



TRANSGENDER WOMEN NETWORK FOR RESEARCH: Revealing community HIV and health risks

A pioneering study conducted in collaboration with South African transgender women revealed the advantages of community-driven research in asking the right questions and accessing knowledge that exists outside of academic spaces. Based in three metro-municipalities, the study revealed that the high HIV risk faced by transgender women occurs in a confluence of public-health problems, including homelessness, poverty, substance use, violence, victimisation and discrimination.

By *Andrea Teagle and Dr Allanise Cloete*

Transgender women in three South African metro municipalities face a disproportionately higher HIV risk than the general population.

This was one of the key findings of the Botshelo Ba Trans study, which lead researcher Dr Allanise Cloete, from the HSRC's Social Aspects of Public Health (SAPH) unit, presented at the SA AIDS conference earlier this year.

The study, which involved 888 transgender women, found that 45.5% of participants in the City of Cape Town and 46.1% of those in the Buffalo City metropolitan area were living with HIV. In the Johannesburg metropolitan area, this figure was 63.4%. The HIV prevalence for the general adult population in the Johannesburg area was 12.9%, according to 2017 estimates.

The higher HIV risk faced by the participants in the study points to wider challenges faced by this often overlooked and marginalised group. One in four transgender women reported having experienced stigma, and about the same percentage (23%) reported having experienced violence due to their transgender status. In addition, while many had completed matric, some had not completed their schooling. In Johannesburg, 14.5% of participants reported having lost a home due to their gender identity.

One transgender woman said, "Some of [my trans sisters who are sex workers] have been on their own since a young age. Nobody accepted them for who they are." Other interviews with key informants revealed that for some transgender women, sex work provided a rare space where they could express their identities positively.

A new approach

The findings of Botshelo Ba Trans are critical to improving access to health care and reproductive and human-rights services for transgender women. But the study also has wider implications, as a torch bearer of a new model of



Leigh Ann van der Merwe, a transgender woman and an activist, speaking at the launch of the Botshelo Ba Trans study.
Photo: Antonio Erasmus

research that positions participants as knowledge holders in their own right.

“The meaningful involvement of civil society in the research study itself had significant implications in creating ownership of the study, for community mobilisation and data collection,” Cloete said.

Before the study, little was known about the HIV risk profile of transgender women in South Africa. Reaching them to take part in the study was always going to be a challenge. From the start, the study’s success relied on the participants to mobilise other transgender women, in a chain-referral process called respondent-driven sampling.

Gaining the trust of a widely stigmatised community was a slow process. Together with co-investigator Leigh Ann van der Merwe, a transgender woman and an activist, Cloete worked with civil society organisations to build relationships with the community over a period of around eight months.

With the help of Social, Health, Empowerment (S.H.E.), Feminist Collective of Transgender Women in Africa based in East London, Sex Workers’ Advocacy and Education Taskforce (SWEAT), Gender Dynamix (GDX) and Access Chapter 2 (AC2), the team recruited “seed” individuals from each geographical area to start the chain-referral process. To be included in the study, participants had to have been assigned male at birth, identify as female, or trans, or “other” than male.

The participants were engaged at each stage of the process, say Cloete and Van der Merwe. The write-up of the findings was a collaborative effort involving transgender women activists, programme implementers, funders, academia and participants, culminating in a five-day writing workshop.

“Several small discussion groups were conducted with transgender women to share lessons learnt across the duration of the study,” Van der Merwe said, adding that the inclusion and leadership of transgender women were central tenets of the effort.

In traditional research, there is a clear separation between researchers and participants. “We’ve never worked with communities from the start, [asking them] ‘You tell me what I need to focus on,’” Cloete said. “It’s a challenge for us because it’s power relations. You know, [assuming] ‘I know best’. And that’s not true. We’re doing this work for the community. So why not engage in an equal way with the community?”

Becoming visible

According to Van der Merwe, the study was a chance for transgender women in South Africa to be seen and heard. At the 2018 [launch of the study](#), she said, “For too long our reality as transgender women has been invisible to society.”

She says, while the majority of transgender women reported living as a woman in the past six months, most have not applied for a change in gender marker. Rights organisations like S.H.E, of which Van der Merwe is the founder, work with transgender women to help them navigate the legal system. “From the transgender women who access our services, we know that there is a strong desire by transgender women to make a change in their gender markers,” said Van der Merwe.

The waiting list for gender-affirming surgeries at the two hospitals in South Africa that offer them is about 20 years, Van der Merwe said. Only about 5% to 12% of transgender women across the three metros surveyed had made use of gender-affirming hormone treatment.

This, Van der Merwe notes, is not evidence of a lack of desire to

undergo the treatment, but of a lack of knowledge about accessing it.

The study also highlighted the diversity of the transgender women and the challenges they face, between and within cities. For example, half of the sample from the Buffalo City metropolitan area reported that they were students (with a similar, and probably largely overlapping proportion indicating that they were aged 18-24); while about 40% reported being unemployed. In the Buffalo City and Cape Town metros, 13.9% and 13.2% respectively reported ever engaging in sex work. In the Johannesburg metro, the proportion was 38.3%, reflecting the likelihood that sex workers gravitate to bigger cities to find work.

The particular makeup of the samples in the three metros also would have been influenced by respondent-driven sampling that recruits via social networks (i.e. friends, sex partners, acquaintances, family members etc.).

One encouraging finding was the widespread knowledge of HIV, with over 75% of participants in every metro, and almost 90% in Johannesburg, reporting having tested for HIV in the past year.

Cloete and Van der Merwe hope that the study will seed new research to empower transgender women in South Africa in other ways. “What I found with the study – the one thing that remains consistent, despite a multitude of social and public-health problems – is that transgender women are resilient and for any future programmes, this resilience of transgender women has to be drawn upon,” says Cloete.



*Olwethu Sigenu interviewing a transgender woman as part of the HSRC's Botshelo Ba Trans study.
Photo: Antonio Erasmus*