**Access to HIV treatment and care for people who inject drugs in Kenya: A short report.**

**Word count**

1474

**Abstract**

People who inject drugs (PWID) experience a range of barriers to HIV treatment and care access. The Kenyan government and community based organisations have sought to develop HIV care for PWID. A principal approach to delivery in Kenya is to provide care from clinics serving the general population and for this to be linked to support from community based organisations providing harm reduction outreach. This study explores accounts of PWID accessing care in Kenya to identify care barriers and facilitators. PWID accounts were collected within a qualitative longitudinal study. In-depth interviews with PWID living with HIV (n=44) are combined with interviews with other PWID, care providers and community observation. Results show that some PWID are able to access care successfully, whilst other PWID report challenges. The results focus on three principal themes to give insights to these experiences: the hardship of addiction and the costs of care, the silencing of HIV in the community and discrimination and support in the clinic. Some PWID are able to overcome, often with social and outreach support, barriers to clinic access; for others the challenges of addiction, hardship, stigma and discrimination are too constraining. We discuss how clinics serving the general population could be further adapted to increase access. Clinic based care, even with community links, may however be fundamentally challenging for some PWID to access. Additional strategies to develop stand-alone care for PWID and also decentralise HIV treatment and care to community settings and involve peers in delivery should be considered.

**Keywords**

people who inject drugs; HIV; ART; Kenya; community

**Introduction**

HIV treatment and care access for People Who Inject Drugs (PWID) is a major challenge globally (Feelemyer, Des Jarlais, Arasteh, Abdul-Quader, & Hagan, 2015). In Kenya HIV prevalence for PWID is estimated at 18.3%, and 44% for women (National AIDS Control Council, 2014; Tun et al., 2015; Kurth et al., 2015), with just 8% of PWID in Nairobi living with HIV accessing ART in 2012 (Rhodes et al., 2015a).

PWIDs’ access to HIV treatment is limited by social and structural factors (Grubb et al., 2014) including: norms and understandings of treatment, social exclusion and stigma, drug policy, homelessness and criminalisation (Krusi, Wood, Montaner & Kerr, 2010; Rhodes & Sarang, 2012; Wolfe, Carrieri & Shepard, 2010).

The Kenyan government and partner community based organisations (CBOs) are seeking to respond to potential barriers and provide accessible HIV care for PWID. The principal mode of delivery for ART and ongoing HIV care – including initiation and prescription of medications, counselling, CD4 testing – is through fixed site HIV focused clinics serving the general population. Drug and harm reduction focused CBOs support care access through outreach or from ‘drop in centres’ with interventions such as counselling and assisted referrals (Lizcano, Muluve, Cleland, Kurth & Cherutich, 2014) and ART delivery from one drop in centre is also being piloted.

We explore accounts of PWID accessing care in Kenya to identify care barriers and facilitators in order to support the future development of services.

**Methods**

We report analysis of data collected through a longitudinal qualitative study that explored the social contexts for drug use and HIV risk in Kenya (Ref; Ref; Ref; Ref). The study was implemented across three sites in Kenya: Nairobi, Malindi and Ukunda, in partnership with Nairobi Outreach Services Trust (NOSET), The Omari Project and Teenswatch respectively. There were three waves of data collection between December 2012 and January 2014.

In-depth interviews with PWID explored experiences of HIV care as well as drug use, drug treatment, the emerging needle and syringe programme, and other issues as raised by respondents. Interviews were semi-structured and started with open questions around a respondent’s current concerns and situation around their drug use, before investigating specific themes of interest. Interviews were conducted in English or Swahili. Sampling for wave one of data collection was purposive, seeking a range of experiences according to gender and age. Later sampling was theoretical and sought to explore specific experiences.

PWID interviews were supplemented by observation in community settings, including drug using sites, and interviews with health care providers and staff working in community based outreach projects (n=15). All participants gave informed consent. Interviews were audio-recorded, transcribed, and translated in to English where necessary.

The analysis presented here focuses on accounts of PWID living with HIV (see table 1). Of the 118 people who use drugs interviewed, 44 disclosed they were living with HIV. A thematic analysis (Ezzy, 2002) approach was used. PWID LHIV accounts were open coded, with coding driven by focus issues for respondents and evidence from existing literature; these codes were triangulated with experiences from other PWID, providers and outreach staff, and community observation. The codes were then grouped in to overarching themes.

[insert table 1 here]

**Findings**

We developed three themes that give insight to PWID experiences of care. Table 2 has illustrative data extracts.

[insert table 2 here]

*The hardship of addiction and the costs of care*

The hardships of living with addiction – withdrawal pains and poverty, and the related need to constantly seek money (commonly through casual labour, sex work or petty crime) – were described as not possible by some to reconcile with the demands of clinic based care: “You go for money, or you go to the hospital”. Whilst HIV care is free, the costs of travel to clinics was often viewed as prohibitive: “I have to go to [nearby town], sometimes I don’t have fees to go there”. Time spent queuing at the clinic is also a ‘cost’, taking time away from sourcing money.

Arrangements between clinics and community based outreach projects helped overcome barriers of time, cost and queuing. There were adjustments to clinic routines such as priority for PWID within queues when accompanied by an outreach worker and assistance with transport by outreach projects to the clinic. The piloting of ART delivery at a community based drop in centres was welcomed for its ease of access: “I think it is good because this place is near… it is just here”. For some their experience of addiction meant they couldn’t prioritise care even with this support. Outreach projects also weren’t always able to offset cost constraints PWID faced through having limited funding themselves.

Drug treatment through residential rehabilitation was one route allowing people to prevent addiction limiting care access, although the long-term effects of this could be limited and it was prohibitively expensive for most (Ref). A few PWID, even whilst still actively using drugs, described how they could ‘find the time’ to get to clinics and struggle to source food to enable treatment access.

*The silencing of HIV in the community*

Some feared disclosing their HIV status to intimate partners, family, outreach projects, or the community, so limiting seeking care. HIV is seemingly rarely discussed openly amongst PWID, with people reporting they didn’t know which other PWID were HIV positive. Such discretion and secrecy arises from a context where being HIV positive could be seen as a symbol of being ‘already dead’. Social isolation was not total for PWID LHIV, with hopeful interpretations of HIV available and linked to support from family, friends and other people injecting drugs.

*Discrimination and support in the clinic*

Not attending a clinic and not wanting to seek care was linked to a fear or experience of discrimination. Some managed this potential for stigma and discrimination by hiding their injecting drug use from providers. Others spoke of HIV clinics as accepting, ‘respectful’ of PWID and treating people as ‘human’: “Those who distribute the medicine are courteous. The doctors who treat and give us medicine don’t look down upon us.”

**Discussion**

Some PWID in Kenya describe successfully engaging with HIV care in clinics serving the general population and overcoming barriers of travel, time and stigma. Outreach support is instrumental for some (Needle et al., 2005), while others draw on support from family, friends and providers. These findings also draw attention to social and structural barriers to care access in Kenya (Krusi et al., 2010): deferring treatment under the weight of addiction, the direct and indirect costs for clinic access, and fears and experiences of stigma from PWID, the community and care providers.

Adaptations to clinics serving the general population care could further support access for PWID (Beyrer et al., 2011), for example: extended opening hours and training of providers. Enabling interventions such as sufficient resourcing of CBOs supporting harm reduction efforts (Harm Reduction International, International Drug Policy Consortium & International HIV/AIDS Alliance), action on stigma (Stangl, Lloyd, Brady, Holland & Baral, 2013), the recent introduction of methadone (Rhodes et al., 2015a) and action to address PWID poverty (Ogembo, Angira, Mbugua, Abdallah & Abdool, 2014) could also support this clinic access.

The distance, costs and fear of stigma may however fundamentally limit for some PWID the potential to access clinics that serve the general population. Care models are needed that respond to a diversity of experiences: ‘one size does not fit all’ (Beyrer et al., 2011). ‘Stand-alone’ care for PWID – i.e. separate to care for the general population – could be acceptable for some, including in the context of methadone as now emerging in Kenya (and Tanzania (Bruce et al., 2013)).

Decentralised HIV treatment and care delivery in community based centres and mobile clinics (WHO et al., 2014; Altice et al., 2004) would also respond to structural challenges of cost, time and stigma in clinics. This decentralised support could include ART delivery from outreach drop in sites as currently piloted, and also peer support roles, such as community ART groups or distribution points (Bemelmans et al., 2014). Community delivery and task shifting to PWID could also be instrumental in tackling stigma (Ti & Kerr, 2013).

The study was limited by the contingencies of research with a highly marginalised population; heroin withdrawals and the demands of addiction often limited time in interviews and follow-up was limited by migration and incarceration. The analysis still provides an in-depth insight in to PWID experiences of HIV care access.

**Conclusions**

Community supported clinic based HIV care serving the general population is accessible for some PWID in Kenya, but the structural and social barriers of distance, time and community and facility level stigma and discrimination limit care for others. Clinics should adapt further, as well as develop additional entry points for care, including stand-alone care and decentralised community level delivery.

**References**

Altice, F.L., Mezger, J.A, Hodges, J., Bruce, R.D., Marinovich, A., Walton, M.,…Friedland, G.H. (2004) Developing a Directly Administered Antiretroviral Therapy Intervention for HIV-Infected Drug Users: Implications for Program Replication. *Clinical Infectious Diseases*, 38 (Supplement 5), S376-S387. doi: 10.1086/421400

Bemelmans, M., Baert, S., Goemaere, E., Wilkinson, L., Vandendyck, M., Van Cutsem, G., … Ford, N. (2014). Community-supported models of care for people on HIV treatment in sub-Saharan Africa. Tropical Medicine & International Health, 19(8), 968-977. doi:10.1111/tmi.12332

Beyrer, C., Baral, S., Kerrigan, D., El-Bassel, N., Bekker, L. & Celentano, D. (2011). Expanding the Space: Inclusion of Most-at-Risk Populations in HIV Prevention, Treatment, and Care Services. *Journal of Acquired Immune Deficiency Syndrome*, 57 (Supplement2), S96-S99. doi:10.1097/QAI.0b013e31821db944

Bruce, R.D., Lambdin, B., Chang, O., Masao, F., Mbwambo, J., Mteza, I., … Kilonzo, G. (2014). Lessons from Tanzania on the integration of HIV and tuberculosis treatments into methadone assisted treatment. *International Journal of Drug Policy*, 25(1), 22-25. doi:10.1016/j.drugpo.2013.09.005

Ezzy, D. (2002). *Qualitative analysis: Practice and Innovation*. London: Routledge.

Feelemyer, J., Des Jarlais, D., Arasteh, K., & Uusküla, A. (2015). Adherence to Antiretroviral Medications Among Persons Who Inject Drugs in Transitional, Low and Middle Income Countries: An International Systematic Review. *AIDS and Behavior*, 9, 575-83. Doi: 10.1007/s10461-014-0928-3

Harm Reduction International, International Drug Policy Consortium, International HIV/AIDS Alliance. The funding crisis for harm reduction. London: International Harm Reduction Association 2014.

Guise, A., Dimova, M., Ndimbii, J., Clark, P. & Rhodes, T. (2015). A qualitative analysis of transitions to heroin injection in Kenya: implications for HIV prevention and harm reduction. *Harm Reduction Journal*, 12; 27. doi: 10.1186/s12954-015-0061-2

Grubb, I.R., Beckham, S.W., Kazatchkine,M., Thomas, R.M., Albers, E.R., Cabral, M., … Beyrer, C. (2014). Maximizing the benefits of antiretroviral therapy for key affected populations. *Journal of the International AIDS Society*, 17:19320. doi: 10.7448/IAS.17.1.19320

Krüsi, A., Wood, E., Montaner, J. & Kerr, T. (2010). Social and structural determinants of HAART access and adherence among injection drug users. International Journal of Drug Policy, 21(1), 4-9. doi: 10.1016/j.drugpo.2009.08.003

Kurth, A., Cleland, C., Des Jarlais, D., Musyoki, H., Lizcano, J., Chhun N. & Cherutich, P. (2015). HIV Prevalence, Estimated Incidence, and Risk Behaviors Among People Who Inject Drugs in Kenya. *Journal of Acquired Immune Deficiency Syndromes,* 70(4):420-7. doi: 10.1097/QAI.0000000000000769.

Lizcano, J., Muluve, E., Cleland, C.E., Kurth, A. & Cherutich, P. (2014, June). Seek, Test, Treat and Retain (STTR) for People Who Inject Drugs (PWID) in Kenya: Findings from the TLC IDU stepped wedge study. Paper presented at the 9th International Association of Providers of AIDS Care, Miami, Florida.

National AIDS Control Council of Kenya. (2014). *Kenya AIDS Response progress report 2014, progress towards zero.* Nairobi: Government of Kenya. Retrieved from http://www.unaids.org/sites/default/files/country/documents/KEN\_narrative\_report\_2014.pdf

Needle, R.H., Burrows, D., Friedman, S.R.., Dorabjee, J., Touzé, G., Badrieva, L. …. Latkin, C. (2005). Effectiveness of community-based outreach in preventing HIV/AIDS among injecting drug users. *International Journal of Drug Policy,* 16, Supplement 1, 45-57. doi: 10.1016/j.drugpo.2005.02.009

Ref.

Ogembo, H.P., Angira, C.O., Mbugua, B., Abdallah, S. & Abdool, R. (2014, July). ***Reducing vulnerability of marginalized drug dependent communities in Nairobi Kenya through socioeconomic opportunities.* Paper presented at the 20th International AIDS Conference, Melbourne, Australia.**

Rhodes, T. & Sarang, A. (2012). Drug treatment and the conditionality of HIV treatment access: a qualitative study in a Russian city. *Addiction*, 107, 1827-1836. doi: 10.1111/j.1360-0443.2012.03880.x

Ref

Ref

Stangl, A.L., Lloyd, J.K., Brady, L.M., Holland, C.E. & Baral, S. (2013) A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: how far have we come? *Journal of the International AIDS Society, 1*6(Suppl 2):18734. doi: 10.7448/IAS.16.3.18734

Ti, L. & Kerr, T. (2013). Task shifting redefined: removing social and structural barriers to improve delivery of HIV services for people who inject drugs. Harm Reduction Journal, 10, 1. doi: 10.1186/1477-7517-10-20

Tun, W., Sheehy, M., Broz, D., Okal, J., Muraguri, N., Raymond, F. … Geibel, S. (2015). HIV and STI Prevalence and Injection Behaviors Among People Who Inject Drugs in Nairobi: Results from a 2011 Bio-behavioral Study Using Respondent-Driven Sampling. *AIDS Behavior*, 19, 24-35. doi: 10.1007/s10461-014-0936-3

Wolfe, D., Carrieri, M.P. & Shepard, D. (2010). Treatment and care for injecting drug users With HIV infection: A review of barriers and ways forward. *Lancet*, 376, 355-366. doi: 10.1016/S0140-6736(10)60832-X

World Health Organisation. (2014). *Consolidated guidelines on HIV prevention, diagnoses, treatment and care for key populations*. Geneva, Switzerland: World Health Organisation.

**Tables**

Table 1 Summary of study respondents and experiences of HIV

|  |  |  |
| --- | --- | --- |
| **People interviewed** | **Experiences of HIV** | |
| **HIV testing** | **HIV treatment and care** |
| 33 women (29%)  85 men (71%)  Average age 31 (range 19-49)  109 people interviewed at baseline, with selected repeat interviews at wave 2 (32 respondents) and 3 (26 respondents), with 20 people interviewed 3 times, and 13 interviewed 2 times. | 44 PWID reported living with HIV  16 women  28 men  109 reported testing for HIV, 4 had never tested, 5 didn’t report whether or not they had tested. | 22 people reported challenges  7 women and 15 men had either experienced temporary challenges – for example, an interruption to ART – and were not engaged in care at the time of interview, or had previously faced challenges and were now reengaged in care, or had never accessed care since receiving a positive test result. |
| 20 people reported ongoing care without challenges  8 women and 12 men reported being engaged in ongoing HIV treatment and care without interruption, involving regular clinic attendance and adherence to medicines – whether antiretroviral treatment or antibiotic prophylaxis (septrin). |
| 2 people gave no account of their care. |

Table 2 - Illustrative quotes from PWID experiences of care

|  |
| --- |
| **Theme 1: the hardship of addiction and the costs of care**  *Deferring care: Since I left prison, I left those drugs [ART], I have not taken […] It is this addiction that we put ahead to the point that you are defeated to take care of your own health. (Baba)*  *Outreach support: If I need to go to hospital today and I have not dealt with withdrawal, I will not go to hospital, you see? And [the outreach project] help us. Because [the outreach worker] comes for you…. you are wanted...they pick you up, you will be taken and given medicine. (Debbie)*  *Limits on outreach support: Yeah they [outreach workers] have tried. They are telling me each and every time. ‘Let’s go, this and this’, but I’m ignoring, and thinking of the stuff. The stuff has taken control of my life. (Ricky)* |
| **Theme 2: the silencing of HIV in the community**  *Fear of community stigma: R: I’m afraid to go and…I’m afraid, I don’t know why… I can go to the hospital to have some help. Then I go back (coughs)…*  *I: Why do you feel afraid of the treatment of the hospital?*  *R… I don’t know, I don’t like so many people to see I’m sick. (Martha)*  *Secrecy amongst PWID: I do not know any other sick person. These are discreet people. I can't tell… I do not know. Others are afraid, they cannot tell you that they are infected. (Haj)*  *Community support: I wanted to kill myself, but someone told me don’t kill yourself because you are HIV positive, you go to the hospital, you take the medicine, you eat good and maybe you recover your body. And I listened to that guy and when I went there they gave me the medicine, the septrin and I started eating. (Maggie)* |
| *Theme 3: Discrimination and support in the clinic*  Discrimination in the clinic: *When you go there he tells you to go back and bathe first, then come back. You see? Sometimes he tells you, sit there. He segregates you from others, tells you to sit somewhere else, he will attend to you later, now you see, you start feeling like you do not belong in such a place. You see that, you go away. (Jimmy)*  *Hiding your identity: I: I was wondering whether drug users get treated differently.*  *R: They won’t know, eh, unless you say you are a drug user.*  *I: Ooh, okay.*  *R: They won’t know, unless you tell them.*  *I: And would you tell them?*  *R: No*  *I: No*  *R: I won’t dare to do that.(Juma)*  Supportive providers: *I went to the VCT center and told them that I am going for rehabilitation and I will stay there for three months so they should give me drugs that will last the three months. I am thankful they gave and listened to me.(Azima)* |