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Social representations in young Africans' HIV-related narratives from six countries

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Global Health

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An abstract of
a thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
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Abstract

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HIV testing and counseling is a critical intervention to support treatment access and prevention of new infections. Despite high rates of infection and attempts to increase testing in this age group, young Africans are those least likely to have tested for HIV. With the aim of informing interventions that encourage HIV testing and promote healthy testing outcomes, this study seeks to understand how young Africans imagine and make sense of HIV testing. 'Scenarios from Africa' scriptwriting contests invite young people to contribute ideas for short films about HIV. Using thematic narrative-based approaches, we analyzed a stratified random sample of 586 (~5%) of these narratives written in 2005 by males and females aged 10-24 from Senegal, Burkina Faso, South-East Nigeria, Kenya, Namibia and Swaziland. The factors influencing testing behavior and outcomes are represented as complex, interactive and multifaceted. Personal perception of risk, whether low or high, was shown to both inhibit and facilitate HIV testing. Social support from family, peers and the community was depicted as instrumental in promoting testing and beneficial testing outcomes, such as preventative behavior change and adoption of positive living. Counseling was represented as a crucial element of the testing process. Young authors depicted the benefits of integrating testing into the standard 'ABC' ('abstinence', 'be faithful', 'use condoms') of HIV prevention. As multiple factors mediate the testing decision-making process, one-dimensional interventions are unlikely to effect a shift towards increased testing or more beneficial testing outcomes. Interventions need to operate with greater understanding of the multi-layered and context-specific factors that motivate and impede the decision to test. Despite current low levels of testing, the narratives demonstrate the potential for favorable attitudes toward testing among young Africans and the opportunity to increase HIV testing in this demographic.

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Definition of Terms

AIDS – acquired immune deficiency syndrome

ANC – antenatal care

ART – antiretroviral therapy

HIV – human immunodeficiency virus

PLWHA – persons living with HIV or AIDS

PMTCT – prevention of mother to child transmission

UNAIDS – Joint United Nations Programme on HIV/AIDS

VCT – voluntary counseling and testing

WHO – World Health Organization

Introduction

In 2009, 22.5 million people were living with HIV in sub-Saharan Africa. There were 1.3 million AIDS-related deaths.(1) Approximately 40% of all new infections in the region were in young people between the ages of 15 and 24.(2) A study conducted in 2005-7 found that only 10 – 12% of people in sub-Saharan Africa had tested and learned their HIV status.(3) Despite both high rates of infection and attempts to increase testing among young Africans, few have tested.(4) Studies consistently find young age to be associated with not testing.(4-8)

HIV testing and counseling is a critical intervention to support treatment access and prevention of new infections among people testing both positive and negative.(1, 9) In addition to fostering uptake of prevention of mother-to-child transmission (PMTCT), treatment of opportunistic infections, antiretroviral therapy (ART) access, and a range of prevention behaviors, testing supports people's right to know their HIV status.(10) Testing allows for information sharing and guidance, supports referral to medical treatment, and promotes safer sex practices.(11, 12) The UN General Assembly affirmed a commitment to voluntary counseling and testing including pre and post-test counseling (VCT) as a prevention strategy in 2006.(13) Testing can also reduce stigma by raising social awareness of HIV.(1)

Testing data vary by country. Looking at the countries in this study, according to DHS data the proportions of 15-24 year old ever requesting, receiving and learning results from and HIV test are as follows: Swaziland 6.3% male, 13.6% female (2006-7), Namibia 15% male, 23.1% female (2006), Kenya 6.8% male, 8.6% female (2003), Nigeria 4.2% male, 3% female (2003), 5.5% male, 5.1% female (2008), Burkina Faso 4.3% male, female unavailable (2003) and

Senegal 1.3% male, 1.4% female (2005). The distribution of young people testing roughly follows the distribution of HIV prevalence across the countries.(14)

It is important to understand the factors that facilitate and inhibit testing and the mechanisms and contexts through which they operate. This knowledge is important for targeting interventions that can encourage testing and ensure that testing leads to outcomes such as prevention, care, treatment, increased knowledge and reduced stigma.

'Scenarios from Africa' scriptwriting contests offer a unique data set through which to understand the social representations of young Africans.(15-18) The 2005 contest provided narratives written by young people aged 10-24 years from six African countries/regions with estimated adult HIV prevalence rates ranging from 1 to 33%.(19) Narratives are a source of insight into how people make sense of the world, and how they communicate those understandings to others.(20) In this study, they provide access to the voices and imaginings of young Africans in a largely unmediated way, revealing their spontaneous mentions of testing, rather than their responses to specific interview or focus group questions. The narratives illuminate cultural resources available to young people in and across the six settings as they strive to make sense of HIV and the role of testing in its response, highlighting commonalities and differences in social representations across countries and demographic categories.

This research seeks to understand how young Africans imagine and make sense of testing in relation to HIV. How do the motivations for and barriers to HIV testing identified by the young authors operate to influence testing decisions and outcomes in the narratives? How do varying social situations and other external factors influence decision-making around testing and testing outcomes? Using both country-specific and cross-country results, this research aims to inform and influence HIV testing interventions that encourage healthy testing outcomes for young Africans.

Literature Review

Introduction

The literature reviewed covers testing-related knowledge, factors associated with testing including motivations and barriers, the special case of mandatory pre-marital testing in Nigeria, behavior change, counseling, social interactions, couples testing, disclosure, and HIV treatment. It focuses on sub-Saharan African, young person-specific research but includes studies relating to mixed age groups and conducted in other geographic areas to reflect the breadth of the available research.

The majority of the studies looking at HIV testing among young Africans are quantitative with many conducted in the Republic of South Africa. Approximately half of the studies included in this literature review are specific to young people aged 24 and under. Among those, the data are concentrated in Zambia, South Africa and Nigeria with most studies coming from southern and eastern Africa. While there are several strong qualitative studies, most of the literature focuses on quantitative measures examining testing and individual-level factors associated with testing or the desire to test and post-test behavior rather than the socio-cultural context of testing and testing-related behaviors.

Several existing studies are particularly salient to this research. MacPhail, et al., conducted focus group discussions with 240 12-24 year old South Africans and 120 parents from the same two townships in the municipality of Ekurhuleni near Johannesburg to understand the perceptions of and needs for VCT among young people. Young people discussed being afraid to know their status, the negative influence of stigma on decisions to test, a belief that the test is only for symptomatic individuals and persons to whom they would disclose their status.(21) Another study by MacPhail analyzed data from a national survey of 7,665 sexually experienced South Africans aged 15-24 to examine individual-level characteristics associated with past HIV testing.(4) The Horizons project, supported by the Population Council, sought to understand VCT contexts, delivery models, and impacts for young Africans through multiple different studies.(22) One associated study surveyed 135 Ugandans who had tested and 210 who had not tested as well as 105 Kenyans who had tested and 122 who had not, all between 14-21 years old. Also interviewing parents and service providers, this study examined the appropriateness of VCT services for young people, finding that young people valued counseling as an element of testing, that most intended to change their behavior after testing and that most disclosed their status, negative or positive, to someone.(23) A follow-up study in Uganda used service exit interviews (n=1,200) and in-depth interviews (n=60) to evaluate the impact of making VCT services more youth-friendly in two different service sites. The study showed what populations were testing, what challenges to testing existed and the receptivity toward peer counselors.(24) Phased Horizons work led by Denison, et al. included 40 in-depth interviews with Zambian 16-19 year olds who had tested and 11 family members to understand social interactions before, during and after VCT in the first phase of the research. The second phase included 550 young Zambians surveyed in the same area to identify individual-level factors associated with the desire to test.(25, 26) While not exclusively among young people, a unique study in Malawi focusing on the context in which testing and testing behaviors take place used ethnographic journals to record conversations about testing in the community. It found that negative elements of testing mentioned by community members included a belief that testing would lead to death, that clinic staff could not be trusted, that testing is pointless if someone is convinced of their status and that testing will lead to social disruption. Constructive elements of testing mentioned included access to ART, knowledge of one's self and one's body, the prudence of pre-marital testing and an opportunity to change behavior if one tests negative. (27)

Testing-related Knowledge and Access

Young Africans are shown to demonstrate positive attitudes toward testing. However, those attitudes do not guarantee testing uptake. There is a gap between awareness of testing and acting on awareness to take the test. Young people's knowledge about testing and access to testing affect testing behavior.

Studies consistently find that more people report openness toward testing than have actually tested.(4, 10, 11, 21, 28) For example, a survey of 400 Nigerian young people aged 15-29 years showed that while 78.6% reported a positive attitude toward VCT only 11.5% reported having tested and only 22.5% went for a voluntary test.(29) Further, while young people were generally positive about the idea of testing, few seemed to know what it entailed, demonstrating a need among young people for more information about the testing process and experience.(26) A recent qualitative study of out-of-school youth in South Africa showed that even though there were high levels of HIV literacy, only 7 of the 32 young people interviewed could provide a description of what VCT was or entailed.(11) This demonstrates the gap between the idea of testing and the act of taking the test. A lack of knowledge can serve as a barrier to learning one's status through testing.   A different qualitative study of 12-24 year old South Africans found that while general HIV knowledge was high, complex concepts such as post-exposure prophylaxis and ‘the window period’ were less well understood.(21)

Availability of testing and access to testing also affect testing uptake. Nationally stratified random samples of 16-66 year old residents show that 96% of Namibians and at least 85% of Swazi people knew where to get an HIV test in 2007.(30) In the same year, 31% of health facilities in Burkina Faso offered HIV testing compared to 68% of facilities in Swaziland. Uptake reflects availability with 11 per 1000 Burkinabe over 15 years old testing compared to 75 per 1000 people in Swaziland.(9)

It is well established that testing is generally perceived in a positive way but that positive perception is not enough to lead to actual testing. The following sections review factors supporting and inhibiting the act of testing, especially among young people.

Factors Associated with HIV Testing

Motivations for testing

While HIV testing remains low among young people in sub-Saharan Africa, across countries, several consistent facilitators of testing have been identified in studies looking at factors associated with testing and reported readiness to test.

Talking about HIV, HIV prevention or HIV testing is associated with testing or the desire to test in studies from across sub-Saharan Africa. Dialogue about testing can increase awareness of and interest in testing. Discussing condoms in connection with HIV prevention was associated with a reported readiness to test among Nigerian youth ($n=3844$, $OR=1.43$, $p <0.05$ males; $OR=1.47$, $p <0.05$ females) while talking with parents about HIV/AIDS was a factor supportive of testing among South African young people ($n=7665$, $OR=1.67$, $p=0.004$).(4, 10)

Encouragement from a partner or friend can influence young people's decisions about testing. Qualitative research with young Ugandans found that one motivation for testing was that a partner asked them to do so.(24) Focus group discussions with young Ghanaians who tested and interviews with counselors providing the testing outside a market area demonstrated a strong belief that peer educator outreach was a reason young people had tested. For the young people, this was both due to having another person encourage them to test and because the information provided by the peer educator helped them to understand their risk and need for testing.(31) Knowing someone with HIV was a motivation for testing and informed a desire to test, as was not rejecting a friend with HIV.(4, 29) These factors may represent less stigmatizing attitudes towards PLWHA on the part of young people who had tested or reported willingness to test compared to other young people. Negative social constructs can also lead to testing, however. Ugandan young people reported mistrust of their partner as a motivation for testing.(23) A more thorough exploration of social interactions and testing behavior is explored later.

Health providers and health facilities play a role in supporting testing behaviors. In a survey of 24, 069 16-60 year olds conducted across ten southern African countries, the two factors consistently associated with HIV testing were having talked with someone about HIV and having heard about HIV from a clinic or health centre.(30) Kenyan youth cited service provider referral and an adult such as a parent or doctor deciding the young person would test as reasons for testing while health care provider recommendation was also a key factor for young Americans who tested.(23, 32) Parent and clinician-initiated testing may represent a care-taking decision due to a need for diagnostic testing or it may represent a less beneficent exercise of power over the young person. Visiting a health center with greater frequency was associated with HIV testing among South African youth.(4) Given low routine health care uptake among South

African men, it is possible that more frequent health center attendance is also associated with illness among men. Free services motivated young Ghanaians to test in a mobile outreach setting.(31) Testing exit interview data from Uganda show that young people want confidential, low-cost, friendly, professional counseling services.(23) The majority of American youth who tested did so in an anonymous or confidential facility.(32)

Risk perception and risk behaviors also motivate young people to test. Self-perception of being at risk of HIV infection was associated with testing or the desire to test in several large surveys.(10, 33) Having multiple sexual partners and inconsistent condom use were associated with testing among young South Africans.(4) Testing exit interviews with young Ugandans at youth-friendly VCT service sites showed that exposure to risk was their main motivation for testing but that youth-friendly services were also important, demonstrating the importance of perceptions of the testing experience itself as a part of the decision-making process for young people who are motivated to test.(24) Knowledge about HIV in general, including knowing where to access testing, was associated with a desire to test among Nigerian youth.(10)

Wanting to know one's status was a common driver for wanting to test. It was mentioned in in-depth interviews and surveys of young people from South Africa, Kenya and Uganda.(11, 23, 34) The 22 interviews and 5 focus group discussions with Ugandan youth showed that their desire to know their status was unrelated to their anticipated testing outcome.(34) Counsellors who tested mobile young people through a special outreach in Ghana and Tanzania reported that wanting to know one's status was a main reason young people chose to test, in addition to getting more information about HIV and accessing condoms.(28, 31)

Consideration of the future motivates testing. Pregnancy, having made a girl pregnant and consideration for the health of a future child are associated with testing or the desire to test.(4, 11, 23, 34) Other concerns such as preparation for marriage and planning for the future were reasons Ugandan youth gave for testing.(24, 34)

Among young people and adults in sub-Saharan Africa and the United States, certain demographic factors including urban residence, female gender, and being more educated were also associated with HIV testing and the desire to test.(4, 24, 29, 30, 32) Interestingly, being HIV positive was associated with testing for South African males but not for females.(4) This may be due to overall higher rates of female testing in the study cohort or increased female testing associated with ANC. Although a commonly cited reason for testing among adults, illness was not a significant predictor of testing in young people in a repeated cross-sectional study disaggregated by youth and adults in Zambia.(33, 35)

Factors affecting testing operate on many levels including health access, personal demographic, interpersonal, psychosocial and behavioral.(36) Studies including adults showed both similar and different motivations for testing to those seen in young people. More education, female gender, higher socioeconomic status for men and lower socioeconomic status for women were important factors associated with testing among adults.(7, 8, 36) Wanting to know your status, pregnancy, concern about a partner’s sexual behavior, and having had a partner test were reasons to test cited by clients of public sector clinics in South Africa.(35) Having knowledge of HIV in general and having access to testing facilities were associated with testing in a survey of 2,671 Namibian adults.(36) As seen among young people, analysis of DHS data from Zimbabwe shows that knowing someone with HIV is associated with increased testing among adults.(37) This could be explained by an increased perception of risk. Access to treatment, positive living, a desire to stay negative, and marriage were motivations to test mentioned by Malawians during an ethnographic study of conversation topics in a community.(27) A survey of 1,539 men and1,877 women in urban South Africa showed that adults who had discussed HIV, heard of ART, and experienced physical violence before the age of 12 had a higher odds of having tested for HIV as did women who had ever been physically abused by a sex partner.(7) A different analysis of the same study data showed that a history of testing is associated with decreased negative attitudes toward PLWHA, increased perception that PLWHA experience discrimination and increased perception that PLWHA should be treated equitably. The magnitude of the impact varied according to gender and age.(8) While having tested was associated with decreased stigma, varying levels of stigma did not affect testing uptake in this data set. Contradictory to the findings of other studies, where risk behaviors and social norms are related to testing, testing uptake was not associated with condom use, the number of sex partners in past 6 months or HIV stigma.(7)

Many of the same motivators for testing are identified throughout the literature. Further research should be conducted to understand the contexts and mechanisms through which these factors operate in order to support interventions that can effectively address them.

Barriers to testing

Several barriers to HIV testing among young people are consistently identified in research from sub-Saharan Africa. It is important to remember that barriers operate simultaneously on many levels, demonstrating the impact on testing behaviors of the cultural context in which the young people live.(11) MacPhail et al. propose barriers operating on the individual, group (family, friends and peers) and community levels.(21)

Across countries and types of studies, young people are shown to fear the social and individual-level consequences of testing, especially of testing positive.(4, 11, 12, 21, 23, 28)

Social consequences could include being stigmatized, ostracized or having people gossip about you, or disappointing your family.(11, 21, 23, 31) Young people fear negative reactions, including being chastised by adults for having sex, and abandonment or neglect by family and friends.(26, 31, 34, 38) There is a fear of having to end relationships or give up the possibility of having a child.(21, 24, 39) Individual-level consequences include dealing with the post-test stress of knowing your status including the possibility of depression or a desire to commit suicide.(11, 21, 24, 25) Young people were afraid that they would not be able to handle the consequences of a positive result, not least in view of their dependence on adults for things such as school fees.(24, 34, 38) In in-depth interviews and focus group discussions, young Ugandans questioned whether they could cope with the result at their age, or if it was better to wait until they were older.(34) There is a belief that knowing one's status can lead to a shortened life, "when you know earlier, you die quickly" (p. 219).(34) Particularly for young women, the ability to decide about sex, HIV risk taking and accessing VCT is influenced by financial considerations and power imbalances. Ugandan women raise sexual violence and associated trauma as barriers to testing and other prevention behaviors.(34)

Stigma operates at many levels to create obstacles to testing.(9, 11, 12, 24, 29) Young people suggest that expressing a desire to test or being seen at a testing center can lead to stigma, by implying that one is HIV positive or sexually active.(21, 23-25) An in-depth look at the impact of stigma among young people in northern Nigeria showed that for males, holding a stigmatizing belief that one should keep a testing result private was associated with decreased readiness to test. For females, decreased readiness to test was associated with stigmatizing labeling of persons living with HIV or AIDS, including believing that they should be separated from others, that they 'got what they deserved' and that they should not be allowed to attend school. High HIV stigma in the community was associated with a decreased readiness of males to test, but not females, showing that stigmatizing community norms may operate differently for different population sub-groups. For males, levels of community stigma were more powerful in predicting testing behavior than measures of individual stigma.(10) While the targeting may be different depending on the population, it is necessary for intervention to address stigma in order to support testing and HIV prevention.(5)

A lack of information or accurate information may be driving some of the barriers to testing. Young people from South Africa, Uganda and Kenya saw testing as something that is for people who are ill or experiencing symptoms, not people who feel or appear to be healthy.(4, 21, 23) Young Ugandans identified their conviction that they would receive a positive result as a reason to have no need for testing.(24) These barriers may be reduced as access to ART increases. Other reasons for not testing reported in Horizons studies in Uganda include not knowing about the test(24) while some young Nigerians said they did not test because it did not occur to them to do so.(29)

Logistical issues associated with testing can produce barriers. These include waiting time, cost, mistrust of the test's accuracy, fear of the pain of having blood drawn and, according to the FHI VCT Toolkit, an 18 year-old age of consent for medical procedures in multiple African countries.(12, 24, 29, 34) A potential breach of confidentiality is a concern for young people.(9, 11, 12) In rural Zimbabwe, when testing was offered in rural health center, less than 5% of young people to whom outreach was directed chose to test. When offered in a non-clinical setting after a survey, over one-quarter of young people tested. This could be due to the reduced stigma of the non-clinic setting.(38) A lack of access to treatment was mentioned as a disincentive by a mobile youth population in Ghana.(31) This barrier could be less significant , at least in the short term, as access to ART has increased in the past five years.(1)

Across countries, not perceiving oneself to be at risk for HIV is an obstacle to young people testing.(11, 12, 23, 28, 29, 38) While some youth appropriately note a lack of involvement in risk behaviors such as not having had sex as a reason not to test (24, 34), certain studies demonstrate that young people underestimate their risk of contracting HIV. In a South African survey, over half of young people who were HIV positive reported feeling little or no risk for being infected with HIV while the same was true for almost twenty percent of young women and ten percent of young men in Zimbabwe.(38) A study of Tanzanian health students showed a similar outcome when comparing low reported perceived risk against reported high risk behaviors.(28)

VCT programs need to take the diversity of possible target audiences into account. Out-of-school youth, for example, would need services adapted to them that could provide additional support for the challenges of their situation.(11)

Across countries, adults, while often better equipped to act independently than young people, cite many of the same and some different barriers to testing as young people. These include fear of the test or of negative consequences from family and the community, (7, 13, 27, 35) fear of violence,(13, 30) not perceiving themselves as being at risk,(7, 35, 40) lack of time for testing,(35) not thinking to test,(7, 35) fear of breach of confidentiality,(27, 35, 40) a belief that testing is only for people who are ill,(35) internalized stigma measured by high levels of shame or blame or perceptions of stigmatizing social norms,(35, 37, 40) negative views of testing services,(40) belief that testing positive will lead to worry and death, and already believing oneself to be positive obviating the need for testing.(27)

More research is needed to understand how the barriers consistently identified across studies influence testing behavior. This would assist in designing interventions to effectively reduce the barriers and encourage testing and the benefits testing can provide.

Pre-Martial Testing

While marriage is mentioned as a motivation for testing among youth, in Nigeria mandatory pre-marital HIV testing was instituted in most traditional Protestant and Pentecostal churches in the late 1990s with the intent that marriage would be refused to couples should one or both individuals test positive. Mandatory pre-marital testing can promote stigmatization of those who test positive as well as the denial of human rights, such as the right to marry a consenting partner. While pre-marital testing has the potential to support prevention and positive prevention goals when handled appropriately, it can lead to significant social stigma if couple identity is not protected.(41) In a study among 571 unmarried, 15 – 24 year olds in northwest Nigeria, the majority agreed that mandatory pre-marital testing can be a tool for churches/mosques to protect their congregations from HIV.(42) Respondents who were female and Christian were more likely to be aware of mandatory pre-marital testing than other respondents. While the mean attitude score among all the respondents was positive toward mandatory pre-marital testing and 51% did not think that testing should be made voluntary, concern about the potential for mandatory testing to lead to stigma remained. For example, the majority, 57%, of those surveyed believed that testing positive is shameful for one’s family and over one-third believed that HIV testing would make one’s status public knowledge. Contrary to many studies showing that stigma is a barrier to testing, 58% disagreed that fear of stigma will prevent couples from testing.(42) If denial of marriage is the result of an HIV-positive status and the marriage is desired, it is difficult to see how fear of testing would not be a result. There is also a concern that mandatory premarital testing can lead to a false sense of security, fostering a belief that once a person has tested, he or she is protected from HIV.(42) If either partner is at high risk of infection, this could increase the likelihood of transmission during marriage by creating a false sense of security.

Post-test behavior change

Evidence that HIV testing leads to reduced HIV risk behaviors is mixed but there are strong indications that testing has a positive effect on HIV prevention. The evidence that testing leads to treatment access and other services where referral systems exist is well established.(4) Much of the evidence focuses on adults or mixed populations of adults and young people.

A meta-analysis of adult VCT-related behavior change in developing countries in Africa, Asia and the Caribbean showed that testing had a moderate affect on reducing unprotected sex. The largest effects were found for serodiscordant couples and people who were HIV positive as well as ANC attendees but also looked at all sex acts and sex with casual partners. Evidence for the effect of testing on partner reduction was inconclusive based on a limited number of studies in the meta-analysis.(13) Despite initial concerns, no studies found an increase in risk behavior post-testing.(13, 43) The ‘Voluntary HIV-1 Counseling and Testing Efficacy Study Group’ randomized controlled trial in Kenya, Tanzania and Trinidad, included in Denison’s meta-analysis, showed that unprotected intercourse with non-primary partners decreased significantly among those who used VCT compared to those who just got health information; the change was maintained through the second follow-up (13.9 months average). Couples who underwent VCT together showed a significant reduction in unprotected sex with their enrolment partner compared to those couples who only got health information. Couples where one or both members were HIV positive showed greater reductions in unprotected sex than couples where both members were seronegative.(44, 45) Other studies have shown increased condom use and increased ability to plan for the future but no decrease in number of sex partners following voluntary counseling and testing.(9) In a longitudinal cohort from Zimbabwe examining sustained behavior change, females who tested reduced their reported number of sexual partners independent of their test outcome, while those testing positive showed a larger decrease. Surprisingly, declines in number of sex partners and visits to bars were steeper with time since testing. Other than the increased risk behavior of increased visits to bars, which were also found among women testing negative, reported behavior change in men was not statistically significantly different before and after testing. In the study cohort overall, significant declines in risk behaviors were noted; those significantly associated with testing were over and above those experienced by all participants.(43) Amongst adults testing at public sector clinics in Johannesburg, South Africa, 38.7% of respondents reported more condom use, 19.4% reported becoming monogamous and 7.5% reported abstinence after testing.(35)

Some studies looking at post-test behavior change focused on young people exclusively. Qualitative interviews with South African out-of-school youth supported the theoretical concept of testing-associated behavior change, especially for those testing positive. Almost all youth said that if they were to test positive, they would change their behavior to prevent new infections of others or re-infection of themselves. Fewer young people said they would change their behavior to stay negative if they tested negative. Some of the young people indicated that their ability to change their behavior if they were to test negative largely depended on their partner and his or her willingness to use condoms or be faithful. Being in a relationship limited their behavior change ability, as they would likely have less control over their partners than themselves.(11) This study was limited by thin data resulting from relatively inexperienced interviewers. Discussing a fictitious scenario where a character tests negative in another qualitative study using focus groups among 240 South African adolescents, some participants thought it would be a starting point for behavior change for risk reduction while others thought it would lead to repeat testing to close the 'window period' and still others believed it could lead to celebration and not changing behavior. When the scenario was changed so that the character tested positive, this led to discussions about eating healthy foods and exercising to support positive living.(21) Interviews and focus groups among Ugandan youth expressed optimism that knowing your status would lead to positive living or staying negative.(34) According to interviews with 10 VCT counsellors conducting testing among mobile, young Ghanaians in a targeted testing intervention, 80% of the youth who tested reported an intention to change their behavior. At the end of the two year testing intervention in Ghana, 100% of the 33 sexually active former clients who participated in focus groups reported behavior change post-testing, including abstinence, partner reduction, faithfulness and two condom users.(31) Social desirability bias could affect reported behavior.

In data from Uganda and Kenya, intention to practice safer sex including reducing the number of sex partners, abstaining, using condoms or being monogamous was higher among young people who had tested than those who had not. Over half of tested youth reported an intention to begin practicing safer sex with almost 100% of Kenyan youth saying they plan to practice monogamy.(23)

To have the greatest possible prevention impact, testing would need to be used in combination with other prevention measures. Condom use and partner reduction are commonly measured outcomes of interest when evaluating the potential for testing-related behavior change. Understanding the context of condom promotion and partner reduction interventions for young people, however, is important. In focus group discussions about faithfulness among Tanzanian young people, testing was spontaneously raised in connection with faithfulness. Respondents supported the idea of testing with your partner in order to know each other's results and identified before marriage or before the start of a sexual relationship as the best times to test. The need for repeat testing within "presumed monogamous" relationships was not discussed, however. The use of condoms in a 'faithful' relationship and repeat testing were raised as potentially demonstrating a lack of trust.(46)

Given the equivocal evidence but the general attitude among young people that HIV can lead to behavior change, more evidence demonstrating circumstances and factors that would facilitate changed behaviors post-testing is needed. Good counseling, for example, is important in supporting post-test behavior change, a subject explored more thoroughly below.(43) It would be important to understand what testing or counseling-related factors support youth to enact their intention to practice reduced risk behaviors.

Counseling

One factor which may influence testing-related behavior change is counseling. Although WHO guidance recommends that all testing be accompanied by pre-test information or counseling, informed consent, confidentiality, post-test counseling and referral to services as necessary, these practices do not always occur.(9) Counseling is "an opportunity to provide information on HIV, correct misconceptions, assist with risk assessment, provide emotional support, encourage disclosure of serostatus to partners, and discuss a risk reduction plan if necessary. To prevent new infections VCT must motivate individuals to adopt safe sexual behaviour" (p. 708).(43) Elements of pre and post-testing counseling are theorized to influence testing behavior as well as more distal health outcomes working through psycho-social (attitudes, knowledge), relational (partner disclosure), community-level (reduced stigma) and individual behavioral (increased use of condoms, reduced numbers of partners) mechanisms.(13) The Horizons study in Kenya and Uganda showed that counseling is a valued part of testing for young people. Youth respondents expressed disappointed when counseling was absent from the testing process. However, 25% of the young respondents from Kenya did not receive pre-test counseling and the same proportion did not receive post-test counseling.(23) There is a belief among young South Africans that counseling mitigated negative outcomes of testing.(21)

Social Interactions

Dialogue and social support play key roles in supporting HIV testing for adults and young people.(28, 45) While it differed between Kenya and Uganda there was evidence from Horizons that peers are a primary source of information around HIV and testing for young people. Partners, siblings and cousins also play a role, as do other family members and the radio.(23)

Two-thirds of Ugandan and Kenyan youth in the Horizons study told someone they were going for an HIV test. Young people in Kampala often told sex partners but Kenyan youth and young people from rural Uganda rarely told partners. Most of the young people surveyed were more likely to tell peers and sometimes parents.(23) Talking with family and friends, as opposed to sexual partners, was common before and after HIV testing in Zambia, as well.(25) If the friend or family member with whom they spoke did not encourage testing, the young person would delay getting tested until one of the social supports to whom they reached out was encouraging.(25)

Mixed methods research with Zambian youth showed that families play an important role in young people's decision making around HIV testing and that encouraging family dialogue around testing and access to services after testing can help to encourage young people to test. Survey data showed that young people who talked to their families about testing were six times more likely to test. Reasons for not discussing testing with family included the fear that parents would be upset that the young people were having sex.(26)

Studies from Zambia and South Africa show that parents can play a key role in reducing HIV risk among young people.(4) While parental consent should not be required as a precondition of testing in the interests of confidentiality, targeting families and working with family networks to support HIV testing for young people may be a meaningful way to encourage youth testing. Fewer than half of the Zambian young people who tested were accompanied to the testing location by a friend.   Often, the young people did not have a family member accompany them for fear of drawing more attention to themselves and potentially jeopardizing their confidentiality. (25, 26)

A street intercept survey of adults in a South African township outside Cape Town showed that HIV testing, independent of the result, is associated with higher levels of communication about HIV, HIV testing and condoms within the community.. Also, the presence of HIV-related discussion in the community is associated with condom use. This means that not only might testing lead to greater communication around HIV with the potential for stigma reduction, it may also encourage HIV prevention through indirect routes.(47)

The limited number of studies that explore the role of social support in testing among young Africans show that more research is needed to understand how social networks influence testing so that outreach can better support testing. A better understanding of how young people engage with sexual partners around testing is also needed.

Couples testing

Couples testing, mostly studied in adults, is increasingly seen as an important intervention to reduce HIV risk and support treatment access.(9) Couples counseling and testing has been shown to lead to increased condom use among serodiscordant couples leading to reduced risk of transmission.(48) A study from South Africa showed that disclosure of both positive and negative testing results to a sex partner after testing led to condom use, the partner testing or a relationship ending. However, it also led to physical violence in a small number of cases.(35) Counseling can facilitate disclosure among serodiscordant couples. Higher rates of disclosure were seen in a cohort of serodiscordant couples in Uganda among those who were part of a phased, counselor-facilitated disclosure process than couples using standard approaches in other countries.(49) More support for couples testing and support for prevention services for serodiscordant couples is warranted.(1)

Disclosure

Horizons data showed that, while it is difficult, most young people disclosed their testing outcome to someone, independent of their HIV status.(25) The surveys conducted among young people in Kenya and Uganda showed a high rate of affirming responses to disclosure, suggesting that youth disclose to people who will react positively.(23)

The Zambian study interviewed 40 young people who had tested, most of whom reported being sexually active and one third of whom self-reported being HIV positive. These young people most commonly disclosed their HIV status to family followed by friends and then unmarried sex partners. The interviews indicated that youth, in talking with their families, had a need to know that they would be accepted and supported. Family members, when the young person told them, encouraged positive behavior change such as stopping sex and not drinking beer .(26) In contrast, fewer than 25% of Ugandan and Kenyan youth disclosed their status to their parents but more disclosed to their peers and sex partners. The young people cited not wanting to worry their parents or reveal that they were sexually active as reasons for not disclosing to parents.(23) Outside of the Horizons work, focus group discussions among South African youth revealed a belief that disclosing to their peers could lead to gossip while disclosing to their family would lead to support but could also anger their parents. Sex partners were considered to be the most stressful group to whom one could disclose. Disclosure to sex partners was seen as potentially leading to abandonment, the loss of the potential to have a relationship or to have children. Some young people saw couples counseling as a solution to the partner disclosure dilemma.(21)

Additional research into how young people imagine disclosure and the associated positive and negative consequences is warranted to help support testing, treatment access, and prevention.

HIV treatment

As ART access expands, it is even more critical that people test to learn their HIV status.(1) One in three Americans testing HIV positive does not test in time to get the full benefits treatment can offer. Testing after symptoms develop, for example, is often too late. It shortens life span and increases their likelihood of transmitting HIV to others by allowing unsuppressed viral loads to persist for longer.(5)

While ART has only been widely available for several years and is still not reaching approximately 15 million people who need it(1), treatment can encourage testing uptake. More research is needed to understand how young people view treatment in relation to HIV testing uptake.

Recommendations for the future in testing

Given the central role of HIV testing in HIV prevention and treatment, WHO is recommending an opt-out approach to provider-initiated testing, with varied application by target group according to prevalence, at all health facilities.(3) To improve uptake of HIV testing among young people, they should routinely be offered testing upon presentation at health facilities.(4) While more data are needed, new testing outreach strategies such as routine testing, mobile outreach and home-based VCT hold promise for increasing testing uptake across age groups.(40) While protecting patient confidentiality and providing counseling remain key, such strategies can help decrease stigma by normalizing testing, decrease access barriers such as cost and distance, and allow less independent populations such as young people and women to make decisions for their own health.(3, 40)

Study relevance

Much of the existing research on HIV testing among young people originates from the Republic of South Africa with other studies representing young people from Zimbabwe, Zambia, Kenya, Uganda, Nigeria and a few other nations. More comparative research is needed among populations from other countries. This study will examine young people’s social representations of testing in Swaziland, Namibia, Kenya, Nigeria, Burkina Faso and Senegal. While some research has looked at young people and testing, there is still a gap in the understanding of what factors support testing and, particularly, in understanding the socio-cultural context of HIV testing among sub-Saharan African youth. This research will examine the mechanisms through which various factors act to support testing and healthy testing outcomes.

Manuscript

Making sense of HIV Testing: Social representations in young Africans' HIV-related narratives from six countries

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Keywords: HIV/AIDS; testing; Africa; youth; social representations.

Contribution of the student

A team of researchers, led by Dr. Kate Winskell, have contributed to this manuscript. The data collection, sampling and cleaning were performed by this team, before the involvement of the student researcher. They also wrote summaries of the 586 narratives which comprise the sample then coded the narrative texts and summaries for presence of topics and themes. Using this base, the student identified narratives depicting testing scenarios (n=88) from the narratives that had been pre-coded with “testing”. The student inductively and deductively created a code book for this sub-set of data and applied these codes to the testing scenario narratives. There was an existing foundation of quantitative attributes of the narratives that had been identified and recorded. The student had contributed to the development of this foundation. The research team, without the student, prepared the tables used in this manuscript. Using the ‘testing’ narratives, she confirmed and recorded attributes specific to this data. She analyzed the coded and attribute-level data to describe representations of testing and their distribution across the sample. The student wrote the text of the manuscript with suggested revisions from Dr. Winskell. The student conducted and wrote the literature review that contributed to the manuscript’s framing, introduction and discussion.

Abstract

HIV testing and counseling is a critical intervention to support treatment access and prevention of new infections. Despite high rates of infection and attempts to increase testing in this age group, young Africans are those least likely to have tested for HIV. With the aims of informing interventions that encourage HIV testing and promote healthy testing outcomes, this study seeks to understand how young Africans imagine and make sense of HIV testing. ‘Scenarios from Africa’ scriptwriting contests invite young people to contribute ideas for short films about HIV. Using thematic narrative-based approaches, we analyzed a stratified random sample of 586 (~5%) of these narratives written in 2005 by males and females aged 10-24 from Senegal, Burkina Faso, South-East Nigeria, Kenya, Namibia and Swaziland. The factors influencing testing behavior and outcomes are represented as complex, interactive and multifaceted. Personal perception of risk, whether low or high, was shown to both inhibit and facilitate HIV testing. Social support from family, peers and the community was depicted as instrumental in promoting testing and beneficial testing outcomes, such as preventative behavior change and adoption of positive living. Counseling was represented as a crucial element of the testing process. Young authors depicted the benefits of integrating testing into the standard ‘ABC’ (‘abstinence’, ‘be faithful’, ‘use condoms’) of HIV prevention. As multiple factors mediate the testing decision-making process, one-dimensional interventions are unlikely to effect a shift towards increased testing or more beneficial testing outcomes. Interventions need to operate with greater understanding of the multi-layered and context-specific factors that motivate and impede the decision to test. Despite current low levels of testing, the narratives demonstrate the potential for favorable attitudes toward testing among young Africans and the opportunity to increase HIV testing in this demographic.

Introduction

In 2009, 22.5 million people were living with HIV in sub-Saharan Africa. There were 1.3 million AIDS-related deaths.(1) Approximately 40% of all new infections in the region were in young people between the ages of 15 and 24.(2) A study conducted in 2005-7 found that only 10 – 12% of people in sub-Saharan Africa had tested and learned their HIV status.(3) Despite both high rates of infection and attempts to increase testing among young Africans, few have tested.(4)

HIV testing and counseling is a critical intervention to support treatment access and prevention of new infections among people testing both positive and negative.(1, 5) In addition to fostering uptake of prevention of mother-to-child transmission (PMTCT), treatment of opportunistic infections, antiretroviral (ART) access, and a range of prevention behaviors, testing supports people’s right to know their HIV status.(6) Testing allows for information sharing and guidance, supports referral to medical treatment, and promotes safer sex practices.(7, 8) The UN General Assembly affirmed a commitment to voluntary counseling and testing including pre and post test counseling (VCT) as a prevention strategy in 2006.(9) Testing can also reduce stigma by raising social awareness of HIV.(1)

It is important to understand the factors that facilitate and inhibit testing and the mechanisms through which they operate in order to design meaningful interventions to support testing and healthy testing outcomes among young people. Understanding how young people make sense of testing can contribute to this knowledge base.

‘Scenarios from Africa’ scriptwriting contests offer a unique data set through which to understand the HIV-related social representations of young Africans.(10-13) In this study, we analyze narratives written for the 2005 contest by young people aged 10-24 years from six African countries/regions with estimated adult HIV prevalence rates ranging from 1 to 33%.(14) Narratives are a source of insight into how people make sense of the world, and how they communicate those understandings to others.(15) In this study, they provide access to the voices and imaginings of young Africans in a largely unmediated way, revealing their spontaneous mentions of testing, rather than their responses to specific interview or focus group questions. The narratives illuminate cultural resources available to young people in and across the six countries as they strive to make sense of HIV and the role of testing in the response to it. Our analysis highlights commonalities and differences in social representations across countries and demographic categories.

Methods

Since 1997, contests organized by the ‘Scenarios from Africa’ communication process have invited young Africans, up to age 24, to contribute scripts for short fiction films to educate their communities about HIV and AIDS.(16, 17) The young contest participants are mobilized by non-governmental and community-based organizations and local, national and international media across sub-Saharan Africa. A leaflet, available in several major languages, is used continent-wide to provide young people with instructions on how to participate. The winning ideas in each contest are selected by local juries and, following adaptation, transformed into short fiction films by leading African directors. Thirty-five films have been produced to date (18) and are available in over 25 languages for television broadcast and use at community level. By 2008, the process had generated an archive of approximately 55,000 narratives written by young people from 47 countries.

Study sample and population

The research described in this paper is part of a six-country study of young Africans' social representations of HIV and AIDS. Our theoretical foundations, sampling procedures and analytical methods are described in detail elsewhere.(19) The narratives analyzed here were submitted to the Scenarios from Africa contest held continent-wide from 1st February to 15th April 2005. Over 63,000 young people from 35 African countries participated in this contest, submitting approximately 23,000 narratives. For this study, we selected six non-contiguous countries in which at least 500 submissions were received and with contrasting estimated adult HIV prevalence rates in2005: Senegal (0.9%), Burkina Faso (2%), Nigeria (3.9%), Kenya (6.1%), Namibia (19.6%), and Swaziland (33.4%).(20) A questionnaire completed by all participants provided data on socio-demographic variables (Table 1).

Testing behavior varies by country. According to Measure DHS data the proportions of 15-24 year olds ever requesting, receiving and learning results from an HIV test are as follows: Swaziland 6.3% male, 13.6% female (2006-7), Namibia 15.0% male, 23.1% female (2006), Kenya 6.8% male, 8.6% female (2003), Nigeria 4.2% male, 3.0% female (2003), 5.5% male, 5.1% female (2008), Burkina Faso 4.3% male, female unavailable (2003) and Senegal 1.3% male, 1.4% female (2005).(21) The distribution of young people testing roughly follows the distribution of HIV prevalence across the countries.

Scenarios were ineligible for inclusion in the study sample if they were team-authored or written in response to one of the thirteen thematic story-starters provided on the contest leaflet (e.g. 'Write a story about HIV/AIDS in a country experiencing armed conflict'). After eliminating these scenarios, we stratified our data by sex, urban/rural location and age (10-14, 15-19, 20-24) and randomly selected ten narratives from each of the twelve strata. In some countries certain strata contained fewer than ten narratives; hence some country samples have fewer than the maximum 120 narratives (Table 2). In light of the size and cultural diversity of the Nigerian population, only those narratives from the Igbo-speaking South-East were sampled. An overall sample of 586 texts for the six countries resulted.

As contest participants self-select, the data is not representative of the youth populations; participants are likely to be better educated, and more knowledgeable and motivated about HIV than the general youth population. As a product of the same contest mechanism, however, these biases are likely to be consistent across the six countries hence the country samples, though not representative, are comparable for our purposes. Social representations are properties of social groups rather than individuals. (22) Our interest lies with the cultural meanings that frame HIV testing among this youth population in and across these countries.

Data processing and analysis

The data were transcribed verbatim in English or French and entered into MAXQDA 2007 qualitative data analysis software (23), where they were labelled with descriptive codes with reference to a detailed codebook covering a range of HIV-related themes including HIV testing. The testing code was applied to descriptions of the process or occurrence of testing, and ideas, dialogue or thoughts about testing and testing motivations. A summary was written for each narrative and this was coded with up to six out of a possible forty-five keywords, which included testing. The narratives whose summaries were coded for testing were then subdivided into narratives where the plot was driven by a testing result and narratives which explored a testing scenario. The latter 88 narratives were coded as ‘testing narratives’ and comprise the testing-themed data analyzed in this study.

Interpretive codes were then identified, both deductively – with reference to existing literature on testing and inductively – from the themes that emerged in the testing-themed data (24). Examples of interpretive codes included motivations, barriers, counseling, and testing outcome. These interpretive codes were applied to the testing-themed data, and analyzed to describe representations of testing and their distribution across the countries, sex and age of author.

Certain quantifiable characteristics of the narratives were also analyzed, for example, the presence or absence of a hopeful ending, a positive test, a negative test, whether a character accessed antiretroviral therapy (ART) and whether the narrative focused on prevention, infection, the post-infection period, or some combination thereof. Data were double-entered in a database. Any discrepancies were resolved by means of dialogue. The data were transferred to Microsoft Excel, where descriptive statistics were computed.

This study, comprising the secondary analysis of existing data, was approved by Emory University's Institutional Review Board. We cite the narratives verbatim. Country names are abbreviated as follows: SZ – Swaziland; NM – Namibia; KY – Kenya; NG – Nigeria; BF – Burkina Faso; and SN – Senegal. Excerpts are identified by the country, sex, age and geographic location of the author. For example, an excerpt followed by '(NM, F 15-19 R)' comes from a female participant in the 15-19 age group from rural Namibia.

Purpose

This analysis seeks to understand how young Africans imagine and make sense of testing in relation to HIV. How do motivations for and barriers to HIV testing identified in the narratives operate to influence characters' testing decisions and outcomes? How do the young authors represent varying social situations and other external factors as influencing decision-making around testing and testing outcomes? Using both country-specific and cross-country results, this research aims to inform HIV interventions that promote testing and encourage healthy testing outcomes for young Africans.

The analysis addresses motivations, barriers, the role of social interactions in testing decisions and outcomes, couples testing and status disclosure, post-test behavior change, counseling, and the integration of testing with other prevention strategies. While social representations are not uniform(22), the analysis focuses on prominent commonalities and differences both within and across the country samples which may illuminate the cultural meanings that frame testing in these settings. Our analysis builds on the motivations and barriers to HIV testing established in existing literature to explore the mechanisms through which they act to influence testing behavior and outcomes. Motivations identified by the literature that are also present in our data include illness, health provider recommendation, self-perception of risk, preparation for marriage, social support, and treatment access.(1, 4, 25-27) Our data also include representations of testing motivated by avoiding infection. Barriers established in the literature that are seen in our data include fear, stigma, self-perception of risk, and informational and logistical barriers.(5, 8, 28, 29)

Results

Overall treatment of testing

Testing is mentioned in 337 of the 586 narratives (58%). The young authors frequently use the moment when a character learns his or her status through an HIV test as a turning point in their narratives. A more thorough exploration of a testing scenario, however, where testing is a central theme in the narrative, occurs in 88 (15%) of the narratives. Roughly one quarter of testing-themed narratives originate from Burkina Faso and Senegal, respectively, 15% from Kenya and Namibia, respectively and 10% from Swaziland and Nigeria, respectively. Male and rural authors were slightly more likely to write testing-themed narratives. The narratives were evenly distributed across the author age groups. Authors wrote about characters of their own sex testing, and testing positive, with somewhat higher frequency than characters of the opposite sex. Prominent concurrent themes present in testing-themed narratives include engagement/marriage, condoms, multiple partners and peer dialogue/influence.

The narratives include both client-initiated and provider-initiated testing. Client-initiated testing often resembles a ‘VCT’ model including some element of counseling. Provider-initiated testing is generally diagnostic. Routine testing is most often depicted within the context of ante-natal visits. The testing narratives contain roughly twice as many positive as negative test results.

There are many similarities in the testing-themed narratives across countries, particularly with regard to the types of barriers to testing depicted. However, differences also exist. Counseling and access to ART feature more prominently in testing-themed narratives from Swaziland, a higher prevalence country, whereas couples’ testing is most prominent in the sample from Burkina Faso. Pre-marital testing is more common in the narratives from Burkina Faso, Senegal and Nigeria than other countries. Nigerian narratives are often moralizing in nature, portraying stigma and blame as prominent obstacles to testing. This is also true of some Kenyan narratives. Approximately half of testing-themed narratives had hopeful endings.

Motivation for testing

The decision to test in the narratives is often represented as resulting from a complex interaction of motivations.

Illness or Symptoms

Across country samples, illness is rarely a stand-alone motivation for HIV testing but one that is acted upon following peer, parental or child encouragement, support from a counsellor, health care provider intervention, or after a character has gained additional information about HIV. In one Swazi narrative, a hospitalized teenage man refuses to test despite illness, clear treatment benefits, clinician recommendation and self-perception of HIV risk. His peer group culture includes alcohol, marijuana and sex with multiple partners. He fears the test and also fears the reaction of his friends. It is not until he receives a letter from a past girlfriend sharing her positive status and reassuring him that testing, independent of the outcome, is an opportunity to take control and begin a healthy life, that he seriously considers testing. He waivers still, "But the last phrase from the letter made him become brave again, 'and you will be happy, I promise'"(SW F 15-19 R).

After testing positive, the young man encourages his friends to test, talking about the 'free life' post-testing: living longer, better and without the stress of not knowing your status. His friends respond to his advocacy by also testing.

Personal risk perception

Self-perception of risk as a motivation to test features prominently in the Namibian sample but is seen in narratives from across the data set. Characters recognize themselves to be at risk and get tested after they reflect on prior multiple partners, and their failure to use condoms or get tested before sex. Other high-risk activities that lead to risk recognition and testing include rape and exposure to potentially infected blood. Several characters spontaneously recall past risk behaviors before testing while others do so after they fall ill, gain additional HIV-related knowledge, or learn of a partner's HIV exposure. In negative cases, characters who recognize their risk after learning of the AIDS-related death of a past partner are overcome by fear and do not test.

Health care providers

Across all country samples, but with particular prominence in narratives from Swaziland and Nigeria, health care providers motivate characters to test. Often this is depicted as a patient presenting at a health facility with an unspecified illness then receiving encouragement from a clinician to undergo HIV testing. Where patients have agency in deciding whether to test or not, the clinician is portrayed as playing a supportive role, often incorporating counseling into the testing experience. The decision to test is thus not only influenced by a medical recommendation but also by additional information and social support. In most but not all cases, this type of provider interaction leads to treatment or another hopeful resolution to the narrative.

Health care providers are not, however, always depicted as playing a beneficent role in testing decision-making. Some representations of clinician-motivated testing include coercion to test or testing patients without their knowledge or consent. These scenarios end with mixed but largely unfavorable outcomes. In one particularly morally-loaded and stigmatizing narrative from Nigeria, the doctor refuses to offer the HIV positive young woman post-test guidance until she brings to him the person with whom she “committed adultery” so that he can also be tested (NG M 10-14 U).

Risk Avoidance: Pregnancy & Marriage

Where pregnancy serves as a motivation to test, testing is represented as a routine part of antenatal care (ANC) or is utilized after a character learns about the potential for prevention of mother-to-child transmission. In several narratives, a father’s positive test leads to a mother testing, and the birth of an HIV-negative child. In the only testing-themed narrative that ends with the birth of an HIV-infected child, a mother, fearful and separated from the child’s father, declines the opportunity to test (SN M 13 U).

Pre-marital HIV testing is commonly depicted in narratives from Nigeria, Senegal and Burkina Faso. It is required by a Reverend in one Nigerian narrative (NG F 20-24 R). In other narratives, uncles, parents, one or both of the future spouses, and detached observers all recommend the period before marriage as a good or necessary time to test. Like other motivations, however, marriage alone is often insufficient to bring about testing. Parental support, self-perception of risk and accurate information about HIV accompany characters’ decisions to test.

Frequently, empowered female characters are depicted protecting their health by requesting that their partner test before marriage. Upon learning that the partner proposed for her by her father has been exposed to HIV, a young Senegalese woman named Rama agrees to the match on condition that the man takes an HIV test. Demonstrating that tests hold meaning beyond their diagnostic capacity, the test not only averts a possible infection, but is also used to release her from an undesired marriage (SN M 17 R).

The primary benefit attributed to pre-marital testing in the narratives is HIV prevention. In all cases where serodiscordance between the proposed couple is disclosed, the marriage does not proceed. Narratives of this kind from Nigeria use stigmatizing language to highlight the risks associated with pre-marital sex. When the fiancés test separately and do not disclose their status to one another, the negative partner and the couple's future children are shown to be at risk of HIV infection.

Risk Avoidance: Sex

The desire to avoid sexually-transmitted HIV infection motivates testing in several narratives. Both male and female-authored narratives again feature empowered female characters who demand testing as a preventative measure or cite a lack of testing as a reason to refuse sex. Where the woman is depicted as acting in the context of a mutually respectful, affectionate relationship, her wishes are respected, despite initial reluctance on the part of her partner. Factors inhibiting testing before sex include disbelief that a healthy-looking partner could be positive, fear of the partner, and the context of a transactional relationship. Failure to test is depicted as leading to infection while refusing to have sex before testing leads to avoidance of infection. Testing may have beneficial social consequences, such as experiences of social support and a feeling of control, or negative social consequences, such as the loss of a desired relationship or stigmatization.

Treatment

A Burkinabe character who suffers from a long illness then sees a doctor and accesses ART articulates the role treatment plays in motivating testing:"The HIV test allows everyone to know from what he suffers now, and he can recover his health" (BF M 20-24 U). Approximately one quarter of the testing-themed narratives mention ART or PMTCT as a treatment or prophylaxis option, though the distribution differs by country. Narratives that include the possibility of access to ART are more likely to be hopeful than those that do not; but ART alone is not a guarantee of hope, nor is hope absent from all narratives in which ART is absent.

Barriers to testing

Similar to motivations, the barriers to testing depicted in the narratives are complex and interactive, operating simultaneously on multiple levels. These barriers may be explicitly voiced by characters or indirectly identified by authors through their representations of characters' unfavorable testing experiences or post-testing outcomes.

Fear

Fear of testing, the most prominent barrier depicted, stems from multiple sources of concern. It encapsulates a fear of the death sentence that HIV is presumed to confer, fear that knowledge of status will hasten death, and fear that an inability to cope with the results will cause immediate death or other negative consequences. Across the country samples, testing-related fear is also linked to the secondary social consequences of testing. These include rejection, stigma and mistrust from peers or partners, abandonment by one's family, destruction of one's family, the need to change one's lifestyle, loss of career, and the possibility of suicide. There is a fear that, even in death, an HIV positive person would be singled out and socially reproached.

A young Nigerian woman, despite never having had sex, highlights these fears as she prepares to get tested,

> And what if I be positive?, ‘God, I am finished’ I cried if I happen to be positive, I shall begin to die immediately, I shall begin to Count my days, I shall know that I shall surely die one day and have my name Announced as one of those who died of HIV/AIDS. ... ‘Does that mean that I shall not marry?’ I thought ‘Look at charles we have been dating and when once he finds out that am HIV positive, he will leave me for another and then what shall become of me’ (NG F 20-24 U)

In this case, however, the young woman’s desire to know her status, ultimately overcomes here fears and she tests.

A Kenyan narrative offers a particularly thoughtful examination of the reasons why people do not test and potential rebuttals for them. It features a young, college-aged man listening to a debate between his ‘good conscience’, represented by an African female (Voice 2), and his ‘bad conscience’, represented by an African-American male (Voice 1), on the subject of whether or not he should test. This excerpt identifies barriers including low risk perception, blame, and stress.

Voice 2 begins by outlining why the young man is at risk for HIV and, therefore, why a test would be appropriate. In reply, ‘Voice 1’ argues that socially acceptable behavior does not necessitate testing. This belief could fuel stigma and skew personal risk perceptions by invoking socially-driven, as opposed to scientifically-driven, risk assessments.

> Voice 2 good girl (in a thick African Womans accent): AND YOU DON'T HAVE ANYTHING TO WORRY ABOUT'??? U??? Don't make me laugh. How many girls? How many'? Eh? And can u honestly tell me u knew them that well? I kno u didn't. They're probably doing the same thing with some other guy right now. And condoms? How many times were u using

> them?- more importantly how many times were u NOT using them. Eh? I need to know. U need to kno. WE need to kno.
>
> College student:- *[He lowers his head and slides into the bench]*
>
> Voice 1:Yo come on now. U a young African man in college dog. Sowing his wild oats. Nothing wrong with that. U living life to the fullest.
>
> College student:- *[He nods his head with a wry smile. As if reminiscing the good times]*

Voice 2's arguments in favor of knowledge, access to life-extending early treatment, and the potential to prevent infections if one is positive are countered by Voice 1 with the more immediate concern of the negative experience of stress. As in numerous other narratives, a disincentive for testing lies in the debilitating anxiety that is depicted surrounding testing preparations and waiting for one's result. The latter is shown in other narratives to be in a dose-response relationship with the amount of time one has to wait.

> Voice 2:Doesn't mean he can't be responsible. You learn ur status and now where u stand in life... cause trust me it'll catch up with you one day. And then what? We all want to come out negative. but what if... What if ur positve?.
>
> Voice I;- And what if ur negative? All that stress and drama for nothing… (KY M 20-24 U)

Risk Perception and Disbelief

As illustrated in the above example, risk perception can both inhibit and facilitate testing. For some characters, perceiving themselves to be at high risk for HIV creates fear that hinders testing. Alternatively, assuming as a foregone conclusion that they are HIV-positive creates resolve and a greater willingness to test in other characters when treatment is available (SZ F 15-19 R). Similarly, a low perception of risk to the point of disbelief that one could be infected is depicted as blocking access to testing by eliminating its perceived utility. However, for other characters, the belief that their test will come out negative gives them the confidence to test.

From a prevention perspective, low risk perception, if accurately reflecting low risk behaviors and exposures, is desirable. Unfortunately, the narratives represent the low risk perception of certain characters to be unfounded. Disbelief around HIV risk frequently stems from characters not believing that they or their partners could be infected if they are healthy-looking, tall, elegant, well educated , ‘good’ people or do not fit another specific profile. When told his one-time sex partner tested positive, Akoly does not believe it and does not want to test , responding, “That beautiful girl, she is not from the city, she is fat. What could prove that she has HIV in her blood?” (BF M 20-24 R)

Other factors driving disbelief include not wanting to believe that one is at risk (NM M 20-24 R), not knowing about HIV, seeing testing as a drastic step (NM M 20-24 U), moralization, and associating the presence of trust in a relationship with the absence of risk. For example, when encouraged by her friend to test, Mnenna, who is having unprotected sex with a new boyfriend, says, “…that she trust her boy friend that he will not do such a thing to contact disease” (NG F 10-14 R).

Testing is only for symptomatic individuals

The young authors depict multiple characters believing that as long as one is not symptomatic, there can be no reason to test. Given that the most common motivation for testing depicted in the narratives is illness it is possible that many of the young authors implicitly share this belief.

Logistical challenges

Other barriers depicted in the narratives include logistical challenges such as lack of funds for testing, mistrust of the test or of health care workers, including fear of a breach of confidentiality and fear of being chastised for having sex, and an attitude that accepts personal HIV risk as unavoidable.

Possibly due to the testing-themed nature of the sample, characters are generally depicted overcoming the identified barriers to testing. Social support, in the form of encouragement, reassurance and assistance, is the factor most commonly represented as helping characters to surmount obstacles to testing.

Social Interactions

Across the country samples, the narratives represent social interactions as instrumental elements of testing decision-making. Social interactions include encounters with peers, family members and romantic partners as well as community-level support. They are included as a component of the motivation to test in many narratives and are nearly always successful in influencing a character to test or to collect test results.

Peers provide support in dialogues in which they encourage testing and by physically accompanying each other to the testing location. Generally, support is gendered with a male character talking with or accompanying a single male friend or a group of male friends or a female character talking with or accompanying one or two female friends. Dialogue between romantic or married partners is also depicted. Most examples show female partners asking males to test, but there are a few examples of males encouraging female partners to test.

In several cases, peer encouragement to test is unsuccessful. This occurs where the target of the encouragement is disinterested or refuses to believe his partner could be HIV positive. It also occurs in a Senegalese narrative where a single peer advocates unsuccessfully against a larger peer-group's belief that HIV testing will lead to social alienation. In this narrative, it is only after the peer group recognizes its involvement in a high risk behavior (sharing a razor with an HIV positive peer) that they agree to test (SN M 20-24 U).

Support from family members also positively influences the decision to test in the narratives. Parents, particularly mothers, play a prominent role in encouraging young people to test, with aunts, uncles, brothers, sisters, and children also encouraging testing.

Community-level support is demonstrated primarily, but not exclusively, in Senegalese narratives that depict youth groups which encourage testing and testing-focused community gatherings led by health educators, teachers or chiefs.

Peers, family and other agents of social influence are most often motivated by their concern for a friend's health, seeing them as at risk for HIV even when they themselves do not. In a Namibian narrative, Sophia, seeing no reason to test, is encouraged by her friend Mimi after she hears that Sophia's ex-boyfriend had more than one girlfriend."I would advice you to go for a Pregnancy And HIV/ AIDS test at New Start Centre as they also do counseling. A cheating boyfriend should be the last thing on your mind. He isn't worth your life, dear...” (NM M 20-24 U). In other cases, friends facilitate testing merely by suggesting it as an option.

In one Burkinabe narrative a lack of social support, amplified by wife-husband power imbalance, is depicted as a serious obstacle to testing,

> There was a young woman who had a cough for many months. One day she told her husband she would like him to go with her to get an HIV test - he refused, and she told him she did not want to do it alone. But the husband refused.
> (BF F 15-19 U)

Disclosure

Couples Testing and Disclosure

In addition to depicting testing motivated by marriage, pregnancy or initiation of sex, the young authors represent couples testing motivated by infidelity, illness, self-perception of risk and, in one case, a mass media communication. There are no explicit representations of a couple receiving pre- and post-test counseling and their testing results in the same room at the same time. However, there are narratives from all 6 countries in which either a dyad tests at the same time and the partners learn each other’s results or the negative consequences of this not taking place are depicted. Testing in the context of a couple often leads to the continuation of relationships in the case of seroconcordance and termination of relationships in the case of serodiscordance. The authors represent couples testing leading to access to additional counseling, reconciliation of estranged partners and commitments to positive living including faithfulness and the use of condoms. With the exception of several stigmatized, unhappy male characters who lose their partner after testing positive, testing in a couples context, independent of the test results, is portrayed as beneficial with hopeful outcomes.

In several narratives, one or both partners in a couple testing provides an opportunity for disclosure. In a Senegalese narrative, for example, it is not until Madame Badiane, motivated by her pregnancy and her husband's verbal and financial support, tests and shares her positive status that Monsieur Badiane reveals, with much apology, that he had known his positive status for some time but did not know how to tell his wife. With a focus on PMTCT, they agree to go to the hospital together the following day (SN F 20-24 R).

In contrast, a Burkinabe author depicts a male character who does not disclose his positive status to his wife as having

> deliberately punished [her] to die like him. [He] was irresponsible and did not think of his children. If he disclosed his status to his wife, it would have been possible for them to live together for many years and have seronegative children, thanks to newly-developed medicine and by taking ARVs at the time indicated by their doctors. (BF F 15-19 U)

Recognizing the potential difficulty of disclosure within a couple, the authors represent the process of testing as assisting with the communication, highlighting the supportive role of counsellors or testing providers. A newly married Senegalese man and wife each test positive but with different doctors and without disclosing to each other. "Fortunately, the two doctors knew each other. They decided to bring the couple together and explain to them what happened. They explained how to live together without problems and how to have HIV negative children." The couple goes on to have nine negative children (SN F 20-24 U).

In the context of restrictive cultural norms and power differentials, a Burkinabe narrative further demonstrates the potential value of the testing process in supporting disclosure and beneficial health outcomes. A wife, exposed to HIV in a previous marriage, becomes ill and tests positive.

> She tried to think of ways to tell her husband but her husband was having unprotected sex with her as usual. She could not ask him to use condoms because that would be grounds for a divorce, and now she was worried about re-infection from her husband. The counsellor listened to the woman's story and told her to tell her husband to come in for an HIV test. This was the only way to make him realize the situation they were in. (BF M 15-19 U)

Individual testing and disclosure

Individual characters who test positive often disclose their status to someone after testing. Female characters are represented disclosing most often to family members, followed by friends and partners. Male character disclosure is evenly divided between the three groups.

Various disclosure situations are depicted. Often characters self-disclose to people who supported the idea of testing including friends who accompanied them to test and school HIV awareness organizations. In narratives from Swaziland, disclosure is connected to some level of acceptance of one’s status. “I did the blood test and the results came back positive. I denied and I was a little bit stressed. It takes me a long time to accept. Then I told my older sister about my stauts…” (SZ M 20-24 R) Disclosure also happens in orchestrated situations where a caregiver, such as a parent, is told the young person’s status by the testing clinician or where a doctor demands that the person testing also bring in their sex partner for testing.

Disclosure to a sex partner is depicted as supporting future prevention and early access to care and treatment. Although the initial reaction may be one of reproach when characters share their status with current or past partners, the narratives represent many beneficial ultimate outcomes. In one Swazi narrative, the young woman's boyfriend breaks up with her but she goes on to find a new, HIV positive boyfriend (SZ F 20-24 U). A male's disclosure to a sex partner in a Burkinabe narrative leads the female partner to test. When they learn that she is both HIV positive and pregnant, they marry and together raise a happy family (BF M 20-24 R).

Disclosure initiated by the young person generally leads to affirming, constructive outcomes. These include social acceptance, moral support, access to care and ART, a platform from which to educate others about HIV and AIDS, and the voluntary testing of friends and past sex partners.

Behavior Change

In the narratives, testing is represented as facilitating constructive post-test behaviors. While just under half of the testing-themed narratives do not explicitly address post-test behavior change, those that do show largely beneficial outcomes.

Across country samples, after receipt of both positive and negative test results, characters educate others about HIV and encourage them to test. Characters who test positive are represented as feeling a desire to help others who need or want to test. Depicted as working with supportive friends and family, characters share their experiences, often deriving a sense of purpose from the advocacy. Characters who test negative are represented as relieved by the result with a desire to help others avoid HIV and encourage them to test. They are also depicted supporting the advocacy work of friends who tested positive. Testing often strengthens the bonds of friendship between characters who test together. In narratives from Nigeria and Kenya, advocacy following a negative test is also represented as motivated by gratitude to God.

Some narratives include post-test behaviors that directly reduce characters' and their networks' risk of HIV infection. Narratives include married couples, after learning that both partners are HIV positive, adopting condom use, ART and faithfulness to protect each other and live a healthy life. In two cases involving polygamous marriages, a wife who tests negative facilitates testing for the husband and other wives, presumably providing her with an opportunity for HIV prevention. On the individual level, the post-test behaviors depicted vary somewhat by HIV status. Characters who test negative commit to abstinence or using condoms in their resolve to prevent future risk. This often follows interaction with HIV positive family or peers. Several HIV positive characters decide to abstain from sex post-testing. A Burkinabe narrative also shows a woman, Caroline, giving up high-risk commercial sex work to start a successful cosmetics business (BF F 15-19 U). Both positive and negative characters reduce risk behaviors such as alcohol or drug use.

Other post-test behaviors represented include uptake of PMTCT, initiation of ART, eating healthy food, living positively, and, in Nigeria, turning to God. These behaviors are almost always facilitated by support from family, friends or organizations of people living with HIV and AIDS.

Counseling

While counseling accompanies testing in fewer than half of testing-themed narratives, where it is present, it is depicted as a crucial component of the testing process. Counseling is present in narratives from all countries with particular prominence in Swaziland. Most counseling in Swaziland comes before the test, as preparation, while most counseling in other countries occurs only after a positive test result, with the exception of the sample from Burkina Faso which features a mix of pre and post-test counseling. In many narratives, counseling is portrayed as somewhat formulaic. This may be due to a lack of experience among the authors of actual testing situations.

Counselors are represented as serving many roles. They psychologically prepare characters to receive their results, convince reluctant but interested characters to test and repair relationships damaged by unanticipated testing results. Counseling helps characters to avoid detrimental outcomes such as suicide, to adopt positive behaviors such as starting ART, to sustain a negative status, and to gain information about HIV. Having had unprotected sex and encouraged by her two friends to test, Thandi finds out she is positive. “After 2 days without eating, all Thandi thinks about is suicide, but she remembers the counsellors words that she could live for many years.” She goes on to disclose to her friends and mother, educate others and win the recognition of her community (SZ F 10-14 U). In another Swazi narrative, absence of counseling is explicitly identified as a barrier to post-test ART access.

Testing and other prevention strategies

The narratives demonstrate the potential for testing to be integrated into a ‘prevention toolkit’. Narratives from Namibia, Kenya, Swaziland and Burkina Faso depict the beneficial interaction of testing with other prevention methods. Testing is paired with condoms and faithfulness to further reduce infection risk.

Several narratives show that condoms can provide protection in the absence of a test or pending a test result. In a Burkinabe narrative, a young man beginning a new relationship uses condoms even though they have both tested due to the potential for repeated risk exposure.,

> In order to have sex, I have to wonder how long ago she got tested. She got tested 2 months ago, but isn't it possible that she could have been infected during that period? This means I need to be careful and use a condom. (BF M 15-19 U)

Other narratives show that, in the context of human fallibility and power differentials in condom use, testing before the start of a sexual relationship can provide a means of preventing infection.

> One night, they decided to sleep together. She was a virgin and they used a condom, but in the heat of the moment he convinced her to let him take it off. She contracted HIV. … This is why before becoming lovers it is necessary to do an HIV test. (SN M 10-14 R)

A Kenyan narrative advocates only having sex with partners who know their status and being faithful to one partner. One Burkinabe narrative encourages condoms, faithfulness and testing, with testing taking the place where one might usually find ‘abstain’.

Unfortunately, many narratives depict characters testing positive immediately after risk exposure when antibodies would not yet be detectable. This may reflect a lack of accurate information among the authors, calling for education to help young people effectively operationalize testing as a prevention tool.

Discussion

The prevalence of testing-themed scenarios by country sample stands in a roughly inverse relation to the country's HIV prevalence. The prominence of post-infection scenarios (focusing on the time period when a character already knows his or her status) in high prevalence countries likely explains this distribution.(11)

Across countries, the motivations for and barriers to testing depicted in our data were largely consistent with existing findings concerning young people in sub-Saharan Africa.(4, 27, 28) Our data indicate that the factors influencing testing behavior and mediating testing outcomes may be complex and multifaceted, however. The narrative data are particularly valuable for revealing the interactions between multiple factors. These findings suggest that one-dimensional interventions are unlikely to effect a shift towards increased testing or more beneficial testing outcomes. Interventions need to operate with greater understanding of the multi-layered and context-specific factors that motivate and impede the decision to test.

The young authors represent social support as a crucial piece of the testing process across the various motivations, barriers and testing contexts. Throughout the data, social support is the most consistent contextual factor facilitating testing and the adoption of healthy post-test behaviors. It plays a particularly prominent role in convincing fearful or reluctant characters to test. Testing interventions should consider the value of a supportive social network, potentially including family, friends, partners and other community-level influences, in successfully facilitating testing and healthy testing outcomes. Perceived community-level stigma is prominently represented as inhibiting testing. This suggests the need for testing interventions to both reduce stigmatizing societal norms and promote individual-level support coming from one-on-one or small group interactions.

The narratives represent personal perception of risk, low or high, as both inhibiting and facilitating HIV testing. Accurate information about how to understand one's HIV risk needs to be effectively communicated to young people. The stigmatizing association represented in the narratives between morality and HIV risk affects characters' risk perceptions by associating an absence of blame or the presence of trust with an absence of risk. Efforts should be made to de-link blame, morality and HIV status in order to facilitate accurate personal and partner risk assessment. The narratives suggest that interventions that target those who may perceive themselves to be at high risk for HIV infection should address the fear that facing a positive result may induce. Social support is depicted as useful in overcoming that barrier with the message that 'life after testing has value' having special resonance.

The narratives suggest that reassuring young people that informed consent and access to counseling will be a part of the testing process is an important consideration. In addition it is necessary to address the perception that providers may chastise young clients. This may be particularly salient as countries implement current recommendations around provider-initiated, opt-out testing.(3)

While a thorough exploration of country-specific practices and policies that might influence testing is beyond the scope of this paper, it is relevant to note that in Nigeria, mandatory pre-marital HIV testing was instituted in most traditional Protestant and Pentecostal churches in the late 1990's with the intent that marriage would be refused to couples if one or both individuals test positive.(27) In the narratives, pre-marital testing is largely portrayed as a useful prevention tool, although characters who test positive frequently experience rejection and stigmatization. While encouraging pre-marital testing can support prevention, it can lead to significant social stigma if couple identity is not protected.(27) The depictions of relationships terminating in all cases of serodiscordancy and the subsequent stigmatization experienced by the positive partner demonstrate a need for care in the implementation of pre-marital testing. In a 2010 study conducted in northwest Nigeria, 57% of the unmarried young people surveyed (n=571) believed that testing positive is shameful for one's family. Over one-third believed that HIV testing would make one's status public knowledge.(30) These beliefs could act as significant disincentives to testing, especially among those who perceive themselves to be at highest risk. In several narratives, despite going to the testing location together, only one member of a couple tests. While the partners in a couple may not share the same risk profile, creating a norm where both test will help to reduce testing-related stigma, support disclosure and facilitate subsequent prevention efforts. More research is needed into how to conduct pre-marital testing and manage all potential outcomes in a sensitive and non-stigmatizing way, while facilitating disclosure and subsequent risk reduction.

The narratives show that parents and other relatives play a significant role in pre-marital HIV testing. Often the desire of the young woman to have her partner test must be reinforced by her parents in order for testing to take place. These male-female and female-parent power imbalances must be considered in program planning. Families need to be educated about pre-marital testing, particularly in contexts where marriages may be arranged for young people without their agreement.

Post-test access to ART as a motivation to test received varied treatment in the narratives. While the promise of access convinced some characters to test, in other cases concerns about social stigma, moral condemnation and adherence, among other factors, trumped the motivation treatment could provide. As delaying testing serves to delay treatment for people living with HIV, compromising health outcomes, facilitating timely testing is of particular relevance. While the scale-up of ART availability(1) will likely increase motivation for testing, it may not do so automatically. It will be important that communication efforts reinforce the hope it provides and educate social networks to support adherence.

Fear is represented as a strong and far-reaching barrier to testing across the country samples. To address the varied root causes of fear, different messaging is required, as allaying the concern that you will not die immediately after testing may have little impact on the fear of social isolation or rebuke that could accompany testing positive.

Testing-related anxiety is depicted as a significant barrier to testing. In some cases, the longer the characters had to wait for results, the more anxiety they experienced. The increased use of rapid tests could help mitigate the anxiety by reducing the time required to test and obtain results. However, even the general idea of testing produced great anxiety for other characters. Studies consistently find that more young people report openness toward testing than have actually tested.(4, 6, 31, 32) Other studies have shown that few young people seemed to understand what testing entails, suggesting a need for more specific information about the testing process and experience.(7, 33) While the narratives were generally positive about the idea of testing, few depicted the testing experience in detail. This may reflect a lack of experience with testing among the authors. More information about the process itself might help address these barriers.

The generally constructive depiction of couples testing as leading to beneficial, prevention-oriented testing outcomes demonstrates a potential opportunity to encourage testing and prevention among young people. Outside of pre-marital testing, couples testing is represented as an activity in which already-married couples or couples who have been together for a long time participate. More research is needed to understand how unmarried couples could access the additional prevention benefits and support for disclosure depicted as part of couples testing.

The agency of female characters plays a significant role in motivating HIV couples testing within the narratives. The authors represent female characters' wishes for their partners to test being accommodated in the context of solid relationships characterized by mutual respect. The efforts of female characters to motivate couples testing are inhibited by fear based on power differentials within a couple, disbelief of HIV risk and situations involving transactional sex. The data identify counseling as one way to facilitate disclosure, help couples stay together and utilize positive prevention when necessary. More research is needed to understand how female agency in promoting testing can be supported and respected and vulnerability reduced.

Among individual characters who test, disclosing one's status to friends, family and partners is common in the narratives. Disclosure is represented as a pathway to social support and ART access. Across the various types of relationships depicted, characters are represented disclosing their status to current and past sex partners. While negative consequences such as rejection result, there are many positive consequences too. Characters are depicted supporting

HIV-infected partners to access ART, starting a new relationship or finding new happiness in a marriage. Lack of disclosure in the narratives is represented as having negative consequences. Our data suggest that interventions that facilitate increased social acceptance and support, including counseling and treatment access may help support disclosure. More research is needed, however, to effectively design interventions that support disclosure with beneficial outcomes.

Advocacy is the most common post-test behavior for characters testing both positive and negative. Demonstrating civic action and contributing to the response to a problem facing their communities, the characters educate their peers, families and communities about HIV and testing. Being careful not to impinge on the rights to confidentiality, anonymity, and self-determination, testing interventions should consider the role young people who have tested can play in supporting additional testing in their peer and family networks and spreading accurate information about HIV.

While couples who test are explicitly described as adopting measures to reduce their risk of sexual transmission post-test, most individuals who test do not outline specific risk-reduction efforts. Several characters adopt abstinence while other characters who test negative pledge to use condoms. Given the promise in the initial mentions of post-test behavior change depicted in the narratives and established in the literature, it is important that interventions connect testing to risk reduction through counseling or other means.(9)

Counseling is portrayed as highly beneficial. It is depicted as preventing suicide, facilitating disclosure, healing rifts in relationships and facilitating access to care and treatment. The absence of counseling in over half the narratives may indicate limited awareness of or experience with the process of testing among the young authors. If young people are not aware of what the testing experience entails or of the resources upon which they can draw, it may be more difficult to commit to testing. Interventions should place special emphasis on provision of counseling and increasing awareness among young people of what counseling can offer.

The representation of the integration of testing into the prevention strategies employed by characters shows that young authors are aware of the potential role of testing in prevention efforts. Both male and female authors depicted testing being used as a primary means of prevention. Just as the characters consider the benefits and drawbacks of applying different prevention tools based on the situation they are in, prevention initiatives targeted at young people must see the traditional ABC, ‘abstinence’, ‘be faithful’, ‘use condoms’ and HIV testing as an integrated toolkit. The scenarios offer examples of young people carefully considering and applying various prevention strategies in a way that could be used as a teaching tool.

The narratives and the 2010 UNAIDS Global AIDS report represent testing as contributing to a positive feedback loop.(1) When individuals test, they are likely to get more people to test and each additional test is likely to increase accurate information around HIV and testing, decrease stigma, and support prevention efforts. This can create more social resources on which new testers can draw while also shifting community-level norms around HIV. It is important that interventions address the mechanisms through which motivations and barriers to HIV testing among young people operate and foster social contexts that facilitate testing and beneficial testing outcomes.

Limitations

A thorough analysis of factors which influence testing including country-specific testing campaigns and testing resource availability is beyond the scope of this paper. While age has been shown to be associated with testing, the age of the characters represented as testing is often not discernable from the narratives.

Conclusion

Testing interventions need to consider the complex nature of testing. The development of pro-testing social norms within peer and family groups including reduced testing-related stigma may be a significant element in facilitating testing among young people. Interventions need to consider and address the context-specific layers of testing motivations and barriers. Special attention should be given to the testing process including counseling and the ability of young people to envision the testing experience. Despite current low levels of testing, the narratives demonstrate the potential for favorable attitudes toward testing among young Africans and suggest opportunities to increase HIV testing in this demographic.

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Tables

Table 1: Demographics of participants in the 2005 contest from six study countries (n=11,354)

	Total narratives submitted in 2005	Total participants	Mean age of author	% male author	% urban author	% author with TV at home
Swaziland	510	1,244	14.6	34%	26%	73%
Namibia	657	963	14.8	50%	13%	80%
Kenya	673	966	16.7	53%	69%	81%
Nigeria	1,869	2,712	16.7	30%	40%	85%
Burkina Faso	4,821	15,710	16.8	61%	66%	57%
Senegal	2,824	4,360	15.4	46%	80%	90%
TOTAL	11,354	25,955				

Table 2: Characteristics of study sample (n=586)

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

Public Health Implications

This research suggests ways to support HIV testing among young Africans as well as considerations important to maximizing the benefits which may be gained from testing. When well executed, testing can provide education and guidance to prevent infection, linkage to treatment and support for positive living. Initiatives aimed at scaling up testing in sub-Saharan Africa need to pay special attention to young people, as they are the group with the highest rate of new infections but the lowest rates of testing.

The data suggest that the factors influencing and mediating testing behavior and testing outcomes may be complex and multifaceted. One-dimensional interventions are unlikely to effect a shift towards increased testing or more beneficial testing outcomes. Interventions need to operate with greater understanding of the multi-layered and context-specific factors that motivate and impede the decision to test. For example, the data suggest that an increased risk perception without a reduction in the fear associated with a positive testing result is unlikely to lead to increased testing. Interventions need to consider and address the various elements influencing testing and testing behavior and consider how their interactions may support or inhibit testing goals.

Interventions should carefully consider the type of motivations and barriers that are most likely to influence their target population. For example, the young authors often represent social implications as more influential over the decision to test than clinical implications. Until receiving assurance of social support, fear of social rejection outweighs fear of not receiving treatment for many of the characters depicted. Structuring interventions that address the most influential factors for the target group of interest may be more successful than directly promoting testing as an activity.

The narratives suggest that individual-level or small group support is more influential to testing decisions than large-scale information sharing. While deconstructing stigma at the community-level is important to reduce the fear that might be associated with testing, the young authors represent the advice of family and friends as the factor most often mediating the final decision to test. While it may be more time intensive, finding ways to influence social networks and interactions might be more successful in increasing testing uptake than large-scale information dissemination.

The testing-themed narratives represent largely positive responses to disclosure. Literature suggests that young people disclose their status to those who would be likely to support them.(23) The narratives suggest that young people can envision finding supportive social contacts in the community and constructive responses to disclosure. Interventions that build on this to foster supportive social networks may help encourage testing.

The narratives portray various factors inhibiting and facilitating disclosure. Given that the most common mode of transmission in Africa is heterosexual sex, it is meaningful to reflect on the importance of counseling and couples testing in relation to disclosure as depicted in the narratives. Without these support mechanisms, disclosure of status and preventative behavior change is inhibited. These data suggest that individual testing, while appropriate for some people, will not maximize the benefit testing can contribute to prevention. These data corroborate the WHO recommendation that additional attention and resources should be devoted to couples testing.

Implications for testing interventions can be drawn from the central role stigma plays in mediating testing decisions in the narratives. The 2010 Global AIDS Report discusses a new framework meant to increase ART access called ‘Treatment 2.0’. It outlines community mobilization as a key component of achieving treatment goals.(1) While communities can help increase testing and treatment demand, they can also stifle it when HIV stigma dominates the social discourse. All interventions that rely on the community must ensure that existing norms do not act as barriers to testing, particularly among populations, such as young people, who are most dependent on societal structures for support or most vulnerable to criticism.

Similarly, provider-initiated and opt-out modalities can increase testing.(3) The narratives suggest that perceptions about the testing environment and provider characteristics such as protection of client confidentiality, respect of young people and availability of supportive counseling may influence testing decisions. While these elements are included in the WHO guidelines for provider-initiated testing(3), vigilance in ensuring compliance with the guidelines will be important to maintaining a favorable community-level understanding of testing and not increasing the existing fears around testing identified in the narratives.

In the response to HIV/AIDS, testing in and of itself is rarely a goal. Testing is a means to other ends such as prevention and treatment. However, if testing is seen as merely a step along the way and not given proper consideration, uptake may remain low or the full benefits it can offer may not be accessed. If, in an effort to scale-up treatment, testing is seen as solely diagnostic, this may preclude proper resource allocation to support prevention-related testing outcomes. Particularly among young people, it is important to not sacrifice long term for more short term gains. Understanding the context in which young people are making testing decisions may help achieve the full benefits from testing, independent of the means through which it is delivered – client or provider-initiated.

The content of the narratives and past Scenarios from Africa experience indicate that the young authors may not be aware of what the counseling process entails. This is demonstrated by the high value attached to counseling in many of the narratives but its absence from over half of the testing-themed data. If young people do not know the resources that are available to them during the testing process, they may be less inclined to test. Further, if they are not able to envision what the testing process entails, it may be more difficult to decide to test. Interventions should help young people to understand the testing process.

Increased testing among young people would allow this high-risk group to take advantage of the associated prevention and treatment benefits. The recommendations made in this study for improving public health practice around testing could increase testing among young people and maximize the realization of testing benefits.

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