HIV-related stigma: A negative & intersecting life experience

Taylor Beckwith
Whittier College, tbeckwit@poets.whittier.edu

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Abstract

In 2016, human immunodeficiency virus (HIV) affected over 1.1 million people in the United States. Antiretroviral therapy (ART) medications have allowed HIV-positive individuals to live longer lives, but this has meant greater exposure to HIV-related stigma. This literature review examines how HIV exists as a chronic disease and how HIV-related stigma contributes to a negative life experience. The concept of intersectionality is used to analyze the overlapping identities of (a) gay, bisexual men, (b) women, (c) and youth and adolescents. Even though individuals may be managing their diagnosis, added stress, stigma, and maladaptive coping mechanisms can lead to negative health outcomes. This review reveals the importance of understanding intersectional identities surrounding HIV-related stigma and individuals’ experiences in the societal environment.

Keywords: intersectionality, stigma, identities, mental health, coping, stress
HIV-Related Stigma: A Negative & Intersecting Life Experience

In 2016, 1.1 million people, ages 13 and above, had been diagnosed with human immunodeficiency virus (HIV) in the United States and its six dependent areas (Center for Disease Control and Prevention (CDC), 2019). In that same year, another 162,500 people were reported to have HIV, but did not have an official diagnosis (CDC, 2019). Then in 2017, 38,739 more individuals were diagnosed with HIV (CDC, 2019). Due to the serious implications and ongoing effects of this disease, 15,807 people who had been diagnosed with HIV died in 2017, which demonstrates just how problematic this disease is in the United States (CDC, 2019).

The Center for Disease Control and Prevention currently defines HIV as human immunodeficiency virus, a medical condition that can turn into acquired immunodeficiency syndrome (AIDS) if left untreated (CDC, 2019). Once contracted through bodily fluids, the HIV virus remains in the body as a lifelong condition that barrages one’s immune system (CDC, 2019). HIV impacts T-cells, specific cells in the body that specialize in preventing infections, and therefore makes individuals more susceptible to other diseases and cancers (CDC, 2019). When HIV is left untreated, the condition can progress into AIDS, which is when HIV has the most severe impact on the immune system (CDC, 2019). There is no cure for HIV, but treatments and preventative medications, such as pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP), have been developed to slow the progression of HIV into AIDS and limit the rate of transmission between individuals (CDC, 2019; Travaglini, Himelhoch, & Fang, 2018). Antiretroviral therapy (ART) medications have also proven to be effective in reducing the presence of the HIV virus in diagnosed individuals, therefore, allowing them to have longer and better lives with less risk of transmission and infection (CDC, 2019; Fletcher et al., 2016; Glynn
et al., 2019). This is a benefit of medical advancements and societal shifts, but a longer life also means lifelong stigma (Darlington & Hutson, 2017).

Today, an HIV diagnosis does not have to mean AIDS and an early death sentence, but it could still mean more mental and psychological health concerns. Since individuals with HIV have longer life expectancies, they now face greater daily risk and exposure to HIV-related stigma that could affect their quality of life (Darlington & Hutson, 2017). Stigma surrounding HIV has become an area of focus in HIV research because this stigma can negatively affect one’s likelihood of getting tested, one’s maintenance of treatment regimens (Kerr et al., 2014), one’s stress levels, one’s substance use tendencies, and one’s overall mental and physical health (Glynn et al., 2019).

A literature review is necessary to examine how HIV-related stigma impacts individuals’ overall life experiences and how this stigma has varied implications across identity groups. Previous literature reviews have focused on specific subgroups, for instance the effect on women and adolescents (Durvasala, 2014; Piper, Enah, & Daniel, 2014), but an analysis must be developed to compare how HIV-related stigma affects groups differently based on prior exposure to societal factors, such as racism and the intersectionality of their identities (Algarin, Zhou, Cook, Cook, & Ibanez, 2019). Additionally, the majority of the literature reviews were conducted five years ago (Durvasala, 2014; Piper et al., 2014), so the literature must be updated to include more recent studies portraying HIV as a chronic illness, the impact of HIV-related stigma in today’s society, and how one’s identity groups alter the effects of stigma.

In the literature reviewed here, criteria for inclusion as a participant with HIV was an individual who had a clinical or medical diagnosis verified through ART use, community groups, or medical records, and was living at any stage of the disease (e.g. Algarin et al., 2019; Berg,
Carter, & Ross, 2017; Brown, Serovich, Kimberly, & Hu, 2016; Fletcher et al., 2016; Hernandez et al., 2018; Travaglini et al., 2018). HIV-related stigma was defined in the literature as any shame, disgrace, negative attitudes or beliefs, devaluation, and discrimination portrayed onto or personally felt by individuals with HIV and any negative experiences they endure because of this diagnosis (e.g. Algarin et al., 2019; Bennett, Hersh, Herres, & Foster, 2016; Berg et al., 2017; Darlington & Hutson, 2017; Travaglini et al., 2018). Societal stigma around different groups is rooted in assumptions about HIV transmission (Darlington & Hutson, 2016), individuals’ sexual preferences (Murray, Gaul, Sutton, & Nanin, 2018), their substance use (Glynn et al., 2019), and their ethnic and cultural makeup (Algarin et al., 2019; Fletcher et al., 2016).

This literature review examines how HIV-related stigma contributes to an overall negative life experience and can place individuals at higher rates of discrimination and social rejection (Kerr et al., 2014). The effects HIV-related stigma has on individuals depends on other intersecting identities that can contribute to further stigma, marginalization, and discrimination. For example, gay, bisexual men made up 66% of the new HIV diagnoses in 2017, which shows the intersecting identities of one’s sexuality and gender, and 43% of all HIV diagnoses were African Americans, demonstrating their racial and ethnic identities (CDC, 2019).

To better understand varying levels of HIV-stigma, I will begin by reviewing the research on HIV as a chronic disease and negative life experience. Then, I will continue by analyzing and extrapolating the overlapping identities of (a) gay, bisexual men, (b) women, (c) and youth and adolescents. These categories are only one interpretation of these intersecting identities, but groups can and should be categorized differently to better analyze the effects of these layered identities. Overall, HIV-related stigma will be examined in relation to individuals’ lifelong experiences and their persisting intersectional identities.
HIV as a Negative Life Experience

Advancements in treatments and the creation of medications such as PrEP and PEP, have shifted the concern regarding HIV; the focus is now on how the disease creates a chronic negative life experience for individuals (CDC, 2019; Darlington & Hutson, 2017; Fletcher et al., 2016; Glynn et al., 2019). The rate of contracting HIV is higher for different groups of people who fit common stereotypes (CDC, 2019). This risk of HIV infection depends on the individuals’ number and type of sexual partners, intravenous drug use, and access to sexual education and prevention, which are all factors that have contributed to some groups being disproportionately affected (CDC, 2019). The stigma surrounding HIV is overwhelmingly due to a lack of education on how HIV is transmitted and the fear of the disease (CDC, 2019). This fear is rooted in the history of HIV and the blame that the United States placed on gay men and those who used drugs in the 1980s when HIV was initially on the rise (CDC, 2019). An HIV diagnosis now carries diverse implications that were not considered as important back in the 1980s.

Now, HIV must be analyzed as a long-term unfavorable life experience because of this recent shift of understanding HIV as a chronic condition with interconnected physical, social, and psychological risks and implications (Glynn et al., 2019). This stigma commonly associated with HIV creates negative life experiences that can manifest in various ways for those with the disease. HIV-related stigma can contribute to higher rates of depression, lead to greater alcohol use, heighten the effects of other comorbid metabolic disorders, and generate poorer total functional health, which are examples of how an HIV diagnosis and HIV-related stigma can contribute to these negative life experiences (Glynn et al., 2019; Hernandez et al., 2018).

In particular, HIV-related stigma and life stress precipitated a relationship between depression and overall health (Glynn et al., 2019). Research conducted with individuals from
HIV clinics that self-reported their stigma, stress, depression symptoms, and ART use found that depression was connected to an HIV diagnosis as a negative life experience (Glynn et al., 2019; Hernandez et al., 2018). Depression was defined as a psychiatric condition, and individuals with depression were defined as someone with this diagnosis and those who were currently using anti-depressants (Glynn et al., 2019; Hernandez et al., 2018). Through the creation and analysis of a model, researchers found that as HIV-related stigma and other life stressors, such as abuse and discrimination increased, one’s overall functional health, including one’s general physical functioning, psychological health, and management of HIV symptoms declined because of an increase in depression symptoms (Glynn et al., 2019). Increases in depression led to poorer health, such as an increase in one’s susceptibility to illnesses and lack of treatment adherence, which serves as a compounding factor and creates an adverse life experience for those with an HIV diagnosis (Glynn et al., 2019). This study provides a useful explanation of how HIV-related stigma can impact one’s physical and psychological health.

Enacted HIV-related stigma, stigma such as discrimination or avoidance, was shown to have an indirect positive relationship with depression, with alcohol being a significant mediator in this relationship (Hernandez et al., 2018). This significant effect associates greater reported HIV-related stigma with more alcohol use and higher reported depressive symptoms (Hernandez et al., 2018), showing the negative psychological impact of this stigma. There has also been attention on the relationship between HIV-related stigma and one’s increase in alcohol use (Glynn et al., 2019), because alcohol use is a maladaptive coping strategy often used as an attempt to deal with the impacts of HIV-related stigma and the stress surrounding this diagnosis (Hernandez et al., 2018). Addressing HIV-related stigma also connects to improving the overall health of individuals living with HIV because of how this stigma relates to increased alcohol use.
Specific education and training on positive coping strategies for living with HIV as a chronic illness should be developed to address this interrelated issue (Glynn et al., 2019).

The relationship between HIV-related stigma and stress, alcohol use, and depression explains how HIV-related stigma has interconnected negative effects that surpass psychological consequences, leading to increased risk behaviors and poor life choices. Increased alcohol consumption also affected HIV-positive individuals’ ART use and adherence (Glynn et al. 2019; Hernandez et al., 2018). Alcohol use impacts ART effectiveness because it alters how available ART is in the body, especially in an individual with a comorbid metabolic condition, further complicated by HIV-related stigma (Hernandez et al., 2018). ART adherence is also affected if individuals do not drink responsibly and fail to take their medications. The relationship between alcohol use and depression can also impact ART adherence because if individuals’ lack hope surrounding their chronic illness, then they have less motivation to take their medications. Disrupted ART use and adherence demonstrates how stress and HIV-related stigma can impact individuals’ comprehensive health and behaviors (Glynn et al., 2019; Hernandez et al., 2018).

HIV-related stigma was also examined in relation to its impact on other medical conditions, such as hyperlipidemia and diabetes mellitus, which are common comorbid diseases in HIV patients (Hernandez et al., 2018). Results show that an increase in alcohol use, due to the effects of HIV-related stigma (Hernandez et al., 2018), have psychological consequences, such as depression (Glynn et al., 2019; Hernandez et al., 2018), and can exacerbate existing comorbid metabolic conditions (Hernandez et al., 2018). Alcohol use was a predictor for greater rates of depression and worse health outcomes for individuals managing these comorbid metabolic conditions and HIV (Hernandez et al., 2018). Further research should address larger societal factors such as health disparities, gaps in health education, and levels of societal HIV-related
stigma that influence this relationship, in particular, individuals’ susceptibility to alcohol use and their access to health care (Glynn et al., 2019; Hernandez et al., 2018). Individuals’ personal stressors and maladaptive behaviors, such as alcohol use and sexual risk behaviors, can be a focus for intervention, but if the broader societal context is not addressed, then HIV-related stigma will continue to permeate individuals’ lives.

The long-term implications of an HIV diagnosis and the added life stress and stigma because of this diagnosis needs to be considered medically, socially, and psychologically to understand its various negative impacts on one’s health outcomes (Glynn et al., 2019). These quantitative findings show the importance of psychosocial and contextual treatments for HIV, especially related to stigma, treatment, substance use, and other comorbid conditions (Hernandez et al., 2018). Individuals’ mental and physical health and one’s negative life experience caused by HIV and HIV-related stigma can also be affected by “intersectional stigmatized identities” that have lasting negative health (Glynn et al., 2019, p. 292). Three of these intersectional identities will be more deeply analyzed in the following sections.

The Intersections between HIV-Related Stigma and Other Identities

HIV-related stigma is often coupled with other types of discrimination due to individuals’ confounding identities (Algarin et al., 2019). The theoretical framework of intersectionality is necessary to understand the interrelatedness of one’s identities and how stigma must be placed in these contexts to fully comprehend these individuals’ life experiences (Belgrave et al., 2018; Fletcher et al., 2016). Some identities that may intersect include one’s age, race, gender, sex sexual orientation, and HIV diagnosis, which can be layered on top of one another to create a compounded negative life experience (e.g. Algarin et al., 2019; Arnold, Rebchook, & Kegeles, 2014; Bennett et al., 2016; Fletcher et al., 2016). HIV-related stigma, paired with discrimination
from other identities, can create worse, long-term negative life effects and alter how individuals interact, encounter, and cope with HIV-related stigma (Algarin et al., 2019). These intersecting identities must be addressed to improve HIV-related stigma, interventions, and individuals’ health (Algarin et al., 2019). Specific groups of individuals widely affected by HIV-related stigma and these intersecting identities are gay or bisexual men, women, and youth and adolescents.

**Gay and Bisexual Men**

According to the CDC, gay and bisexual men, also known as men who have sex with men (MSM), composed 67% of the new HIV diagnoses in 2015 (Murray et al., 2018). Due to this group’s high HIV rates, quantitative and qualitative studies have explored and found common themes and intersections surrounding HIV-positive MSM and their life experiences (Arnold et al., 2014; Arscott, Humphreys, Merwin, & Relf, 2019; Berg et al., 2017; Murray et al., 2018). MSM are directly and indirectly affected by HIV-related stigma, leading to negative health implications, for instance greater HIV-relate stigma relating to worsening psychosocial health (Berg et al., 2017). Examples of indirect subtle stigma include gossip, rejection, rudeness, avoidance, distance, glares, and negative attitudes that can create unfavorable mental health outcomes (Berg et al., 2017). A study with majority White MSM participants, revealed that 75% of their participants had been “shunned or avoided sexually” due to their HIV-positive status and another 39% faced social exclusion (Berg et al., 2017). Although this study described experiences for one dominant racial group, these experiences with HIV-related stigma can be experienced by other racial groups, which creates another unique, dynamic experience.

**Homophobia and racism.** On top of HIV-related stigma, gay or bisexual men can also endure the added discriminatory effects from homophobia and racism. With homophobia, the
stress caused by HIV-related stigma coupled with additional rejection from family, friends or their community because of one’s sexual orientation, can expand gay and bisexual men’s marginalized position and increase their negative physical and mental health outcomes (Berg et al., 2017). Racism also builds another layer of stigma that is felt the most by the African American community (Arscott et al., 2019). Gay and bisexual men, especially Blacks and Latinos, reported that they must negotiate and navigate between their racial and sexual identities, as well as the added stigma and implications from an HIV diagnosis (Arnold et al., 2014; Murray et al., 2018). As one participant stated in his interview, minority gay and bisexual HIV-positive men are “triply cursed,” by three layers of stigma and discrimination (Arnold et al., 2014). Due to history and inaccurate stereotypes, HIV-positive Black gay men are discriminated against and face more negative encounters than other racial and sexual identity groups because of society’s stigmatized view that HIV is a homosexual disease for Black men (Arscott et al., 2019). Other groups, such as Latinos, face racial discrimination, but Black individuals face greater rates in comparison to these other racial groups because of social stereotypes (Arscott et al., 2019). These qualitative interviews reveal the more complex layers of individuals’ identities, which show the compounding detrimental health and social outcomes.

Since HIV is a stigmatized disease, HIV-related stigma can generate a fear of disclosure and of possible societal rejection that leads to negative coping strategies and isolation (Berg et al., 2017). On top of rejection because of one’s HIV status, gay or bisexual men must also endure another possible rejection from their families and society because of their sexual preferences (Arnold et al., 2014). In a study of Black and Latino men, this combined potential rejection based around HIV-related stigma and homophobia created a fear of losing social support (Berg et al., 2017), which could be linked to low self-esteem (Murray et al., 2018). This fear of rejection and
loss of social support may force HIV-positive MSM to hide both of these identities and become socially isolated. More research should focus on the relationship between HIV-related stigma and rejection, and how this may establish more negative life experiences and less social support.

This fear of rejection and loss of social support because of homophobia and HIV-related stigma, created barriers for individuals who wanted to disclose their sexual identities and health statuses with family, friends, the community, or potential sexual partners (Arnold et al., 2014; Berg et al., 2017). Studies showed that men who feel that they must hide their sexual identity, have higher HIV risk behavior, and when they also feel the pressure to hide their HIV status, their likelihood of HIV risk behavior increases (Arnold et al., 2014; Murray et al., 2018). Men who hide their gay or bisexual identities often use the term “down-low,” which means that they state that they are heterosexual, but sleep with both men and women without revealing this to others and keeping it on the “down-low” (Arscott et al., 2019; Murray et al., 2018). This behavior initiates a higher risk of using unsafe sex practices as a way to cope with the negative effects of HIV-related stigma (Arnold et al., 2014). The intersection of HIV status and sexual preference has created stigma strong enough to cause individuals to hide their identities to protect themselves from societal mistreatment (Arnold et al., 2014; Murray et al., 2018), which could potentially endanger their health as well as the health of their unsuspecting partners (Arnold et al., 2014).

HIV-related stigma can also arise from individuals’ families or other gay and bisexual men, which are the same people who are supposed to be these men’s main support system (Berg et al., 2017). This can detrimentally affect their social support and health, especially HIV-related stigma, racism, and homophobia that is perpetuated within the identity group (Arnold et al., 2014; Berg et al., 2017). Research shows that an HIV diagnosis makes acceptance into the gay
minority community more difficult because men in this group are more aware and afraid of HIV transmission (Arnold et al., 2014; Arscott et al., 2019; Berg et al., 2017). In a study exclusively focused on Black MSM, participant interviews revealed that men within this community carry internalized racist and homophobic views and exhibit behaviors that contribute to the HIV-related stigma, racism, and marginalization that persists in their own community (Arscott et al., 2019). This could be explained by individuals failing to accept their own identities.

Understanding stigma from the individual’s first possible support system and their own internalized stigma, when related to risk behavior, will be key to creating successful HIV prevention programs, especially for gay or bisexual men.

Besides facing exclusion from their minority gay community for their HIV status, Black men are often also rejected by their racial or ethnic community because of their sexual preferences (Arnold et al., 2014). These men must endure exclusion and discrimination from multiple identity groups and then society as a whole based on their skin color (Arnold et al., 2014; Arscott et al., 2019; Murray et al., 2018). These multiple exclusions force this subgroup of men to lose their community and possible social support from all of the groups that they would normally be able to identify with; gay, Black, and HIV-positive identity groups.

Overall results found that high levels of social support mediated the relationship between stressors, such as HIV-related stigma, and therefore this social support could limit the negative psychological and physiological impacts of an HIV diagnosis (Berg et al., 2017) by possibly also buffering against the effect of other life stressors, such as racism and homophobia. It is also possible that openness surrounding HIV, further education, and greater acceptance of the gay or bisexual and HIV-positive community would benefit the health outcomes of this specific population through increased social support networks and improved perceptions (Berg et al.,
Unfortunately, men who encountered more HIV-related stigma perceived that they did not have as much social support (Arnold et al., 2014; Berg et al., 2017; Murray et al., 2018).

**Sexual risk.** Another implication of HIV-related stigma is the effects this diagnosis has on one’s sexual risk. Stigma surrounding one’s sexual identity appeared as a main theme in research, and in one study, as minority men experienced increased HIV-related stigma, their sexual risk behaviors, such as having unprotected sex or having sex with strangers, also rose (Murray et al., 2018). As discussed earlier, low self-esteem due to a lack of social support leads many gay or bisexual men to hide their identities, which may lead to an increase in sexual risk behaviors (Murray et al., 2018). Sexual risk behaviors were also used by individuals as an avoidance strategy to combat and cope with the interrelated damaging impacts of HIV-related stigma, homophobia, and racism (Arnold et al., 2014; Murray et al., 2018). Additionally, these individuals may also avoid HIV clinics or community groups, which could interfere with the effectiveness of disease prevention and treatment (Arnold et al., 2014; Murray et al., 2018).

Layered stigma from one’s varied identities, as mentioned above, can inhibit an individual from visiting an HIV clinic for testing or treatment out of fear of indirectly disclosing their status and exposing themselves to HIV-related stigma (Arnold et al., 2014). This fear of indirect disclosure prevents them from accessing healthcare and reaching out to others for support, which illustrates how the combination of racism, homophobia, and HIV-related stigma contributes to delayed treatment and creates barriers in healthcare delivery (Arnold et al., 2014).

Men who maintained strong relationships were more likely to have been HIV tested in the last two years and have lower rates of sexual risk behaviors (Murray et al., 2018), which is consistent with studies that show the detrimental effects of a weak social support system (Berg et al., 2017).
Gay and bisexual men also reported that they often assess sexual risk in the context of their own risk of contracting HIV from a potential partner (Arscott et al., 2019). Gay and bisexual men shared that they utilized their knowledge about a person’s race, class, gender, and sexual orientation identity to “vet” them and determine their HIV risk of having sexual relations with them (Arscott et al., 2019). This finding highlights the stigma within the community based on compounding identities (Arscott et al., 2019), and underscores the need to clarify the action steps required to reduce and address HIV-related stigma in all aspects of the individual’s identity and community. Together these findings support creating awareness around the impacts of layered stigma, making improvements in social support systems, and providing better education about stigma prevention and treatment outcomes for HIV to improve individuals’ overall health.

The Unique Impacts of HIV-Related Stigma on Women

Women, a group where one in 139 will receive an HIV diagnosis (Relf, Williams, & Barroso, 2015), also carry marginalized identities, such as race and age, which create stigma and inequities that can intersect with HIV-related stigma (Fletcher et al., 2016). Women who experienced greater stigma reported greater depressive and anxiety symptoms (Brown et al., 2016), and suffered increased frequency and severity of depressive, anxiety, and PTSD symptoms due to increased anticipated HIV-related stigma (Travaglini et al., 2018). The judgement and double-bind society places on women regarding their sexuality and sexual activity could possibly be another factor that compounds with the mental health effects of HIV-related stigma. Women also described how HIV-related stigma, whether enacted, anticipated, or internalized, negatively impacted their life and caused them to question their true worth, sense of self, and their relationships (Relf et al., 2015), which could have negative psychological consequences and contribute to women’s fear of disclosure and isolation (Relf et al., 2015).
Children add another dynamic to women’s fear of disclosure because women with children have to deal with the added stress of whether they want to disclose their status to their children and then must combat stigma from others who criticize their ability to care for their children because of their HIV status (Fletcher et al., 2016). These findings demonstrate the psychological effects of HIV-related stigma and how this stigma can lead to worsening mental health and more severe psychological symptoms (Brown et al., 2016; Travaglini et al., 2018).

HIV-positive women, through their personal narrative logs, shared that they socially isolated themselves because of their HIV diagnosis and avoided intimate relationships out of fear of rejection and fear of the need to disclose their status (Relf et al., 2015). Social stigma surrounding HIV perpetuates these behaviors as women with HIV consistently have more negative encounters in society (Fletcher et al., 2016; Relf et al., 2015). Having to keep one’s HIV diagnosis a secret can have negative physical health effects because it can negatively influence individuals’ immune systems and cause “psychological and physiological fatigue” (Relf et al., 2015), which may further damage women’s overall health.

African American women face additional layers of stigma because of their disease status, gender, and racial identities (Fletcher et al., 2016; Travaglini et al., 2018). These societal conditions, such as racism, are then exacerbated by HIV-related stigma and combined with gender discrimination (Fletcher et al., 2016), where women who faced higher rates of stigma also reported higher rates of perceived discrimination (Travaglini et al., 2018). This marginalized intersecting subgroup also expressed that because of this stigma and marginalization, they did not feel empowered to push back against these societal stigmas (Fletcher et al., 2016). This area of HIV-stigma research should be expanded in order to better understand why women did not feel empowered to push back and if it was due to their identity as a woman or as HIV-positive.
African American women’s overlapping identities of HIV-related stigma, gender, and race can also disrupt their willingness to disclose their HIV status (Travaglini et al., 2018). It should be noted that stigma from these women’s other identities, such as their race or gender, could further influence this relationship. Research found that there was more anticipated stigma and a greater number of trauma experiences among African American women living with HIV (Travaglini et al., 2018). These minority women face three or more layers of stigma, so it is possible that they encounter more traumatic experiences in society because of their stigmatizing identities. These findings may be explained through an analysis of the interrelations of one’s identities (Travaglini et al., 2018), and how these identities compound for a unique experience.

Age is yet another identity that can impact women’s experiences surrounding HIV-related stigma. Surprisingly, older women (50+), constitute a large proportion of United States HIV diagnoses (Belgrave et al., 2018; Grodensky et al., 2015). Older women face HIV-related stigma, ageism, sexism, and if they are also a minority, then racism as well (Belgrave et al., 2018). This high rate is thought to be caused by a lack of education and knowledge, limited partner communication, and a decrease in information regarding protective sex practices (Belgrave et al., 2018; Grodensky et al., 2015). Qualitive studies present the common theme that HIV-related stigma contributes to shame and embarrassment among older women (Belgrave et al., 2018; Grodensky et al., 2015), and older women shared that they also faced stigma surrounding their sexuality because of their age and HIV-positive status (Belgrave et al., 2018).

Similar to other groups, older women with HIV felt lonely and isolated, but their age and HIV-related stigma additionally negatively influenced their access to social support (Grodensky et al., 2015). Women also expressed feelings that they should have known better, which led them to experience additional shame that pushed them to further isolate themselves (Grodensky et al.,
This self-isolation and fear of disclosing their status led to feelings of “loneliness, depression, fear, anger, shame, and embarrassment” that these women reported experiencing because of their HIV diagnosis and HIV-related stigma (Relf et al., 2015). The impacts of HIV-related stigma on social isolation and non-disclosure may need to be further analyzed.

Church and religion were also key factors in the research on HIV-related stigma and older women (Belgrave et al., 2018; Grodensky et al., 2015). Older women reported feeling HIV-related stigma or anticipated stigma from their church, which negatively impacted their HIV status disclosure and the social support they received from their church community (Grodensky et al., 2015). Church and religion should be further explored in regard to HIV-stigma because older women identified church as a social support network, but also as a place of stigmatization (Belgrave et al., 2018). This research shows the conflict between churches possibly providing social support, while also perpetuating negative HIV-related stigma (Belgrave et al., 2018; Grodensky et al., 2015). Utilizing churches and religion as spaces for HIV education and prevention programs should be considered. Churches are established in communities and could possibly deliver better health messages and interventions to marginalized populations (Belgrave et al., 2018; Coleman, Tate, Gaddist, & White, 2016; Fletcher et al., 2016), while also possibly mediating the effects of HIV-stigma through social support, education, and prevention (Coleman et al., 2016; Payne-Foster et al., 2018).

HIV-Related Stigma in Youth and Adolescents

Youth and adolescents are another specific group impacted by HIV-related stigma and are at a high risk of internalizing the effects of their diagnosis (Bennett et al., 2016). Their HIV status and age are intersecting identities that can contribute to their internalization of their life experience, and increased HIV-related stigma was related to greater symptom internalization in
HIV-related stigma was shown to contribute to increased shame in these youth and adolescents, which could possibly lead to avoidant coping strategies and connect to internalizing symptoms of HIV-related stigma (Kerr et al., 2014). This internalization of HIV-related stigma symptoms can lead to negative health implications. For instance, HIV-related stigma can also have negative health consequences for youth and adolescents, as HIV-related stigma was found to be associated with more depressive and PTSD symptoms (Bennett et al., 2016). If these experiences are internalized, they may possibly have even more detrimental effects on youths’ and adolescents’ developing bodies.

Youths’ and adolescents’ mental health, in relation to HIV-related stigma, should be emphasized since this population is in a crucial developmental period where these negative health consequences could have long-term overall implications. Research needs to explore how to teach youth and adolescents positive coping strategies and ways to limit these negative consequences.

Youth and adolescent HIV education and knowledge could also be a factor that impacts HIV-related stigma. In youth and adolescents, as their knowledge about HIV increased, their HIV-related stigma decreased (Kerr et al., 2014). Gender differences were also exposed and supported these findings as youth and adolescent males exhibited less HIV- knowledge and more HIV-related stigma than females (Kerr et al., 2014). Females also experienced more guilt and depressive, anxiety, or PTSD symptoms as the result of HIV-related stigma in comparison to males (Bennett et al., 2016), which suggests that HIV education may need to be presented differently to males and females. Future studies should also consider possible program differences for gender non-binary youth and adolescents.

Youth and adolescents can also be exposed to an exclusive type of stigma coined “stigma by association” (Mason, Sultzman, & Berger, 2014). This was defined as stigma felt by youth
and adolescents, whose mothers were HIV-positive, but who did not have an HIV diagnosis themselves (Mason et al., 2014). Mothers described disclosing their own HIV status to their children as eliciting reactions of “shock, fear, and stigma” (Fletcher et al., 2016, p. 352), and these youth and adolescents experienced “felt stigma,” from stigma that was not directly enacted on them (Mason et al., 2014). This “felt stigma” was experienced through their peers who would joke or throw insults about people who are HIV-positive, which connects to their stigma by association (Mason et al., 2014). The anticipation or indirect impact of this stigma changed how they interacted or related with others, as they reported often keeping silent regarding HIV, dismissing insults and ignorance, and trying to avoid using shame as a response to experienced stigma from the community, family, and peers (Mason et al., 2014). Stigma by association should be further investigated, to determine if youth and adolescent stigma by association is felt differently if the person with HIV is a partner or other family member.

These findings suggest the necessity of inclusive youth and adolescent HIV education, especially regarding disease transmission and prevention. HIV and HIV-related stigma education should be emphasized at an earlier age in hopes of creating a societal shift in future generations regarding HIV-stigma and the negative perceptions that are portrayed and experienced by those with HIV and their loved ones. This is important because HIV-related stigma affects prevention, societal acceptance, and discrimination in youths’ and adolescents’ lives that could detrimentally impact their mental and physical development and overall well-being for the rest of their lives.

Conclusions and Future Directions

HIV-related stigma, an issue that individuals now face because of medical advancements and their longer life expectancies, (CDC, 2019; Darlington & Hutson, 2017; Fletcher et al., 2016; Glynn et al., 2019), creates a negative life experience for those with disease (Algarin et al.,
This literature review, using research from the past five years, explored the general effects of HIV-related stigma and further analyzed the specific experiences, discrimination, and stigma that gay and bisexual men, women, and youth and adolescents face in society because of their overlapping identities (Algarin et al., 2019). Future research on HIV-related stigma and intersecting identities should consider the greater impact that societal, historical, environmental, and macro level factors have on marginalized individuals (Arnold et al., 2014; Fletcher et al., 2016; Glynn et al., 2019; Hernandez et al., 2018; Murray et al., 2018). An integrated approach addressing individual and societal factors (Travaglini et al., 2018) should be used in intervention programs to address intersecting identities, layered stigma, health inequities, and healthcare barriers (Algarin et al., 2019; Arscott et al., 2019; Glynn et al., 2019; Hernandez et al., 2018), which can initiate societal change through stigma reduction programs (Fletcher et al., 2016).

Coping strategies and mental toughness should be another area of intervention focus to support those facing HIV-related stigma (Bennett et al., 2016; Relf et al., 2015). If individuals can be taught the skills to combat the negative effects of stigma, then they will have better overall health and a less negative life experience. The possible causal connection between HIV-related stigma and increased negative mental health symptoms needs to be further explored (Brown et al., 2016; Hernandez et al., 2018) and supported through a psychosocial approach (Bennett et al., 2016), especially in relation to how stigma can inhibit social support (Berg et al., 2017). Programs that increase social support for HIV-positive individuals could aid in reducing the stigmatizing climate surrounding HIV and therefore improve individuals’ health.

Faith-based interventions could also be a key to the success of stigma interventions, especially for the African American population and those in the Southern United States (e.g. Coleman et al., 2016; Murray et al., 2018; Payne-Foster et al., 2018): an area with a high number
of churches and high HIV prevalence (Belgrave et al., 2018). A few studies have analyzed the effectiveness of these types of programs (Coleman et al., 2016; Payne-Foster et al., 2018), but future research should further explore how churches can provide spiritual and social support through opportunities, such as counseling, that would bring individuals together to share their personal experiences and challenges with HIV-related stigma (Grodensky et al., 2015).

Since most studies used qualitative interviews to explore HIV-related stigma, social desirability could have been problematic, as individuals could have censored themselves in these interviews (Arnold et al., 2014; Berg et al., 2017; Kerr et al., 2014; Payne-Foster et al., 2018). Methodology such as narrative logs (Relf et al., 2015) could be more widely used, which could remove the issues of interviewer bias and possible lack of rapport with the interviewer. Despite the limitations, interviews are extremely beneficial because they provide first-hand knowledge and personal insight into the experience of those living with HIV and HIV-related stigma. A better quantitative HIV-related stigma measurement should also be developed to attempt to separate the effects of HIV-related stigma from the effects of other marginalized identities and stigma. These methodological improvements would provide for a more complete analysis of the negative life experiences that individuals with HIV and other marginalized identities face.

HIV-related stigma and its interaction with intersecting identities should be further examined to clearly identify the effects of HIV-related stigma and how this can compound with one’s other identities and other forms of stigma. This supports the concept of using the intersectionality framework to further analyze HIV and HIV-related stigma (Belgrave et al., 2018; Fletcher et al., 2016). Individuals carry multiple identities that cannot be teased apart, and until they are acknowledged within their larger, macro societal environments as individuals with complex identities, then HIV-related stigma will remain.
References


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