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## Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward

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### Abstract

Although stigma is considered a major barrier to effective responses to the HIV/AIDS epidemic, stigma reduction efforts are relegated to the bottom of AIDS program priorities. The complexity of HIV/AIDS related stigma is often cited as a primary reason for the limited response to this pervasive phenomenon. In this paper, we systematically review the scientific literature on HIV/AIDS related stigma to document the current state of research, identify gaps in the available evidence, and highlight promising strategies to address stigma. We focus on the following key challenges: defining, measuring, and reducing HIV/AIDS related stigma as well as assessing the impact of stigma on the effectiveness of HIV prevention and treatment programs. Based on the literature, we conclude by offering a set of recommendations that may represent important next steps in a multifaceted response to stigma in the HIV/AIDS epidemic.

### Keywords

HIV; AIDS; stigma; discrimination; systematic review

### Introduction

HIV/AIDS related stigma (H/A stigma) is invoked as a persistent and pernicious problem in any discussion about effective responses to the epidemic. In addition to devastating the familial, social, and economic lives of individuals, H/A stigma is cited as a major barrier to accessing prevention, care, and treatment services [1–3]. Despite widespread recognition of the differential treatment of persons living with HIV/AIDS (PLHA) by society and its institutions, over the first 25 years of the epidemic, community, national, and global actors have only had limited success in alleviating the deleterious effects of H/A stigma. In describing a sustained response to the HIV/AIDS epidemic, Peter Piot, Executive Director of UNAIDS, identifies tackling stigma and discrimination as one of five key imperatives for success [4]. At the same

time, Piot notes that stigma reduction efforts are relegated to the bottom of AIDS program priorities, often without funding to support such activities [4].

Much of the rhetoric and literature has cited the complexity of H/A stigma and its diversity in different cultural settings as the primary reasons for the limited response to this pervasive phenomenon [5,6]. The complexity of the phenomenon has led to difficulties and disagreement about how to define H/A stigma and sometimes, to an erroneous conflation of stigma with its related concept of discrimination. The manifestation of H/A stigma not only varies by cultural/national setting, but also by whether one is considering intrapersonal versus societal levels of stigma. The variability in manifestations of stigma by setting and level has led to difficulty in measuring the extent of stigma, assessing the impact of stigma on the effectiveness of HIV prevention/treatment programs, and devising interventions to reduce stigma. These four challenges – defining, measuring, assessing impact of, and reducing stigma – among others have hampered local and global efforts to address H/A stigma.

In this paper, we systematically review the scientific literature on H/A stigma to document the current state of research, with an emphasis on identifying gaps in as well as summarizing existing knowledge on the four aforementioned challenges to effective intervention—defining, measuring, assessing impact of, and reducing stigma. In assessing impact, we critically examine the literature to elucidate the relationship of H/A stigma to the effectiveness of HIV prevention and treatment programs. Finally, based on the available literature, we offer recommendations for each of the four challenges that we believe represent critical next steps in ameliorating the devastating effects of H/A stigma.

## Methods

### Search Strategy & Article Selection

In April 2007, we searched PubMed for all published articles pertaining to HIV/AIDS related stigma. To perform as broad a search as possible, we utilized the search term “HIV AND stigma.” One member of our study team (VAP) reviewed each of the abstracts identified. Data extracted from each abstract included the study’s objective, methodology, and key findings. The geographic region of the study was also recorded. The study team then developed a set of mutually exclusive categories in which to place each of the articles. Categories were created to facilitate summarizing the state of the literature on defining, measuring, assessing impact of, and reducing H/A stigma. To systematically categorize articles, specific criteria were devised for each category. Each article was then placed into one of the categories. In the few instances that an article met criteria for more than one category, the article was placed in the category that more closely resembled the overall objective of the article. Categories and the criteria are as follows:

**Theory Based Analyses**—Articles mainly explore the theoretical causes and effects of H/A stigma or conceptualize and define H/A stigma.

**Psychometric Measurement**—Articles mainly focus on the methodology of measuring H/A stigma. The objective of these studies is to create and/or validate a set of items to measure H/A stigma or determine the reliability of such items in various contexts.

**Stigma Assessment**—Articles assess the various manifestations of H/A stigma among persons living with HIV/AIDS (PLHAs), specific groups such as healthcare workers, or the general population. Articles assessing the consequences of stigma on uptake and effectiveness of HIV prevention and treatment interventions were also included in this category.

**Stigma Reduction Interventions**—Articles utilize a model to measure H/A stigma, apply a stigma reduction intervention to a specific population, and evaluate the post-intervention burden of H/A stigma.

**Legal or Policy Analyses**—Articles explore the legal consequences or explore the policy implications of H/A stigma.

**Excluded Articles**—Articles that did not qualify for any of the above criteria were excluded from the review.

Following the PubMed search, we reviewed bibliographies of major articles for further references not indexed in the search engine. We also reviewed relevant documents from international organizations such as UNAIDS and the World Health Organization. Based on expert suggestions, we also reviewed a subset of relevant articles published after April 2007. Due to the very large number of conference abstracts and the absence of a uniform search engine to identify abstracts related to H/A stigma, we excluded conference abstracts from this review.

### Development of Recommendations

After summarizing the state of the literature, we next identified gaps in the available evidence, critical unanswered questions, and promising strategies to address H/A stigma. Based on this, we developed a list of recommendations for responding to the challenges of defining, measuring, assessing impact of, and reducing H/A stigma. We discussed this list of recommendations with a multidisciplinary group of HIV/AIDS professionals including social scientists, clinical researchers, international agency officials, and others at the UCLA Social Justice, Human Rights, and HIV Prevention Think Tank meeting in Sydney, Australia in July 2007. Based in part on our discussion, we further developed and designated 7 of those recommendations as priority next steps to addressing the problem of H/A stigma.

### Results

Figure 1 depicts the articles identified in the PubMed search, stratified by category and geographic region. Articles and documents that were not indexed in PubMed, but were identified by other means, are not included in Figure 1. The literature on H/A stigma is dominated by ‘Stigma Assessment’ studies. Studies in this category generally utilize interview or survey methodology to explore the perceived or enacted stigma experienced by PLHAs, stigmatizing beliefs held by specific groups or the general population, or the effects of stigma on access to and utilization of care, prevention, or treatment services. Fewer articles were found in each of the remaining 4 categories, with surprisingly small numbers of articles focused on developing valid and reliable measures of stigma or on assessing stigma reduction interventions. The dearth of psychometric measurement studies is noteworthy given that a major critique of the available stigma assessment studies is their use of stigma measures that have not been validated. Finally, the majority of articles in each category relate to the North American/European context, revealing a relative paucity of peer-reviewed work on H/A stigma pertaining to generalized HIV epidemics and resource-limited countries.

### Defining Stigma: Conceptual Considerations

The conceptualization of H/A stigma that underlies most of the literature today mirrors the stigma concept utilized for a broader set of health and social issues, such as mental illness or unemployment [7,8]. In the H/A stigma literature, the concept of stigma is often not explicitly defined, but rather, is referred to cursorily as “a mark of disgrace” [8]. The absence of an explicit

conceptualization of stigma precludes meaningful appraisal and comparisons of study findings and limits the ability to design effective programs and interventions [5].

**Early Work**—Based on his work in psychiatric hospitals and among criminals and homosexuals, Erving Goffman provided a seminal theorization of health-related stigma in the 1960s [9,10]. Goffman defined stigma as “an attribute that is deeply discrediting,” and that reduces the bearer “from a whole and usual person to a tainted, discounted one” [10]. He established that society stigmatizes on the basis of what is constitutes as “difference” or “deviance,” and results in a “spoiled identity” [5,10]. The social label of deviance compels stigmatized individuals to view themselves and others to view the stigmatized as discredited or undesirable [10,11].

**Socio-cognitive Approach**—Goffman’s theorization of stigma was fruitfully adapted and extended by social psychologists interested in how individuals construct categories and link these categories to stereotyped beliefs [5,8,12]. This body of work emphasized perceptions of individuals, the origins of stigma in human cognition, and the consequences these individual perceptions have for social interactions [5,8]. When applied to HIV/AIDS, this socio-cognitive framework constrained the concept of H/A stigma to an examination of how PLHAs are labeled and stereotyped by the public, based on their incorrect beliefs and attitudes [8,15], and/or a focus on the specific emotions and cognition of PLHAs. This, in turn, limited the scope of stigma reduction interventions to strategies that might increase the empathy and altruism towards as well as reduce the anxiety and fear of PLHAs among the general population or individual based interventions to assist PLHAs to cope with perceived or experienced stigma. The great majority of articles on H/A stigma measurement and reduction interventions identified in this review either implicitly or explicitly utilizes a socio-cognitive conception of stigma. While important, these approaches exclude a detailed consideration of structural aspects of stigma – the dynamic social/economic/political processes that simultaneously produce and intensify stigma and discrimination [8,13,14].

**Structural Understanding of Stigma**—Recent work in the sociologic and anthropologic disciplines has broadened earlier conceptions of stigma to encompass the structural conditions that contribute to stereotyping [5,8]. One of the key insights is that the process of stereotyping based on an attribute is not only a cognitive phenomenon at the level of the individual but also is determined by a constantly changing social process [5,8]. Parker and Aggelton argue that “it is especially important to think of stigma as a social and cultural phenomenon linked to actions of whole groups of people in the developing world, where bonds and allegiances to families, village, and neighborhood, and community abound” [5]. Theorizing stigma in this way also highlights the necessity of power – social, economic, or political power – to enable a community to move from individual level perceptions to collectively identify an undesirable difference/attribute, construct stereotypes, and ultimately, to act on the negative stereotype by discriminating against the stigmatized [5,8]. Parker and Aggleton further argue that structural (or social) power is not only needed to enable stigmatization, but also that stigmatization plays key role in producing and reproducing relations of power and control [5,16]. Stigmatization, they argue, is intricately linked with the workings of social inequality by its capacity to cause some groups to be devalued and other groups to feel that they are superior [5]. In acknowledging that stigma functions at the intersection of culture, power, and difference, Parker and Aggleton argue that stigmatization is central to the constitution of the prevailing social order. Most of the existing research examined in this review does not study H/A stigma within a structural framework that accounts for social processes and social inequality.

**Discrimination**—By acknowledging the role of social processes and power in the promulgation of stigma, a more precise understanding and definition of discrimination

emerges. Discrimination focuses attention on the individual and social producers of stigmatization rather than the recipients of stigma [8]. Discrimination is a consequence of stigma and defined as “when, in the absence of objective justification, a distinction is made against a person that results in that person being treated unfairly and unjustly on the basis of belonging or being perceived to belong, to a particular group” [16,17]. Stigmatized groups, including PLHAs, are in this way systematically disadvantaged in a variety of ways including in income, education, housing status, medical treatment and health [8]. Conceptualizing stigma as a combination of individual and social phenomenon underscores the importance of addressing self-imposed, individual, as well as structural (or institutional) discrimination [8]. Self-imposed discrimination occurs when an individual comes to expect the application of a stereotype to him/herself and out of fear of the expectant rejection and resignation, a priori acts as if discrimination has already been imposed [8,18,19]. Individual discrimination refers to more obvious and overt discrimination taking place between two people [8]. Structural discrimination refers to accumulated institutional practices that work to disadvantage stigmatized groups, and can work in the absence of individual prejudice and discrimination [8]. Like in other stigmatized medical conditions, most research and intervention for H/A stigma has targeted self-imposed and some aspects of individual discrimination, largely excluding the structural dimensions of discrimination.

**Towards a Comprehensive Framework for H/A Stigma**—Bruce Link and Jo Phelan offer a broader conceptualization that elucidates both the socio-cognitive and the structural aspects of stigma and the relationship between them [8]. In their conception, stigma exists when the following four interrelated components converge: 1) individuals distinguish and label human differences, 2) dominant cultural beliefs link labeled persons to undesirable characteristics (or negative stereotypes), 3) labeled persons are placed in distinct categories to accomplish some degree of separation of “us” from “them,” and 4) labeled persons experience status loss and discrimination that lead to unequal outcomes [8]. Stigmatization is entirely contingent on inequalities in social, economic, and political power that enable the four aforementioned components of stigma to unfold [8]. Link and Phelan’s conceptualization of stigma may serve as a good starting point for developing a comprehensive framework for H/A stigma, since no such framework was identified in this literature review.

To optimally explain H/A stigma and potential intervention strategies, Link and Phelan’s model may be adapted to reflect the biophysical trajectory of HIV disease [11] as well as the concept of structural violence [16,20]. Given the several stages of HIV disease from the period of infection onwards – first, a transient flu-like syndrome associated with seroconversion that can last a few weeks, followed by an asymptomatic period of at least a few years, followed by a symptomatic period involving opportunistic infections of varying severity – vulnerability to being stigmatized along the Link and Phelan’s continuum of components varies. For example, a PLHA in the asymptomatic period does not exhibit physical manifestations of HIV disease and is thus more difficult to identify as different by society. Even if he is known to be positive, he may still be less vulnerable to stigmatization since he is stable capable of working and providing for his family, thereby limiting potential separation and status loss despite being labeled. On the other hand, a PLHA who is late in the course of infection and suffering from wasting syndrome is easily identifiable and increasingly vulnerable to discrimination along Link and Phelan’s continuum. In addition to considering the effect of HIV disease stage on H/A stigma, the individual and social context preceding infection should also be understood. Social forces such as poverty, sexism, racism and others create overlapping and reinforcing stigmatized conditions that predispose individuals to HIV infection and limits their ability to access diagnostic and treatment services [16]. Such forces constitute structural violence and victims of such violence are at increased risk of H/A stigma [16].

In Figure 2, we offer a schematic that illustrates a starting point for a conceptual framework for H/A stigma, derived from this review of the literature.

## Measuring Stigma

Valid and reliable measures of H/A stigma are integral to ensuring the rights of PLHA as well as the effectiveness of HIV prevention and treatment programs. Standardized sets of stigma measures, or indicators, can also be developed into scales, which are quantitative instruments that give a numerical result that indicates the severity or extent of H/A stigma measured [21]. Indicators or scales would enable the tracking of stigma burden over time as well as a comparison of stigma across different regions [7,22,23]. Such indicators could determine how stigma is affected by implementation of routine HIV testing and scale up of anti-retroviral therapy. Indicators are needed to evaluate stigma-reduction interventions and assist program managers and donors to identify which anti-stigma approaches are most likely to be successful and how they should be applied in different contexts and among different populations [22]. Indicators may also be useful to detect if programs or policies are inadvertently exacerbating HIV stigma in the community [22].

The scope of the indicators needed for fully assessing stigma depends on the overall conceptualization of H/A stigma being utilized. A comprehensive framework requires measurement of stigma across a number of domains and at the individual and structural levels (Figure 2). Indicators are operationalized in the form of questionnaires or derived from thematic analysis of qualitative data such as interviews or focus group discussions [21]. Questionnaire based indicators are often preferred since they are easier to implement and enable quantification and the development of scales.

**Currently Available Indicators**—H/A stigma indicators available in the literature to date were generally constructed for research purposes and few have been tested and utilized for surveillance purposes at programmatic or regional levels. These indicators mainly attempt to measure the socio-cognitive aspects of H/A stigma, and most were developed in the U.S. context [15,24]. They are designed to assess stigma from one of two perspectives: the ‘stigmatizers,’ who include the general public or specific groups like healthcare workers, and the ‘stigmatized,’ who include PLHA or high risk groups like commercial sex workers [23]. For assessing attitudes of stigmatizers, indicators that measure social distancing and support for coercive measures are available. These indicators assess the respondent’s willingness to interact with PLHA in a range of situations, through a set of hypothetical questions about interaction in homes, neighborhoods, and workplaces [23]. Indicators also query respondents about their support for quarantining PLHA or denying entry of PLHA into the country [25]. Another set of indicators elicits data on emotional reactions toward PLHA. These indicators are designed to measure the extent to which respondents blame PLHA for their illnesses, consider HIV a retribution from God, and harbor anger, fear, or disgust for PLHA [23,25,26]. For assessing perceived or experienced stigma among PLHA, indicators that query how PLHA perceive that their partners, friends, family and community treat PLHA in general and how they would expect them to react if they knew of their HIV status are available [23,27–31].

Recent work in Tanzania [6,22] and South Africa [32] has tested the validity of HIV stigma measures of general population and healthcare provider attitudes toward PLHA. In Tanzania, indicators that captured social distancing consisted of questions about fear of casual contact with PLHA were tested. Utilizing 9 items measuring attitudes toward PLHA, support for coercive measures, and social distancing, Kalichman and colleagues validated an AIDS related stigma scale and demonstrated its reliability among over 2000 respondents in five South African communities [32].

**Gaps In Stigma Measurement**—While the aforementioned studies represent important initial steps in developing measures for some aspects H/A stigma, further work is needed to enable accurate and comprehensive assessments. For the categories of existing indicators discussed above, further psychometric refinement of the wording, validation in a diverse range of populations, and standardization of items is needed. As important, however, is developing new sets of indicators to capture the multiple domains of H/A stigma. Indicators measuring social distancing and support for coercive measures do not capture the underlying cause of stigma or the full breadth of experienced discrimination [22,23]. There are few, if any, H/A stigma measures capable of capturing pre-existing and overlapping stigmas of commercial sex work, IV drug use, or homosexuality [23]. Perhaps most problematic, little research has systematically measured H/A stigma at the structural or institutional levels [31]. Structural and institutional aspects of stigma are critical drivers of H/A stigmatization and discrimination at all levels, from the individual, household, and social levels to employment and health services access [6,8,16]. Taking the institution of healthcare as an example, research on H/A stigma has provided descriptive information about how individual providers think about and serve PLHA but has not revealed how the prevalence and determinants of stigma and discrimination vary by institutional or social context [31]. Without robust measures of such institutional stigma and the identification of potential levers to affect change, effective stigma reduction interventions cannot be designed.

In the past few years, UNAIDS has been coordinating a concerted effort of international organizations and networks of PLHA to develop a more structurally informed tool to measure stigma experienced by PLHA [33,34]. In addition to creating robust measures of stigma that would enable monitoring programmatic progress over time, ensuring that initiatives are not actually making stigma worse, and comparing regional burdens of stigma, the explicit objectives of the stigma index tool include increasing the understanding of the causes and effects of stigma and increasing the empowerment, involvement, and capacities of PLHA in responding to stigma [35]. An assessment of stigma reduction activities are now also included among the core indicators of country-level responses to AIDS for the United Nations General Assembly Special Session on HIV/AIDS monitoring program [36].

### **Relationship of HIV/AIDS related Stigma to Prevention & Treatment Programs**

H/A stigma is considered a barrier to effective HIV prevention and treatment programs. H/A stigma is blamed for low uptake of and poor adherence to prevention and treatment services. Drawing largely on articles from the ‘Stigma Assessment’ category of the review, this section aims to evaluate the evidence for these widely prevalent assertions. We chose to focus our attention on fundamental prevention and treatment challenges, such as reducing HIV risk behavior and maintaining adherence to antiretroviral therapy, respectively, as this approach enabled us to assess the effects of H/A stigma on both general population and PLHA behavior. Additionally, in reference to HIV testing, we looked for evidence that supports the argument that routine provider-initiated HIV testing reduces the deterrent effect of H/A stigma on uptake of testing. Of note, the majority of the literature on H/A stigma and programs identified here utilizes a socio-cognitive conception of H/A stigma.

**Stigma & HIV risk behavior**—While H/A stigma is widely invoked as a major facilitator of the epidemic, only a few studies have demonstrated an association between stigma and increased risk behavior. Presumed HIV-negative or unknown status individuals in China holding greater stigmatizing attitudes were more likely to be engaged in high risk behavior [37,38]. Among PLHA in South Africa, those who experienced stigma or discrimination were less likely to disclose their HIV status to their sexual partner, and non-disclosure was associated with transmission risk behavior [39]. Similarly, in a sample of over 2000 sexually active PLHA in France, experiences of H/A discrimination was associated with increased unsafe sex [40].

To develop prevention programs that effectively reduce risk behavior, more rigorous investigation that better delineates the relationship between stigmatizing attitudes and HIV risk behavior is needed. In particular, the role of social inequalities as well as overlapping stigmas (such as those related to homosexuality or migrancy) in mediating the relationship between H/A stigma and risk behavior must be examined.

**Stigma & Biomedical Prevention**—Novel biomedical interventions to prevent HIV infection, such as adult male circumcision, pre-exposure prophylaxis, microbicides, and vaccines, represent immense potential to limit the spread of the epidemic. As many of these technologies are still being tested or are in development, little is known about how they will effect and be affected by H/A stigma. HIV vaccine acceptability studies have revealed fear of vaccine induced HIV infection and concerns about being stigmatized based on receiving the vaccine [41–43]. Study participants have also reported that vaccines may be misunderstood by the community as treatment for HIV infection, resulting in being labeled a PLHA and experiencing the attendant stigma [42–45]. Though no empiric data is yet available, the theoretical interplay between H/A stigma and the religious and cultural meaning of circumcision may be a major determinant of the acceptability of adult male circumcision as a prevention intervention. Sawires and colleagues argue that male circumcision offers a new opportunity to engage religious leaders in occupying a central role in advocating for HIV prevention [46], thereby addressing H/A stigma. Others are more circumspect about the potential benefits of promoting circumcision on H/A stigma, citing the possible contamination of male circumcision by the stigma of female genital mutilation as well as the long history of social power imbalance in the promulgation of circumcision among populations [47]. As biomedical prevention interventions are rolled out in the future, a detailed understanding of how H/A stigma will affect uptake and use of the interventions is critical to ensure population level effectiveness. Along with this, an over-reliance on biomedical solutions for HIV prevention at the expense of equity, social justice, and human rights mission must be avoided [46].

**Stigma and Prevention of Mother to Child Transmission (PMTCT)**—Pregnant women may avoid participating in PMTCT programs due to fear of stigma, discrimination, and violence, particularly from partners when disclosing their HIV status [48,49]. Numerous studies have demonstrated that going against community norms of feeding leads to questions about mother's HIV status, unwanted disclosure, and fear of stigma from partner, family, and the community [50–53]. Interventions aimed at engaging male partners in PMTCT services, such as sending an invitation home with the partner with a direct request that the man attend the clinic with his partner, have been tried with varying success [54]. Community level education about specific PMTCT services, targeting pregnant women, community leaders, and people of childbearing age, is critical to improving acceptability of services and diminishing the effects of stigma [54,55].

**Stigma, Testing, & Treatment**—H/A stigma is documented as a barrier to uptake of HIV testing and treatment services in numerous settings, particularly in resource limited countries [1–3,24,56–59]. In a study of HIV testing and stigma in South Africa, individuals who were not tested for HIV exhibited significantly greater stigmatizing attitudes towards PLHA [3]. In a study of 112 patients receiving antiretroviral therapy in Botswana two years before the implementation of universal access to treatment, 69% of patients did not disclose their HIV status to their family and a majority of those who reported delaying testing for HIV did so due to fear of H/A stigma [60].

Without questioning that H/A stigma exists and needs redress, some argue that the profound lack of access to antiretroviral therapy in resource limited countries, rather than stigma, is the real driver of poor uptake of testing and treatment services [16]. Individuals with advanced



HIV/AIDS who exhibit visible signs of disease and are no longer able to work experience severe H/A stigma. Access to therapy triggers a ‘virtuous social cycle’ by treating these individuals and alleviating their visible signs of disease, enabling them to return to a socially and financially productive lives, and sparking interest in testing and treatment among others in the community [16]. In theory, widespread scale-up of treatment access may turn HIV into a treatable and chronic (rather than deadly) disease, increase uptake of testing, and thereby, ultimately reduce H/A stigma.

The institution of universal access to antiretroviral therapy in Botswana in 2002 provides an opportunity to investigate the effect of scale-up of treatment on testing behavior and stigma. Two years after universal access was in place, enrollment in the treatment program remained far below the targeted projection of eligible patients [61]. Since low uptake of HIV testing was considered a primary reason for poor enrollment, a routine opt-out HIV testing program was implemented in Botswana in 2004. In opt-out testing, all patients are to be tested as a routine part of medical visits unless they explicitly refused. By increasing the proportion of individuals aware of their status, one of the expected effects of routine opt-out testing is the reduction of H/A stigma [61], though some have pointed out the potential for increased stigma among women due to problems around disclosure, partner violence, and other gender based stigma [62]. Eleven months after the introduction of opt-out testing, a cross-sectional study of a probability sample of adults in Botswana was performed to assess attitudes towards routine HIV testing [61]. Although this study found that 81% of respondents were extremely or very much in favor of routine testing and 60% felt that the policy would reduce stigma, 43% of respondents also believed that routine testing would lead people to avoid going to the doctor for fear of testing and 14% thought that the policy could increase gender based violence [61]. Individuals with stigmatizing attitudes towards PLHA were significantly less likely to have been tested for HIV/AIDS or have heard of routine testing. These data from Botswana underscore the need for further research on the relationship between stigma and routine HIV testing/universal treatment access programs, especially with the 2007 release of the WHO/UNAIDS Guidance for Provider-Initiated Testing and Counseling in Health Facilities [63].

Even as improving access to antiretroviral treatment in resource limited settings is critical to stemming the HIV epidemic and reducing the underlying social inequities that perpetuate stigma, stigma persists in developed countries which have had near universal access to therapy over the last decade. H/A stigma impedes access to and retention in HIV care [64–66] and adherence to antiretroviral medications [67–70]. Non-disclosure of HIV status for fear of stigma may result in missing doses of medications in order to maintain secrecy about one’s illness [70]. Studies demonstrating the adverse effects of stigma on retention in care and adherence are emerging in Africa [71,72] and Asia [73] as well.

### **Interventions & Social Programs to Reduce HIV/AIDS related Stigma**

There are only a small number of published studies on interventions and programs designed to reduce H/A stigma. Given the difficulties in defining and measuring stigma, few such interventions and programs described in the literature have been rigorously evaluated. An overview of stigma reduction strategies for a variety of health conditions summarized the types of approaches that may be employed to address stigma in HIV/AIDS (Table 1) [74].

The majority of HIV/AIDS specific interventions are designed to reduce stigma at the community level by increasing the tolerance of PLHA among the general population [75]. The predominant strategy underlying these interventions was education through provision of factual information about HIV/AIDS [76,77]. Most of these were studies of interventions implemented among a small convenience samples of university students in the U.S. without the use of specific stigma measures [75]. A few studies about interventions aimed at increasing the willingness of healthcare providers to treat PLHAs and at developing coping skills among

PLHA were also identified in the literature. These studies were also limited by small sample sizes and the use of ambiguous and untested measures of stigma.

Mass-media campaigns relating to HIV/AIDS knowledge, attitudes and behaviors represent a relatively understudied but widely implemented intervention in resource-limited countries. Such campaigns are broadcast (radio, television, etc) interventions targeting national audiences or small media (posters, pamphlets, dramas, etc) interventions aimed at localities that disseminate messages about HIV/AIDS and could potentially reduce H/A stigma. A systematic review of the effectiveness of H/A mass communication programs revealed only a small positive impact on knowledge of HIV transmission and reduction in risk behavior [78]. The review, however, was limited by the fact that many of the included studies had weak designs, precluding a definitive conclusion about the impact of the intervention [78]. Also of note, none of the 24 studies included in the review explicitly evaluated H/A stigma as an outcome. A more recent broadcast intervention specifically designed to address H/A stigma demonstrates that mass media interventions can be effective in reducing stigma. In Botswana, viewers exposed to a 2-year HIV story line in the soap opera, *The Bold and the Beautiful*, exhibited significantly lower levels of HIV stigma, measured by a validated 5-item stigma scale, compared to non-viewers [79].

**Structural Targets for Social Programs**—The majority of existing stigma reduction interventions are based on cognitive-behavioral and social-cognitive models, employing such activities as information dissemination, empathy induction, counseling, and cognitive behavioral therapy [5]. The focus of these interventions is the individual level. A more comprehensive conceptualization of H/A stigma and discrimination indicates the need to develop stigma reduction programs at the institutional/structural levels. Further, the design of these programs must be informed by the prevailing social and cultural forces that provide dominant groups the power to create stigmatizing and discriminatory conditions [5]. Parker and Aggelton suggest the need for community level mobilization, with the goal of unleashing the power of resistance on the part of PLHA, in tandem with intervention at the structural level to effectively respond to stigma [5]. Important structural targets include religious leaders, the judiciary, and the legislative arenas [5,76]. Appropriate reporting and enforcement mechanisms, such as legal aid services and hotlines to report discrimination, are needed along with a socially endorse rights based approach [5].

Based on principles of community organizing and community building, new models for advocacy and social change in response to HIV/AIDS related stigma should be encouraged [5,80]. The principle of GIPA (Greater Involvement of People Living with HIV/AIDS) is central to effective social program responses to H/A stigma. GIPA aims to realize the rights and responsibilities of PLHA, including the right to self-determination and participation in decision-making processes that affect their lives [81]. The GIPA Principle, adopted unanimously as part of the Declaration of Commitment on HIV/AIDS, calls for a greater involvement of PLHA at all levels and the creation of supportive political, legal, and social environments [81]. Public participation of PLHA at community and social levels would not only promote individual level responses to internalized stigma on the part of PLHA, but could also prove a powerful deterrent to stigmatizing impulses of the general population.

## Discussion

H/A stigma is considered a major barrier to effective responses to the HIV epidemic. Yet, there is little consensus among policy-makers and program implementers about how best to define, measure, and diminish the phenomenon. In this systematic review of stigma and the HIV/AIDS epidemic, we examined the existing literature on how H/A stigma is conceptualized, the methodologies for measuring stigma, the available data on the relationship of stigma to the

effectiveness of HIV prevention and treatment programs, and interventions and programs for reducing stigma. Link and Phelan's [8] theory that stigma is the convergence of labeling, stereotyping, separation, and discrimination by a stigmatizers with access to social, political, and/or economic power offers a good starting point for conceptualizing H/A stigma, particularly when the potentiating effects of structural violence [16] and pre-existing stigmas are accounted for. Though valid measures of stigma that capture perceived and enacted stigma among PLHA as well as stigmatizing attitudes of healthcare workers and the general population are increasingly available, widespread use of the measures in research and program implementation has not yet occurred. Also, few measures of structural or institutional measures of H/A stigma have been developed or rigorously tested. The literature on HIV prevention and treatment programs indicates that stigma does indeed limit uptake of such critical services as PMTCT, testing, and antiretroviral therapy, even as access to such programs has improved with scale-up. Finally, few specific interventions and social programs to reduce H/A stigma have been rigorously evaluated. Perhaps more problematic, most interventions are individual focus, aiming to increase the knowledge and empathy of potential stigmatizers or improving the ability of PLHA to cope with stigma and discrimination. Few social programs that address stigma promulgated by structural and institutional factors were found in the peer reviewed literature.

Prior to describing our recommendations, we highlight two important limitations of this analysis. In this paper, we systematically reviewed the life sciences and biomedical literature, the primary repository of peer-reviewed academic articles on H/A stigma. Although we supplemented the literature from PubMed with references found in the articles as well as relevant grey literature including reports from international organizations, other relevant sources, particularly relating to sociological, policy, and legal analyses, may not have been captured. Similar systematic searches in search engines such as Socio-file and Westlaw should be conducted. A second and related limitation concerns the restricted assessment of discrimination in this review. Due to the already broad scope of the review, discrimination was only examined as it directly relates to stigma. Broader aspects of discrimination pertaining to legal systems and human rights initiatives and their effects on stigma were not explored in depth.

### Recommendations For the Way Forward

Based on the literature review and discussion with a multidisciplinary set of HIV/AIDS experts at the 2007 UCLA Social Justice, Human Rights, and HIV Prevention Think Tank, we developed the following recommendations for addressing stigma in the HIV/AIDS epidemic. Due to the multifaceted nature of H/A stigma, these recommendations are intended for the broad array of individuals, communities, and institutions involved in responding to the HIV/AIDS epidemic, including PLHA, researchers, program implementers, and civil society/government leaders. These recommendations are in no way meant to be exhaustive, but rather, represent what we feel are critical next steps for responding to H/A stigma given the current state of the epidemic.

**Defining H/A Stigma**—Develop a comprehensive conceptual framework for H/A stigma that incorporates both the socio-cognitive and the structural aspects of stigma as well as captures the effects of pre-existing and overlapping stigma related to poverty, race, gender, sexual orientation, etc.

Recent work in the fields of sociology and anthropology has persuasively demonstrated that the process of stigmatization relies as much on socio-cultural processes and power as on the cognitive processes of labeling and stereotyping at the individual level. Conceptualization of H/A stigma to date, however, is mostly based on a socio-cognitive approach. A more complete

understanding how H/A stigma manifests and operates in a multifaceted way is integral to developing effective strategies to measure, assess the impact of, and reduce H/A stigma.

### Measuring H/A Stigma

**Whenever applicable, encourage the use of valid and reliable stigma measures by research projects and program implementers:** Although stigma is considered one of the greatest challenges to addressing the HIV epidemic, data that accurately describes and quantifies stigma is often not available to program implementers and policy-makers. This type of data is not only important for determining the efficacy of specific stigma reduction interventions, but also crucial to understanding the effect stigma may have on the success of prevention and treatment programs. Consistent and widespread surveillance of stigma utilizing valid measures would also enable program implementers to identify and assist specific at-risk and HIV-positive subgroups who may be experiencing heightened perceived or enacted stigma when accessing prevention and treatment programs.

**Support the development of a standardized set of measures for the structural/institutional domains of H/A stigma:** Although social and cultural forces in the family, neighborhood, or workplace often play an integral role in systematically discriminating against PLHAs, research on developing measures of stigma has mostly focused on individuals and their potentially stigmatizing attitudes. Policy-makers and funders should support research that aims to develop valid measures of structural and institutional H/A stigma. In addition to enabling a more comprehensive assessment of stigma over time, such measures would help identify and evaluate potential levers to reduce stigma at the structural/institutional level.

**Assessing Impact of H/A Stigma on Programs—**The following recommendations emerge from stigma related concerns associated with provider-initiated opt-out HIV testing: 1) promote a supportive social and legal framework to minimize unintended consequences of provider initiated opt-out HIV testing, 2) implement stigma reduction interventions among healthcare providers, and 3) support further research on the relationship between stigma and routine HIV testing.

Though H/A stigma is a barrier to accessing the entire spectrum of HIV prevention and treatment services, perhaps the most urgent research questions from a programmatic perspective relate to how the stigma of HIV testing can be overcome, particularly in generalized epidemics where fewer than 15% of the population has ever been tested [63]. HIV testing is the primary gateway to both prevention and treatment services. While provider initiated opt-out testing as recommended by the W.H.O. and UNAIDS is likely to increase the numbers of people tested [63], data from Botswana indicates that some people may avoid going to the doctor out of fear of testing and women who are tested may be subject to intimate partner violence [61], suggesting that prevailing stigma in the general population leads to unintended but significant consequences. Policy-makers and civil society should encourage community preparedness and social mobilization as well as engage relevant legal and public service organizations to minimize these unintended consequences. Provider-initiated programs also underscore the problem of stigmatizing attitudes of healthcare providers [64,82–84] and the potential for coercion of patients to test. As provider initiated testing is rolled out, program implementers should institute specific stigma reduction interventions for healthcare providers and ensure consistent monitoring and evaluation of the opt-out testing process. Finally, further research on how stigma effects and is affected by provider initiated testing programs is needed both in real time and in the long run to identify potential adjustments to enhance uptake of testing and novel social consequences of the program.

Promote and document the ‘virtuous social cycle’ that access to antiretroviral therapy provides for stigmatized individuals by 1) linking the rollout of treatment programs with community level stigma reduction interventions and 2) measuring stigma longitudinally as universal access and utilization is achieved.

By treating visible signs of disease and enabling PLHA to return to socially and economically productive lives, antiretroviral therapy can trigger a ‘virtuous social cycle’ [16,85]. However, access to therapy alone is often not sufficient to ensure improvement in the lived experiences of PLHA, due to persistent social stigma as well as the attendant challenges of adhering to pill-taking and following up at provider appointments in the setting of limited social support. Policy-makers and program implementers should link treatment programs with specific interventions to empower PLHA to cope with disclosure of HIV status to a trusted family member or friend as well as maintain or re-integrate into family and community life while on therapy. Rollout of antiretroviral therapy should also be accompanied with specific social marketing and mass media campaigns to address stigmatizing attitudes and stereotypes in the general population.

**Reducing H/A Stigma**—Promote reform of laws and policies that enable stigma and discrimination of men who have sex with men (MSM), injecting drug users (IDUs), commercial sex workers (CSWs), and migrants.

Current law and policy in many countries directly contribute to and/or exacerbate pre-existing stigma and discrimination associated with at-risk groups. Pre-existing stigma not only predisposes these vulnerable individuals to greater H/A stigma and discrimination, but also critically reinforces stereotyping and status loss of all afflicted with HIV/AIDS, regardless of how they may have acquired the infection. Funders and civil society should support advocacy groups that promote the repeal of laws and policies that criminalize consensual homosexual activity, prohibit syringe possession and needle exchange [86], facilitate violent policing of CSWs [87], and require proof of residency status to access services. On the other hand, where protective legislation on HIV/AIDS discrimination is in place, support for enforcement and targeted information campaigns for stakeholders about rights afforded by such legislation should be provided. The work of the Lawyer’s Collective HIV/AIDS Unit [88], an Indian non-governmental organization engaged in a variety of legal and policy activities to secure and protect the rights of PLHA as well as groups vulnerable to HIV infection, is a good example of the kind of sustained advocacy needed at the structural level while stigmatizing attitudes and norms about HIV/AIDS at the individual level are addressed.

Develop and implement community-based interventions that are designed to mobilize PLHA and the range of other sympathetic social actors (opinion leaders, clergy, etc) to address maladaptive self-stigmatizing behaviors and to advocate against discrimination in the wider community.

Approaches to reducing stigma must be multifaceted and multilevel. Multifaceted to account for the range of stigmatizing conditions that track with HIV/AIDS stigma. Multilevel to account for individual and structural levels of stigma and discrimination. Parker and Aggleton persuasively argue that stigma and stigmatization function at the intersection between culture, power, and difference, and thus, are central to establishing the prevailing social order [5]. Thus, interventions based on community organizing and building among PLHA as well as potentially sympathetic social and community entities, that aim to ‘unleash the power of resistance on the part of the stigmatized,’ are important avenues for the root causes of H/A stigma and discrimination [5,80,89].

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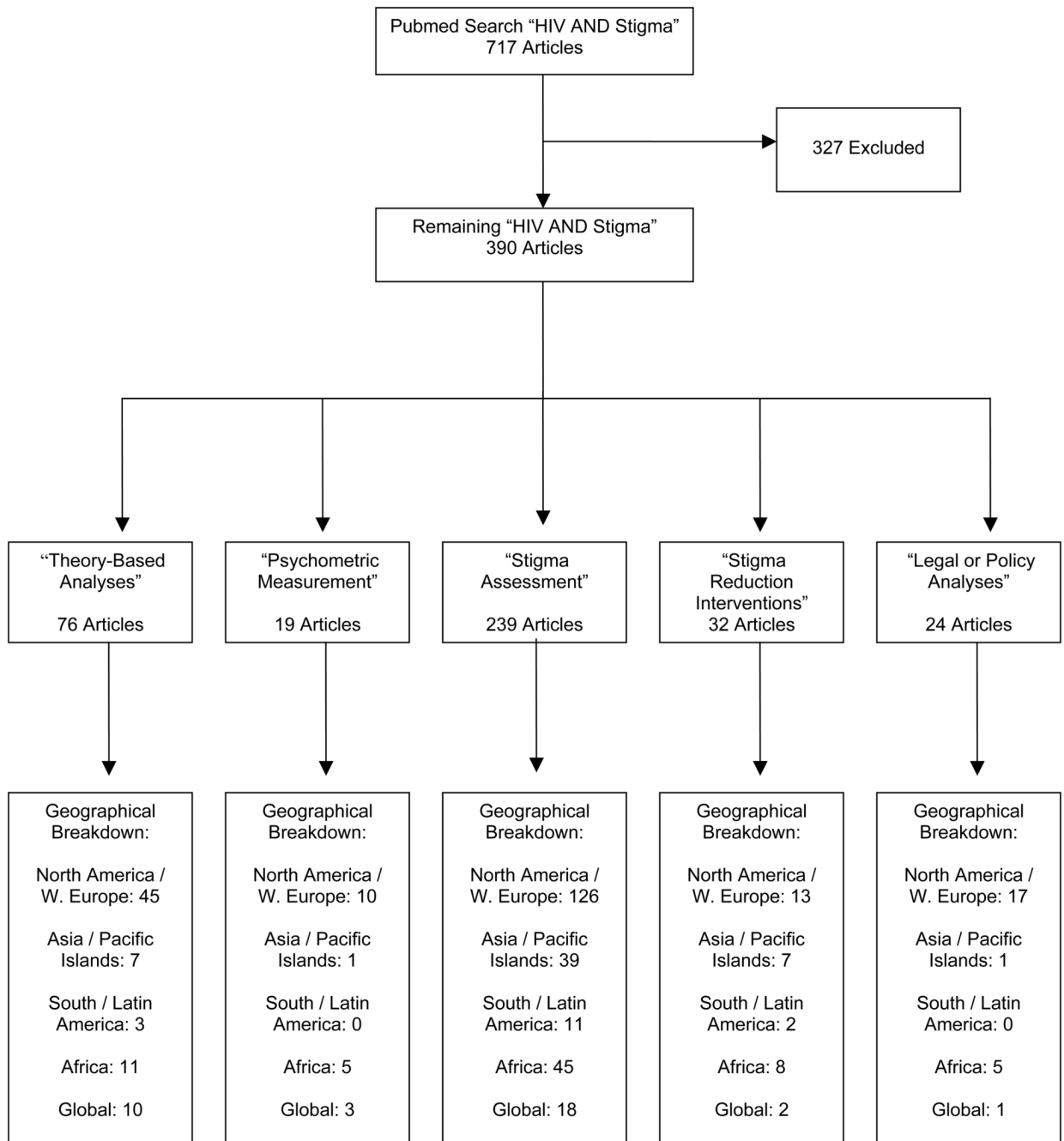
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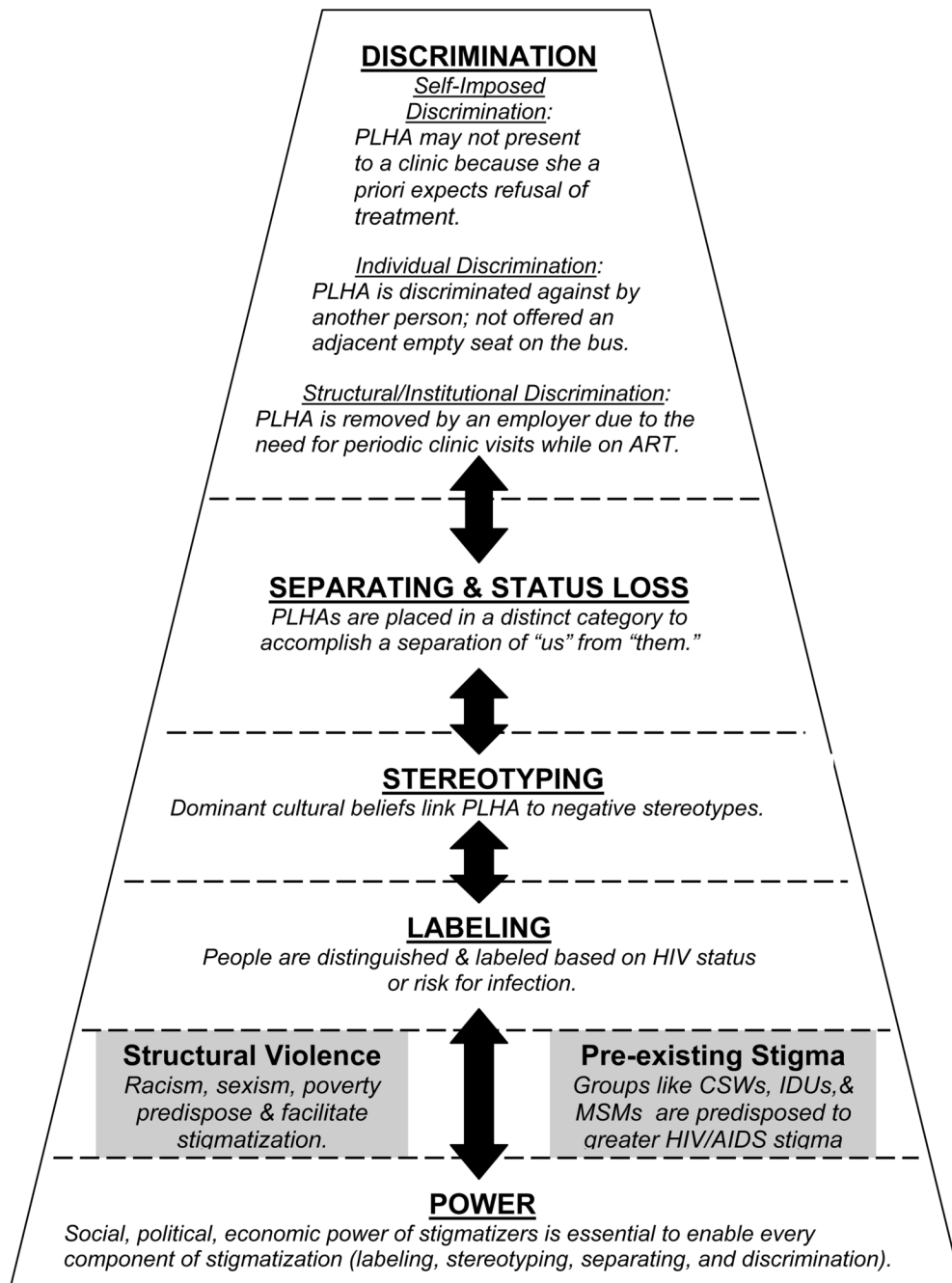
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**Figure 1.**  
Flow diagram of articles included in the review.



**Figure 2. Conceptual framework for HIV/AIDS related stigma**

Inequalities in social, political, and economic power are the foundation on which stigmatization is promulgated. For HIV/AIDS related stigma, structural violence and pre-existing stigmas potentiate the power of stigmatizers and enable even more intense stigmatization and discrimination. Stigma exists when labeling, stereotyping, separation/status loss, and discrimination in the setting of power imbalance simultaneously converge. [Ref 5,8,16,17].

**Table 1**

## Stigma reduction strategies\*

Level	Strategies
Intrapersonal level	Counseling
	Cognitive-behavioral therapy
	Self-help and support groups
	Treatment
	Empowerment
Interpersonal level	Care and support
	Home care teams
	Community-based rehabilitation
Community level	Education (social marketing, mass media)
	Contact with PLHAs
Institutional level	Training programs
	Policy development
Governmental/structural level	Legal interventions
	Rights-based approaches

\* Adapted from Hiejjnders M & van der Meij S [74].