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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

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Abstract

International recommendations related to the prevention of mother-to-child transmission (PMTCT) of HIV have evolved rapidly over time; recommendations have also varied contextually in line with local constraints and national policies. This study examines how young Africans made sense of mother-to-child transmission (MTCT) and PMTCT and related barriers and facilitators between 1997 and 2014 in the context of these complex and changing recommendations. It uses a distinctive data source: 1,343 creative narratives submitted to HIV-themed scriptwriting competitions by young people aged 10–24 from 5 African countries (Senegal, Burkina Faso, Nigeria, Kenya and Swaziland) between 1997 and 2014. The study triangulates between analysis of quantifiable characteristics of the narratives, thematic qualitative analysis, and narrative-based approaches. MTCT occurs in 8% of the narratives (108), while it is prevented in 5% (65).

Narratives differ according to whether they depict MTCT or PMTCT (or, rarely, both), evolve over

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time, and show cross-national thematic variation. In the aggregate, representations shift in line with increased access to testing and antiretroviral medications, with PMTCT narratives becoming more frequent and MTCT narratives becoming more hopeful as diagnosis becomes the gateway to ART access. However, storylines of intergenerational tragedy in which MTCT is depicted as inevitable persist through 2014. Alongside cross-national differences in theme and tone, narratives from higher prevalence Swaziland and Kenya situate MTCT/PMTCT more centrally within descriptions of life with HIV. Findings illustrate the need to improve communication about PMTCT, reframing negative cultural narratives to reflect the full promise of developments of the past decade and a half.

Keywords

HIV; sub-Saharan Africa; PMTCT; MTCT; social representation; youth; narrative; health communication

Introduction

Of the estimated 1.8 million new HIV infections in 2016, 160,000 were in children (UNAIDS, 2017). Most of these infections in children were in sub-Saharan Africa and the result of mother-to-child transmission (MTCT). While infections in children have declined substantially since 2000, when over 600,000 children were newly infected (UNAIDS/WHO, 2000), there is still scope for progress in the prevention of MTCT (PMTCT): in 2016, 89% of HIV-infected pregnant women in Eastern and Southern Africa and 50% in Western and Central Africa accessed antiretroviral medications (ARVs) for PMTCT as either prophylaxis or lifelong antiretroviral therapy (ART) (UNAIDS, 2017).

Currently over half of all MTCT occurs during the breastfeeding period (Sidibe & Birx, 2017). Strict adherence to current WHO guidelines allows transmission to be reduced from 35% without intervention to 5% in the breastfeeding population and less than 2% in the non-breastfeeding population (WHO, 2010a). Although we have known how to prevent MTCT since the mid-1990s, differential access to and uptake of information, HIV testing, antenatal care (ANC), PMTCT services, infant formula, safe water, and ARVs have resulted in crushing global health disparities.

Information about MTCT and recommendations regarding PMTCT for low-resource settings have evolved with scientific advances, with progress in HIV treatment at global and local levels, and with recognition and perception of local, contextual constraints regarding the feasibility of safe replacement feeding. Although replacement feeding eliminates the possibility of transmission through breastfeeding, it carries substantially increased risk of malnutrition and vulnerability to life-threatening infectious diseases if practiced sub-optimally. Mixed feeding, common across sub-Saharan Africa, whereby infants receive liquids and other foods in addition to breast milk, carries the same risks for child survival as replacement feeding and also 3–4 times higher risk of HIV transmission than exclusive breastfeeding (UNICEF, 2017).

Global statements issued by UN agencies in 1987 and 1992 recommended that HIV-positive mothers in low-income settings continue to breastfeed. The option of facilitating replacement feeding was first introduced in a 1998 technical consultation (Chinkonde, Sundby, de Paoli, & Thorsen, 2010). Subsequent guidelines sought to identify under what conditions replacement feeding should be recommended, drawing on the studies available at the time (e.g., Thior et al., 2006). These studies incrementally built an evidence base to demonstrate that formula feeding was more dangerous to infant health even in the context of HIV infection. As a result, early recommendations based on poor or incomplete evidence were later reversed.

While generally favoring breastfeeding, PMTCT recommendations were dominated in the 2000s by a focus on the mother's 'informed choice'. More recently, they have come to place increasing emphasis on exclusive breastfeeding, both in the interests of child survival and to capitalize on increasing evidence of the reduced risk of HIV transmission through breast milk in the context of longer pediatric and maternal prophylactic ARV regimens and of maternal ART. In 2000, WHO recommended an individualized approach based on the context and circumstances of the mother: if replacement feeding was not acceptable, feasible, affordable, sustainable, and safe (AFASS), mothers should practice exclusive breastfeeding for the first months of life and cease breastfeeding as soon as feasible to minimize MTCT risk (WHO, 2000). In light of the socio-contextual and nutritional challenges of rapid cessation of breastfeeding, the 2006 recommendations advocated breastfeeding for the first six months and continuing beyond six months unless cessation was AFASS. The 2000 and 2006 recommendations required health workers to individually counsel all HIV-positive mothers to allow them to make context-specific decisions about whether to breastfeed. In the context of resulting confusion among mothers, health workers, and policymakers (Chinkonde et al., 2010; Våga, Moland, Evjen-Olsen, & Blystad, 2014), this approach was abandoned with WHO's 2010 guidelines, which recommended a consistent national policy on infant feeding, amounting to exclusive breastfeeding for the first 6 months and ongoing breastfeeding thereafter in low-income countries even in the absence of ARVs.

Recommendations on ARV use for PMTCT and maternal health have ranged over time from a range of prophylactic regimens, to determinations based on a mother's CD4 count of whether she should receive ARVs for MTCT prophylaxis or for her long-term health, to – more recently – life-long ART for all pregnant or breastfeeding women. In 2000 WHO first introduced recommendations for short-course prophylactic use of ARVs in late pregnancy or during labor for mothers and infants (WHO, 2000). Guidelines published in 2006 placed increased emphasis on the importance of providing ARVs to pregnant women for their own health (WHO, 2006). In 2010, in the context of widely expanded access to ART, WHO unified treatment and prophylaxis, recommending that ARV access be ensured for maternal health and PMTCT (WHO, 2010a). Option B+, whereby all HIV-positive pregnant or breastfeeding women would be given ART for life, was endorsed by WHO in 2013.

We are aware of no studies that have explored how general populations have made sense of MTCT/PMTCT over time in the context of these complex, changing and context-specific recommendations. In addition, although over 40% of new infections among African women

are in the 15–24 age group (UNAIDS, 2014) and approximately one in four women in sub-Saharan Africa gives birth before age 18 (UNFPA, 2013), little is known about African youth perspectives on MTCT/PMTCT.

Communication efforts play a central role in HIV prevention and treatment literacy (Vermund, Van Lith, & Holtgrave, 2014) and in informing stigma and its effects. Communication outside the clinic setting could play an important role in normalizing PMTCT, and in nurturing the development of a supportive and enabling environment for increasing uptake of PMTCT services. However, very few studies (e.g., Dwadwa-Henda et al., 2010; Frizelle, Solomon, & Rau, 2009) directly address the intersection between PMTCT and communication: PMTCT is, for example, not specifically mentioned in a valuable framework addressing communication in the HIV cascade of care (Babalola et al., 2017). In the context of increased biomedicalization of the response to HIV and increased access to ART, it is important to assess and address how a general population of young Africans are making sense of the information they are receiving about PMTCT and what implications this has for their HIV communication needs. It is essential that young people are equipped with understanding, skills, and positive social representations (Moscovici, 1981) of PMTCT to allow them to promptly access services themselves and to support access for others.

In this context, it is noteworthy that use of the term *mother-to-child transmission* has been rightly criticized for perpetuating blame and stigma towards mothers and undermining efforts to increase male involvement (Frizelle et al., 2009; UNAIDS, 2015). The preferable term *parent-to-child-transmission* unfortunately appears to have caught on in India alone (Sgaier et al., 2012), while the more clinical term *vertical transmission* lacks explanatory power for a lay population. The term *mother-to-child transmission* is used here on account of its dominance and historical relevance.

In this paper, we analyze young Africans' social representations of MTCT/PMTCT over a period of 18 years across five countries in sub-Saharan Africa. Coined by Moscovici in 1961 (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 (Laszlo, 1997; Murray, 2002). Often employed in studies of how new scientific ideas are integrated into lay thinking (e.g., Markova & Wilkie, 1987), social representations theory provides a particularly apt framework for a longitudinal study of youth narrative sense-making in the context of changing recommendations about MTCT/PMTCT.

We use a distinctive form of secondary data: a large sample of creative narratives submitted by young Africans to a scriptwriting competition between 1997 and 2014 from five countries situated in West, East and Southern Africa: Senegal, Burkina Faso, Nigeria (South-East),

Kenya, and Swaziland. This paper situates the social representations of MTCT/PMTCT of young people from five African countries within the context of changing recommendations with a view both to shedding light on cultural meanings and contextual factors that influence uptake of PMTCT services, and highlighting communication challenges and opportunities in the context of rapidly changing scientific recommendations.

Methods

Study context

We compare social representations of MTCT/PMTCT in five epidemiologically and socio-culturally diverse countries (Senegal, Burkina Faso, Nigeria, Kenya and Swaziland) and at four successive time points (1997, 2005, 2008, and 2014), while stratifying for the country, age, gender and urban/rural location of the young author. Over this eighteen-year period, the epidemic and its response have evolved differently across the five countries, as regards prevalence, ART, and PMTCT coverage; national populations have also grown substantially (Table 1). Although Kenya, Nigeria and Swaziland are priority countries of The Global Plan, which was transformative in reducing MTCT by 60% in 21 priority countries between 2009 and 2015 (Haroz, von Zinkernagel, & Kiragu, 2017), there are striking disparities in the most recent PMTCT coverage rates across the five countries in our study. Swaziland has the highest rates at 95%, Nigeria the lowest at 32%. Burkina Faso, Kenya and Senegal stand at 83%, 80% and 55% respectively. By the end of 2015, Nigeria was also the only WHO-identified priority country not to have rolled out Option B+.

Study sample

The research described in this paper is part of an ongoing five-country longitudinal study of young Africans' social representations of HIV (K. Winskell, Singleton, & Sabben, 2018). We analyzed a sample of de-identified narratives about HIV submitted to scriptwriting competitions by young people aged 10–24 from the five African countries at the four discrete time points; 1997 narratives are from Senegal and Burkina Faso alone as the scriptwriting competition was not held in the other countries at this time point. The competitions were coordinated internationally by the non-profit organization Global Dialogues (www.globaldialogues.org). 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.

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. In some countries, certain age/sex strata still contained fewer than 20 narratives, hence some country samples have fewer than the maximum 120 narratives. In light of the size and cultural diversity of the Nigerian population, only those narratives from the Igbo-speaking Southeast were sampled; the majority of these were from Imo State. From

a pool of 25,859 narratives for the five countries across the four time points, an overall sample of 1,343 texts resulted (Table 2).

Data processing and analysis

Our methodological approach is situated at the intersection of grounded theory (Corbin & Strauss, 2008) and thematic narrative analysis (Riessman, 2008) and triangulates between three primary analytical components:

1. analysis of quantifiable characteristics of the narratives (“quantitative attributes”);
2. thematic qualitative data analysis, focusing on thematically-related text segments and memoing for emergent themes; and
3. a narrative-based approach, focusing on plot summary and thematic keywords.

Our methods were developed to enable cross-national and longitudinal analysis and have three main advantages: (i) they ground the analysis in three distinct, though intersecting, dimensions of the data; (ii) allow triangulation; and (iii) facilitate the generation and validation of interpretive hypotheses.

The three primary analytical components were addressed as follows:

1. We quantified discrete components of each narrative, double-entering them into Qualtrics research software (Qualtrics, Provo, UT); in cases of discrepancy consensus was reached via dialogue and/or adjudication by a third team member. Examples of these quantitative attributes of the narratives included whether an HIV-related death occurred, whether the narrative ended with hope, and whether transmission resulted from sexual intercourse, blood route, or mother-to-child transmission. Data were downloaded to Excel files; descriptive statistics were calculated and tests for significance conducted in SAS software, Version 9.4 (SAS Institute Inc., Cary, NC).
2. Narratives (overwhelmingly handwritten) were transcribed into English or French and entered verbatim into MAXQDA 12 qualitative data analysis software (VERBI Software, 1989–2016), where they were labeled with reference to a codebook of 54 codes, including MTCT/PMTCT.
3. Each narrative was summarized and independently double-coded with up to six of 44 keywords, which included MTCT/PMTCT. Discrepancies in coding were resolved through dialogue. The narrative summaries served as an aide-memoire and data-management tool, allowing us to easily identify common story arcs or to rapidly situate segments of data within the context of the overall plot or argument. The summaries also function in combination with thematic coding, allowing us to isolate both individual text segments related to a specific theme, for example, MTCT, and those narratives in which MTCT is a central theme.

Our qualitative analysis addresses both narratives coded with the MTCT/PMTCT keyword (3. above) and segments of other texts thematically coded “MTCT/PMTCT” (2. above). Existing thematic coding across a range of deductive (e.g. “testing, counseling and

diagnosis”) and inductive themes (e.g. “personal reactions”) was complemented with fine-coding specific to the MTCT/PMTCT theme. Examples of fine codes include “PMTCT modalities”, “barriers and facilitators”, and “likelihood of transmission”.

From the sample of 1,343 narratives (Table 2), 310 narratives had MTCT/PMTCT-related quantitative attributes (1. above), thematic codes (2. above), and/or keywords (3. above). The distribution of this MTCT/PMTCT-themed subsample across time points and countries is presented in Table 3. Intersecting quantitative, narrative-based and thematic analysis was conducted on these 310 narratives to describe social representations of MTCT/PMTCT and compare them by author demographics, cross-nationally and longitudinally.

This study, comprising the secondary analysis of existing data, was approved by Emory University Institutional Review Board. We cite the narratives verbatim with the exception that names have been changed. Excerpts are identified by the country, contest year, sex, age, and geographic location of the author.

This study has limitations related to its distinctive data source. Data for 1997 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 information about individual participants other than their sex, age, country of origin, and type of place of residence. In light of the circumstances in which the texts were written, it is impossible to know which depict lived versus imagined experience. We do not have information on the extent of young authors’ direct personal experience of HIV, for example as people living with HIV themselves or through family members (personal and/or social proximity to HIV could be expected to inform social representations). We treat all narratives as social representations providing insights into sense-making around MTCT/PMTCT; social representations are dynamic systems of social knowledge and are properties of social groups, not individuals (Howarth, 2006). The data are embedded within cultural norms of performance, discourse and persuasion (Farmer and 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 story and thereby win the contest.

With the caveats outlined above and to the extent possible in light of the programmatic realities of the scriptwriting competitions, the collection of these secondary data is consistent across sites and over time, allowing for meaningful systematic cross-cultural and longitudinal comparison of a large number of narratives. Despite their limitations, the data provide distinctive insight into evolving sense-making about MTCT/PMTCT among a presumed general population of young Africans from five countries and across a time period of increasing availability of PMTCT and changing WHO recommendations. In so doing, they shed light on the evolution of social representations of MTCT/PMTCT and on related communication needs and practices.

Results

MTCT/PMTCT is mentioned in approximately 1 in 5 narratives. The theme is equally popular among female and male authors and slightly more prominent among urban authors. Based on keyword allocation, MTCT/PMTCT is a central theme in around 5% of the 1,343 narratives.

MTCT occurs or is presumed or anticipated in 8% of the 1,343 narratives (108 narratives, referred to as “MTCT narratives”) and PMTCT is successful or presumed or anticipated in 5% (65 narratives, referred to as “PMTCT narratives”). In eight narratives, the outcome of either MTCT or PMTCT is unknown and in four MTCT does not occur, despite risk and no precautions. The remaining narratives mention PMTCT or MTCT but do not explore the themes in depth. Authors of PMTCT narratives are, on average, somewhat older than those of MTCT narratives.

The proportion of PMTCT to MTCT represented in the narratives evolves over time. While MTCT is prevented in only one (6%) out of 18 cases in the 1997 sample (consisting only of narratives from Burkina Faso and Senegal; see Table 3), this ratio increases dramatically from 2005 (34%, n=59), reaching parity in 2008 (51%, n=51). The ratio drops back to 40% in 2014 in part due to a parallel steady growth of MTCT narratives in which the protagonist is growing up or living as an adult with HIV following vertical transmission and by virtue of ART. The vast majority of these MTCT narratives are from higher prevalence Swaziland and Kenya.

Characteristics of the narratives

As the contest did not directly elicit the MTCT/PMTCT theme, the narratives that address this topic are diverse. They differ according to whether they feature MTCT or PMTCT (or, rarely, both), evolve over time, and show cross-national variation. Analysis of quantitative attributes showed no striking differences by sex of author, age, or urban/rural residence in terms of presence of hope, blame, stigma/support, access to treatment and death/suicide in the narratives.

Close to twice as many PMTCT as MTCT narratives end hopefully. However, both sets of narratives become progressively more hopeful over time, with almost all PMTCT narratives ending hopefully in 2008 and three in five MTCT narratives ending hopefully by 2014. This hopefulness is driven by increased access to treatment over time in both types of narratives and reaches a peak in 2008. While scientific and programmatic developments related to ART appear to undergird longitudinal shifts in some of the narratives, leading to an aggregate positive trend, the trend is far from universal. Some 2014 narratives resemble those from 18 years earlier in terms of information, messaging and outcome.

The 1997 MTCT narratives tend to be bleak in tone, with suicide occurring in one in four. About half nonetheless share an explicit message of support for people living with HIV and AIDS (PLWHA), often despite a mode of infection – e.g. multiple sexual partners, infidelity – regarded as blameworthy. In several narratives, MTCT is one component of a

multigenerational chain of infection (heightened in the context of polygynous marriages) that serves to communicate the tragic consequences that unfold once HIV enters a family.

The 2005 sample marks a watershed, with PMTCT narratives characterized by testing, access to ARVs, and the theme of disclosure. The 2008 sample brings growing focus on the possibilities of living with HIV, including “happily-ever-after” narratives, in which romantic love and ART allow couples to overcome HIV, including in cases of serodiscordance. The 2014 sample is one of contrasts, with tragic narratives in which ARVs receive no mention juxtaposed with those explicitly expressing that HIV is not the end of the world.

Alongside many commonalities, certain cross-national differences in tone and centrality of MTCT/PMTCT to the plot emerge. Senegal narratives are especially bleak in 1997 and 2005, with the majority of infants infected with HIV via MTCT dying, followed by their parents. Representations of MTCT in Burkina Faso are distinguished by the role played by traditional cultural practices, such as polygyny and levirate, and male control over resources and decision-making, in facilitating HIV transmission within a sexual network.

Nigerian authors situate MTCT and PMTCT within broader narratives of melodrama, romance and morality. Certain Nigerian narratives depict MTCT as the tragic outcome of immoral sexual behavior, typically followed by the death of the parents. Nigerian PMTCT narratives include melodramatic confessions of love, betrayal and couples navigating HIV diagnosis during pregnancy. These narratives, while positive in their representations of PMTCT, continue to incorporate blame for HIV transmission. Burkinabé narratives depicting PMTCT, in contrast, promote discourses of support for PLWHA while representing HIV-positive couples having healthy children.

In all countries, the death of an infant or a prenatal HIV diagnosis announces that HIV has entered a relationship. MTCT, therefore, functions as an event within a larger plot that typically describes sexual transmission coupled with related messages about HIV and sexuality. In Swaziland and Kenya, however, MTCT and PMTCT are integrated as central components into storylines describing life with HIV. Several Swazi narratives depict female characters deciding if and when to have a child, and strategies to prevent HIV transmission. Kenyan authors describe the challenges and realities for youth growing up with HIV following perinatal infection, including AIDS orphans. In these narratives, MTCT and PMTCT represent core themes that drive plotlines, rather than smaller events that support the authors’ overall message about HIV.

Modes of transmission and prevention

General reference to MTCT/PMTCT is made most often in narratives from 1997, where it frequently appears in the form of factual information, for example, listing MTCT as one of the three major modes of transmission (alongside unprotected sex and blood), and acknowledging that MTCT can occur during pregnancy, at delivery, and/or through breastfeeding. Information of this kind is generally presumed in later years.

Pregnancy prevention and termination

Isolated narratives across all years express the belief that an HIV diagnosis means the end of any chance of a family life. In the absence of ARV-based methods of PMTCT in 1997, several narratives state that HIV-positive women should be discouraged from getting pregnant. In addition, in around 5% of cases, across all years, expectant parents respond to a positive HIV diagnosis by contemplating abortion or pressuring their spouse to terminate the pregnancy. In most cases, these mothers decide to carry their pregnancy to term, in some cases in defiance of their partners and at the cost of their relationship. In one Nigerian narrative, the woman's husband congratulates her and himself on having saved the world "from more HIV carriers" by means of abortion (15-year-old rural female, Nigeria, 2014).

Antiretroviral medication

One 1997 narrative refers explicitly to a modern ARV-based PMTCT protocol unlikely to be available in that country at that time (23-year-old urban male, Burkina Faso, 2005), pointing to the likelihood of an international information source. From 2005 onwards, however, narratives make frequent reference to PMTCT through the provision of ARVs.

The impact of increased access to antiretroviral medications is felt in roughly two-thirds of PMTCT narratives from 2005. Upon learning of their status, pregnant women or expectant couples expressing concern about their unborn children are told to their delight: "don't worry. There are medicines for that" (17-year-old urban female, Burkina Faso, 2005) or "these days HIV-positive women give birth to HIV-negative children" (14-year-old urban female, Burkina Faso, 2005). While some 2005 narratives refer to ARVs for PMTCT alone (often using the phrase "before and after birth"), in others, there is explicit reference to long-term ART for the mother as well.

In one in five MTCT or PMTCT narratives from 2005, diagnosis during or following pregnancy is the gateway to ART for mothers and, occasionally, for all infected family members. In some cases, diagnosis resulting from MTCT in one pregnancy allows PMTCT to be implemented in the next. In 2005, the first in a growing number of narratives appears in which an adult who was infected through MTCT is able to have an uninfected child thanks to PMTCT (17-year-old urban male, Kenya, 2005).

In 2008, there is an increasing – though far from consistent – focus on the mother's antiretroviral therapy as a means of PMTCT, particularly in Nigerian narratives:

"but doctor", Blessing intercepted, "you've been talking about me and me alone. What of the innocent baby? [...] I mean, won't the baby contract the virus?" "of course not, because the consumption of the Anti-Retro-viral drugs by you, will save the baby the stress of being infected." (20-year-old urban male, Nigeria, 2014)

Some recommend ARV prophylaxis in addition to long-term ART and C-section. One 2008 narrative even proposes prophylactic use of ART in a serodiscordant couple so the wife is not infected when trying to conceive (20-year-old urban male, Nigeria, 2014), an *avant la lettre* proposal for pre-exposure prophylaxis.

While scientific and programmatic developments in PMTCT are manifest in some of the narratives, this is far from consistent over time. For example, in one 2014 narrative, replacement feeding and C-section are the only forms of PMTCT referred to; neither ART nor PMTCT is mentioned in the majority of MTCT narratives across all years.

The 2014 sample is notable for the emergence of a new theme: non-adherence to treatment. In one narrative, a mother dies because she “angrily” stops taking her ART once her babies are born as she doesn’t think they are working (22-year-old urban female, Nigeria, 2014), while a young woman in another takes ARVs only during pregnancy because she felt she was not ready to be compliant in the long term and encourages other women not to start long-term ART until they are ready to commit (15-year-old urban female, Nigeria, 2014).

Breastfeeding

Information provided in the narratives about breastfeeding highlights the challenges of interpreting complex and evolving recommendations. In the overwhelming majority of narratives across all years, mothers are advised to use replacement feeding, even if they are taking ART. Through 2014, avoidance of breastfeeding is depicted as the best means to increase a child’s chances of survival and take good care of a child. Only two narratives, from 1997 and 2005 (by a 23-year-old urban male from Burkina Faso and a 19-year-old rural female from Nigeria, respectively), articulate concern about the risks of replacement feeding.

While replacement feeding allows a baby to avoid infection in one 1997 narrative (20-year-old rural male, Senegal, 1997), the 2005 and 2008 samples present a wider range of messaging related to infant feeding. There are narratives in which the mother must decide whether to use replacement feeding or practice exclusive breastfeeding, and others in which both practices are validated as PMTCT strategies by health workers and/or by the narrative outcome, i.e. a healthy child free of HIV. In one narrative, infection occurs through non-exclusive breastfeeding (when the mother is deprived of information because she fails to disclose to others for fear of stigma): “the mixed feeding – breastfeeding together with solid feeding – had caused the baby to be infected with the virus, causing different opportunistic infections” (24-year-old urban female, Kenya, 2008). None of these specific narratives engages with the contextual constraints of adhering to any one infant feeding practice. Confusion about recommendations is evident in some narratives. For example, a 2014 Kenyan narrative states authoritatively that the child will not become infected as long as it is not breastfed for the first two weeks (13-year-old rural female, Kenya, 2014).

Delivery

While the overwhelming majority of narratives take place in sub-Saharan Africa, there is some acknowledgement of the disparity in HIV-related care between high and low-resource settings, above all, in relation to delivery of the baby. There are several cases of MTCT occurring due to traditional childbirth practices, while some babies avoid infection because they were born in ‘more developed’ countries (18-year-old urban female, Kenya, 2005) or in modern hospitals (15-year-old urban male, Nigeria, 2005; 20-year-old urban male, Kenya, 2005).

Barriers and Facilitators

In isolated cases, poverty threatens to act as a constraint to PMTCT. For example, friends offer to contribute to the costs of replacement feeding (20-year-old rural male, Senegal, 1997), or a woman is initially unable to afford treatment (18-year-old urban female, Senegal, 2014). More common barriers presented are: ignorance of HIV status; non-disclosure, often due to anticipated stigma and rejection; and misinformation about the likelihood of transmission. Common facilitators of PMTCT include support from family and friends and counseling from health professionals.

Information

The most frequently presented barrier to PMTCT is misinformation about the likelihood of transmission. While doctors in most PMTCT narratives express optimism about preventing infection if action is taken promptly, MTCT narratives *across all years* commonly present MTCT as inevitable and/or portray babies diagnosed as HIV-positive before or at delivery. In these narratives, neither PMTCT nor ART are mentioned.

Testing

Across time, the most likely reason for testing in PMTCT narratives is prenatal care, in contrast to illness or death in MTCT narratives. In the vast majority of 2005 narratives, what differentiates a PMTCT from an MTCT narrative is the timing of diagnosis. Expectant mothers in 2005 PMTCT narratives find out they are HIV-positive at antenatal care, because they fall ill, during a testing campaign, or because their husband gets tested either when he falls ill or on the advice of friends. In 2005 MTCT narratives, in contrast, testing is frequently triggered by the illness or death of the infant (or, occasionally, that of the father or mother). A loving couple in one narrative is distraught, “I cannot believe what is happening with us, every baby that we have dies” (18-year-old urban male, Swaziland, 2005).

From 2008 onwards, however, an increasing proportion of women in PMTCT narratives are simultaneously diagnosed HIV-positive and pregnant when presenting with undifferentiated symptoms following possible exposure, for example, after the death of a spouse, learning that a previous partner has died, or rape. They go on to have healthy children thanks to ART. In a number of 2008 MTCT narratives, in contrast, women are diagnosed prenatally. These diagnoses fail to lead to PMTCT if the doctor states that the baby is already infected or that MTCT is inevitable, or fails to inform the mother about PMTCT services, or if the mother fails to adhere to medical advice regarding delivery, breastfeeding or, above all, treatment.

Starting in 2005, the importance of testing – particularly before marriage and starting relationships – and serodisclosure are key take-home messages in both PMTCT and MTCT narratives. Expectant mothers may hesitate to test out of fear but their concern for their child’s health prevails: it is above all their spouses who are represented as resisting getting tested.

Disclosure

Failure to disclose HIV infection to a spouse is common across all years. In several cases, MTCT occurs when a husband, who has often become infected through infidelity, fails to

disclose to his pregnant wife. In the Burkinabe narratives in particular, the need to disclose is prominent in overt messaging, with individuals who disclose and avoid transmitting to their family praised (20-year-old rural female, Burkina Faso, 2005), while virulent castigation is reserved for fathers who could have prevented MTCT through timely disclosure: “If he had disclosed his status to his wife, they could have lived together for years and had HIV-negative children thanks to medical progress. It’s irresponsible people like this who spread HIV/AIDS” (17-year-old urban female, Burkina Faso, 2005).

Women’s failure to disclose leads explicitly to MTCT when they are thereby deprived of information; it also denies them the possibility of support that facilitates good physical and mental health outcomes in other narratives. These women fail to disclose primarily out of fear of rejection and abandonment. Multiple accounts of husbands and families throwing them out and withdrawing support following disclosure provide context to this fear, although some husbands and family members do come around once they learn more about HIV and/or test positive themselves. Rejection, often brutal, points to the patriarchal gender norms and gendered imbalances of power and finances which foster non-disclosure among women. Women go to some lengths to avoid disclosure, including hiding their ARVs. Some fear or experience discovery when doctors insist they formula-feed or adopt PMTCT precautions at delivery.

Disclosure scenarios and the emotions that accompany or follow them are examined in depth in some narratives. While some characters react to MTCT with guilt, shame, depression, or blame of their partner, more positive examples include narratives in which couples are united around the birth of a healthy child in a “happily-ever-after” scenario facilitated by ART and PMTCT; or disclosure to a husband leading to the discovery of seroconcordance or to acceptance and support in the case of serodiscordance. The first person narrator in a Swazi narrative, under pressure from her husband’s family to conceive, has not disclosed her status to her husband. She finally tells him:

I begged him not to kill me [...] I told him that was why I was not ready to have a baby. He woke up and turned the lights. He went straight to the ward rope [wardrobe], I knew he was going to collect his gun, I could not scream, I kept crying. He came back with a white envelop. [...] I was also shocked to learn my husband was also HIV positive moreover he was now on ARV’S.

They hugged and comforted each other and the next morning they went for counseling. Within two months they were expecting a baby boy and went on to have three children (17-year-old rural female, Swaziland, 2008).

Discussion

In the aggregate, the social representations of MTCT/PMTCT in the narratives evolve in line with increased access to testing and antiretroviral medications, with PMTCT narratives becoming more frequent and MTCT narratives becoming more hopeful as diagnosis becomes the gateway to ART access. However, storylines of intergenerational tragedy in which MTCT is represented as inevitable persist through 2014. While it is possible that the diversity of representations of MTCT/PMTCT may reflect the diverse composition of

contest participation and their differing levels of understanding, we found no evidence of an association between certain types of representations (e.g. MTCT vs. PMTCT) and demographic characteristics of the young authors (i.e. rural/urban location, or sex), although narratives ending without hope are more often written by younger authors.

Longitudinal developments

While there is clear evolution in representations of PMTCT, testing, and access to ARVs, certain social representations of MTCT that are now outdated prove particularly durable in the narratives. MTCT is represented as inevitable in a substantial proportion of narratives through 2014. The fact that this information is delivered by authoritative sources, e.g. doctors, within the narratives suggests a widespread conviction.

These representations point to missed opportunities in efforts to effectively communicate the promise of dramatic developments in the treatment and prevention of HIV to the lay public. They also suggest that certain kinds of information are particularly “sticky”. Dan and Chip Heath (2007) use the SUCCESS acronym to convey characteristics of sticky messaging: Simple, Unexpected, Concrete, Credible, Emotional, Stories. Informational content in the 1997 narratives attest to the success in communicating the *simple* message of three modes of transmission of HIV (unprotected sex, blood, and mother-to-child; (Taverne, 1999)) and three modes of MTCT (pregnancy, delivery and breastfeeding). MTCT is *unexpected* (in more than one case, characters express bemusement that a child could be infected without having had sex), *concrete*, and *emotionally compelling*. It violates schemas of natural and social justice, and it invites narrative elaboration (*story*). As such, it may be particularly difficult to displace even when highly effective ARV-based methods of PMTCT become available. Some young authors may also focus on cautionary tales of MTCT that could have been avoided, seeking to capitalize on the deterrent effect of a loss-framed message (Rothman & Salovey, 1997). There is a need to “unstick” these representations with more compelling gain-framed narratives of successful PMTCT, ideally facilitated through social support.

The avoidance of breastfeeding, meanwhile, features in the 2014 narratives despite both vastly increased access to ART and explicit WHO recommendations from 2010 encouraging exclusive breastfeeding even if ARVs are not available for the mother (WHO & UNICEF, 2016). The social representations in the narratives point to the challenges of making sense of complex, contextually specific, and evolving recommendations around infant feeding, and the intuitive cognitive appeal of a simple equation of formula feeding with HIV (disregarding the real-life social, logistical and socioeconomic challenges of replacement feeding).

There is evidence that this confusion also extended to health workers – and indeed policymakers – at the national level in countries across sub-Saharan Africa and was responsible for considerable variability in infant feeding counseling and policies. Chinkonde et al. (2010), for example, describe how health workers feared they would lose patients’ trust and that of the community at large if they encouraged mothers to continue breastfeeding beyond six months in line with WHO’s 2006 guidelines. In a study comparing divergent infant feeding policies practiced simultaneously at two Tanzanian hospitals, Våga et al.

(2014) conclude that the unambiguous message to practice exclusive breastfeeding, delivered at the more rural hospital, was likely to produce “more confidence, less confusion, and hence, better results in terms of HIV-free survival of the baby” (p. 22); this suggests that attempts to implement an ethos of “informed choice” in resource-constrained circumstances may have been ill-advised. Alice Desclaux (2013) describes the “rapid and poorly managed” (p.39) policy transition in Senegal from free provision of infant formula to the cessation of that policy in favor of ARV prophylaxis and exclusive breastfeeding, highlighting inadequate communication by care providers in the context of differing perceptions of what constitutes an acceptable level of risk. In a study from Kenya, meanwhile, Odeny et al. (2016) conclude, “Each change and recommendation has contributed to the confusion and stigma associated with exclusive breastfeeding, especially when implemented with inadequate support of health education” (p.256).

WHO’s 2010 guidelines acknowledged the general confusion, stating, “comprehensive communications strategies are now needed to give health workers confidence to recommend breastfeeding and ARVs and for HIV-positive mothers to want to breastfeed” (WHO, 2010b, unpag.). Our data suggest that the legacy of these shifting recommendations endures and point to the ongoing need to accord due attention to communication in PMTCT efforts and attempt to “unstick” outdated and/or ill-advised messaging.

Cross-national comparison

There is a need for cross-national comparative studies documenting differing government policies on PMTCT and ART in the context of national HIV prevalence, population size, and ART/PMTCT coverage rates (Table 1). The cross-national differences observed in this study were consistent with our cross-sectional study of our data from 2005 (Kate Winskell, Hill, & Obyerodhyambo, 2011), with narratives from high prevalence Swaziland showing higher levels of social proximity, narratives from Burkina Faso (where estimations of adult prevalence have evolved dramatically) showing less blaming, while Nigerian narratives were found to be more stigmatizing in line with a prevalent conservative sexual morality. While the MTCT/PMTCT theme was more central to the plotline in higher prevalence Kenya and Swaziland, cross-national differences were otherwise not particularly prominent despite radically different prevalence levels and related services. This is notable in light of the striking cross-national differences we have observed in, for example, representations of condoms (Kate Winskell, Obyerodhyambo, & Stephenson, 2011). The relative uniformity of representations of MTCT/PMTCT may be attributable to a lack of motivation or effort to frame the cultural narrative around MTCT/PMTCT (a much less contentious subject than condoms) at the national level and a concomitant reliance on more generic messaging that is relatively undifferentiated from country to country.

Barriers and Facilitators

A sizable literature, including several systematic reviews, identifies barriers and facilitators at various stages of the PMTCT cascade. Despite our distinctive data source, our findings concur strongly with these studies in their identification of community-level barriers and facilitators, focusing on fear of stigma and mistreatment, disclosure and support, particularly related to male partners, and lack of or incorrect knowledge (Gourlay, Birdthistle, Mburu,

Iorpenda, & Wringe, 2013; hIarlaithe, Grede, de Pee, & Bloem, 2014; Morfaw et al., 2013; Tam, Amzel, & Phelps, 2015; J. M. Turan & Nyblade, 2013).

Gourlay et al. (2013) incorporate a longitudinal perspective in their systematic review of barriers and facilitators. They note that stigma and fear of disclosure “remain entrenched across sub-Saharan Africa” (p. 18), continuing to plague PMTCT programs. However, they indicate that knowledge/education (and some psychological barriers) appear less frequently in more recent studies and cautiously propose that familiarity with PMTCT may be growing or that education and counseling may be showing some effect. In our youth-authored narratives, misinformation remained an important barrier to PMTCT through 2014, pointing to the need to place more emphasis on educating the general youth population as part of broader efforts of community engagement.

Turan and Nyblade (2013) suggest that one key mechanism whereby stigma functions as a barrier to PMTCT is through lack of disclosure, especially to male partners and family members, providing context to the importance accorded to disclosure in our data. There is strong evidence that disclosure is critical to improving PMTCT outcomes (Tam et al., 2015). Studies further acknowledge the role played by fear of violence, rejection and blame as barriers to disclosure, and how fear of unintended disclosure can impede PMTCT. This fear found expression in the storylines of several of our narratives featuring pill hiding, fear or experience of unintended disclosure at clinic delivery or through replacement feeding.

Several studies stress the importance of encouraging and facilitating safe disclosure through counseling incorporating the development of individualized disclosure plans (Tam et al., 2015), while others suggest the value of intermediaries in the disclosure process, of which there are several examples – primarily friend groups – in our narratives. Turan and Nyblade (2013) have highlighted the importance of anticipated stigma as a barrier to disclosure, while Medley et al. (2004) found that this fear of negative reactions may be unfounded. Negative social representations undergird anticipated stigma and may be amenable to influence through communication efforts that model successful disclosure and related outcomes.

Recent studies place increasing emphasis on the need for community engagement (and male involvement) to reduce stigma and encourage a supportive environment, and on the importance of education and communication efforts to increase broader treatment literacy, particularly in the context of policy transitions (Desclaux, 2013; Gourlay et al., 2013; Katirayi et al., 2016; J. M. Turan & Nyblade, 2013). In a striking example, Odeny et al. (2016) document how, for both HIV-positive and HIV-negative women, stigma acts as a barrier to exclusive breastfeeding, which has come to be perceived as a practice for HIV-positive women only; a similar phenomenon has been observed for facility delivery in Kenya, with health facility delivery commonly being viewed as only for women who face special risks, such as HIV (Janet M Turan et al., 2012). This points to the need to ensure that messaging around the health benefits of exclusive breastfeeding is directed to all women, regardless of their HIV status.

Implications for communication strategies

While national and community-level communication strategies were critical to the HIV response in the early days of the epidemic, they may be less prominent today as the focus has become increasingly clinical in the context of access to ART. The risk is that we thereby exclude the populations that can help catalyze and sustain a supportive and enabling environment. A 2009/10 study in South Africa highlighted very low public understanding of PMTCT among all populations except women of childbearing age and HIV-positive women (among whom understanding was variable) and highlighted the limitations of having most PMTCT communication take place in the clinic context (Frizelle et al., 2009).

In the context of a cascade of diminishing PMTCT service use, Frizelle et al. advocate for improving PMTCT communication via implementation of an ecological model, addressing a range of audiences including rural and urban healthcare workers, policymakers, community organizations and opinion leaders, and a broader general population, and using a range of channels including interpersonal, community and mass media communication strategies.

While the literature is limited, it does contain some examples of such PMTCT-related communication. Stephan et al. (2015) describe the development and evaluation of a website designed to provide centralized, easy-to-access and easily updated information to address the PMTCT-related information needs of healthcare workers and other stakeholders in Tanzania, while Jennings et al. (Jennings, Ong'ech, Simiyu, Sirengo, & Kassaye, 2013) describe findings from a pre-intervention assessment of preferences for a mobile phone-based platform engaging men and women to enhance PMTCT. Literature on mass media in PMTCT communication is limited to a study on a radio drama in Botswana (Sebert Kuhlmann et al., 2008), which found that “women who spontaneously named a PMTCT character in the serial drama as their favorite character were nearly twice as likely to test for HIV during pregnancy as those who did not” (p.260) and that “Coupled with other supporting elements, serial dramas could contribute to HIV prevention, treatment and care initiatives” (p.260).

Our study suggests the need for expanded use of these and other communication channels and approaches to: counteract a common perception that MTCT, including in utero transmission, is inevitable and disseminate “positive and motivating stories about women with HIV having uninfected infants” (Dwadwa-Henda et al., 2010, p.44); address the legacy of evolving and complex infant feeding recommendations and ensure that accurate, positive, up-to-date information about MTCT/PMTCT is circulating in the public arena so that social representations may reflect reality; stress the benefits of testing for the health of future children and model disclosure, including from men to women; and model a more supportive social environment, including male involvement. The narratives point to the need for health communication efforts to disseminate authentic narratives to counteract socio-contextual barriers to PMTCT, not least various forms of stigma – anticipated, normative, felt and internalized. Communication has the potential, through testimonial and other narrative-based forms (e.g. entertainment-education), to model supportive behaviors and norms, to trigger dialogue, and thereby to shift expectations. This can only happen if PMTCT-related communication expands beyond the clinic setting.

Conclusion

The social representations of MTCT/PMTCT in the youth-authored narratives reveal how a presumed general population of young Africans made sense of information and cultural narratives about MTCT/PMTCT and HIV/AIDS circulating and being communicated at that time. The narratives chart evolutions in youth sense-making over time and cross-national differences. They also reveal the durability of misinformation, perhaps reflecting the legacy of evolving and overly complex recommendations, and of certain MTCT narratives of hopeless intergenerational tragedy. As such, they highlight the importance of communication to past and future PMTCT efforts, not least to ongoing efforts to roll out Option B+. As Taverne (1999) highlighted, the stakes associated with HIV communication are very high. The case of PMTCT is illustrative, with its shortcomings ranging from the framing of vertical transmission as “mother-to-child”, through changing and overly complex infant feeding recommendations, to the focus on clinic-based communication to the exclusion of broader community-based and mass media approaches. Communication needs to be recognized as critical to efforts to respond to HIV and to reframe the epidemic in ways that reflect the full promise of scientific and programmatic developments of the past decade and a half. The historic shortfalls of PMTCT communication carry instructive lessons for the ongoing response to HIV and for the response to future complex and evolving epidemics.

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Research Highlights

- Longitudinal and cross-national analysis of social representations of MTCT/PMTCT
- Uses distinctive data source: young Africans' creative narratives
- Identifies representations of MTCT/PMTCT in general youth population in 5 countries
- Analyzes data 1997–2014 as PMTCT availability and WHO recommendations evolved
- Links findings to communication needs and practices

Table 1:

Population, Adult HIV Prevalence, ART coverage, ART for PMTCT coverage for the five study countries, 1997–2014 (Data from UNAIDS, World Bank, WHO, and UNICEF)

	Senegal	Burkina Faso	Nigeria	Kenya	Swaziland
Population					
1997	9,196,528	10,665,546	113,522,705	28,954,114	1,003,995
2005	11,251,266	13,421,930	138,939,478	36,048,288	1,105,873
2008	12,203,957	14,689,726	150,347,390	39,148,416	1,158,897
2014	14,546,111	17,585,977	176,460,502	46,024,250	1,295,097
Adult HIV prevalence					
1997	0.5%	3.2%	3.4%	11.1%	25.5%
2005	0.8%	1.5%	3.9%	7.4%	28.3%
2008	0.7%	1.2%	3.6%	6.4%	27.2%
2014	0.5%	0.9%	3.1%	5.7%	27.6%
ART for PMTCT coverage					
2005	2%	11%	<1%	21%	36%
2007	6%	18%	7%	69%	67%
2010	22%	48%	15%	51%	77%
2014	41%	74%	37%	64%	>95%
2016	55%	83%	32%	80%	95%
ART coverage					
2000	0%	0%	0%	0%	0%
2005	1%	7%	3%	4%	6%
2007	17%	14%	5%	12%	14%
2008	21%	20%	8%	17%	19%
2010	28%	31%	11%	29%	33%
2014	39%	48%	23%	48%	60%
2016	52%	60%	30%	64%	79%

Table 2:

Overall Study Sample (1997, 2005, 2008 and 2014)

Year	1997*	2005	2008	2014	All
Burkina Faso	44	112	100	56	312
Kenya	N/A	88	25	116	229
Nigeria	N/A	120	93	88	301
Senegal	86	107	79	67	339
Swaziland	N/A	72	50	40	162
All	130	499	347	367	1343

Table 3:

PMTCT/MTCT Subsample

Year	1997	2005	2008	2014	All
Burkina Faso	25	28	26	8	87
Kenya	N/A	17	6	17	40
Nigeria	N/A	19	20	12	51
Senegal	29	26	24	18	97
Swaziland	N/A	12	8	15	35
All	54	102	84	70	310