

# Understanding barriers to HIV testing and treatment:

a study of young men and healthcare providers in KwaZulu-Natal and Mpumalanga

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Several personal, cultural and social issues inhibit men's HIV testing and treatment-seeking. Healthcare providers also face many difficulties in providing these services to men.

In South Africa, men experience worse HIV-related outcomes than women. It is estimated that seventy-eight per cent of men living with HIV know that they are HIV-positive, versus 89% of women. Sixty-seven per cent of men who have been confirmed as HIV-positive are on treatment, compared with 72% of women. Research is needed to understand the dynamics of this disparity and to design interventions to close the gap.

This qualitative study aimed to describe both men's experience accessing HIV services and the experience of healthcare providers delivering such services in order to understand why men at risk often do not test for HIV or initiate treatment after testing positive. Fifty-eight black South African men were interviewed: the respondents were from KwaZulu-Natal and Mpumalanga, aged 25 - 34 years, sexually active, and had not undergone voluntary medical male circumcision. Sixty-four healthcare providers working in public or non-governmental organisation clinics in the same provinces were also interviewed; each interviewer had at least five years' experience testing and treating men. The interviews were analysed thematically.

Many men live in an environment of uncertainty and perceive testing and treatment as burdensome. While social norms prime them to appear indifferent, many are afraid. They believe that a positive diagnosis will bring loss of status and relationships, so many prefer not to test, or they delay treatment. This is compounded by traumatic childhood memories of the early days of the AIDS epidemic.

At clinics, some men perceive care to be judgemental, which discourages them from testing. Providers express frustration with men's apparent apathy, although this is often a misreading of men's fear. Health worker frustration is compounded by the challenges of the healthcare system, including pressure to reach ambitious targets and to comply with administrative requirements.

Although the study was geographically limited and the sample was not designed to be representative, the results suggest that current approaches may be inadvertently driving men away from services. Clinic reorganisation, provider training, and greater understanding of the needs of men and healthcare providers may increase men's uptake of HIV services.

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## Introduction

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In South Africa, men experience worse HIV-related outcomes than women. It is estimated that 78% of HIV-positive men know that they are living with HIV, versus 89% of women. Sixty-seven per cent of HIV-positive men who have been diagnosed are on treatment, compared with 72% of women.<sup>1</sup>

In 2001, prior to the widespread availability of antiretroviral therapy (ART), the adult HIV prevalence rate was over 25% in several South African provinces.<sup>2</sup> Today, South Africa has the largest HIV treatment programme in the world, providing treatment for 4.4 million people living with HIV (PLHIV).<sup>3</sup>

While the scale-up of HIV testing and treatment represents progress, the data also show that more needs to be done if South Africa is to achieve the UNAIDS 90-90-90 goals for epidemic control, namely 90% of people living with HIV know their status; 90% of those who know their status are on treatment; and 90% of those on treatment are virally suppressed.<sup>3</sup> Recent estimates show that HIV incidence rates may be starting to rise again,<sup>4</sup> and emerging research has increased understanding of the sexual networks driving transmission.<sup>5</sup>

A large body of literature describes vulnerability to HIV acquisition among adolescent girls and young women.<sup>5-8</sup> Comparatively less is known about men, even though men are less likely to test for HIV, less likely to initiate treatment if positive, and less likely to adhere to treatment once started, all of which results in significantly lower rates of viral suppression.<sup>1</sup> Gender disparities are reflected in mortality data: women are 27% less likely to die from HIV than men, and more than half of all male HIV-related deaths occur in men who have never sought HIV and AIDS care.<sup>9</sup>

The literature shows that men's vulnerability to HIV can be partially attributed to masculine gender norms. An extensive body of work reveals the role of masculine constructs in fuelling HIV acquisition, e.g. the value placed on strength, self-sufficiency and overt expression of sexuality.<sup>10-12</sup> Myths of male invulnerability and shame in seeking help,<sup>10,13</sup> pervasiveness of excessive alcohol consumption;<sup>14</sup> social marginalisation of certain groups of men, which along with unemployment, "creates a nexus of trauma, poverty, and depression";<sup>15</sup> anticipated stigma;<sup>16</sup> and exclusionary language and policies in health clinics<sup>17</sup> act together to inhibit men's HIV testing and care-seeking. This is especially problematic for black men in South Africa, who experience higher HIV prevalence than other racial groups.<sup>1</sup> This has been attributed to differences in sexual behaviour,<sup>18</sup> but should also be considered in the context of socio-political factors including colonialism, apartheid and forced migration, which have facilitated the spread of HIV among this group.<sup>19,20</sup>

While previous research has explored men's barriers to HIV testing and treatment initiation in South Africa, current service-delivery models are still not reaching enough men to achieve epidemic control. There is also poor understanding of the difficulties that healthcare providers (HCPs) face in providing HIV services to men. This study aimed to map men's routes to HIV testing and treatment in selected sites in KwaZulu-Natal (KZN) and Mpumalanga (MP) provinces. Psychological and practical facets of the journey were included in order to understand men's engagement with the healthcare system and to develop recommendations on how to increase service uptake. The study also aimed to understand the attitudes and behaviours of HCPs regarding HIV testing and treatment, and to develop recommendations on how to improve provider effectiveness in reaching men.

## Methodology

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### Study sites

KwaZulu-Natal and Mpumalanga were selected because of their high HIV prevalence rates compared with other provinces.<sup>1</sup> Eight sites across the two provinces were selected non-randomly, following consultation with local district governments about the areas of highest HIV burden and greatest need for improved interventions. The samples of men and providers were split proportionally according to population size across urban and rural areas.

Men were eligible to participate if they were between 25 and 34 years old, black, and sexually active. Men who had been voluntarily circumcised in a medical facility as adults were excluded, as they were considered to have already demonstrated a relatively high level of engagement with the healthcare system and they were also biologically at lower risk of HIV acquisition. The sample comprised men from different stages of the HIV testing and treatment continuum, including HIV-positive men on ART, HIV-positive men not on ART, HIV-negative men, and men who did not know their status.

Providers were eligible for the study if they had at least five years' experience testing or treating clients for HIV, or if they were responsible for linking clients to care. It was necessary for them to have experience working with men similar to the participants in the study target group. Providers were eligible if they worked in a government or non-governmental organisation (NGO) clinic, hospital, or community setting. Private providers were not eligible for participation.

### Recruitment and interview process

Specialist recruiters used a screening questionnaire to select respondents. Respondents living with HIV and who were known to health services were recruited through registered South African HCPs. Informed consent was obtained from all respondents and an incentive was

provided (R160/\$11 for men and R185/\$13 for HCPs). The research was approved by the Population Services International Research Ethics Board in the USA, and the Foundation for Professional Development Review Board in South Africa. Approval was granted from all districts and provinces where the research took place.

In June and July 2018, 58 men were recruited to the study, 38 (66%) from KZN and 20 (34%) from MP. Fifty-two per cent were from urban areas, and 48% from rural sites. Fifty-two per cent of participants were 25 - 29 years old, and 48% were 30 - 34 years old (Table 1). A total of 64 HCPs were recruited, 43 (67%) from KZN and 21 (33%) from MP. The

sample was evenly split between facility- and community-based providers (Table 1).

Respondents completed a two-hour in-depth interview administered by trained male data collectors using a semi-structured discussion guide. The guide was developed based on a literature review and insights from formative ethnographic research. Interviews were conducted in the language of the participant's choosing by a moderator fluent in that language. The interviews were recorded, transcribed, translated into English, and analysed thematically by a team of researchers. Themes were developed inductively from the data and refined iteratively through group discussions.

Table 1: Sample of men and healthcare providers in HIV services, KwaZulu-Natal and Mpumalanga, 2018

Men							
Province	District	Subdistrict	Urban	Rural	Community-based	Clinic-based	Total
KwaZulu-Natal	eThekweni	Inanda C and Newtown A (these are both in Inanda)	11	0	5	6	11
	Ugu	uMuziwabantu	0	8	4	4	8
	Zululand	Ulundi	0	9	5	4	9
	Umgungundlovu	uMsunduzi	10	0	5	5	10
Province total			21	17	19	19	38
Mpumalanga	Ehlanzeni	Mbombela	9	0	5	4	9
	Gert Sibande	Lekwa	0	6	3	3	6
	Nkangala	Empumelelweni	0	5	3	2	5
Province total			9	11	11	9	20
Grand Total			30	28	30	28	58

  

Healthcare Workers							
Province	District	Subdistrict	Urban	Rural	Community-based	Clinic-based	Total
KwaZulu-Natal	eThekweni	Inanda C or Newtown A (these are both in Inanda)	13	0	6	7	13
	Ugu	uMuziwabantu	0	10	5	5	10
	Zululand	Ulundi	0	10	5	5	10
	Umgungundlovu	uMsunduzi	10	0	5	5	10
Province total			23	20	21	22	43
Mpumalanga	Ehlanzeni	Mbombela	7	0	3	4	7
	Gert Sibande	Lekwa	0	7	4	3	7
	Nkangala	Empumelelweni	0	7	4	3	7
Province total			7	14	11	10	21
Grand Total			30	34	32	32	64

## Key findings

Thematic analysis identified barriers to men accessing health services for HIV testing and treatment. Unless otherwise specified, the terms 'men' and 'HCPs', will be used throughout to refer to respondents who fit the sample criteria in the geographical area of interest. The findings should be interpreted in the context of the qualitative sample sizes and limited geographical scope of the research, and caution should be taken in generalising beyond the groups sampled or to other areas of South Africa.

### HIV trauma

The analysis revealed significant personal and social trauma associated with HIV. Many of the men first experienced HIV in the pre-ART era, which created lifelong traumatic associations that continue to condition their current behaviours. Loss of parents and other family members to AIDS was widespread among the sample, and this trauma was compounded by a culture of shame and silence in which AIDS deaths were rarely spoken about openly.

For many of the men, early experiences of HIV education also inculcated strong negative associations. Early educational methods were often designed to instill fear in children, with respondents recalling visits to AIDS wards and graphic pictures of AIDS victims:

*When I first heard of HIV it was the scariest disease that anyone could think of, it was even scarier than cancer.* (Respondent, KZN)

Despite advances in HIV treatment, formative childhood experiences conditioned many of the men to associate HIV with death and to avoid the topic reflexively.

### Navigating an environment of stress and uncertainty

Many of the men reported living with a high level of daily pressure and anxiety, including financial difficulties, experience of violence, and the pressure of providing for their families, often without steady employment. This meant that HIV was a less immediate concern, and often ranked low in their order of priorities. Men frequently expressed concern about the indirect costs of HIV testing and treatment, including the time it takes to visit a clinic:

*Queuing at the clinic is the reason men don't like going there. Men don't have time to sit there.* (Respondent, KZN)

Many men reported acute economic pressure and few had stable employment. Most said that they hustled daily to make ends meet by seeking 'piece jobs', and they spoke of the uncertainty of not knowing how long their current job would last or when the next job would come. They also

frequently reported experiencing violence, both as victims and perpetrators, within and outside the home, and often associated with excessive alcohol use.

For the respondents, HIV was another source of stress in their already stressful environment, and therefore a topic often avoided. At the same time, the stressors in the men's lives sometimes acted as triggers for unhealthy 'escape' behaviours that exacerbate HIV risk:

*I often feel sad. It is because of being unemployed. I usually go and speak to my friends and discuss the progress of our projects. Sometimes I smoke dagga with my friends and maybe get a beer or two, get drunk, and go to my girlfriend.* (Respondent, MP)

### Masculine norms and risk assessment

Respondents often characterised social norms around manhood as being rigid and restrictive. The men's attempts to comply with these norms may inhibit health-seeking behaviour and contribute to increased risk of HIV transmission.

The men provided many definitions of masculinity and what it means to be a man in their community, but the concept of self-reliance and the notion of providing for others were dominant themes:

*It is important for a male figure to take responsibility, to be a provider in our homes.* (Respondent, KZN)

This emphasis on self-reliance inhibited many of the men in the sample from presenting at clinics out of fear of being seen as 'weak':

*Men don't take men who take medication or tablets every day seriously. There is a mindset that men are naturally strong.* (Respondent, KZN)

Men also described norms of masculinity in the context of relationships. Having multiple partners was simultaneously viewed as shameful, desirable and inevitable. Men reported hiding additional partners from their wives or main girlfriends, and feeling some level of shame about these side relationships. However, they also described these additional relationships as a way to build social capital. One respondent observed:

*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.* (Respondent, KZN)

The ubiquity of multiple sexual partners, combined with low and inconsistent condom use, contributes to a high level of HIV transmission risk. Many men reported that if they use condoms at all, this tends to fall away quickly with a new

partner. While they initially perceive a high level of risk with a new partner, particularly a casual partner, that perception of risk can quickly reduce due simply to familiarity and the belief that she 'is a nice girl', 'lives a decent lifestyle', or 'comes from a good family'. Many men also believed that they could assess a woman's HIV status using visual clues such as weight and body shape:

*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. (Respondent, MP)*

The men reported being less likely to use condoms with a woman they assumed to be 'healthy' and HIV-negative.

Social and cultural norms around masculinity inhibited men in the sample from taking meaningful steps towards health-seeking behaviour, such as visiting health facilities, taking medication, assessing HIV risk accurately, and using condoms consistently.

### Cost versus benefit of engaging with HIV services

Many men associated HIV services with expected loss and little corresponding gain. Expected loss took many perceived forms for them, including but not limited to the following:

#### Loss of relationships

For the men in the study, disclosure involved not just one's sexual partner(s) but also one's family, friends, co-workers, and the broader community. Disclosure also extended beyond verbally sharing an HIV diagnosis to include being seen at a clinic, or having a partner or family member discover anti-retroviral (ARV) medication.

Many men said that if they discovered they were HIV-positive, it would mean serious and sustained conflict with their primary partner, or perhaps even loss of the relationship. Disclosure to the main partner could become a major source of anxiety, both prospectively when considering testing, and after a positive diagnosis.

With family members, the dominant emotion was often fear of causing disappointment:

*I tried telling my mom [about my HIV diagnosis] 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 want it for myself. (Respondent, KZN)*

With friends or peers, the primary consideration was generally loss of status and respect in the peer group, although there was little indication in the research as to whether this fear was justified or whether it was a result of men's anxieties.

#### Loss of pleasure

An HIV diagnosis can trigger fears that the few pleasures men have will be taken away. Men frequently reported that post-test counselling following an HIV diagnosis focused on deprivation: reducing one's number of sexual partners, drinking less alcohol, eliminating unhealthy foods, and avoiding traditional healers. Combined with taking daily medication, many respondents viewed the anticipated change in lifestyle as fraught with loss:

*We are afraid of the responsibilities that follow finding out, for example, having to stop alcohol. (Respondent, KZN)*

#### Loss of life

Although most respondents knew that effective HIV treatment was available, they associated HIV with sickness and death, and this impression often remained strong:

*They say that once you get the news that you are positive, you die quickly. (Respondent, MP)*

#### Loss of identity and sense of self

Some men equated contracting HIV with a complete loss of self:

*I would be worried if they told me that I am indeed positive, then it will be game over. I will no longer be myself. (Respondent, KZN)*

### Interactions with the healthcare system

The clinical environment exacerbates men's fears. Healthcare providers have their own set of traumas, anxieties and pressures around HIV; they also operate in a difficult environment and reported numerous issues with the health system. This means that encounters between men and HCPs are often sub-optimal. In this section, the analysis includes responses from the men interviewed but also responses from the HCPs in the study in order to understand how the interactions between these two groups may lead to frustration and disengagement.

#### Mutual distrust and misunderstanding

A comparison between the interviews with the men and those with the HCPs showed that each group often approaches the other with suspicion and expectation of conflict or difficulty, often borne out of past experiences, which can then become self-fulfilling or self-perpetuating. Several moments of disconnection were identified in the analysis, namely when men and HCPs appeared to misunderstand each other's intentions.

Healthcare providers in the sample reported consistently that they found their male patients much more difficult to manage than their female patients, characterising them as 'evasive', 'stubborn', 'ignorant', 'self-interested', 'controlling' and 'disrespectful'. Taken in conjunction with what men reported, it is likely that HCPs are misreading their male patients' demeanour. What HCPs view as apathy or stubbornness, could be fear covered by a veneer of

bravado. Many men reported extreme levels of anxiety when going for testing, borne of expectations of poor treatment, and fear of an HIV diagnosis and of being seen by community members:

*I was terrified. I was not ashamed or embarrassed. I was just terrified.* (Respondent, KZN)

Many men described HCPs as being aloof and uncaring, even verging on punitive:

*Men are afraid of going to the clinic, they say they get shouted at.* (Respondent, MP)

However, this interpretation of HCP demeanour also misses the full picture. As revealed in the HCP interviews, patriarchal gender norms are inverted in clinical interactions, with mostly female HCPs in positions of authority over male patients. Men's reported behaviour suggests that as they attempt to restore the gender dynamics to which they are accustomed, providers may have to deal with threatening behaviour and overt sexism. Experiences of violence were common among HCPs, particularly among those working in community settings:

*Sometimes you get turned back and rejected the moment you step into somebody's yard. Sometimes they threaten to have the older boys in the neighbourhood remove you, all because they don't want to get tested. So we do feel threatened this way.* (Community Health Worker, MP)

Healthcare providers also reported various other pressures and constraints, including high patient volume, unattainable targets, burdensome paperwork requirements, and problems with supplies and human resources:

*Sometimes the healthcare system fails me. You sometimes order stuff only to find that it is out of stock.* (Nurse, MP)

Behaviour that men view as uncaring or punitive may in fact be a reaction to the adverse circumstances in which HCPs find themselves.

### Provider-initiated testing and same-day initiation

A comparison of answers between the two sample subgroups showed that provider-initiated testing can be a source of tension between men and HCPs. Several men reported that they disliked being approached for testing when they were at the clinic for an unrelated reason:

*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 then I will be compelled to test even though that's not what I came in for.* (Respondent, KZN)

While HCPs have a mandate to encourage HIV testing and same-day initiation, many men experience this as being pursued or hunted.

### Counselling

The counselling provided before and after an HIV test can be a point of disconnection between the provider and the patient. HCPs tended to describe counselling as an absolute necessity:

*I have to explain to patients what HIV is and what AIDS is because people do confuse the two. I have to tell them how the procedure will go and how to read the results.* (Nurse, KZN)

Men, however, were not positively predisposed toward any form of counselling and expressed resentment that the results were being delayed by the counselling:

*I didn't want to talk, I just wanted to know the results. I was anxious to know the outcome.* (Respondent, MP)

Many men experienced counselling as moralising and judgemental, and described the language used as overly technical. Messages were often scripted and didactic rather than tailored to individual needs and circumstances. Counselling often reinforced the fears men had about testing positive, with messages focusing on everything that a man must give up rather than how to continue living an enjoyable life:

*They also told me not to take [my pills] with any traditional Zulu drinks, that I must take them on their own. When I was told that I was a little heartsore because I am a traditionalist.* (Respondent, KZN)

### Privacy and confidentiality

Privacy and confidentiality were overriding concerns for many men, who feared that their status would be revealed by indiscreet HCPs or through being seen at the clinic:

*A lot of people hate the idea of sitting around at the clinic in queues and hate the fact that their friends might see them there. If they see you there they start to gossip.* (Respondent, KZN)

However much HCPs may wish to safeguard confidentiality, the physical set-up of the clinic can make this difficult:

*In the consultation room there's two of us doing counselling; when we're both busy we have to split the room with a screen. People come in to use the computer, to print results or whatever, so you see there is no longer any privacy.* (Community Health Worker, KZN)

The clinic experience is often sub-optimal for both men and HCPs. In an environment of stringent targets and resource shortages, compounded by threats of violence, HCPs may lose sight of the anxieties that men bring to the clinic. Similarly, men may misread HCP behaviour as being uncaring, rather than as stemming from the pressures of their work situation.

## Conclusions and recommendations

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This research considered men's life context, their full physical and emotional journey to testing and treatment, and the relationship between men and HCPs, and uncovered contextual and environmental factors, as well as more practical barriers that block testing and linkage to treatment. While this qualitative study did not test interventions, the findings point to some practical recommendations that could improve the experiences of both patients and HCPs. This work therefore contributes to the evidence base behind the 'service delivery' and 'health workforce' elements of the World Health Organization's six building blocks for an effective, efficient and equitable health system.<sup>21</sup>

Given the qualitative nature of the study, these recommendations may not be applicable to the country as a whole. Instead, they should be read as potential areas for further investigation and research, or suggestions that could be piloted in a practical setting.

- **Services should take a harm-reduction and empathetic approach**

Service providers should reframe testing and treatment services in ways that relieve fear and anxiety, offer acceptance and support, provide a greater sense of control over personal health decisions, and create safe spaces for honest discussion. The public health community may have limited impact in trying to change deeply entrenched attitudes and behaviours around masculinity. Scarce resources may be better spent on emulating key population programmes by taking a harm-reduction approach that focuses on helping men to reduce risk in realistic ways, while taking their fears and motivations into account. For example, discussions around treatment could be more interactive and clearly communicate prevention benefits. Rather than focusing on what men must not do, ART counselling could focus on how to live a fun, fulfilling life and not just a long, healthy one, and how to make it easier to incorporate ART into daily life.

- **Services should understand HCP barriers and challenges**

Many HCPs have also experienced HIV trauma and stigma, and face numerous challenges in their work, including stock and staff shortages, high administrative burdens, ambitious targets, and threats of violence. Both government and funders should prioritise the needs of patients and providers above reporting and administrative priorities. Healthcare providers should receive supportive training, both to foster deeper understanding of the populations they serve, and to prevent and cope with physical dangers encountered in their work.

- **Services should be as responsive and relatable as possible**

There can be difficulties around gender norms and sexism when interactions rest on acceptance of patriarchal patterns of male superiority and female inferiority and passivity. Similarly, there can be difficulties with sex-segregated services, even though these can be effective in certain contexts. In such environments one should be careful about making dogmatic suggestions. Nevertheless, clinics and providers could and should do more to create a comfortable, familiar environment where men feel seen and respected. Simply orienting men on what to expect during a clinic visit could assist, and active listening could help to address individual barriers and challenges and improve perception of respect and responsiveness. Rather than responding punitively, empathising with non-compliant 'problem patients' could increase adherence and retention.

- **Services should prioritise privacy, confidentiality and disclosure support**

Among men's fears, disclosure ranks high (especially unintentional disclosure). Clinics should be structured so that the testing and treatment process is as private and inconspicuous as possible, and clinic managers should stress and enforce principles of patient confidentiality with staff. Particularly in the case of index testing, providers should be trained to offer disclosure support in a range of forms, including assisted partner notification and anonymous notification, as is routinely done with other sexually transmitted infections.

These recommendations are not prescriptive or exhaustive. Additional quantitative research is needed to investigate barriers and solutions. The data will then feed into an intervention design process, the results of which will be piloted in KZN and MP.

Understanding and addressing men's barriers to HIV testing and treatment will have many benefits, including improved health and longevity for men, reduced community viral load and lower HIV transmission to female partners, and a strong, more resilient healthcare system in South Africa. However, challenges still remain, including adherence when treatment is begun, and many of the identified barriers (such as the impact of gender norms and economic difficulties) are complex and will require multiple interventions to secure long-term benefits.

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