Chapter 19 The Drive to Take an HIV Test in Rural Uganda: A Risk to Prevention for Young People?



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19.1 Introduction

The effectiveness of recent efforts to scale up universal test and treat (UTT) for HIV to ensure those living with HIV are initiated promptly on antiretroviral treatment (ART), relies on the high uptake of HIV testing (World Health Organization (WHO) 2016). Recent trials and studies of UTT in sub-Saharan Africa have shown modest success in reducing HIV incidence (Iwuji et al. 2018; Abdool Karim 2019; Havlir et al. 2019; Hayes et al. 2019; Havlir et al. 2020), with one longitudinal study in Rakai, Uganda, showing a significant drop in HIV incidence over a 16-year period attributed to HIV combination prevention efforts (Grabowski et al. 2017). Much attention is being focused on those not being tested, and for those who do test and are found to be living with HIV who do not link to care. The missing are often young people, particularly young men (Baisley et al. 2019; Seeley et al. 2019).

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Yet, testing HIV-negative is also an entry point into HIV prevention (Hargreaves et al. 2016; Nall et al. 2019), and with HIV testing being more widely available, repeat testing is encouraged to ensure that people know their HIV status and can seek appropriate prevention and care support (Perkins et al. 2018; Harichund et al. 2019). In this chapter we look at young people's engagement with HIV prevention options and how, why and with what consequences some prioritise HIV testing not as an entry into HIV prevention or care options but as their preferred (and often singular) prevention method.

Evidence from a systematic review of the uptake and positivity rate of HIV testing services among children and adolescents (ages 5–19) indicates that approaches evaluated to date have not been tailored to the needs of this age group (Govindasamy et al. 2015). Rather, they replicate strategies for adults and do not consider the specific barriers that adolescents face (Fox et al. 2013), or indeed the ways in which young people may view testing (Gottert et al. 2018). HIV testing is encouraged as the responsible thing to do, infusing the push for testing with a moral tone (Bond et al. 2016).

In 2018, 2.8 million children and adolescents (aged 0–19 years) were living with HIV, the majority (nearly nine out of 10) in sub-Saharan Africa (UNICEF 2019); three in four new HIV infections in adolescents (aged 15-19 years) occur in sub-Saharan Africa (UNICEF 2017). Concern about the high levels of HIV-infection among young people, particularly adolescent girls, has prompted bodies, such as the President's Emergency Plan for AIDS Relief, to support targeted interventions such as DREAMS (Determined, Resilient, Empowered, AIDS-Free, Mentored, and Safe), providing a broad combination of health, educational and social interventions targeting young women and girls to prevent HIV in ten countries in sub-Saharan Africa (Abdool Karim et al. 2017; Saul et al. 2018). Recent data from three districts in Uganda where DREAMS has been implemented show that male partners of the young women in the programme tested for HIV frequently, often after having had sex for the first time with a partner, or when wishing to stop using condoms, but also as a result of concerns after separating from a partner (Gottert et al. 2018). Interestingly, the authors observe that 'for many men, testing seemed to serve as validation for continuing their practice of having multiple partners' (p. 11)—few respondents in that study described changing their behaviour after receiving a negative HIV-test result.

19.2 Methods

We draw on findings from a qualitative methods study with young people (aged 16–24 years old) living in rural South-West Uganda to explore how HIV testing is situated within their portfolio of HIV prevention strategies. We sought to understand these young people's lived experiences in relation to sexual health practices and knowledge, particularly in relation to perceptions of HIV-risk and patterns of engagement with prevention services. We adopted a longitudinal design, using

repeat waves of data collection over a year, to both capture some of the dynamism of their lives as well as to develop rapport.

Over a month we conducted a rapid participatory assessment of the study site, holding informal discussions with young and older people we encountered in the community, individually and in groups, to inform our approach to recruitment of young people, many of whom had recently moved into the area. We focused primarily on those who had recently arrived into the fieldwork area because it is very common for youth to move to pursue economic opportunities (Barratt et al. 2012), but also included those who had been living within the area for many years and were more familiar with the setting. After this formative stage, we conducted in-depth interviews with 50 young people living in the area, roughly evenly distributed by gender. Our recruitment approach involved approaching young people on the streets in the community and then adopting a snowballing approach, in which they would introduce the researchers to their friends. We followed up 30 of these same young people in a second individual interview approximately 6 months later. Although ideally our tapered sample would have been shaped by emerging analytical interests, given that several of the original sample had left the area and were no longer contactable, recruitment had instead to rely on availability. We invited those participants from the 30 interviewed, still resident in the area, to participatory workshops approximately 6 months later to discuss emerging findings and engage in co-design activities to develop an intervention model to address the concerns identified in the study. Thirteen participants attended. Four workshops were held: with eight young men and five young women.

Research ethics approvals were granted by all relevant institutional and national bodies. Participants were approached and invited to take part by the local research team and asked to provide written consent. Following Uganda National Council for Research and Technology guidance on Human Subjects Research (https://www.uncst.go.ug/guidelines-and-forms/), participants aged 16–17 living independently and providing for themselves financially were considered emancipated minors and able to give their own consent without requiring guardian approval.

We conducted an iterative thematic analysis of our data, discussing the data through weekly meetings during collection. This approach informed ongoing recruitment, sampling and revision of topic guides and formed the basis of analytical memos in which emerging themes were identified and explored. To expedite the data management process, we summarised audio-recorded data into detailed interview scripts in English using a mixture of reported speech and verbatim quotes. Pertinent linguistic phrases, such as idioms, were written verbatim and then translated into English with attention paid to capture their equivalent meaning. The completeness of the scripts was tested by transcribing verbatim some of the interviews and comparing them with draft scripts for detail. Requiring a high degree of training and skill, this is an approach increasingly adopted to facilitate timely analytical attention to emerging data, which can be disrupted by delays in transcription and translation (Bernays et al. 2018; Rutakumwa et al. 2019). Scripts were coded initially using an open-coding approach, then using a coding framework. Coded data were checked against themes identified in the team's ongoing analytical discussions. Emergent themes were

corroborated between the analytical memos and the coding process and discussed by the team to ensure accuracy of representation. These were developed into the key findings.

19.3 Findings and Implications

The young people involved in this study lived in a trading town on the highway leading from Uganda to Tanzania and Rwanda or in the surrounding more rural areas in Kalungu District. The town has been a hub for the sale of produce from the rural areas, and from nearby fishing sites, for many years. Recently a rice farm and processing plant opened on the outskirts of the town, which employs several hundred young people as labourers.

19.3.1 What it Takes to 'Get by': Sex as a Currency

Young people's lives were characterised in many cases by exploitative employment situations, precarious living conditions and meagre incomes. Limited economic opportunities for these youth mean that transactional sex, where sex is used as a resource to be leveraged for material and social gain, has become increasingly normative (Bernays et al. 2020). Such sexual relationships tend to be transient in character, often concurrent and desired not only for their personal and relational pleasure, but also for their economic value. Within the context of these relationships, which are outside of explicitly commercial transactional sex, the acceptability of condom use is virtually nil; shaped by power, individual preference, and stigma associated with condoms. Jane (all names are pseudonyms) explains that should a man find a condom in a girl's house he will call her a 'Malaya' (prostitute). She goes on to describe the logic which disrupts the use of condoms for prevention.

Generally, most young people do not want to abstain, but yet in not abstaining, they do not want to use these condoms they are giving out. In the majority of situations, you can ask him to use it and he says; 'Is a sweet eaten while in its cover?' That is what has caused illnesses among young people here. He or she thinks of what he or she is going to do that time without thinking of the consequences. (Jane, 22 years, IDI-1)

Engaging in unprotected sexual encounters, multiple relationships, and related substance use are described by young people as almost inevitable elements in what it means to be young: something that one must endure to 'get by' in the economic environment. Whilst acknowledging unprotected sex increased exposure to potential pregnancy, HIV and other sexually transmitted infections (STI) acquisition, these risks are 'traded-off' in favour of maximising immediate economic benefits.

It is very easy because if there is someone who has come having money, even if he is an old man these days us girls, we are not selective that that one is older than me. Whether he has given you how much, he does what he wants without you knowing about his status. We do not mind and there you also get infected because of the money you wanted. (Flavia, 17 years old, IDI-2).

It is surrendering oneself, tolerating whatever situation that comes her way in that relationship or whatever hardship she faces. You say whatever comes... when it fails then one gets into another relationship with someone else. (Jane, 22, and Edith, 21, workshop).

Effective HIV prevention, which in this context is to insist on condoms or pursue abstinence, 'costs' because it diminishes the value that can be gained from engaging in this pertinent economy, which is one of only a few available to young people. This extract from an interview summary with Betty illustrates the economic hardship she endured while she abstained, demonstrating that precious few real alternatives exist for the majority.

For the first two years Betty resisted taking up the option of sleeping with a man for financial support but relied singularly on her income as a waitress. This was insufficient to cover her basic needs and she either skipped meals or relied on her colleagues to share their food. Her colleagues encouraged her to adopt their approach and accept a man's proposals, so that she too could have more food to eat, buy herself cosmetics and get a phone. Both her colleagues and the patrons mocked her, asking: 'What are you waiting for? This is the way to survive.' Unable to find any alternatives to supplement her income, Betty now has a partner whom she sleeps with and he gives her money for items, previously beyond her means. (18, IDI-1).

Within a context characterised by risk, HIV is seen as just one of the many risks that they face. Other than financial hardship, young women voiced their desire to avoid unwanted pregnancy. Preventing the latter was their primary concern about unprotected sex, and if able to they used long acting contraception. However, the numbers that did were relatively low, with only two utilising the implant, and one the coil.

As a girl you do not want to get pregnant, at least you get HIV. It is because for HIV it is not seen that you are infected, but the pregnancy grows in front and there they will know that she got pregnant. (Sylvia, 23, IDI-2).

For these young women, accessing family planning and HIV testing services both carry some degree of social stigma. Integrating them into a broader delivery of combination sexual and reproductive health to go beyond a singular focus on HIV would have multiple advantages (Narasimhan et al. 2019). Services need to engage with the contextual drivers of risks to reduce the interconnected harms to which young people are exposed. We may increase the appeal of engaging in HIV prevention if we respond to the perceived risks of young people by targeting their priority concerns alongside HIV.

	HIV test status
Females (n = 15)	13 tested for HIV within the last 6 months 2 tested for HIV more than 6 months ago 0 never tested for HIV
Males (n = 15)	6 tested for HIV within the last 6 months 3 tested for HIV more than 6 months ago 6 never tested for HIV

Table 19.1 Reported HIV testing behaviour of participants (at phase 2, n = 30)

19.3.2 The 'Value' of HIV Testing a As Prevention Method

For young people who had recently migrated, who acknowledged that they might, at times, be at a heightened risk of acquiring HIV, negotiations around sex involve adopting prevention behaviour which did not diminish their opportunities to maximise the value of each sexual encounter or relationship. With condoms continuing to be an unappealing option and Pre-Exposure prophylaxis (PrEP) not widely available nor yet in considerable demand, many young people reported that they relied on HIV testing as their only HIV-prevention strategy (see Table 19.1).

Their engagement in HIV-testing was irregular, infrequent and often poorly timed. For example, young people described going for tests within a few days of having engaged in what they perceived to have been an acutely 'risky' sexual encounter ('The girl I had sex with looked ill'; 'I knew that she had a reputation of being with everyone'). This meant that the tests were commonly performed during the virus window period. Illustrative of this misunderstanding was that some young people berated the poor sensitivity of the locally available tests. Ahmed articulated a commonly held view:

....they (health workers) should ensure that they get machines (testing kits) that can detect the HIV virus immediately after you have contracted it because sometimes we do not have time to go back to the health facility again (23, workshop).

Testing was ordinarily done at the HIV clinic and given the continued social risks from the stigma associated with attending, young people were reticent to go often lest they be seen. Many participants described receiving a negative test result. While this was celebrated as a relief, their interpretation of the implications of these results illuminates a pivotal problem in the drive for people to get HIV-tested.

Testing has the advantage of operating as an entry point to facilitate young people's engagement in a combination of prevention options, such as access to condoms or, if available, PrEP, as well as nurses or counsellors to discuss monogamy and abstinence (Carlos et al. 2016; Starbird et al. 2016). The concerns surrounding sero-discordance within couples, which would threaten the protection of monogamy as a safe sex strategy, were not mentioned as being discussed. However, this relies on utilising the testing opportunity to enable discussion and provide relevant and targeted education. This was not a feature of the participants'

experiences. Baker describes how informal payments were asked for to access explanatory counselling:

...when you reach there they tell you that the counsellor is not around and they ask you for money to give him/her a phone call [...]. He asks you for five thousand shillings, five hundred for beeping the health worker and four thousand five hundred his. And he asks you to wait for a few minutes for the health worker will be around (19, workshop).

Within the narrowing framework of the 95–95-95 global targets, it has been a national and regional trend for thinned resources to be increasingly prioritised towards linking those receiving a positive diagnosis into HIV treatment and care (Wong et al. 2019). Participants themselves observed that the local surge in testing drives had not been accompanied by increased access to HIV-counselling services, rather they reported reductions in the availability of counselling staff.

I think counsellors should increase in number so that they come to the community and teach young people how they can protect themselves (about HIV). Right now, I see that the number of counsellors who used to come has reduced. When I was still young many counsellors used to come and mobilize young people and talk to them (Joshua, 21, IDI-1).

19.3.3 The 'Event' of Testing: Missed Opportunities for Primary Prevention

Testing is a part of a process (Church et al. 2017), yet considerations of the 'before' (what led someone to test) and the 'after' (what the consequences of the result are) which should be addressed in counselling around testing are increasingly been confined to those who receive a positive result. The policy of UTT creates health system pressures to move individuals through the HIV treatment cascade to achieve viral suppression as soon as possible (Witzel et al. 2017). This leaves little space to allow individuals the time they may need to come to terms with committing to a life on treatment (Mitiku et al. 2017; Kawuma et al. 2018; Horter et al. 2020).

Within our study for those who tested negative, the process was truncated into an event, with limited consideration of what provoked the decision to test, nor the after-effects of a negative result on risk exposure. Despite evident interest from the young people to receive pre and post-test counselling, only four (of 24) participants who received a negative test result reported being advised how to remain HIV-negative. Where advice was provided there was very little engagement with the contextual realities of young people's lives. Young people were advised to assume every person is HIV-positive and to use condoms if unable to abstain. The vast majority received nothing. In being shown the door upon receiving a negative result, critical opportunities are missed to respond to the reasons (and risks) that led these young people to get tested. Other studies have demonstrated a desire at a community level to have time for one-to-one discussions about testing options, implications and strategies to mitigate risk (Orne-Gliemann et al. 2016). This is a necessary component to augment the effectiveness of testing as a biomedical technology to encourage people to

engage in and maximise the value of regular HIV testing, alongside ongoing investment in structural interventions which address broader gendered and economic configurations of risk (Malhotra et al. 2019).

Participants often entered the HIV testing facility with low HIV literacy, which explains their inappropriate timing. Critically though they left arguably with heightened risk, as they interpreted their test results as falsely reassuring about the limited risks of their behaviour.

When you test HIV negative you do not go back for testing until you have had another woman because you are negative. You only go for testing after having sex with another woman and you are worried about this one having infected you with HIV (Ahmed, 23, workshop).

This approach to testing may potentially be an unintended consequence of selftesting too, where the linkage to prevention may be overshadowed by the narrow attention to those who need to be connected to care.

In settings of pressurised service delivery, such as resource-constrained areas, haste to embed testing within the treatment cascade risks rendering other essential prevention efforts perimetric. We are at risk of losing hard-won learning about combination prevention (Mannell et al. 2019). The push to meet ambitious targets funnel the care that is offered, which compromises the ability to meet the needs of uninfected young people. Current prevention efforts are failing if they do not engage with young people's concerns (Mulaudzi et al. 2018) and only then after their personal prevention strategies fail, and they have become HIV-positive.

19.3.4 The Moral Performance of Responsibility through Occasional Testing

Young people reported that they commonly relied on their own and their partner's test results, as a form of preventive sero-sorting to justify unprotected sex. Some men relied on their partners' HIV testing results, rather than their own, as their personal prevention strategy. Some attention was paid to recency of the test results; with evidence of negative test results within the last 12 months generally considered an adequate period.

.... You also look at the date when the (HIV) test was done because you may bring a test slip of January and yet we are in December and there I can't trust you. At least you have to show me test results of the testing that was done around August or September (Samuel, 23, IDI-1).

Like a number of other participants, Samuel hinted at the fluidity of the evidential threshold required to satisfy his concerns, explaining that verbal confirmation would have been sufficient. He reported appraising the extent to which the prospective partner's body language indicated her confidence in the results. This was interpreted as a proxy assessment of her 'trustworthiness' and relatedly the authenticity of the test result.

Although the impact of an HIV test on expectations and engagement in prevention behaviours is complex, (Delavande and Kohler 2012) the configuration of this and the consequences of testing are shifting. The acceptability of HIV testing in part remains constrained by poor self-assessment of HIV risk (Corneli et al. 2014), however the shadow of stigma is changing shape as HIV testing among young people is increasingly infused with a moral tone in which it is framed as a 'responsible' act (Lambert et al. 2018) rather than singularly indicative of transgression. Engagement in occasional HIV testing thus constitutes a means to preserve the construction of being 'on the socially acceptable side' of HIV prevention, due to its linkage with an identity of 'responsibility' and positive self-image in the management of relative and occasional risk.

However, despite the commonalities that might be drawn elsewhere, for example in the UK, with PrEP as another strategy of 'responsibilised' HIV prevention, young people perceived there to be an important distinction between the two prevention technologies. The limited discussion that circulated around PrEP suggested that while testing may be perceived as a responsible approach to exercising preventive care, PrEP was perceived to align with ART as being an indicator of HIV. Young people wanted to distance themselves from both PrEP and ART, commensurate with emerging evidence from Kenya and Zimbabwe among the general population (Van der Elst et al. 2013; Gombe et al. 2020; Skovdal et al. this volume). Perceiving that the need to initiate either could be interpreted as a signal of having already 'fallen' and be a marker of individual culpability for engagement in undesirable behaviors.

19.4 Conclusion

The emphasis in global and national policy has been on combination prevention packages in sub-Saharan Africa for the past decade (Grabowski et al. 2017). However, there is a risk that if we observe the confluence of the funding emphasis, which privileges biomedical prevention technologies, and the inhibiting impact of the social landscape on young people's use of condoms, the principle of multiple prevention tools begins to disintegrate. The momentum towards investing in siloed prevention technologies, despite the compelling evidence for the need for integrated, combination prevention, has unintended consequences (Gilbertson et al. 2019). The young people's accounts demonstrate that an unintended consequence of the 'push' for HIV testing may be the justification of its replacement of other behavioural prevention strategies.

If, as in this case study, the uptake of widely available testing serves to justify not using condoms, which is a welcome pathway given that they are unappealing for sensual, social and economic reasons, then this becomes problematic. It is likely that the limited uptake of condoms or abstinence preceded the drive for HIV testing among youth, but its availability with limited counselling serves to erroneously justify infrequent testing as a singular, yet 'responsible', prevention strategy. This case study illustrates what impact such biomedical interventions may have if

implemented as a priority and in isolation from the structural drivers of vulnerability: the social context of young people's lives.

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