Glob Public Health. Author manuscript; available in PMC 2016 September 01.

Published in final edited form as:

Glob Public Health. 2015 September; 10(8): 917-929. doi:10.1080/17441692.2015.1045917.

Making sense of HIV stigma: representations in young Africans' **HIV-related narratives**

Kate Winskella,*, Kathleen Holmesa, Elizabeth Neria, Rachel Berkowitza, Benjamin Mbakwemb, and Oby Obyerodhyamboc

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

^bCommunity & Youth Development Initiatives, Owerri Municipal, Imo State, Nigeria cPATH Kenya, Nairobi, Kenya

Abstract

In addition to undermining the quality of life of those infected and affected by HIV, HIV-related stigma impedes access to prevention and treatment services, thereby threatening to erode the promise of recent advances in these areas. This paper provides insights into the socio-contextual and sense-making processes that inform HIV stigma through an innovative form of empirical data: creative fictional narratives written by young Africans (aged 10-24) for an HIV-themed scriptwriting competition. From a sample of 586 narratives from six sub-Saharan countries, we selected for illustrative purposes three on account of the complexity of their representation of HIV stigma. We conducted a close reading of each, using stigma theory as a lens. Through their explicit accounts of stigmatizing attitudes and behaviours of characters and through implicit contradictions, tensions, and ambivalence in their messaging, the narratives provides insights into the symbolic and social processes that create and sustain HIV stigma. Our analysis illuminates the authors' struggles to navigate the cultural resources available to them in their efforts to make sense of HIV, gender and sexuality. It highlights some limitations of current communication efforts and the potential for narrative-based communication approaches to engage with representations that devalue women and people living with HIV.

Keywords

| HΙV | stigma; sub-Sanaran Africa | ; youtn; narrative | |
|-----|----------------------------|--------------------|--|
| | | | |

Introduction

In the fourth decade of the epidemic, HIV stigma jeopardizes human rights and threatens to undermine the promise of recent advances in prevention, treatment and services. The past decade has seen increasing theoretical elaboration on HIV stigma that is explicitly grounded in qualitative data from sub-Saharan Africa, where HIV remains highly prevalent and stigmatized (Campbell, Foulis, Maimane, & Sibiya, 2005; Campbell, Nair, Maimane, &

^{*}Corresponding Author. swinske@emory.edu.

Nicholson, 2007; Holzemer et al., 2007). As a further corrective to the earlier dominance of quantitative research studies from the developed world, there have been calls to prioritize the understanding of 'moral experience, or what is most at stake for actors in a local social world' (Yang et al., 2007, p.1524) and specifically 'the unique social and cultural processes that create stigma in the lived worlds of the stigmatised' (Kleinman & Hall-Clifford, 2009, p.418).

In light of the sensitivity of the subject matter and its vulnerability to social desirability bias, such studies would benefit from diversification in research methodologies and from increased understanding of the contributions of different methods of eliciting data (Campbell, Skovdal, Mupambireyi, & Gregson, 2010; Yang et al., 2007). Creative data collection methods that rely on less directive modes of elicitation and that are enjoyable for participants have been used in the study of stigma among young children. Campbell et al. (2010), for example, used a draw-and-write methodology to access the complex and nuanced social representations and understandings of young children in Zimbabwe vis-à-vis their AIDS-affected peers.

This paper draws on a unique form of empirical data, creative fictional narratives submitted by young Africans to an HIV-themed scriptwriting competition that invites young people to come up with ideas for films to educate their communities. The narratives provide access both to the explicit accounts of stigmatizing attitudes, behaviours and experiences of their characters and to the implicit, often contradictory, sense-making processes the young authors engage in as they navigate the cultural resources available to them in their attempts to represent and make sense of HIV, gender and sexuality.

The concept of representation has come to occupy a central place in the study of culture over recent decades (Hall, 1997). An essential part of the process by which meaning is produced and exchanged between members of a culture, the practices of representation have been described as "the embodying of concepts, ideas and emotions in symbolic form which can be transmitted and meaningfully interpreted" (p.10). Representation thus enables us to communicate intersubjectively about either the "real" world of objects, people or events, or the imaginary worlds of fictional objects, people, and events. Although fictional representations are invented depictions of social fact, they are culturally-determined social facts in and of themselves and are a source of insight into how people make sense of the world, and how they communicate those understandings to others in their cultural community (Rabinow, 1986). A body of research from a range of disciplines documents the impact of symbolic representations on HIV prevention, stigma, treatment-seeking, and illness experience (e.g., Farmer & Good, 1991; Goldstein, 2004; Sontag, 1988; Treichler, 1999).

Some HIV-related studies in this vein (e.g., H. Joffe, 1996; H. Joffe & Bettega, 2003; Markova & Wilkie, 1987) are situated theoretically within the Theory of Social Representations, which focuses on the complex symbolic and social aspects of everyday lay meaning-making (Jovchelovitch, 2007). Social representation refers both to the content of understandings of the everyday world ("the ideas that circulate in a society and constitute common sense," p.91) and the processes by which these contents are shaped (Helene Joffe,

1999). Narratives are intimately involved in the forging and organization of social representations as they give the storyteller the opportunity to define the social world (Jovchelovitch, 2002). They have been identified as a particularly valuable and underused data source for the study of social representations (Laszlo 1997; Murray 2002).

One of the reasons we tell stories is "to 'make sense' of what we are encountering in the course of living..." (Bruner and Lucariello 1989:79). In their creative writing, young people draw on their own lived or imagined experience and on other culturally determined sources of social understanding to create narratives imbued with context, meaning, and values. In this way, the narratives provide insights into young people's explanatory models about HIV and into their appropriation of dominant cultural norms around gender, sexuality, and stigma. These norms are themselves embedded within cultural norms of performance, discourse, and persuasion (Farmer and Good 1991), which may be informed by performative and rhetorical considerations specific to the scriptwriting competition, reflecting the young authors' motivation, for example, to tell what they consider to be a good story and thereby win the contest, or to educate their communities about HIV.

In earlier work we have compared symbolic stigma across six sub-Saharan African countries with varying HIV prevalence levels through the analysis of social representations in almost 600 narratives (Winskell, Hill, & Obyerodhyambo, 2011). In this paper, we take a different approach. In order to preserve the richness of the ethnographic detail, we have selected individual narratives that illustrate the interplay of distinct yet intersecting dimensions and mechanisms of HIV stigma. We conduct a close reading of three narratives, using stigma theory as a lens. The objective of this paper is to examine stigma both in their referential dimension (the claims they make about the "real" world) and in their evaluative dimension (e.g. the often contradictory or ambivalent messages they communicate) in order to better understand the symbolic and social processes that perpetuate HIV stigma.

Theoretical Background

HIV stigma literature was long dominated by a socio-cognitive approach, based on a restrictive and misleading reading of Erving Goffman (1963), that focused on how individual perceptions – in isolation from their social and community context – fuel stigma and discrimination. This led to stigma reduction efforts that, in line with the dominant global health communication paradigm of the time, primarily provided information and education with the objective of reducing ignorance and normalizing HIV. While the majority of stigma reduction interventions over the past three decades have been based on this approach (Mahajan et al., 2008), research suggests these efforts have had only limited effectiveness (Brown, Macintyre, & Trujillo, 2003).

Over the past decade, several correctives to this model have been proposed that introduce valuable critical perspectives from social and political theory (Parker & Aggleton, 2003), ethnography and social medicine (Castro & Farmer, 2005), and social and community psychology (Campbell et al., 2007). These perspectives move beyond the individual level to incorporate the influence of broader social and structural processes and power relationships that create and reinforce inequality. Although compatible, each privileges a different perspective and a different mitigation approach.

Parker and Aggleton (2003) emphasized that stigmatization is a process that is used by individuals, communities and the state to produce and reproduce power and to legitimize hierarchy and inequality. They advocated that traditional individual-level mitigation approaches be complemented by community mobilization and transformation approaches and, above all, by structural approaches, including judicial and policy interventions and legal protections of people living with HIV, to transform the social climate so that stigmatization and discrimination are no longer tolerated. Structural, rather than symbolic, violence lay at the centre of Castro and Farmer's conceptual framework for understanding HIV-related stigma based on their ethnographic findings in Haiti (Castro & Farmer, 2005). They contended that in resource-poor settings where stigma is fuelled by poverty and lack of access to services, antiretroviral therapy (ART) can catalyse a 'virtuous social cycle' (p.55) and alter the course of HIV stigma. Where Parker and Aggleton and Castro and Farmer focused predominantly on macro-social factors in their conceptualization of HIV stigma, Campbell, Deacon and colleagues proposed a multi-level model, spanning intra-psychic to macro-social factors (Campbell & Deacon, 2006; Campbell et al., 2007; Deacon, Stephney, & Prosalendis, 2005). They contended that 'social spaces for critical dialogue' (2007, p.414) can contribute toward building the capacity of the marginalized to articulate their needs provided the wider macro socio-political environment is receptive to such processes (Campbell, 2014).

Each of these approaches acknowledges the role played by symbolic processes – or the intersection between culture and power – in the creation and perpetuation of HIV stigma and inequitable social structures. Parker and Aggleton (2003), for example, drew on Bourdieu, Foucault, Gramsci, and Williams to describe "the complex webs of meaning and power" that underlie HIV stigma, situating their analysis theoretically within processes of symbolic violence and hegemony. Dominant cultural meanings and social practices embody the interests of the powerful and reproduce and legitimize inequitable social systems. This process of legitimation elicits the complicity of the dominated (a process which Parker and Aggleton align with internalized or self-stigma) and influences the practices and judgements of social groups.

A multilevel model of stigma, while acknowledging the macro-social and ideological forces at play, also accommodates a range of micro-level dimensions and mechanisms of HIV stigma, differentiated based on cause (e.g. fear or moral disapproval) and object (self, person living with HIV, family member, etc.). These multilevel dimensions and mechanisms are summarized in Table 1, which is adapted from Roura (2009), and used as a lens through which to analyse the narratives and interpret findings.

Methods

The data are part of a vast and growing cross-national and longitudinal archive of narratives about HIV and related topics authored by young people, primarily in sub-Saharan Africa. Since 1997, Global Dialogues (known as 'Scenarios from Africa' until 2012) contests have invited young Africans to contribute scripts for short fiction films about HIV/AIDS and related topics (Winskell & Enger, 2005). The contestants are mobilised by non-governmental and community-based organisations and local, national and international

media. A leaflet, 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 to educate their communities. The winning ideas in each contest are selected by local juries and, following adaptation, transformed into short fiction films by prominent directors (Global Dialogues, 2015). By 2014, the process had generated 39 short films (www.youtube.com/globaldialogues) and an archive of over 75,000 narratives.

The research described in this paper is part of a six-country study of young Africans' social representations of HIV/AIDS. Our sampling procedures and methodologies are described in detail elsewhere (Winskell, Obyerodhyambo, & Stephenson, 2011). The narratives analysed 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. A stratified random sample of 586 narratives from six countries with diverse HIV prevalence rates (Senegal, Burkina Faso, South-East Nigeria, Kenya, Namibia and Swaziland) was constructed as part of the broader study. The data were transcribed verbatim in English or French and entered into MAXQDA 2007 qualitative data analysis software (VERBI Software 1989–2010). A summary was written for each story and this was coded with up to 6 out of a possible 45 keywords, including 'Stigma, mistreatment, rejection'; these keywords were double-entered and discrepancies debated and adjudicated by a third coder.

For the present paper, we reviewed the 93 narratives assigned the keyword 'Stigma, mistreatment, rejection' with reference to the stigma dimensions described in Table 1. Via discussion among ourselves, we purposively identified three narratives (from a final subsample of nine) in which multiple stigma dimensions and mechanisms (see Table 1) were evident both at the level of the plot and in the contradictions, tensions and ambivalence in the their messaging. Our objective was to illustrate the potential contributions of creative narratives to understandings of stigma. The narratives date from 2005, a time when ART was beginning to be more widely available in sub-Saharan Africa. Two narratives were from South-East Nigeria and one was from Kenya. The origins of these narratives was consonant with our prior cross-national comparative analysis of symbolic stigma which had revealed that representations were most stigmatizing in narratives from South-East Nigeria and, to a lesser extent, Kenya (Winskell, Hill, et al., 2011) where a conservative Christian sexual morality, often resonant with Pentecostal themes, was prevalent. This study was approved by Emory University Institutional Review Board.

Our analytical approach was dictated by the distinctive characteristics of the data and our illustrative purpose. We conducted a close reading, or case-based narrative analysis (Riessman, 2008) of the texts. In line with our focus on sense-making, we adopted a broadly hermeneutic approach (Bernard & Ryan, 2010). Our aim was specifically to highlight contradictions, tensions and ambivalence in order to illuminate young people's efforts to navigate divergent cultural meanings in their attempts to make sense of HIV. We drew on conventional constructs of literary analysis (plot, narration, characterization, etc.) to articulate the relationship between parts and whole, plot and narrator's commentary, and explicit and implicit meanings. Throughout this process, we applied the lens of existing HIV

stigma theory, in particular the stigma dimensions and mechanisms presented in Table 1. We undertook this analysis individually and shared our interpretations collectively; minor differences in interpretation were resolved through dialogue.

Results

Our narratives contrasted in their stylistic approaches and in the overtness of the narratorial voice.

1. 'The Gossips' (original title) by a 23-year-old female author from rural South-East Nigeria

Written in the form of a series of dialogues, 'The Gossips' follows two friends, Mrs Losa and Mrs Toji, over the course of a year as they chat about their HIV positive neighbour whom they refer to as Madam Ajadu. The gossips' moral disapprobation and the neighbour's outsider status is evident in their use of the title 'Madam', often associated with sex workers, and the name Ajadu meaning 'widow', 'adulterer' or 'prostitute' in Ibo.

Mrs. Toji: You mean it is true that she has been caught by the web of AIDS? I thought as much, since my life I have not see a women dress as gorgeous as she does. Now she will pay with her dear life.

Mrs Losa: Thank God I am not like her (smiles). Even if it means having one cloth over a year, I know I won't go to look for men outside the way she did.

It is presumed that transactional sex is the only way a poor woman like Madam Ajadu is able to dress well. This stigma is at once moral or symbolic (see Table 1) and, insofar as it is gendered, layered. Social and sexual power are at play here, with Madam Ajadu's fine clothes (and the sexual threat that she, as a woman whose sexuality is not controlled by a husband, is presumed to represent for married women) fuelling jealous reprisal.

Over time Madam Ajadu's physical health improves, thanks to antiretroviral medications. Mrs Toji reveals that she now 'looks so strong that I am beginning to doubt if she has that thing they call AIDS.' This does not, however, mitigate Mrs Toji's stigmatizing attitudes and behaviour and she eventually decides to move houses 'because [she] heard madam Ajadu is still carrying AIDS and [doesn't] want to get it'. In the meantime, Mrs. Losa falls ill and is given a blood transfusion with HIV-infected blood. Following her diagnosis with HIV six months later, she internalizes negative beliefs and feelings about HIV and anticipates stigmatizing social reactions: 'so I will soon die with my family members. I am going to become the topic of the day.'

At their next meeting, Mrs Losa gradually discloses her status to Mrs Toji, who expresses scepticism in light of Mrs Losa's healthy disposition. Mrs. Losa shares her doctor's reassurances that HIV is not only sexually transmitted, that it is not the same as AIDS, that it cannot be casually transmitted and that it can be managed with ART. The story ends with Mrs Toji discreetly indicating that she will keep Mrs Losa's news to herself, thanking her for the information she has shared, and saying she will go and visit Madam Ajadu.

The narrative takes the form of a series of dialogues without any narratorial commentary; as such, Mrs Toji's decision to go and visit her former neighbour is left open to interpretation. It is possible that: her fear-based instrumental stigma has been overcome by the information she has received on non-casual transmission; that she is ready to acknowledge that Madam Ajadu could have contracted HIV non-sexually, defusing the moral (or symbolic) dimension of her stigmatizing attitudes; and/or that her friend's disclosure has increased her social proximity to HIV and thereby her ability to empathize. What is clear, however, is that the married women have no sympathy for the structural and symbolic violence faced by Madam Ajadu as a result of her widowhood. They participate in the 'complex social process linked to competition for power and tied into existing mechanisms of exclusion and dominance' (Deacon et al., 2005, p.4).

Castro and Farmer (2005) predicted that dramatically increased access to ART would alter the course of HIV stigma. Unfortunately, the current situation is less clear cut (see, e.g., Campbell et al., 2011) and this ambiguity is reflected here. ART may mitigate one dimension of stigma but not another, with layered stigma being most recalcitrant to change. Although ART reduces Madam Ajadu's symptoms, it does not prevent Mrs Toji from moving house to avoid proximity to her. It will, however, allow Mrs Losa to 'pass' as normal and, in Goffman's terms (1963), to avoid transitioning from a 'discreditable' to 'discredited' status. The promise of ART thus allows her to safeguard what matters most to her. It has the potential to allow characters to live what constitutes a normal life within their local moral worlds (Kleinman & Hall-Clifford, 2009), but it does so not by undermining normative stigma but by obviating the need for disclosure and limiting internalized stigma, a phenomenon documented elsewhere (e.g., M Roura et al., 2009).

2. 'A true story of a young husband of three kids, who was HIV/AIDS victim, and his scolding deceitful wife' (original title) by a 16-year-old female author from rural South-East Nigeria

This narrative opens in a short-story format, with conventional narration, characterization and dialogue, but ends with harsh narratorial commentary. Ben Aziba had discovered he was HIV positive. He and his wife Lorita did not want their family, friends and community to know this, so they invented stories to explain his symptoms: Ben 'told some of his friends that he had being attacked by witches and wizards, some he told that he had being poisoned by his enemy.' However, this subterfuge came at a cost: he remained unaware that 'there are existing drugs with which HIV/AIDS would be treated and his life prolonged in this planet (earth)'.

Lorita was terrified of the fate she would face if it were known publicly that she was a woman widowed by AIDS: 'friends and relatives would desert her. No man could think of having her in anyway whatsoever, because they all had known her as a victim too.' She therefore isolated the couple by 'spreading false information of how people and her enemy had afflicted her husband with poison' and tuberculosis. She also prevented her husband from seeking care as they feared this would reveal his status. Instead, she consulted with spirits and sent her husband to a prayer house ('all in the name of pretence because Mrs.

Aziba had no faith in God and did not go to church'), where he died without receiving a single visit from her.

Lorita's anticipation of the *layered, symbolic, secondary* stigma assigned to women left widowed and disempowered by AIDS, thus sealed Ben Aziba's fate. Her characterization as a scolding, deceitful and neglectful wife allows the lonely fate that she feared awaited her as an AIDS widow to be viewed dispassionately.

The narrative demonstrates the disastrous effects of anticipated stigma on the social support network of people living with HIV and their access to information and life-saving medication. A cautionary tale, it implies that the anticipated stigma that drives Ben and Lorita's behaviour is unwarranted and catastrophic in its consequences. However, in her closing commentary, the narrator shifts her role from storyteller to teacher directly expounding her own views that HIV/AIDS is a divine punishment (symbolic stigma elevated to an eschatological level) and calls for institutional discrimination in the form of mandatory testing and forced exposure. She comments:

Youth and adults should stay from sex scandals among themselves, yes, I called it sex scandals because, sex without marriage should be termed so... People who are carriers of HIV/AIDS must be exposed... by taken them to medical test before they may be employed in any establishmen, whether or private or public.... I strongly believe that, that HIV/AIDS is a strong weapon with which God judges people of their sin, especially on fornication and adultery.

This contradicts the ostensible moral of her story, suggesting that Ben and Lorita's anticipated stigma is actually well-founded as Ben would have reason to fear for his social status in the social and policy world proposed by the narrator. The narrative is torn between early anti-stigma efforts that framed those infected as 'victims' and conservative Christian moralizing that frames infection as punishment for sin. The narrative illustrates the conflicted performance—and reproduction—of social identities by young authors who are struggling to decide where their sympathies and affiliations lie.

As in 'The Gossips', central characters are both (potentially) stigmatized and stigmatizers. This fluidity of stigmatizer-as-stigmatized and vice versa suggests the need for increasingly flexible models of HIV stigma that are not dominated by serostatus alone (see, e.g., Earnshaw & Chaudoir, 2009), not least in the age of ART when PLHIV can 'pass' (Goffman, 1963) as uninfected and the previously untested can rapidly join the ranks of the infected. The narrative belongs to several in the 2005 dataset in which young authors struggle to integrate ART into their moral sense-making around HIV: it is as if the potential ART affords people living with HIV to live well despite infection (which is presumed to be well-deserved) falls foul of the moral imperative the young authors see themselves as tasked with conveying in their narratives.

3. 'The Glass Lily' (original title) by a 17-year-old male author from urban Kenya

On one level, 'The Glass Lily' is a story of the devastating impact of a parent's HIV infection on a family and, on one level, one of resilience and resistance to HIV stigma. However, as in the other two narratives, sympathy for those experiencing HIV stigma

intersects uneasily with the treatment of gender and sexuality. The narrative extends over many years and is more complex in its structure than the other two, featuring flashbacks and the return of the protagonist as a ghostly apparition.

The ghost of Noelle Bahati walked through the streets of Nairobi, observing the sex workers and their johns, and recalled the life she had led. She and her twin brother had been born to well-off parents: her mother, a lawyer, and her father, a star athlete. When her mother's HIV positive serostatus was made public during a tabloid interview, her brother suffered taunting at school. He was beaten up by peers who jeered 'we don't need people like you in this school-you'll give our mums the bug.' Noelle challenged this stigmatizing treatment, founded in ignorance, by standing up to her brother's bully. She also applauded her mother's use of the law to resist institutional discrimination following attempts to fire her on account of her serostatus.

As her mother was dying of AIDS, teenage Noelle – 'part of the MTV generation' – went through a phase of sexual promiscuity, which included losing her virginity with a client in the red-light district and a twilight job appearing in explicit music videos. Upon her mother's death, she was distraught, 'her family was so sad about her mother dying and then here she was trying so ardently to go down the same lonely path.' Subsequently, she underwent 'a sudden personality change,' abandoned her sex work and lifestyle, and applied herself at school, winning a prize for being the best orator in a debate on the subject 'AIDS PATIENTS SHOULD BE ACCORDED EUTHANASIA'. Despite blaming the rapist who infected her mother, she decried her scantily clad friends for inviting rape (and, by association, AIDS) with their dress and demeanour.

Didn't I tell what happened to my mother? Didn't we talk about how easy you could make it for a man to rape you? Don't you know what can come from that rape? [...] If you want to go auctioning your virginity like fresh vegetables then go ahead! Just don't forget about AIDS.

Noelle attended college and became a sex and AIDS education teacher at her former high school. When disruptive students questioned her ability to teach the class in light of her reputation, she insisted that her past made her well qualified for the job. Unlike her brother who committed suicide, she failed to succumb to internalized stigma following her diagnosis with HIV, instead becoming a resource in society and a role model. She continued to teach until her death to AIDS five years later. 'On her death bed, Noelle wasn't sad. No Not at all…she knew that she had lived her life to the fullest so all she had left was death-a rest for her tired spirit.'

'The Glass Lily' ostensibly provides a role model for resistance to internalized and other forms of stigma but the multiple-infection narrative, replete with teenage girls seeking sexual gratification as underage sex workers and porn stars, conforms to a melodramatic genre and associates HIV with sexual promiscuity. At a time when ART was increasingly accessible, not least among the better off in urban Nairobi, the author chooses to have two infected characters succumb to AIDS and one to suicide, without reference to ART and relying on an out-dated representation of HIV as inexorably a death sentence. Despite overt

acknowledgement of HIV stigma and its deleterious effects, the narrative is replete with the very types of representations that serve to perpetuate it.

Discussion

Narratives, as a fundamental tool of sense-making, have a distinctive role to play in the study of stigma. The three narratives described above feature: indeterminacy around the cause and depth of stigma mitigation in 'The Gossips'; overt internal propositional tensions in the Ben Aziba narrative; and implicit contradictions related to the representation of gender, sexuality and HIV in the 'The Glass Lily'. In their referential dimension, the narratives shed light on the contextual experience and mechanisms of stigma, revealing, for example, the role played by gendered power dynamics and sexual reputation in vulnerability to stigma. In their contradictions, tensions and ambiguities, they reveal the challenges young people face when trying to make sense of HIV and stigma with recourse to the plethora of divergent resources culturally available to them. While contradictions between overt statements and actions certainly can be detected in stigma research using more traditional methodologies (Nyblade et al., 2003; Yang et al., 2007), we argue that creative narratives can provide a particularly efficient means of identifying them.

Each of the three narratives consciously addresses the theme of HIV stigma in ways that suggest sympathy with efforts to reduce or mitigate it. However, the internal contradictions in the Ben Aziba and 'Glass Lily' narratives and the ambivalence of 'The Gossips' suggests that HIV anti-stigma efforts risk teaching surface-level awareness of terms and representations to be avoided, without challenging stigma in any depth, unless they also engage with the symbolic violence of representations of gender and sexuality that sustains the devaluation of women and of people infected with HIV. Such social representations can have a pervasive influence on the practices and judgements of social groups even despite structural changes (Howarth, Foster, & Dorrer, 2004). Thus, in spite of the life- and gamechanging promise that increased access to ART held in 2005, ART is treated with ambivalence in these narratives. This points to the ongoing importance of communication efforts in the context of broader structural approaches to stigma reduction and mitigation.

One of the advantages of creative narratives of this kind is that they are arguably more readily applicable to communication practice than many other forms of data, particularly in the context of increasingly prominent narrative-based communication strategies. Mass mediated entertainment-education and highly participatory approaches drawing on Freirean approaches (Freire, 2003 (1973)), often employ narratives either to propose alternative cultural models and/or to empower affected communities to deconstruct and challenge existing ones (Campbell et al., 2005; Singhal, Cody, Roger, & Sabido, 2004; Storey & Sood, 2013). Narratives have multiple advantages for this purpose, both on an individual and a collective level, including their ability to contextualize human experience holistically, to elicit empathy and identification, and to foster the social renegotiation of meaning (Winskell & Enger, 2014). These strengths offer important opportunities to challenge representations of gender and sexuality that sustain HIV stigma.

Limitations

In this paper, we conduct a close reading of three fictional narratives selected with the purpose of illustrating the insights such narratives can provide into the symbolic and social processes that create and perpetuate HIV stigma. Our purposive sampling sought not to construct a representative sample but rather to maximize the potential to illustrate the interplay between a range of dimensions and mechanisms of HIV stigma in both the referential and evaluative dimensions of the narratives. It is impossible to know to what extent, if any, the narratives are based on personal experience. We follow Farmer and Good (1991) in acknowledging the role that performative and rhetorical considerations may be playing in these representations. It is, however, clear that they draw on – and provide insight into – cultural meanings and social practices that are prevalent within the youth authors' communities.

Conclusion

Our analysis illustrates the insights fictional narratives such as these can provide into the symbolic and social processes that perpetuate HIV stigma. Our narrative data source has the advantage of providing access to the explicit accounts of stigmatizing attitudes and behaviours of characters in the narratives, on the one hand, and also to the contradictions, tensions and ambivalence in messaging that illuminate the young authors' struggles to make sense of HIV, gender and sexuality, on the other. Communication efforts to reduce stigma may risk teaching surface-level awareness of terms and representations to be avoided without challenging stigma in any depth, unless they also engage with the symbolic violence of representations of gender and sexuality that sustains the devaluation of women and of people infected with HIV. Narrative-based communication approaches using mass-media entertainment-education or participatory Freirean methodologies are well-placed to engage with the symbolic representations that help sustain HIV stigma.

Acknowledgments

The research described here was supported by Grant 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. We are grateful to Kim Miller for her advice and to research assistants Chris Barnett, Laura Beres, Liz Coleclough, Wendee Gardner, Rosalie Haughton, Samantha Huffman, Caddie Putnam Rankin, and Kanaka Sathasiyan.

References

- Bernard, HR.; Ryan, GW. Analyzing Qualitative Data: Systemic Approaches. Thousand Oaks, New Delhi, London, Singapore: Sage; 2010.
- Brown L, Macintyre K, Trujillo L. Interventions to Reduce HIV/AIDS Stigma: What Have We Learned? Aids Education and Prevention. 2003; 15(1):49–69.10.1007/s10461-010-9847-0 [PubMed: 12627743]
- Campbell C. Community mobilisation in the 21st century: Updating our theory of social change? Journal of Health Psychology. 2014; 19:46–59.10.1177/1359105313500262 [PubMed: 24000384]
- Campbell C, Deacon H. Unravelling the contexts of stigma: From internalisation to resistance to change. Journal of Community & Applied Social Psychology. 2006; 16(6):411–417.10.1002/casp. 901

Campbell C, Foulis CA, Maimane S, Sibiya 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):808–815.10.2105/AJPH.2003.037499 [PubMed: 15855456]

- Campbell C, Nair Y, Maimane S, Nicholson J. 'Dying twice' A multi-level model of the roots of AIDS stigma in two South African communities. Journal of Health Psychology. 2007; 12(3):403– 416.10.1177/1359105307076229 [PubMed: 17439992]
- Campbell C, Skovdal M, Madanhire C, Mugurungi O, Gregson S, Nyamukapa C. "We, the AIDS people...": How Antiretroviral Therapy Enables Zimbabweans Living With HIV/AIDS to Cope With Stigma. American Journal of Public Health. 2011; 101(6):1004–1010.10.2105/AJPH. 2010.202838 [PubMed: 21164081]
- 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; 71:975–985.10.1016/j.socscimed.2010.05.028 [PubMed: 20591546]
- Castro A, Farmer P. Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti. American Journal of Public Health. 2005; 95(1):53–59.10.2105/AJPH.2003.028563 [PubMed: 15623859]
- Deacon, H.; Stephney, I.; Prosalendis, S. Understanding HIV/AIDS Stigma: A theoretical and methodological analysis. Cape Town: Human Sciences Research Council; 2005.
- Earnshaw VA, Chaudoir SR. From Conceptualizing to Measuring HIV Stigma: A Review of HIV Stigma Mechanism Measures. AIDS and Behavior. 2009; 13(6):1160–1177.10.1007/s10461-009-9593-3 [PubMed: 19636699]
- 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.
- Freire, P. Education for Critical Consciousness. New York & London: Continuum; 2003. 1973
- Genberg BL, Hlavka Z, Konda KA, Maman S, Chariyalertsak S, Chingono A, Celentano DD. 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):2279–2287.10.1016/j.socscimed.2009.04.005 [PubMed: 19427086]
- Global Dialogues. 2015. www.globaldialogues.org
- Goffman, E. Stigma: Notes on the management of a spoiled identity. New York: Simon & Schuster; 1963.
- Goldstein, DE. Once Upon a Virus: AIDS Legends and Vernacular Risk Perceptions. Logan, Utah: Utah State University Press; 2004.
- Hall, S., editor. Representation: Cultural Representations and Signifying Practices. London, Thousand Oaks, New Delhi: Sage Publications in association with The Open University; 1997.
- Holzemer WL, Uys L, Makoae L, Stewart A, Phetlhu R, Dlamini PS, Naidoo J. A conceptual model of HIV/AIDS stigma from five African countries. Journal of Advanced Nursing. 2007; 58(6):541–551.10.1111/j.1365-2648.2007.04244.x [PubMed: 17484748]
- Howarth C, Foster J, Dorrer N. Exploring the Potential of the Theory of Social Representations in Community-Based Health Research and Vice Versa? Journal of Health Psychology. 2004; 9:229–243. [PubMed: 15018725]
- 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]
- Jovchelovitch, S. Social representations and narrative: Stories of public life in Brazil. In: Laszlo, J.; Stainton Rogers, W., editors. Narrative Approaches in Social Psychology. Budapest, Hungary: New Mandate; 2002.
- Jovchelovitch, S. Knowledge in Context. Representations, community and culture. London and New York: Routledge; 2007.
- Kleinman A, Hall-Clifford R. Stigma: a social, cultural and moral process. Journal of Epidemiology & Community Health. 2009; 63:418–419.10.1136/jech.2008.084277 [PubMed: 19439576]

Mahajan AP, Sayles JN, Patel VA, Remien RH, Sawires SR, Ortiz DJ, Coates TJ. 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]

- 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.
- Nyblade, L.; Pande, R.; Mathur, S.; MacQuarrie, K.; Kidd, R.; Banteyerga, H.; Bond, V. Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia. 2003.
- 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]
- Rabinow, P. Representations are Social Facts: Modernity and Post-Modernity in Anthropology. In: Clifford, J.; Marcus, GE., editors. Writing Culture: The Poetics and Politics of Ethnography. Berkeley and Los Angeles, CA: University of California Press; 1986. p. 234-261.
- Riessman, CK. Narrative Methods for the Human Sciences. Thousand Oaks: Sage; 2008.
- Roura M, Urassa M, Busza J, Mbata D, Wringe A, Zaba B. Scaling up stigma? The effects of antiretroviral roll-out on stigma and HIV testing. Early evidence from rural Tanzania. Sexually Transmitted Infections. 2009; 85:308–312.10.1136/sti.2008.033183 [PubMed: 19036776]
- Roura M, Wringe A, Busza J, Nhandi B, Mbata D, Zaba B, Urassa M. "Just like fever": a qualitative study on the impact of antiretroviral provision on the normalization of HIV in rural Tanzania and its implications for prevention. Journal of International Health and Human Rights. 2009; 9(22)10.1186/1472-698X-9-22
- Singhal, A.; Cody, MJ.; Roger, EM.; Sabido, M., editors. Entertainment-Education and Social Change: History, Research, and Practice. Mahwah, New Jersey: Lawrence Erlbaum Associates; 2004.
- Sontag, S. AIDS and its Metaphors. New York: Picador; 1988.
- Storey D, Sood S. Increasing equity, affirming the power of narrative and expanding dialogue: the evolution of entertainment education over two decades. Critical Arts: South-North Cultural and Media Studies. 2013; 27(1):9–35.10.1080/02560046.2013.767015
- Treichler, PA. How to Have Theory in an Epidemic: Cultural Chronicles of AIDS. Durham and London: Duke University Press; 1999.
- 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.; Enger, D. Storytelling for Social Change: Reflections on Narrative and Narration in Global Health Communication. In: Wilkins, KG.; Tufte, T.; Obregon, R., editors. Handbook of Development Communication and Social Change. Chichester: Wiley-Blackwell; 2014.
- Winskell K, Hill E, Obyerodhyambo O. Comparing HIV-related symbolic stigma in six African countries: social representations in young people's narratives. Social Science & Medicine. 2011; 73:1257–1265.10.1016/j.socscimed.2011.07.007 [PubMed: 21864965]
- 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):953–961.10.1016/j.socscimed.2011.01.014 [PubMed: 21388731]
- Yang LH, Kleinman A, Link BG, Phelan JC, Lee S, Good B. Culture and stigma: Adding moral experience to stigma theory. Social Science & Medicine. 2007; 64:1524–1535.10.1016/ j.socscimed.2006.11.013 [PubMed: 17188411]

Table 1

Dimensions of HIV Stigma, adapted from Roura (2009, p.309)

| Enacted stigma or discrimination | What people do to unfairly disadvantage known or suspected HIV positive persons or those associated with them, such as exclusion from shared activities | |
|--|---|--|
| Anticipated stigma | The stigma people expect from others if they were known to be HIV positive or associated with someone who is HIV positive | |
| Internalized stigma or self- stigma | Internalized feelings of shame or blame derived from accepting stigmatizing judgements of one's identity | |
| Secondary stigma | Stigma which, by association, affects those related to, or associated with, the infected | |
| Symbolic, or blame-based, stigma | Stigma from the association of HIV with negatively defined behaviours or groups in society, which are subsequently blamed for their infection | |
| Instrumental, or fear-based, stigma | Stigma derived from the fear of being infected by HIV through casual or sexual contact | |
| Layered, or compound, stigma | Stigma that is compounded by other socially stigmatized conditions (Genberg et al., 2009) and related to overarching power inequalities | |
| Symbolic Violence | The "process whereby symbolic systems (words, images, practices) promote the interests of dominant groups as well as distinctions and hierarchies of ranking between them, while legitimating that ranking by convincing the dominated to accept existing hierarchies through processes of hegemony" (Parker & Aggleton, 2003, p.18). | |