

# Chapter 2

## Stigma Experienced by People Living with HIV/AIDS

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### 1 Introduction

A diagnosis of HIV infection carries both physical and social ramifications. Physically, testing HIV-positive means that one has contracted a life-threatening disease. People living with HIV/AIDS (PLWHA) typically suffer detriments to their immune systems which increase their vulnerability to opportunistic diseases (e.g., bacterial and viral infections, neurological diseases, and cancers) that may ultimately result in death. Socially, HIV infection also means that one has gained a mark of stigma that can lead to devaluation in a variety of contexts. PLWHA may face discrimination in the workplace, education, places of worship, and healthcare settings and may experience social ostracism from friends and family. Therefore, HIV infection not only means that one has to face living with and managing a chronic health condition; it also means that one will likely face social stigma that may fundamentally change the way one perceives oneself and interacts with others. Stigma associated with HIV/AIDS represents a significant barrier to the quality of life of PLWHA as well as efforts to engage PLWHA in services and prevention.

In this chapter, we discuss three approaches to understanding how HIV stigma shapes the quality of life of PLWHA. We aim to gain insight into how to intervene in HIV stigma to improve efforts to engage PLWHA in services and enhance HIV prevention. The first approach contextualizes HIV stigma by stressing that experiences of PLWHA are shaped by the sociocultural contexts in which they live.

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This approach suggests that understanding and intervening in HIV stigma requires attention to the unique structural and interpersonal drivers of HIV stigma that exist within a particular sociocultural context. The second approach reconceptualizes the multiple stigmas that many PLWHA experience (e.g., drug use, sexual orientation, race/ethnicity) as intersectional stigma. This approach provides a way of understanding and measuring multiple stigmas and how they interact to impact PLWHA. The third approach specifies how HIV stigma impacts PLWHA via a series of stigma mechanisms, suggesting concrete points of intervention to disrupt the relationship between stigma and its deleterious impact on PLWHA. Finally, we apply these three approaches to understanding HIV stigma in the context of South Africa. We consider the ways in which social context, intersectional stigma, and stigma mechanisms shape the experience of HIV stigma by PLWHA in South Africa and explore potential strategies for interventions. Additionally, we provide a table defining and providing examples of terminology commonly used with regard to HIV stigma (see Table 2.1).

## **2 Contextualizing Stigma: HIV Stigma as Dependent on Sociocultural Context**

HIV stigma is a global phenomenon; PLWHA encounter stigma in every sociocultural context in which it has been studied (Aggleton and Parker 2002; see also other chapters in this volume). However, the nature of HIV stigma, including its prevalence and the ways in which it is expressed, varies across cultural contexts. For example, although HIV is stigmatized in Africa, Asia, and the Americas, the endorsement of stigmatizing attitudes and behaviors by general populations (Genberg et al. 2007) as well as the experience of stigma by PLWHA (Kalichman et al. 2009) differ between these contexts. Conceptualizing stigma as a social construct dependent on sociocultural context provides a more nuanced understanding of HIV stigma that better explains why and how HIV stigma varies among societies.

Stigma theorists starting with Goffman (1963) have stressed the importance of building an understanding of stigma that is rooted within individual sociocultural contexts. Goffman (1963: 3) defines stigma as “an attribute that is deeply discrediting” and noted that “a language of relations, not attributes, is really needed” to understand stigma. According to this definition, an attribute is constructed as a marker of tarnished character within the context of social relationships. This marker, in turn, leads to the discrediting or devaluing of anyone who bears it. In the case of HIV stigma, HIV is the attribute that has become a marker of tarnished character. PLWHA are discredited or devalued because they bear the mark of HIV. Importantly, because stigma is a social construct, there is nothing innate about the character of PLWHA that justifies their devaluation or discrediting (see also Chaps. 1 and 6, and chapters in Part II in this volume).

**Table 2.1** Terminology commonly used with regard to HIV stigma

Term	Definition	Example(s)
Stigma	A personal attribute, mark, or characteristic that is socially devalued and discredited	HIV, drug use, sex work, sexual minority, racial/ethnic minority, female gender, poverty
Stigma mechanism	Ways in which people react to either possessing or not possessing a stigma	Prejudice, stereotype, discrimination, enacted stigma, anticipated stigma, internalized stigma
Prejudice	Negative emotions and feelings felt toward stigmatized people	Feelings of disgust, anger, and fear toward PLWHA
Stereotype	Group-based beliefs about stigmatized people that are applied to stigmatized individuals	Beliefs that PLWHA are promiscuous, dangerous, and immoral
Discrimination	Behavioral expressions of prejudice directed toward stigmatized people	Social rejection of, violence toward, refusal to employ, and refusal to medically treat PLWHA
Enacted stigma	Experiences of prejudice, stereotyping, and discrimination by stigmatized people	Experiences of social rejection, violence, employment discrimination, and medical discrimination by PLWHA
Anticipated stigma	Expectations of experiencing prejudice, stereotyping, and discrimination in the future by stigmatized people	Expectations of social rejection, violence, employment discrimination, and medical discrimination by PLWHA
Internalized stigma	Endorsement of negative beliefs and feelings associated with stigma by stigmatized people	Feelings and beliefs of PLWHA that they are disgusting and immoral
Intersectional stigma	Conceptualization suggesting that multiple stigmas interact to impact the self and cannot be teased apart or layered hierarchically	A PLWHA's unique experience of HIV stigma due to their female gender and history of sex work

Theorists since Goffman (1963) further characterize stigma as a social construct shaped by social processes. Link and Phelan (2001), for example, theorize that stigma emerges from a social process involving labeling, stereotyping, separation, status loss, and discrimination. They emphasize that this social process relies on power to reproduce social inequity and inequality between stigmatized and nonstigmatized people. Additionally, Parker and Aggleton (2003) conceptualize stigma as a social process that operates at the intersection of culture, power, and difference. They stress the importance of studying the relationships between culture, power, and difference within social contexts to understand stigma. Both Link and Phelan (2001) and Parker and Aggleton (2003) highlight social processes involved in the construction of stigma. Each of these social processes may operate differently in sociocultural contexts, helping to explain why and how HIV stigma varies across cultures.

These conceptualizations of stigma suggest that to study and intervene in HIV stigma within a particular sociocultural context, we should first develop an understanding of the social processes that contribute to the construction of HIV stigma within that context. Attending to the unique structural and interpersonal drivers of HIV stigma within social contexts represents a starting point for building this understanding. Structural drivers of HIV stigma include laws, policies, and politics that disadvantage PLWHA. Interpersonal drivers of HIV stigma include stigmatizing thoughts, feelings, and behaviors of community members that are directed toward PLWHA.

Societies have instituted numerous structural interventions over the course of HIV/AIDS that have fostered and even proliferated HIV stigma. These structural drivers of HIV stigma have ranged from subtle to extreme. At the subtle end of this spectrum, failures of leaders to act on HIV/AIDS, such as occurred in the United States throughout the 1980s, signal devaluation of those affected. At the extreme end of this spectrum, policies for control and containment of people infected with HIV have been the most stigmatizing. For example, countries have quarantined people infected with HIV (e.g., Cuba; see Sheper-Hughes 1993), restricted HIV-positive children from attending schools, and banned people infected with HIV from entering their country (e.g., the USA prior to 2010). Less extreme policies, including those that ban people living with HIV/AIDS from certain lines of employment, such as in the education sector, also fuel HIV stigma. Furthermore, policies directed toward groups designated as “at risk” for HIV/AIDS are prevalent and stigmatizing. Repressive drug policies, for example, stigmatize drug users, reduce access to drug treatment, and prohibit access to clean injection equipment (Friedman et al. 2011). Institutionalized and structural sources of HIV stigma have impeded HIV prevention efforts and limited access to care services for those infected with HIV.

In addition to social processes at the societal level, social processes at the interpersonal level contribute to the construction of HIV stigma. Interpersonal drivers of HIV stigma encompass the ways in which stigma is constructed within interpersonal interactions between community members and PLWHA. These drivers include the stigma mechanisms of prejudice, stereotyping, and discrimination (Earnshaw and Chaudoir 2009). Prejudice is characterized by negative emotions and feelings (e.g., disgust, anger, and fear) that HIV-negative people feel toward PLWHA (Allport 1954; Brewer 2007). Stereotyping is characterized by group-based beliefs about PLWHA that are applied to specific individuals living with HIV/AIDS by HIV-negative people (Kanahara 2006). Discrimination is characterized by behavioral expressions of prejudice by HIV-negative people directed at PLWHA (Allport 1954; Brewer 2007).

Interpersonal drivers of HIV stigma, which may vary in content and intensity between different sociocultural contexts, ultimately impact the lives of PLWHA. Although the content of prejudice toward PLWHA may be characterized by negative emotions and feelings in many places of the world, the strength of prejudice may vary greatly. For example, prejudice may be stronger in places where the HIV epidemic is more prevalent and the perceived threat of HIV is greater. The

association between stigma and HIV prevalence may be counterintuitive because a higher prevalence of HIV also means a greater likelihood of knowing someone affected by HIV. Nevertheless, stereotypes of PLWHA as immoral or engaging in illicit activities (e.g., drug use and prostitution) persist in face of high HIV prevalence (Zelaya et al. 2008). Stereotypes may vary in both content and strength depending on the sociocultural context and are shaped, in part, by the unique history of the HIV epidemic within a specific sociocultural context. For example, in the USA the epidemic was first largely associated with gay men and intravenous drug users (IDUs) (Herek 1999). Today, stereotypes continue to associate HIV with gay men and intravenous drug users in the USA. Like all stereotypes, HIV stereotypes are cognitively convenient but not always reflective of reality. Finally, the content and strength of discrimination toward PLWHA may also vary. Actual discriminatory behaviors and severity of discrimination differ across contexts. In some sociocultural contexts, interpersonal discrimination may be more subtle, involving social rejection, as occurs in exclusionary and distancing practises. In other contexts, interpersonal discrimination may be more severe, involving extreme violence and severe rejection (Aggleton and Parker 2002; Visser et al. 2006).

In addition to contextualizing HIV stigma by geography, it is important to attend to time because HIV stigma mechanisms evolve. In the USA, for example, prejudice, stereotypes, and discrimination directed at PLWHA decreased throughout the 1990s (Herek 2002). Therefore, PLWHA in the USA may have encountered more stigmatizing feelings, thoughts, and behaviors from others earlier in the US HIV epidemic than in later years (see also Chaps. 8–9, 11, and 19 in this volume).

Thus far, we have suggested that because the nature of HIV stigma varies between sociocultural contexts, it is critical to attend to the unique structural and interpersonal drivers of HIV stigma within particular places at particular times. Doing so will provide greater insight into how HIV stigma is experienced by PLWHA within sociocultural contexts. In addition to varying between sociocultural contexts, the nature of HIV stigma varies between people. For example, within the same sociocultural context, a black heterosexual woman may experience HIV stigma differently than a Latino gay man (see Chap. 11). Therefore, to continue to understand how PLWHA experience HIV stigma, we now turn to the intrapersonal processes by which PLWHA experience HIV stigma. We focus on other aspects of the self that are also socially devalued or stigmatized and consider how these multiple stigmas intersect to shape PLWHA's experience of HIV stigma.

### **3 Intersectional Stigma: Reconceptualizing the Multiple Stigmas Experienced by PLWHA**

All PLWHA have one thing in common: the human immunodeficiency virus (HIV) infection. Arguably, this one commonality is stigmatized because it is a contagious and severe disease which represents an often misunderstood physical threat to

others (Crandall et al. 1997; Kurzban and Leary 2001; Park et al. 2003; Stevenson and Repacholi 2005; Tybur et al. 2009). Beyond their common HIV status, however, PLWHA are diverse. Many PLWHA belong to marginalized groups and may experience stigma related to their race/ethnicity, age, and/or gender (for a review see Henkel et al. 2008). Unlike HIV stigma, stigma related to marginal-group membership may be due to group-based exploitation and domination (Kurzban and Leary 2001; Phelan et al. 2008). That is, members of marginalized groups may be stigmatized so that dominant group members can exploit and maintain power over them. PLWHA may also be associated with other stigmas (e.g., drug use, sex work, LGBT orientations), sometimes termed HIV-related stigmas (Pryor et al. 1999). HIV-related stigmas may arise because they break social norms (Phelan et al. 2008). The function of this type of stigma may be to acquire conformity to social norms by either stopping or preventing people from engaging in deviant behavior. Taken together, PLWHA may experience multiple stigmas, including marginal-group member status, HIV-related stigma, and stigma directly tied to HIV/AIDS.

At least two conceptualizations have been suggested to explain how having multiple stigmas, including marginal-group member status and/or HIV-related stigma, impact PLWHA's experience of HIV stigma. The first conceptualization suggests that HIV stigma is layered upon other stigmas (Reidpath and Chan 2005). This conceptualization, referred to as *layered stigma*, is common within HIV research and theory (Reidpath and Chan 2005; Nyblade 2006; Henkel et al. 2008; see also Chap. 15 in this volume). The second conceptualization suggests that HIV stigma intersects or interacts with other stigmas (Crenshaw 1996; Berger 2004). This conceptualization, referred to as *intersectional stigma*, is common within several disciplines including sociology (Collins 2000), psychology (Purdie-Vaughns and Eibach 2008), and political science (Berger 2004). In the remainder of this section, we review both conceptualizations and point toward adopting an intersectional approach to studying how PLWHA experience multiple stigmas.

Layered stigma, also referred to as compound stigma (Nyblade 2006), is an additive model of multiple stigmas. Conceptually, it suggests that multiple stigmas uniquely contribute to the experience of stigma. To understand the full impact of stigma on a PLWHA, one adds the unique impact of each individual stigma to create a sum such as:

$$\text{Marginalized-group member stigma} + \text{HIV-related stigma} + \text{HIV stigma} = \text{Total stigma}$$

For example, according to the layered approach, if one wanted to capture the stigma experienced by a female sex worker who is HIV-positive, one would quantify the amount of stigma associated with her marginal-group membership (i.e., female gender), the amount of stigma associated with her HIV-related stigma (i.e., sex work), and the amount of stigma associated with her HIV-positive status. Using a standard metric, those quantities are summed to obtain a total score for stigma experienced by PLWHA. Reidpath and Chan (2005: 431) provide a more sophisticated conceptualization of layered stigma by further taking into account shared stigma, defined as “the degree to which the ... characteristics overlap,” as well as

synergistic stigma, defined as excess stigma due to the combination of stigmas. Their model takes each of these types of stigmas into account in the following way:

$$\text{HIV-related stigma} + \text{HIV stigma} + \text{Shared stigma} + \text{Synergistic stigma} = \text{Total stigma}$$

According to Reidpath and Chan (2005), capturing the experience of stigma by a sex worker who is HIV-positive would again require quantifying the amount of stigma associated with sex work and HIV. Next, one would quantify the amount of stigma that is shared by sex work and HIV as well as the excess stigma due to being both a sex worker and HIV-positive. Again, summing these scores yields a total score of how much stigma is experienced by this PLWHA.

Conceptualizations of layered stigma are generally limited in their ability to capture the complexities of how multiple stigmas are experienced by PLWHA. A critique of additive models is that they rest on the assumption that multiple stigmas can be parceled out, or separated from each other, and examined uniquely. Critics of the additive model argue that multiple stigmas cannot be parceled out because they are experienced by people as one (Purdie-Vaughns and Eibach 2008). For example, a female sex worker living with HIV may not experience stigma related to being a woman, stigma related to being a sex worker, and stigma related to HIV independently. Rather, she may experience these identities simultaneously. Another critique of additive models is that they have historically prioritized certain stigmas over others (Berger 2004). Additive models necessarily conceptualize stigmas hierarchically by layering one on top of another. In doing so, they risk assuming that some stigmas are more important than others. For example, layering HIV stigma on top of stigma ascribed to marginal-group membership may assume that HIV stigma is more important than marginal-group member stigma. This may or may not be true for different PLWHA. Reidpath and Chan's (2005) methodology addresses some of these concerns by including the roles of shared and synergistic stigmas. However, Reidpath and Chan do not address how to examine more than two stigmas. Specifically, it is unclear how to quantitatively tease apart unique, shared, and synergistic stigmas when more than two stigmas are involved in the equation. This is problematic given that PLWHA often possess more than two stigmas. Overall, additive models of stigma are limited due to their assumption that stigmas can be parceled out from each other, hierarchical conceptualization of multiple stigmas, and limited ability to quantitatively capture more than two stigmas.

Conceptualizing multiple stigmas as intersectional largely addresses these concerns. Intersectionality is defined by Berger (2004: 30) as "the interlocking forms of oppression which can be identified as separate, singular systems, but whose explanatory power is greatly enhanced when they are seen as interactive and interdependent on each other." Conceptually, therefore, an intersectional model of stigma suggests that multiple stigmas interact with each other to impact the self. This approach specifically argues against parceling out stigmas from each other. It recognizes that marginalized-group member status stigma, HIV-related stigma, and HIV stigma can be identified and studied as separate entities but ultimately argues that considering how these stigmas interact with each other provides a fuller understanding of how they impact PLWHA. For example, a female sex worker who is



HIV-positive experiences stigma related to being HIV-positive uniquely because she is female and a sex worker. The stereotypes that others hold of her as a PLWHA are necessarily shaped by her gender and engagement in sex work. Because intersectional approaches to stigma assert that stigmas interact with each other, each stigma is equally weighted. Stigmas are not conceptualized in a hierarchical manner, but rather are allowed similar positioning to impact the self.

Quantitatively, intersectional stigma can be studied using a multiplicative rather than additive approach. To understand the full impact of stigma on a PLWHA, the total experience of stigma is the product of each stigma multiplied together:

$$\text{Marginalized-group member stigma} * \text{HIV-related stigma} * \text{HIV stigma} = \text{Total stigma}$$

This multiplicative approach allows for the quantity of total stigma to be greater than the sum of the individual stigmas. In this way, the approach more easily captures the excess stigma that Reidpath and Chan (2005) account for with the inclusion of synergistic stigma. This approach can also be understood as a case of moderation (Baron and Kenny 1986), which is a powerful way to measure the simultaneous impact of multiple variables within psychology. A moderation approach suggests that the impact of one variable depends on that of another. For example, the impact of HIV stigma depends on that of HIV-related stigma. Importantly, this approach allows researchers to quantitatively capture more than two stigmas. There can be more than one moderator of HIV stigma, including marginalized-group membership and HIV-related stigmas.

An intersectional approach to HIV stigma may be uniquely positioned to provide greater insight into how PLWHA experience stigma as opposed to how the community stigmatizes PLWHA. Much of the work on multiple stigmas among PLWHA has focused on the endorsement of prejudice, stereotypes, and discrimination directed at PLWHA by community members (Crandall et al. 1997; Herek 1999, 2002; Pryor et al. 1999). In other words, this work has focused on the point of view of “HIV-negative” people who do not possess the stigma of HIV. Nonstigmatized people may hold different levels of prejudice, endorse different types of stereotypes, and perpetuate different types of discrimination toward people who possess different stigmatized attributes. For example, they may hold distinct sets of stereotypes about drug users (e.g., untrustworthy, immoral), gay men (e.g., immoral, promiscuous), and race (e.g., lazy, unintelligent). They may apply multiple stereotypes for each stigmatized attribute to an individual. Therefore, in perceiving a PLWHA with multiple stigmas, community members may pull from their cognitive representations of the multiple attributes that the PLWHA is perceived as possessing to form an overall impression.

In contrast, an intersectional approach to HIV stigma may be better positioned to capture how multiple stigmas are experienced by PLWHA who possess these devalued attributes simultaneously. Research on PLWHA with multiple stigmas suggests that HIV stigma is manifested differently depending on other stigmas and individual attributes. For example, PLWHA with multiple stigmas have different levels of disclosure concerns, which are closely linked to HIV stigma (Derlega et al. 2004;



Smith et al. 2008; Wolitski et al. 2008). Mason and colleagues (1995) found that Latino men were less likely than white men to disclose their HIV status and that there were differences in HIV disclosure concerns and expectations of rejection between Latino and white men. This suggests that disclosure concerns vary as a function of marginal-group member status. Latkin and colleagues (2001) found that current injection drug users were less likely to disclose their HIV status than noninjection drug users. This further suggests that disclosure concerns vary as a function of possession of HIV-related stigmas. Körner (2007), examining marginal-group member status and HIV-related stigma simultaneously, found differences in disclosure due to cultural background, gender, and sexual orientation. If HIV stigma is experienced in an additive manner, then HIV stigma should be experienced and reacted to similarly by members of marginalized groups and people who possess HIV-related stigmas. They should experience HIV stigma *in addition to* their other stigmas rather than *differently because of* their other stigmas. However, research on disclosure suggests that PLWHA experience HIV stigma differently because of their other stigmas, and therefore, an intersectional approach may be most appropriate for studying their experience of HIV stigma.

#### 4 HIV Stigma Mechanisms: Understanding How HIV Stigma Is Experienced by PLWHA

It is clear that HIV stigma, marginal-group status stigma, and HIV-related stigma negatively impact the people who live with them. For example, HIV stigma is associated with decreased mental health (Fife and Wright 2000; Berger et al. 2001; Sayles et al. 2008; Kalichman et al. 2009), decreased social support (Berger et al. 2001; Sayles et al. 2008; Kalichman et al. 2009), and increased HIV symptoms (Holzemer et al. 2007; Visser et al. 2008; Kalichman et al. 2009). Less clear is the process by which stigma has its impact. Therefore, in this section we explore the process by which stigma is experienced by people who possess it and ultimately impacts their outcomes. Although we focus on HIV stigma, this process is theoretically grounded in understandings of other stigmas such as mental illness, sexual orientation, and marginal-group member status (Brewer and Brown 1998; Link and Phelan 2001; Meyer 2003; Phelan et al. 2008). It is therefore applicable to all stigmas experienced by PLWHA.

Stigma mechanisms represent the ways in which PLWHA react to the knowledge that they possess a devalued attribute and include internalized stigma, enacted stigma, and anticipated stigma (Earnshaw and Chaudoir 2009). Internalized stigma, sometimes called self-stigma (Mak et al. 2007), is characterized by endorsement of negative beliefs and feelings associated with HIV/AIDS that are directed toward the self (Link 1987). Enacted stigma, sometimes called experienced stigma or perceived stigma, is characterized by actual experiences of prejudice, stereotyping, and discrimination from others in one's sociocultural context (Scambler and Hopkins 1986). Anticipated stigma is characterized by expectations that one will experience

prejudice, stereotyping, and discrimination from others in the future (Markowitz 1998). Each of these stigma mechanisms is related to negative outcomes for PLWHA (see Chaps. 9, 11, 12, 16, and 17 in this volume).

Internalization of HIV stigma is related to a variety of deleterious outcomes among PLWHA, including poor mental health. Specifically, PLWHA who have internalized HIV stigma experience increased depression (Berger et al. 2001; Lee et al. 2002; Simbayi et al. 2007; Kalichman et al. 2009), increased psychological distress (Mak et al. 2007), increased shame (Sayles et al. 2008), increased anxiety (Lee et al. 2002), decreased self-esteem (Fife and Wright 2000; Berger et al. 2001), decreased feelings of personal control (Fife and Wright 2000), and decreased hope (Lee et al. 2002). Internalized stigma is also related to poor physical health. PLWHA who have internalized HIV stigma experience increased physical symptoms related to HIV (Kalichman et al. 2009). In addition to impacting the mental and physical health of PLWHA, internalized stigma impacts the social spheres of PLWHA. Internalized stigma is related to decreased social support (Berger et al. 2001; Sayles et al. 2008; Kalichman et al. 2009) as well as decreased social integration and increased social conflict (Berger et al. 2001). Internalized stigma may therefore undermine the social support systems of PLWHA. Finally, internalized stigma is related to decreased quality of life (i.e., subjective well-being) of PLWHA (Holzemer et al. 2007).

Internalized stigma has been conceptualized and measured as an individual difference variable. That is, some PLWHA have strongly internalized stigma, whereas others have not. There are several factors associated with the degree to which PLWHA internalize stigma. Lee and colleagues (2002) found that PLWHA who were more recently diagnosed with HIV, whose families were less supportive, who had not attended HIV support groups, and who knew fewer other PLWHA experienced higher levels of internalized stigma. Decreased internalized stigma among PLWHA is associated with engagement in treatment, including antiretroviral therapy, and “normalization” of HIV within sociocultural contexts (Roura et al. 2009). Interestingly, attributions of blame to the self for one’s HIV status may not be related to internalized stigma (Mak et al. 2007), suggesting that accepting responsibility for one’s HIV status is not enough to predict internalized stigma.

Beyond internalized stigma, which is an intrapersonal phenomenon, stigma experienced interpersonally also leads to negative outcomes among PLWHA. As described earlier, prejudice, discrimination, and stereotypes vary in content and strength between different sociocultural contexts. Therefore, enacted stigma is experienced differently by PLWHA in different sociocultural contexts. Despite this variability in specific experiences, enacted stigma seems to be related to negative outcomes across sociocultural contexts. Enacted stigma is related to decreased mental health generally (Sayles et al. 2008) as well as decreased self-esteem (Fife and Wright 2000; Berger et al. 2001), increased depression (Berger et al. 2001), increased shame (Sayles et al. 2008; Zukoski and Thorburn 2009), and increased self-blame (Sayles et al. 2007) specifically. Enacted stigma is further related to decreased physical health, including increased HIV symptoms (Holzemer et al. 2007). Importantly, PLWHA who experience greater enacted stigma are also less adherent to their HIV treatments (Peretti-Watel et al. 2006), which may help to

explain the relationship between enacted stigma and increased HIV symptoms. Enacted stigma is also detrimental to the interpersonal relationships of PLWHA. Individuals who experience enacted stigma report decreased social support (Berger et al. 2001; Sayles et al. 2008), increased social isolation (Berger et al. 2001; Zukoski and Thorburn 2009), and increased social conflict (Berger et al. 2001). Furthermore, PLWHA who experience enacted stigma report having to renegotiate their social contracts with others (Sayles et al. 2007). Despite the negative outcomes of enacted stigma, it is important to note that some PLWHA report engaging in increased advocacy as a result of experiencing prejudice and discrimination from others (Zukoski and Thorburn 2009; see also Chap. 22 in this volume).

Anticipated stigma has received relatively less empirical attention than enacted stigma and internalized stigma. What evidence there is, however, suggests that expecting to experience prejudice and discrimination from others in the future is further related to adverse outcomes. For example, anticipated stigma is related to decreased mental health and social support (Berger et al. 2001). Research on people living with a wider range of concealable stigmatized identities suggests that anticipated stigma is associated with increased psychological distress and physical illness and that this relationship is amplified for people living with stigmas that are more devalued within their sociocultural context (Quinn and Chaudoir 2009). Indeed, anticipated stigma may play a powerful role in PLWHA's interactions with others. For example, anticipated stigma is related to nondisclosure of one's HIV status (Yoshioka and Schustack 2001; Derlega et al. 2004; Sayles et al. 2007; Smith et al. 2008; Wolitski et al. 2008).

Taken together, internalized stigma, enacted stigma, and anticipated stigma potentially shape the life experiences of PLWHA. We have discussed them as separate entities, but they are likely related in important ways. For example, internalized stigma and enacted stigma may work together to predict anticipated stigma. There is some evidence that people tend to think that others see them as they see themselves (Kenny and DePaulo 1993). Therefore, PLWHA who have internalized stigmatizing attitudes and beliefs toward the self may also think that others view them in stigmatizing ways. They may then expect that others will treat them in prejudicial and discriminatory ways. Experiences of prejudice, stereotyping, and discrimination are also related to perceptions that stigma in one's sociocultural context is normative (Steward et al. 2008), which could, in turn, be related to expectations of future experiences of prejudice, stereotyping, and discrimination. Further exploration of the relationships between these three stigma mechanisms will provide a fuller understanding of how HIV stigma is experienced by PLWHA.

## 5 Stigma in Sociocultural Context: The Case of South Africa

Southern Africa is home to two-thirds of the more than 33 million people living with HIV/AIDS in the world. Although only 10 % of the world's population lives in Sub-Saharan Africa, more than 85 % of the world's AIDS-related deaths have

occurred in this region (UNAIDS 2010). In parallel to the rampant spread of HIV is an ever-present shroud of HIV stigma.

HIV stigma in South Africa has been fostered by more than a decade of governmental policies that sharply divided the nation. At the end of institutionalized racial segregation, the Apartheid era, South Africa concentrated on rebuilding its country, including its healthcare system. Focusing on creating a new South African society came at the expense of neglecting the rapidly growing AIDS epidemic of the 1990s (Mandela 1994). At a time when HIV was rapidly exploding, South Africa entered a period of AIDS policies that would baffle the world. Former President Thabo Mbeki questioned the well-established fact that HIV causes AIDS. His health policies created barriers to HIV testing and blocked the scaling up of HIV treatments, resulting in the senseless deaths of over 330,000 South Africans, including tens of thousands of HIV-infected infants (Chigwedere et al. 2008). This period of AIDS denialism in South Africa kept HIV/AIDS from being treated as a chronic illness, rather suggesting it may not even exist at all. Denying the legitimacy of those affected by AIDS added a unique dimension to HIV stigma propagated by policies established by the central government. Although the official period of AIDS denialism ended in South Africa with the resignation of President Mbeki in 2008, the aftereffects of years of AIDS denialism remain apparent as South Africa now tries to manage one of the world's most severe HIV epidemics (Chigwedere and Essex 2010).

In addition to these structural drivers of HIV stigma, population-based studies conducted in South Africa have reported alarmingly high rates of interpersonal drivers of HIV stigma. For example, a recent representative national survey found that nearly 30 % of South Africans would not buy food from an HIV-positive vendor and nearly 60 % stated that they would want to keep the HIV-positive status of a family member a secret (Shisana et al. 2009). Research focused on segments of South Africans at higher risk for HIV infection finds similarly high numbers of stigma endorsements. For example, a survey of people living in an urban township outside of Cape Town showed that more than half of people sampled believed that PLWHA should not be allowed to work with children and more than half stated that PLWHA should expect to have their freedom restricted (Kalichman et al. 2005). Not surprisingly, adverse experiences of PLWHA are prevalent in this context, with 40 % of persons with HIV/AIDS having experienced discrimination resulting from having HIV infection and one in five having lost a place to stay or a job because of their HIV status (Simbayi et al. 2007; see also Chaps. 6, 12, and 15 in this volume).

In South Africa, HIV stigma is more strongly endorsed by people who hold more traditional beliefs about the causes of HIV/AIDS. Traditional beliefs often hinge on the supernatural, such as believing that HIV/AIDS is caused by spirits, supernatural forces, or the wishes of ancestors. A survey of people living in an impoverished township outside Cape Town found that believing HIV/AIDS is caused by spirits and the supernatural was associated with prejudice, including a sense of repulsion, and endorsement of discriminatory practises, including support for social sanctions against PLWHA (Kalichman and Simbayi 2004). One in three people who held traditional beliefs stated that PLWHA are cursed and half said that PLWHA cannot be trusted. However, analyses revealed HIV stigma found among individuals who

held traditional beliefs about the cause of AIDS were accounted for by knowledge about the basic facts of HIV/AIDS. This suggests that interventions that focus on increasing knowledge about HIV/AIDS may also reduce HIV stigma in South Africa.

HIV stigma impairs every aspect of HIV prevention and treatment in South Africa. For example, HIV stigma creates an avoidance that can turn young people away from prevention programs (Campbell et al. 2005). Individuals who hold more stigmatizing views of PLWHA are least likely to get tested for HIV and are least likely to practise risk-reducing behaviors (Kalichman and Simbayi 2003). Further, HIV stigma serves to distance individuals from the threat of AIDS and this distancing can promote risk by insulating perceived risks and impeding protective motivations. Stigma mechanisms experienced by PLWHA have additional deleterious effects. South African PLWHA who have internalized HIV stigma demonstrate poorer health and greater social isolation than PLWHA who have not internalized HIV stigma (Simbayi et al. 2007).

Today, South Africa is scaling up HIV testing and expanding access to HIV treatments. Information campaigns are underway to rectify the damage done by AIDS denialism and prevention programs are becoming increasingly available. As these structural and community-level changes take hold, we may see reductions in HIV stigma. South Africa therefore offers an important natural experiment in the impact of social policies on HIV stigma that should continue to be monitored for lessons learned.

## 6 Conclusion

HIV stigma represents a social construction with far-reaching consequences. Social distancing and discrimination divide communities and deprive individuals of human rights. Understanding HIV stigma is complicated by related stigmas that interact with multiple mechanisms and drivers. Viewing stigmas through sociocultural contexts can lead to interventions as well as policy and attitude changes that can improve the outlook for PLWHA.

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