# Chapter 1 Stigma, Discrimination, and HIV/AIDS: An Introduction

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## 1 Stigma and Discrimination: An Introduction

The word stigma is derived from Ancient Greece, meaning "mark" (see Chap. 12 in this volume). Marks were impressed on slaves as a way to identify their position in the social structure and indicated that they were of lesser value (Crawford 1996; Whitehead et al. 2001; Sherman 2007). Stigma is a socially constructed concept. However, it has a negative impact on the life as well as the health and well-being of the individuals and groups who are so labeled (Liamputtong and Kitisriworapan 2012). Stigma has its basis on "differences." These differences can be in physical appearance, age, gender, personality, sexuality, illness, disability, and specific behaviors which evoke discontent, abhorrence, panic, or sympathy from others (Mason et al. 2001).

According to Mason and colleagues (2001: 4), the main element of the stigmatizing strategies is to create the "them and us" principle (see also Chap. 8). Its aim is to lay a foundation which could separate individuals who are perceived as "good and in favor" from those who are "bad and out of favor" within a given social norm (Foucault 1973). Once this principle is initiated, stigmatization is permitted. This process is then established and confirmed by the prejudiced position which accentuates the difference, that is, the "them and us." Sontag (1991) suggests that HIV/AIDS symbolizes "sinful" and "evil." Hence, people living with HIV/AIDS are perceived as discredited individuals who have "[im]moral characters." As a consequence, they are socially conditioned as not "one of us" (Mason et al. 2001: 4). Often, this leads to discrimination against the discredited persons (see also all chapters in this volume).

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Goffman (1963) proposes three kinds of stigmatizing conditions. "Tribal identities" refer to such identities as gender, race, religion, and nationality. The "blemishes of individual character" may include such blemishes as having mental illness, having a history of addiction or incarceration, and living with HIV/AIDS. "Abominations of the body" could include such bodily conditions as deformities and physical disabilities (LeBel 2008: 411; see also Chap. 19 in this volume). Basing on Goffman's stigmatizing conditions, there are many individuals who would be stigmatized due to their social and health statuses in many societies. See chapters in Parts I and II for further discussions on different types of stigma.

## 2 Stigma and HIV/AIDS

From the onset of the epidemic, HIV/AIDS has been seen not only as a medical condition but also as a stigmatized illness (Herek and Glunt 1993; Letteney and LaPorte 2004). Scambler (2003: 199) puts it clearly that HIV/AIDS "has been both medicalized as 'disease' and moralized as 'stigma'." HIV/AIDS was first recognized in 1981 and since then it has provoked forceful reactions from others (Scambler 2003). HIV/AIDS uniquely combined "sex, drugs, death and contagion" (Scambler 2003: 199). This unique combination made HIV/AIDS a powerfully stigmatizing disease. It is also prevalent among those who are already members of stigmatized groups, initially gay men, later injecting drug users (Scambler 2003; Parker and Aggleton 2003). Now we have also witnessed the prevalence of stigma among HIVpositive individuals who also live with hepatitis C virus (HCV) (Butt 2008; Lekas et al. 2011; see Chap. 18 in this volume). Globally, in countries where HIV/AIDS is predominantly heterosexually transmitted, stigmatization and discrimination are also pervasive. Those who are from marginalized groups such as women, mothers, sex workers, poor people, gay men, and injecting drug users heavily bear the brunt of the impact of HIV/AIDS (Lekas et al. 2011; Liamputtong 2013; see chapters in Part II of this volume). Some have suggested that the stigmatization and discrimination of these people have violated human rights of human beings (see Chaps. 8, 15, and 20). Clearly, as Mann and Tarantola (1998: 4–5) put it, "those who – before the arrival of HIV/AIDS - were socially marginalized, stigmatized or discriminated against, were found gradually and increasingly to bear the brunt of the HIV/AIDS epidemic. Human rights violations are now recognized to be primordial root causes of vulnerability to the epidemic."

It is argued that HIV/AIDS has particular traits which initiate a high level of stigma (Brimlow et al. 2003; Parker and Aggleton 2003; Lekas et al. 2011). Stigma, according to Goffman (1963: 3), is a "process of devaluation" associated with stereotyping and prejudice. It is employed by individuals to define certain attributes of others as "discreditable or unworthy, resulting in the person stigmatised becoming 'discounted' or 'tainted'" (Thomas 2006: 3175). Stigma has also been referred to as "a reaction to fear or perceived threat" (Sivaram et al. 2009: 234). Parker and Birdsall (2005: 5) posit that stigma is part of prejudiced "identity" and sets apart

"individuals or groups through the attachment of heightened negative perceptions and values."

Stigma, according to Deng and colleagues (2007: 1561), is socially constructed and is attributable to cultural, social, historical, and situational factors (see also Dovidio et al. 2000). Stigmatized individuals are subject to "feelings of shame and guilt." A major consequence of stigmatization is "discrimination" and it occurs when an individual "is treated unfairly and unjustly" due to the perception that the individual is deviant from others (Deng et al. 2007: 1561; see also Aggleton and Parker 2002). As such, HIV/AIDS stigma is perceived as "an individual's deviance from socially accepted standards of normality," and these can include such deviances as "immorality," "promiscuity," "perversion," "contagiousness," and "death." As such, people living with HIV/AIDS (PLWHA) are socially constructed as the "others" who are "disgracefully different from and threatening to the general public" (Zhou 2007: 2856) (see chapters in Parts I and II in this volume).

HIV/AIDS stigmas continue to retell race, class, and gender inequalities (Parker and Aggleton 2003; Simbayi et al. 2007). Those who are seen to be associated with sexual promiscuity, drug use, and homosexuality are particularly vulnerable to stigma (Lekas et al. 2011). Women are more vulnerable to the stigma associated with HIV/AIDS as a sexually transmitted disease (deBruyn 1993; Green 1995; Lawless et al. 1996; Solomon et al. 2004; Cullinane 2007; Ndinda et al. 2007). Women living with HIV/AIDS are frequently referred to as "vectors," "diseased," and "prostitutes," but these terms are seldom used with infected men (Ndinda et al. 2007: 93). Clearly, discrimination toward PLWHA is not simply about HIV/AIDS as a disease. Rather, it always intersects with other social prejudices and these include homophobia, sexism, and racism (Aggleton and Parker 2002). As such, when women living with HIV/AIDS, for example, feel stigma, it is not "only their internalization of the AIDS stigma, but also an effect of their interactions with others or actual experiences with public attitudes through which AIDS-related social standards are manifested" (Zhou 2007: 2856; see also Chaps. 2, 3, 5, 7, and 8).

Often, HIV-related stigma is multidimensional. Three broad types of HIV/AIDS-related stigma can be identified. Self-stigma occurs through "self-blame and self-deprecation" of individuals living with HIV/AIDS. Perceived stigma is related to the fear they have that if they disclose their HIV-positive status, they may be stigmatized. Enacted stigma occurs when these individuals are actually discriminated against because of their HIV status: actual or perceived (Thomas 2006: 3175; see also Bond et al. 2002; VanLandingham et al. 2005; Steward et al. 2008; see Chaps. 2 and 3 and chapters in Part II in this volume).

Stigma may be manifested in actions such as verbal abuse, gossip, and distancing from people living with HIV/AIDS. It can be subtle actions or "extreme degradation, rejection and abandonment" (Thomas 2006: 3175; see also Bond et al. 2002; Deng et al. 2007). The manifestations may, however, change over time (Alonzo and Reynolds 1995; Thomas 2006). Often, ignorance, a lack of accurate information about HIV/AIDS, and misunderstanding about HIV transmission are a common source of HIV/AIDS stigma (Sweat and Levin 1995; Apinundecha et al. 2007; Zhou 2007).

Nevertheless, Parker and Aggleton (2003: 17) warn us that it is crucial to recognize that stigma occurs "within specific contexts of culture and power." They also suggest that "discrimination is characterized by cross-cultural diversity and complexity" (p. 14). Hence, as Zhou (2007: 285) contents, sociocultural beliefs, values, and morals within the local contexts have played a major role in constructing stigma and discrimination. Stigma also changes over time. What has been stigmatized in the past may not be stigmatized now. As several chapters in this volume show, people have developed a more positive attitude toward people living with HIV/AIDS (see chapters in Part III in this volume).

How stigma manifests itself is inextricably linked to the social and cultural contexts (Mechanic 1995). Stigma may appear far more transparent to some groups of people, but not so for others (Reidpath and Chan 2005; Henkel et al. 2008; Lekas et al. 2011). For example, VanLandingham and colleagues (2005) expect that the levels of stigma in Thailand would be different from those in the United States, as the Thai epidemic is not closely associated with socially stigmatized behaviors and groups as is the US epidemic. In Thailand, although there have been high rates of HIV/AIDS among drug users and sex workers, most infections have occurred in heterosexual relationships and via behaviors which are not as socially problematic as in the USA. Stigma toward PLWHA in the United States tends to be governed by negative feelings about male homosexual behavior and injecting drug use. As VanLandingham and associates have shown in their study, although there is a variation in community reaction toward PLWHA, there are more positive responses toward PLWHA and their families. More PLWHA reported "positive community reactions than negative ones." Women, in particular, expressed "responses of sympathy, support and help" more than men did (p. 404). The main reason for this is that over half of the women in their study were widowed and they were infected by their husbands. What VanLandingham and colleagues (2005) have found clearly attests to the widely reported notion that women living with HIV/AIDS are treated much worse by their communities than men (see also Chap. 3).

# 3 Stigma and Discrimination: Health Impact and Strategy for Management

Stigma has great impact on the health and well-being of individuals (Valdiserri 2002; Link and Phelan 2006; Mak et al. 2007; Zhou 2007), particularly as it induces high rates of psychological distress among those infected with HIV/AIDS (Schmitz and Crystal 2000; Lee et al. 2002; Simbayi et al. 2007). Stigma also results in social distance which excludes PLWHA from accessing healthcare services and social support (Mason et al. 2001; Kielmann et al. 2005; LeBel 2008; Sivaram et al. 2009; see also Chaps. 6 and 8). This further reduces their social capital (Sivaram et al. 2009). For example, individuals may attempt to avoid stigma associated with "deviant" sexuality (promiscuity), which may include not seeking healthcare and not

informing their sex partners (including spouses) about their HIV status (Zhou 2007: 286; see also Busza 2001; Liu et al. 2002; Link and Phelan 2006; see Chaps. 3, 5, and 7 in this volume).

The effect of stigma on the stigmatized individuals can differ in its manifestation and magnitude (Link and Phelan 2001; Mason et al. 2001; Corrigan et al. 2003a, b). Often, stigma generates negative credibilities; these are termed stereotypes. It then gives legitimacy to the negative credibilities; this is referred to as prejudice. This prejudice then leads to a wish to shun individuals who possess stigmatized statuses. This is called discrimination (Pescosolido et al. 2008: 431; see also Link and Phelan 2001; Williams et al. 2008; see Chap. 8).

Individually, the effects of stigma and discrimination can be destructive. They can result in isolation, low self-esteem, depression, self-harm, poor academic achievement and social relationships, and poor physical and mental health (Mason et al. 2001; Major and O'Brien 2005; Yang et al. 2007). For stigmatized individuals with major health problems like HIV and AIDS, stigma can also "intensify the sense that life is uncertain, dangerous, and hazardous" (Yang et al. 2007, p. 1528). Therefore, it is clear that stigma and discrimination have a negative impact on the quality of life of the stigmatized persons (Pescosolido et al. 2008; see chapters in Part II of this volume).

Stigma has great impact on the public health of the stigmatized individuals and groups. Herek (2002: 604) puts it bluntly that "stigma and discrimination are the enemies of public health." In the area of HIV/AIDS, it is now clear that the stigmatization of certain groups such as commercial sex workers, injecting drug users, and gay men would only make them more susceptible to HIV infection and push them out of reach of those who are attempting to help them modify the behaviors that put them and others at risk (Stuber et al. 2008; see Chap. 6 in this volume).

Despite its great impact on the health and life of many people living with HIV/AIDS, there are strategies that individuals and groups adopt in their attempts to fight against stigma and discrimination. According to LeBel (2008), protest and advocacy can work effectively as a tactic to reduce stigma. Collective strategies such as "social activism" have proved to be valuable. Thus far, we have witnessed these collective responses from several stigmatized groups including gays/lesbians, individuals with physical disabilities, people living with mental illness, and other stigmatized groups including those living with HIV/AIDS, which have been successful in changing official policies and laws. It is argued that this strategy is the most powerful and long-lasting means for the reduction and eradication of prejudice and discrimination for many stigmatized groups (Major et al. 2000; see also Sayce 2000; Corrigan and Lundin 2001; Parker and Aggleton 2003; Shih 2004).

The motive and ability to resist or deny the label of deviance among stigmatized groups is an interesting aspect of stigma-related reduction and eradication. In Foucault's term (1981), these people would employ "reverse discourse" as a way to resist the label of deviance and hence avoid being stigmatized. This discourse allows individuals and groups to "present a positive affirmation of their identity and perspectives rather than a deviance designation" (Roach Anleu 2006: 422). Collectively, the stigmatized groups can generate a strategy which can be used to reject the

standard social values and norms (Anspach 1979). In HIV/AIDS area, according to Taylor (2001: 795–796), there have been many strategies that individuals and groups have used to combat and abolish stigma. Gay men have adopted such symbols as the pink triangle, which is a symbol that the Nazis used in the Holocaust to mark out homosexuals before slaughtering them, to counteract their stigmatization (Gilmore and Somerville 1994). Two UK voluntary organizations, "Gay Men Fighting AIDS" and "ACT UP" (AIDS Coalition to Unleash Power), are good examples of political activation which make use of power as a response to combat stigma. The establishment of AIDS support groups in several nations is a good example of this collective strategy (Lyttleton 2004; Lyttlteon et al. 2007; Oosterhoff and Bach 2013). See also chapters in Part III of this volume about strategies that people living with HIV/AIDS adopt as a means to resist the stigmatization of their health condition.

### 4 About the Book

This book comprises 3 parts and 23 chapters. This introductory chapter sets the scene for this book. It discusses salient issues and theoretical understandings pertaining to stigma and discrimination, which have occurred to people living with HIV/AIDS in different parts of the world. The chapter also introduces other chapters included in the volume.

Part I is concerned with theoretical understanding of stigma and discrimination and HIV/AIDS. Chapter 2, written by Valerie A. Earnshaw and Seth C. Kalichman, is about the stigma experienced by people living with HIV/AIDS. In this chapter, they argue that HIV stigma represents a significant barrier to successful efforts to engage PLWHA in services. They discuss three approaches to better understand HIV stigma experienced by PLWHA. First, they contextualize HIV stigma as a social process. Therefore, the ways that HIV stigma is expressed and experienced by PLWHA vary widely depending on sociocultural contexts. Understanding the structural and interpersonal drivers of HIV stigma within a particular social context is critical for intervening to reduce the stigma experienced by PLWHA. A second approach for understanding stigma reconceptualizes multiple stigmas that PLWHA may experience such as those associated with drug use, sex work, homosexuality, racial/ethnic minorities, and poverty. HIV stigma interacts with these other intersecting stigmas to shape the stigma-related experiences of PLWHA. Consequently, it may be impossible to intervene in HIV stigma without also addressing PLWHA's experience of intersecting stigmas. The third approach to understanding HIV stigma concentrates on the mechanisms of stigma experienced by PLWHA. HIV stigma mechanisms represent the ways that PLWHA respond to stigma, including internalized, anticipated, and enacted stigmas. Each of these mechanisms is linked to a variety of adverse psychological, behavioral, and health outcomes. Intervening in HIV stigma mechanisms aims to disrupt the relationship between HIV stigma and its deleterious impact on PLWHA. Finally, they conclude their chapter by discussing a case example of HIV stigma in South Africa.

Robert Wyrod writes about gender and AIDS stigma in Chap. 3. He suggests that in the last decade, greater attention has been paid to AIDS stigma as a social process, including how stigma both reflects and reproduces entrenched power dynamics. While gender relations have been recognized as part of these processes, the links between stigma and gender power dynamics have not been systematically examined. His chapter presents a novel conceptual framework that links the structure of AIDS stigma to gender as a social structure. This framework helps clarify why 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.

In Chap. 4, Connie Y. Y. Ho and Winnie W. S. Mak write about HIV-related stigma across cultures within and beyond the family context. They point out that the experience of people living with HIV/AIDS (PLWHA) and that of their family are intertwined in varying extent across cultures. Although the lives of both parties would be affected by the disease, the impact may be manifested differently in different cultures. Within individualistic cultures, HIV contraction is more likely to be regarded as a personal issue or responsibility, and thus, the reputation of the family having a member with HIV/AIDS may be left intact. On the other hand, within collectivistic cultures, HIV-related stigma may, in a moral sense, bring shame to the family, which may threaten the reputation and identity of the entire family. In this chapter, the situation of HIV-related stigma within and beyond the family context is discussed. In addition to addressing the effects of HIV-related stigma on the family, the effects of family relationships and communication on self-stigma and wellbeing of people living with HIV/AIDS are explored. On the one hand, family can be an essential resource for promoting the health and well-being of PLHA; on the other hand, it can potentially be a source of stress and burden to them and affect how they perceive the illness. Moreover, the heightened HIV-related stigma in collectivistic cultures is examined with illustration from research on the Chinese communities. Some current family-based HIV interventions and recommendations on related research are made at the end of the chapter. They contend that since HIV/AIDS is a chronic illness that impacts both physical and mental health of PLHA, the integration of familial and cultural considerations in the promotion of PLHA's well-being is essential in service planning and delivery.

Chapter 5 is about stigma and disclosure from a cross-cultural perspective and is written by Minrie Greeff. She suggests that disclosure or nondisclosure as a phenomenon is complex, with many variants that impact on the process of disclosure as well as the experiences of the PLWHA who discloses his or her HIV status. This complexity lies in the close link between disclosure, stigma, and culture. High stigma levels prevent disclosure, and disclosure practises vary greatly according to cultural practises and beliefs. The choice of disclosure should always be a well-informed and responsible decision involving both the PLWHA and healthcare

workers. Even if the PLWHA is well informed, the results following disclosure are always mixed. However, disclosure by others without the consent of the PLWHA is also a reality that the PLWHA has to face. Most health literature seems to favor disclosure by persons living with HIV. This is not necessarily always to the advantage of the person disclosing his/her status and there could be some normalcy in not disclosing. In this chapter, a Comprehensive Framework for the HIV Disclosure Process is provided, focusing on categories of disclosure, factors before disclosure, as well as factors during and after the process of disclosure. Responsible disclosure management is a shared experience between the PLWHA and the healthcare workers involved in their care. To conclude this chapter, a practical approach to responsible disclosure management is offered.

In Chap. 6, Jessie Naughton and Peter A. Vanable review evidence regarding HIV stigmatization among healthcare providers and suggest implications for HIV care. They argue that HIV-related stigmatization is associated with a number of adverse consequences among HIV-positive individuals. Given the direct role healthcare providers play in promoting and maintaining the overall health of HIV-positive individuals, it is important to understand the extent to which stigmatization among healthcare providers exists and the potential effects that such negative attitudes and behavior may have on the well-being of HIV-positive patients. In this chapter, they provide a review of the literature on stigmatization among healthcare providers, with a focus on studies that report information on stigmatizing healthcare experiences from the patients' perspective. They describe the potential effects of stigmatization on the well-being of HIV-positive patients, offer a methodological critique of the existing literature, and provide directions for future research and training interventions. Overall, findings confirm that HIV-positive patients experience stigmatization within healthcare settings in the form of negative demeanor from providers as well as more overt examples, including patient avoidance, lowered quality of care, and treatment refusal. Review findings also confirm that provider stigmatization remains a concern for HIV-positive patients and may exert negative effects on medical care. In reviewing the literature, they suggest directions for research that informs the development of interventions to assist healthcare providers and HIVpositive patients in creating more positive treatment experiences and health outcomes.

Part II comprises 12 chapters which discuss stigma and discrimination experienced by different sociocultural groups. Issues concerning morality, discrimination, and silence surrounding HIV stigma and discrimination within the sociocultural context of China are discussed in Chap. 7 by Yanqiu Rachel Zhou. She contends that stigma associated with HIV/AIDS in China has largely been shaped by the sociocultural meanings of this disease. Based on an empirical study of the daily experiences of Chinese PLWHA, this chapter explores the ways in which HIV stigma is constructed, experienced, and understood. The actual interactions between PLWHA and others reveal that the sociocultural meanings of this disease are not fixed, but coconstructed on an ongoing basis by the various participants (such as PLWHA and their families, friends, and health workers) in various interactions. Despite people's mastery of knowledge, prejudices toward HIV/AIDS and PLWHA

can be generated, spread, and, perhaps, made worse through interpersonal interactions. To effectively fight HIV stigma in the Chinese context, she argues that the non-biomedical and interactive dimensions of stigma and discrimination associated with this disease must also be taken into account.

Chapter 8 introduces the work of Chantal Aristizábal-Tobler on stigma and discrimination toward people living with HIV as seen through sociocultural aspects, experiences, and ethical and legal responses in Colombia. Chantal suggests that stigma and discrimination toward individuals infected with HIV or AIDS have been recognized as worldwide issues, but they show specific characteristics among the different socio-economic and cultural contexts. It is a complex and dynamic process whose genesis, manifestations, and consequences are influenced by different elements that interact from the biological to the social aspect, with very important roots in prejudice and social inequalities. The approaches for the explanation and understanding of these processes have been diverse: theoretical reflections through historical, psychological, social, or mixed focuses and empirical tests through quantitative and qualitative research. In this chapter, she discusses the issues related with HIV infection in the world and Colombia, based on a review of empirical research and the different conceptual approaches in the theories of stigma and discrimination in health that are reported in the local and international literature. She reviewed the medical, political, social, and cultural aspects that underlie the stigma and discrimination associated with HIV infection, as well as the ethical and legal regulatory responses, and explored their relationship with the perceptions of those who suffer the experiences related to the stigma and discrimination in the world and Colombia. Her review and hermeneutical analysis of the rulings of the Colombian Constitutional Court in response to the writ for the protection of fundamental rights filed by people living with HIV illustrate with examples the rifts and gaps found between the ethical and legal theories based on fundamental rights and the right to health in Colombia.

In Chap. 9, Deepa Rao and colleagues write about their preliminary scale development based on qualitative data on internalized stigma among African-Americans living with HIV. They point out that in 2004, the Centers for Disease Control reported that in the United States, AIDS was the leading cause of death for African-American women between the ages of 25 and 34 and African-American men between the ages of 35 and 44. They suggest that researchers have explained the impact of HIV/AIDS in African-American communities in terms of delays in accessing care and difficulties in adhering to medication regimens. Research findings suggest that culturally appropriate interventions developed to reduce HIV/ AIDS stigma could help improve treatment adherence and, in turn, improve health outcomes for African-Americans living with HIV/AIDS. In order to better understand the cultural experience of HIV stigma, they conducted 20 individual cognitive interviews with African-American men and women living with HIV in Chicago who were seeking treatment from an HIV clinic based at a large academic medical center. They analyzed transcriptions of these interviews using a phenomenological and content analytic framework. The data helped them to adapt a stigma scale to

help them better assess the severity of stigma as it is experienced, perceived, and internalized by their participants.

Chapter 10 presents the work of Lisa R. Norman on HIV-related stigma and discrimination in Puerto Rico and the role of sympathy on attitudes toward PLWHA. Lisa contends that as the number of PLWHA continues to increase in Puerto Rico, it becomes increasingly important to address the issues of stigma and other discriminatory attitudes. This chapter presents the findings of her study which examined the attitudes toward PLWHA of a large sample of women living in public housing in Puerto Rico, including sympathy and support for PLWHA in the workplace and in school. A total of 1,138 women completed a self-administered 218-item survey made up of questions that measured HIV-related knowledge, attitudes, and behaviors. Levels of sympathy varied depending on the target group, with HIV-infected drug users receiving the least sympathy. Most women reported that HIV-positive teachers should be allowed to teach and that HIV-positive children should be allowed to attend school. However, a significantly lower percentage reported that HIV-infected nurses should be allowed to continue working. Women who were more sympathetic toward PLWHA were more tolerant of PLWHA in the workplace and school, while those with inaccurate knowledge concerning HIV transmission were less tolerant. Also, those who knew a PLWHA were more tolerant. Lisa also points out that levels of discriminatory attitudes in Puerto Rico are high and warrant both individual- and societal-level interventions.

In Chap. 11, John A. Sauceda and colleagues write about HIV-related stigma and HIV disclosure among Latinos on the US-Mexico border. They suggest that Latinos in the USA have lower levels of disclosure and higher levels of HIV-related stigma when compared to non-Hispanic whites. However, the nature of the stigmadisclosure relation has not been fully explored. They hypothesize that the path between HIV-related stigma and disclosure may be through a mediating attitude toward disclosure. As a secondary hypothesis, they predicted differences in the strength of association that cognitive attitudes and affective attitudes share with disclosure. They interviewed 241 HIV-positive individuals on Highly Active Antiretroviral Therapy (HAART) at an outpatient clinic in El Paso, Texas, a large city that borders Mexico. They found that the significant association between HIVrelated stigma and HIV disclosure was fully mediated by attitudes toward disclosure. In addition, the differences between correlations (i.e., both affective and cognitive attitudes with disclosure behaviors) were statistically significant for family members and casual sex partners (Steiger's Z-test, Z=5.15 and 2.54, ps<.01). Their model of disclosure-related attitudes suggests that as stigma becomes more salient, negative evaluations about disclosing may become more important during the disclosure decision-making process. Also, despite evidence from the literature that disclosure to certain targets (e.g., intimate partners) may occur for emotional reasons related to catharsis or emotional relief, their data suggest that cognitive appraisals (e.g., responsibility to educate) are more strongly related to disclosure rates to family members and casual sex partners.

Maretha Visser and Heather Sipsma discuss the experience of HIV-related stigma in South Africa in Chap. 12. In their research in a South African community, they

examined HIV-related stigma among women who were HIV infected (n=609) and a community sample of unknown status (n=1,077) using qualitative and quantitative methods. Their research showed that an HIV diagnosis was often associated with death, immoral behavior, punishment, and lack of adherence to cultural traditions. HIV-infected women perceived the community to be highly stigmatizing rand they internalized aspects of the stigma in their own self-evaluation. The degree to which they perceived community members to be stigmatizing was directly linked to their own internalized stigma. This perception had a negative influence on their psychological well-being, including increased depression and decreased self-esteem and disclosure of their HIV status. Despite their fear of disclosure, women did not report high levels of enacted stigma. Internalized stigma and the stigma attributed to others both declined slightly over the last several years, largely due to increases in HIV/AIDS knowledge. In contrast, although community members did not reveal high levels of personal stigma, they regarded others in their community to be highly stigmatizing. Factors contributing to community stigma were age, gender, level of education, HIV knowledge, and personal experience of knowing someone with HIV. Typical stigmatizing reactions were mostly observed in subtle behavior, though acts of overt discrimination were also reported. These data highlight the importance of different perspectives on HIV-related stigma. Results are interpreted in the context of developments around HIV/AIDS policy in South Africa which allow them to make suggestions to address HIV stigma in this community.

Chapter 13, by Ajay Bailey and Shrinivas Darak, introduces spaces of disclosure and discrimination using case studies from India. This chapter examines the spaces where HIV status is disclosed and the spaces of discrimination as perceived and experienced by the people. A spatial approach is applied to garner the understandings of what makes different spaces accessible/inaccessible, empowering/disempowering, and personal/impersonal to disclosing an HIV status. Further, they explore time and gender differences in disclosure in the said spaces. Stigma, referred to as an attribute deeply discrediting by Goffman, is understood with the elements of it being feared and enacted. In this chapter, they look at both the perceived and enacted spatiality of discrimination. These spaces include institutional, social, family/kin, and interpersonal spaces. Additionally, they construct, through the narratives on risk, blame, and morality, the images and spaces of a "typical" HIV-infected person. They base this chapter on two studies carried out in India in community and institutional settings. The data comprise rich ethnographic interviews, focus groups, and observations. By focusing on the spatiality of disclosure and discrimination, they do not want just to describe these spaces but make an effort to see how people affected in these spaces can be empowered to manage disclosure and fight discrimination.

Chapter 14 presents the work of Eli Lieber, Ioakim Boutakidis, and Dorothy Chin on stigma, modernization, sex behavior, and infection risk among Chinese youth in China. They argue that HIV intervention and education efforts in China continue to be frustrated by the clear stigma associated with the disease inherent in Chinese culture. While modernizing and evolving rapidly, the Chinese sociocultural context continues to be influenced by traditional Confucian and Taoist philosophies.

At the same time, there is growing tolerance of premarital and extramarital sex, particularly among younger groups as a result of their access to and interest in media and other resources exposing them to the world outside traditional Chinese culture. The dangers of sexual behavior risk inherent in this changing environment are clear and worthy of serious attention. In this study, they address the issues surrounding a need for innovative and effective HIV/STD prevention efforts given the influence of social stigma, traditional values and expectations, a relative absence of reliable and trustworthy information about sexual health, and expanding and unguided exposure to information from outside sources. Identifying and working respectfully within the cultural belief systems dominant in the sociocultural context is as important to intervention design as a thorough evaluation of a target population's needs, behaviors, and characteristics. Findings from a relatively young and uneducated sample expose and explicate the salient cultural schemata in this context as well as how these schemata, coupled with the rapidly changing social environment, should inform intervention planning and implementation. They hope that the benefits of their study's approach, framework, and findings can be incorporated into future intervention design among Chinese populations. These considerations will help guide a program's effectiveness by enhancing the "fit" of the intervention to the target population and help boost program strength and sustainability.

In Chap. 15, Allanise Cloete, Seth C. Kalichman, and Leickness Chisamu Simbayi discuss layered stigma and HIV/AIDS from the experiences of men who have sex with men (MSM) in South Africa. In this chapter, we hear that the first cases of AIDS in the Republic of South Africa were diagnosed primarily in young men who had sex with men. Although HIV has spread heterosexually from neighboring countries and established a generalized HIV/AIDS epidemic, gay men remain, according to recent evidence, a significant population affected by AIDS in South Africa. Moreover, issues of homophobia, cultural definitions of masculinities, and AIDS stigma have created barriers to reaching MSM for HIV prevention, testing, and treatment services. This chapter examines the stigma and discrimination experiences of MSM within South Africa's generalized HIV/AIDS epidemic. Results from a qualitative study data show a layering of stigmatization regarding homosexuality and HIV/AIDS, further complicating efforts to engage gay and bisexual men living with HIV/AIDS. Although healthcare services like HIV testing and other services are freely available at public healthcare facilities, research findings suggest that MSM are reluctant to access HIV prevention, treatment, care, and support services. A lack of MSM-friendly healthcare facilities, combined with previous experiences of stigma and discrimination, may deter MSM from seeking out healthcare services. Stigma associated with being gay and a fear of being HIV-positive serve as barriers to making use of the available voluntary HIV testing and counseling services. In addition, stigma and discrimination experiences of MSM may impede disclosure of HIV-positive status and thus lead to further transmission of HIV. From a human rights perspective, all people in South Africa who are infected with HIV should be treated with life-prolonging medications without discrimination. Reaching MSM, however, for the provision of testing and treatment services requires specialized attention given the invisibility of this population.

In Chap. 16, Jenny X. Liu and Kyung-Hee Choi discuss emerging gay identities in China and examine the prevalence and predictors of social discrimination against MSM. They point out that the emergence of gay identities and communities in contemporary China clashes with many traditional cultural values and norms. As a result, MSM experience a variety of subtle as well as blatant rejection and discrimination on the basis of their sexual orientation, which can result in deterioration of physical and mental well-being. Social discrimination against MSM in China may also have deleterious consequences for public health as individuals avoid taking health precautions as a means to avoid discovery or avert suspicion. To understand the extent of discrimination that Chinese MSM face and identify which individuals may be disproportionately affected, they queried 477 MSM in Shanghai, China, about their lifetime encounters with discrimination. Almost 97 % of respondents had perceived some stigma at least once in their lifetime whereas only 23 % had experienced at least one instance of discrimination. Results of multivariate regression analyses show that disclosure of one's homosexuality differentially affects one's experiences of each type of discrimination. For example, coming out to other MSM may have a protective effect against perceived stigma, but significantly increases the likelihood of experiencing overt discrimination. On the other hand, being out to family members significantly increases perceived stigma, but being out to friends and colleagues decreases experiences of discrimination. Important interactions with migrant status are also found. In this chapter, they also discuss implications for social redress and public health interventions.

Chapter 17 in this volume is concerned with stigma and discrimination among gay men in Australia and is written by John B. F. de Wit and colleagues. They suggest that HIV-related stigma and discrimination among gay men have remained largely under-researched. Also, there generally is a lack of research that directly compares the HIV-related stigma experienced by people living with HIV and the stigma expressed by people not living with HIV. This chapter reports an online community study in Australia, undertaken to investigate and compare HIV-related stigma as experienced by HIV-positive gay men and expressed by non-HIV-positive gay men. From 1 December 2009 to 31 January 2010, the HIV Stigma Barometer Survey recruited 1,258 HIV-positive (17.0 %), HIV-negative (72.6 %), and HIV status unknown (10.4 %) gay men. Participants answered a range of questions regarding stigma-related attributions of responsibility, social distancing, negative emotional reactions, and sexual exclusion. Their findings show that HIV-positive men overall experienced low levels of stigma, including attributions of responsibility and social distancing. However, they experienced higher levels of negative emotional reactions and in particular experienced exclusion as sexual or romantic partners. HIV-related stigma expressed by non-HIV-positive men was highly comparable to the experiences of HIV-positive men. These findings provide evidence of HIV-related stigma and a "serostatus divide" in the gay community. Stigma seems located primarily in the domain of sex and relationships and this possible sexual divide may reflect and drive the adoption of serostatus-based risk reduction strategies. An important contribution of this study is its comparison and cross-validation of reports of experienced as well as expressed stigma in gay men. This was enabled

by a new stigma measure that was informed by a conceptual analysis of the stigma concept and draws on existing scales.

In Chap. 18, Gareth J. Owen presents the hierarchical experience of stigma in HIV- and hepatitis C-coinfected gay men living in London. Drawing on qualitative research investigating the impact of HIV and hepatitis C coinfection in gay men living in London, this chapter explores the complications that arise when two sexually transmitted viral infections are stigmatized differently within a particular social group. Exploring the emotional impact of stigma in a gay male sexual subculture where "serosorting" is used to select other HIV-positive men for unprotected sex, the narratives tell of how hepatitis C was experienced as more stigmatizing than HIV. This hierarchical stigmatization complicated the disclosure of hepatitis C and therefore threatened strategies of "HIV serosorting" as a method of negotiated safety. Models of the hierarchical stigmatization process and hepatitis C transmission risk in gay male sexual subcultures are constructed from the data. The chapter also explores how stigma can both reinforce and disrupt the supportive camaraderie of subcultural communities in different circumstances. The findings suggest that health promotion in the gay community needs to particularly address the stigmatization of hepatitis C by raising awareness and facilitating greater empathetic ownership of hepatitis C as a gay community issue.

In Part III of the volume, chapters concerning how individuals and groups deal with and manage stigma and discrimination are included. In Chap. 19, HIV/AIDsrelated stigma among African-Americans in the southern United States is presented by Pamela Payne Foster and Susan W. Gaskins. As other chapters have presented, stigma is defined as a discrediting attribute leading to discrimination in this chapter. For people with HIV/AIDS, stigma refers to negative feelings and behaviors toward individuals, groups, and communities. Specific African-American populations have different stigma-related experiences. This chapter addresses stigma in older adults living with the disease as well as the larger community in the rural South. Additionally, because stigma is reported to impact disclosure decisions of HIVinfected individuals, those decisions and their context are discussed. Additionally, because spirituality/religion plays an important cultural role in the lives of African-Americans, the role of the Black church in HIV/AIDS prevention is also addressed. Pamela and Susan also discuss faith-based strategies to respond in a supportive manner to individuals with HIV/AIDS. They draw from their work in the Black Belt region of the rural South, an area with high incidence and prevalence rates of HIV/ AIDS. They hope that issues discussed in their chapter would ultimately result in not only positive outcomes for people who are infected but also prevention of infection for others.

Lucy Stackpool-Moore and colleagues write about *The People Living with HIV Stigma Index* in Malawi and the United Kingdom (UK) as an antidote to stigma in Chap. 20. They contend that living with HIV today is a different experience for every individual. For some, taking treatment, seeking support, and accessing health services is routine and part of a wide selection of services and choices available. For others, information is limited, support insufficient, or choices denied because of fear or marginalization. Stigma relating to HIV still remains a significant challenge

because it has an impact on the accessibility and orientation of services (not only health but also legal, care, and support services) as well as on the self-esteem and general quality of life. Conversely, stigma can also trigger positive forces for change and networks of solidarity that rise to challenge the social norms and practises that marginalize, stigmatize, and discriminate. In this chapter, they consolidate some insights about the process of The People Living with HIV Stigma Index from two very different countries and contexts—the United Kingdom (UK) and Malawi and explore the notion of performative research through a discussion of power, participation, and social change. Their chapter does not review the detailed findings from the Stigma Index research nor does it explore the degrees and realities of stigma in these two very different contexts. Rather, it focuses on the reflections shared by some of the research team in both countries and their experiences of being involved in a common initiative—one that has a framework similar enough to be comparable but flexible enough to be adapted to the local context. Questions are explored about the potential of such an initiative as a transformative model for generating personal and social change in tackling HIV-related stigma.

Chapter 21 is concerned with the issue of achieving harmony, moving from experiencing social disgust to living with harmony in people with HIV/AIDS in the Thai context, and is written by Quantar Balthip, Julie Boddy, and Jirapa Siriwatanamethanon. This chapter discusses the ways Thai PLWHA come to terms with their diagnosis and learn to manage their lives in the context of stigma and discrimination. The chapter draws on the results of two grounded theory studies which were conducted in the South and Northeast of Thailand respectively. Data were gathered from 33 participants with HIV/AIDS in the South and 30 in the Northeast through in-depth interviews and participant observations. Interviews were tape recorded, then transcribed verbatim. The authors suggest that being diagnosed with HIV/AIDS resulted in the lives of most participants being "turned upside down." In a society in which HIV/AIDS has been highly stigmatized, the diagnosis results in both a devalued self and the risk of "social disgust" from others in society. Both studies explored the processes by which participants used selective disclosure to reconnect with others for support, enabling them to find meaning in life, and to understand and revalue themselves, to overcome their life crisis, and to live life as normal. For some participants, finding an ultimate meaning in life—consistent with Buddhist teaching—enabled them to obtain peace and harmony.

In Chap. 22, Pranee Liamputtong, Niphattra Haritavorn, and Niyada Kiatying-Anguslee write about AIDS support groups and women living with HIV/AIDS in central Thailand. In this chapter, they examine community attitudes toward women living with HIV/AIDS in Thailand. They also look at strategies employed by women in order to deal with any stigma and discrimination that they may feel or experience in the community. The chapter is based on their larger study of the experiences of women living with HIV/AIDS and their participation in clinical trials in Thailand. They carried out a number of in-depth interviews with women living with HIV/AIDS still deal with stigma and discrimination in their everyday lives. However, from the women's narratives, they also find more positive attitudes from local communities. Women

deal with stigma and discrimination by joining and participating in HIV/AIDS support groups that have emerged in response to the AIDS epidemic in Thailand. They argue that women are not passive victims, but that they act in their own agencies to counteract any negativity they might encounter.

Fumihiko Yokota and Mark VanLandingham write about gender differences in stigma and community support among PLWHA in Thailand in Chap. 23. This chapter compares the levels of both stigma and community support as perceived and experienced by Thai men and women living with HIV/AIDS and investigates individual factors, which can explain the gender differences in stigma and community support in Thailand. Data were collected from 412 members of PLWHA support organizations in Bangkok and Northern Thai provinces in 2000. An assisted, selfadministered survey instrument was used. The proportion of respondents who reported perceived stigma from people in their communities was significantly higher among male PLWHA (46 %) than females PLWHA (34 %). Male PLWHA were significantly less likely than female PLWHA to perceive community support (58 % vs. 73 %) and also to experience community support (15 % vs. 26 %). The multivariate analyses presented in the chapter indicate that much of the male disadvantage with regard to HIV-related social stigma and community support in Thailand appears largely due to differences between men and women in the sample; several of these differences are also found in the population of male and female PLWHA throughout Thailand. These differences include the following: (1) male PLWHA had on average more visible AIDS symptoms than females, a factor associated not only with more advanced illness but also increased stigma and less community support; (2) male PLWHA were less likely than females to be widowed, a factor strongly associated with increased community sympathy and support; and (3) male PLWHA in their sample were more likely than females to reside in Bangkok, which has more hostile community responses toward PLWHA than Northern Thai provinces.

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