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

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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 programme 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 programmes. 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.

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 \cite{1–3}. Despite widespread recognition of the differential treatment of individuals living with HIV/AIDS (PLWHA) 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, Piot \cite{4}, Executive Director of the Joint United Nations Programme on HIV/AIDS (UNAIDS), identified tackling stigma and discrimination as one of five key imperatives for success. At the same time, Piot \cite{4} noted that stigma reduction efforts are relegated to the bottom of AIDS programme priorities, often without funding to support such activities.

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 \cite{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 programmes and devising interventions to reduce stigma. These four challenges: defining, measuring, assessing the 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 the 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 programmes. 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 and 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 (V.A.P.) reviewed each of the abstracts identified. Data extracted from each abstract included the study’s objective, methodology and key findings. The geographical 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 the impact of and reducing H/A stigma. To categorize articles systematically 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. The categories and 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 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 PLWHA, specific groups such as healthcare workers or the general population. Articles assessing the consequences of stigma on the 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 the 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. As a result of 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. On the basis of this, we developed a list of recommendations for responding to the challenges of defining, measuring, assessing the 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 Think Tank on Leadership, Equity, and Accountability at the International AIDS Society Meetings in Sydney, Australia, in July 2007. Based partly on our discussion, we further developed and designated seven 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 geographical region. Articles and documents that were not indexed in PubMed, but were identified by other means, are not
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 PLWHA, 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 four 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 current literature 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 programmes and interventions [5].
Early work
Based on his work in psychiatric hospitals and among criminals and homosexuals, Erving Goffman [9,10] provided a seminal theorization of health-related stigma in the 1960s. Goffman [10] 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’. 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].

Sociocognitive 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 sociocognitive framework constrained the concept of H/A stigma to an examination of how PLWHA are labelled and stereotyped by the public, based on their incorrect beliefs and attitudes [8,13] and a focus on the specific emotions and cognition of PLWHA. 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 PLWHA among the general population, or individual-based interventions to assist PLWHA 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 utilize a sociocognitive conception of stigma. Although 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 [8,14,15].

Structural understanding of stigma
Recent work in the sociological and anthropological 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 is also determined by a constantly changing social process [5,8]. Parker and Aggelton [5] 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, neighborhood, and community abound’. 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 Aggelton [5] further argue that structural (or social) power is not only needed to enable stigmatization, but also that stigmatization plays a key role in producing and reproducing relations of power and control [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 Aggelton [5] 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 is 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 PLWHA, 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 an 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]. As 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 HIV/AIDS-related stigma
Link and Phelan [8] offer a broader conceptualization that elucidates both the sociocognitive and the structural aspects of stigma and the relationship between them. In their conception, stigma exists when the following four
interrelated components converge: (i) individuals distinguish and label human differences; (ii) dominant cultural beliefs link labelled persons to undesirable characteristics (or negative stereotypes); (iii) labeled persons are placed in distinct categories to accomplish some degree of separation of ‘us’ from ‘them’; and (iv) 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]. The conceptualization of stigma of Link and Phelan [8] may serve as a good starting point for developing a comprehensive framework for H/A stigma, because no such framework was identified in this literature review.

To explain H/A stigma and potential intervention strategies optimally, the model of Link and Phelan [8] 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 [8] continuum of components varies. For example, a PLWHA 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 because he is stable and capable of working and providing for his family, thereby limiting potential separation and status loss despite being labeled. On the other hand, a PLWHA who is late in the course of infection and is suffering from wasting syndrome is easily identifiable and increasingly vulnerable to discrimination along the continuum of Link and Phelan [8]. 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 limit 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 Fig. 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 PLWHA as well as the effectiveness of HIV prevention and treatment programmes. 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 the implementation of routine HIV testing and scale-up of antiretroviral therapy (ART). Indicators are needed to evaluate stigma-reduction interventions and assist programme 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 programmes 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 the measurement of stigma across a number of domains and at the individual and structural levels (Fig. 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 because 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 sociocognitive aspects of H/A stigma, and most were developed in the US context [13,24]. They are designed to assess stigma from one of two perspectives: the ‘stigmatizers’, who include the general public or specific groups such as healthcare workers, and the ‘stigmatized’, who include PLWHA or high-risk groups such as 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 PLWHA 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 PLWHA or denying the entry of PLWHA into the country [25]. Another set of indicators elicits data on emotional reactions towards PLWHA. These indicators are designed to measure the extent to which respondents blame PLWHA for their illnesses, consider HIV a retribution from God, and harbor anger, fear, or disgust for PLWHA [23,25,26]. For assessing perceived or experienced stigma among PLWHA, indicators that query how PLWHA perceive that their partners, friends, family and community treat PLWHA 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 towards PLWHA. In Tanzania, indicators that captured social distancing consisted of questions about the fear of casual contact with PLWHA were tested. Utilizing nine items measuring attitudes towards PLWHA, support for coercive measures and social distancing, Kalichman and colleagues [32] validated an AIDS-related stigma scale and demonstrated its reliability among over 2000 respondents in five South African communities.

**Gaps in stigma measurement**

Although the aforementioned studies represent important initial steps in developing measures for some aspects of 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, intravenous drug use or homosexuality [23]. Perhaps most problematical, 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 HIV/AIDS-related 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 PLWHA, 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 PLWHA to develop a more structurally informed tool to measure stigma experienced by PLWHA [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 PLWHA 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 programme [36].

**Relationship of HIV/AIDS-related stigma to prevention and treatment programmes**

H/A stigma is considered a barrier to effective HIV prevention and treatment programmes. H/A stigma is blamed for the 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
Stigma and HIV risk behavior

Although 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 PLWHA 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 PLWHA in France, experiences of H/A discrimination was associated with an increased incidence of unsafe sex [40]. To develop prevention programmes 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 and biomedical prevention

Novel biomedical interventions to prevent HIV infection, such as adult male circumcision, pre-exposure prophylaxis, microbicides and vaccines represent an 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 affect 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 labelled a PLWHA and experiencing the attendant stigma [42–45]. Although no empiric data are 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 [46] argued that male circumcision offers a new opportunity to engage religious leaders in occupying a central role in advocating for HIV prevention, 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 overreliance 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

Pregnant women may avoid participating in PMTCT programmes because of the 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 mothers’ 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 to receive HIV testing or couples counselling, 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 the acceptability of services and diminishing the effects of stigma [54,55].

Stigma, testing and treatment

H/A stigma is documented as a barrier to the 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 PLWHA [3]. In a study of 112 patients receiving ART in Botswana 2 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 because of the 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 ART in resource-limited countries, rather than stigma, is the real driver of the 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 socially and financially productive lives, and sparking interest in testing and
treatment among others in the community [16]. In theory, the widespread scale-up of treatment access may turn HIV into a treatable and chronic (rather than deadly) disease, increase the uptake of testing, and thereby, ultimately, reduce H/A stigma.

The institution of universal access to ART in Botswana in 2002 provides an opportunity to investigate the effect of the scale-up of treatment on testing behavior and stigma. Two years after universal access was in place, enrollment in the treatment programme remained far below the targeted projection of eligible patients [61]. As the low uptake of HIV testing was considered a primary reason for poor enrollment, a routine opt-out HIV testing programme was implemented in Botswana in 2004, now known as ‘provider-initiated testing and counselling’. In opt-out testing, all patients are to be tested as a routine part of medical visits unless they explicitly refuse. 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], although some have pointed out the potential for increased stigma among women as a result of problems around disclosure, partner violence and other sex-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 provider-initiated testing and counselling would lead people to avoid going to the doctor for fear of testing and 14% thought that the policy could increase sex-based violence [61]. Individuals with stigmatizing attitudes towards PLWHA 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 programmes, 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 ART 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 that have had near universal access to therapy over the past 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 also emerging in Africa [71,72] and Asia [73].

Interventions and social programmes to reduce HIV/AIDS-related stigma

There are only a small number of published studies on interventions and programmes designed to reduce H/A stigma. Given the difficulties in defining and measuring stigma, few such interventions and programmes 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 PLWHA among the general population [75]. The predominant strategy underlying these interventions was education through the provision of factual information about HIV/AIDS [76,77]. Most of these were studies of interventions implemented among small convenience samples of university students in the United States without the use of specific stigma measures [75]. A few studies about interventions aimed at increasing the willingness of healthcare providers to treat PLWHA and at developing coping skills among PLWHA 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 HIV/AIDS-related stigma. A systematic review of the effectiveness of HIV/AIDS mass communication programmes revealed only a small positive impact on the knowledge of HIV transmission and reduction in risk behavior [78]. The

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*Adapted from Heijnders and Van Der Meij [74].
Discussion

H/A stigma is considered a major barrier to effective responses to the HIV epidemic. There is, however, little consensus among policy-makers and programme 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 programmes and interventions and programmes for reducing stigma. The theory of Link and Phelan [8] that stigma is the convergence of labelling, stereotyping, separation and discrimination by stigmatizers with access to social, political and 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. Although valid measures of stigma that capture perceived and enacted stigma among PLWHA as well as stigmatizing attitudes of healthcare workers and the general population are increasingly available, the widespread use of the measures in research and programme 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 programmes indicates that stigma does indeed limit the uptake of such critical services as PMTCT, testing and ART, even as access to such programmes has improved with scale-up. Finally, few specific interventions and social programmes to reduce H/A stigma have been rigorously evaluated. Perhaps more problematic, most interventions are individually focussed, aiming to increase the knowledge and empathy of potential stigmatizers or improving the ability of PLWHA to cope with stigma and discrimination. Few social programmes that address stigma promulgated by structural and institutional factors were found in the peer-reviewed literature.

Before 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. As a result of 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. As a result of 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 PLWHA, researchers, programme 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 HIV/AIDS-related stigma**

Develop a comprehensive conceptual framework for H/A stigma that incorporates both the sociocognitive and the structural aspects of stigma as well as capturing 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 sociocultural processes and power as on the cognitive processes of labelling and stereotyping at the individual level. Conceptualization of H/A stigma to date, however, is mostly based on a sociocognitive approach. A more complete understanding of 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 HIV/AIDS-related stigma**

Whenever applicable, encourage the use of valid and reliable stigma measures by research projects and programme implementers.

Although stigma is considered one of the greatest challenges to addressing the HIV epidemic, data that accurately describes and quantifies stigma are often not available to programme implementers and policy-makers. This type of data is not only important for determining the efficacy of specific stigma reduction interventions, but is also crucial to understanding the effect stigma may have on the success of prevention and treatment programmes. The consistent and widespread surveillance of stigma utilizing valid measures would also enable programme 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 programmes.

Support the development of a standardized set of measures for the structural/institutional domains of HIV/AIDS-related stigma.

Although social and cultural forces in the family, neighborhood, or workplace often play an integral role in systematically discriminating against PLWHA, 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 HIV/AIDS-related stigma on programmes**

The following recommendations emerge from stigma-related concerns associated with provider-initiated opt-out HIV testing: (i) promote a supportive social and legal framework to minimize unintended consequences of provider-initiated opt-out HIV testing; (ii) implement stigma reduction interventions among healthcare providers; and (iii) support further research on the relationship between stigma and provider-initiated opt-out HIV testing.

Although 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 in which fewer than 15% of the population has ever been tested [63]. HIV testing is the primary gateway to both prevention and treatment services. Whereas provider-initiated opt-out testing as recommended by the WHO and UNAIDS is likely to increase the numbers of people tested [63], data from Botswana indicate 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 programmes also underscore the problem of the stigmatizing attitudes of healthcare providers [64,82–84] and the potential for coercion of patients to test. As provider-initiated testing is rolled out, programme 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 affects and
is affected by provider-initiated testing programmes is
needed both in real time and in the long run to identify
potential adjustments to enhance the uptake of testing and
novel social consequences of the programme.

Promote and document the ‘virtuous social cycle’ that
access to ART provides for stigmatized individuals by:
(i) linking the roll-out of treatment programmes with
community-level stigma-reduction interventions; and
(ii) measuring stigma longitudinally as universal access
and utilization is achieved.

By treating visible signs of disease and enabling PLWHA to
return to socially and economically productive lives, ART
can trigger a ‘virtuous social cycle’ [16,85]. Access to
therapy alone is, however, often not sufficient to ensure
improvement in the lived experiences of PLWHA, as a
result of 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 programme implementers
should link treatment programmes with specific interven-
tions to empower PLWHA to cope with the disclosure of
HIV status to a trusted family member or friend as well as to
maintain or re-integrate into family and community life
while on therapy. The roll-out of ART should also be
accompanied by specific social marketing and mass media
campaigns to address stigmatizing attitudes and stereo-
types in the general population.

Reducing HIV/AIDS-related stigma

Promote the reform of laws and policies that enable stigma
and discrimination of men who have sex with men,
injecting drug users, commercial sex workers and migrants.

Current laws and policy in many countries directly
correlate to or exacerbate pre-existing stigma and
discrimination associated with at-risk groups. Pre-
oxisting stigma not only predisposes these vulnerable
individuals to greater H/A stigma and discrimination, but
also critically reinforces stereotyping and status loss of all
affected 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 homo-
sexual activity, prohibit syringe possession and needle
exchange [86], facilitate violent policing of commercial
sex workers [87] and require proof of residency status to
access services. On the other hand, when 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
PLWHA 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 PLWHA 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
[5] persuasively argued that stigma and stigmatization
function at the intersection between culture, power and
difference, and thus are central to establishing the
prevailing social order. Interventions based on com-
munity organizing and building among PLWHA as well as
potentially sympathetic social and community entities,
which 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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References

1. Bond V, Chase E, Aggelton P. Stigma, HIV/AIDS prevention,
and mother to child transmission in Zambia. Eval Program


53. Doherty T, Chopra M, Nkoulou J, Jackson D, Greiner T. Effect of HIV epidemic on infant feeding in South Africa: ”When they see me coming with tins they laugh at me”. Bull WHO 2006; 84:90–96.


