Published in final edited form as:

Soc Sci Med. 2011 October ; 73(8): 1257–1265. doi:10.1016/j.socscimed.2011.07.007.

Comparing HIV-related symbolic stigma in six African countries: social representations in young people's narratives

Kate Winskell,

Hubert Department of Global Health, Rollins School of Public Health, Emory University, Atlanta, GA, USA

Elizabeth Hill, and

Hubert Department of Global Health, Rollins School of Public Health, Emory University, Atlanta, GA, USA

Oby Obyerodhyambo

Center for Health, Culture and Society, Emory University, Atlanta, GA, USA

Abstract

HIV-related symbolic stigma arises from moralistic value judgements attached to people living with HIV and has negative consequences from both public health and human rights perspectives. Relatively little is known about cross-national variation in symbolic stigma. With the purpose of informing stigma reduction efforts within and across settings, we compared social representations of HIV in six African countries with estimated adult HIV prevalence rates ranging from 1 to 33%. Our study used a unique data source, namely a stratified random sample ($n=586$, ~5%) from 11,354 creative ideas contributed from six countries to a continent-wide HIV-related scriptwriting contest held between February and April 2005. The narratives were written by equal numbers of males and females aged 10–24 in urban and rural areas of Swaziland, Namibia, Kenya, South-East Nigeria, Burkina Faso and Senegal. We combined three analytical approaches: descriptive statistics on certain quantifiable characteristics of the narratives, thematic data analysis, and a narrative-based approach. The association of HIV with outsiders (“othering”) and preoccupation with the circumstances of infection are more common in lower prevalence countries but vary substantially in tone depending on the sociocultural context. The highest proportion both of moralising narratives and of narratives with pessimistic outcomes come from South-East Nigeria and, to a lesser extent, from Kenya, countries with prevalence levels of 3.9 and 6.1% respectively, in which evangelical Christian movements, including Pentecostalism, have sizeable followings. The data provide a rare cross-cultural overview of symbolic stigma, identify country-specific needs, and point to strategies for future programming. Social representations from the highest prevalence countries, Swaziland and Namibia, and from lower prevalence Burkina Faso offer potential models for the framing of HIV in ways that serve to increase social proximity and counteract symbolic stigma.

Keywords

Swaziland; Namibia; Kenya; South-East Nigeria; Burkina Faso, and Senegal; HIV; Stigma; Youth; Social Representations; Narratives

Introduction

Described by United Nations Secretary-General Ban Ki-moon (2008) as “a chief reason why the AIDS epidemic continues to devastate societies around the world”, HIV-related stigma remains a major concern almost thirty years into the epidemic from both public health and human rights perspectives. Stigma has negative effects across the prevention to treatment continuum. It reduces access to testing and to services to prevent mother-to-child transmission, inhibits treatment uptake and adherence, negatively impacts disclosure, exacerbates the psychosocial effects of HIV infection, and reduces the life prospects and quality of life of people living with HIV (PLWHA) and their families (Deacon, Uys, & Mohlahlane, 2009; Mahajan, Sayles, Patel, Remien, Sawires, Ortiz et al., 2008). Evidence that increased access to antiretroviral therapy (ART) in sub-Saharan Africa is mitigating stigma is mixed (Genberg, Hlavka, Konda, Maman, Chariyalertsak, Chingono et al., 2009; Maman, Abler, Parker, Lane, Chirowodza, Ntogwisangu et al., 2009; B. Maughan-Brown, 2010). While ART may have loosened the association of HIV with death, it maybe less successful at loosening the association of HIV with shame, blame and immorality (C. Campbell, Foulis, Maimane, & Sibiyi, 2005).

Stigma has been defined as an ideology that allows people to distance themselves and their self-defined in-groups from the risk of infection by blaming contraction of the disease on characteristics normally associated with out-groups, who are classified as deviant and ‘other’ (Deacon, 2005; Helene Joffe, 1999). This moralistic shaming and blaming, termed symbolic stigma, is often distinguished from instrumental stigma, or the misplaced fear of infection through everyday contact with PLWHA (Herek, 2002). Our focus in this paper is symbolic stigma.

Negative beliefs are much more prevalent than negative behaviours (i.e. discrimination) toward PLWHA (B. G. Maughan-Brown, 2006). It is widely accepted that the content and intensity of stigmatising beliefs are influenced by epidemiological, sociocultural and political context. However, there is limited contextual research on stigma and relatively few studies describe stigma across settings with a view to increasing understanding of cross-cultural variability (Aggleton, 2000; Genberg et al., 2009; Holzemer, Makoe, Greeff, Dlamini, Kohi, Chirwa et al., 2009; Makoe, Greeff, Phetlhu, Uys, Naidoo, Kohi et al., 2008; Maman et al., 2009; Ogden & Nyblade, 2005; Stephenson, 2009). Contextual and comparative data of this kind are important for the development of locally-appropriate HIV/AIDS programs and for the purposes of priority-setting.

Much work remains to be done on the development of valid indices and scales to measure stigma cross-culturally, especially in generalised HIV epidemics and resource-limited countries (Mahajan et al., 2008). While survey instruments to measure stigma have recently been developed and validated for southern Africa (Deacon et al., 2009), few scales have been implemented across multiple contexts (Nyblade, 2006). Demographic and Health Surveys (DHS) remain the only comparable source of quantitative data on HIV-related stigma for many developing countries. These measure self-reported intended behaviour (e.g. willingness to interact with PLWHA in a range of hypothetical situations) and tend to focus on instrumental stigma. Concerns have been raised about their construction and cross-cultural validity (Nyblade, 2006; Stephenson, 2009; Visser, Kershaw, Makin, & Forsyth, 2008).

In parallel with attitudinal research on stigma, scholars have drawn on Social Representations Theory (Moscovici, 1981) to investigate the social construction of HIV/AIDS in the popular imagination (C. Campbell et al., 2005; Catherine Campbell, Skovdal, Mupambireyi, & Gregson, 2010; H. Joffe, 1996; H. Joffe & Bettega, 2003; Markova &

Wilkie, 1987). Social representations reflect social processes that take place between members of a social unit (Raudsepp, 2005) and communicate norms and values in symbolic form; they are therefore of particular value for research on symbolic stigma. Social representations are often pre-conscious and therefore less subject to informant bias than conscious evaluative judgements like attitudes. Narratives have been identified as a particularly valuable and underused data source for their study (Laszlo, 1997; Murray, 2002).

In this paper, we compare symbolic stigma in six African countries with contrasting HIV prevalence rates through the analysis of social representations in fictional narratives written by young people. The data provide access to the voices and imaginings of young Africans in a largely unmediated way, rather than through direct elicitation via survey, interview or focus group questions. In their creative writing about AIDS, young people draw on their own lived or imagined experience and on other culturally-determined sources of social understanding to create context, meaning and values. The narratives thus provide unique insights into their appropriation and adaptation of dominant cultural scripts around sexuality, morality and stigma.

Our analyses are informed by the emergence of specific themes from the data and by literature from a range of disciplines that identifies symbolic representations associated with HIV stigma (Gilman, 1988; Goldstein, 2004; Helene Joffe, 1999; Sontag, 1988; Treichler, 2006 (1999)). Deacon's definition of stigmatisation (Deacon, 2005, p.85), for example, identifies blame, moralization, and the association of HIV with outsiders ("othering") as key components:

a social process by which people use shared social representations to distance themselves and their in group from the risk of contracting a disease by: (a) constructing it as preventable or controllable; (b) identifying 'immoral' behaviours causing the disease; (c) associating these behaviours with 'carriers' of the disease in other groups; and (d) thus blaming certain people for their own infection and justifying punitive action against them.

In our comparative study we focus on blame, moralization and "othering" as expressed in the following dimensions of the narratives: the prominence given in plotlines to the circumstances of infection; the association of HIV with stigmatised populations or behaviours; expressions of individual blame and shame; and the demonization of PLWHA. As the affective framing and outcomes of a narrative often serve as vehicles for communicating the moral of the story, we also examine the tone of the endings of the narratives and the prevalence of HIV-related death across the country samples.

Our narrative data source allows us both to examine the content of stigmatising representations in these six distinct settings and to compare them cross-culturally. Our purpose is to inform stigma reduction efforts within and across countries.

Methods

Since 1997, contests organised by the "Scenarios from Africa" communication process have invited young Africans to contribute scripts for short fiction films to educate their communities about HIV/AIDS (Global Dialogues, 2011; Winskell & Enger, 2005). The young contest participants are mobilised by non-governmental and community-based organisations and local, national and international media across sub-Saharan Africa. A leaflet, identical in all countries and available in several major languages, is used continent-wide to provide young people with instructions on how to participate in the contest, inviting them to come up with a creative idea for a short film about HIV/AIDS up to 5 minutes in

length for distribution on national and international television. The winning ideas in each contest are selected – first at national, then at international level – by local juries and, following adaptation, transformed into short fiction films by leading African directors. Thirty-seven films (Scenarios from Africa, 2010) have been produced to date. These are donated to television stations and widely broadcast. Available in over 25 languages, the films are also used extensively as an educational resource at community level. By 2008, the process had generated an archive of approximately 55,000 narratives from 47 countries. The first author is one of the initiators of Scenarios from Africa and Oby Obyerodhyambo is national coordinator of the process in Kenya.

Study population and sample

The research described in this paper is part of a six-country study of young Africans' social representations of HIV/AIDS. Our theoretical foundations, sampling procedures and analytical methods are described in greater detail elsewhere (Winskell, Obyerodhyambo, & Stephenson, 2011). The narratives analyzed for this paper were submitted to the Scenarios from Africa contest held continent-wide from 1st February to 15th April 2005. Over 63,000 young people from 35 African countries participated in this contest, submitting approximately 23,000 narratives. For this study, we selected six non-contiguous countries/regions in which at least 500 narratives had been received, with estimated adult HIV prevalence rates in 2005 distributed along a near-exponential curve: Swaziland (33.4%), Namibia (19.6%), Kenya (6.1%), South-East Nigeria (3.9%), Burkina Faso (2%), and Senegal (0.9%) (Figure 1) (UNAIDS, 2006). A questionnaire completed by all participants provided data on socio-demographic variables (Table 1). This study was approved by Emory University Institutional Review Board.

Having stratified the data by the sex, age (10–14, 15–19 and 20–24) and urban/rural location of the author, we randomly selected ten narratives from each of the twelve strata. In some countries certain strata contained fewer than ten narratives; hence some country samples have fewer than the maximum 120 narratives (Table 2). In light of the size and cultural diversity of the Nigerian population, only those narratives from the Igbo-speaking South-East were sampled. An overall sample of 586 texts for the six countries resulted.

As contest participants self-select, the data is not representative of the youth populations; participants are likely to be better educated, and more knowledgeable and motivated about HIV than the general youth population. As a product of the same contest mechanism, however, these biases are likely to be consistent across the six countries hence the country samples, though not representative, are comparable for our purposes. Social representations are properties of social groups rather than individuals (Catherine Campbell et al., 2010). Our interest here lies with the cultural meanings that frame HIV among this youth population in and across these countries.

Data processing and analysis

The sampled narratives were transcribed verbatim in English or French and entered into MAXQDA qualitative data analysis software (VERBI Software, 1989–2010). Our analytical methodology combined: (i) descriptive statistics on certain quantifiable characteristics of the narratives (e.g. whether an HIV-related death occurred); (ii) qualitative data analysis, focusing on thematically-related text segments and memoing for emergent analytical themes; and (iii) a narrative-based approach, focusing on plot summary and thematic keywords. In the quantitative component, data were double-entered in a database. Any discrepancies were resolved by means of dialogue. The data were transferred to Microsoft Excel, where descriptive statistics were computed. For the qualitative component, descriptive codes (Miles & Huberman, 1994) were applied to the data with reference to a

detailed codebook covering 65 HIV-related themes, including “commercial sex work(er)”, “multiple partners”, “intentional infection”, etc. For the narrative-based component, a one-paragraph narrative summary, comprising the key elements of plot and message, was written for each story and this was coded with up to six (of 45 available) keywords per story. All coding was completed by trained research assistants and reviewed in detail by the first author to ensure consistency.

We triangulated between the methodological approaches, for example, using the qualitative analyses to illuminate the quantitative data, and vice versa. Our qualitative analyses also drew on code frequencies and intersections. This was important in light of the size and scope of our data and our focus on comparing the representations across countries. The narrative-based component provided a holistic perspective to counteract any fragmentation or decontextualisation of the data resulting from the other analytic components.

In the quotes that follow, country names are abbreviated as follows: SZ – Swaziland; NM – Namibia; KY – Kenya; NG – Nigeria; BF – Burkina Faso; and SN – Senegal. Excerpts are identified by the country, sex, age and geographic location of the author. For example, an excerpt followed by “(NM, F 15–19 R)” comes from a female participant in the 15–19 age group from rural Namibia.

Results

HIV Genre

Genre is regarded as a measure of the cultural resources available to people as they try to make sense of a new phenomenon (Plummer, 1995). We categorised the narratives into HIV-related genres based on whether the plot focused thematically on prevention, infection, the post-infection period, or a combination of these (Figure 2).

Narratives from countries with lower prevalence have a higher proportion of plots focusing on a character becoming infected, suggesting that preoccupation with the circumstances of infection is more dominant in these settings. The sample from South-East Nigeria has the highest proportion of infection narratives. Approximately half of the Nigerian and Senegalese narratives focus on infection, compared to fewer than one in five of the Swazi sample. In contrast, one third of the Swazi narratives focus on the post-infection period, the focus of only one in ten narratives in the Nigerian and Senegalese samples. There are no notable differences by sex, age or urban/rural location of the author.

The Nigerian narratives are distinguished by an unforgiving moral agenda, dominated by conservative Christian dogma on sexuality, and tend to focus on the misdeeds of characters, primarily female, that lead to their infection. This is often evident from the tone in which characters are described. One narrative, for example, characteristically describes its female protagonist as “a very bad girl who sniked out of school every night to sleep with men in hotels” (NG, F 15–19 R). The young Nigerian authors rarely envisage situations in which characters take timely action to avoid infection. For example, condoms are used in only three acts of sex described in the 120 Nigerian stories and fail in each case, leading to infection.

The narratives from high-prevalence Swaziland are, in contrast, more diverse in basic plot structure and are framed more positively. One narrative describes a young woman going through the painful process of coming to terms first with her father’s then her mother’s illness and death, under the care of her aunt and grandmother, seeking inspiration from her mother’s advice that God would help them and she would “grow to be a young woman of tomorrow” (SZ, F 10–14 R). In another story, a young boy who is stigmatised at school,

dreams of becoming a doctor so he can care for his infected father (SZ, M 15–19 R). Despite the palpable presence of AIDS, the characteristic tone of the stories is not one of tragedy, but of human resilience and agency, suggesting that the country's extremely high prevalence may be favouring the emergence of cultural resources that promote coping.

Othering

Across the sample, there are occasional references to homosexuality as a risk factor for HIV; those in the Nigerian texts are most stigmatising. However, the populations most frequently associated with HIV are commercial sex workers and their clients, characters with multiple partners and, in certain country samples, foreigners. Despite stating that “virtually every body is at risk of getting AIDS,” one young Nigerian author leaves no doubt about which populations he considers to be especially affected and blameworthy:

Those who have indiscriminate or casual sex with many sex partner Those who indulge in lewd sex practices for eg, anal sex (homosexuality) Those who patronise the sex trade, that is those who patronise harlots and prostitutes. (NG, M 10–14 U)

Commercial sex work

The theme of commercial sex work is rare in the Swazi and Namibia samples, but present in around one in five narratives from the four lower prevalence country samples, where it may be treated as a mark of immorality or opportunism on the part of sex workers or their clients, or as a symptom of extreme poverty. While all four country samples include narratives with greater or lesser sympathy for commercial sex workers, those in the Burkinabè, Senegalese and Kenyan samples – the countries in our study with the lowest per capita GDP – are most likely to contextualise sex work within material need. Here, poor women may resort to sex work to support their families or meet basic needs, including school fees, while some are tricked or coerced into the industry. Even when the reason for commercial sex work is unspecified, the narratives may be non-moralistic. In one narrative from Burkina Faso, a young village man falls in love and marries a young city woman without taking the time to get to know her. He later learns that she had been a commercial sex worker, so they get tested for HIV. Their results are negative, allowing them to resume their lives without fear of infection (BF, F 15–19 U).

The Nigerian texts are much more likely to dwell on the blame and shame of sex work; isolated examples in the Kenyan sample strike a similar note. One Kenyan narrative, for example, recounts the narrator's conversation with a recently-diagnosed neighbour, “I told her that if you get AIDS that's not the end of the world the worse thing was that before she got infected she was a prostitution and the leader” (KY, F 10–14 U). While implying support for her neighbour's current predicament, the narrator perpetuates moral judgement around the circumstances of her infection. Mixed messages such as these are particularly distinctive of the Kenyan sample.

Foreigners

In around 5% of narratives, foreigners are the source, or international travel the context of HIV infection. This is the case in occasional texts from Swaziland, Kenya and Burkina Faso, and in a handful of the Nigerian narratives. However, the sample from Senegal, the lowest prevalence country, dwarfs all others in this respect, with Senegalese characters being infected by foreigners in one in eight texts. The primary source of infection for the Swazi and Burkinabè texts is neighbouring South Africa and Côte d'Ivoire respectively; for the Kenyan and Nigerian texts it is the USA, represented as a place of lax sexual morality; and for the Senegalese texts it is Europe or the European tourists who frequent the country's coastal resorts. In the Senegalese sample both male and female characters, lured by money

and the promise of travel, are infected by foreign tourists, sometimes intentionally. In one narrative, a doctor reprimands the parents of a newly-diagnosed young woman for letting their child marry a foreigner, arguing that they bring the virus and corrupt people with their money (SN, M 15–19 R).

Promiscuous

Across the six countries, the proportion of narratives in which characters are “promiscuous” or have multiple sexual partners increases as prevalence decreases, from fewer than one in ten in Swaziland to one in five in Senegal. For male characters, having multiple partners may be facilitated by wealth, good looks and being good at football. For female characters, it may be associated with beauty, a desire for material goods, a lack of parental supervision and guidance, or poverty. Like commercial sex work, the theme can therefore be inflected in ways that associate it either with immorality or with mitigating circumstances.

Despite the prevalence of the theme of promiscuity in the Senegalese sample and its clear identification as a risk factor for HIV, it tends to be treated with relative moral equanimity. Thus one male character is described in the following terms, “everyone in the neighbourhood loved Laye. He was a good son, but his only fault was that he liked girls too much and never used protection” (SN, M 20–24 U). Laye goes on to test negative for HIV and becomes an advocate for HIV prevention. In another narrative, a young female character has sex with all her prior suitors in order to raise money for her mother to have a life-saving operation. When she learns she has contracted HIV, she has no regrets as her action had saved her mother’s life (SN, M 10–14 U).

Although the term “vagabondage sexuel” (i.e. promiscuity, or literally “sexual tramping”) recurs repeatedly in narratives from Burkina Faso, the second lowest prevalence country, the tone is rarely blaming. It is unprotected sex rather than indiscriminate sex that is vilified. Blame is reserved primarily for those who knowingly put others at risk, including wealthy men who pay young women to have unprotected sex with them or men who neglect their family responsibilities.

The multiple-partner narratives that are most moralistic are those from Nigeria, where behaviour is frequently inflected in terms of religious morality. Thus, characters have “good” or “bad” behaviour, succumb to “temptation”, ask “forgiveness” from family members, and “repent their sins”. In one narrative, a young man returning sick to his wife after two years in the US expresses his regrets, “look at what pursuing women have done to me... now I have contacted disease HiV AiDS. my life is no more with me, I can remember what bible said that the wages of sin is death” (NG, F 10–14 R). Around half of the Kenyan narratives that address the theme of multiple partners use similarly moralistic language. Several narratives illustrate the speed with which HIV spreads through a chain of sexual partners, leading to multiple deaths. One particularly melodramatic narrative, in which an entire family is infected, ends with the words, “All the family in one frying pan. God forgive us” (KY, F 15–19 R).

Expressions of personal blame and shame

While no country sample is devoid of expressions of personal blame and shame, these differ in volume and intensity. They are rarest in the Swazi, Namibian and Burkinabè samples. Expressions of blame are most likely to draw on conventional sexual morality derived from conservative religious sources in the Nigerian and Kenyan samples, while in the Burkinabè sample in particular they are more likely to relate to a secular code of ethics based on individual responsibility to others.

In many of the Nigerian narratives, characters become infected either as a result of a moral character flaw or because they fall victim to peer pressure. Statements attributing HIV to divine punishment for fornication and adultery recur and there is a pervasive presumption that “HIV/AIDS is spread through wrong morality and wrong sex life” (NG, M 15–19 R). In one narrative, a post-test counsellor bluntly tells a newly-diagnosed young woman, “You invited problems to yourself. So you have to bear it. You had unprotected sexual intercourse with them” (NG, M 15–19 R). In a similar vein, one young Kenyan author presents her narrative with the following words, “Here is our example of someone who misbehaved and got AIDS” (KY, F 10–14 U).

The Kenyan narratives are, however, highly polarised. Both the country sample as a whole and individual narratives are divided between a rigid sexual morality that blames individuals for infection and empathy with those who are infected, affected or vulnerable. The association of HIV with immorality is challenged in an emotionally powerful way in isolated narratives from Kenya and from Namibia when children question whether they were orphaned by AIDS as punishment for their bad behaviour or if their deceased parents were sinners. The Kenyan narratives, like those from Burkina Faso and Senegal, are also particularly sensitive to the economic vulnerability of young women.

In several narratives in the Senegalese sample, individuals become infected not because they are bad people, but because they make mistakes with serious consequences. However, of the four lowest prevalence countries, the Burkinabè sample is most accepting and forgiving of human foibles, allowing characters to change their behaviours without penalty. Of all country samples, for example, it has the highest proportion of narratives in which characters test negative for HIV. A recurrent theme in the Burkinabè narratives, however, is the responsibility of PLWHA who know their status to ensure that they do not infect others. In one narrative, an HIV+ husband is castigated for failing to disclose the results of his pre-marital test to his wife, thereby condemning her to die like him and their children to be infected and orphaned. The narrator concludes, “It is these kinds of irresponsible people who spread HIV/AIDS” (BF, F 15–19 U).

Demonization of PLWHA

Two countries – Nigeria and Senegal – dominate in the proportion of narratives (one in ten in each country) focusing on HIV-infected characters who intentionally infect others. Characters deliberately infect others or plan to do so in a spirit of revenge, on the pretext that someone gave it to them, or because they do not want to die alone. The Senegalese sample, for example, includes narratives in which HIV-infected female characters, in a biologically implausible plan to infect others, add their blood to red bissap juice and distribute it for widespread consumption. In one such narrative, three women writhe in diabolical laughter as they share their demonic plans (SN, M 15–19 U). These representations are nonetheless more consistent with the moral tenor of the Nigerian than the Senegalese narratives.

Outcomes and tone of narratives

The proportion of narratives in each country sample in which a character dies as a result of HIV (whether due to AIDS-related causes or suicide) is highest in the sample from South-East Nigeria, followed by Kenya. There are no notable differences by sex, age or urban/rural location. A similar pattern is observed in the distribution of narratives categorised as “ending with diagnosis or death without envisaging a fulfilling life between”, a measure of hopelessness.

An HIV-related death occurs in almost two-thirds of Nigerian narratives and a similar proportion end without hope. Suicide in response to diagnosis is common and there are several examples of parents dropping dead or hanging themselves in response to a child's disclosure. Although 80% of Senegalese narratives are related to infection, characters die an HIV-related death in only one in four texts. Some of the Senegalese narratives end with diagnosis or disclosure, or with characters contemplating suicide, and thereby circumvent the occurrence of death in the closing paragraphs. Contemplated, attempted, or completed suicide is nonetheless prominent in the Senegalese sample, occurring in around 13% of the narratives.

Across the country samples, the ending may be framed positively by virtue of one or a combination of the following: support from friends or family, the PLWHA assuming an advocacy role, the PLWHA accessing ART and/or other HIV-related services, and/or the birth or prospect of a healthy child thanks to PMTCT (prevention of mother-to-child transmission). In the Swazi sample, there are cases where characters die or commit suicide or are abandoned or rejected. However, more commonly, friends or doctors support them and tell them how they can live a long life with HIV. Particularly frequent in the Swazi scenarios are calls for PLWHA to eat a balanced diet, exercise regularly and have a positive attitude. Even in the absence of ART, there are statements that "being HIV positive does not mean the end of your life, but still your dreams can come true" (SZ, M 10–14 R). In some cases, however, ART is pivotal. After the death of their newborn, a couple in one Namibian narrative tests positive for HIV. With the help of a counsellor, they learn about ART and their next baby is born healthy (NM, M 20–24 U).

Discussion

In their quantitative study of HIV stigma in four countries, Genberg et al. (2009) found more negative attitudes in sites with the lowest HIV prevalence. There are some parallels to these findings in our own analysis of representations in the narratives. Plotlines that focus on the circumstances of infection and the association of HIV with outsiders ("othering") are, for example, more common in samples from lower prevalence countries. In these more concentrated epidemics, there are epidemiological grounds for HIV being associated in the popular imagination with higher-risk groups and behaviours. In the higher prevalence countries, in contrast, where risk may be considered ubiquitous (Maman et al., 2009), closer social proximity to the epidemic may promote greater compassion and personal risk perception and reduce blaming (Genberg et al., 2009).

While the association of HIV with high-risk groups in narratives from lower prevalence countries implies social distancing, representations in these country samples vary substantially in tone depending on the sociocultural context. Concentrated epidemics have been associated with the layering of HIV stigma onto other socially stigmatised conditions (Genberg et al., 2009). However, in narratives from Burkina Faso in particular, the "othering" we observe appears to be more epidemiologically than morally-driven, with the young authors demonstrating empathy and sensitivity to the structural factors that increase vulnerability. The association of HIV with commercial sex work in these representations thus serves less to reinforce an existing social stigma than to acknowledge the HIV-related risks that accompany poverty. It is notable that those countries whose narratives are most likely to situate commercial sex work within material need – Burkina Faso, Senegal (where prostitution has been legal since 1969) and Kenya – have the lowest per capita GDP in our study. In the case of Senegal's consistently concentrated epidemic, the representation of sexually predatory tourists as sources of HIV appears to be grounded both in lay epidemiology and in post-colonial resentment of the vast economic disparities between tourists and host population.

Such references to socioeconomic vulnerability are absent from the most stigmatising representations from South-East Nigeria and Kenya. Here, Christian references play a dominant role. Prince et al. (Prince, Denis, & van Dijk, 2009) highlight the growing influence of Christianity in framing understandings of and shaping responses to AIDS in some African countries, citing both the visibility of faith-based organisations supported by the US President's Emergency Plan for AIDS Relief (PEPFAR) since 2004 and Pentecostalism's rapid growth and its increasing engagement with AIDS.

The influence of Christianity, particularly evangelical and Pentecostal, on HIV-related stigma among young Igbo people has been described in depth by Smith (2004). Within the narratives from South-East Nigeria there is a pronounced focus on upward social mobility associated with adherence to strict sexual morality that is consonant with Pentecostalism's Prosperity Gospel. In Kenya, members of Pentecostal and charismatic movements account for more than half of the population (Pew Forum on Religion & Public Life, 2006). Describing the response to HIV/AIDS of Kenyan Pentecostal churches, Parsitau (2009) cites growing sensitivity towards stigma among some leaders in recent years. While several of the Kenyan narratives demonstrate the ongoing influence of a Christian rhetoric that associates AIDS with sin, tension between this inflexible ideology and anti-stigma messaging may shed some light on the mixed messages we observe in the country sample.

In a recent nationally representative survey, 86% of Kenyan Christians, 80% of Nigerian Christians and 98% of Senegalese Muslims (who comprise over 90% of that nation's population) said that religion was very important in their lives (Pew Forum on Religion & Public Life, 2010). Despite very high levels of religiosity in Senegal, both specific programmatic and pre-existing cultural factors may have led to less overtly stigmatising discourse there. Religious leaders were first involved in HIV prevention in Senegal in 1995, when two government-sponsored summits on AIDS were held for Muslim and Christian leaders (Gilbert, 2008). In their study of Senegalese religious leaders and HIV, Ansari and Gaestel (2010) found Muslim leaders willing to acknowledge the severity of the epidemic and to challenge the environment that promotes negative conditions for PLWHA, but more likely to focus on prevention than care-related issues. Despite Islam's tradition of fighting stigmatisation and leaving moral judgments to God, they concluded that there was still much work to be done. Burkina Faso's largely harmonious mix of Islam, animism, and Christianity may contribute to the lack of overt moralising in that country sample (US Department of State, 2010).

Genberg et al. (2009) found that negative attitudes towards PLWHA were related to never having tested for HIV, lacking knowledge of ARVs, and never having discussed HIV/AIDS. They observed the highest perceived discrimination of PLWHA in sites with the least support and care available to PLWHA. Our findings specific to symbolic stigma are more mixed. For example, the narratives from the countries with the highest and lowest prevalence rates are the most hopeful, while those from Kenya and South-East Nigeria include the highest proportion featuring HIV-related deaths and bleak endings. Comparison of data from DHS surveys conducted in the six countries closest in date to the 2005 contest shows that the percentage of young people aged 15–24 testing for HIV relates approximately to prevalence, although rates for Swaziland, particularly among males, are lower than for Namibia and occasionally for Kenya (Measure DHS, 2009). ART coverage, however, diverged substantially from prevalence. Estimated ART coverage in the six countries at December 2005 was Swaziland 31%, Namibia 71%, Kenya 24%, Nigeria 7%, Burkina Faso 24% and Senegal 47% (World Health Organization, 2006). Although ART coverage rates disaggregated by region are not available for Nigeria, it is likely that South-East Nigeria had much lower ART coverage rates than any of the other sites in our six-country study. While this may account for some of the pessimism observed in the Nigerian narratives, the fact that

Burkina Faso and Kenya have identical estimated coverage rates and that Swaziland's is only 7% higher suggests that more is at play in the distribution of stigmatising representations than ART coverage alone.

Within our symbolic data, it could be that ART coverage is less important for low prevalence countries than perceived effectiveness of ART, given that most of the young authors in these countries are likely to have limited social contact with PLWHA. In addition, HIV-related services in these settings may be less important as a means of mitigating the burden of HIV on families (i.e. reducing resource-based stigma), and more important for their symbolic value, indicating that the provision of services to PLWHA is socially sanctioned.

Recourse to a range of plot developments, including ART, that allow the narratives to be framed more positively, is contingent on the author's willingness to allow their characters to survive and live fulfilling lives despite HIV infection. In the Nigerian sample, it appears that the potential to live well with HIV thanks to ART – or to avoid HIV transmission during pre-marital sex through condom use – may fall foul of the moral imperative many young authors see themselves as tasked with conveying in their narratives. Many of the Nigerian and some of the Kenyan narratives suggest an implicit commitment to the power of the threat of AIDS and the social stigma it entails as a moral deterrent.

While HIV prevalence, sociocultural factors, and HIV-related services all appear to contribute to the young Africans' social representations, additional research is needed to better understand the cross-national variation we observe and to examine how this relates to national or bilateral policy, country-level response, education and communication efforts, and aspects of local sociocultural context. Future longitudinal research on narratives collected by Scenarios from Africa between 1997 and 2011 will also allow us to track changes in social representations of HIV in the six countries over time.

Although there is limited evidence of interventions designed to reduce stigma leading to sustained effects (Mahajan et al., 2008), it is clear that cultural meanings about HIV in the six countries are informing the kinds of narratives that young people tell, especially in lower prevalence countries where the young authors are likely to have less personal exposure to the epidemic. Our data suggest that the holistic framing of HIV at the country level (as opposed to discrete stigma reduction campaigns) inform these social representations and play an important role in influencing how young people make sense of HIV and those infected. This suggests that there are opportunities to frame HIV in increasingly constructive ways.

Although we have highlighted stigmatising representations in this paper, it is important not to neglect representations that may mitigate HIV stigma and reveal possibilities for agency, resistance and intervention (Catherine Campbell et al., 2010). The positive empowering representations of HIV that are present in the narratives are instructive for mass media and community-based communication efforts. While there are examples of favourable representations in each of the country samples, these are most notable in narratives from the highest prevalence countries, Swaziland and Namibia, and from lower prevalence Burkina Faso.

Within our data, empathic and empowering post-infection narratives from Swaziland and Namibia model a powerful emotional response to hyperprevalence. Macintyre and Kendall's theory of social proximity (2008) posits that, *regardless of prevalence*, denial of HIV – at the community and national level – fuels stigma and stymies the potential for widespread behaviour change; social proximity, in contrast, implies a greater public sense of immediacy and risk, with potentially transformative consequences. It would appear that the response to

HIV in relatively low-prevalence Burkina Faso, like that in high-prevalence Swaziland and Namibia, has served to emphasise vulnerability and to weaken the association of HIV with immorality in young people's social representations, reflecting comparatively high social proximity. A partial explanation may lie in the fact that the first national population-based seroprevalence survey, part of the 2003 Burkina DHS+, resulted in a revision of estimated adult prevalence from 4.2% to 2.0%: social representations of HIV among young Burkinabè in 2005 may reflect the original higher perceived prevalence rate and the concomitantly more vigorous country-level response. In Nigeria, where 60% of a nationally representative sample agreed that AIDS is God's punishment for immoral sexual behaviour (Pew Forum on Religion & Public Life, 2010), the potential for the development of social proximity appears to be inhibited by a cultural context of virulent moralization, which perpetuates stigma and denial.

Although the DHS stigma measures are contentious, composite scores for the surveys conducted in the study countries closest in date to the 2005 contest approximate to our findings (Measure DHS, 2009). They are, for the most part, inversely related to prevalence, with the exception that South-East Nigeria scores lower than Senegal despite having a higher prevalence. Unfortunately, a composite score for Burkina Faso is not available.

We cannot extrapolate from our analysis of symbolic stigma to the experience of stigma by PLWHA in these countries. There is ample evidence of the burden of stigma on PLWHA and its negative impact on access to services in high prevalence Swaziland (Root, 2010) and lower prevalence Burkina Faso (Hejoaka, 2009) alike. What is clear, however, is that the ways in which young people in the different settings make sense of HIV in their narratives differs substantially and that this tells us about the cultural meanings that frame HIV for them. Elements of these same cultural meanings may be expected to inform other forms of stigma among young people in these settings. Additional research is needed to better understand the relationship between symbolic stigma and other forms of perceived or enacted stigma and the pathways through which they are linked.

This study is not without limitations. Participants in the Scenarios from Africa contests self-select and the sample is not representative of the youth population. We follow Farmer and Good (1991) in acknowledging the potential role that culturally-specific performative and rhetorical considerations may be playing in these representations: the young authors' motivation to tell what they consider to be a good story – and thereby win the Scenarios contest – may be influencing the ways in which they represent HIV/AIDS. Despite these limitations, the opportunities that the data present to gain insight into social representations of HIV/AIDS among young people in six countries are unique. This is to our knowledge the first study of its kind to explore and compare social representation across six countries as a measure of HIV-related symbolic stigma.

Conclusion

The data provide a rare cross-cultural overview of symbolic stigma, identify country-specific needs, and point to strategies for future programming. "Othering" and preoccupation with the circumstances of infection and are more common in lower prevalence countries but vary substantially in tone depending on the cultural context. Social representations from the highest prevalence countries, Swaziland and Namibia, and from lower prevalence Burkina Faso offer potential models for the framing of HIV in ways that serve to counteract symbolic stigma.

Young people's representations in their fictional narratives reveal the "powerful symbolic apparatus" (Parker & Aggleton, 2003) on which stigma depends. It is important to mobilise

communities to engage in critical thinking about the webs of representation that feed stigma (C. Campbell et al., 2005). These narratives identify context-specific social representations which may be deconstructed in community dialogue or challenged through the dissemination of alternative cultural models.

Acknowledgments

The research described here was supported by Grant Number 1R03 HD054323 01 A1 from the National Institute of Child Health and Human Development. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the National Institute of Child Health and Human Development. This research was also supported in part by the Emory Center for AIDS Research (P30 AI050409) and by Emory Global Health Institute. Special thanks go to Kim Miller and Rob Stephenson for their advice and guidance. Thanks also to research assistants Chris Barnett, Laura Beres, Camilla Burkot, Liz Coleclough, Wendee Gardner, Rosalie Haughton, Samantha Huffman, Amy Patterson, Caddie Putnam Rankin and Kanaka Sathasivan. We are grateful to Peter J. Brown, Jennifer Hirsch and Kimberly Hagen for their support during early stages of this research.

References

- Aggleton, P. HIV and AIDS-related stigmatization, discrimination and denial: forms, contexts and determinants: Research studies from Uganda and India. Geneva: UNAIDS; 2000.
- Ansari DA, Gaestel A. Senegalese religious leaders' perceptions of HIV/AIDS and implications for challenging stigma and discrimination. *Culture, Health & Sexuality*. 2010; 12(6):633–648.
- Campbell C, Foulis CA, Maimane S, Sibiyi Z. "I Have an Evil Child at My House": Stigma and HIV/AIDS Management in a South African Community. *American Journal of Public Health*. 2005; 95(5):808–815. [PubMed: 15855456]
- Campbell C, Skovdal M, Mupambireyi Z, Gregson S. Exploring children's stigmatisation of AIDS-affected children in Zimbabwe through drawings and stories. *Social Science & Medicine*. 2010; 71:975–985. [PubMed: 20591546]
- Deacon, H. Understanding HIV/AIDS Stigma: A theoretical and methodological analysis. Cape Town: Human Sciences Research Council; 2005.
- Deacon, H.; Uys, L.; Mohlahlane, R. HIV and Stigma in South Africa. In: Rohleder, P.; Swartz, L.; Kalichman, SC.; Simbayi, LC., editors. *HIV/AIDS in South Africa 25 Years On: Psychosocial Perspectives*. New York: Springer; 2009. p. 105-120.
- Farmer, P.; Good, BJ. Illness Representations in Medical Anthropology: A Critical Review and a Case Study of the Representation of AIDS in Haiti. In: Skelton, JA.; Croyle, RT., editors. *Mental Representations in Health and Illness*. New York: Springer-Verlag; 1991. p. 132-162.
- Genberg BL, Hlavka Z, Konda KA, Maman S, Chariyalertsak S, Chingono A, et al. A comparison of HIV/AIDS-related stigma in four countries: Negative attitudes and perceived acts of discrimination towards people living with HIV/AIDS. *Social Science & Medicine*. 2009; 68(12):2279–2287. [PubMed: 19427086]
- Gilbert SS. The Influence of Islam on AIDS Prevention among Senegalese University Students. *AIDS Education & Prevention*. 2008; 20(5):399–407. [PubMed: 18956981]
- Gilman, SL. *Disease and Representation: Images of Illness from Madness to AIDS*. Ithaca and London: Cornell University Press; 1988.
- Global Dialogues. 2011. www.globaldialogues.org
- Goldstein, DE. *Once Upon a Virus: AIDS Legends and Vernacular Risk Perceptions*. Logan, Utah: Utah State University Press; 2004.
- Hejoaka F. Care and secrecy: Being a mother of children living with HIV in Burkina Faso. *Social Science & Medicine*. 2009; 69(6):869–876. [PubMed: 19540644]
- Herek GM. Thinking about AIDS and stigma: A psychologist's perspective. *Journal of Law Medicine & Ethics*. 2002; 30(4):594–607.
- Holzemer WL, Makoe LN, Greeff M, Dlamini PS, Kohi TW, Chirwa ML, et al. Measuring HIV stigma for PLHAs and nurses over time in five African countries. *Sahara-J Journal of Social Aspects of HIV-AIDS*. 2009; 6(2):76–82.

- Joffe H. AIDS research and prevention: A social representational approach. *British Journal of Medical Psychology*. 1996; 69(3):169–190. [PubMed: 8883972]
- Joffe, H. *Risk and ‘the other’*. Cambridge: Cambridge University Press; 1999.
- Joffe H, Bettega N. Social representation of AIDS among Zambian adolescents. *Journal of Health Psychology*. 2003; 8(5):616–631. [PubMed: 19177721]
- Ki-Moon, B. The stigma factor. *The Washington Times*; 2008.
- Laszlo J. Narrative organisation of social representations. *Papers on social representations*. 1997; 6:155–172.
- Macintyre, K.; Kendall, C. A Theory of Social Proximity: Accounting for Societal-Level Behavior Change. In: Feldman, DA., editor. *AIDS, Culture and Africa*. Gainesville: University of Florida Press; 2008. p. 57-73.
- Mahajan AP, Sayles JN, Patel VA, Remien RH, Sawires SR, Ortiz DJ, et al. Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *Aids*. 2008; 22(Suppl 2):S67–S79. [PubMed: 18641472]
- Makoe LN, Greeff M, Phetlhu RD, Uys LR, Naidoo JR, Kohi TW, et al. Coping with HIV-related stigma in five African countries. *Janac-Journal of the Association of Nurses in Aids Care*. 2008; 19(2):137–146.
- Maman S, Abler L, Parker L, Lane T, Chirowodza A, Ntongwisangu J, et al. A comparison of HIV stigma and discrimination in five international sites: The influence of care and treatment resources in high prevalence settings. *Social Science & Medicine*. 2009; 68(12):2271–2278. [PubMed: 19394121]
- Markova I, Wilkie P. Representations, Concepts and Social Change -The Phenomenon of AIDS. *Journal for the Theory of Social Behaviour*. 1987; 17(4):389–409.
- Maughan-Brown B. Stigma rises despite antiretroviral roll-out: A longitudinal analysis in South Africa. *Social Science & Medicine*. 2010; 70(3):368–374. [PubMed: 19892454]
- Maughan-Brown BG. Attitudes towards people with HIV/AIDS: Stigma and its determinants amongst young adults in Cape Town, South Africa. *South African Review of Sociology*. 2006; 37(2):165–188.
- Measure DHS. HIV/AIDS Survey Indicators Database. 2009.
- Miles, MB.; Huberman, MA. *Qualitative Data Analysis: An Expanded Sourcebook*. Thousand Oaks, London, New Delhi: Sage Publications; 1994.
- Moscovici, S. On social representations. In: Forgas, JP., editor. *Social cognition: Perspectives on everyday understanding*. London: Academic Press; 1981. p. 181-209.
- Murray M. Connecting narrative and social representation theory in health research. *Social Science Information*. 2002; 41(4):653–673.
- Nyblade L. Measuring HIV stigma: Existing knowledge and gaps. *Psychology, Health & Medicine*. 2006; 11:335–345.
- Ogden, J.; Nyblade, L. *Common at its Core: HIV-Related Stigma Across Contexts*. Washington, DC: International Center for Research on Women; 2005.
- Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine*. 2003; 57(1):13–24. [PubMed: 12753813]
- Parsitau DS. “Keep Holy Distance and Abstain till He Comes”: Interrogating a Pentecostal Church’s Engagements with HIV/AIDS and the Youth in Kenya. *Africa Today*. 2009; 56(1):45–64.
- Pew Forum on Religion & Public Life. Overview: Pentecostalism in Africa. 2006.
- Pew Forum on Religion & Public Life. Topline Survey Results. 2010. *Tolerance and Tension: Islam and Christianity in Sub-Saharan Africa*.
- Plummer, K. *Telling Sexual Stories: Power, Change and Social Worlds*. London: Routledge; 1995.
- Prince R, Denis P, van Dijk R. Introduction to Special Issue: Engaging Christianities: Negotiating HIV/AIDS, Health, and Social Relations in East and Southern Africa. *Africa Today*. 2009; 56(1):v–xviii.
- Raudsepp M. Why Is It So Difficult to Understand the Theory of Social Representations? *Culture & Psychology*. 2005; 11(4):455–468.

- Root R. Situating experiences of HIV-related stigma in Swaziland. *Global Public Health*. 2010; 5(5): 523–538. [PubMed: 19787517]
- Scenarios from Africa. 2010. www.scenariosfilms.org
- Smith DJ. Youth, sin and sex in Nigeria: Christianity and HIV/AIDS-related beliefs and behavior among rural-urban migrants. *Culture, Health & Sexuality*. 2004; 6(5):425–437.
- Sontag, S. *AIDS and its Metaphors*. New York: Picador; 1988.
- Stephenson R. Community factors shaping HIV-related stigma among young people in three African countries. *AIDS Care*. 2009; 21(4):403–410. [PubMed: 19283643]
- Treichler, PA. *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*. Durham and London: Duke University Press; 2006 (1999).
- UNAIDS. Report on the global AIDS epidemic. Geneva: UNAIDS; 2006.
- US Department of State. International Religious Freedom Report 2010. Washington, DC: 2010. Burkina Faso.
- VERBI Software. MAXQDA, software for qualitative data analysis. Berlin-Marburg-Amöneburg, Germany: Consult. Sozialforschung GmbH; 1989–2010.
- Visser MJ, Kershaw T, Makin JD, Forsyth BWC. Development of parallel scales to measure HIV-related stigma. *AIDS and Behavior*. 2008; 12(5):759–771. [PubMed: 18266101]
- Winskell, K.; Enger, D. Young Voices Travel Far: A Case Study of Scenarios from Africa. In: Hemer, O.; Tufte, T., editors. *Media and Glocal Change: Rethinking Communication for Development*. Buenos Aires/Goteborg: Clasco/Nordicom; 2005. p. 403-416.
- Winskell K, Obyerodhyambo O, Stephenson R. Making sense of condoms: Social representations in young people's HIV-related narratives from six African countries. *Social Science & Medicine*. 2011; 72(6):953–961. [PubMed: 21388731]
- World Health Organization. Progress on Global Access to HIV Antiretroviral Therapy: A Report on “3 by 5” and Beyond. Geneva: World Health Organization; 2006.

Figure 1.
Study countries/regions and 2005 estimated HIV prevalence (ages 15–49) (UNAIDS, 2006)

Figure 2.
Distribution of HIV-related genre within the country samples

Table 1

Demographics of participants in the 2005 contest from six study countries (n=11,354)

	Total narratives submitted in 2005	Total participants	% team authored	Mean age of author	% male author	% urban author
Swaziland	510	1,244	27%	14.6	34%	26%
Namibia	657	963	10%	14.8	50%	13%
Kenya	673	966	14%	16.7	53%	69%
Nigeria	1,869	2,712	9%	16.7	30%	40%
Burkina Faso	4,821	15,710	25%	16.8	61%	66%
Senegal	2,824	4,360	16%	15.4	46%	80%
TOTAL	11,354	25,955				

Table 2

Characteristics of study sample (n=586)

	Number of narratives	Mean age of author	% male author	% urban author
Swaziland	73	15.4	47	37
Namibia	75	17.2	55	31
Kenya	91	18.0	52	66
SE Nigeria	120	17.1	50	50
Burkina Faso	120	16.8	50	50
Senegal	107	16.5	48	56
Totals	586	16.9	50	49