PERSPECTIVE

Contextualising the lived experience of sex workers living with HIV in South Africa: a call for a human-centred response to sexual and reproductive health and rights

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Introduction

Heterogeneity exists in every population for all health outcomes, including HIV acquisition and transmission among female sex workers (FSW) in South Africa. An estimated 58% of FSW in South Africa are living with HIV.[1] While antiretroviral therapy (ART) is free at primary health clinics, ART coverage among FSW is estimated to be 24% and viral suppression rates, when available, are poor.[1,2] These data highlight the current gaps in sexual and reproductive health and rights (SRHR) services for FSW in South Africa, which stem from multi-level barriers to SRHR service access, sustained engagement, and overall health and well-being.[3] Creating programmes that assume homogeneity of needs for FSW living with HIV are unlikely to be successful. Even interventions designed to address complex barriers to SRHR services will fall short, and treatment outcomes will remain suboptimal, if we do not recognise that the context of women's lives matters.

The Siyaphambili study, launched in June 2018, addresses multi-level barriers to ART.[4] Siyaphambili builds on the understanding that risk is heterogeneously distributed across FSW, and aims to identify the minimum cost-effective package and duration of additional services needed by different FSW in Durban, South Africa, beyond the standard of care, to promote retention and viral suppression.[4] As of 7 June 2019, 769 FSW have been enrolled, with <40% virally suppressed (<50 copies/mL) and a mean CD4 count of 551 mm^3 (SD ± 317) at baseline. Siyaphambili data reinforce the layered complexity of women's lives; even when viral suppression has been achieved, young women particularly remain at high risk of dying. The objective here is to describe lived experiences of South African FSW, using preliminary data and illustrative vignettes from Siyaphambili which highlight the need for tailored, comprehensive and adaptive SRHR services applied within the current policy- and community-level environments.

Policy, violence and sex work

SRHR care, including HIV care and treatment, can be intrinsically shaped by structural barriers (such as criminalisation and corruption), national policy around sex work and experiences of

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violence. Selling and buying sexual services in South Africa remains criminalised and drug use is a special offence by law,[1] yet enforcement of such laws is inconsistent and can be biased or leveraged against FSW. Our data show that 63% of enrolled participants reported drug use in the past 30 days, and FSW reported forced drug use by pimps or via client demands.[3] To-date, 46% of participants reported ever being arrested on prostitution-related charges and 13% reported ever feeling harassed or intimidated by a uniformed officer for being a FSW. In the first year of enrolment, five participants were known to be arrested or imprisoned.

In November 2018, the team observed a 27-year-old participant being arrested for smoking an illegal substance. She returned shortly after in good spirits, explaining that although initially detained, she ultimately had sex with the officer and he paid her with new drugs. She knew the police officer, noting he often demanded sex (only sometimes paying) and often used drugs with her.

In December 2018, a 24-year-old participant explained to staff that she had been drugged and kidnapped from Durban, finding herself in Pretoria [617 kms away] three days later. She now experiences post-traumatic stress and seizures, undermining her ART adherence and quality of life.

The individual and community context, serious morbidity and premature mortality

Due to sex work, addictions and HIV, many FSW face intersections of multiple stigmatised identities, further magnified by the context within which they live. Forty-four per cent of participants reported having no living parents and 26% reported living in a shelter or were homeless in the preceding six months.

In November 2018, the team went to a shelter to visit a 49-year-old participant. At enrolment, her viral load was 116,000 copies/mL and her CD4 count was 49 mm^3. Upon arrival, the participant was found weak, with an oozing abscess on her neck, and she collapsed walking to the mobile van. The team drove her to the hospital, supported her admission, and followed her through discharge. The participant, homeless, returned to the shelter to heal and continued to engage with Siyaphambili. In January 2019, the shelter was condemned and closed, forcing all to leave. In the subsequent months, the team has not been able to contact or locate the participant. She is no longer known to be accessing ART.

At the individual-level, 55% and 36% reported a history of physical and sexual abuse, respectively. Of those reporting sexual abuse, nearly half experienced forced sex within the prior six months. The context of daily life impacts not only sustained engagement in SRHR services but morbidity and mortality. A quarter of women reported moderate to severe depression in the prior two weeks, and 11% reported attempting suicide in the preceding six months. Approximately one in ten women enrolled reported hospitalisation in the six months preceding enrolment. Six women have reported being hospitalised since enrolment, and two women were violently injured but did not seek medical attention – one was stabbed in her arm and the other was pushed into oncoming traffic by another FSW. Since Siyaphambili commenced, four women have died prematurely.

In January 2019, two participants died. One woman, aged 33 years, was virally suppressed when enrolled in June 2018. She had been engaged in ART care since 2015, when she was released from prison. In December, she was diagnosed with tuberculosis and did not start treatment. Under the heavy influence of drugs, despite support from program staff, she refused care and continued to sicken. She was homeless and was found dead under a bridge by a peer. The other woman, aged 35 years, was also virally suppressed when enrolled, but died two weeks later. She reported living in a shelter, and peers reported that she had died via stabbing. When two staff visited the hospital to confirm the death, the hospital administration was relieved as the participant's identity had been unknown. She was in the intensive care unit for six days; she had been stabbed 15 times by her boyfriend. He had forced her into sex work and they were fighting over her cell phone. The participant left a four-year-old behind.

In February 2019, a 33-year-old participant was enrolled. Her viral load was 58 copies/mL. The team unsuccessfully tried to connect subsequently with the participant, called twice (phone was not working) and followed-up at her venue three times. In mid-April, the team was informed by her peers that she had been hospitalised, noting she had a cough and was losing weight. She died a few days later.

In May 2019, a 26-year-old participant was enrolled. Her viral load and CD4 count were 434,000 copies/

mL and 175 mm^3, respectively. She told the nurse at enrolment that she had received sputum testing for tuberculosis and reported being hospitalised for tuberculosis in the preceding six months. Two weeks later, the team was at a shelter and was informed that she had died. She was found dead at the bus stop where she lived/worked (she reported being homeless).

Discussion

While access and adherence to ART can facilitate healthy lives with the promise of no onward HIV transmission, the slow declines in population-level incidence in South Africa, despite continued scale-up of ART, suggest that those at highest risk of poor health outcomes and onward HIV transmission are not having their treatment needs met. Preliminary Siyaphambili results demonstrate low levels of viral suppression and complex intersecting individual and structural barriers leading to morbidity and premature mortality among FSW in South Africa. There is a need for responsive, human-centred interventions to address individuals' health within the context of complex lives. Meeting the SRHR needs of FSW is critical, and the lived experiences of FSW demonstrate the challenge in improving health outcomes; focusing only on facilitating treatment adherence and meeting SRHR needs is inadequate.

National-level structural barriers to SRHR – including criminalisation, police corruption, and gender-based violence – are systemic matters. Intervention within these domains will have impact, yet implementation of research and programmes for FSW must continue within the existing national setting and policies. However, failure to consider other issues which affect people's lives at community and individual level, such as housing, environments, trauma, and mental health, may continue to undermine use of services, retention and adherence outcomes. Even when individual ART treatment achievements are met, the quality and lives of FSW living with HIV in South Africa may still be threatened.

The eThekwini Declaration, launched in June 2019 following the 9th South African AIDS Conference in Durban, calls for radical action and demonstrates multi-sector support for reinvigorating programmes. Moving forward, recognising the heterogeneity of people living with HIV and implementing adaptive, individually-responsive approaches, is critical if health achievements are to be shared by all.

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