Chapter 3
Gender and AIDS Stigma

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1 Introduction

In the last decade, greater attention has been paid to AIDS stigma as a social process, including how stigma both reflects and reproduces entrenched social inequalities. While gender relations are recognized as part of these processes, the links between stigma and gender power dynamics have not been systematically examined. This chapter draws on AIDS-stigma research in sub-Saharan Africa to propose a conceptual framework that links the structure of AIDS stigma to gender as a social structure. This framework helps clarify why African women and men often experience AIDS stigma in different ways and the role gender relations play in these processes.

Understanding these complex social dynamics will allow us to integrate a more robust gender analysis into AIDS prevention programs. This is an especially pressing issue today given advances in using antiretroviral drug therapy to reduce HIV transmission. For such biomedical approaches to fulfill their promise, they need to incorporate an awareness of how gender is intertwined with AIDS stigma. The framework presented here helps illuminate these links and underscores the importance of integrating biomedical, behavioral, and social-structural factors into AIDS prevention efforts.
2 The Intertwined Structures of Gender and Stigma

Understanding the interconnected nature of gender and stigma requires building on relatively recent reconceptualizations of stigma as a social process. While the social dimensions of stigma have long interested sociologists, especially Erving Goffman (1963), much stigma research has been preoccupied with the individual level, especially the perceptions of individuals and how these attitudes orient everyday social interactions (Link and Phelan 2001). Largely due to the global AIDS pandemic, however, there has been a critical reassessment of such conceptualizations and a renewed emphasis on stigma as a social process tied to power relations and the reproduction of social inequalities (see also Chaps. 1 and 2 in this volume).

A key contribution to the reformulation of stigma comes from Parker and Aggleton (2003). They stress that inordinate attention has been paid to individual stereotyping and perceptions of stigma, rather than how stigma is tied to the social-structural conditions that exclude individuals from fully participating in social and economic life. For Parker and Aggleton (2003: 18), stigma reproduces relations of domination and control, which makes stigmatization “a process linked to competition for power and the legitimization of social hierarchy and inequality.” Castro and Farmer (2005) echo these sentiments, including the need to analyze stigma not as individual traits or attributes but in terms of social relationships. They emphasize the need to recognize the large-scale forces that determine forms of social inequality in a given society (what they call structural violence) and to see stigma as both a cause and consequence of such inequality. Campbell and colleagues (2005: 808) present similar arguments and stress that various types of stigma are united in the way in which they work to buttress the dominant status of powerful social actors and “the legitimacy of the status quo.”

This emphasis on the ties between stigma and macro-level manifestations of social inequality is now firmly established in the stigma literature. Conceptual models of stigma all include references to forms of stigma operating on multiple levels. In their recent review of the stigma literature, Mahajan and colleagues (2008) combine both sociocognitive approaches to stigma with those emphasizing the social-structural dimensions of stigma. They place power and inequality at the base of their conceptual framework and discuss how this drives various manifestations of stigma at individual, community, and institutional levels. Holzemer and colleagues (2007) put forth a similar framework, arguing that the AIDS-stigma process can only be understood in relation to the larger sociocultural environment and the organization of the healthcare system.

Gender inequalities are nearly always recognized as integral to stigma as a social process in these new frameworks. However, how gender is intertwined with stigma is not conceptualized in any detail. This is a critical issue because if stigmatization reproduces social inequalities, one of the primary axes along which it operates is gender difference. In their study of AIDS stigma in Swaziland, Shamos and colleagues (2009) provide one of the few attempts to outline connections between
gender inequality and types of stigma. However, there is a need for a more thorough framework that clearly defines the links between the various dimensions of gender and stigma.

### 2.1 The Structure of Gender

While gender is often thought of as a characteristic of an individual, it is best conceptualized as a type of social structure. As sociologist Barbara Risman (2011: 19) argues, we need to understand gender as having a structure:

> Just as every society has a political structure (e.g., democracy, monarchy) and an economic structure (e.g., capitalist, socialist), so, too, every society has a gender structure (from patriarchal to at least hypothetically egalitarian).

As a social structure, gender creates durable patterns of social interactions primarily in relation to sexed bodies (male vs. female). These interactions reflect prevailing power dynamics and are evident in robust and often resilient gender hierarchies and inequalities (Lorber 1994).

Barbara Risman’s model of gender as a social structure is one of the most detailed and especially helpful here in understanding how gender and stigma are intertwined. For Risman (2004), we need to distinguish between three dimensions of the structure of gender: individual, interactional, and institutional. Gender as a social structure operates on the individual level through the development of gender identities and senses of gendered selves. These processes, whether they occur during childhood development or adult socialization, are central to how a person comes to think of himself or herself as gendered and to have certain expectations of themselves as gendered individuals (Risman 2011: 20). This individual, or intrapersonal, dimension is where cultural schemas that reinforce gender inequalities are internalized and how normative gender identities are made to seem natural (Epstein 2007).

At the interactional level, gender structures the everyday interactions between individuals and groups by shaping what is understood as proper and expected behavior by others. There are engrained rules that govern social interaction in a given society, and men and women face different cultural expectations, even if they have otherwise identical class positions or racial and ethnic backgrounds (Risman 2004: 433). At an aggregate level, these routine social interactions are manifest in gender hierarchies and inequalities. However, it is important to add that while gender power relations are reproduced through ordinary social interactions, they can also be reconfigured through those everyday gestures and exchanges that subvert established cultural expectations of gendered social interaction (Butler 1990).

Finally, there is the institutional level where gender hierarchies are made explicit through the laws, organizational structures, and distribution of resources that favor men over women. As Risman (2004: 436) notes, there has been considerable progress in the United States and other developed nations on addressing these institutional inequalities. However, there is also much evidence that gender stratification
nonetheless persists. Thus, no one dimension of the structure of gender should be understood as necessarily more fundamental. Gender structures can and do change, but how that change happens and what dimension may be the catalyst for change remain empirical questions.

2.2 The Structure of Stigma

If gender can be conceptualized as a social structure with three dimensions, is there a similar framework for thinking about stigma? As noted above, there is broad consensus that stigma is a social process, although it would not be correct to suggest that stigma is a social structure along the lines of gender, class, race, or sexuality. Nonetheless, it is useful to think about stigma as having multiple dimensions, and in this sense we can talk about the structure of stigma.

There are two dimensions of stigma that are well established in the literature. The first of these is intrapersonal stigma, or what is also referred to as emic, internal, or felt stigma (Weiss et al. 1992; Aggleton and Parker 2002; MacQuarrie et al. 2009). Intrapersonal stigma centers on an individual’s own sense of self and how it is threatened or diminished because she or he embodies a stigmatized identity. At times, a distinction is also made between felt normative stigma, which an individual experiences because of perceptions of possible discrimination, and internalized stigma, which is the self-stigmatization an individual experiences when she or he internalizes a devalued status (Steward et al. 2008; see also Chaps. 2, 9, 11, 12, 16, and 17 in this volume).

A second dimension of stigma is interpersonal stigma, or etic, external, or enacted stigma. This dimension of stigma is focused not on how a diminished sense of self-worth is internalized but instead on actual experiences of discrimination a stigmatized person has encountered. This dimension of stigma can be thought of as the sum total of stigmatizing behavior toward a person as described by themselves or others (Holzemer et al. 2007: 548). It is along this dimension that stigma is more obviously intertwined with other structures of social inequality, such as class, race, and gender. Much of the recent literature on stigma as a social process attempts to capture how interpersonal stigma fuels, and is fueled by, structures of social inequality (Parker and Aggleton 2003; Campbell et al. 2005; Holzemer et al. 2007; see Chaps. 2, 9, 11, and 12).

This then dovetails into the third dimension of stigma, namely, institutional stigma. This refers to the laws and policies that formalize and make explicit discrimination based on a stigmatized identity. The more recent, sociologically informed work on AIDS stigma has also drawn attention to this level of stigma as a social process (Castro and Farmer 2005; see Chap. 8 in this volume).

By outlining the structures of both gender and stigma, it becomes evident that there are significant points of convergence between the two. Figure 3.1 summarizes my framework for the interrelationship of gender and stigma. It illustrates the links between the individual, interactional, and institutional levels of gender and
the intrapersonal, interpersonal, and institutional forms of stigma. There is an important synergistic relationship between these two structures. Gender inequalities, like those of class, race, and sexuality, provide the social context for stigma. These inequalities are, in turn, reinforced through stigmatization, with stigma integral to those social processes that continually enforce the boundaries of “proper” gender identities and “appropriate” gender roles and interactions. In this sense, stigma is itself a social force which maintains a given gender order and perpetuates the status quo.

2.3 Gender, Stigma, and Masculinity

This conceptualization of gender and stigma, however, raises questions about how conceptions of masculinity are tied to stigma. If stigma reproduces gender inequalities, why would men, who largely benefit from such inequalities, experience stigma? For insight we need to draw on the expanding literature on masculinity and health (Sabo and Gordon 1995; Oliffe 2005), much of which is rooted in Connell’s (1995) conception of masculinity, especially her notion of hegemonic masculinity. This is the dominant form of masculinity in a given social context, and it is central to the reproduction of patriarchal power relations. As Connell and others have stressed, there are multiple forms of masculinity in any setting, and this creates a hierarchy of masculine identities that naturalizes not only the subordination of women to men but also the dominant position of some men over other men (Hearn and Collinson 1994; Connell 1995). In this sense, masculinity is a “homosocial enactment” where men need to have their manhood repeatedly confirmed by other men (Kimmel 1994: 129).

Researchers on masculinity and health have argued that behaviors that undermine men’s health are often “signifiers of masculinity” used by men to negotiate social power and status (Courtenay 2000: 1385). These signifiers can include independence, self-reliance, physical strength, toughness, risk taking, and emotional detachment. The enactment of normative masculine gender identities, therefore, often has deleterious consequences for men’s health and in the process reproduces gender hierarchies and inequalities that have serious health consequences for women as well.
This literature on masculinity and health provides a connection between masculinity and stigma because the demonstration of hegemonic masculinity requires men to deny weakness and vulnerability. As Courtenay (2000: 1397) argues, acknowledging health problems requires men to “cross over socially constructed gender boundaries, and risk reproach and sometimes physical danger for failing to demonstrate gender correctly.” Living openly with AIDS can be seen as a particularly intense form of crossing-over for men because it is an incurable disease associated with long-term, physical disability. AIDS stigma, therefore, is an effective means of reinforcing gender boundaries and deterring the types of crossing-over that could destabilize hegemonic masculinity.

This conceptual framework helps us understand men’s experiences of AIDS stigma and see how stigma is tied to masculinity and gender inequality. At an intrapersonal level, men feel their illness will result in discrimination, and for some this can lead to an internalization of stigma, or self-stigmatization, for failing to demonstrate gender correctly. Living openly with AIDS can be seen as a particularly intense form of crossing-over for men because it is an incurable disease associated with long-term, physical disability. AIDS stigma, therefore, is an effective means of reinforcing gender boundaries and deterring the types of crossing-over that could destabilize hegemonic masculinity.

This conceptual framework helps us understand men’s experiences of AIDS stigma and the structure of stigma and gender inequality. At an intrapersonal level, men feel their illness will result in discrimination, and for some this can lead to an internalization of stigma, or self-stigmatization, for failing to embody hegemonic notions of being a man. In many contexts, fears of discrimination may in fact be justified, and men may experience interpersonal stigma from men and women. Together, these micro-level processes work to reinforce the dominant gender order which not only subordinates HIV-positive men but also undergirds gender inequality more broadly at a social-structural level. This is because the burdens of hegemonic masculinity also come with significant gender privileges, especially male sexual privilege—benefits that are accorded to men regardless of their ability to embody hegemonic masculine ideals (Connell 1995).

This is not to suggest that men are doomed to reproduce hegemonic notions of masculinity because this would ignore the ways men and women are active agents in the ongoing construction of gender relations (Courtenay 2000: 1388). Forms of masculinity in a given context are not static but historically contingent and subject to change (Morrell 2001; Connell and Messerschmidt 2005). This leaves open the possibility for emergent forms of masculinity, including those which counter the dominant gender order.

Research on masculinity and health has captured these deviations from hegemonic masculinity. In their study of men suffering from depression in the United Kingdom, Emslie and colleagues (2006) demonstrate how the stigma these men felt was tied to their gender identities. While most of the men relied on hegemonic notions of masculinity to reconstruct senses of themselves as men, a minority sought new, counter-hegemonic models of masculinity as ways to cope with their illness and the associated stigma. O’Brien and colleagues (2005) also found a minority of Scottish men were willing to challenge and deviate from those hegemonic masculine norms that stigmatized men who were more proactive about seeking help for health problems. Such studies indicate there are avenues for disrupting links between masculinity and health-related stigma—findings that are relevant to AIDS stigma as well. Men who experience AIDS stigma, like other stigmatized groups, may in fact be in a position to critique not only AIDS stigma but also the dominant notions of masculinity that structure how men experience stigma.

Overall, this framework not only helps reveal important ties between the structure of gender and the structure of stigma but also highlights important questions for
empirical exploration. Are different dimensions of stigma equally salient for men and women? If not, why not? Do specific types of stigma, such as AIDS stigma, affect women and men differently? Do we need to incorporate a gender analysis to combat certain types of stigma effectively? The remainder of the chapter examines such questions, drawing on a range of studies on AIDS stigma in sub-Saharan Africa.

3 Gender and AIDS Stigma in Africa

The conceptual framework outlined above suggests there may be important gender differences in how AIDS stigma is experienced. Some insights into this issue are provided by research exploring how AIDS-related discrimination is experienced by African women, especially in relation to HIV testing. According to a study by Maman and colleagues (2001), interpersonal issues figure prominently in women’s reluctance to test for HIV in urban Tanzania. Women cited fear of conflict with their partners and relationship power dynamics as the two most important factors influencing their decision to test, with some noting that testing positive could result in domestic abuse or abandonment. These findings are echoed in a study in rural Zambia (Bond et al. 2002) which found women were the primary focus of stigmatization and highly reluctant to disclose a positive status, again fearing discrimination and isolation by their partners and families (see also Chap. 5 in this volume).

Stigma studies that include both African women and men living with HIV provide greater evidence for gender differences in AIDS stigma. In a study conducted in rural and urban Uganda in the late 1990s, Monico and colleagues (2001: 14) note that the “different treatment accorded to women in the epidemic was evident throughout the research.” HIV-positive women were much more likely to experience interpersonal forms of stigma, especially neglect by parents, parents-in-law, and husbands. A more recent study in Uganda by Nyanzi-Wakholi and colleagues (2009) indicates such gender differences persist. They report that positive Ugandan women were more likely to describe overt experiences of discrimination, especially family-inflicted stigma such as receiving inadequate care or being abandoned by relatives. The authors see men’s position as heads of households as protecting them from family-inflicted stigma. However, men were more likely to recount feelings of psychological torture, or self-inflicted stigma, due to their fears of how the community perceived HIV-positive men.

Russell and Seeley (2010) provide another perspective on these issues in their study of how positive Ugandans transition to living with HIV. They found beginning antiretroviral therapy was a positive, transformative experience for women. Men, however, stressed frustration about rebuilding their economic livelihoods and restoring the social status they perceived as diminished because they were HIV-positive men.

Research in other African countries also indicates that HIV-positive men are more likely than women to experience such intrapersonal forms of AIDS stigma,
especially internalized stigma. In interviews with positive men and women in Swaziland, Shamos and colleagues (2009: 1686) found intrapersonal stigma more prevalent than interpersonal stigma for both men and women. However, on average, women received less social support and “experienced more discrimination than men, particularly in intimate relationships, and were not guaranteed support from family and friends.” The authors conclude stigma is significantly impacted by gender with women’s stigma related to potential interpersonal conflicts and men’s stigma more internalized.

Similarly, a quantitative study measuring levels of intrapersonal stigma experienced by people living with HIV in Kenya found significant gender differences. Women were less likely than men to agree with four of six measures of intrapersonal stigma, including blaming oneself for becoming infected and seeing oneself as irresponsible and lacking self-control (Yebei et al. 2008). Another quantitative study in South Africa that specifically examined internalized stigma corroborates the Kenyan findings (Simbayi et al. 2007). Men were significantly more likely to report experiences of internalized stigma, including feeling dirty, ashamed, and guilty as an HIV-positive person. Beyond the African continent, stigma studies that include heterosexual HIV-positive men also point to the significance of intrapersonal forms of stigma, including survey research in southern India indicating men were more likely to experience internalized AIDS stigma than women (Steward et al. 2008).

While such studies illuminate important gender differences in experiences of AIDS stigma, they provide limited insight into what exactly drives such differences and how they are tied, more broadly, to gender relations. To gain greater perspective on these issues, it is helpful to turn to the limited number of studies focused on how heterosexual African men experience AIDS stigma. These studies move beyond descriptive analyses of men’s experiences of stigma to address the links between stigma and normative notions of “proper” gender identities and gender roles.

In his study of HIV-positive Xhosa men in South Africa, Beck (2004: 10) argues that context-specific conceptions of masculinity shape men’s AIDS-related stigma. Men’s reluctance to disclose being positive, which was common, was rooted in the concern that “if a man becomes sick, not only does he feel a sense of failure to fulfil his manly duties, but he also fears rejection from his society for failing to embody suitable characteristics.” The psychological distress of being a positive man also emerges in Lynch and colleagues’ (2010: 15) study of South African men living with HIV. They identify a discourse of internalized stigma voiced by these men which “constructs HIV and AIDS as disrupting normative masculinity, in that it restricts men’s agency through illness and the need for care.”

Colvin and colleagues (2010: 1185) similarly connect men’s intrapersonal stigma to masculinity in their research with a South African AIDS support group for

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1I stress heterosexual men here because where men and AIDS stigma has been the center of analysis, in Africa and elsewhere, it is largely in relation to men who have sex with men (e.g., Cloete et al. 2008; Feng et al. 2010; Padilla et al. 2008). The focus, therefore, has been primarily on stigma and sexual identities, rather than stigma and gender identities.
men. Entrenched expectations of being a family provider shaped the experiences these men had of living with HIV such that “when they fail to find work, or are too sick to work, gendered expectations around their responsibility to provide for themselves and their families lead to stigmatization and social exclusion.”

The extent to which culturally specific notions of masculinity can shape stigma are vividly illustrated in a study by Doyal and colleagues (2009). They describe the difficulty HIV-positive African men in London had living with HIV because it conflicted with their idealized conceptions of “African” masculinity. These connections are, of course, not specific to African men. Lyttleton’s (2004) study of an AIDS support group in Thailand indicates Thai conceptions of masculinity were incompatible with the self-directed scrutiny necessary for men’s successful group participation. Finally, Poku and colleagues (2005) underscore the importance of examining the contextual factors that mediate links between masculinity and AIDS stigma. In their unusual cross-cultural study of HIV-positive men in Ghana and African-American men in the southeastern United States, they found that while internalized stigma was significant for both groups, it was significantly more pronounced for men in Ghana.

My own research (Wyrod 2011) with HIV-positive men in urban Uganda further substantiates the bond between masculinity and men’s experiences of AIDS stigma. Similar to Colvin and colleagues (2010), I worked with a support group for men living with HIV, and I found members had a heightened sense of insecurity about their identity as productive and valuable men in the community. AIDS remains so stigmatizing for men in this context, I argue, because the disease symbolically encapsulates the challenges men in urban Uganda face living up to local ideals of masculinity. Stigma turns on fulfilling norms of social status in culturally appropriate ways, and a man gains respect and status in this context first and foremost by providing for his family. While poverty and unemployment make this difficult, it is not impossible for many men. Yet, AIDS is a challenge of a different order, and the group members suggested that coming to terms with a protracted, fatal illness was too troubling to acknowledge for many men. Male peers would be of little support, according to the group members, because they too had been socialized to be independent, with relationships between men defined more by hierarchy and deference than mutual support and cooperation.

It is significant that men in this Ugandan support group rarely recounted any actual experiences of being discriminated against for being HIV-positive. Such interpersonal forms of stigma were much less salient in their narratives than were the repeated articulations of their fears of being stigmatized as men living with HIV (felt normative stigma) or feelings of diminished self-worth (internalized stigma). For such men, AIDS was perceived as a formidable obstacle in their attempts to be “productive” men, which included being self-sufficient, earning money, having children, and supporting a family. Given the entrenched poverty in this community, the need for men to embody these characteristics was intense which fueled AIDS stigma, especially self-stigmatization.

There is, therefore, an abundance of evidence that experiences of stigma are closely intertwined with gender identities and inequalities. This makes clear the
importance of recognizing that there are multiple forms of stigma, and these forms affect groups of individuals in different ways. We, therefore, need to remain attentive to differences in how men and women experience AIDS stigma.

There is ample evidence that HIV-positive African women experience overt forms of stigma and discrimination that are rooted in structures of gender inequality. In their study of AIDS-related discrimination in South Africa, Campbell and colleagues (2005: 813) connect the intense levels of interpersonal stigma women experience to entrenched social inequalities. They argue that such forms of AIDS stigma are “part and parcel of a conservative reassertion of power relations of gender and generation and a public reinforcement of social institutions whose moral authority rested on their ability to control the sexuality of women.” The interconnections between African women’s experiences of interpersonal AIDS stigma and gender inequality are also stressed by Nyblade and colleagues (2003: 1, 27). From their research in Ethiopia, Tanzania, and Zambia, they conclude that “the consequences of HIV infection, disclosure, stigma and the burden of care are higher for women than men” and “the structure of gender-based power means that women are more easily blamed and that women’s transgressions tend to be regarded more severely than men’s.”

While men as a group benefit from such gender hierarchies, research indicates that stigma experienced by HIV-positive men is also tied to these normative gender relations. In particular, hegemonic notions of masculinity that frame men as self-reliant family providers subordinate HIV-positive men as unmanly, inadequate, and unable to live up to ideals of “proper” manhood. For many positive men, this leads to experiences of intrapersonal stigma, especially internalized stigma, for failing to embody hegemonic masculinity. Thus, normative gender relations are intertwined with AIDS stigma for both women and men, and stigmatization in turn reproduces entrenched gender inequalities that have deleterious consequences for both women and men.

4 Conclusion: Gender, Stigma, and New Frontiers in AIDS Prevention

In conclusion, it is useful to consider how this framework for gender and stigma could inform new approaches to AIDS prevention. In Uganda and other African countries, there is now a recognition that a significant number of new HIV infections occur within the context of long-term relationships (UNAIDS 2009). Of particular concern is transmission in serodiscordant couples where one person is HIV-positive and the other negative. However, there is also much optimism that new interventions using antiretroviral drug treatment as a form of prevention could do much to block these avenues of transmission. Several large-scale studies have indicated dramatic reductions in HIV infections among discordant couples when the positive person is placed on antiretroviral therapy earlier than normal or when the negative person receives drug therapy as a form of prophylaxis (Anglemyer et al. 2011). Such advances in “treatment as prevention” have revitalized AIDS prevention and provide new hopes of dramatically curtailing the epidemic.
While these innovative biomedical interventions are promising, treatment as prevention needs to remain cognizant of the social dimensions of AIDS, including how gender relations shape the dynamics of HIV transmission. The framework presented here makes clear that AIDS stigma can be experienced very differently by women and men. These experiences of stigma drive an individual’s motivation to test and disclose his or her status. A willingness to disclose a positive status, whether to healthcare providers or an intimate partner, is obviously crucial to the success of any intervention focused on discordant couples.

This chapter highlights that addressing stigma and the associated fear of disclosure requires approaches tailored to the different needs of men and women. It is not enough to enable greater access to testing services and drugs. These important steps need to be linked to programs that explicitly address the structural forms of gender inequality that shape women’s interpersonal experiences of stigma. In addition, they must also tackle the gender-specific issues that create barriers for disclosure for men, especially those aspects of hegemonic masculinity that drive the intrapersonal stigma so prevalent among men.

Although structures of gender inequality are formidable, they are not resistant to change, and AIDS stigma is not inevitable. Interventions such as the IMAGE study in South Africa indicate that mobilizing women to confront gender inequalities can reduce domestic violence, a known risk factor for HIV infection (Pronyk et al. 2006). With regard to changing conceptions of masculinity, work with AIDS support groups for men demonstrates that the experience of living with HIV can lead some men to critically reassess notions of manhood, thereby cultivating alternative models of masculinity (Lynch et al. 2010; Wyrod 2011). It is only by remaining attentive to the dynamic interplay between gender and AIDS stigma that the full potential of new approaches to prevention can be realized.

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