Transgender women outreach workers and their role in South Africa’s HIV response

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Transgender women (TGW) are women whose gender identity differs from the sex assigned to them at birth. South Africa’s legal framework protects the rights of TGW and their right to health care. Improving our nation’s health requires that health services be accessible and appropriate for all. However, TGW are often reluctant to access health care due to the lack of services that affirm their gender and meet their needs in a holistic manner. Many who do access these services experience stigma and discrimination. Innovation and efficient and effective utilisation of human resources are critical for health-system strengthening, and peer-driven delivery approaches are considered best practice to access, foster and provide responsive, quality health services to marginalised groups, including TGW.

This chapter provides a synopsis of the global and local context for TGW from an HIV perspective. The role of TGW outreach workers in South Africa’s HIV response is described. Three case studies are presented to provide insight into how TGW outreach workers support their clients to cope with the key issues they face, namely stigma and discrimination; the consequences of non-conforming gender expression; scarce employment opportunities; the inadequacies of bio-medically focused HIV services and limited resource allocation for TGW programming. The case studies highlight how outreach can comprise mentorship between older and younger TGW and support community building among the women. Important challenges facing outreach services for TGW in South Africa include the uncertain funding landscape; limited interventions for socio-economic empowerment and harm reduction around substance use; and lack of access to hormone therapy and gender-affirming surgery. Recommendations are made for increased support of outreach services and initiatives that take a multi-sectoral and comprehensive approach to TGW.

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Introduction

"Transgender" is an umbrella term that refers to people whose gender identity differs from their assigned sex.\(^a\) Transgender women (TGW) (male to female) were assigned male sex at birth but identify socially as women. They include people along the continuum of hormone therapy and gender-affirming surgery.\(^a\)\(^b\)

The National Department of Health (NDoH) High Transmission Area (HTA) Guidelines [2014] define outreach workers, or peer educators, as people with similar socio-demographic characteristics, experiences or beliefs as the intended service beneficiaries.\(^2\) They may also have first-hand understanding of the issues and HIV risk factors in the community that could influence health outcomes.\(^3\) In HIV programmes, this involves selecting, training and supporting outreach workers to become experts in HIV and related topics tailored to their peers. Outreach workers should be supported to use a life skills approach to stimulate dialogue around HIV and related topics and thus improve knowledge. They also need to share skills that support behaviour changes to reduce the risk of HIV infection and/or the consequences thereof. Where possible, they provide HIV prevention commodities and HIV testing services (HTS), and they refer (and ideally accompany) clients to services and support retention in treatment.\(^2\) Transgender outreach is a new, small and unique element in South Africa's health system and HIV response.

While the context of transgender health leaves much to be desired, this chapter focuses on HIV programming since HIV has received the most focused funding to date, albeit insufficient.\(^4\) Furthermore, HIV is a major part of the health burden for TGW.\(^5\)\(^6\) The literature demonstrates that TGW have a higher likelihood of living with HIV than cisgender women and yet they are unlikely to be retained in care without appropriate action.\(^6\) The evidence shows that harsh socio-economic determinants facing TGW contribute to high-risk behaviours for HIV acquisition and transmission.\(^7\)–\(^9\) Therefore, one cannot focus on the broader context of TGW health without addressing HIV. This chapter outlines the global and South African context of HIV for TGW. The aim of the three illustrative case studies is to identify key issues affecting TGW and increase understanding of the role, process and influence that TGW outreach workers have within South Africa's HIV response.

Global context

There are few transgender population size estimates, partly due to the varying definitions used.\(^4\)\(^10\) In 2016, Winter and colleagues used estimates from four countries where population-level proportions were available and extrapolated a worldwide estimate of 25 million transgender persons.\(^11\)\(^b\) A systematic review done in 2012 estimated that one in five TGW are living with HIV.\(^12\) However, data on TGW in Africa are limited.\(^4\)

There are numerous underlying drivers of HIV among TGW. The UNAIDS Gap Report describes these factors and how they may manifest through gender identity and/or expression.\(^13\) Social rejection by family, friends and society, together with harassment, stigma and violence may lead to anxiety, depression and suicidal thoughts, affecting self-perception and self-worth and limiting engagement in society. These factors may act as deterrents to access, uptake and retention in HIV and other services. Lack of engagement with the healthcare system potentially exacerbates the HIV epidemic among TGW and broader society.\(^13\)

South African epidemiology, context and policy

Participants in a South African stakeholder consensus workshop estimated there to be between 17 000 and 22 000 TGW in South Africa.\(^14\) However, there are insufficient data to measure South Africa's progress towards achieving the UNAIDS 90-90-90 HIV treatment targets for TGW.\(^15\) While the findings of the few available studies are not generalisable, they suggest cause for concern. For example, more than half (57%) of gender non-conforming participants (n = 36) recruited through a survey of 316 men who have sex with men (MSM) in Cape Town screened HIV-positive, which was significantly more than their male-identifying counterparts (31%).\(^16\) The study found that one in four TGW had never tested for HIV, despite only 28% reporting consistent condom use.\(^16\) A qualitative study examining the access of TGW to sexual health services in six provinces revealed that alcohol and other drug use, considered a pathway to HIV risk-taking behaviours, was prevalent among several participants.\(^17\) This is consistent with another study that included TGW sex workers in four cities, where 66% reported being drunk during their last paid sexual encounter.\(^18\)

In South Africa, TGW face pervasive stigma and discrimination.\(^19\) Gendered cultural practices\(^20\) and social vulnerability put them at risk for violence. For example, in a national five-year monitoring project 8% of participants reporting prejudice-motivated attacks were TGW.\(^21\)

In South Africa, the Alteration of Sex Description and Sex Status Act (49 of 2003) makes provision for transgender people to align their bodies with their gender identity without surgery.\(^22\) Legislation and policy also support appropriate health responses for TGW; this includes the Constitution,\(^23\) the South African National Strategic Plan on HIV, TB and STIs (2017–2022),\(^24\) and the South African National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) HIV Plan (2017–2022).\(^25\) However, there are currently no national transgender healthcare guidelines.

Programmes and funding

Due to limited domestic information, local TGW programming relies on global research\(^2\) and will be informed by the ongoing Botshelo Ba Trans study\(^5\) and future research.

The overall context of transgender health in South Africa is inadequate. The establishment of Gender DynamiX in 2005, the first transgender-focused organisation, saw unprecedented mobilisation around trans health. Advocacy efforts have yielded notable results, including the Global Fund recognition of TGW as a distinct funding category, and the debut of a biennial Trans Health Advocacy and Research Conference in 2011. However, more work is required for TGW to realise their sexual and reproductive health and rights.

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\(^a\) This definition does not capture the complexity of being confined to a ‘male body’ while identifying with a feminising gender social position. Transgendered bodies can be at any stage of medical transition and are not defined in terms of a male-female binary.

\(^b\) Transgender people includes transgender women, transgender men and people who are gender non-conforming.
Sexual reaffirming surgeries are currently offered through two public hospitals,\textsuperscript{d} with an average waiting time of over 20 years.\textsuperscript{26} Medically prescribed hormone therapy\textsuperscript{e} takes place at the primary health care level subject to a psychologist’s recommendation. As a result of barriers to access, many TGW self-medicate with oestrogen-containing contraceptives.\textsuperscript{17,27} Right to Care (a Global Fund principal recipient) supports most of the transgender-led HIV outreach service providers (Global Fund sub-recipients). Between April 2017 and March 2018, 783 TGW were reached and 595 were tested for HIV. Eight per cent of the women (47/595) tested positive for HIV; of these, 85% were referred for HIV services, but only 4% were linked successfully. Outreach service providers included Anova Health Institute, Enhancing Care Foundation, Free State Rainbow Seeds, the LGBTI Community Centre, Lifeline Northern Cape, and the Social, Health and Empowerment Feminist Collective of TGW of Africa (S.H.E.), operating services in selected areas in all provinces except Limpopo and the North West.\textsuperscript{i}

Transgender outreach workers are also employed by organisations that provide HIV prevention and related services to sex workers in metropolitan areas (e.g. the Sex Workers Education and Advocacy Taskforce (SWEAT), TB HIV Care, and Wits Reproductive Health and HIV Institute). However, there are few formalised, safe spaces to which outreach workers can refer TGW sex workers. Examples in Cape Town include the ‘SistaazHood’;\textsuperscript{28} and until 2017, the ‘Glitz and Glamour’ support club for TGW sex workers living with HIV.\textsuperscript{g}

Anova Health Institute offers gender-affirming services at its key populations clinics in Cape Town and Johannesburg and has trained more than 3 500 healthcare workers on trans issues. Transgender and Intersex Africa, Gender Dynamix and Access Chapter 2 focus on rights, psychosocial services and gender-affirmation advocacy for TGW, but not outreach services.\textsuperscript{29} Themba Bonke and Trans Power Care Centre (described later) are TGW-led organisations that provide HIV outreach.

It is encouraging that the South African country concept note and funding request submitted to the Global Fund for the funding cycle 2019–2022 includes transgender programming.\textsuperscript{h} Additionally, the United States Agency for International Development (USAID) will be funding a transgender programme through the United States President’s Emergency Plan for AIDS Relief (PEPFAR) for the programme cycle 2018–2023.\textsuperscript{i} Both of these programmes are likely to include peer-led interventions.

Methods
Due to limited published literature, a descriptive case study approach was employed. Grey literature was used and case studies were analysed to gain insight into and reflect on lessons learned from the field in this new area of service delivery. The case studies were used to provide detailed examples and to highlight the contextual and other factors influencing peer outreach work among TGW. Representatives from six non-governmental organisations (NGOs) working with TGW in different contexts were approached by the authors of the study in their capacity as researchers and programme implementers working with TGW in South Africa. Participants were contacted in person or telephonically, and given an outline of the aim of the chapter, the risks of participation, and how information would be used. Consenting TGW outreach workers completed a template outlining their context, TGW work force and service provision. Participants were not remunerated and gave permission for their names, roles and responsibilities to be used. Data were entered into a password-protected excel spreadsheet and analysed using directed content analysis.\textsuperscript{30} Direct quotes were used where appropriate, and comments from the organisations and consenting TGW were integrated.

Findings
Four of the six organisations approached provided feedback, namely Anova Health Institute, S.H.E., Trans Power Care Centre and Themba Bonke. They employ an average of four (range 1–8) TGW outreach workers who provide HIV services. The following case studies demonstrate how credibility and shared experience establish trust and increase access to and use of HIV services in the TGW community. The first case study reveals the cultural pressures, stigma and discrimination faced by TGW, especially in rural South Africa. The second case study involves a peer outreach worker in the Western Cape who describes her experience working with TGW in a peri-urban setting. It highlights the pervasiveness of victimisation and violence affecting TGW and the unique role that TGW outreach workers can play in supporting TGW survivors of violence. The third case study highlights how leadership in the TGW community can be used to counter experiences of stigma and discrimination.

d Groote Schuur Hospital (Cape Town) and Steve Biko Academic Hospital (Pretoria) provide about four gender-affirming surgeries annually.

e Oestrogen for hormone therapy is used off label as it is listed on the Essential Medicine’s List primarily for the management of menopause.

f Personal communication: B. Mokube, M&E Manager: Global Fund, Right to Care, 29 May 2018.

g Personal communication: J. Hugo, Senior Clinical Advisor, Health4Men, Anova Health Institute, 27 January 2017.

h Personal communication: G. Oberth, Lead Consultant, South African Global Fund concept note development team, 18 August 2018.

i Transgender programming is included in the “Advancing the South African HIV Response for Key Populations” request for applications (RFA 720674188FA00003) issued in December 2017.
Case study 1: Outreach to TGW in rural Eastern Cape

Kwelera is a rural area outside East London (Eastern Cape). It has poor infrastructure and most people live in huts, without adequate lighting, ventilation and electricity. Kwelera is part of the Xhosa Kingdom where a strict gender binary is assigned according to birth sex and maintained through cultural rituals. Ulwaluka (cultural circumcision) is a cultural ritual for people assigned male at birth, regardless of sexual orientation and/or gender identity. Transgender women are often coerced into this ritual, which is linked to the attainment of a masculine identity – countering a TGW’s feminine identity.

Mama Afrika was 17 years old when her family started pressurising her to undergo cultural circumcision. She explained: “Most TGW that I work with have migrated to East London because of the harsh conditions in these areas. In the rural areas, they cannot be themselves. Most don’t have jobs or education opportunities”. According to Mama Afrika, many socially rejected TGW end up living on the street and frequently become involved in the sex industry.

Considering that HIV risk among TGW is embedded in multiple co-occurring social and public health problems, Ayanda Zaza Kwinana, a peer educator working at S.H.E. in the Eastern Cape, observed: “I think we should not only provide HIV services, we should provide other services that improve the economic aspect of TGW … many TGW did not attend school and so the economic situation is bad.” Ayanda suggested that peer educator training should be broader and take into account the different facets of TGW’s lives, for example, the high prevalence of sex work, drug use, etc.: “Some TGW sex workers only trust other TGW to do HIV testing for them.”

Like Ayanda, Mama Afrika is now an outreach worker for S.H.E. In this capacity, she helps TGW cope with family and community pressures. Mama Afrika walks through her own and neighbouring villages on a daily basis offering HTS, and screening for STIs and TB, and has accompanied 40 TGW to clinic visits. She faces a backlash from the community, which accuses her of promoting homosexuality. She often experiences verbal harassment aimed at her gender expression and has difficulty dressing and working as a woman as she fears for her safety. Ayanda shares similar experiences of negotiating cultural pressure and her gender expression: “We sometimes face triple stigma: trans, HIV-positive and sex worker. I am a sex worker and I am also a peer educator. I reach out to my clients wherever they work.”

The TGW community trusts Mama Afrika. This is reflected in their demand for her health and support services. She uses her lived experience to enhance health worker sensitisation training. According to Mama Afrika: “Referrals to health facilities are difficult for TGW because they do not trust nurses to uphold confidence on the issues that they experience. It takes time to win the confidence of TGW to ensure they test for HIV.”

Ayanda also refers TGW to health facilities. Busi is one of Ayanda’s clients and friends. She is a TGW living with HIV and uses substances. She lives in a village in the rural Eastern Cape, and works as a sex worker in East London. Busi reached out to Ayanda in her role as an outreach worker to open a case against a client who misread her as a cisgender woman and assaulted her. This was not easy as police officers felt that the client was within his rights to act violently because Busi misrepresented herself. Furthermore, the police felt that because sex work is criminalised, not much could be done for her. Ayanda supported Busi through this ordeal by paying attention to her emotional trauma, ensuring referral to sensitised health services, including access to HTS, and supporting her to lay a charge. Ayanda also referred Busi to an organisation to manage her substance use, although with little success. Busi describes herself as being psychologically able to deal with her substance use. She continues to receive safer sex commodities from Ayanda.

Case study 2: Doing peer outreach work in violent times

Gita November is a 34-year-old TGW living in Cape Town. She established the organisation Themba Bonke, which consists of eight TGW outreach workers. They provide HIV risk-reduction services, facilitate support groups and mentor younger TGW in the Western Cape. According to Gita: “[TGW] are stigmatised and labelled as the carriers of HIV. Because of their gender identity, many of them were kicked out of their family homes because of the perceived shame they bring to their families.”

Many TGW use (illicit) substances to cope with the daily stressors of having to navigate the threat of victimisation and the violence they frequently face. According to Gita: “There is very little knowledge about how to manage and treat substance use amongst TGW … it is very important to get training on this as it is making TGW including TGW sex workers vulnerable to HIV infection. Currently we have no partners to refer such cases to.”

Outreach workers are often the only source of psychosocial support for TGW survivors of violence. Indeed, for Gita being a TGW and being exposed to the HIV virus herself she can directly relate to the lived experience of her fellow sisters and has a deep understanding of the daily struggles they face. Thembu Bonke offers mentorships in the Atlantis area where older TGW draw from their experiences to mentor and support younger TGW, reducing their vulnerability to HIV.

In her words, Gita advocates: “[We need] to have TGW navigators assist TGW to local [trans-friendly] clinics. Also trans navigators who are trained human rights defenders to assist TGW to the police stations when opening a case. In some of the areas we conduct our outreach it becomes dangerous as we do outreach on foot and many TGW can only be reached at night. Because of no funding we cannot appoint a contract driver.”

Case study 3: Using leadership to create bonding, social cohesion and a TGW community in Johannesburg

Zsa-Zsa Fisher is a TGW living in Johannesburg. Asked about the social context in her city, Zsa-Zsa responded: “TGW are stigmatised more than the rest of the LGBTI community. TGW are made to feel small or inferior and most times are disowned by family members, which contributes to the inferiority.”

When Zsa-Zsa worked as a TGW outreach team leader at a large NGO she noted the lack of knowledge and understanding of TGW. She recalls providing Bianca, an 18-year-old TGW from Soweto, a South African township in Gauteng, with HTS. Bianca was not certain when she was infected with HIV and by whom as she had many sex partners. According to Zsa-Zsa, two weeks after having received a HIV-positive test result, Bianca was ready to receive additional information. She took time to process her result. During this time, Bianca did a second HIV test with another organisation, which confirmed her status. A month after starting ART, Bianca stopped treatment because it made her sick. After Zsa-Zsa allayed her fears, she supported her to visit and restart treatment at a sensitised clinic. Bianca remains on treatment and encourages other young TGW to test for HIV.

Zsa-Zsa became involved in the LGBTI Safety Council for Gauteng through her earlier work with different NGOs and governmental departments. She identified a need to expand on this and formed the Trans Power Care Centre. Her goal “is to make sure that the TGW community within Johannesburg is acknowledged and given as many opportunities as any other persons. This being done in a non-prejudiced manner.”

This goal drives Zsa-Zsa because in her community, “many TGW are unemployed and are severely stigmatised within their communities and within the health sector. There is a lack of skills distribution and education for TGW.”

Unlike other TGW, Zsa-Zsa combines the qualities of activism and glamour. As Miss Gay South Africa 2017/18, she has a following of TGW who admire her leadership in the glamorised industry of gay beauty pageants, where she advocates for TGW rights.
Discussion

The case studies describe a persistence of common issues affecting TGW that TGW outreach workers support their clients to overcome. These issues include: stigma and discrimination; the consequences of non-conforming gender expression; scarce employment opportunities; the inadequacies of biomedically-focused HIV services, and limited resource allocation for TGW programming.

First, stigma and discrimination make it difficult for TGW to trust other people. Frequently there are also community perceptions of TGW as carriers of HIV. Stigmatising attitudes towards TGW are often also held by healthcare workers. Health facilities and providers that lack the knowledge, experience or desire to care for the unique clinical and social needs of TGW often contribute to stigmatising TGW. The result is differential access to healthcare services, which creates a barrier to the achievement of health. Transgender outreach workers bridge these gaps and foster social connections within the transgender, healthcare and broader communities.

Next, the gender expression of TGW challenges cultural expectations resulting in a disruption of home and family, with cascading effects impacting the mental health, as well as educational and employment opportunities of TGW. In fact, non-adherence to cultural expectations impacting the mental health, as well as educational and employment opportunities of TGW often contribute to stigmatising TGW. The result is differential access to healthcare services, which creates a barrier to the achievement of health. Transgender outreach workers bridge these gaps and foster social connections within the transgender, healthcare and broader communities.

Thirdly, the lack of education and employment opportunities for TGW leads to some TGW entering the sex industry, some to survive and others to be affirmed as women. In South Africa, all aspects of sex work are criminalised. This increases vulnerability to violence and illness and reduces access to legal recourse and health services for sex workers. The case studies highlight the need for skills building and education for TGW to increase their economic opportunities. The case studies also reflect how many TGW are survivors of verbal, physical and sexual violence. Outreach workers have to overcome the discrimination they experience and limited acknowledgement of the issues affecting TGW among health, social service and law enforcement agencies to support survivors of these violations. Services that support TGW to reduce the potential harms of substance use and that enable access to hormone therapy and gender affirming surgery are also limited. The complex social and health issues reflected in the case studies highlight the limitations of viewing TGW through a narrow HIV, biomedical or health lens. Programmes in other countries have demonstrated the effectiveness of combining HIV programming with gender-affirming therapies to retain TGW in HIV care.

A final common theme is the limited allocation of resources to programmes intending to improve the health and wellbeing of TGW holistically. In going beyond HIV, the NDoH has made provision for TGW to access reproductive health services that meet their needs. These needs include specialised clinics and increased access to hormone therapy and surgery. Furthermore, the Adolescent Sexual and Reproductive Health and Rights Framework commits to addressing the needs of underserved groups, including TGW. The health of TGW would improve holistically if these policies were implemented effectively within the public healthcare system. Donor funding for TGW will come to an end, and government financing of TGW is essential for sustainability as well as to increase NDoH support for TGW beyond the HIV prevention sub-directorate.

Limitations

This chapter relied largely on grey literature and feedback from selected organisations. This may have limited the identification and presentation of other challenges and approaches used in TGW outreach programming, thus reducing the scope of experience and the ability to draw lessons.

Conclusions and recommendations

TGW outreach workers described their lives and those of their beneficiaries beyond HIV as they navigate health, socio-economic and structural issues on a daily basis. In the current South African landscape donor funding for TGW is focused on HIV, which has the (unintended) potential to enable a discourse where TGW are blamed for ‘spreading HIV’.

Peer outreach workers play a vital role in engaging with the TGW community and helping TGW to navigate clinical and social services. TGW outreach workers are reaching their peers and providing essential services in an array of contexts. Champions of TGW have emerged and established TGW-led organisations that create spaces for TGW to be visible and to network.

In this context and in light of the issues that the case studies identify, we recommend:

➢ HIV programmes for TGW should have consistent and meaningful community engagement and include healthcare worker sensitisation as recommended in normative guidance.

➢ Findings from the ongoing HIV bio-behavioural survey among TGW (the Botshelo Ba Trans study) should be used to inform HIV-related decision-making. The TGW-led nature of this study should be considered as best practice for future TGW research.

➢ NDoH should work towards enabling access to hormone therapy at the primary health care level, removing requirements for a psychologist’s recommendation.

➢ The NDoH should allocate funding for and increase the number of centres specialising in TGW health. This will also lead to an increase in the number of TGW benefitting from gender affirming surgery.

➢ In addition to existing services, government, funders and development partners should support the capacitation of TGW outreach workers to counsel their peers around hormone therapy [and the risks of self-medication]; gender-affirming surgery; violence mitigation strategies and harm reduction.

➢ HIV programmes for TGW should work alongside programmes such as the Love not Hate Campaign to document crimes against TGW on the basis of their gender identity. Findings should be disseminated to the National Departments of Health, Social Development, Justice and Constitutional Development and Police to advocate for safer environments for TGW to realise their health.

➢ Programmes for TGW should adopt evidence-based interventions that outreach workers can deliver to empower TGW, and work towards improved socio-economic conditions.
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