

# “I will take ARVs once my body deteriorates”: an analysis of Swazi men’s perceptions and acceptability of Test and Start

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Swaziland has the highest HIV prevalence in the world. To mitigate the spread and devastation caused by HIV and to improve the wellbeing of people living with HIV, the country has adopted the latest available HIV prevention campaigns, including “Test and Start”. Because evidence from randomised controlled trials has demonstrated a significant risk reduction in HIV transmission when HIV-positive people start antiretroviral therapy (ART) early, Swaziland aims to find these people and link them to treatment. This study presents findings regarding the perceptions of this promising HIV-prevention intervention among men aged 17–69 years. A combination of qualitative methods including focus group discussions (12), in-depth interviews (17), informal conversations and participant observation (21) were used to collect data in two peri-urban communities in 2013–2014. Findings illustrate that men still fear taking an HIV test because of a relatively high probability of a positive test which some still interpret as a death sentence. Other potential barriers to the effectiveness of Test and Start programmes include lack of hospitality in hospitals, fear of starting treatment early related to side effects of ART, poverty, and lack of trust in the financial stability of the Swazi government. We argue that several social factors need to be considered for the Test and Start programme to be more effective.

**Keywords:** 90-90-90, ARV, HIV, Swaziland, testing

## Introduction

The strategy known as “Test and Start” has been receiving increasing attention from researchers and policy makers as a promising way to stem the spread of HIV. Based on studies affirming the benefits of early HIV treatment as a prevention method (see, for example, Cohen et al., 2011; Hayes et al., 2015; Hull & Montaner, 2013; WHO, 2012), governments and agencies involved in HIV and AIDS-related activities have adopted the use of antiretroviral therapy (ART) as a fundamental strategy in their HIV prevention programmes. The goal of these strategies is to diagnose people living with HIV by scaling up HIV testing, and by initiating antiretroviral treatment (ART) irrespective of CD4 count. With studies confirming the benefits of starting ART early (INSIGHT START Study Group, 2015; The TEMPRANO ANRS 12136 Study Group, 2015), Test and Start programmes also aim to improve prognosis and the health of people living with HIV. Despite the known benefits of Test and Start, the question of men’s perceptions and acceptance of this strategy, especially in resource-limited settings has not been adequately examined. Part of the reason for the dearth of research in men’s perceptions has been the focus of many HIV programmes on women such as antenatal care, prevention of mother-to-child transmission, Determined, Resilient, Empowered, AIDS-Free, Mentored, and Safe women (DREAMS) among others. This has been largely because Swazi women are biologically, epidemiologically,

and socially more vulnerable to acquiring HIV than men (Ministry of Health, 2017; Whiteside, Hickey, Ngcobo, & Tomlinson, 2003). In response to this, global public health policy makers focusing on HIV prevention in Africa have viewed HIV as a problem largely affecting African women. HIV prevention interventions have thus been to a large extent, and rightly so, designed to focus on them. However, success in combating the spread of HIV calls for inclusive approaches that place both men and women at the centre of all prevention interventions. Men’s low access to HIV testing services (HTS), their poorer health outcomes, higher morbidity and mortality due to HIV/AIDS (Beckham et al., 2016; Johannessen, 2011) has been well documented. This study therefore aimed to address this lacuna in engaging males in HIV programmes.

Despite HIV prevention efforts spanning about three decades now, control of the epidemic is still a challenge. With a 31% prevalence of HIV among the 18–49-year-old age group, Swaziland bears the undesirable distinction of being the country with the highest HIV prevalence in the world (Ministry of Health, 2012, 2017). Key HIV-prevention interventions, such as abstinence, being faithful, using condoms (ABC), voluntary medical male circumcision (VMMC), treatment, and other programmes, have made some fairly substantial progress on HIV mitigation. HIV incidence has dropped from 2.38% in 2011 to 1.39% in 2017 among those aged 18–49 years, and women of the same age group continue to have higher HIV prevalence (32.5%)

than men (20.4%). However, in some cohorts prevalence is worryingly high: it peaks at 54.2% in women aged 35–39 years and 48.8% among males ages 45–49 years (Ministry of Health, 2017). Men have higher morbidity and mortality related to HIV (Beckham et al. 2016; Cornell et al., 2012) primarily because they do not visit health facilities as much as women do, and if they do, it is usually only after they have become very sick (Courtenay, 2000; Schneider et al., 2012; Skovdal et al. 2011; Verbrugge, 1988). The Swaziland HIV Incidence Measurement Survey (Ministry of Health, 2017) has also shown that among those who were diagnosed HIV-positive, 48% of the men were unaware of their status compared to 32% of the women. Men's lower access to health services has put them in a precarious position (Courtenay, 2000) and has caused major setbacks in terms of HIV prevention.

Given that men underutilise HIV services such as testing, they may not be aware of their HIV status and consequently have a higher viral load because they would not be on treatment (Ministry of Health, 2017). This could lead to men having higher chances of unknowingly transmitting HIV to their partners. Realising this, the Government of the Kingdom of Swaziland recently classified men as a key HIV intervention group to decrease the number of new infections (SAN, 2012). VMMC programmes led the way in directly engaging Swazi men in HIV prevention, followed by Test and Start (SAN, 2010). Hayes et al. (2015) assert that the effectiveness of Test and Start depends on uptake of HIV testing, treatment initiation, linkage to care, retention in care and a maintained viral load. They thus called for rigorous empirical studies to determine whether Test and Start programmes can be successfully implemented in practice. Importantly, they argue for the need to investigate the acceptability of the intervention to local communities. This study therefore aimed to investigate how Swazi men perceived Test and Start, and how their perceptions shaped their acceptance of the Test and Start programme.

### The rise of Test and Start

Although HIV treatment was initially designed to reduce HIV-related morbidity and postpone mortality, evidence from the HIV Prevention Trials Network 052 (HPTN 052) randomised controlled trial conducted by Cohen et al. (2011) pointed out that through ART, an HIV-positive person may have a lower viral load in their body fluids thereby reducing illnesses related to HIV and also drastically decreasing chances of infecting others by up to 96%. This finding came after several other studies had highlighted the possible benefit of ART in horizontal HIV prevention (Attia, Egger, Muller, Zwahlen, & Low, 2009; Donnell, et al., 2010). With men's continued sub-optimal access to health services, such as the low uptake of VMMC (Adams & Moyer, 2015) and the mounting evidence of the effectiveness of Test and Start, donors have refocused their efforts and put HIV treatment at the forefront of attempts to halt the spread of the epidemic, which is so far not showing significant signs of dissipating as evidenced by the number of new infections (Ministry of Health, 2017).

Initially, HIV-positive people only started treatment when their CD4 count reached certain levels. The treatment

initiation threshold has been increasing over the years and it started at 200 cells/mm<sup>3</sup> to 350 cells/mm<sup>3</sup> in 2010. In 2013 WHO guidelines called for treatment initiation at 500 cells/mm<sup>3</sup>. Two years after this recommendation, in September 2015, WHO recommended a "treat all" approach to remove the eligibility criterion for all people diagnosed HIV-positive (WHO, 2015). This was based on the above evidence which showed that early use of ART can increase the individual's quality of life and decrease chances of HIV transmission. The WHO recommendation came after Swaziland had already started the Early Access to ART for All (EAAA) studies in the Hhohho and Shiselweni regions by MaxART<sup>1</sup> consortium and Medicines Sans Frontiers (MSF) respectively. Unlike other Test and Start studies, the objectives of the EAAA studies were not to measure the impact of Test and Start on HIV incidence, but to assess the feasibility of implementing the intervention in Swaziland. Beginning in October 2016, Swaziland adopted Test and Start which is linked to the exciting but ambitious Joint United Nations Programme on HIV and AIDS (UNAIDS) strategy of 90-90-90 (UNAIDS, 2014). The 90-90-90 strategy aims to:

- Find and test 90% of all those who are HIV-positive in the whole country.
- 90% of all those who are tested and found to be HIV-positive initiate treatment.
- And 90% of those who are on treatment be virally suppressed by 2020.

Drawing on evidence from ethnographic fieldwork, this study explored Swazi men's perceptions of Test and Start, with a major focus on the first two 90s of the UNAIDS strategy.

### Methods

Data collection for this study was conducted by the lead author in Kwaluseni and Ludzeludze, Swaziland, between May 2013 and July 2014 as part of a larger study that focused on men's uptake of relatively new HIV prevention technologies, namely VMMC and Test and Start. These adjacent communities are peri-urban and are about three to five kilometres from Matsapha, the biggest industrial town in Swaziland. Data were collected in these communities because the MaxART consortium was implementing male-focused health days in Ludzeludze and the only men's health clinic in the country is less than a kilometre away from Kwaluseni. For the first 6 months data were collected in Kwaluseni and 6 more months were spent in Ludzeludze. The final stages of data collection, which lasted 2 months, were spent in Kwaluseni. All data were collected by the lead author, a Swazi man who shared the same language, gender and was the average age of the participants.

Using siSwati as the main language, a combination of qualitative methods, including informal interviews and participant observation, focus group discussions (FGDs), and in-depth interviews were conducted. In total, 17 in-depth interviews and 12 FGDs were conducted. Sixteen of the informal interviews were with people who had participated in FGDs and in-depth interviews and 5 were with new participants, making a total of 76 participants in this study. The focus groups were also a platform to recruit clients for in-depth and informal interviews. Both FGDs

and in-depth interviews were audio recorded and informal interviews were recorded as field notes. A convenience sample of participants of men aged 17–69 years old living in the study areas and FGD participants were purposively sampled. All adult male participants living in the study areas were eligible to be part of the study. HIV status was not considered when recruiting for this study, but those who revealed their HIV-positive status during data collection were given additional attention due to their scarcity during data collection. Six participants revealed their HIV-positive status while 23 claimed to be HIV-negative. The rest stated that they were unaware or unsure since they had never taken an HIV test or had not taken an HIV test in the previous year. Participants were mostly unemployed men who hung around the community, but some were educated such as lecturers, teachers and graduate students who were unemployed.

### **Focus group discussions**

To generate more themes and to get a broader sense of the participants' perceptions towards the issues being studied, we opted for FGDs as the first method of data collection. This was the main method of data collection for the first 2 weeks and was conducted using an interview guide. This setup allowed for several themes to be identified during ongoing data analysis. Older males were separated from younger ones to ensure they were comfortable when making their contributions. FGDs normally consisted of between 3 and 8 men, with a total of 59 men participating in FGDs. Each FGD lasted between 25 and 90 minutes, with an average of about 1 hour 15 minutes. In total, 12 FGDs were conducted.

### **In-depth interviews**

In total, 17 in-depth interviews were conducted using an interview guide modified from the FGDs. The in-depth interviews had a more structured interview guide than the other methods, with key themes already developed from FGDs. Virtually the same questions were asked in FGDs and in-depth interviews although there were more probes during in-depth interviews. Some interviews would last as long as 2 hours and some were as brief as 30 minutes and the average was about 1 hour. Compared to informal conversations, in-depth interviews were held in a relatively quiet area to allow for clear recording and privacy for the participants. Usually, participants chose a comfortable spot for the interviews to take place.

### **Participant observation and informal interviews**

As a principal ethnographic technique, participant observation and informal interviews formed the backbone of data collection with 21 interviews. These ran concurrently with FGDs and in-depth interviews. Field notes were used to record conversations from informal interviews and participant observation. A fly-on-the-wall approach or "deep hanging out" (Geertz, 1998) was used when collecting data from informal interviews and participant observation. When gaining entry in the community, the lead author identified himself as a researcher. However, as time passed by the lead author, a 30-year-old Swazi male, participated in the daily lives of the men in both communities. This was done by hanging out with them in various places, such as markets,

car washes, football pitches, bars, and *sheebens* (informal bars normally found in townships). Spending time in such everyday activities improved rapport and enabled the lead author to be part of conversations which otherwise would be closed off to a stranger. Sensitive information about HIV status, sexually transmitted infections, sexuality, financial matters, and other private matters was obtained through participant observation and informal conversations. These data were recorded in a notebook later and relevant information was then transcribed from informal interviews and written as field notes from participant observation. In some cases, such observation included participants who had participated in FGDs or in-depth interviews, and others who had not. None of the information gathered using this approach was taped and participants were later asked for consent. All the participants gave the lead author permission to use the data partly because their names were not used.

Most of the men in this study were unemployed and spent time in the places mentioned. After long sessions such as FGDs, soft drinks and a snack of buns would be provided as a token of appreciation. Forming an FGD required some coordination because a time and location had to be set, and some of the men had to halt their daily chores to attend. Sharing a bit of food afterwards led, in some cases, to further discussions about the topics from the FGDs and at this time even those participants who were less vocal during the FGD would express themselves freely. A *braai* (barbecue) would often be followed by cold beers and further discussions among the initial FGD participants and other men who later joined in, forming a natural group that discussed relevant topics for the study. These kinds of discussions added the depth and richness of the data because of "naturalism" (Green & Thorogood, 2004). Although the lead author did not belong to the community, he blended fairly easily in these conversations because of his age, gender, language and nationality. Much of our insight emerged from conversations, jokes, and arguments in naturally-occurring groups. In these discussions, issues related to HIV such as testing, antiretrovirals (ARVs), VMMC, and other health-related topics were jotted down. These constituted the bulk of the field notes.

### **Data analysis**

Data were transcribed from siSwati mixed with *siTsotsi* (local slang) to English after listening to the recordings twice to increase accuracy, especially in recordings with low audio quality, and uploaded into QSR International NVIVO 10.0 by the lead author. Codes were defined in the early stages of data analysis and this was done inductively by the lead author. Data were analysed manually by both authors together using thematic content analysis. The findings were also organised according to recurrent themes that emerged from data analysis. Data analysis was guided by data and not by a prior hypothesis meaning our data analysis approach drew on grounded theory principles (Green & Thorogood, 2004). In an iterative process: data analysis was done alongside data collection until saturation and this explains why there was no pre-determined sample size for the study. Saturation was determined when the same themes were recurring and the researchers felt there enough data had been collected to answer the research questions.

### **Ethical considerations**

This study received ethical clearance from the Swaziland Scientific and Ethics Committee and the University of Amsterdam. The first author had been trained in human subjects' protection previously when working for Icap at the Columbia University Mailman School of Public Health. Before FGDs and in-depth interviews commenced, an informed consent process was started by the lead author, in which he first explained the details of the study, then read the informed consent form aloud. After permission was granted through verbal consent, interviews would commence. For informal interviews, consent was sought after data collection, as already explained. Transcribed data was stored on a laptop disk encrypted with a password and the lead author had exclusive access. To maximise participants' confidentiality, none of their real names appeared on the transcripts.

### **Limitations of the study**

The intrinsic aim of ethnographic studies is to provide an in-depth emic perspective of the problem being studied. To increase internal validity, three data collection techniques were used to triangulate findings. The major disadvantage of this methodology is its lack of focus on the generalisability of study findings. In this study, like most ethnographic studies, this is largely due to the small sample size that may not be representative of the population being studied. This therefore means that the findings of this study may not be generalised to the wider population of Swaziland, but instead offer a "thick description" of the participants' perspectives. Another limitation is that this study lacks a perspective from women since all participants were men. Additionally, Test and Start is for HIV-positive people and most participants in this study were unaware of their HIV status. The findings therefore should be interpreted in that context.

### **Findings**

The findings are presented using the UNAIDS 90-90-90 framework and focus is on the first two 90s; finding and testing 90% of those living with HIV and initiating the 90% on treatment. The process in Test and Start begins with finding those who are HIV-positive and diagnosing them. Linkage to care, treatment initiation and viral suppression come after this crucial and seemingly difficult step. The findings are therefore presented in this fashion.

#### **90% of all people living with HIV should be aware of their status — "The guilty are afraid": reasons for not taking an HIV test**

Due to the very high HIV prevalence in the country and its impact being widely covered in the media and social spaces, participants feared that chances were high for a positive HIV test result. Although participants generally agreed that ART, casually called *phinduvuke* (rise again) in local slang, is effective and can prolong life, they still referred to HIV as being a fatal disease. This emanates from the portrayal of HIV in the country during the earlier decades of the epidemic as a deadly disease. In the media, HIV used to be called *umbulalave* (nation killer) and, mirroring

this media representation of the virus, participants referred to it as *silwane* (animal). During an informal interview, one 29-year-old man said: "*Once you know your HIV status, then problems will start. It will be difficult to have long-term goals because you will be facing an inevitable death*".

In the same vein, a 30-year-old man during an in-depth interview said: "*The fact that there is no cure means you will be killed by HIV unless you are maybe involved in an accident*".

Although acknowledging the similarity between HIV and illnesses like cancer, which also does not have a cure, some of the interviewees' conviction that HIV is a death sentence contrasted sharply with their views regarding other terminal illnesses. A 39-year-old interviewee explained during an in-depth interview:

*You know, just like cancer, HIV has no cure and that means it will kill you. Actually cancer is better because there are cancer survivors and ever since HIV came, there has been no survivor. Some live for a long time but we have buried many of our young relatives and friends because of HIV. No one has ever survived HIV so if you have it you are doomed because it will kill you one day. A positive HIV test is a death sentence, which is in some cases postponed if you have strong soldiers [CD4].*

The apprehension regarding HIV testing is heightened by the belief held by many that they could be HIV-positive given the high prevalence of HIV in the country and high number of deaths related to HIV/AIDS, especially in the last two decades. Despite ART being available for over a decade in Swaziland, many people Swazis have died in the past due to HIV/AIDS related illnesses and participants argued that many of their friends and relatives died from AIDS while treatment was available. Participants felt that the high prevalence of HIV makes it more likely to be engaged in sexual activities with an infected person. As a 29-year-old interviewee put it during an informal interview: "*The guilty are afraid my brother. Most of us have had unprotected sex before and the way HIV is so prevalent in this country, it increases your chances of sleeping with someone who has HIV*".

Participants argued that things have changed and they are no longer in control of their partners' sexualities. They argued that being unemployed and poor put them at risk of contracting HIV from women, and not the other way around. This "masculinity in crisis" talk was very prevalent because of the high unemployment rate among the participants and women's increasing involvement in employment. The study areas were a few kilometres away from the biggest industrial town in Swaziland, Matsapha, where there are textile industries. These industries barely pay the legal minimal wage and most of their employees are women. Participants argued that women may meet other men at work or sleep with richer men for money, and they feared that they may get HIV from their women in this way. An unemployed 39-year-old interviewee aptly stated during an FGD:

*You would be fooling yourself by believing that your partner is not having sex with other men. Some of us cannot support them financially and women love money, that is a fact. They want cell-phones, airtime, eating out, new clothes, and cars... So if you cannot give them what they want they will get it elsewhere.*

This belief was common, and some of the men argued that the only way to “bring their women to order” was by beating them if they did not want to listen. This was a challenge to the participants because most define a “real Swazi man” as someone who has a wife, children, and a home and is able to support them. The bread winning role is expected by society to be played by the man and not the woman. If a man fails to do this then he is seen as a weak man and not respected by other men and women.

### 90% of people living with HIV will be on treatment

#### **“The nurses treat you like you are a nobody” — poor hospitality in public health facilities**

Most of the participants argued that there is no hospitality in public hospitals, which is where they can afford to go. These public health facilities are the only place where they can get ART. Participants argued that hospitals are not spaces designed for men and that long queues were also a major factor in keeping them away. They argued that they hardly feel comfortable when visiting health centres because of ill-treatment from staff and that they normally find women and children there. During an in-depth interview a participant summed up the behaviour of nurses in these facilities as follows:

*The nurses there treat you like you are a nobody. They do not even respect the fact that you are sick and you are in pain. It's like they do not care whether you receive care at the end of the day. They just want to report how many patients they have seen but not how those patients have been helped. I have had enough of these pompous nurses.*

Participants often claimed that nurses were very unfriendly and showed them no respect, a quality that Swazis hold in high regard (Booth, 2003). A 42-year-old man during an FGD said:

*It seems like those nurses do not like their job. I understand that there are long queues but they should at least respect patients, especially old people. One time I had a genital problem and a young female nurse of foreign origin just told me to take off my pants without even greeting me or even explaining what was going to happen. She treated me like a dumb child. I really did not like her attitude.*

Participants said that the health care they received from these hospitals was worse than the care they received from traditional healers. In fact, they argued that traditional healers are similar to private practitioners because there is privacy and they are given time to express their health and social problems and receive adequate care.

#### **Exposure and stigma — social consequences of accessing ART services**

We found that the seemingly never subsiding presence of stigma was a major barrier to participants' uptake of ART. This ranged from self-stigma to the physical setup of health centres, and the geographical and cultural homogeneity of the context that could easily expose HIV patients. In an informal conversation, a former nurse who declared his HIV status argued that Swaziland was too small and that he knew almost everyone in the health care sector: “I only refill my medication in Piet Retief because no one knows

*me there. I have worked in the Swazi health sector for more than 15 years so everybody knows me here”.*

He feared that if he went to the local healthcare facilities he would be exposed as being HIV-positive. He therefore preferred to drive all the way to Piet Retief, a small town near the Swaziland–South Africa border. The small geographic and demographic size of the country, coupled with the country's cultural homogeneity, make it easy for Swazis to know each other. Participants argued that this would expose illnesses such as HIV that they would prefer to keep confidential due to stigma. As a 41-year-old participant said during an FGD: “If you go to the local clinic you may find that the people working there are your former schoolmates, and those clinic workers now stay in the community and they know us. That is why if I want to refill my tablets I go to Mbabane”.

In addition, participants argued that the structural design of the clinic also exposed their status because rooms were clearly designated for specific illness, including HIV. Swaziland's HIV services are largely shaped by donors who invested in infrastructure with the aim of improving HIV services. In some clinics, donors have donated clinics in a box specifically for HIV services and these are normally stationed next to the main clinic. This then makes the HIV department a separate structure and, according to the participants, this is likely to expose them and compromise confidentiality. A 34-year-old FGD participant said: “There is no confidentiality in these clinics. If you go to the white rooms opposite the [main] clinic, then everybody knows you are going there to get HIV treatment”.

They also argued that in big clinics and hospitals, queues are divided according to the type of illness. A 28-year-old FGD participant stated:

*The nurse at the clinic shouts out loud and says, 'All those suffering from skin illnesses form a line here, all those suffering from sexually transmitted infections form a line here', and she goes on and on ordering people to stand in designated queues. This is very embarrassing, I tell you, and especially if you would see someone you know in that hospital.*

Some of the clients went as far as accusing healthcare workers of lacking confidentiality about their illnesses. They argued that their files, which bear their names and HIV status, are kept unsecured in the clinic offices and anyone working there could have access to the information.

#### **Concerns about early initiation of ART**

Participants had concerns about taking treatment while feeling healthy. They argued that taking treatment may require them to purchase certain foods (to “live a healthy life”), which they argued that they could not afford on a daily basis. They also raised concerns about side effects, damage to the liver, and drug resistance. Other concerns included having to drop habits such as drinking and smoking. During an informal conversation, following an FGD with a group of men, a 44-year-old HIV-positive man said the following:

*My only problem is that once I start treatment I would have side effects. For now, very few people know that I am sick. When they check my soldiers [CD4 count] they tell me I am not eligible for treatment, and I also feel very strong. My cousin who I stay with is on pre-ART [primary prophylaxis] and he always*

*complains about how bad the drugs affect him. I prefer to eat healthy, exercise, and live positively. I will take ARVs once my body deteriorates so that I can regain my strength...*

A 24-year-old male during an FGD said:

*They say you have to eat healthy when taking ARVs. I can barely afford to buy a healthy meal right now. So if for example they say I am HIV positive right now and have to swallow ARVs for the rest of my life, where will I get all that money from? Imagine I have to buy fruits, vegetables and meat every day?*

Participants who were unaware of their HIV status stated that quitting habits such as drinking and smoking may be very difficult, especially when taking treatment to protect another person. They were concerned that pills in general do not mix well with alcohol and taking ART would mean quitting their lifestyle, even though they would still be very healthy and fit.

### **HIV conspiratorial theories and lack of trust in commitment and financial capacity of the Swazi Government**

The notion that HIV is man-made was found to be a common belief among our participants, especially the older ones. Participants argued that HIV was a way of reducing the black population and this was based on the fact that blacks all over the world are disproportionately infected by HIV (Adams & Moyer, 2015; Castle, 2003; Fassin, Jacobs, & Varro, 2007). During an in-depth interview a participant stated:

*You yourself [meaning the lead author] know very well that HIV was created in laboratories in America or Europe. Ebola was also created by whites and these deadly diseases were designed to kill us Africans. You will never hear of such a deadly and contagious disease affecting the West. Never.*

Another 39-year-old FGD interviewee expressed his conviction that HIV is man-made:

*Africa is a rich continent and whites have always been interested in this continent and that is why they colonised us. They want our minerals and now that Africans are being clever and educated they cannot colonise us so they want to colonise us in another form. They want to put us on treatment so that we rely on them and then they will regain their control over us. They know that once you are on treatment you will be dependent on them forever.*

Participants frequently cited historical events, where black people were killed by whites such as during apartheid in neighbouring South Africa. They backed their arguments by highlighting that even in Africa, whites are rarely infected by the virus. They further argued that early treatment would be a way of controlling Africans because ART is manufactured in the West.

Our participants stated that if people were to start treatment early then more people would have to be supported by government to get free drugs. They raised concerns about the Swazi government's financial capacity to sustainably procure and provide free HIV treatment:

*I have heard many times that ARVs have run out in the country. Imagine then that all those who are HIV positive are on treatment. What will happen to*

*all those people when the government cannot buy drugs for the people? There are no guarantees that the Swazi government's finances have improved. This may happen again in the near future.*

The above excerpt came from a 22-year-old participant during an in-depth interview. He claimed that his uncle, who had taken care of his school fees, had died because he stopped taking his HIV medication for other reasons. He clearly understood the benefit of being on treatment but was also concerned about the consequences when one stopped taking ART. A 30-year-old man who worked as a locum counsellor in one of the clinics in Manzini raised concerns about the availability of ART in the country during an in-depth interview, saying:

*So if they increase the number of people on ART will we have enough money as a country to buy more drugs? They are already struggling with buying a simple drug such as panado [paracetamol]. Sometimes they even do not have money to pay civil servants. So do you think they can be able to buy these drugs until all the people who are on ART die? They are busy buying expensive cars yet they cannot pay people's salaries. Unfortunately our government is selfish and does not care about the people, especially the poor ones. They are busy building expensive airports while we are hungry. The airports will only benefit them and their friends because they can afford to buy an air ticket. I cannot even afford to buy a decent meal right now.*

The Government of Swaziland has faced serious financial problems in the last few years. At the same time, unconnected to these financial problems, crucial drugs such as ARVs and HIV test kits have been out of stock in the country. The *Times of Swaziland* has published articles noting the shortage of ARVs in the country (Infocentre, 2015). Participants were concerned about a situation in which all HIV-positive people would be put on ART and then government might fail to keep on providing ARVs for those who are on treatment.

### **Discussion**

This study sought to examine how Swazi men perceived Test and Start, and how their perceptions would potentially affect their acceptance of the Test and Start programmes. As far as we know, this is the first in-depth study focusing on Swazi men and their perceptions on Test and Start. Most of the issues discussed in this study can be considered as sensitive and our ethnographic approach may have increased the internal validity and could possibly inform future larger studies. Our ethnographic methods may have also helped in the ground-breaking findings, which as far as we know have never been reported in this context. This then makes our study timely and important, especially for HIV programmes in Swaziland and beyond. Analysis of the social and cultural factors that shape men's perceptions regarding these programmes is consistent with claims by some scholars that, although Test and Start is one of the most promising HIV-prevention technologies available and that its efficacy at the randomised control trial level is astounding (Cohen et al., 2011), balancing science

and the social realities on the ground may be a complex process (Walach, Falkenberg, Fonnebo, Lewith, & Jonas, 2006; Wilson, Fraser-Hurt & Gorgens, 2014; Zachariah, et al., 2010). Our analysis has highlighted several social barriers that may need to be addressed for this promising HIV-prevention technology to have a positive impact on the ground. Most of the barriers discussed do not necessarily affect Test and Start alone but Swazi men's uptake of health services in general. Wilson et al. (2014) argue that Test and Start may face challenges with HIV diagnosis, ART initiation, ART adherence and retention in care, and ART-related drug resistance if enrolled for long periods of time.

Findings in this study illustrate that men's limited participation in HIV testing, poor hospitality in public health facilities, fear of stigma, fears of early initiation of ART related to poverty and side effects, and lack of trust in the financial stability of the Swazi government pose a serious threat to this technology being implemented effectively. The participants' perception of the quality of health services, which can potentially have an impact on the uptake of HIV-related programmes, was found to be poor. In addition, the fact that women and children usually visit health facilities men felt that they were not catered for in health settings and this was exacerbated by the poor hospitality from nurses. This finding is consistent with findings from studies that have identified the behaviour of healthcare workers as a major barrier to accessing healthcare services (see, for instance, Zamberia, 2011). Although our finding about participants' beliefs about the nature and origins of HIV may not be ground-breaking, as other social scientists have confirmed similar beliefs in other contexts, this analysis has demonstrated the persistence of these beliefs, and serves to emphasise the fact that the limited flow of knowledge from grassroots levels and localities adversely affects global public health programmes such as Test and Start. Feerman, Kleinman, Stewart, Farmer, and Das (2010, p. 123) argue that: "They [anthropologists] are able to elucidate how medical interventions are experienced by those with little power...Unfortunately, inequalities in power and influence serve to obstruct the flow of information from local realities to global actions."

Men's poor health has long been documented. However, from a programmatic perspective, this issue is arguably not being adequately addressed. Harrison (1978) published a paper in which he clearly pointed out the negative effects of men's socialisation on their own health and their reluctance to use health services. Clatterbaugh (1997) argues that as men participate in the construction of powerful masculinities and patriarchies, they often place themselves in a disadvantaged position when it comes to healthcare access. Views of men and their behaviours associated with hegemonic masculinities can therefore be deeply restrictive to both men and women. From their study conducted in Zimbabwe, Skovdal et al. (2011) conclude that men's fear of being diagnosed with HIV led them to avoid or delay accessing HIV testing services. In this study, participants feared taking an HIV test, especially while feeling healthy due to the relatively high chances of positive test results. This statement highlights the limitations of HIV and AIDS prevention and control messages in striking a balance between discouraging risky behaviour and presenting HIV

as a manageable condition. Without reassurance of survival after diagnosis and the stigma associated with HIV/AIDS, many individuals find HIV testing daunting.

In contrast, more programmes aim to empower women, as is evident in the intensification of "behaviour change" and women's-empowerment programmes. Because men are for the most part seen as the problem, "gender and health" is only perceived as "women's health" (Bates, Hankivsky & Springer 2009). In fact, "development" is synonymous with women's empowerment, as Millennium Development Goal number four aims to "promote gender equality and empower women" (UNDESA 2008). The limited focus on men's health has not been very helpful in controlling the spread of HIV because men continue to underutilise HIV services and consequently infect their partners due to their high viral load.

Test and Start offers a substantial promise for HIV prevention but it also faces several challenges, most of which are social. At the 21st International AIDS Conference in July 2016, Dr Francois Dabis reported that they found no impact on HIV incidence in their randomised control trial which aimed to evaluate the effect of early ART, initiated irrespective of CD4 count criteria, on HIV incidence in the general population in the same setting (Iwuji et al., 2016). One of the key explanations for the results was "suboptimal linkages" to care. Our findings suggest that an interdisciplinary approach may be required to successfully combat the spread of HIV. No matter how much biomedicine may advance in developing effective HIV-prevention technologies such as Test and Start, understanding health-seeking behaviour and navigating the health system in each context is important.

## Conclusion

Technological advancements in HIV prevention suggest this a defining moment in combatting the disease. Like most cutting-edge health interventions, Test and Start faces social and cultural complexities that may need to be considered in its implementation. This study has shown that a focus on men can provide valuable understandings of men's health and, in this way, offer insights into factors that HIV-related agencies need to consider as they explore how to effectively implement such programmes. Investing in health interventions that target barriers to HIV testing and incorporate an understanding of the socio-cultural context within which these interventions are implemented is therefore imperative.

This paper has discussed a range of social factors that constitute barriers to the successful implementation of Test and Start. As far as we know, this is the first ethnographic study that has explored Swazi men's perspectives in relation to the uptake of Test and Start. This study therefore addresses an important lacuna in HIV prevention in the country. Based on our findings, we recommend interventions that aim to empower men through HIV education and focus on messaging that can help alleviate fears of death due to HIV/AIDS. Early access to ART despite CD4 count is relatively new and people who hardly visit health centres like men need to be targeted in their spaces so that they can potentially agree to take an HIV test and be linked to care and treatment.

## Note

- <sup>1</sup> MaxART stands for maximising ART for better health and zero new HIV infections. This early access to ART for all (EAAA) demonstration study was funded by the Dutch Postcode Lottery.

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