Breaking the Cycle of Transmission:

Improving uptake of prevention, testing and linkage to treatment among young men in South Africa

Hearing from men in their own words...
The goal: Support South African stakeholders in finding ways to reach more young men

How can we better understand young men’s decisions and behaviours around HIV testing, prevention and treatment?

How can we identify different segments of young men to enable better tailoring/targeting?

How can we reach each segment more effectively with HIV prevention, testing and treatment?
Study design

**Geographic focus**
- 5 districts of KwaZulu-Natal
- 3 districts of Mpumalanga

**Methods and sampling**

**Qualitative phase**
(n=76 men aged 25-34, 67 providers)
- Targeted sample to achieve mix of HIV-positive (linked and not linked) and HIV-negative
- Ethnographic shadowing and in-depth interviews

**Quantitative phase**
(n=2019 men aged 20-34)
- Random sample / enumerated area sampling
- One-hour tablet-based survey

**Design phase**
(n=60 men aged 20-34)
- Three-day design workshop

All phases carried out by trained interviewers from similar demographics in the respondents’ preferred language
What men told us about HIV
They may wear a mask of indifference, but underneath it many are deeply afraid.

When I first heard of HIV it was the scariest disease that anyone can think of, it was even scarier than cancer. - Man, 25, frequent tester

I was terrified. I was not ashamed or embarrassed, I was just terrified. - Man, 28, infrequent tester

I don't trust myself. I'm so scared. I think I will test positive. It will just kill me. - Man, 30, never tested

[Testing] was tough, really tough. I actually felt like I was in a dark forest. I was numb with fear, I can’t lie to you. Until the sister said that I am negative, that is when I was free. - Man, 28, frequent tester

I'm scared. I started with my girlfriend last August and if I were to test HIV+ she would just kill herself. - Man, 31, never tested

HIV is an animal which lives inside of someone and eats away at them. - Man, 25, never tested
I lost people who died from AIDS. I’ve only just realised now that my mother died from an illness and I believe it was not just TB, it was AIDS. My uncle also died with exactly the same illness as my mum. I think he also died of AIDS...I think the family were trying to hide it from us.
- Man, 28, never tested

My father died of HIV. It really devastated me. I was very close to him.
- Man, 27, HIV+, not linked

All of my immediate family are all dead. My mom, my dad, and my brother all died. I am the only one still living.
- Man, 32, infrequent tester

He is an orphan because both parents died. When I tried to talk to him, he said to me ‘like father, like son’.
- Nurse

Many carry unprocessed HIV-related grief and trauma from childhood.
They aspire to traditional masculine roles but often feel prevented from fulfilling them.

Men should provide, they should take responsibility for people near them...It is important for a male figure to take responsibilities, to be a provider in our homes” - Man, 30

My girlfriend cleans a hotel. It is embarrassing... Sometimes it feels like what I have to say doesn't matter, like I don't have a voice. I haven't always been unemployed, but things changed...When she got a job, I saw for myself that my role was no more. - Man, 28, HIV+, not linked

It is not a good feeling when only the mother has a good job. There are things that are needed and I can’t contribute fully. She always contributes and that does not sit well with me. I sometimes have thoughts where I feel I am not man enough... - Man, 30, infrequent tester

I often feel sad, it is because of this situation of being unemployed... Sometimes I go smoke dagga with my friends and maybe get a beer or two, get drunk and go to my girlfriend. - Man, 34
Traditional masculine norms can impede health-seeking.

Men don’t take men who take medication or tablets every day seriously. There is a mindset that men are naturally strong.  
- Man, 26, infrequent tester

I do not take medication at all right now, I fear medication. When I have a cold, I struggle to finish my medication. I need reminders until I get used to it. I am battling by myself – if I give in to the pills will I be able to take them daily?  
- Man, 27, HIV+, not linked

Men are scared to know their status, they assume that if they are positive, they no longer have a future and people won’t respect them in the community.  
- Man, 27, HIV+, not linked

You will lose respect if you continuously ask for help.  
- Man, 25, never tested

Men here at the taxi rank love to make fun of each other and people who are taking ARVs.  
- Man, 30, never tested
Traditional masculine norms can also impede risk reduction.

It is the women who go and test and they come and tell me they are clean, so that also means I am clean.  
- Man, 25, never tested

They say you are not a guy unless you have at least six girlfriends.  
- Man, 25, never tested

Lindo goes to the clinics for check-ups. She’s the one who tells me whether we are OK or not.  
- Man, 28, never tested

There is a lot of peer pressure [to have multiple girlfriends.] Like when chilling with the guys one would ask when did you last have sex or how many girlfriends do you have, then you start feeling like having one girlfriend is not cool.  
- Man, 30
Many men engage in high-risk behaviours that they misunderstand or rationalize.

If I have sex with someone then I think I won’t get sick if she is beautiful. I can tell the difference between a sickly person and one who is not sick. I just look at the person’s eyes and I tell my friend ‘You are going to die there, don’t go there.’ - Man, 27, never tested

Her lifestyle choices show me I can trust her. - Man, 34, never tested

I didn’t trust this girl; she was all the way from Nelspruit and would come by to visit every now and then. She was also very skinny.
- Man, 27, frequent tester

Maybe I use condoms on six of them but the other four they are too sexy. - Man, 34, never tested
Few men have someone they feel they can really talk to.

There is nobody that I talk to about HIV, not even with my own mother. I think I am shy to bring it up and I think it’s a scary topic. - Man, 26, infrequent tester

Men in community do talk about HIV but they talk about it jokingly not in a serious conversation. - Man, 30, never tested

I don’t talk to anyone about HIV and it’s not something that I like to talk about even though I put myself at risk every day. - Man, 28, never tested

I've only been able to tell one person since 2011. One of my brothers, and he laughed. He doesn't believe me, but he knows. My friends are not very mature, and they make fun of people, so I can't tell them. I'm a secretive person. I believe that my problems are mine and I shouldn't burden others with them. - Man, 27, HIV+, not linked

I'm very close to my mother...I've tried to tell her many times, but I look at her face and she looks stressed and I then can't tell her. - Man, 27, HIV+, not linked
I would be worried if they tell me that I am indeed positive, then it will be game over. I will no longer be [Thabo].
Man, 30, never tested

They say that once you get the news that you are positive, you die quickly.
- Man, 27

They also told me not to take [my pills] with any Zulu traditional drinks, I must take them on their own. When I was told that I was a little heart sore because I am a traditionalist.
- Man, 34

When I think of HIV I think of an early grave. After that my mind comes back to the fact that there are pills for this illness, but that comes as an after thought.
- Man, aged 30, frequent tester

I didn’t know what happens after they find out that you have HIV and I felt like I would get even more sick once I knew I have HIV.
- Man, 34, HIV+, linked

Testing positive can feel like life is over.
Disclosure and its consequences are the #1 fear.

[The counselor] asked me if I tested positive, would I tell my partner or keep quiet. I said I would have to tell them and if I chose not to, I would break up with them so they don't find out my status. - Man, 27, HIV+ not linked

I tried telling my mom [about having HIV] but I couldn’t go through with it. She believes in me and I didn’t want to lose that. I’ve seen this happen to other people and I didn’t what it for myself. - Man, 26

I’d ask myself: how should I tell her? How should I tell her that she should go for a HIV test? Because I know that I might have got this virus from somebody else. A person you love cannot be thought of as a cleaning rag. - Man, 30

When I hear HIV I think of death and the way I will be perceived in society if I have the disease. - Man, 25, never tested
Loss of personal autonomy and a sense of control can also feel threatening.

I walked to the [VMMC] center in a great mood, not even thinking I'll be tested when I'm there. When I got there, they said I must be tested, my mood changed. I wanted to turn back, but I was already there!...When she told me I was positive I was shattered into pieces.
- Man, 27, HIV+, not linked

They are so difficult, especially the ones that are referred... They come here and tell you "I am not here for an HIV test." ...Some are positive then they default because they say they were not at the clinic for that.
- Nurse

I don’t like the fact that when I go in for a headache the nurse will ask me when I last tested for HIV and now I will be compelled to test even though that’s not what I came in for.
- Man, 30, infrequent tester
Clinics can be unfamiliar, unpleasant, inconvenient and lacking in privacy.

The thought of going to the clinic scares me. I would be embarrassed and might meet people I know there. My status would not be confidential, I'm full of doubt and procrastination. - Man, 27, HIV+, not linked

Men are afraid of going to the clinic, they say they get shouted at. - Man, 34

The nurses are female most of the time so that makes one a bit uncomfortable. There is also the fear that if you go to a clinic near you then people will know your business. - Man, 26, infrequent tester

A lot of people hate the idea of sitting around at the clinic in the queues and hate the fact that their friends might see them there...If they see you there, they start to gossip” - Man, 34

The queues at the clinic is the reason men don't like going there. Men don't have time to sit there. - Man, 32
The benefits of early testing and treatment are poorly understood or not compelling.

**Why? I'm not sick. My body shape has not changed, I am not losing or gaining weight.**
- Man, 25, HIV+, not linked

**I went home and I was over thinking about it, but then I thought I'm okay, I'm healthy and everything is normal, so I just kept it all to myself.**
- Man, 27, HIV+, not linked

**No one has ever explained the need to test to me.**
- Man, 28, never tested
Despite all the barriers, there are signs of hope.

*Having HIV is not the end, it's the beginning. It's a new challenge for how to treat yourself.*

- Man, 32, HIV+, linked
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