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Using a Multi-level Framework to Test Empirical Relationships among HIV/AIDS-related Stigma, Health Service Barriers, and HIV Outcomes in KwaZulu-Natal, South Africa

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Abstract

HIV/AIDS-related (HAR) stigma is still a problem in Sub-Saharan Africa, and is thought to impede HIV preventive and treatment interventions. This paper uses a systematic sample of households (Level 1) nested within near-neighbor clusters (Level 2) and communities (Level 3) to examine multilevel relationships of HAR stigma to health service barriers (HSBs) and HIV outcomes in KwaZulu-Natal, South Africa, thereby addressing methodological and conceptual gaps in the literature from this context. Findings suggest differential patterns of prediction at Level 1 when examining two different dimensions of stigma: more highly stigmatizing attitudes predicted more household health service barriers; and perceptions of greater levels of community normative HAR stigma predicted higher household HIV ratios. Level 2 findings were similarly dimension-differentiated. Cross-level analyses found that near-neighbor cluster-level (setting level) consensus about (standard deviation) and level of (mean) community normative HAR stigma significantly predicted household-level HSBs and HIV ratio, controlling for household-level community normative HAR stigma. These differential patterns of prediction suggest that HAR stigma is an ecological, multi-dimensional construct that relates to important outcomes differently within and across multiple ecological levels. This has important implications for future research, and for developing interventions that address setting-level variation in stigma.

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Compliance with Ethical Standards:

Research Involving Human Participants. Institutional review boards at both New York University in New York, NY (HS# 10–0613); and Human Sciences Research Council in Durban, South Africa (protocol # 1/10/03/10) approved all study procedures.

Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Ethical approval: This article does not contain any studies with animals performed by any of the authors.

Informed Consent. Informed consent was obtained for all study participants. For child participants, informed consent was obtained from their primary caregivers. After this caregiver consent was obtained, children were informed about the study using child-appropriate language, and asked whether they wanted to give assent to participate. All consent and assent forms were reviewed and approved by institutional review boards at both New York University in New York, NY and Human Sciences Research Council in Durban, South Africa.

Introduction

HIV prevalence rates in some Sub-Saharan African countries are among the highest in the world (UNAIDS, 2009). More than 60 percent of the world's HIV-positive population lives on the African continent (UNAIDS, 2006). In many regions there, people living with HIV (PLWH) face discrimination or public shame and humiliation as a result of their HIV-status, and may even be outcast from their families or communities (Rankin, Brennan, Schell, Laviwa, & Rankin, 2005). An anonymous survey of over 1000 HIV-positive men and women in Cape Town, South Africa, for example, found that 40% of the sample had experienced discrimination resulting from HIV/AIDS-related (HAR) stigma, 20% had lost a job or a place of residence because of their HIV status, and more than 33% reported feeling ashamed, dirty, or guilty because they were HIV-positive (Simbayi et al., 2007). Such descriptive findings are corroborated by other studies of HAR stigma in other Sub-Saharan African regions (e.g. Kohi et al., 2006); and a longitudinal study of the results of population-based surveys from 31 African countries found that on average, anticipated stigma increased over time between 2003 and 2013 (Chan & Tsai, 2016), even during periods of expansion of antiretroviral treatment.

Particularly in this context, where incidence of HIV is so high and knowledge about its prevention and treatment can be low, stigma is thought to impede the effectiveness of available preventive and treatment-based health services (Kalichman & Simbayi, 2004; Kalichman & Simbayi, 2003; Nachega et al., 2004; Weiser et al., 2003). A better understanding of the nature and dynamics of HAR stigma in this context can help the prevention field to understand setting-level patterns of utilization of HAR health services, and to more accurately estimate the impact such preventive interventions may have on HIV incidence and HIV/AIDS mortality.

HIV/AIDS-related Stigma and Barriers to Accessing HIV Treatment & Preventive Services

Many qualitative studies have been conducted in Sub-Saharan Africa which support the existence of a relationship between individual-level beliefs about stigma towards PLWH and barriers to accessing HIV treatment and preventive health services (health service barriers = HSBs). Specifically, this work has found that PLWH report avoiding clinics or hospital visits, refusing to allow health service workers into their homes (Greeff et al., 2008), and failing to adhere to treatment regimens largely because of fear of stigmatization, shame, and retaliation or other stigmatizing responses from family members (Campbell, Foulis, Maimane, & Sibiya, 2005). Qualitative research near Durban, South Africa (in the KwaZulu-Natal province) has also found that young people (who are not necessarily HIV-positive) are afraid to visit HIV testing or care facilities because they are afraid of stigma (Campbell et al., 2005) in their communities and from their families; and more recent qualitative research in South Africa's North West Province has found similar results (Treves-Kagan et al., 2016). Quantitative research, too, has found that many people (e.g., 40% of respondents to a survey in Free State Province, South Africa) perceive stigma to be a barrier to HIV testing (Khan et al., 2015) and that individual-level fear of stigma is related to lower utilization of health services (e.g., Nachega et al., 2004; Weiser et al., 2003).

Qualitative research has also found that HIV-positive individuals expect stigmatizing responses from healthcare professionals (Okoror et al., 2014; Greeff et al., 2008) that could compromise their health care if they did try to receive health services. One ethnographic study which conceptualized stigma at a more contextual level even found that cultural or contextual stigma fosters a health services culture in which medical facilities frequently refuse to diagnose or treat patients with HIV/AIDS (Duffy, 2005). This research suggests that there are important barriers to receipt of health services in the Sub-Saharan African context which are potentially related to HAR stigma. However, future quantitative research on this relationship needs to reduce the reliance on clinical and convenience sampling found in extant studies in order to reduce potential biases.

HIV/AIDS-related Stigma as a Predictor of HIV Outcomes

There is ample evidence that use of health services is related to improved HIV outcomes, in Sub-Saharan Africa and elsewhere. Use of HIV-preventive services is related to reduced transmission and lower HIV incidence (e.g., Ahmed et al., 2001; Creese, Floyd, Alban, & Guinness, 2002; Ngugi et al., 1988; Suksomboon, Poolsup, & Ket-aim, 2007; Weiss, Quigley, & Hayes, 2000), while consistent use of HIV-treatment services is related to lower HIV/AIDS-related mortality (e.g., Lima et al., 2009; Murphy et al., 2001). However, despite this evidence, and despite research conducted in Sub-Saharan Africa and elsewhere that has found some evidence of relationships between HAR stigma and access to or use of HIV-related health services (e.g., Abaynew, 2011; Nyamathi, 2013), antiretroviral adherence (e.g., Nachega, 2004; Nozaki, 2011; Nyamathi, 2013), and other health outcomes (Rueda et al., 2016), neither a direct nor an indirect (via health service barriers) relationship between HAR stigma and HIV prevalence in Sub-Saharan Africa has been tested quantitatively.

Further support for this potential relationship comes from a small number of quantitative studies in Sub-Saharan Africa which link HAR stigma to risky sexual behaviors (e.g., Nelson et al., 2015; Simbayi, Kalichman, Strebel, Cloete, Henda, & Mqeketo, 2007). Risky sexual behaviors, in turn, are widely understood to be strongly related to HIV outcomes. Such links support a potential indirect relationship between HAR stigma and HIV outcomes. In order to better understand the consequences of HAR stigma for public health in high-prevalence, high-stigma communities in Sub-Saharan Africa, this potential relationship should be examined empirically.

Stigma as a Setting-level Phenomenon

Stigma can be understood theoretically as a phenomenon which varies at the level of groups, communities, or other supra-individual or system levels (i.e., settings). According to system-level theories about norms, these settings dictate social standards for acceptable behavior (Kelly, Ryan, Altman, & Stelzner, 2000), including norms around stigmatization. Through this lens, stigma is a phenomenon which requires classification by the members of a system of a certain characteristic as “other,” abnormal, and negative. HAR stigma then, can be conceptualized as a setting-level normative notion that individuals with HIV/AIDS are abnormal and fall outside of the range of acceptable characteristics (Williams, 2014). Based on this theory, one individual’s negative perceptions of PLWH are not sufficient to reflect stigma, but would constitute only an individual prejudice. Theory developed specifically for

the Sub-Saharan African context (Williams, 2014) posits that HAR stigma varies at the setting (e.g., community) level, and influences important HIV-related outcomes via various distinct within-level and cross-level relationships that should be studied ecologically. Additionally, the ethnographic work of Duffy (2005), described above, provides some very preliminary empirical evidence that HAR stigma might operate at the system- or setting-level in the Sub-Saharan African context.

Empirical work on HAR stigma in Western and other contexts has begun to simultaneously measure multiple dimensions of stigma, distinguishing between perceived and internalized stigma (e.g. Li, Lee, Thammawijaya, Jiraphongsa, & Rotheram-Borus, 2009), for example. But research on HAR stigma conducted in Sub-Saharan Africa has so far been comprised of studies which measure only a single dimension or type of stigma, such as stigmatizing attitudes towards PLWH (referred to as internalized stigma if measured among PLWH) (e.g. Simbayi et al., 2007).

Additionally, very little quantitative research in Sub-Saharan Africa has explicitly conceptualized stigma as a setting-level or supra-individual construct. Few studies have aggregated HAR stigma measures to attempt to draw inferences about normative attitudes within settings. The extensive literature on this topic has therefore not yet produced an adequate understanding of the inherently supra-individual nature of this phenomenon. One study of the relationship between HAR stigma and HIV testing behaviors aggregated “anticipated HIV stigma” to the community level, using a sample from 22 villages in the Mpumalanga province of South Africa (Treves-Kagan et al., 2017), representing an important step in empirically examining supra-individual HAR stigma. However, more empirical work is needed in South Africa and other Sub-Saharan African settings which conceptualizes and measures stigma at a supra-individual level, and which attempts to measure stigma as a normative phenomenon within settings, and not simply as an aggregation of individual attitudes. A context-appropriate measure of HAR stigma is also needed which assesses the extent to which the setting in which an individual is embedded is one that is normatively stigmatizing of PLWH. In other words, to understand setting-normative HAR stigma, a measure is needed which assesses normative level of stigma (or the degree of stigmatization that is commonly thought to be present or acceptable within a setting by its members). Such a measure could improve direct assessment of variation in HAR stigma between settings. Additionally, a related measurement technique is needed, in combination with such a new measure, which assesses consensus among setting members about the stigma level in order to ascertain the degree to which it is truly normative, or to which there is variation between setting members’ understanding of stigma in the setting. Both methodological theory (Chan, 1998) and precedent from organizational psychological literature (e.g., Lindell & Brandt, 2000) suggest that consensus among setting members about a given construct can be assessed using the standard deviation of the measure for that construct in combination with the setting-level mean. The application of this consensus measurement strategy to a new measure assessing the level of community normative stigma could greatly increase understanding of how HAR stigma operates within and varies between settings in the Sub-Saharan African context.

Sub-Saharan African studies are also needed which use conceptually distinct measures of HAR stigma simultaneously, to better distinguish and understand the various dimensions of this complex phenomenon as they operate uniquely in this context. The simultaneous use of both a more commonly used, individual measure of HAR stigma, and a measure which of normative levels of stigma within a setting, as called for above, could help to illuminate differences in the processes underlying conceptually distinct dimensions of HAR stigma.

Because of the relative dearth of research in Sub-Saharan Africa which conceptualizes stigma at the system- or setting-level, there is as yet little empirical research which aims to understand the multilevel processes and relationships through which this system-level phenomenon may exert its influence on individual-level and setting-level outcomes of interest. Both epidemiological and developmental theories suggest that it is beneficial to measure the influence of setting-level predictors over and above the influence of individual-level influences (Bronfenbrenner & Morris, 2006; Von Korff, Koepsell, Curry, & Diehl, 1992). However, not only have the relationships between setting-level HAR stigma and setting-level HSBs or HIV outcomes not been tested, but the cross-level relationship indicating whether setting-level HAR stigma predicts HSBs or HIV outcomes over and above the influence of individual-level attitudes about stigma has not been tested either. These relationships should be tested in order to achieve a more holistic and comprehensive understanding of the potential mechanisms through which this setting-level phenomenon may exert its influence across multiple levels within an ecological setting.

Covariates of Stigma in the Sub-Saharan African Context

Some important correlates of HAR stigma have been consistently supported by the HAR stigma literature in Sub-Saharan Africa. For example, in the Sub-Saharan African context, older people have been found to have more stigmatizing attitudes towards persons with HIV/AIDS (Shisana et al., 2002); and urban residence or locale, higher socioeconomic status, formally employed status, white racial background, and higher education level have also been found to be associated with less-stigmatizing attitudes at the individual level (Shisana et al., 2002). Additionally, some qualitative work suggests that stigma may present an especially large treatment barrier to HIV-positive women (Bond, Chase, & Aggleton, 2002). Such covariates are utilized inconsistently in the extant HAR stigma literature in the Sub-Saharan African context. Additionally, setting-level covariates of HAR stigma have not yet been identified in this context. There is a need for better multivariate analysis of HAR stigma in this context which empirically accounts for a comprehensive set of covariates at multiple ecological levels in order to isolate the association between stigma and both HSBs and HIV outcomes, net of the influence of other correlated factors.

The Present Study

The present study aims to address a number of the limitations of the extant literature. First, it will improve upon the sampling strategies reflected in the extant literature on HAR stigma in Sub-Saharan Africa by using a community-representative sample of 1,961 households nested within 406 near-neighbor clusters which were randomly selected from 24 communities in KwaZulu-Natal, South Africa. Second, it will address a gap in the extant literature by testing for a direct relationship between HAR stigma and variation in HIV

prevalence in this context, and utilizing a multivariate analytic framework which controls for a comprehensive set of covariates of HAR stigma. Third, by using a nested sample and multilevel analyses, it aims to address the failure of the majority of the extant literature in this context to measure and examine HAR stigma as a setting-level, multi-dimensional construct which relates to individuals ecologically, at multiple levels of influence. It will take an initial exploratory step towards understanding variation in HAR stigma not only between communities but also between near-neighbor clusters, and whether such variation is related to individual-level and setting-level HSBs and HIV outcomes. It will also take an initial exploratory step towards measuring setting-level *consensus* around normative HAR stigma in this context and using this measure of consensus as an additional predictor of important outcomes (in addition to settings' mean levels of stigma). Finally, it will use two conceptually distinct measures of HAR stigma. The first focuses on individual stigmatizing attitudes towards PLWH. The second focuses on individual perceptions of community normative HAR stigma, and more directly conceptualizes stigma as a setting-level phenomenon.

In order to improve understanding of how HAR stigma operates ecologically and multi-dimensionally within the Sub-Saharan African context, the present study will address three specific research questions: 1) Does individual-level HAR stigma (measured in two conceptually distinct ways) significantly predict household-level HSBs and HIV outcomes among a systematic sample of KwaZulu-Natal households, while controlling for a comprehensive set of household and setting-level covariates?; 2) Does HAR stigma (measured in two conceptually distinct ways), aggregated to higher settings levels, predict household-level HSBs and HIV outcomes, over and above the ability of individual-level HAR stigma to do so?; and 3) Do the same patterns of relationships among HAR stigma, HSBs, and HIV outcomes hold at supra-individual levels (i.e., setting levels) of analysis? Improving understanding of the extent to which each of these specific ecological levels of stigma is important in predicting HIV outcomes and health service barriers could have implications for how best to design and target stigma-reducing interventions that aim to prevent stigma from impeding public health efforts to address HIV.

Methods

Sample and Procedure

Data for this study come from the "Well-being of South African Children: Household, Community, and Policy Influences" project in KwaZulu-Natal, South Africa. HIV prevalence for KwaZulu-Natal in 2012 was estimated to be 16.9% - higher than in any other South African province (Shisana et al., 2014). Researchers in the United States and South Africa selected 24 communities from an area with a population that is 95% Zulu. Communities were selected based upon having a school serving 7–11 year old children, and were demarcated using a combination of data about the school's principal-defined catchment area, and geographic boundaries identified by satellite aerial maps. The aerial maps were then used to identify and enumerate all building structures within each community. A small number of building structures were randomly selected from each community for use as cluster nodes, around each of which a "near-neighbor cluster" of the nearest 30 building

structures was selected. All residential structures (households) in each near-neighbor cluster of structures (including the cluster node) were screened for eligibility (defined as being primary residences for at least one child aged 7–10 years, whose members spoke isiZulu) asked to participate in the study. This process was repeated until approximately 75 households in each community were enrolled.

A total of 1,961 (96.5% of screened, eligible) households were successfully recruited to the study. These households were nested in 410 near-neighbor clusters, which were nested in 24 communities. An average of 17 near-neighbor clusters were sampled in each community, and an average of 4.8 households were sampled in each cluster (min = 1; max = 15). In multiple-child households, A Kish grid (McBurney, 1988) was used to randomly select one child as the focal child for the study.

Data collection was completed at two time points, or “waves,” approximately 18 months apart. Wave 1 data collection consisted of three surveys administered on three separate dates, within a time span of approximately one month. Following a consent process, one member of each household completed an interview about the household. At a later date, following an additional consent process, the primary caregiver of the 7–10 year old focal child in each household completed an interview about himself/herself and the child. In approximately 85% of households, the caregiver was the same person who completed the household survey. Following an additional process of caregiver consent and child assent, the focal child completed a face-to-face survey and a series of cognitive assessments. All survey responses were recorded electronically. Respondents were modestly compensated for their time with a healthy snack. This entire data collection process was repeated at Wave 2, approximately 18 months later. Institutional review boards in both the United States and South Africa approved all study procedures.

For the present study, the sample is limited to Wave 2 data from the subsample of HIV-affected households (defined as households with at least one living HIV-positive household member at the time of Wave 2 data collection) (N = 508). Wave 2 data was utilized because of the unique availability of the measure of stigmatizing attitudes towards PLWH in this wave only. The full Wave 2 sample was composed of 1,745 households that completed all three Wave 2 surveys. These households were nested within 406 clusters at Wave 2, with an average cluster size of 4.3 households. All members of the sample were of Zulu cultural/tribal background. Female-headed households constituted approximately 62% of the sample. The average household had a mean age of 25.8 years. The average household had 7 members and a monthly earned income between $248 and $300, with 37.0% of the households in the sample reporting no earned income. This full sample of households, not all of which were HIV-affected, was used to compute all aggregate community-level variables used in the study analyses.

Missing Data and Attrition

The sample experienced an 89.0% retention rate between the first Wave 1 survey and the final Wave 2 survey. Individuals who did and who did not complete Wave 2 did not differ significantly on any of the constructs of interest or covariates included in the present analysis as measured in Wave 1 (although HAR Stigmatizing Attitudes were not measured in Wave

1), based on a series of t-tests. Some caregivers (7.9%; N = 138) either elected not to answer any of the items from the Perceptions of Normative Community HAR Stigma measure, or chose “Don’t know” for all of these items, and were therefore not included in the analyses containing this measure. Missingness for other analytic variables was considerably lower (0.1% - 3.6%).

Measures

Stigmatizing attitudes towards PLWH.—The “HIV/AIDS-related Stigma and Discrimination Scale” (Genberg et al., 2009) was used to measure individual stigmatizing attitudes towards PLWH. This well-cited and validated scale comprises 19 items that ask respondents to rate, using a 5-point Likert scale, the extent to which they have negative perceptions of PLWH and the extent to which they believe that PLWH should be allowed to participate in society and engage with others. Caregivers’ mean responses to these items were utilized for the present study. Reliability analyses revealed a high internal consistency rating among all 19 items for the present sample of caregivers (Cronbach’s $\alpha = .86$).

Perceptions of Community Normative HAR Stigma.—Perceptions of the extent to which stigmatization of PLWH is normative in respondents’ communities was measured using seven dichotomous items from a measure developed by the SIZE research team using adapted items from the Perceived Stigma of HIV/AIDS: Public Views Scale (Westbrook & Bauman, 1996). For each item, caregivers indicated which of four groups (those with HIV or AIDS; those in extreme poverty; those with mental illness; those reliant on social grant income), or “none,” they believed to be most likely to experience a specific stigmatizing response from members of their community. Examples of stigmatizing responses asked about in these items include verbal abuse or teasing, rejection by peers, loss of respect, and disallowance from playing with children. This measure assessed the extent to which stigmatization of PLWH was perceived as normative, as compared to the extent to which stigmatization of other groups was perceived as normative. Thus, it effectively measured the degree to which PLWH were the most stigmatized group in the setting. Additionally, a ratio was calculated of the number of items for which each respondent selected PLWH as most likely to be stigmatized, over the total number of items answered by the respondent. Among the full sample of caregivers, the Kuder-Richardson Formula 20 coefficient (analogous to α, but able to estimate reliability of dichotomous measures) for the items on this measure was .92, demonstrating good reliability. A categorical factor analysis accounting for nesting within communities found that each item loaded highly (range of loadings = 0.86–0.95) onto a single factor (X^2 (6) = 55.28; $p < .0005$; CFI = 0.99; TLI = 0.99; RMSEA = 0.07).

Health Service Barriers (HSBs).—HSBs were measured using 2 items from Speak for the Child (AED, 2002), a study of HIV-affected children in Kenya. Respondents to the household survey were asked whether anyone in the household had experienced the following barriers to accessing care in the past six months: unavailability of required medication, staff turned patient away. Respondents were also asked whether anyone in the household had failed to visit health care facilities or treatment centers when they wanted to or needed to because of any of the following reasons: fear/embarrassment, prevention from going by person of authority within the household, shortage of money for treatment,

shortage of money for transportation, acuteness of illness which prevented sick person from leaving, inability to miss work, or inability to get away from household responsibilities. Affirmative responses to each of these dichotomous items were added, with equal weight, to a sum indicating the total number of HSBs experienced.

HIV Outcomes.—HIV/AIDS-related illness was measured using an adapted set of items from Speak for the Child (AED, 2002). Household survey respondents indicated whether household members suffered from an illness that had required ongoing care for more than a month, or currently suffered from any illness that did not require ongoing care. For each household member who was said to have either type of illness, the respondent was asked whether it was HIV/AIDS. The total number of household members reported to have HIV/AIDS were then summed, and divided by the total number of household members (household HIV ratio). Community-level HIV prevalence was calculated by summing the total number of individuals in each community who were reported as having HIV/AIDS, and dividing that sum by the total number of all household members reported on for all sample households within each community.

Level 1 Covariates.—Respondents reported on household characteristics, eight of which (other illness, ratio of persons aged 15–49, ratio of adult females, access to transportation, importance of church membership, % employed adults, ratio of highly educated adults, and HIV/AIDS-related death) were empirically or theoretically related to the constructs of interest and were therefore used as covariates in the present analyses. Respondents' perceptions of community cohesion, community safety, and subjective SES were also used as covariates in the present study. The online supplement for this article contains a full description of each covariate.

Analyses

The online supplement for this article presents descriptive statistics (Table S1) and bivariate correlations (Table S2). Hierarchical generalized linear modeling (HGLM) was used to address study Questions 1 and 2. HGLM accounts for shared variance of nested data, as well as for the use of both continuous and dichotomous variables in the analytic models. It is also robust to violations of the assumption of a normal distribution (Garson, 2013). For all multilevel models, Level 1 reflects variation at the level of households[1], Level 2 reflects variation at the level of near-neighbor clusters, and Level 3 reflects variation at the level of communities.

The analytic sample for all multilevel analyses which included stigmatizing attitudes towards PLWH as a predictor included N = 1,658 households, nested within j = 406 near-neighbor clusters and k = 24 communities. The analytic sample for all multilevel analyses which included perceptions of community normative HAR stigma as a predictor included N = 1,568 households, nested within j = 401 near-neighbor clusters and k = 24 communities.

[1]It is important to note that both measures of HAR stigma were completed only by a single respondent (the caregiver) in each household. The data for the present study do not contain a true household measure of HAR stigma. Therefore, although the caregiver measures of HAR stigma are analyzed at the same level (Level 1) as are the inherently household-level outcomes, they will hereafter be referred to as "caregiver perceptions of community normative HAR stigma" and "caregiver stigmatizing attitudes towards PLWH" to avoid implying that they describe characteristics of household settings.

This variation in sample size is due to variation in data missingness on the two stigma measures, as reported in the Methods section above. To address Question 3, ordinary least-squares regression was used on a near-neighbor cluster-level (Level 2) aggregate data set (N = 406 near-neighbor clusters). Community-level (Level 3) variation was not modeled in the analyses addressing Question 3, given limited power to draw inferences due to the community-level sample size. Intraclass correlations (ICCs) for key study constructs suggest sufficient uniquely attributable variation at each level to justify a multilevel analysis (see Section S3 of the online supplement for details).

The following equation (Equation 1) was used to compute models addressing Question 1 of the present study: $Y = b_0 + b_1 \times_{1ijk} + \Sigma b_c x_{cijk} + \zeta_{0k} + \eta_{0jk} + \alpha_{0ijk}$, with $\zeta_{0k} \sim N(0, \sigma^2_{\zeta 0})$, $\eta_{0jk} : N(0, \sigma^2_{\eta 0})$, $\alpha_{0ijk} : N(0, \sigma^2_{\alpha 0})$, independently of one another, where *i* indexes households, *j* indexes near-neighbor clusters, and *k* indexes communities, and *c* indexes all covariates; where ζ_{0k} reflects variability across communities, η_{0jk} reflects variability across near-neighbor clusters, and α_{0ijk} reflects variability across households; where x_1 = caregiver stigmatizing attitudes towards PLWH (Models 1 & 3) or x_1 = caregiver perception of community normative HAR stigma (Models 2 & 4); and where Y = household HSBs (Models 1 & 2) or Y = household HIV ratio (Models 3 & 4). Variations of this model were used to address Questions 2 and 3 as well, as described below.

Results

HAR Stigma as a Predictor of HSBs and HIV Outcomes at Level 1

Models 1–4 (Table 1) address the first question of the present study by using the two different measures of stigma, in separate models, to predict household HSBs and HIV ratio while controlling for a full set of Level 1 and Level 3 covariates.

At Level 1, more highly stigmatizing caregiver attitudes towards PLWH predicted higher numbers of HSBs (Model 1; b = 0.268; p < .001), but did not significantly predict household HIV ratio (Model 3). At Level 1 (household level), perceptions of higher community normative HAR stigma predicted higher household rates of HIV, on average (Model 4; b = 0.050; p < .001), but did not significantly predict household HSBs (Model 2).

Cross-level Relationships between Stigma and both HSBs and HIV Outcomes

The models in Table 2 address this study's second question by testing for relationships between setting-level (Level 2 or Level 3) HAR stigma and Level 1 outcomes (HSBs or household HIV ratio), controlling for Level 1 HAR stigma. The equation used for these models is the same as Equation 1, but with the addition of the mean and the standard deviation of one of the HAR stigma measures, at the setting level (Level 2 or Level 3). Near-neighbor cluster level (Level 2) stigmatizing attitudes towards PLWH were not found to be significantly related to either Level 1 HSBs (Model 1a) or to Level 1 HIV ratio (Model 3a). The standard deviation of near-neighbor-cluster level (Level 2) perceptions of community normative HAR stigma was found to significantly predict household health service barriers (b = 0.955; p < .007) above and beyond the ability of individual-level perceptions of community normative HAR stigma to predict them, with greater variation in perceptions of

community normative stigma predicting higher numbers of reported HSBs (Model 2a). Both the mean (b = 0.093; p = 0.041) and standard deviation (b = −0.143; p = 0.014) of near-neighbor cluster level (Level 2) perceptions of community normative HAR stigma were found to significantly predict household HIV ratio over and above the ability of individual-level perceptions of community normative HAR stigma to predict it (Model 4a). The results of this model indicate that higher levels of community normative HAR stigma at Level 2, and lower variation in perceptions of community normative stigma at Level 2 predicted higher household HIV ratios. When aggregated to the community level (Level 3), neither measure of HAR stigma significantly predicted either Level 1 HSBs or Level 1 HIV ratio (Models 1b-4b).

Relationships among HAR Stigma, HSBs, and HIV Outcomes at Level 2

The models in Table 3 address this study's third question by examining the patterns of relationships at the near-neighbor cluster level. The equation used for these models is the same as Equation 1, except that Level 1 variables were here replaced with their corresponding Level 2 aggregate means. These models found that higher Level 2 mean stigmatizing attitudes towards PLWH significantly predicted higher Level 2 HSBs (Model 1c; b = 0.345; p = .024), but did not significantly predict Level 2 HIV prevalence (Model 3c). Models in Table 3 using the community-normative measure of stigma found that Level 2 mean perceptions of community normative HAR stigma significantly predicted higher Level 2 HIV prevalence (Model 4c; b = 0.085; p = .003); and that the standard deviation of Level 2 perceptions of community normative HAR stigma was significantly related to HSBs at Level 2 (Model 2c; b = 0.745; p = .026), with greater variation in community normative HAR stigma predicting higher numbers of reported HSBs at Level 2.

Discussion

This paper examines the relationships among HAR stigma and both HSBs and HIV outcomes across three levels of analysis, with the aim of addressing several important methodological and conceptual gaps in the Sub-Saharan African literature on HAR stigma. It aims to build upon literature which finds a relationship between HAR stigma and HSBs (e.g. Khan et al., 2015; Nachega et al., 2004) by addressing methodological and conceptual gaps in this literature. This study improves upon the sampling designs of previous studies of HAR stigma in Sub-Saharan Africa by using a systematic sample of households nested within randomly selected near-neighbor clusters and within 24 communities. The present study also uniquely controls for a comprehensive set of household and community-level covariates, and improves upon measurement strategies of previous Sub-Saharan African studies (e.g. Genburg et al., 2009, Nachega et al., 2004; Weiser et al., 2003) by measuring two dimensions of HAR stigma, one of which attempts to assess setting-level norms. Findings are summarized in Figure S1 in the online supplement, and discussed in detail below.

HAR Stigma as a Predictor of HSBs and HIV Outcomes at Level 1

In addition to addressing the conceptual and methodological gaps above, the first question of this study addresses the dearth of studies in this context that test for a direct relationship

between HAR stigma and HIV outcomes. Results suggest that more highly stigmatizing caregiver attitudes towards PLWH are associated with a significantly greater number of household-level HSBs, but are not associated with household HIV outcomes (Table 1). Conversely, they suggest that caregiver perceptions of community normative HAR stigma are not related to household HSBs, but are significantly positively related to household HIV ratio.

The traditional interpretation of the significant relationship between stigmatizing attitudes towards PLWH and HSBs is that fear of stigma engenders reluctance to access health services (e.g., Okoror et al., 2014; Treves-Kagan et al., 2016; Weiser et al., 2003). However, when we understand the stigmatizing attitudes measure to be more reflective of individual caregivers' negative attitudes towards PLWH than of a stigmatizing *setting*, we must consider alternative interpretations. It is possible that individuals with negative attitudes towards PLWH avoid using health services where they are more likely to encounter PLWH, and report other barriers to accessing them due to social desirability. Alternatively, it is possible that those with negative attitudes towards PLWH are less informed or educated about HIV/AIDS, perhaps in part due to an inability to engage with health service systems due to higher levels of barriers to doing so. A third alternative is that barriers experienced during engagement with the health service system, such as rudeness of health staff towards PLWH, are actually instructive in terms of how PLWH should be viewed or treated. Under this interpretation, HIV-specific HSBs could lead individuals to view PLWH negatively as a result of observing discrimination in health service settings. These last two interpretations suggest that HSBs could potentially exert an influence on attitudes towards PLWH, and not the other way around, as has been most often implied by the extant literature. Future work needs to uncover the processes underlying this relationship.

The significant association between community normative HAR stigma and household HIV ratio can be understood primarily as the extant theoretical literature suggests (Williams, 2014). There has been both empirical and theoretical support for a relationship between HAR stigma and risky sexual behavior (Simbayi et al., 2007; Williams, 2014). Perceptions of stigma could lead to reticence to disclose one's HIV status, which in turn could easily lead to riskier sexual choices and higher rates of HIV transmission. Future work must test this theory-based, risky sex-mediated model of this relationship. Another common explanation for this association is that an individual's perception of greater setting-wide HAR stigma contributes to a reluctance to access preventive health services, lest he or she be incorrectly identified by others as HIV-positive (e.g., Treves-Kagan et al., 2016; Weiser et al., 2003; Williams, 2014). Although the present data do not support a direct relationship between community normative HAR stigma and HSBs, the present study has not examined actual health service access.

Cross-level Relationships between Stigma and both HSBs and HIV Outcomes

This study's second question takes a first step in testing the ability of setting-level (both mean setting level of and setting-level consensus about) HAR stigma to predict the proportion of household members who are HIV-positive, over and above the ability of individual-level stigma to do so. Its findings build on the work of Treves-Kagan et al. (2016),

who assessed cross-level relationships between mean village-level stigma and individual HIV testing behaviors, and found that mean village-level stigma predicted female (but not male) participants' likelihood of having been tested for HIV. The present findings suggest that individual stigmatizing attitudes towards PLWH, when aggregated to the cluster or community levels, do not significantly predict either HSBs or household-level HIV outcomes, over and above the ability of individual-level stigmatizing attitudes to do so (see Table 2). However, near-neighbor cluster level perceptions of community normative stigma significantly predicted both of these outcomes. Specifically, a higher standard deviation of perceptions of community normative HAR stigma at the near-neighbor cluster level was significantly associated with higher numbers of reported health service barriers (Table 2). This suggests that the extent to which a neighborhood's members' perceptions of normative HAR stigma vary predicts household-level HSBs, with greater variation (lower consensus) predicting more reported HSBs. Additionally, a higher mean level of perceptions of community normative HAR stigma at the near-neighbor cluster level was significantly associated with a higher household-level HIV ratio (Table 2); and a smaller standard deviation of perceptions of community normative HAR stigma at the near-neighbor cluster level predicted a higher HIV ratio at the household level (Table 2).

It is perhaps somewhat intuitive that individual stigmatizing attitudes towards PLWH do not meaningfully predict household-level outcomes when aggregated to settings levels, given the focus of this measure on the perceptions of individuals. Ecological measurement theory suggests that aggregating purely individual-level measures is often insufficient to assess characteristics of settings themselves (Shinn, 1990). Because this individual-focused measure significantly predicts Level 1 outcomes in its Level 1 form, and because it is not intended, conceptually, to capture setting-level characteristics, its aggregate form does not explain additional variation in household-level outcomes. Similarly, when we attempt to understand the significant cross-level findings (Table 2) using ecological measurement theory, we can attribute some of the success of near-neighbor cluster-level perceptions of community normative HAR stigma in predicting household-level outcomes to the setting-focused nature of the measure itself, as it was designed to gauge setting-level stigma norms. Its aggregate form can therefore assess something unique about settings and the HAR stigma therein, above and beyond individual perceptions.

These findings suggest that more highly-stigmatizing mean cluster-level norms around HIV/AIDS predict higher household-level rates of HIV, over and above the ability of Level 1 norms to predict them. They also suggest that greater variation in (less consensus about) community normative HAR stigma at the cluster level predicts higher rates of experiencing health service barriers, but lower household-level rates of HIV. The interpretation that higher mean levels of stigma at the cluster (i.e. neighborhood) level of analysis could potentially contribute to higher HIV rates through reluctance to disclose one's HIV status to partners or through reluctance to discuss condom use with sexual partners, for fear of being assumed HIV-positive, is in line with extant theory (Williams, 2014) and empirical research (Treves-Kagan et al., 2016; Campbell et al., 2005; Nachega et al., 2004; Weiser et al., 2003) on HAR stigma and risky sex in Sub-Saharan Africa. However, the findings related to variation in (consensus about) stigma are somewhat more difficult to interpret. Perhaps consensus about stigma is indeed differentially related to HSBs and to HIV outcomes, as suggested by the

findings of the present study. It is theoretically plausible that the relationship between high setting-level consensus about (low variation in) HAR stigma norms and higher rates of HIV is also attributable to the potential mediating mechanism of risky sex. The presence of greater consensus on highly stigmatizing attitudes towards PLWH may result in greater difficulty electing to use safe sex methods or to disclose one's HIV status, leading to riskier sex and more HIV transmission. It is also plausible that low consensus about community normative HAR stigma predicts higher rates of HSBs because of an inability to predict health care workers' and others' reactions to one's HIV status or to one's attempts to seek HIV-related services. Such uncertainty could decrease motivation to overcome barriers to healthcare, if it were impossible to anticipate what kind of care one would receive upon doing so. Alternatively, it is possible that the opposing directions of the relationships could be explained by a potential curvilinear relationship between consensus about setting-level stigma and household-level health outcomes of interest. Such a relationship has been posited in theoretical work by Williams (2014). Much more empirical work needs to be done to unpack these preliminary cross-level findings.

Relationships among HAR Stigma, HSBs, and HIV Outcomes at Level 2

This study's final question addresses the gap in the extant Sub-Saharan African literature around a lack of setting-level analysis of relationships between HAR stigma and both HSBs and HIV prevalence (Table 3). Results suggest that the patterns of relationships between HAR stigma and both HSBs and HIV outcomes found at Level 1 hold true at the near-neighbor cluster-level as well. Additionally, higher variation in (lower consensus about) perceptions of community normative HAR stigma at the cluster level predicted higher rates of cluster-level HSBs. However, cluster-level consensus about community normative HAR stigma was not found to be related to cluster-level HIV outcomes. These results suggest that there is something unique about the significant cross-level relationship of cluster-level consensus about community normative HAR stigma to household-level HIV. These findings again highlight the need for more research which examines multilevel and cross-level relationships among these and related phenomena.

Limitations and Future Directions

The present study, although an important first step in addressing some of the methodological and conceptual gaps in the literature highlighted above, is limited by the fact that it relies upon cross-sectional data and analysis, so the relationships it describes can only be understood as associations. It is possible, for example, that experiences of HSBs exert an influence on individuals' perceptions of HAR stigma, rather than the other way around. Future work should use longitudinal data to begin to understand the directionality of the relationships.

The present study is also likely limited by measurement error. Its use of participant self-report on measures related to sensitive topics such as HIV/AIDS-related illness and death and endorsement of stigmatizing attitudes makes it likely that these phenomena were underreported by participants in response to social desirability bias. This kind of underreporting is widely noted in HIV research (e.g., Latkin & Vlahov, 2002), and is sometimes also due to participants' lack of HIV status knowledge. Measurement of other

health outcomes may thus be over-reported, in instances where HIV-related illness is incorrectly reported as non-HIV-related illness. Future research should try to limit reliance upon self-report measures of HIV-related phenomena.

The study is also limited by its inability to examine relationships at the community level. Although the authors would have liked to report results of community-level analyses comprised solely of Level 3 constructs, we unfortunately had insufficient statistical power to adequately test Level 3 relationships, given the very small number of communities (N = 24) available for the completion of such a Level 3 analysis, and the large number of covariates included in our models. Future research should strive to examine these relationships among a larger sample of communities.

The present study was limited by the fact that it did not have available measures of all covariates which have been found to predict HAR stigma in this context. Specifically, incorrect or lack of knowledge about HIV/AIDS (Hamra et al., 2006; Shisana et al., 2002) and supernatural beliefs around HIV/AIDS (Kalichman & Simbayi, 2004) have both been found to do so. However, the present study was not able to measure these constructs, or risky sexual behavior, upon which its interpretation of present findings often relied as a theoretically plausible mediator of the relationship between HAR stigma and HIV outcomes. Such speculative interpretations rely heavily on previous theory (Skinner & Mfecane, 2004; Williams, 2014).

Finally, the present sample was composed of a homogeneous cultural/tribal group (Zulu) from a relatively small geographic region, limiting its external validity. The present findings are not generalizable to other settings or to other sociocultural groups. Future work should replicate this study among other populations in order to assess the extent to which patterns of relationships among these phenomena vary across sociocultural contexts.

Conclusions

The present study uses an innovative, multi-dimensional measurement strategy to improve understanding of variation in HAR stigma both between and within settings in KwaZulu-Natal, South Africa, and takes a first step towards ecologically examining the relationships of multiple dimensions of stigma to HSBs and HIV prevalence at multiple levels of analysis. Findings suggest that it is important to continue this line of empirical inquiry, and to better understand HAR stigma in Sub-Saharan Africa as a setting-level phenomenon which exerts influence on constructs of interest through a series of multilevel relationships and processes.When stigma is measured in a way that supersedes individual attitudes in order to truly capture unique characteristics of a setting’s norms around HAR stigma, and both setting-level and cross-level influences of HAR stigma on constructs of interest are tested, then relationships between the setting and individual outcomes and behaviors can be better understood.

Through using an ecological, multilevel framework to conceptualize and measure HAR stigma, the HIV prevention field can develop a more holistic understanding of the complex multilevel processes and relationships through which HAR stigma exerts its influence on

health service system engagement and public health in high-HIV-prevalence contexts such as Sub-Saharan Africa, and will thereby be better able to design and implement new interventions (and adjust existing interventions) to address the complex relationship between HAR stigma and population health and to prevent stigma from stymieing public health efforts.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Results of Multilevel Analyses Predicting HSBs and HIV Outcomes from CG Stigma

	Household Health Service Barriers		Household HIV Ratio	
	Model 1	**Model 2**	**Model 3**	**Model 4**
	b	***b***	***b***	***b***
Level 1(Household Level)				
CG Stigmatizing Attitudes	0.268 ***	-------	0.003	-------
CG Perception of Community Stigma	-------	0.026	-------	0.050 ***
Household Other Illness	0.758 ***	0.767 ***	−0.046 *	−0.038 †
HH Ratio Aged 15–49	0.017	0.041	0.029	0.027
HH Ratio of Adult Females	0.035	0.081	0.052 ***	0.047 ***
HH Access to Transportation	0.017	0.009	0.006	0.006
CG Subjective SES	−0.330 ***	−0.312 ***	−0.003	−0.002
CG Perception of Comm. Safety	−0.052 †	−0.084 **	0.000	0.001
PR Perception of Community Cohesion	−0.002	−0.005	0.003	0.005
HH Church Membership Importance	0.040 **	0.041 **	−0.002	−0.002
HH Ratio of Employed Adults	−0.051	0.014	−0.016	−0.010
HH Ratio of Highly Educated Adults	0.071	0.031	−0.054 ***	−0.052 ***
Household HIV-Related Death	0.115	0.154	0.019	0.017
HH Asset Index	−0.008	−0.004	−0.011 ***	−0.012 ***
Level 3 (Community Level)				
Community-Level HIV Ratio	2.776 †	1.936	0.855 ***	0.869 ***
Urban Community (rural reference)	−0.135	−0.102	0.006	0.007
High Matriculation Community	0.075	0.070	0.003	0.004
Individual-level Variance	0.923	0.930	0.015	0.015
Near-neighbor cluster-level Variance	0.015	0.023	0.001	0.001
Community-level Variance	0.015	0.020	0.000	0.000

Note.

*** $p < .001$.

** $p < .01$.

* $p < .05$.

† $p < .10$.

Table 2.

Cross-Level Relationships of HAR Stigma to HSBs and HIV Outcomes

	HSBs				Household HIV Ratio			
	Model 1a	**Model 1b**	**Model 2a**	**Model 2b**	**Model 3 a**	**Model 3b**	**Model 4a**	**Model 4b**
	b	***b***	***b***	***b***	***b***	***b***	***b***	***b***
CG Stigmatizing Attitudes	0.229***	0.262***			−0.000	0.004		
Cluster-level Stigmatizing Attitudes (m)	0.162				0.002			
Cluster-level Stigmatizing Attitudes (sd)	0.003				0.001			
Comm-level Stigmatizing Attitudes (m)		0.846†				−0.035		
Comm-level Stigmatizing Attitudes (sd)		−0.970†				0.028		
CG Perception of Community Stigma			−0.032	0.020			0.053***	0.052***
Cluster-level Per. of Comm. Stigma (m)			−0.744				−0.143*	
Cluster-level Per. of Comm. Stigma (sd)			0.955**				0.093*	
Comm-level Per. of Comm. Stigma (m)				−0.041				−0.035
Comm-level Per. of Comm. Stigma (sd)				0.463				−0.035
Level 1 (Household Level)								
Household Other Illness	0.794***	0.754***	0.832***	0.769***	−0.048*	−0.046*	−0.042†	−0.039†
HH Ratio Aged 15–49	0.036	0.008	0.038	0.040	0.035†	0.029	0.031	0.027
HH Ratio of Adult Females	0.071	0.038	0.101	0.081	0.050***	0.052***	0.046**	0.047***
HH Access to Transportation	0.017	0.015	0.008	0.008	0.006	0.006	0.005	0.006
CG Subjective SES	−0.332***	−0.332***	−0.312***	−0.311***	−0.002	−0.003	−0.001	−0.002
CG Perception of Comm. Safety	−0.054†	−0.052†	−0.081**	−0.084**	−0.001	0.000	−0.000	0.001
PR Perception of Community Cohesion	−0.004	−0.001	−0.002	−0.005	0.003	0.003	0.005	0.005
HH Church Membership Importance	0.041**	0.042**	0.040**	0.041**	−0.003	−0.002	−0.003	−0.002
HH Ratio of Employed Adults	−0.051	−0.043	−0.001	0.014	−0.018	−0.016	−0.013	−0.010
HH Ratio of Highly Educated Adults	0.092	0.067	0.069	0.032	−0.053***	−0.054***	−0.050***	−0.052***
Household HIV-Related Death	0.111	0.092	0.150	0.153	0.019	0.019	0.020	0.018
HH Asset Index	−0.011	−0.005	−0.010	−0.004	−0.012***	−0.011***	−0.013***	−0.012***
Level 3 (Community Level)								
Community-Level HIV Ratio	2.621†	2.665†	1.886	1.854	0.835***	0.863***	0.867***	0.881***

	HSBs				Household HIV Ratio			
	Model 1a	**Model 1b**	**Model 2a**	**Model 2b**	**Model 3 a**	**Model 3b**	**Model 4a**	**Model 4b**
	b	***b***	***b***	***b***	***b***	***b***	***b***	***b***
Urban Community (rural reference)	−0.135	−0.133†	−0.095	−0.106	0.007	0.006	0.009	0.008
High Matriculation Community	0.070	0.073	0.080	0.070	0.003	0.004	0.004	0.004
Individual-level Variance	0.927	0.924	0.934	0.930	0.015	0.015	0.015	0.015
Near-neighbor cluster-level Variance	0.016	0.015	0.019	0.023	0.001	0.001	0.001	0.001
Community-level Variance	0.016	0.011	0.019	0.020	0.000	0.000	0.000	0.000

Note.

*** $p < .001$.

** $p < .01$.

* $p < .05$.

† $p < .10$.

Table 3.

Results of Cluster-Level Analyses Predicting HSBs and HIV Outcomes from Cluster- Level HAR Stigma

	Cluster-Level Health Service Barriers		Cluster-Level HIV Prevalence	
	Model 1c	**Model 2c**	**Model 3c**	**Model 4c**
	b	***b***	***b***	***b***
Level 2 (Near-Neighbor Cluster Level)				
Cluster-Level Stigmatizing Attitudes (m)	0.345 *	-------	0.031 †	-------
Cluster-Level Stigmatizing Attitudes (sd)	0.001	-------		-------
Cluster-Level Per. of Comm. Stigma (m)	-------	−0.520	-------	0.085 **
Cluster-Level Per. of Comm. Stigma (sd)	-------	0.745 *	-------	
Cluster-Level Other Illness	1.248 ***	1.264 ***	−0.057	−0.050
Cluster Ratio Aged 15–49	0.630 †	0.526	−0.081 †	−0.086 †
Cluster Ratio of Adult Females	0.066	0.002	0.059 †	0.057 †
Cluster-Level Access to Transportation	0.094	0.084	0.009	0.014
Cluster-Level Subjective SES	−0.228 *	−0.241 *	0.004	0.005
Cluster-Level Per. of Comm. Safety	−0.065	−0.053	0.001	−0.001
Cluster-Level Per. of Comm. Cohesion	0.025	0.066	0.010	0.014
Cluster Church Membership Importance	0.049	0.049	0.003	0.005
Cluster Ratio of Employed Adults	0.038	−0.068	−0.003	0.000
Cluster Ratio of Highly Educated Adults	−0.132	−0.083	−0.074 **	−0.072 **
Cluster HIV-Related Death	−0.123	−0.121	−0.001	−0.004
Cluster Asset Index	0.010	−0.007	−0.006	−0.008
Cluster-Level HIV Prevalence	0.986 *	0.933 *	-------	-------
Level 3 (Community Level)				
Urban Community (rural reference)	−0.101	−0.081	0.025 **	0.024 *
High Matriculation Community	0.064	0.080	−0.008	−0.007
R^2	0.114	0.110	0.123	0.134

Note.

*** $p < .001$.

** $p < .01$.

* $p < .05$.

† $p < .10$.