

From Conceptualizing to Measuring HIV Stigma: A Review of HIV Stigma Mechanism Measures

Valerie A. Earnshaw · Stephenie R. Chaudoir

Published online: 28 July 2009
© Springer Science+Business Media, LLC 2009

Abstract Recent analyses suggest that lack of clarity in the conceptualization and measurement of HIV stigma at an individual level is a significant barrier to HIV prevention and treatment efforts. In order to address this concern, we articulate a new framework designed to aid in clarifying the conceptualization and measurement of HIV stigma among individuals. The HIV Stigma Framework explores how the stigma of HIV elicits a series of stigma mechanisms, which in turn lead to deleterious outcomes for HIV uninfected and infected people. We then apply this framework to review measures developed to gauge the effect of HIV stigma since the beginning of the epidemic. Finally, we emphasize the utility of using three questions to guide future HIV stigma research: who is affected by, how are they affected by, and what are the outcomes of HIV stigma?

Keywords Stigma · Prejudice · Discrimination · Scales · Measurement

Since the beginning of the HIV epidemic, researchers have noted that the stigma associated with HIV is a considerable barrier to HIV prevention and treatment efforts. Attention to stigma has steadily increased throughout the course of the epidemic, even becoming the focus of the World AIDS Campaign for the years 2002–2003 [1]. Despite this

attention, HIV stigma continues to be a significant barrier to HIV prevention and treatment efforts nearly 30 years after the start of the epidemic.

Recent analyses have noted that the lack of a comprehensive conceptual framework with which to study the effects of HIV stigma is a core reason why HIV stigma continues to be such a formidable barrier [2, 3]. Whereas a number of theorists have developed elegant conceptual frameworks to understand the structural and social processes that contribute to the creation and maintenance of stigma [4, 5], existing theorizing has yet to delineate a framework for understanding how stigma impacts individuals [2]. Existing conceptual frameworks have not clearly identified how individuals experience HIV stigma in ways that may affect their psychological, health, and behavioral outcomes and, in turn, fuel the epidemic. Given that individual level interventions are a core component of comprehensive HIV prevention efforts [6], understanding how HIV stigma affects individual outcomes is of tremendous import.

In order to address this gap, we first provide a conceptual model—the HIV Stigma Framework—that captures how the existence of HIV as a stigmatized “mark” [7] can elicit individual level stigma mechanisms [8] which can, in turn, impact important outcomes for both people who are HIV uninfected and those who are HIV infected. This conceptual model disentangles parallel, yet distinct, individual processes that occur for HIV uninfected and HIV infected people in response to the stigmatized nature of HIV. Therefore, this framework is designed to provide a way to understand and measure the individual processes of stigmatization—the ways in which stigma is *experienced* by individuals who are HIV infected and those who are not.

Secondly, we use the HIV Stigma Framework to systematically review measures that have been developed to assess HIV stigma in order to identify existing gaps in

V. A. Earnshaw (✉) · S. R. Chaudoir
Department of Psychology, University of Connecticut,
406 Babbidge Road, Unit 1020, Storrs, CT 06269-1020, USA
e-mail: valerie.earnshaw@uconn.edu

S. R. Chaudoir
Center for Health, Intervention, and Prevention,
University of Connecticut, Storrs, CT, USA

stigma measurement and outline suggestions for future research. Our review addresses three major components of these measures. First, whose perspective do these measures assess? Given that HIV infected and uninfected individuals are affected by HIV stigma in unique ways, we identify the degree to which HIV stigma measures have examined each of these two perspectives. Second, within each of these different perspectives (i.e., HIV infected vs. uninfected), to what degree do existing stigma measures assess each of the stigma mechanisms identified in the HIV Stigma Framework? We examine how existing HIV stigma measures have assessed prejudice, stereotypes, and discrimination among HIV uninfected individuals and enacted, anticipated, and internalized forms of stigma among HIV infected individuals. And third, what do HIV stigma measures predict and are they psychometrically sound? We review the external validity and basic psychometric properties of existing HIV stigma measures.

HIV Stigma Framework

Like many HIV researchers and theorists [5, 9–13], our understanding of stigma stems from Goffman's work [7]. Goffman defined stigma as “an attribute that is deeply discrediting” (p. 3). At its core, a stigma is a “mark” or aspect of the self that is *socially* devalued. Goffman stressed that “a language of relations, not attributes, is really needed” (p. 3) to describe stigma. Stigma is not solely a product of the “mark” itself, but rather of social interactions and relationships in which the “mark” is constructed as a reflection of its possessor's tarnished character. Recent stigma theory has stressed this aspect of Goffman's theory, characterizing stigma as a social process contingent on social context. Link and Phelan [4], for example, conceptualize stigma as a social process that exists when the following components co-occur within a power structure: labeling, stereotyping, separation, status loss, and discrimination. Parker and Aggleton [5] emphasize the role of social context in the construction of stigma by arguing that stigma operates at the intersection of culture, power, and difference. They describe stigma as “central to the constitution of the social order” (p. 17). Stigma plays a role in maintaining social inequality between stigmatized and non-stigmatized people. These theoretical considerations of stigma offer important insights into how and why HIV stigma develops and is maintained within different social contexts.

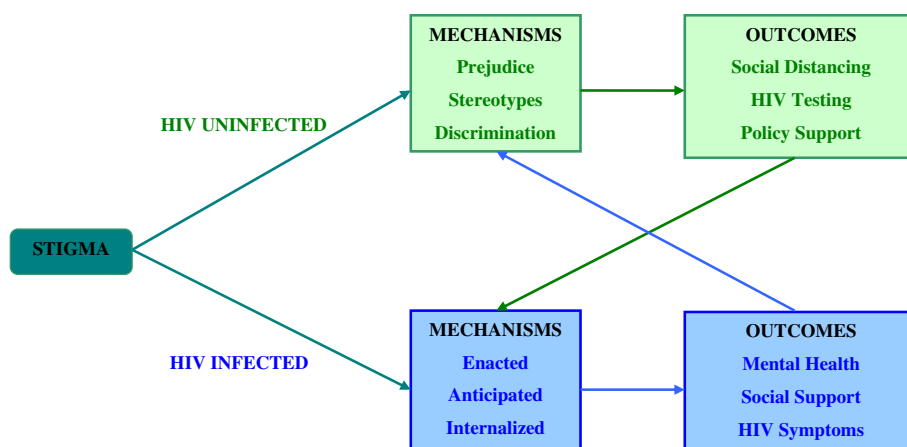
In order to build a more complete understanding of the impact of HIV stigma, however, these societal level conceptualizations of stigma should be complemented by individual level conceptualizations of stigma. Deacon [2] stressed this very point, highlighting the need to integrate

social and individual dimensions of stigma to build a comprehensive theory of health-related stigma. The lack of attention to the individual processes of stigma—the ways in which stigma is experienced or adopted by individuals—has fostered a number of misconceptions regarding HIV stigma. For example, Deacon has noted how the concept of “stigma” has often been stretched to include “discrimination” such that researchers use the term “stigma” to refer to “both the stigmatizing beliefs themselves and the effects of these stigmatization processes” (p. 419). Further, the impact of HIV stigma on individuals who are HIV uninfected (i.e., the “stigmatizers”) are often not differentiated from the impact of HIV on individuals who are HIV infected (i.e., the “stigmatized”). This is especially problematic given that societal level conceptualizations of stigma emphasize the role of power in stigma processes [4, 5]. Stigma serves to keep some people in a relative position of power because they do not possess the devalued attribute and others in a relative position of subordination because they possess the devalued attribute. Therefore, stigma's effect on individuals is necessarily contingent on whether they possess the devalued attribute themselves.

Greater theorizing regarding both the ways in which individuals experience HIV stigma and the individual level outcomes of HIV stigma might help researchers better understand and measure how the social processes of HIV stigma impact individuals. In order to expand this theorizing, we have drawn on insights from the domain of HIV stigma [5, 8], specifically, as well as those from other domains such as mental illness, sexual orientation, and racism [4, 14–16]. In doing so, we draw on the cumulative theorizing offered across multiple domains of stigma in order to build a comprehensive conceptual model that outlines how the social devaluation of HIV impacts people who are HIV uninfected and people who are HIV infected.

This model, which we have named the HIV Stigma Framework, is depicted in Fig. 1. On the left side of the model, we find that this process begins with the assumption that HIV is a *stigma*—it is a “mark” or attribute that is socially devalued [7] (see Parker and Aggleton [5] for a critical analysis of the structural conditions and social inequality that have led HIV to be stigmatized). How do people respond to this socially devalued characteristic? How do they understand what this stigma means for the self? We suggest that the existence of HIV as a devalued attribute necessarily impacts people within a given society through its concomitant *stigma mechanisms* (see also [8]). In essence, stigma mechanisms represent the ways in which people react to the knowledge that they either do not possess the devalued attribute (i.e., HIV uninfected) or do possess the devalued attribute (i.e., HIV infected). Among individuals who are HIV uninfected, stigma mechanisms represent the psychological responses to the knowledge

Fig. 1 Model of HIV stigma mechanisms



that there are people living with HIV who may threaten their health and may possess moral blemishes (e.g., intravenous drug use, risky sexual behavior, homosexuality; for a review, see Herek [17]). Among individuals who are HIV infected, stigma mechanisms represent the psychological responses to the knowledge that they, themselves, may have violated social mores and may be subject to other people's negative treatment. We further suggest that the stigma mechanisms experienced by individuals can impact psychological, behavioral, and health *outcomes*, which are also dependent on individuals' HIV status. It is important to note that the outcomes included in the HIV Stigma Framework are not the only outcomes of HIV stigma. Rather, they are several representative outcomes relevant to this review. In sum, people experience stigma through several stigma mechanisms which have the potential to lead to various—and often deleterious—outcomes.

HIV Stigma Effects for HIV Uninfected Individuals

The top section of the model depicts how stigma impacts individuals who are HIV uninfected and who possess a relative position of power compared to those who are HIV infected. The stigma mechanisms of people who are HIV uninfected largely represent efforts to distance themselves from people who are “tainted” by the “mark” of HIV [4]. According to the proposed HIV stigma framework, stigma mechanisms are manifested in 3 predominant ways among HIV uninfected individuals: prejudice, stereotyping, and discrimination towards people living with HIV/AIDS (PLWHA). Prejudice refers to negative emotions and feelings such as disgust, anger, and fear that HIV uninfected people feel toward HIV infected people [18, 19]. Stereotypes refer to group-based beliefs about HIV infected people that are often applied to specific individuals living with HIV/AIDS [20]. Discrimination refers to behavioral expressions of prejudice by HIV uninfected people directed at HIV infected people [18].

Theories that conceptualize stigma as a social process often do not distinguish between prejudice, stereotyping, and discrimination to the same degree as the HIV Stigma Framework. This perspective, represented by theorists such as Link and Phelan [4] and Parker and Aggleton [5], instead focuses on how prejudice, stereotyping, and discrimination operate in tandem to produce a societal level outcome: the development and maintenance of stigma. Despite the fact that prejudice, stereotyping, and discrimination may ultimately impact societal outcomes in a similar way, they represent distinct psychological responses that may differentially affect outcomes. Prejudice is experienced by individuals as an emotion, stereotypes as a cognition, and discrimination as a behavior [14]. Because these are separate processes, they can be experienced by people to varying degrees and can affect different types of outcomes. For example, an individual may be aware of stereotypes of a stigmatized group but not feel prejudice toward the group [21]. Endorsement of these stereotypes may impact the outcomes of HIV uninfected individuals. To the extent that HIV uninfected people do not consider themselves members of groups that are stereotypically more likely to contract HIV/AIDS (e.g., gay men, intravenous drug users, prostitutes), they may not believe that they are at risk of contracting HIV and may be less likely to get tested [22, 23]. Therefore, stereotypes may be a stronger determinant of HIV testing behavior than prejudice or discrimination.

Through the mechanisms of prejudice, stereotypes, and discrimination, the existence of a stigma can impact a variety of psychological, behavioral, and health outcomes for both people who are HIV infected and people who are HIV uninfected. Importantly, much research and intervention efforts have focused on the ways in which the expression of prejudice and discrimination by HIV uninfected people impact HIV infected people [2, 5, 24]. For example, discriminatory behavior perpetuated by HIV uninfected individuals may be experienced by HIV infected

people in the form of job loss, social rejection, or even physical violence (i.e., enacted stigma) and may also increase their expectations of future experiences of discrimination (i.e., anticipated stigma). Although less studied, these stigma mechanisms may also impact the outcomes of HIV uninfected people. Endorsement of stereotypes may impact HIV testing and risk behavior [22, 23]. Feelings of prejudice may also prevent HIV uninfected people from maintaining relationships with close friends and family members who are HIV infected, thus disrupting their social ties.

HIV Stigma Effects for HIV Infected Individuals

The bottom section of Fig. 1 depicts how stigma impacts individuals who are HIV infected and who possess a relative position of subordination compared to individuals who are HIV uninfected. People who are HIV infected know that their HIV status is an extremely socially devalued aspect of the self, and this knowledge is experienced through at least 3 important stigma mechanisms: enacted stigma, anticipated stigma, and internalized stigma. Enacted stigma refers to the degree to which PLWHA believe they have actually experienced prejudice and discrimination from others in their community [25]. Anticipated stigma refers to the degree to which PLWHA expect that they will experience prejudice and discrimination from others in the future [26]. Internalized stigma refers to the degree to which PLWHA endorse the negative beliefs and feelings associated with HIV/AIDS about themselves [27]. These 3 mechanisms have been previously defined as central, distinct processes through which members of other stigmatized groups experience stigma [27, 28]. Each mechanism is highly relevant to the experiences of HIV infected people.

PLWHA who experience stigma via these mechanisms face a variety of often deleterious outcomes. For example, people who experience a high degree of enacted stigma may experience psychological distress and lowered health well-being [1]. People who experience a high degree of anticipated stigma may be less likely to disclose their HIV status because they fear that they will be socially rejected [29]. Further, people who experience a high degree of internalized stigma may suffer poor psychological well-being [30]. Recent work provides evidence that these three types of stigma predict different types of psychological and behavioral outcomes among gay men [31]. When considered simultaneously, only enacted stigma predicted substance use, only anticipated stigma predicted depression, and only internalized stigma predicted HIV sexual risk behavior. This work provides additional support for the utility of assessing each of these 3 stigma mechanisms because they may be differentially related to psychological, behavioral, and health outcomes.

In sum, the HIV Stigma Framework provides a conceptual model that addresses how the existence of HIV as a highly stigmatized attribute is manifested in individuals as stigma mechanisms and how these mechanisms, in turn, can impact outcomes. In doing so, it highlights the importance of considering perspective because stigma mechanisms and outcomes differ between HIV uninfected and infected people. Finally, this framework provides a way for researchers to consider how the HIV stigma mechanisms and outcomes experienced by HIV uninfected and infected people may be related. With this conceptual framework in mind, we now consider how researchers have measured HIV stigma mechanisms in the extant literature.

Measuring HIV Stigma Mechanisms

The current framework provides a way to consider how HIV stigma—a fundamentally social process—affects individuals. Scholars have recently noted that these individual level conceptualizations of HIV stigma are often inconsistent [2] and that this lack of specificity can compromise the utility of the measures that researchers develop to assess HIV stigma mechanisms [13]. Inadequate assessments of HIV stigma mechanisms would represent a significant limitation to efforts aimed at ameliorating the negative effects of stigma. They could potentially compromise the validity of the measures, the outcomes of empirical research using the measures, and interventions based on this research.

The HIV Stigma Framework provides one such model to consider how HIV stigma affects both HIV infected and uninfected individuals and how measures can be developed to assess these constructs. Below, we systematically review existing HIV stigma measures and focus on addressing three important components of these measures. First, whose perspective is being measured? By considering the effect of HIV stigma for both HIV infected and uninfected individuals within the same framework, the current model highlights the importance of perspective in HIV stigma measures. Second, to what degree do existing stigma measures assess each of the stigma mechanisms? Within the current framework, we have defined three stigma mechanisms and have outlined evidence suggesting that these stigma mechanisms may be differentially related to stigma outcomes. To the extent that these stigma mechanisms are experienced by and predict different outcomes for individuals depending on their HIV status, measures that delineate among these mechanisms may be particularly useful. Third, what do HIV stigma measures predict? Considered within the current framework, measures that assess multiple stigma mechanisms may be particularly useful in predicting important psychological, behavioral and health outcomes. Therefore, we focus on evidence

concerning the relationship between stigma mechanisms and outcomes. In addition, we provide a brief psychometric review of the HIV stigma measures in order to offer a comprehensive review.

Method

We conducted a literature search in *Pubmed/Medline* and *PsycInfo* in order to locate articles published through May 2008 describing the development of quantitative measures of HIV stigma. In order to assess the constructs of interest, we searched for combinations of terms, including: “HIV/AIDS,” “stigma,” “prejudice,” “attitude,” “discrimination,” “measure,” and “scale.” This review excludes articles that were not published in English [32] as well as survey instruments that were not published in scientific journals [33]. Furthermore, the review only includes articles introducing a new measure of HIV stigma. Although a measure may have been introduced in one article, psychometrically evaluated in another, and used to explore health outcomes in a third, only the first article was eligible for inclusion in the current review. It is important to note that the goal of the current review is not to perform a comprehensive psychometric evaluation of the scales included. Rather, the goal is to evaluate the content of HIV stigma in relation to the HIV Stigma Framework and obtain a preliminary idea of what types of outcomes these scales predict. The literature search yielded 23 articles eligible for inclusion in this review, representing 24 different survey instruments (see Table 1). After locating the articles, we coded them to answer our three guiding questions.

Perspectives Taken

In order to discern whether a scale focused on the perspective of HIV uninfected or HIV infected people, we assessed whether the study samples were comprised of HIV uninfected people, HIV infected people, or a combination of both. If the study sample consisted of HIV uninfected people, we coded the instrument as examining the perspective of HIV uninfected people. If the sample consisted of HIV infected people, we coded the instrument as examining the perspective of HIV infected people. If the sample was mixed, we coded the instrument as examining a combination of the two perspectives.

Stigma Mechanisms Measured

For each scale, survey items were coded in order to determine which stigma mechanisms were measured by the instrument. This coding scheme was driven by the definitions of the six stigma processes provided previously in this

review. Therefore, survey instruments examining the perspective of HIV uninfected people were coded for items measuring prejudice, stereotypes, and/or discrimination. Items were coded as prejudice if they measured negative affect toward HIV infected people. Popular prejudice items included anger (e.g., “Angry” [43]), disgust (“Disgusted with sinfulness” [38]), and shaming (e.g., “People with HIV should be ashamed of themselves” [50]). Items were coded as stereotypes if they measured potentially inaccurate thoughts and beliefs about HIV infected people. Many of these items measured beliefs about the types of people who get HIV/AIDS (“Only disgusting people get AIDS” [35]) and the types of behavior in which they engage (“Most women with HIV/AIDS are prostitutes or sex workers” [42]). Items were coded as discrimination if they measured behavioral expressions of prejudice directed at HIV infected people or support of discriminatory social policy. These items often involved social distancing (e.g., “If I was in public or private transport, I would not like to sit next to someone with HIV” [50]) or the removal of rights (e.g., “Persons with AIDS should not be eligible for welfare benefits from the state or federal governments” [39]).

Survey instruments examining the perspective of HIV infected people were coded for items measuring enacted stigma, anticipated stigma, and internalized stigma. Items were coded as enacted stigma if they measured perceived experiences of prejudice and/or discrimination. These items spanned a wide range of experiences, including discriminatory actions (e.g., “At the hospital/clinic, I was left in a soiled bed” [11]), verbal abuse (e.g., “Someone told me HIV is what I deserve for how I lived” [9]), and social rejection (e.g., “I feel some friends have rejected me because of my illness” [8]). Items were coded as anticipated stigma if they measured the expectation of experiencing future prejudice and discrimination. Some of these items referenced discriminatory behaviors (e.g., “Most employers would not employ me because I am HIV+” [50]) while others measured the anticipation of dislike by others (e.g., “My neighbors would not like living next door if they knew I had HIV” [50]). Finally, measures were coded as assessing internalized stigma if they measured the application of shame and/or negative beliefs associated with HIV/AIDS to the self. Items assessing shame (e.g., “I feel ashamed that I have HIV” [50]), guilt, (e.g., “I feel guilty because I have HIV” [9]), and worthlessness (e.g., “I felt completely worthless” [11]) were common examples.

Outcomes and Psychometric Properties

Outcomes examined in conjunction with the measures as well as psychometric evaluations of the scales were coded. Assessments of psychological, behavioral, and health

Table 1 Measures of HIV stigma mechanisms

Year	Authors	Scale title	Perspective: sample	Country	Scale factors	Stigma mechanisms measured	External validity: outcome-related	External validity: other
1988	Pleck et al. [34]	AIDS-phobia	Uninfected: 237 hospital workers caring for PLWHA	United States	Proximity with people with AIDS	Prejudice, discrimination	Willingness to care for HIV infected people (-)	AIDS stress (+), AIDS contact (-)
1989	Shrum et al. [35]	AIDS attitude scale	Uninfected: 299 students	United States	Moral issues Social welfare issues	Prejudice, discrimination Prejudice	Willingness to care for HIV infected people (-)	
1992	Froman et al. [36]	AIDS attitude scale	Uninfected: 167 nursing students	United States	Empathy Avoidance	Discrimination Prejudice, discrimination Prejudice, discrimination	Willingness to care for HIV infected people (-)	
1994	Harrison et al. [37]	AIDS attitude and conservative views scale	Uninfected: 225 nurses	United States	Conservative views Willingness to give care Sympathy for homosexuals and IDUs	Prejudice Discrimination Prejudice	Willingness to care for HIV infected people (-)	
1995	Preston et al. [38]	Nurses' attitudes about AIDS scale	Uninfected: 731 nurses	United States	People with AIDS	Prejudice, discrimination	Willingness to care for HIV infected people (-)	
1996	Mulford and Lee [39]	AIDS victim blaming scale	Uninfected: 824 students	United States	Nursing care concerns Social-professional concerns	Prejudice, discrimination Prejudice, discrimination	Willingness to care for HIV infected people (-)	
1997	Sowell et al. [40]	HIV stigma scale	Infected: 82 PLWHA, women only	United States	Stable/Victim-blaming	Prejudice, stereotype	Social responsibility (-), willingness to discriminate (+), social distance (+)	
1999	Davis et al. [41]	International AIDS questionnaire	Uninfected: 1944 secondary-school and college students	China	Unstable/Victim-blaming Society-blaming	Stereotype	Social responsibility (ns), willingness to discriminate (ns), social distance (ns)	
2000	Fife and Wright [8]	Measure of stigma and social impact of disease	Infected: 130 PLWHA, 76 persons living with cancer	United States	Transmission myths Attitudes Personal vulnerability Facts Social rejection Financial insecurity Internalized shame Social isolation	Enacted stigma, anticipated stigma, internalized stigma Discrimination Enacted stigma Internalized stigma, anticipated stigma Internalized stigma	Social responsibility (+), willingness to discriminate (-), social distance (-)	

Table 1 continued

Year	Authors	Scale title	Perspective: sample	Country	Scale factors	Stigma mechanisms measured	External validity: outcome-related	External validity: other
2001	Berger et al. [9]	HIV stigma scale	Infected: 318 PLWHA	United States	Personalized stigma	Enacted stigma	Self-esteem (-), depression (+), social support (-), social integration (-), social conflict (+)	
					Disclosure concerns	Anticipated stigma	Self-esteem (-), depression (+), social support (-), social integration (-), social conflict (+)	
					Negative self-image	Internalized stigma	Self-esteem (-), depression (+), social support (-), social integration (-), social conflict (+)	
					Concern with public attitudes about people with HIV	Anticipated stigma	Self-esteem (-), depression (+), social support (-), social integration (-), social conflict (+)	
2001	O'Hea et al. [42]	Attitudes toward women with HIV/AIDS scale	Uninfected: 225 psychology students	United States	Child care	Stereotypes, discrimination		Attitudes towards women (+), attitudes towards AIDS (+), AIDS knowledge (nr), female sexuality attitudes (+)
					Myths/Negative stereotypes	Stereotypes		Attitudes towards women (+), attitudes towards AIDS (+), AIDS knowledge (nr), female sexuality attitudes (+)
					Reproduction/Contraception issues	Discrimination		Attitudes towards women (+), attitudes towards AIDS (+), AIDS knowledge (+), female sexuality attitudes (+)
					Sympathy/Transmission route	Prejudice		Attitudes towards women (+), attitudes towards AIDS (+), AIDS knowledge (+), female sexuality attitudes (+)
2002	Herek et al. [43]	AIDS stigma index	Uninfected: 1978 community members	United States		Prejudice, stereotypes, discrimination		
2003	Herek et al. [44]	Feeling thermometer towards PLWA	Uninfected: 1335 community members	United States		Prejudice	Reporting names of HIV infected individuals to government (-), reporting HIV statistics to government (ns)	
2005	Kalichman et al. [45]	AIDS-related stigma scale	Uninfected: 2306 community members	South Africa		Prejudice, stereotypes, discrimination	Indication of past HIV testing (-)	PLWHA should hide HIV status (+), AIDS knowledge (-)

Table 1 continued

Year	Authors	Scale title	Perspective: sample	Country	Scale factors	Stigma mechanisms measured	External validity: outcome-related	External validity: other
2006	Hamra et al. [46]	Expressed HIV/AIDS-related stigma	Uninfected: 873 community members from families caring for HIV positive children	Nairobi, Kenya	Desire to be secretive regarding HIV/AIDS Fear and avoidance Overestimation of risk Restrictive measures Denial of HIV Verbal abuse	Discrimination Discrimination Discrimination Enacted stigma	Condom use (ns), attitudes and behavior toward HIV testing (-) Symptom frequency (+), quality of life (-)	General AIDS knowledge (-), acquaintance with PLWA (-)
2007	Holzemer et al. [11]	HIV/AIDS stigma instrument—PLWA (HASP)	Infected: 1477 PLWHA	Lesotho, Malawi, South Africa, Swaziland and Tanzania	Negative self-perception Healthcare neglect Social isolation Fear of contagion Workplace stigma	Internalized stigma Enacted stigma Enacted stigma Enacted stigma Enacted stigma	Symptom frequency (nr), quality of life (-) Symptom frequency (+), quality of life (-) Symptom frequency (+), quality of life (-) Symptom frequency (+), quality of life (-) Symptom frequency (+), quality of life (-)	
2008	Genberg et al. [10]	HIV/AIDS-related stigma	Uninfected: 209 Thailand, 224 Zimbabwe community members	Thailand and Zimbabwe	Shame, blame, and social isolation Perceived discrimination Equity	Prejudice, discrimination Discrimination Internalized stigma	Depression (+), social support (-), HIV symptoms (+) Shame (+), social support (-), mental health (-), physical health (ns) Shame (+), social support (-), mental health (-), physical health (ns) Shame (+), social support (-), mental health (-), physical health (ns) Shame (+), social support (-), mental health (-), physical health (ns)	Acquaintance with PLWHA (-) Acquaintance with PLWHA (-) Acquaintance with PLWHA (nr) Experiences of AIDS-related discrimination (+), reported non-disclosure (+)
2008	Kalichman et al. [12]	Internalized AIDS-related stigma scale	Infected: 1068 SA, 1087 Swaziland, 219 US PLWHA	South Africa, Swaziland, United States	Stereotypes Disclosure concerns Social relationships Self-acceptance	Enacted stigma Enacted stigma, anticipated stigma Internalized stigma		
2008	Sayles et al. [47]	Internalized HIV stigma scale	Infected: 202 PLWHA	United States				
2008	Stein and Li [48]	Multidimensional stigma scale	Uninfected: 1101 service providers at health care facilities	China	Discrimination intent at work Prejudiced attitudes Internalized shame Fear of AIDS Good care for HIV patients	Discrimination Prejudice Internalized stigma Discrimination		Sympathy (-), ratings of opinions of a PLWHA described in a case vignette (-)

Table 1 continued

Year	Authors	Scale title	Perspective: sample	Country	Scale factors	Stigma mechanisms measured	External validity: outcome-related	External validity: other
2008	Van Rie et al. [49]	HIV/AIDS-related stigma scale	Mixed: 204 tuberculosis patients, 22% of tested patients were HIV positive	Thailand	Community perspectives toward HIV/AIDS Patient perspectives toward HIV/AIDS		Perceived social support (-) Perceived social support (ns)	
2008	Visser et al. [50]	Internalised stigma scale, attributed stigma scale Personal stigma scale, attributed stigma scale	Infected: 317 PLWHA, women only Uninfected: 1077 community members	South Africa	Blame and judgement Interpersonal distancing Blame and judgement Interpersonal distancing	Internalized stigma Anticipated stigma Prejudice Discrimination	Depression (+), self-esteem (-), perceived social support (-)	HIV knowledge (-)
2008	Zelaya et al. [51]	HIV/AIDS stigma scale	Uninfected: 200 male community members	India	Fear of transmission and disease Association with shame, blame, and judgement Personal support of discriminatory actions or policies Perceived community support of discriminatory actions or policies	Prejudice, stereotypes Discrimination		Acquaintance with PLWHA (-), HIV knowledge (-)

outcomes are often included in scale development studies as indicators of external validity, or the ability of a scale to predict theoretically related phenomena [52]. External validity refers to a variety of constructs that are both outcome related and non-outcome related. These two types of external validity were coded separately in order to highlight the types of outcomes that have been measured in relation to the mechanisms specified by the HIV Stigma Framework. The studies described by the articles examined external validity using cross-sectional, correlational study designs that do not allow for empirical tests of causality. Therefore, the individual study hypotheses were relied on to determine which constructs should be considered outcomes of stigma mechanisms. For example, authors of scales measuring stigma mechanisms from the perspective of uninfected people frequently hypothesize that stigma mechanisms act as a barrier to HIV prevention efforts such as HIV testing [45, 46, 51]. In these cases, HIV testing was considered to be an outcome of the scale if it was measured. Additionally, authors of scales measuring stigma mechanisms from the perspective of infected people frequently hypothesize that stigma mechanisms impact mental health and social support [9, 12, 47]. In these cases, constructs such as depression, self-esteem, and quality of life were considered to be outcomes of the scale if they were measured.

In order to provide a comprehensive review, six additional aspects of the measures were coded that assess their psychometric properties. Indicators of reliability, the consistency of a measure [53], included internal consistency and test-retest reliability. Internal consistency estimates the amount of error associated with a scale. Test-retest reliability estimates the extent to which people's answers vary over time. Further indicators of validity, the degree to which interpretations of a measure are consistent with empirical and theoretical understandings of the construct measured [52], included content validity, substantive validity, structural validity, and generalizability. Content validity concerns whether the construct of interest is accurately reflected in the scale. Substantive validity is established through application of theoretical understandings of the construct of interest to the measure. Structural validity represents the extent to which the factor structure of the scale represents the theorized structure of the construct. Generalizability reflects the extent to which the scale can be applied to different populations, locations, and settings.

Results

Tables 1 and 2 include the results of our coding of the HIV stigma mechanism scales organized chronologically according to the date that scales were published. Table 1

presents pertinent information about each scale, including the year of publication, the authors, the scale title, the perspective measured (HIV uninfected, HIV infected, or mixed), the sample size and other sample characteristics, the country in which the scale was developed, the scale factors as labeled by the authors of the scale, the stigma mechanisms according to our coding scheme, and the assessments of external validity. Table 2 includes assessments of reliability and the remaining types of validity. External validity was included in Table 1 rather than Table 2 in order to allow for a more direct comparison between stigma mechanisms, related outcomes, and other constructs.

Perspectives Taken: HIV Uninfected Versus HIV Infected

Table 1 includes information about the extent to which HIV stigma mechanism measures have been developed to examine the perspectives of HIV uninfected and HIV infected people. Sixteen (66.6%) of the measures were developed to study the perspective of HIV uninfected people, 7 (29.2%) of the measures were developed to study the perspective of HIV infected people, and 1 (4.2%) of the measures examined the perspective of both HIV uninfected and infected people. These findings indicate that a greater number of measures have been developed to study the perspective of HIV uninfected people. In fact, there are over two times as many scales measuring the perspective of HIV uninfected people than there are scales measuring the perspective of HIV infected people. This represents a significant imbalance.

Table 1 also provides insight into when and where measures have been developed to examine these two perspectives. This is informative as to whether the two perspectives have been given equal empirical attention across time and locations. While the first measure designed to examine stigma mechanisms from the perspective of HIV uninfected people was published in 1988 [34], the first measure designed to study stigma mechanisms from the perspective of HIV infected people was not published until 1997 [40]. This was almost 20 years into the epidemic and 10 years after the publication of the first measure studying an HIV uninfected population. Therefore, measures designed for HIV infected people were developed much later in the epidemic than measures designed for HIV uninfected people. Because they have been studied for longer, researchers may have developed a stronger understanding of the ways in which HIV uninfected people experience stigma mechanisms compared to the ways in which HIV infected people experience stigma mechanisms.

In addition to being developed over a shorter period of time, measures focused on HIV infected people's perspectives have been developed in fewer geographical locations than measures focused on HIV uninfected people's perspectives. Measures examining perspectives of HIV infected and uninfected people have both been developed in the United States (uninfected: 9 measures; infected: 5 measures) and in Africa (uninfected: 4 measures; infected: 3 measures). However, only measures examining the perspective of uninfected people have been developed in Asia (uninfected: 4 measures). Measures examining perspectives of uninfected individuals have been developed in three continents while measures examining perspectives of infected individuals have been developed in two. This may mean that researchers are better equipped to study the perspective of HIV uninfected people in a greater number of locations.

These observations provide support for the assertion made by others [2, 5] that the perspective of HIV uninfected individuals has been studied to a greater extent than the perspective of HIV infected individuals. The perspective of HIV uninfected people has not only been studied by almost double the number of measures, but it has also been studied for almost double the amount of time and in more geographical locations than the perspective of HIV infected people.

Stigma Mechanisms Measured

The stigma mechanisms measured by each scale are also presented in Table 1. Sixteen scales measured HIV stigma mechanisms from the perspective of HIV uninfected people. Of these 16, 14 (87.5%) measured prejudice, 5 (31.3%) measured stereotypes, and 14 (87.5%) measured discrimination. The majority of these survey instruments measured prejudice and/or discrimination, while far fewer measured stereotypes. This is likely the case because researchers have shown that prejudice and discrimination are predictive of important outcomes, such as willingness to care for HIV infected people [38] and support for discriminatory social policies [44], and therefore recognize the importance of assessing them. The relative significance of prejudice and discrimination, however, should not preclude the measurement of stereotypes which may predict important outcomes for HIV uninfected people [22, 23].

Seven scales measured HIV stigma mechanisms from the perspective of HIV infected people. Of these 7, 5 (71.4%) measured enacted stigma, 5 (71.4%) measured anticipated stigma, and 7 (100%) measured internalized stigma. Every scale that measured the perspective of HIV infected people included items gauging internalized stigma. This suggests a strong consensus among researchers that internalized stigma is an important construct, predictive of significant outcomes

Table 2 Psychometric properties of measures

Scale	Internal consistency	Test-retest reliability	Content validity	Substantive validity	Structural validity	Generalizability
AIDS-phobia [34]	$\alpha = .76$ overall		Expert review		Exploratory factor analysis: 3 factors accounting for 45% of variance	
AIDS attitude scale [35]	$\alpha = .96$ overall, Item-total correlations $r = .24$ – $r = .76$		Expert review		Exploratory Factor Analysis: 2 factors accounting for 75% of variance, Correlation between factors: $r = -.56$	Replication with larger, more diverse sample
AIDS attitude scale [36]	$\alpha = .85$ – $.89$ among subscales		Expert review		Exploratory factor analysis: 3 factors accounting for 39.8% of variance	
AIDS attitude and conservative views scale [37]	$\alpha = .60$ overall, $.69$ – $.90$ among subscales		Expert review		Exploratory Factor analysis: 3 factors accounting for 44% of variance	
Nurses' Attitudes about AIDS scale [38]	$\alpha = .96$ overall, $.72$ – $.96$ among subscales		Expert review	Comparison of scores of nurses with preconceived and postconceived attitudes: $t = .06^{\dagger}$ $-t = -2.82^{**}$		
AIDS victim blaming scale [39]	$\alpha = .71$ – $.81$ among subscales, spearman-brown split-half coefficients: $.70$ – $.80$, interitem correlations: $r = .33$ – $r = .41$		Literature review		Exploratory factor analysis, interfactor correlations: $r = -.02$ $-r = -.16$	
HIV stigma scale [40]			Focus group discussions			
International AIDS questionnaire [41]	$\alpha = .76$ overall, $.45$ – $.71$ among subscales	2 week delay using university students: $r = .74$			Exploratory Factor Analysis: 4 factors, correlations between factors: $r = .08^{**}$ – $r = .36^{***}$	Replication with separate samples of Chinese adolescents and university students
Measure of stigma and social impact of disease [8]	$\alpha = .85$ – $.90$ among subscales		Expert review	Comparison of PLWHA and cancer patients: $t = 2.31^{***}$ $-t = 4.43^{***}$	Exploratory factor analysis: 4 factors accounting for 11.91–51.03% of variance	
HIV stigma scale [9]	$\alpha = .96$ overall, $.90$ – $.93$ among subscales	2–3 week delay: $r = .92$ overall, $r = .87$ – $r = .90$ among subscales	Expert review		Exploratory factor analysis: 4 factors accounting for 46% of variance	
Attitudes toward women with HIV/AIDS scale [42]	$\alpha = .82$ overall, $.71$ – $.84$ among subscales				Exploratory factor analysis: 4 factors accounting for 48.6% of variance, correlation between factors: $r = -.07$ – $r = .39$	
AIDS stigma index [43]	$\alpha = .77$ – $.79$ across time			Comparison at 3 time points, 1991, 1997, 1999: $R^2 = .03$, $b = -0.132^{***}$		

Table 2 continued

Scale	Internal consistency	Test-retest reliability	Content validity	Substantive validity	Structural validity	Generalizability
Feeling thermometer towards PLWA [44]						
AIDS-related stigma scale [45]	$\alpha = .75$ overall, .64–.83 among language samples	1 month and 3 months delay: $r = .68^{**}$ and $r = .67^{**}$	Literature review, formative discussions with experts Focus group discussions			Replication in 5 community samples using 3 different languages
Expressed HIV/AIDS-related stigma [46]			Focus group discussions			
HIV/AIDS stigma instrument—PLWA (HASI-P) [11]	$\alpha = .76$ –.91 among subscales		Focus group discussions		Exploratory factor analysis: 6 factors accounting for 60.7% of variance, correlations between factors: $r = -.10^*$ $-r = -.23^*$	Replication in 5 African countries
HIV/AIDS-related stigma [10]	$\alpha = .71$ –.86 among subscales, item to total correlations: $r = .30$ –.60			Comparison of samples from Thailand and Zimbabwe: $t(419) = 9.02^{**}$, $t(419) = -14.34^{**}$	Exploratory factor analysis: 3 factors accounting for 47% of variance	
Internalized AIDS-related stigma scale [12]	$\alpha = .75$ overall, .64–.83 among separate samples	3 week delay in South Africa, 4 month delay in US: $r = .45^{**}$ and $r = .62^{**}$				Replication in 2 African countries and in the US
Internalized HIV stigma scale [47]	$\alpha = .93$ overall, .66–.91 among subscales		Focus group discussions, cognitive interviews		Exploratory factor analysis: 4 factors, correlations between factors: $r = .33^{**}$ – $r = .61^{**}$	
Multidimensional stigma scale [48]					Exploratory factor analysis: 5 factors accounting for 64% of variance, correlations between factors – $.33^{**}$ $-r = .78^{**}$, confirmatory factor analysis: RMSEA = .05	
HIV/AIDS-related stigma scale [49]	$\alpha = .83$ –.91 among subscales	30 day delay: $r = .33^\dagger$ $-r = .40^\dagger$			Exploratory factor analysis: 2 factors, confirmatory factor analysis: RMSEA = .11 Confirmatory factor analysis: RMSEA = .10–.10	
Internalised stigma scale, attributed stigma scale [50]	$\alpha = .70$ –.77 overall, .61–.71 among subscales		Focus group discussions			

Table 2 continued

Scale	Internal consistency	Test-retest reliability	Content validity	Substantive validity	Structural validity	Generalizability
Personal stigma scale, attributed stigma scale [50]	$\alpha = .73-.87$ overall, $.63-.81$ among subscales		Focus group discussions		Exploratory factor analysis: 2 factors, confirmatory factor analysis: RMSEA = $.06-.07$	
HIV/AIDS stigma scale [51]	$\alpha = .81$ overall, $.72-.86$ among subscales, ICC = $.72-.85$ among subscales		Focus group discussions, consultation with experts		Exploratory factor analysis: 4 factors	

† $p > .05$, * $p < .05$, ** $p < .01$, *** $p < .001$

for HIV infected people. A strong majority of these scales also included items measuring enacted stigma and/or anticipated stigma, indicating that researchers also consider these constructs to be important.

Based on our assessment of the HIV stigma scales, researchers are measuring the stigma mechanisms included in the HIV Stigma Framework. This indicates that there is some degree of recognition among researchers that these mechanisms represent important constructs to assess in relation to HIV stigma. Despite this recognition, many scales measure multiple types of constructs within a single scale or subscale. Of the 24 scales that measured stigma mechanisms, 12 (50%) of them simultaneously measure other constructs. For example, the AIDS-Related Stigma Scale [45] includes items measuring prejudice, stereotypes, and discrimination. These items are combined into one general stigma scale, which is predictive of HIV testing. Because prejudice, stereotypes, and discrimination are not differentiated in this scale, it is impossible to know which stigma mechanism(s) is most predictive of this important outcome. This is problematic to the extent that stigma mechanisms lead to different outcomes. Greater differentiation between stigma mechanisms might allow researchers to identify the mechanism(s) that should be targeted in future interventions addressing the impact of HIV stigma on outcomes such as testing behavior.

Outcomes and Psychometric Properties

Indicators of outcome related and non-outcome related external validity are presented in Table 1. The remaining indicators of psychometric properties are presented in Table 2. Twelve of the 24 (50%) articles assessed outcome related external validity. Five of the 16 (31.3%) measures examining the perspectives of HIV uninfected people assessed an outcome. Two of these measures examined stigma mechanisms independently of other constructs. The first demonstrated that prejudice is related to increased support for discriminatory social policy [44] and the second demonstrated that discrimination is related to decreased attitudes and behavior toward HIV testing [46]. The remaining three articles did not differentiate between items measuring different stigma mechanisms, making it impossible to discern which stigma mechanism is predictive of the reported outcome. Prejudice and discrimination were related to decreased willingness to care for HIV infected people [38], prejudice and stereotypes were related to decreased feelings of social responsibility for, increased willingness to discriminate against, and increased desire for social distance from PLWHA [39]. Finally, prejudice, stereotypes, and discrimination were related to decreased willingness to indicate past HIV testing [45].

Compared to HIV stigma mechanism measures studying the perspective of HIV uninfected people, measures studying the perspective of HIV infected people were more likely to assess an outcome. Six out of 7 (85.7%) of the articles examining stigma mechanisms from the perspective of HIV infected individuals assessed an outcome. Of these 6, 4 examined stigma mechanisms independently of other constructs, one [47] examined stigma mechanisms both independently and non-independently of other constructs within separate subscales, and one [50] measured stigma mechanisms independently within subscales but did not assess outcomes in relation to each subscale. These articles demonstrated that internalized stigma is related to lower mental health [8, 9, 12, 47], lower social support [9, 12, 47], and greater HIV symptoms [11, 12]. Anticipated stigma is related to lower mental health and social support [9]. Enacted stigma is related to lower mental health [8, 9, 47], lower social support [9, 47], and greater HIV symptoms [11]. Of the two articles that did not differentiate between items measuring stigma mechanisms, one demonstrated a relationship between enacted stigma and anticipated stigma with lower mental health and social support [47] and the other demonstrated a relationship between internalized stigma and anticipated stigma with lower mental health and social support [50].

The remaining indicators of the psychometric properties of the scales are presented in Table 2. The authors of the articles used a wide variety of techniques to assess the reliability and validity of the HIV stigma scales. Of the 24 scales, 20 (83.3%) employed the coefficient alpha to assess internal consistency. Item-total correlations, Spearman-Brown split-half coefficients, inter-item correlations, item to total correlations, and intraclass correlations were also reported as measures of internal consistency. Test-retest reliability was assessed in 5 (20.8%) of the scales, with authors allowing up to 3 months before re-administering the scale. Issues of content validity were explicitly addressed in 15 (62.5%) of the scales through a variety of tactics, including expert reviews and focus group discussions. Substantive validity was assessed in 4 (16.6%) of the scales by either comparing samples from different locations or time points that were hypothesized to differ in their endorsement of HIV stigma mechanisms. Structural validity was assessed in 17 (70.8%) of the scales through exploratory and confirmatory factor analyses. Generalizability was assessed in 5 (20.8%) of the scales. Tests of generalizability differed from those of substantive validity in that they did not examine differences between the samples according to stigma-related hypotheses, but rather examined the utility of the scales within different populations. As shown in Table 1, non-outcome related external validity was examined in relation to 9 (37.5%) scales by

examining the relationship between participant scores on the scales and theoretically related constructs.

The psychometric review demonstrates that researchers have used a variety of techniques to establish the reliability and validity of their measures. Over half of the scales included in this review were assessed in terms of internal consistency, content validity, structural validity, and external validity. A fewer number of studies examined the test-retest reliability, substantive validity, and generalizability of their scales. Furthermore, the review of outcome related external validity analyses suggests that stigma does impact HIV infected people differently than it impacts HIV uninfected people. Among infected people, stigma mechanisms were found to be related to lower mental health and social support, and greater symptom frequency. In contrast, among uninfected people, stigma mechanisms were related to outcomes including HIV testing, desire for social distance from infected people, and acceptance of discriminatory social policy toward infected people. Because the outcomes of HIV stigma on individuals are dependent on HIV status, it is critical to differentiate between HIV uninfected and infected perspectives when measuring and theorizing about the effects of HIV stigma.

General Discussion

In this review, we first introduced the HIV Stigma Framework in order to enhance understandings of the impact of HIV stigma on individuals. This framework considers the ways in which stigma impacts the psychological, behavioral, and health outcomes of both HIV uninfected and infected people via multiple stigma mechanisms. We suggest that when studying HIV stigma, researchers will benefit by considering each component of the framework: the perspective of the population, the way in which stigma is experienced, and the outcomes of stigma. We then used this framework to review HIV stigma survey instruments developed since the beginning of the HIV epidemic in order to gauge which of these constructs HIV researchers have been studying in relation to HIV stigma. The results of this review provide insight into the history of HIV stigma research and highlight critical directions for its future.

Reflections on the History of HIV Stigma Research

This review suggests that research on HIV stigma has been limited by an imbalance in attention paid to HIV uninfected versus infected people, a lack of consideration of the mechanisms through which HIV stigma impacts people, and an imprecise understanding of the psychological, behavioral, and health outcomes of HIV stigma. Consid-

ered within the larger HIV prevention and treatment literature, this imbalance parallels that of behavioral interventions. Much of these early intervention efforts targeted HIV uninfected individuals—they were designed to educate HIV uninfected individuals about routes of transmission and reduce sexual and drug risk behaviors in order to protect themselves from infection (e.g., [54, 55]). However, as the epidemic evolved, researchers shifted the emphasis of their intervention efforts to target PLWHA—people who could spread the virus to uninfected individuals through risky sexual and drug use behaviors (e.g., [56, 57]). Therefore, over the course of the epidemic, behavioral intervention efforts first focused on the general, HIV uninfected public and later shifted to PLWHA.

Our review suggests that research aimed to address HIV stigma has followed a similar pattern. The first research examining HIV stigma was published in the late 1980s and primarily focused on assessing the extent to which HIV uninfected people felt prejudice toward and discriminated against HIV infected people [34]. This focus lasted until approximately the turn of the century. In 2003, Parker and Aggleton [5] noted that the “vast majority of the interventions that have been developed and evaluated in the research literature in order to respond to stigma related to HIV and AIDS have been aimed at increasing ‘tolerance’ of people with AIDS on the part of different segments of the ‘general population’” (p. 16). Their analysis suggests that the interventions designed to combat HIV stigma during the first two decades of the epidemic predominantly focused on reducing prejudice and discrimination towards PLWHA among the general, HIV uninfected population. As a result, they rarely focused on examining how PLWHA experience stigma and how these experiences might shape their outcomes.

The focus on HIV uninfected individuals did not result from a consensus to disregard the experiences of PLWHA; rather it resulted, in part, from an implicit and sometimes explicit assumption made by HIV stigma researchers regarding how to most effectively improve the lives of PLWHA. Early HIV stigma research was guided by an assumption that efforts to curb prejudice and discrimination among HIV uninfected individuals would result in improved outcomes for PLWHA. Researchers reasoned that if prejudice and discrimination are harmful to PLWHA, then understanding and ameliorating the general population’s prejudicial feelings and discriminatory actions towards HIV would reduce harm for PLWHA. Following this line of reasoning, much of the early HIV stigma research [36, 37] focused on measuring the attitudes and behaviors of HIV uninfected healthcare workers who provided medical, dental, and other care services to HIV infected individuals [2]. It was assumed that reducing prejudice and discrimination among these healthcare workers would result in improved outcomes for their HIV infected

patients. However, these efforts have met mixed success [24]. Prejudice and discrimination directed at HIV infected people has lessened since the 1980s [43]; in spite of this, the ultimate goal of ameliorating HIV stigma has not been met.

Importantly, a growing body of research has begun to focus on the experience of stigma by HIV infected people. The results of this work have underscored the capacity of HIV stigma to undermine the physical and mental health of PLWHA [40, 58] as well as inhibit important HIV related behaviors such as safer sex practices and antiretroviral medication adherence [59]. These outcomes can both threaten the quality of life of PLWHA and fuel the spread of HIV.

Despite the trend toward greater inclusion of HIV infected people in HIV stigma research, limitations persist in our understandings of how and in what ways HIV stigma impacts individuals. We presented the HIV Stigma Framework in hopes of bringing greater clarity to this issue and then examined HIV stigma measures in comparison to the Framework. Our review suggests that many of these measures have been subjected to tests of reliability and validity, and appear to be psychometrically sound. Furthermore, individual items and/or subscales measuring stigma mechanisms have been included in HIV stigma measures, suggesting that HIV stigma researchers recognize the importance of the stigma mechanisms included in the Framework.

Despite this recognition, it seems that HIV researchers do not always differentiate between these theoretically distinct stigma mechanisms and other constructs. We have argued that differentiating between stigma mechanisms is important, especially to the extent that they predict different outcomes. When stigma mechanisms are not differentiated, it becomes impossible to discern which stigma mechanism (if any) is driving outcomes of interest. Research that differentiates among stigma mechanisms will enable researchers to identify the strongest predictors of important HIV prevention and treatment-related outcomes and, in turn, identify critical points for future intervention work. Therefore, although the measures included in this review are psychometrically sound, they may be limited in their conceptual utility—their ability to measure distinct HIV stigma mechanisms. Differentiating between stigma mechanisms may provide HIV researchers with sharper tools with which to dissect and examine the ways in which HIV stigma impacts both HIV uninfected and infected people.

Recommendations for the Future of HIV Stigma Research

The HIV epidemic is evolving as we close in on its thirtieth anniversary. Infection rates are soaring throughout the

world [60], affecting new societies of people. New treatments are extending the life expectancies of PLWHA [61, 62]. Attitudes towards HIV/AIDS and PLWHA continue to shift [43]. In the U.S., the face of HIV/AIDS is morphing from that of gay men to Black women [63]. These changes both underscore the importance of HIV stigma research and represent new challenges to HIV stigma researchers. As we progress into a new stage of the HIV epidemic, it is crucial to build a stronger understanding of HIV stigma in order to ameliorate its insidious effects. We suggest that a stronger, more comprehensive understanding of HIV stigma is within our grasp if researchers adopt three guiding questions when studying HIV stigma and developing HIV stigma survey instruments.

First, we recommend that researchers ask the question: *who?* Who is being affected by HIV stigma? In this review we stress that researchers should start by answering this question in terms of serostatus. Because of the inequalities in power that accompany this divide [4, 5], serostatus is perhaps the most important factor to consider when attempting to understand people's perspective of and experiences with HIV stigma. We also suggest that it is important for researchers to study their population of interest. Therefore, if researchers are interested in the effect of HIV stigma on PLWHA, it is critical to study HIV infected people. As we noted earlier, reductions in prejudice and discrimination among HIV uninfected people will not necessarily result in improved outcomes for HIV infected people [24, 43].

Future research may also benefit by considering additional moderating factors that may impact individual experiences with HIV stigma, particularly among PLWHA. HIV's association with other devalued identities and behaviors such as homosexuality, drug use, poverty, gender, and certain racial and ethnic groups is a critical reason why the stigma of HIV is so strong (for a review, see Herek [17]). These moderating identities and behaviors likely affect PLWHA's experience of HIV stigma. For example, a white heterosexual man who is HIV positive may have a very different experience with HIV stigma than a black homosexual man. Nyblade [13] has stressed the importance of studying and measuring the effect of layering HIV stigma on top of these and other stigmatized identities and behaviors, an effect termed layered or compound stigma. Further, Reidpath and Chan [64] have suggested a strategy for quantitatively measuring layered stigma. Studying and measuring layered stigma will provide researchers with a fuller understanding of PLWHA's experiences.

Second, we recommend that researchers ask the question: *how?* How does HIV stigma impact individuals? Included in the HIV Stigma Framework are six stigma mechanisms representing distinct ways that individuals experience HIV stigma. These stigma mechanisms are

specific to the perspective of HIV uninfected and HIV infected individuals. Therefore, prejudice, stereotyping, and discrimination are applicable to HIV uninfected individuals and enacted stigma, anticipated stigma, and internalized stigma are applicable to HIV infected individuals. In building an understanding of HIV stigma, we emphasize the importance of accounting for the HIV stigma mechanisms causing stigma-related outcomes. These considerations should shape the questions posed by researchers within HIV stigma scales. Explicitly differentiating between stigma mechanisms will bring clarity to our understanding of the ways in which HIV stigma impacts individuals.

Third, we recommend that researchers ask the question: *what?* What are the outcomes of HIV stigma? Many HIV stigma survey instruments are developed for their predictive value. Researchers hypothesize that HIV stigma results in important outcomes for HIV uninfected and infected populations. Despite their hypotheses, this review demonstrates that developers of HIV stigma survey instruments do not consistently measure outcomes when developing HIV stigma measures. This represents an important step of scale validation [53]. Therefore, we recommend that developers of future HIV stigma survey instruments more explicitly examine outcomes based on theoretical rationale in relation to their scales.

HIV researchers have made huge strides in understanding HIV stigma over the past 30 years [2, 3, 5, 8]. Despite these strides, our conceptualizations of the mechanisms through which people experience HIV stigma and the important outcomes of HIV stigma remain unclear. We have introduced the HIV Stigma Framework in hopes of bringing greater clarity to this issue. This framework differs from past models of HIV stigma in its focus on individual rather than structural processes. Considerations of both individual and structural processes must be made in order to understand and eradicate HIV stigma. However, future work must clarify how these two levels of analysis interact to shape important outcomes. As we move into the next phase of the HIV epidemic, it will be crucial to understand how stigma impacts the outcomes of both HIV uninfected and infected people. A critical step toward this understanding will be to ask *who is affected by, how are they affected by, and what are the outcomes of HIV stigma?*

Acknowledgments Preparation of this manuscript was supported by a training fellowship (T32MH074387) awarded to the first author and by a Ruth L. Kirschstein National Research Service Award predoctoral fellowship (F31MH080651) awarded to the second author, both from the National Institute of Mental Health. Peter Vanable of Syracuse University served as Consulting Editor for this article. We thank Amy Huntington, Seth Kalichman, Kimberly McClure, Nicole Overstreet, Eileen Pitpitan, Diane Quinn, and two anonymous reviewers for their helpful comments on earlier versions of this manuscript.

References

1. Aggleton P, Parker R. A conceptual framework and basis for action: HIV/AIDS stigma and discrimination. Geneva, Switzerland: Joint United Nations Programme on HIV/AIDS; 2002.
2. Deacon H. Towards a sustainable theory of health-related stigma: lessons from the HIV/AIDS literature. *J Community Appl Soc Psychol.* 2006;16:418–25.
3. Mahajan AP, Sayles JN, Patel VA, et al. Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *AIDS.* 2008;22:S67–79.
4. Link BG, Phelan JC. Conceptualizing stigma. *Annu Rev Sociol.* 2001;27:363–85.
5. Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med.* 2003;57:13–24.
6. Coates TJ, Richter L, Caceres C. Behavioural strategies to reduce HIV transmission: how to make them work better. *Lancet.* 2008;372:669–84.
7. Goffman E. Stigma: notes on the management of spoiled identity. New York: Simon & Schuster Inc; 1963.
8. Fife BL, Wright ER. The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AIDS and cancer. *J Health Soc Behav.* 2000;41:50–67.
9. Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. *Res Nurs Health.* 2001;24:518–29.
10. Genberg BL, Kawichai S, Chingono A, et al. Assessing HIV/AIDS stigma and discrimination in developing countries. *AIDS Behav.* 2008;12:772–80.
11. Holzemer WL, Uys LR, Chirwa ML, et al. Validation of the HIV/AIDS stigma instrument—PLWA (HASI-P). *AIDS Care.* 2007;19:1002–12.
12. Kalichman SC, Simbayi LC, Cloete A, Mthembu PP, Mkhonta RN, Ginindza T. Measuring AIDS stigmas in people living with HIV/AIDS: the internalized AIDS-related stigma scale. *AIDS Care.* 2009;21:87–93.
13. Nyblade LC. Measuring HIV stigma: existing knowledge and gaps. *Psychol Health Med.* 2006;11:335–45.
14. Brewer MB, Brown RJ. Intergroup relations. In: Gilbert DT, Fiske ST, Lindzey G, editors. *The handbook of social psychology.* 4th ed. New York: Oxford University Press; 1998.
15. Meyer IH. Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence. *Psychol Bull.* 2003;129:674–97.
16. Phelan JC, Link BG, Dovidio JF. Stigma and prejudice: one animal or two? *Soc Sci Med.* 2008;67:358–67.
17. Herek GM. AIDS and stigma. *Am Behav Sci.* 1999;42:1106–16.
18. Allport GW. *The nature of prejudice.* Cambridge, MA: Perseus Books; 1954/1979.
19. Brewer MB. The social psychology of intergroup relations: social categorization, ingroup bias, and outgroup prejudice. In: Kruglanski AW, Higgins ET, editors. *Social psychology: handbook of basic principles.* New York, NY: The Guilford Press; 2007.
20. Kanahra S. A review of the definitions of stereotype and a proposal for a progression model. *Individ Differ Res.* 2006;4:306–21.
21. Devine PG, Plant EA, Harrison K. The problem of “us” versus “them” and AIDS stigma. *Am Behav Sci.* 1999;42:1212–28.
22. Levy-Dweck S. HIV/AIDS fifty and older: a hidden and growing population. *J Gerontol Soc Work.* 2005;46:37–50.
23. Moore S, Rosenthal D. Adolescent invulnerability and perceptions of AIDS risk. *J Adolesc Res.* 1991;6:167–80.
24. Brown L, Macintyre K, Trujillo L. Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Educ Prev.* 2003;15:49–69.
25. Scambler G, Hopkins A. Being epileptic: coming to terms with stigma. *Sociol Health Illn.* 1986;1:26–43.
26. Markowitz FE. The effects of stigma on the psychological well-being and life satisfaction of persons with mental illness. *J Health Soc Behav.* 1998;39:335–47.
27. Link BG. Understanding labeling effects in the area of mental disorders: an assessment of the effects of expectations of rejection. *Am Sociol Rev.* 1987;52:96–112.
28. Meyer IH. Minority stress and mental health in gay men. *J Health Soc Behav.* 1995;36:38–56.
29. Derlega VJ, Winstead BA, Geene K, Serovich J, Elwood WN. Reasons for HIV disclosure/nondisclosure in close relationships: testing a model of HIV-disclosure decision making. *J Soc Clin Psychol.* 2004;23:747–67.
30. Mak WW, Poon CY, Pun LY, Cheung SF. Meta-analysis of stigma and mental health. *Soc Sci Med.* 2007;65:245–61.
31. Hatzenbuehler ML, Nolen-Hoeksema S, Erickson SJ. Minority stress predictors of HIV risk behavior, substance use, and depressive symptoms: results from a prospective study of bereaved gay men. *Health Psychol.* 2008;27:455–62.
32. Moriya TM, Gir E, Hayashida M. A scale of attitudes towards AIDS: a psychometric analysis. *Rev Lat Am Enfermagem.* 1994;2:37–53.
33. Siyam’kela. HIV/AIDS stigma indicators. A tool for measuring the progress of HIV/AIDS stigma mitigation. Cape Town: Policy Project, South Africa; 2003.
34. Pleck JH, O’Donnell L, O’Donnell C, Snarey J. AIDS-phobia, contact with AIDS, and AIDS-related job stress in hospital workers. *J Homosex.* 1988;15:41–54.
35. Shrum JC, Turner NH, Bruce KE. Development of an instrument to measure attitudes toward Acquired Immune Deficiency Syndrome. *AIDS Educ Prev.* 1989;1:222–30.
36. Froman RD, Owen SV, Daisy C. Development of a measure of attitudes toward persons with AIDS. *Image J Nurs Sch.* 1992;24:149–52.
37. Harrison M, Fusilier MR, Worley JK. Development of a measure of nurses’ AIDS attitudes and conservative views. *Psychol Rep.* 1994;74:1043–8.
38. Preston DB, Young EW, Koch PB, Forti EM. The nurses’ attitudes about AIDS scale (NAAS): development and psychometric analysis. *AIDS Educ Prev.* 1995;7:443–54.
39. Mulford CL, Lee MY. Reliability and validity of AIDS victim blaming scale. *Psychol Rep.* 1996;79:191–201.
40. Sowell RL, Lowenstein A, Moneyham L, Demi A, Mizuno Y, Seals BF. Resources, stigma, and patterns of disclosure in rural women with HIV infection. *Public Health Nurs.* 1997;4:302–12.
41. Davis C, Sloan M, MacMaster S, Hughes L. The international AIDS questionnaire—English version (IAQ-E): assessing the validity and reliability. *J HIV AIDS Prev Child Youth.* 2007;7:29–42.
42. O’Hea EL, Sytsma SE, Copeland A, Brantley PJ. The attitudes toward women with HIV/AIDS scale (ATWAS): development and validation. *AIDS Educ Prev.* 2001;12:120–30.
43. Herek GM, Capitanio JP, Widaman KF. HIV related stigma and knowledge in the United States: prevalence and trends, 1991–1999. *Am J Public Health.* 2002;92:371–7.
44. Herek GM, Capitanio JP, Widaman KF. Stigma, social risk, and health policy: public attitudes toward HIV surveillance policies and the social construction of illness. *Health Psychol.* 2003;22:533–40.
45. Kalichman SC, Simbayi LC, Jooste S, et al. Development of a brief scale to measure AIDS-related stigma in South Africa. *AIDS Behav.* 2005;9:135–43.
46. Hamra M, Ross MW, Orrs M, D’Agostino A. Relationship between expressed HIV/AIDS-related stigma and HIV beliefs/

- knowledge and behaviour in families of HIV infected children in Kenya. *Trop Med Int Health*. 2006;11:513–27.
47. Sayles JN, Hays RD, Sarkisian CA, Mahajan AP, Spritzer KL, Cunningham WE. Development and psychometric assessment of a multidimensional measure of internalized HIV stigma in a sample of HIV positive adults. *AIDS Behav*. 2008;12:748–58.
 48. Stein JA, Li L. Measuring HIV related stigma among Chinese service providers: confirmatory factor analysis of a multidimensional scale. *AIDS Behav*. 2008;12:789–95.
 49. Van Rie A, Sengupta S, Pungrassami P, et al. Measuring stigma associated with tuberculosis and HIV/AIDS in southern Thailand: exploratory and confirmatory factor analyses of two new scales. *Trop Med Int Health*. 2008;13:21–30.
 50. Visser MJ, Kershaw T, Maskin JD, Forsyth BW. Development of parallel scales to measure HIV related stigma. *AIDS Behav*. 2008;12:759–71.
 51. Zelaya CE, Sivaram S, Johnson SC, Srikrishnan AK, Solomon S, Celentano DD. HIV/AIDS stigma: reliability and validity of a new measurement instrument in Chennai, India. *AIDS Behav*. 2008;12:781–8.
 52. Messick S. Validity of psychological assessment: validation of inferences from persons' responses and performances as scientific inquiry into score meaning. *Am Psychol*. 1995;50:741–9.
 53. John OP, Benet-Martínez V. Measurement: reliability, construct validity, and scale construction. In: Reis HT, Judd CM, editors. *Handbook of research methods in social and personality psychology*. Cambridge, UK: Cambridge University Press; 2000.
 54. Kamb ML, Fishbein M, Douglas JM, et al for the Project RESPECT Study Group. Efficacy of risk-reduction counseling to prevent human immunodeficiency virus and sexually transmitted diseases: a randomized, controlled trial. *J Am Med Assoc*. 1998; 280:1161–7.
 55. Kelly JA, St. Lawrence JS, Hood HV, Brasfield TL. Behavioral intervention to reduce AIDS risk activities. *J Consult Clin Psychol*. 1989;57:60–7.
 56. Kalichman S, Rompa D, Cage M, et al. Effectiveness of an intervention to reduce HIV transmission risks in HIV-positive people. *Am J Prev Med*. 2001;21:84–92.
 57. Wyatt GE, Longshore D, Chin D, et al. The efficacy of an integrated risk reduction intervention for HIV-positive women with child sexual abuse histories. *AIDS Behav*. 2004;8:453–62.
 58. Vanable PA, Carey MP, Blair DC, Littlewood RA. Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS Behav*. 2006;10:473–82.
 59. Peretti-Watel P, Spire B, Pierret J, Lert F, Obadia Y. The VES-PAGroup. Management of HIV-related stigma and adherence to HAART: evidence from a large representative sample of outpatients attending French hospitals (ANRS-EN12-VESPA 2003). *AIDS Care*. 2006;18:254–61.
 60. Joint United Nations Programme on HIV/AIDS and World Health Organization. *AIDS Epidemic Update: December 2007*. Geneva, Switzerland: UNAIDS; 2007.
 61. Biswas UN. Promoting health and well-being in lives of people living with HIV and AIDS. *Psychol Dev Soc J*. 2007;19:215–47.
 62. Vetter CJ, Donnelly JP. Living long-term with HIV/AIDS: exploring impact in psychosocial and vocational domains. *Work*. 2006;27:277–86.
 63. Dray-Spira R, Lert F. Social health inequalities during the course of chronic HIV disease in the era of highly active antiretroviral therapy. *AIDS*. 2003;17:283–90.
 64. Reidpath DD, Chan KY. A method for the quantitative analysis of the layering of HIV-related stigma. *AIDS Care*. 2005;17:425–32.