in decreasing stigma and promoting HIV care in a comfortable safe space for patients. It is vital to put all stereotypes aside and look at the whole person with respect and dignity. Another interviewee said: "If healthcare providers are not trained in harm reduction or for working with certain communities, then they often tend to be a little tone deaf and judgmental. [They] don't want to give them certain treatments because they don't think there'll be adherent and are afraid to have them in their waiting rooms."

One respondent commented on the dignity of the human person and disparities present in today's healthcare system. "And I mean, I think it would be more beneficial if somehow research could focus on looking at the whole person and what are the issues they need, and what are the health issues." In addition, it is important to note there is a difference between HIV researchers and providers outlook towards helping infected individuals. HIV researchers truly practice the harm reduction method when dealing with this vulnerable population. One interviewee discussed the differences:

A contribution we make is that we are not guided by a medical (mechanistic) model that is based on the assumptions that people "want" treatment. The medical model assumes - you have a life-threatening condition and I have a life-saving medication, so you'll be happy to have the medication. HIV researchers bring an understanding of how people work, cognitive biases, the role of emotions, etc. We talk about the good things about not taking medication as well as the bad. Medical encounters are very short and that is part of the problem. Medical providers are under pressure to get their patients to take ART. They are responding to structural forces. HIV researchers help articulate that.

The respondent discussed that there is more to an HIV diagnosis than a medication and how providers and researchers have different goals. The provider is mainly focused on treating the individual, whereas the researcher works to understand the individuals' needs, emotions and biases.

Discussion

The goal of public health researchers is to gain insight into how to produce better health outcomes. One of the interviewees discussed the benefit of hearing the perspective of an HIV researcher. "[Researchers help] generate knowledge or contribute understanding to a problem or issue. That information may lead to the development of services or treatments which clinicians/practitioners use to promote health and manage disease. Essentially researchers develop the tools, resources, knowledge or evidence base that will advance/inform the treatments/services clinicians can apply to attend to the disease/illness/injury."

HIV researchers are vital to discover new forms of treatments that can be directly applied by providers when treating HIV positive individuals.

This study systematically explored researcher perspectives on the facilitators and barriers to HIV care in New York City. Three

emerging themes were developed 1) HIV stigma (specifically social) and 2) patient barriers to receiving HIV care, and 3) facilitators to HIV care. The respondents discussed all forms of stigma regarding HIV transmission, the disease itself, the shift once treatment became available, and people who use drugs. The second theme focused on racial, structural, economic barriers to care. The third theme emphasized the importance of education and treatment with dignity and respect for HIV-infected individuals/those at risk. In addition, the interviewees discussed how mHealth interventions may be beneficial in reducing stigma and are promising in reducing barriers to HIV care. However, further research is needed to determine the efficacy of such interventions.

HIV Stigma

HIV stigma contributes to several negative effects on patients including: income loss, loss of employment, broken marriage, difficulty having children and depression [42]. HIV diagnosis also contributes to poorer healthcare services [5] and impacts broken marriages relationships and the mental health of positive-infected individuals [5]. Although HIV transmission stigma has decreased since the 1980s, there is still a public fear of the spread of this disease. In a 2009 survey, approximately 33% of Americans thought that HIV transmission occurred in swimming pools, drinking from the same cup, or using the same toilet seat. There was also a fear of being around someone who was HIV-positive, which is still stigmatizing one's HIV status [43].

In addition, the World Health Organization said stigma contributes to reluctance to use HIV services for testing. The hesitancy to get tested and receive HIV treatment contributes to late HIV diagnoses and increased incidence of HIV [44]. In the early 1980s when the epidemic first began the Gay Men's Health Crisis was created to combat stigma, prevent, and advocate for HIV care [45]. Furthermore, support for HIV has progressed since the early 1980s. During President Barack Obama's presidency, the National HIV & AIDS Strategy has helped combat HIV stigma with a focus on both bisexual and gay men along with transgender women. The Affordable Care Act also impacted those with HIV, as health insurance companies were no longer allowed to refuse giving people health insurance if they were HIV positive [46].

Shift in HIV Stigma

According to the interviewees, HIV stigma has shifted due to treatment options becoming available for patients. Once treatment became available HIV shifted from an acute death sentence to a chronic, manageable disease. Stigma of HIV transmission has drastically shifted due to increased knowledge and education along with the discovery of antiretroviral therapy. Even though the language has changed, stigma still exists today among people who use drugs. Today, some HIV positive individuals still feel uncomfortable disclosing their HIV status with friends and family members due to stigma. Race and ethnicity also still play a role in stigma [47]. There have been several consequences of stigma among HIV-infected individuals and those who use drugs including increased violence, segregation, stereotyping and rejection. Stigma has decreased patient quality of life and has hindered a decrease in HIV prevalence among minority groups [5].

Education and growth in knowledge has helped in its stigma reduction. The hypothesis was confirmed through increased education and awareness about HIV; however it is important to

note the availability of treatment and its impact in reducing stigma. Treatment changed the way people looked at the HIV and it became more normalized as medications became available. The findings in this study confirm the findings of prior studies on HIV barriers and facilitators. There have been qualitative interviews on this topic, however this study is distinct as it is focused on New York City researchers' perspective on the HIV care and does not take into account the perspectives of HIV providers, which could be an interesting comparison study in the future.

Importance of Hearing from HIV Researchers

This article analyzes the perspectives of HIV researchers. Some of the interviewees were able to work directly with HIV patients and gained new knowledge from speaking with participants in their research studies. Researchers bring a different perspective to the table and one interviewee spoke about their positive impact: "Researchers bring knowledge from the research literature of a wide variety of interventions, and circumstances under which they may or may not be effective. Providers may not have this knowledge. They may be able to ask questions related to programs that providers might not be trained in raising. Researchers [also] bring the ability to set up research designs to test out the best ways of implementing new programs, and to also assess the utility of various components of a program".

A few interviewees mentioned the lack of training among HIV providers. "By and large, for issues around policy, prevention interventions, surmounting barriers to getting people onto treatment, or understanding the epidemic, clinicians have very little training or perspective with which to think."

Another interviewee spoke about the mission of HIV researchers and how they researchers and providers complement one another but have different goals. "I think we have a different mission than providers. Our aim is to unearth predictive links and develop programs to change the course of disease trajectories. Providers implement these programs."

The mission of an HIV researcher is to discover new forms of treatment and ways that providers can serve their patients. Researchers appear to focus more on new approaches and innovations; whereas providers/clinicians focus on the implementation of new knowledge gained from these researchers. Sood et al demonstrates provider concern for patient retention in treatment and the quality of care received. Providers are supportive of the Ryan White Program for individuals who cannot afford HIV care and are weary of economic barriers to receiving care such as the inability to pay high copayments for treatment. Case management is key for providers as this links clients to HIV care, mental health support services and healthcare, which promotes integrated care [48]. Having an integrated care system is a key part of patient care and is emphasized by providers. Patient-centered care is emphasized and each individual will have different needs including psychosocial support, medication management or other healthcare services. The collaboration between providers and researchers is vital because the research end emphasizes the implementation of evidence-based practices and providers can use these practices to their advantage when helping an HIV client (i.e. antiretroviral therapy) [49]. A partnership between researchers and providers helps link research to clinical practice through the implementation of evidence-based practice by providers [50].

Although the integration of provider and researcher perspectives is ideal, there are challenges to bringing the two together as they have different roles. One interviewee discussed the different roles of researchers versus providers. "Clinicians operate at more of an individual-level whereas researchers operate at the group and/or population-level. Both perspectives are important, but they are different."

Oftentimes providers have very busy schedules and do not have time for individualized, time-consuming research. Many researchers are part of community-based organizations and the increased rate of staff turnover shortens the amount of time and rapport that they can develop with providers over an extended time period. Providers are also focused on individual clients and research is an iterative and cumbersome process that they may not have time for [51].

Lastly, the idea of researchers aiding providers in HIV care was also mentioned in the interviews. It appears that research contributes to improved medical care and researchers and providers contribute to each other's work and should rely on one another in the battle against HIV/AIDs. An interviewee said: "HIV researchers can and should complement HIV medical care. We need to learn from them and vice versa."

Overall, one major finding is that stigma still exists today in a more subtle form. However, with the growth of knowledge and education about HIV- the disease has decreased dramatically since 1980. The outcomes suggest that stigma exists today and is exhibited in different ways; and can continue to be mitigated through increased education/awareness and dignity/respect for individuals with HIV or those who are at high-risk. Future studies are recommended to get the provider perspective and compare what they perceive to be the barriers and facilitators with researcher perspectives.

Limitations

One limitation to this study is the small sample size of ten respondents. Even though the same size was very small, we did reach saturation. Also, only researchers were interviewed and it could have been beneficial to include providers as they directly deal with HIV patients on a daily basis. Also, talking with HIV patients themselves may have given richer results through using community-based participatory research. Another limitation is the age of participants. Future research should explore younger HIV researchers to discover differences across age groups.

Conclusion

Overall, HIV stigma is still present in today's culture as well as among people who use drugs. The education and knowledge gained about transmission has helped mitigate stigma along with the development of medications for treatment. Even though education is available, some individuals still fear getting HIV and infected individuals are still uncomfortable about sharing their status with those around them. The overall outlook on HIV has changed as it moved from an acute to chronic illness; however, the harm reduction approach is not accepted universally and this contributes to great health inequities for HIV-infected individuals. Further research is needed to end HIV stigma on all fronts, but the progress that has been made is worthy of applause.

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