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Article

Temporal and cross-national comparisons of young Africans' HIV-related narratives from five countries, 1997–2014



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ABSTRACT

Little is known about how young Africans have made sense of the dramatic ways in which the HIV epidemic has evolved, and how that sense-making varies across countries with different epidemiological and sociocultural profiles. Symbolic representations of HIV and people living with HIV influence prevention, stigma, treatmentseeking, and illness experience. We compared social representations of HIV among young people from Senegal, Burkina Faso, Nigeria (South-East), Kenya, and Swaziland between 1997 and 2014. From a pool of 32,759 HIV-themed creative narratives contributed by 10-24 year-olds to scriptwriting competitions at eight time points (1997, 2000, 2002, 2005, 2008, 2011, 2013, and 2014), we randomly sampled 1937 narratives, stratified by author's sex, age, and rural/urban residence. We quantified components of each narrative and calculated descriptive statistics and adjusted odds ratios, controlling for year, country, and author demographics. From 2005 onwards, representations of death, treatment access, and hopefulness improved significantly. Representations of death reached their lowest point in 2013, while biomedical treatment and hope peaked in 2011 and 2008, respectively, then declined. Narratives increasingly focused on female protagonists. Nigerian texts had significantly higher odds of death and blame, and lower odds of hope. A focus on life post-infection and representations of support for characters living with HIV increased with country HIV prevalence. Narratives by older authors were less blaming and more hopeful, supportive, and prevention-focused. While aggregate social representations in the narratives from 2005 to 2008-11 reflect increased optimism fostered by access to antiretroviral therapy (ART), positive developments are not sustained at this level. Stigmatizing representations persist, particularly in Nigeria. The hope-promoting and stigma-reducing influence of the advent of ART access may have partially run its course by 2011/2013. However, significant temporal and cross-national differences point to opportunities to reframe HIV in more constructive ways and contribute to improved education, communication, and stigma-reduction efforts.

1. Introduction

The past decade and a half have seen unprecedented scientific, technical, and programmatic advances in the prevention and treatment of HIV in sub-Saharan Africa. HIV-related deaths worldwide have fallen sharply – from 1.9 million in 2005 to less than 1.0 million in 2017 – since

antiretroviral therapy (ART) became more widely accessible. In sub-Saharan Africa as elsewhere, ART is not only transforming HIV into a chronic condition, but has also offered the potential to control the HIV epidemic through treatment-as-prevention. Despite these gains, there are fears of a resurgence in the epidemic if HIV incidence is not further reduced, as the largest ever generation of young Africans enters

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adolescence and adulthood (Bekker et al., 2018). Young people, particularly young women aged 15–24, continue to account for a high proportion of new HIV infections in sub-Saharan Africa (UNAIDS, 2018). Meanwhile, HIV-related stigma continues to have negative effects across the prevention and treatment continuum, creating a barrier to testing, disclosure, prevention strategies, treatment, adherence, and retention in care (Deacon, Uys, & Mohlahlane, 2009; Mahajan et al., 2008). While ART has been linked to reductions in internalized stigma and is anticipated to lessen associations between HIV and economic incapacity, social isolation, and imminent death (Chan, Tsai, & Siedner, 2015; Tsai et al., 2013), concerns have been raised that the enduring association of HIV with sexual "immorality" (Campbell et al., 2011) may impede the full potential for ART-related reductions in stigma in the general population and indeed that ART may lead to new forms of stigma (Roura et al., 2009).

Remarkably little is known about how Africans have made sense of the dramatic ways in which the HIV epidemic has evolved – and how that sense-making differs across countries with diverse epidemiological, cultural, and policy environments. As the nefarious effects of HIV stigma indicate, symbolic representations of HIV and people living with HIV influence prevention, stigma, treatment-seeking, and illness experience. Understanding the dynamic process whereby HIV is socially constructed and reconstructed in the collective lay imagination has the potential to inform health outcomes at the individual and population levels and is crucial to informing changes in social norms.

Coined by Moscovici in 1961 (Moscovici, 2008), social representation refers to the process whereby social knowledge is constructed and a shared system of meaning elaborated within and across social groups through processes of communication. The term also refers to the product of that process: the shared imagery, metaphors, values, and practices that allow us to make sense of, navigate, and position ourselves within the social world. Social representations are not static, but dynamic systems of social knowledge: they are created and recreated in everyday social interaction and spread through interpersonal and media communication. Narratives have been identified as a particularly valuable and underused data source for the study of social representations and sense-making (László, 1997; Murray, 2002). As social representations are cultural models that act as both barriers to and facilitators of social and behavioural change and are amenable to influence by communication efforts, they have considerable applied relevance (Markova & Wilkie, 1987).

Distinctive temporal qualitative data from 47 countries, collected during a critical 18-year period (1997–2014) in the history of the epidemic, offer an opportunity to examine young Africans' evolving social representations of HIV prevention and treatment. More than 150,000 young people from across sub-Saharan Africa took part in HIV-themed scriptwriting contests held at eight discrete time points between 1997 and 2014, contributing over 75,000 creative narratives from 47 countries. Although fictional narratives are invented depictions of social fact, they are still 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).

In this paper, we analyze young Africans' social representations of HIV over a period of eighteen years across five epidemiologically and socioculturally diverse countries situated in West, East and Southern Africa: Senegal, Burkina Faso, Nigeria (South-East), Kenya, and Swaziland (now known as Eswatini). Our purpose is to determine, through analysis of these social representations, the extent to which opportunities afforded by ART access to reframe HIV and thereby reduce stigma and prevent new infections are being realized across the five countries.

2. Material and methods

2.1. Study setting and population

The five African countries included in the sample - Senegal, Burkina Faso, Nigeria (South-East), Kenya, and Swaziland - vary socioculturally and epidemiologically. While Senegal is overwhelmingly Muslim, religious affiliation among the Burkinabe is more diverse, and Igbospeaking South-East Nigeria is, like Kenya and Swaziland, overwhelmingly Christian. They also differ greatly in terms of total population size: Nigeria grew from 113.5 million in 1997 to 190.9 million in 2017 while Swaziland's population increased from 1 million to 1.4 million across the same timespan (World Bank Group). Over the past eighteen years, the epidemic and its response have evolved differently across the five countries, as regards prevalence, mortality, and ART coverage (Table 1). Based on retrospectively adjusted UNAIDS figures, prevalence peaked in the mid-to-late 90s in Burkina Faso (2.6%, 1997) and Kenya (11%, 1997), and has held steady in Nigeria and Senegal since the late 90s, while in Swaziland ART has averted substantial mortality since 2004, allowing prevalence to continue to rise through 2014 (28.2%) (UNAIDS AIDSInfo). ART coverage has increased steadily since 2004, though levels of coverage vary substantially with Nigeria only reaching 53% coverage in 2017 compared to Swaziland's 86%. Swaziland, Kenya and Nigeria are PEPFAR countries.

We analyzed de-identified narratives about HIV submitted to scriptwriting competitions by young people aged 10–24 at eight discrete time points: 1997, 2000, 2002, 2005, 2008, 2011, 2013, and 2014. The competitions were coordinated internationally by the non-profit organization Global Dialogues (www.globaldialogues.org). Contest participants were invited to contribute a creative idea for a short film about HIV. The young participants in the Global Dialogues contests are mobilized by nongovernmental and community-based organizations and local, national, and international media across sub-Saharan Africa. A leaflet, identical in all countries and available in several major languages, was used to provide young people up to the age of 24 with instructions on how to participate in the contest, inviting them to come up with a creative idea for a short film about HIV.

From 1997 through 2011, the contests specifically focused on HIV; in 2013 and 14, the contest, under the name Global Dialogues, was framed in global terms and included a broader array of themes (sexuality, violence against women, alcohol and drugs, in addition to HIV). Scenarios were ineligible for inclusion in the study sample if they did not mention HIV. Each contest leaflet provided lists of suggested topics which participants could use as a starting point for their stories (which also included themes of sexuality, violence against women, alcohol and drugs), as well as an open "free choice" option. These story starters changed over time, becoming progressively less leading while the "free choice" category was maintained. The data included in our sample are drawn from these "free choice" narratives, with the exception of 2014, when submissions in response to the broad suggested topics related to

Table	1
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Adult HIV Prevalence, ART coverage for the five study countries, 1997–2014 (UNAIDS AIDSInfo).

	Senegal	Burkina Faso	Nigeria	Kenya	Swaziland			
Adult HIV prevalence								
1997	0.5%	2.6%	1.6%	11%	20.2%			
2005	0.7%	1.5%	1.7%	7.3%	26.3%			
2008	0.6%	1.3%	1.6%	6.4%	26.8%			
2014	0.5%	1.0%	1.6%	5.4%	28.2%			
2017	0.4%	0.8%	1.5%	4.9%	27.7%			
ART coverage								
2000	0%	-	0%	0%	0%			
2005	0%	-	5%	4%	8%			
2008	21%	-	16%	17%	22%			
2014	37%	45%	41%	50%	61%			
2017	55%	59%	53%	73%	86%			

sexuality and HIV were also deemed eligible as they were found not to differ from the "free choice" narratives.

We stratified our data into 12 categories by sex, urban/rural location, and age of young author (10–14, 15–19, 20–24) and randomly selected 10 narratives from each of the 12 strata, oversampling locales if necessary to increase likelihood that 20 stories were selected for each age/sex stratum (Table 2). In some countries, certain age/sex strata still contained fewer than 20 narratives, hence some country samples have fewer than the maximum 120 narratives. Our sampling procedures are described in detail elsewhere (Winskell, Singleton, & Sabben, 2018). Prior to 2005, narratives are only available for Senegal and Burkina Faso. Because of the historical importance of these years, we include those data here. In light of the size and cultural diversity of the Nigerian population, only those narratives from the Igbo-speaking Southeast, from which the majority of Nigerian narratives were contributed, were sampled.

Two coders independently quantified discrete components of each narrative, such as the presence of an HIV-related death, entering them into Qualtrics research software (Provo, UT). Data were exported to Excel for cleaning and reconciliation. In cases of discrepancy between coders, consensus was reached via dialogue and/or adjudication by a third team member. Coding was binary with presence of a component at least once in a text coded "1" and the alternative, "0". The presence of each component was classified independently of other components.

3. Calculation

We calculated descriptive statistics (proportions) and adjusted odds ratios (aORs) and 95% confidence intervals in SAS, Version 9.4 (SAS Institute Inc., Cary, NC) to assess the relationship between narrative year or country or author demographics and the narrative component of interest. Both temporal and cross-national analyses controlled for author demographics (exact age, sex, urban/rural residence); we also controlled for year in analyses focusing on comparisons across countries and for country in temporal analyses. Analyses of the relationships between author demographics and narrative component of interest controlled for narrative year and country and the remaining two demographic dimensions (i.e. analyses of effect of author age controlled for author sex and residence in addition to narrative year and country). For each narrative in the sample, we determined the presence or

absence of the following components:

1 *Death & Suicide*: whether it includes a death caused by HIV/AIDS. Death could include suicide of either a person living with HIV or someone connected to that person (some narratives feature a family member of a person diagnosed with HIV committing suicide or dropping dead following disclosure, a measure of HIVrelated stigma). Suicides were also analyzed independently.

- 2. *ART*: whether it states explicitly that a character living with HIV receives ART and/or an unspecified biomedical treatment ("drugs", "medicines", etc.) for HIV.
- 3. *Hope*: whether it ends with diagnosis or death without envisaging a fulfilling life after diagnosis.
- 4. *Subtopic*: whether it focuses on prevention, infection, or life postinfection. These topics were not mutually exclusive.
- 5. *Support*: whether one or more character living with HIV receives support.
- 6. *Blame*: whether it represents HIV as a consequence of wrongdoing by the character living with HIV.
- 7. *Mistreatment:* whether one or more character living with HIV is subject to mistreatment.
- 8. *Gender of the protagonist*: whether it includes one or more female protagonist(s) and/or one or more male protagonist(s). Each gender was analyzed independently.
- 9 Sexual transmission: whether HIV is sexually transmitted.
- 10. Among the subset of narratives that feature sexual transmission of HIV:
 - a. Intentional transmission: whether transmission is intentional.
 - b *Non-disclosure:* whether transmission results from a character not disclosing his/her status

The majority of these variables are independent of narrator or character perspectives. For example, even if the narrator speaks out against mistreatment of a character, it is still represented as occurring and as such recorded in our statistics. Representations of mistreatment thus need to be interpreted differently from stigmatizing representation (e.g. where a narrative represents a character living with HIV intentionally infecting others). In the case of blame, no distinction is made between the use of blaming language by the narrator versus a character. We found that such a distinction was often subject to interpretation and could not be operationalized in a consistent way with multiple coders in the current study.

Presentation of cross-national data is organized from lowest to highest HIV prevalence country. Reference groups were selected based on extreme adjusted odds ratio values and/or highest proportion of narratives including the variable of interest. Where applicable, we also conducted temporal evaluation of concordant/discordant yes/no paired outcomes. This study, comprising the secondary analysis of existing data, was approved by the Emory University Institutional Review Board.

4. Limitations

This study has limitations related to its distinctive data source. Data for 1997, 2000, 2002, and 2011 are available from only two countries. As contest participants self-select, the data are not representative of the youth populations; participants in the scriptwriting competitions may be better educated, and more knowledgeable and motivated about HIV than the general youth population. We have little demographic

Table 2				
Sampling pool an	d Study sam	ples from F	ive Countries,	1997–2014

			-							
		1997	2000	2002	2005	2008	2011	2013	2014	TOTAL
Senegal	Pool	1202	1166	1245	2824	1643	20	228	360	8688
	Sample	86	109	104	107	79	-	14	67	566
Burkina Faso	Pool	450	390	1099	4821	3769	283	-	1190	13,045
	Sample	44	45	103	112	100	27	-	56	487
Nigeria	Pool	-	-	-	1869	1156	409	574	1316	5324
	Sample	-	-	-	120	93	34	65	88	400
Kenya	Pool	-	-	-	673	117	39	137	3007	3973
	Sample	-	-	-	88	25	-	45	116	274
Swaziland	Pool	-	-	-	510	716	56	211	236	1729
	Sample	-	-	-	72	50	_	48	40	210
TOTALS	Total Pool	1652	1556	2344	10,697	7401	807	2193	6109	32,759
	Final Sample	130	154	207	499	347	61	172	367	1937

Legend: -: no data available.

information about individual participants other than their sex, age, country of origin, and type of place of residence. The data are embedded within cultural norms of performance, discourse, and persuasion (Farmer & Good, 1991), which may be informed by rhetorical considerations specific to the scriptwriting competition, reflecting the young authors' motivation, for example, to tell what they consider to be a good or dramatic story (e.g. one in which characters die) and thereby win the contest. The programmatic context of the scriptwriting competitions, including the shift in elicitation and broadening of themes from 2013, may have influenced the consistency of the data in ways of which we are unaware. With the caveats outlined above and to the extent possible in light of these programmatic realities, the collection of these secondary data is consistent across sites and over time, allowing for meaningful systematic cross-national and temporal comparison of a large number of narratives.

5. Results

5.1. Author demographics

Mean author age ranged from 14.8 years (SD = 3.2 years) in the Swazi sample to 18.0 years (SD = 3.9 years) in the Kenya sample. The Burkina sample had the highest proportion of urban (65%) and male (54%) authors, and the Swazi the lowest (34% and 39% respectively) (Table 3).

Controlling for year of writing and country, gender, and residence of the author, narratives by older authors had lower odds of representing HIV as the consequence of some blameworthy action and higher odds of ending hopefully, depicting support for people living with HIV (PLWH), and including a focus on prevention (see supplement, Table 1). Narratives including sexual transmission of HIV by urban authors had higher odds of HIV transmission occurring following a character failing to disclose his/her status (see supplement, Table 2). There were no other significant effects of author demographics.

5.2. Temporal (Fig. 1, supplement, Table 3)

5.2.1. Death

The proportion of texts including an HIV-related death of any kind (including suicide) ranged from 32% in 2000 to 42% in 1997 and 2002 and an HIV-related suicide occurred in approximately 5% of all texts. Controlling for author demographics and country, there were significantly lower odds of an HIV-related death of any kind (including suicide) when compared to 1997 for all contest years except 2000 and 2002. Compared to 2002, the odds of death dropped with each contest year from 2005 through 2013; the odds for 2014 were comparable to those of 2005 and 2008. There was no significant change in the odds of suicide over time.

5.2.2. ART

The proportion of texts in which a character living with HIV accessed ART or biomedical treatment for HIV/AIDS ranged from 2% in 1997 to 30% in 2011. For all years except 2000 and 2002, characters living with HIV had significantly higher odds of accessing ART or other biomedical treatment than in 1997. The odds grew with each contest year from 2005

Table 3 Author demographics.

	Age (mean, SD) ^a	% Female ^a	% Urban ^a
Senegal	16.8 (3.6)	48%	61%
Burkina Faso	17.6 (3.5)	46%	65%
Nigeria	16.4 (3.6)	52%	54%
Kenya	18.0 (3.9)	50%	54%
Swaziland	14.8 (3.2)	61%	34%
Total	16.9 (3.7)	50%	57%

through 2011; the odds for 2013 and 2014 were comparable to those for 2005. Temporal evaluation of paired outcomes (i.e. access to biomedical treatment and absence of mention of death versus no mention of access to treatment and mention of death) identified a significant inverse relationship between these pairs. That is, over time, mentions of access to biomedical treatment without death increased while no mention of access to treatment and mention of death decreased.

5.2.3. Hope

The proportion of texts ending hopefully ranged from 32% in 2002 to 58% in 2008. In 2008, 2011 and 2014, narratives were significantly more likely to end hopefully than in 1997. The odds peaked in 2008 and in 2013 dropped to levels comparable to 2005. Temporal evaluation of paired outcomes for hope and death (i.e. presence of hope and absence of death versus absence of hope and presence of death) showed a significant inverse relationship between these narrative characteristics. A similar analysis for hope and ART showed a significant direct relationship between the presence of both hope and ART versus their absence.

5.2.4. Subtopic

The proportion of texts including infection ranged from 60% in 2000 to 80% in 2011, that of texts including life post-infection from 25% in 1997 to 56% in 2014, and that of texts including prevention from 11% in 2014 to 24% in 2005. Narratives had significantly higher odds of including the topic of infection in 2014 than in all years except 2011 and 2013. Narratives had significantly higher odds of including the theme of life post-infection in 2014 than in all years except 2008, and narratives had significantly lower odds of including prevention in 2014 than in any year except 2011.

5.2.5. Support

The proportion of narratives featuring a character living with HIV receiving support ranged from 24% in 2002 to 53% in 2008. Narratives from 2008 had significantly higher odds of including support than those from any other year, barring 2011.

5.2.6. Blame

The proportion of narratives that blame a character for contracting HIV ranged from 29% in 2008 to 59% in 2011. With the exception of 2011, narratives from 2002 onwards had significantly lower odds than those written in 1997 of including blame.

5.2.7. Mistreatment

The proportion of narratives portraying characters living with HIV being mistreated ranged from 17% in 2000 to 30% in 2011. However, controlling for author demographics, including country, narratives from 1997 to 2014 had significantly higher odds of including mistreatment of PLWH than those from 2000 or 2002; no other significant differences existed.

5.2.8. Gender of protagonist

The proportion of narratives including one or more female protagonists rose from 55% in 2000 to 77% in 2013, while those including one or more male protagonists ranged from 74% in 2000 to 44% in 2013 and 2014. Narratives from 2008 to 2014 had significantly higher odds of featuring female protagonists than those from 2000, 2005, and 2011. Narratives from 2014 had significantly lower odds of including male protagonists than those from all years prior to 2013.

5.2.9. Sexual transmission, intentional infection, and non-disclosure

There were no significant patterns in sexual transmission or in intentional HIV infection or infection due to lack of disclosure.

^a All p-values for comparisons across countries were less than 0.005.



Fig. 1. Proportions, odds ratios and 95% CIs from logistic regression models, adjusted for author age, sex, urban/rural residence, and country of origin. **a.** Year-specific odds of narratives including an HIV-related death (including suicide) relative to narratives from 1997. **b.** Year-specific odds of narratives including an HIV-related death (including suicide) relative to narratives from 1997. **c.** Year-specific odds of narratives ending hopefully relative to narratives from 1997. **d.** Year-specific odds of narratives including a focus on prevention relative to narratives from 2014. **e.** Year-specific odds of narratives from 2014. **f.** Year-specific odds of narratives including a focus on life post-infection relative to narratives from 2014. **g.** Year-specific odds of narratives including a character living with HIV receiving support relative to narratives from 2008. **h.** Year-specific odds of narratives from 1997. **i.** Year-specific odds of narratives from 2014. **g.** Year-specific odds of narratives from 1997. **j.** Year-specific odds of narratives from 1997. **j.** Year-specific odds of narratives from 2014. **k.** Year-specific odds of narrati

5.3. Cross-national (Fig. 2, supplement Table 4)

5.3.1. Death and suicide

The proportion of texts including an HIV-related death of any kind (including suicide) ranged from 32% in Senegal to 50% in Nigeria and that of including an HIV-related suicide ranged from 3% in Burkina Faso and Swaziland to 7% in Senegal. All countries had significantly lower odds of including an HIV-related death than Nigeria. Narratives from Senegal had significantly higher odds of including a suicide than those from Burkina Faso and from Swaziland.

5.3.2. ART

The proportion of narratives in which characters living with HIV accessed ART or other biomedical treatments for HIV generally increased with country HIV prevalence, from 8% in Senegal to 24% in Kenya and 23% in Swaziland. Narratives from Kenya had significantly

higher odds of including characters living with HIV accessing ART or other biomedical treatments for HIV than narratives from any country aside from Swaziland.

5.3.3. Hope

The proportion of narratives featuring hopeful endings ranged from 28% in the Nigerian to 49% in the Swazi sample; all countries had significantly higher odds of having narratives ending hopefully than Nigeria.

5.3.4. Subtopic

The proportion of narratives including infection ranged from 83% in Nigeria to 57% in Swaziland, while the proportion of narratives including post-infection increased with country HIV prevalence, from 29% in Senegal to 60% in Swaziland. The proportion of narratives including prevention ranged from 17% in Senegal to 22% in Burkina



Fig. 2. Proportions, ORs, and 95% CIs from logistic regression models, adjusted for author age, sex, and urban/rural residence, and year of writing. **a.** Country-specific odds of narratives including an HIV-related death (including suicide) relative to narratives from Nigeria. **b.** Country-specific odds of narratives including an HIV-related death (including suicide) relative to narratives from Kenya. **c.** Country-specific odds of narratives ending hopefully relative to narratives from Nigeria. **d.** Country-specific odds of narratives including a focus on prevention relative to narratives from Senegal. **e.** Country-specific odds of narratives including a focus on infection relative to narratives from Senegal. **f.** Country-specific odds of narratives including a focus on life post-infection relative to narratives from Senegal. **g.** Country-specific odds of narratives including a character for contracting HIV relative to narratives from Nigeria. **i.** Country-specific odds of narratives blaming a character for contracting HIV relative to narratives from Nigeria. **i.** Country-specific odds of narratives blaming a character for Kenya. **j.** Country-specific odds of narratives featuring at least one female protagonist relative to narratives from Nigeria. **k.** Country-specific odds of narratives featuring at least one male protagonist relative to narratives from Burkina Faso. **l.** Country-specific odds of narratives featuring sexual transmission of HIV relative to narratives from Nigeria.

Faso and Kenya. Narratives including infection were significantly more likely in Nigeria than in any other country. Narratives including life post-infection were significantly less likely in Senegal than any other country. Odds of including post-infection increased with HIV prevalence. Odds of a narrative including prevention did not differ significantly by country, with the exception of Kenya including more prevention than Senegal.

5.3.5. Support, blame, and mistreatment

Representations of support increased with country HIV prevalence, from 30% in Senegal to 48% in Swaziland. Representations of mistreatment of PLWH was present in between 19% (Kenya) and 28% (Nigeria) of narratives. Blaming texts were most common in the Nigerian (66%) and least prevalent in the Swazi samples (22%). Narratives from Swaziland had significantly higher odds of including support than those from any other country, while those from Nigeria had significantly higher odds of including blame than those from any other country. Kenyan narratives had significantly lower odds of featuring mistreatment of PLWH than those from other countries, with the exception of Senegal.

5.3.6. Gender of protagonist

Overall, the Burkinabe sample included the lowest proportion of female protagonists (present in 58% of narratives) and the highest proportion of male protagonists (present in 69% of narratives). In contrast, Swazi narratives featured the lowest proportion of male and highest of female protagonists, present in 40% and 79% of narratives respectively. Nigerian narratives had higher odds of featuring female protagonists than those from Senegal, Burkina Faso, or Kenya, while Burkinabe narratives had higher odds of including male protagonists than any other country sample.

5.3.7. Sexual transmission, intentional infection, and non-disclosure

The proportion of narratives featuring sexual transmission of HIV ranged from 51% in the Burkinabe to 72% in the Nigerian sample. Among these narratives, intentional infection was present in between 3% (Kenya) and 8% (Nigeria) and infection as a consequence of a character not disclosing his/her status in between 2% (Swaziland) and 11% (Senegal and Nigeria). Narratives from Nigeria had significantly higher odds of featuring sexual transmission than narratives from any other country. Those from Swaziland had significantly lower odds of including HIV transmission following non-disclosure than narratives from Senegal or Nigeria.

6. Discussion

6.1. Author demographics

Our analysis provides an overview of young Africans' representations of HIV in a substantial number of creative narratives over time and across five epidemiologically and socioculturally diverse countries. While the narratives include stigmatizing representations, it is reassuring that those by older authors are significantly less blaming and more hopeful, supportive, and prevention-focused. This suggests that, as they mature, the authors are better placed to challenge stigmatizing social representations.

6.2. Temporal findings

From 2005, changes in the narratives over time – representations of mortality, ART access, and hopefulness – improved. It seems likely that the young authors were responding to the optimism fostered by news and, in higher prevalence countries, evidence within their communities, of increased access to ART.

Deaths in the narratives reached their lowest point in 2013, while treatment and hope peaked in 2011 and 2008, respectively, then declined. It is unclear what may have led to the increase in deaths in 2014, reduced access to ART in 2013 and 2014 (both of which reverted to approximately 2005 levels), and a reduction in hope from 2011. The confluence of these different indicators, including the significant temporal relationships between them, lends weight to a pattern of increased optimism followed by a slight downturn.

There was a parallel increase in the proportion of narratives that included infection from 2011. A focus on the circumstances of infection can be viewed as a marker of symbolic – or blame-based – stigma (Winskell, Hill, & Obyerodhyambo, 2011). Compared to 1997, characters were less likely to be blamed for becoming HIV-positive in later years (with the exception of 2011), and 2008 showed a peak in characters living with HIV receiving support from others. It is possible that the hope-promoting and stigma-reducing dividend of the advent of ART access may have partially run its course by 2011/2013. The three countries where DHS temporal data on stigma is available show a downturn in accepting attitudes towards people living with HIV among 15-24 year-olds (for Senegal from 2010, for Nigeria from 2013, and for Kenya from 2014) (Measure DHS, 2019).

The prevalence of suicide holds at around 5% across the 18-year period (with some cross-national variability). This suggests that, while ART access may have alleviated the association of HIV with death, despair and social stigma still persist. Evidence that increased access to ART in sub-Saharan Africa has mitigated stigma is mixed (Chan & Tsai, 2016; Genberg et al., 2009; Maman et al., 2009; Maughan-Brown, 2010; Wolfe et al., 2008). Studies have indicated that, even after treatment is more widely available and HIV infection is no longer considered fatal, the disease will continue to be associated with sexual "immorality," shame, and disgrace and even that new forms of ART-related stigma may have emerged (Campbell, Foulis, Maimane, & Sibiya, 2005; Roura et al., 2009; Steinberg, 2008).

The 2004 UNAIDS epidemic report revealed the growing

feminization of the global epidemic, driven by the African epidemic, reporting that almost half of people living with HIV worldwide were women, up from 35% in 1985 (Dworkin & Ehrhardt, 2007). The increasing proportion of narratives focusing on female protagonists over time appears to reflect growing awareness of women's vulnerability. Whether the young participants in the scriptwriting competitions observed this phenomenon directly in their communities or indirectly via media representations reflecting epidemiological understandings, they are increasingly propagating and reinforcing a social representation of a feminized epidemic in their narratives.

6.3. Cross-national findings

Cross-national differences in the gender of protagonists, however, relate to the type of sexual risk and vulnerability depicted in the narratives. Narratives from the lowest prevalence countries, Senegal and Burkina Faso, feature a higher proportion of male protagonists. Qualitative analysis of the narratives reveals that Burkinabe authors more frequently represent male peers or mixed peer groups engaging with and navigating risk, while male perspectives are commonly represented in the themes of migration and sex work that feature with distinctive prominence in the Senegalese sample (and which imply that HIV comes from elsewhere or is associated with specific "high-risk" groups). The prominence of female protagonists in the Nigeria sample is related to a preoccupation with female sexuality and a tendency to blame HIV on women's immoral sexual behaviour. In the Swazi narratives, in contrast, it is related to an emphasis on poverty and sexual coercion as drivers of girls' and women's vulnerability. The Kenyan sample is the least distinctive country sample in terms of the proportion of female versus male protagonists; female vulnerability is commonly linked with poverty and social isolation (e.g. due to orphanhood) while male vulnerability most often stems from ignorance or lack of perceived vulnerability to HIV. UNAIDS data on the five countries indicate that in 2018 Nigeria had the lowest proportion (56%) of PLWH who are female, while Senegal had the highest (68%) (UNAIDS AIDSInfo). Retrospectively adjusted data (i.e. that do not necessarily reflect contemporary understandings at the time) indicate that Burkina Faso has seen the largest shift in the proportion of PLWH who are female - from 50% in 1997 to 61% in 2018.

The Nigerian sample has the highest prevalence of death, sexual transmission, intentional transmission or transmission following nondisclosure, and blame, and the lowest prevalence of hope. It is notable that narratives from Swaziland, the country with the highest HIV prevalence, are those least likely to be hopeless and most likely to feature characters showing support for characters living with HIV, a variable that increases with a country's HIV prevalence; this may be at least partially attributable to increased social proximity to HIV (Winskell et al., 2011; Chan & Tsai, 2017).

Nigeria is home to the second highest number of people living with HIV in the world (3.2 million in 2016) (UNAIDS, 2018), yet has very low ART coverage (33%) (UNAIDS AIDSInfo). Representations in Nigerian narratives were however already distinctively stigmatizing in 2005 (Winskell et al., 2011), a time when its ART coverage was comparable to that of other countries in our study. While ART may alleviate certain aspects of HIV stigma, other interventions are needed to engage with its symbolic and instrumental dimensions (Chan & Tsai, 2016).

Our data demonstrate the value to public health efforts of innovative data sources and of approaches rooted in the humanities that take account of symbolic dimensions of population health. They contextualize within narrative-based social representations Chan et al.'s finding of a negative association between ART access and HIV-related stigma, based on their analysis of Demographic and Health Survey (DHS) and AIDS Indicator Survey (AIS) data (Chan et al., 2015; Chan & Tsai, 2016). They reflect symbolic (blame-based) stigma, describe enacted stigma, and have implications for anticipated and internalized stigma. Distinctive cross-national differences in the narratives point to opportunities to reframe cultural narratives around HIV in less stigmatizing ways, particularly in countries like Nigeria.

7. Conclusions

The narratives reflect real-life developments in the history of the epidemic, namely increased ART access, reductions in mortality, associated increased hope, and a growing feminization of the epidemic. They thereby demonstrate that young people are both apprehending these changes in their communities or the media and also contributing to corresponding shifts in narrative-based social representations. However, the partial erosion of gains in optimism from 2011 and cross-national variation in the gender of protagonists indicate that factors other than ART access and epidemiological change may be more important in informing the social representations and related cultural narratives that dominate. Some of these factors appear to be related to historic developments in the response to the epidemic. Others are informed by country-level context and framing. For example, the prevalence of death and hope in the country samples align less with real-life outcomes than with blame associated with the circumstances of sexual transmission, while cross-national differences in the proportion of female and male protagonists reflect not real-life proportions, but rather local perceptions of vulnerability and/or blame. These representations are valuable markers of stigma that can help guide the framing of messaging and efforts to inform cultural narratives around HIV.

While our distinctive data have limitations, they have the advantage of combining cross-national and temporal comparability with ethnographic detail. In their focus on contextualized and often preconscious social representations, they may also be less susceptible to social desirability bias, a major concern in research on stigma, than other forms of data. Given the dearth of comparable or parallel temporal and cross-national data, there is a pressing need for sociocultural surveillance, beyond the limited tracking of knowledge and attitudes in DHS and AIS conducted according to countries' own schedules. This would facilitate temporal and cross-national comparison and thereby assessment of HIV communication needs at national levels and beyond in ways that are responsive to the evolving epidemic.

Our data show a downturn in optimism in later years, following gains starting in 2005. Warning against dangerous complacency, a 2018 Lancet Commission report (Bekker et al., 2018) argues that the dominance of HIV treatment and biomedical approaches have resulted in the neglect and underfunding of primary prevention, along with efforts to address HIV-related stigma and other social and structural drivers. A biomedical response, while essential, will not alone be successful in controlling HIV: community mobilization, behaviour change and condom use in gay communities were successful in preventing HIV before biomedical interventions existed and remain essential today (Piot et al., 2015). There is an urgent need to revitalize these components of the response and ensure that the community-level and mass media dimensions of HIV communication that reach the general public are not lost in increasingly clinic-based approaches (Winskell, Kus, et al., 2018) so that young people's social representations of HIV reflect the true promise of the scientific and programmatic developments of the past decade and a half.

Declaration of competing interest

Dr. Winskell and her spouse Daniel Enger initiated the Scenarios from Africa/Global Dialogues communication process. Dr. Tiendrébéogo, Ms. Nkambule-Vilakati, Dr. Dia, and Mr. Mbakwem were involved in implementation of the scriptwriting contests and in the collection of narratives. Mr. Enger serves as executive director and paid consultant to the Global Dialogues non-profit organization, which provided the data for this study.

CRediT authorship contribution statement

Kate Winskell: Conceptualization, Data curation, Formal analysis, Methodology, Writing - original draft, Funding acquisition, Writing review & editing. Gaëlle Sabben: Data curation, Formal analysis, Methodology, Writing - original draft, Writing - review & editing. Robyn Singleton: Data curation, Methodology, Writing - original draft, Writing - review & editing. Robert A. Bednarczyk: Formal analysis, Writing - original draft, Methodology, Writing - review & editing. Georges Tiendrébéogo: Data curation, Writing - review & editing. Siphiwe Nkambule-Vilakati: Data curation, Writing - review & editing. Benjamin Mbakwem: Data curation, Writing - review & editing. Rob Stephenson: Data curation, Formal analysis, Methodology, Funding acquisition, Writing - review & editing.

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Appendix A. Supplementary data

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References

- Bekker, L.-G., Alleyne, G., Baral, S., Cepeda, J., Daskalakis, D., Dowdy, D., et al. (2018). Advancing global health and strengthening the HIV response in the era of the sustainable development goals: The international AIDS society—lancet commission. *The Lancet*, 392, 312–358.
- Campbell, C., Foulis, C. A., Maimane, S., & Sibiya, Z. (2005). "I have an evil Child at my house": Stigma and HIV/AIDS management in a South African community. *American Journal of Public Health*, 95, 808–815.
- Campbell, C., Skovdal, M., Madanhire, C., Mugurungi, O., Gregson, S., & Nyamukapa, C. (2011). "We, the AIDS people...": How antiretroviral therapy enables Zimbabweans living with HIV/AIDS to cope with stigma. *American Journal of Public Health*, 101, 1004–1010.
- Chan, B. T., & Tsai, A. C. (2016). HIV stigma trends in the general population during antiretroviral treatment expansion: Analysis of 31 countries in sub-Saharan Africa, 2003-2013. Journal of Acquired Immune Deficiency Syndromes, 72, 558–564.
- Chan, B. T., & Tsai, A. C. (2017). Personal contact with HIV-positive persons is associated with reduced HIV-related stigma: Cross-sectional analysis of general population surveys from 26 countries in sub-Saharan Africa. *Journal of the International AIDS Society, 20*, 21395.
- Chan, B. T., Tsai, A. C., & Siedner, M. J. (2015). HIV treatment scale-up and HIV-related stigma in sub-Saharan Africa: A longitudinal cross-country analysis. *American Journal of Public Health*, 105, 1581–1587.
- Deacon, H., Uys, L., & Mohlahlane, R. (2009). HIV and stigma in South Africa. In P. Rohleder, L. Swartz, S. C. Kalichman, & L. C. Simbayi (Eds.), *HIV/AIDS in South Africa 25 Years on: Pyschosocial perspectives* (pp. 105–120). New York: Springer.
- Dworkin, S. L., & Ehrhardt, A. A. (2007). Going beyond "ABC" to include "GEM": Critical reflections on progress in the HIV/AIDS epidemic. *American Journal of Public Health*, 97, 13–18.
- Farmer, P., & Good, B. J. (1991). Illness representations in medical anthropology: A critical review and a case study of the representation of AIDS in Haiti. In J. A. Skelton, & R. T. Croyle (Eds.), *Mental representations in health and illness* (pp. 132–162). New York: Springer-Verlag.
- Genberg, B. L., Hlavka, Z., Konda, K. A., Maman, S., Chariyalertsak, S., Chingono, A., et al. (2009). A comparison of HIV/AIDS-related stigma in four countries: Negative

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attitudes and perceived acts of discrimination towards people living with HIV/AIDS. Social Science & Medicine, 68, 2279–2287.

László, J. (1997). Narrative organisation of social representations. Papers on Social Representations, 6, 155–172.

- Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Sawires, S. R., Ortiz, D. J., et al. (2008). Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. *AIDS*, 22(Suppl), S67–S79.
- Maman, S., Abler, L., Parker, L., Lane, T., Chirowodza, A., Ntogwisangu, J., et al. (2009). 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*, 68, 2271–2278.
- Markova, I., & Wilkie, P. (1987). Representations, concepts and social change the phenomenon of AIDS. Journal for the Theory of Social Behaviour, 17, 389–409.
- Maughan-Brown, B. (2010). Stigma rises despite antiretroviral roll-out: A longitudinal analysis in South Africa. Social Science & Medicine, 70, 368–374.
- Measure Dhs. (2019). STATcompiler.
- Moscovici, S. (2008). Psychoanalysis: Its image and its public: Polity.
- Murray, M. (2002). Connecting narrative and social representation theory in health research. Social Science Information, 41, 653–673.
- Piot, P., Karim, S. S. A., Hecht, R., Legido-Quigley, H., Buse, K., Stover, J., et al. (2015). Defeating AIDS—advancing global health. *The Lancet*, 386, 171–218.
- Rabinow, P. (1986). Representations are social facts: Modernity and post-modernity in anthropology. In J. Clifford, & G. E. Marcus (Eds.), Writing culture: The poetics and politics of ethnography (pp. 234–261). Berkeley and Los Angeles, CA: University of California Press.
- Roura, M., Wringe, A., Busza, J., Nhandi, B., Mbata, D., Zaba, B., et al. (2009). "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*, 9.

- Steinberg, J. (2008). Sizwe's test: A young man's journey through Africa's AIDS epidemic. New York, London, Toronto, Sydney: Simon & Schuster.
- Tsai, A. C., Bangsberg, D. R., Bwana, M., Haberer, J. E., Frongillo, E. A., Muzoora, C., et al. (2013). How does antiretroviral treatment attenuate the stigma of HIV? Evidence from a cohort study in rural Uganda. *AIDS and Behavior*, 17, 2725–2731.

UNAIDS. (2018). UNAIDS data 2018. Geneva: Joint United Nations Programme on HIV/ AIDS.

Winskell, Kate, Hill, Elizabeth, & Obyerodhyambo, Oby (2011). Comparing HIV-related symbolic stigma in six African countries: social representations in young people's narratives. Social Science & Medicine, 73, 1257–1265. https://doi.org/10.1016/j. socscimed.2011.07.007.

Winskell, Kate, Kus, Landy, Sabben, Gaëlle, Mbakwem, Benjamin, C, Tiendrébéogo, Georges, & Singleton, Robyn (2018). Social representations of mother-to-child transmission of HIV and its prevention in narratives by young Africans from five countries, 1997–2014: Implications for communication. Social Science & Medicine, 211, 234–242. https://doi.org/10.1016/j. socscimed.2018.06.006.

Winskell, Kate, Singleton, Robyn, & Sabben, Gaëlle (2018). Enabling analysis of big, thick, long, and wide data: data management for the analysis of a large longitudinal and cross-national narrative data set. *Qualitative Health Research*. https://doi.org/ 10.1177/1049732318759658.

Wolfe, W. R., Weiser, S. D., Leiter, K., Steward, W. T., Percy-de Korte, F., Phaladze, N., et al. (2008). The impact of universal access to antiretroviral therapy on HIV stigma in Botswana. *American Journal of Public Health*, 98, 1865–1871.

World Bank Group. World Bank open data.

http://aidsinfo.unaids.org. (Accessed 11 August 2019).