



Published in final edited form as:

*AIDS Care*. 2021 November ; 33(11): 1436–1444. doi:10.1080/09540121.2020.1808567.

## Mobility and Structural Barriers in Rural South Africa Contribute to Loss to Follow up from HIV Care

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### Abstract

Retention in HIV care is crucial to sustaining viral load suppression, and reducing HIV transmission, yet loss to follow-up (LTFU) in South Africa remains substantial. We conducted a mixed methods evaluation in rural South Africa to characterize ART disengagement in neglected rural settings. Using convenience sampling, surveys were completed by 102 PLWH who disengaged from ART (minimum 90 days) and subsequently resumed care. A subset (n=60) completed individual in-depth interviews. Median duration of ART discontinuation was 9 months (IQR 4–22). Participants had HIV knowledge gaps regarding HIV transmission and increased risk of tuberculosis. The major contributors to LTFU were mobility and structural barriers. PLWH traveled for an urgent family need or employment, and were not able to collect ART while away. Structural barriers included inability to access care, due to lack of financial resources to reach distant clinics. Other factors included dissatisfaction with care, pill fatigue, lack of social support, and stigma. Illness was the major precipitant of returning to care. Mobility and structural barriers impede longitudinal HIV care in rural South Africa, threatening the gains made from expanded ART access. To achieve 90-90-90, future interventions, including emphasis on patient centered care, must address barriers relevant to rural settings.

### Keywords

antiretroviral therapy; re-engagement; rural; mobility; structural barriers; patient centered care

### Background

In 2018, an estimated 7.7 million South Africans were living with HIV, with suboptimal outcomes (UNAIDS, 2018). Though South Africa has expanded access resulting in the largest global ART programme, the maturing HIV epidemic brings challenges with retention

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This data presented in this manuscript has not been presented at conferences.

in care(Bassett et al., 2010; Bassett et al., 2009; Gardner, McLees, Steiner, Del Rio, & Burman, 2011; Geng et al., 2010; Kranzer, Govindasamy, Ford, Johnston, & Lawn, 2012; Kranzer, Zeinecker, et al., 2010; Rosen & Fox, 2011; Sheno et al., 2017; South African Department of Health, 2007, 2013; UNAIDS, 2018; World Health Organization, 2013).

Retention is critical to sustaining virologic suppression, improving outcomes and reducing transmission, yet disengagement(Anand, Springer, Copenhaver, & Altice, 2010; Arnesen, Moll, & Sheno, 2017; Bartlett et al., 2006; Hammond & Harry, 2008; Palella et al., 1998; Prentiss, Power, Balmas, Tzuang, & Israelski, 2004; Thompson et al., 2012) threatens individual outcomes and increases transmission, jeopardizing the progress from ART expansion. Despite this, barriers to adherence and retention facilitate loss to follow up (LTFU). Failure to achieve viral load suppression occurs in 10–20% in South Africa. (Council, 2018) Furthermore, rates of LTFU are 10–20%,(Arnesen et al., 2017; Dalal et al., 2008; Fox M et al., 2016; Fox & Rosen, 2010; Kaplan et al., 2017) and are attributed to transportation costs, missing work or school, wait times, insufficient time with providers, stigma, confidentiality concerns, and treatment fatigue(Rosen & Fox, 2011; Ware et al., 2013), though data from rural settings is sparse. Limited data ascribes reengagement to health concerns, pressure from family members, and engagement with clinic staff. (Cunningham et al., 2014; HB, 2015; Kranzer, Lewis, et al., 2010; Layer EH, 2014; Ndiaye et al., 2009) Here, we assess LTFU and re-engagement specific to rural settings, to inform strategies targeting disengagement.

## Methods

### Setting

Church of Scotland Hospital (COSH) is a 350-bed government hospital in rural KwaZulu-Natal province. Nearly 200,00 traditional Zulu people live in one of the poorest regions nationwide, (Massyn N et al., 2016) characterized by high unemployment (50%), lack of education (41%), lack of access to running water (96%), and high HIV prevalence (30% of antenatal patients) (Naomi Massyn, Ashnie Padarath, Nazia Peer, & Day, 2017; Statistics South Africa, 2017). All PLWH are ART eligible, irrespective of CD4 count(Meintjes et al., 2015) and collect ART monthly; once stable for 12 months, patients can obtain a two-month supply.

### Design

Potential participants were referred by COSH doctors. Per local protocol, those LTFU must be evaluated at COSH prior to restarting ART. Eligible participants were age 18, not taking previous ART for 90 days, and excluded if too sick to walk to a private room or provide consent.

### Data collection and analysis

After written informed consent, questionnaires and interviews were conducted in Zulu, eliciting participants' HIV knowledge, stigma, barriers to care, reasons for disengaging and returning to care. Survey items are listed in Tables 1–4. Stigma items were adapted from a validated scale.(Somma et al., 2008) Qualitative assessment (Tables 5–6) was subsequently

added after identifying the need for nuanced responses (Creswell, 2014). Responses were iteratively grouped into themes by two authors using grounded theory framework (Bradley, Curry, & Devers, 2007). A codebook was developed based on theory-driven themes. Emerging inductive themes were identified and used to iteratively modify the interview guide and initial codebook. Interviews continued until thematic saturation was achieved.

## Results

Among 102 respondents, median age was 36 (IQR 28–44), 47% were male, median ART discontinuation was 9 months (IQR 4–22), and 83% received a government grant. Approximately 80% knew others taking ART, reported a partner living with HIV, had disclosed their status, and denied ART adverse effects (Table 1). Participants had overall high HIV knowledge, though gaps existed regarding transmission. Two-thirds and one-third were unaware that ART prevents transmission to sexual partners and that HIV increases tuberculosis risk, respectively. The majority (75%) first sought care at their local clinic, though 63% and 25% also saw private doctors and traditional healers, respectively (Table 3). Clinics were regarded as distant, too expensive to reach, with extensive wait times; this was strongly substantiated in the qualitative data (Table 5). Simultaneously, respondents were (Table 4) comfortable with doctors and clinic visits (93%), affirmed ability to obtain refills (94%), and not concerned about side effects (74%).

Many participants endorsed embarrassment from having, and worried (Table 4, 5) they will die from, HIV,

“I was scared to go to the clinic because I might come across people who know me. I was ashamed of having HIV.”

However, while 25% had never disclosed their diagnosis to anyone, 95% were not concerned about a household member learning their status. Respondents (99%) wanted to be healthy to take care of their families and had family supporting their ART, however were worried about their employers not being supportive.

“I got a job and I was afraid to tell my manager that I’m taking ARVs. I was scared of losing my job.”

Most (74%) felt that others would think better of them if they took ART.

Mobility and financial challenges accessing clinics were the major identified themes contributing to disengagement (Table 5, 6). Participants reported moving without arranging a formal transfer of care, often for an urgent family need or employment, and perceived barriers to transferring care.

“...My family is poor and I have 4 children...I could not travel to the clinic. I got frustrated with the nurses at clinic and stopped going completely because they refused to understand the situation.”

Participants repeatedly reported a lack of financial resources to access distant clinics.

“I worked far from home and had no money to come back for my appointments.”

Other barriers included lack of social support, medication adverse effects, pill fatigue, alcohol use, traditional medicine use and incarceration.

“When I found out about my HIV status I told my husband and he was in denial about the matter and said I should not take ARVs.”

“I just got tired of taking my medication and stopped collecting it since last year.”

The most common reason for returning to care (Table 6) was severe illness, primarily TB, and participants reported subsequently reinitiating ART.

“I became very sick, so went to the clinic and they told me that I will not be okay anytime soon because I was not taking my treatment anymore.”

Respondents also wanted to take responsibility for themselves or their children, avoid illness, or had finally accepted their HIV diagnosis.

“I realized that this is my life that I am not taking care of, I started to be sick again and I thought I was going to die and leave my children.”

Some re-engaged because clinic staff convinced them to return; some returned because the previous barriers had resolved.

“The sister in charge of the clinic reached out to me when she saw I was not coming to clinic. I explained why I hadn’t been coming. The clinic now lets me leave my blue book at the clinic and I can put my pills in a plastic bag so they do not make the noise that they make in the pill bottle.”

## Discussion

We present a quantitative and narrative evaluation of PLWH in rural KwaZulu-Natal who had previously disengaged and then returned to care, to obtain insight on barriers and facilitators of longitudinal HIV care in rural settings. Major contributors to disengagement were mobility and structural barriers to accessing care, despite high motivation to continue ART.

Moving away, even temporarily, resulted in challenges maintaining ART. Mobility, often for income-generating opportunities, education, and family illnesses,(Katharine Hall, Amina Ebrahim, Ariane De Lannoy, & Makiwane, 2015; Ware et al., 2013) is a barrier to successful long-term retention.(Clouse et al., 2018; Clouse, Vermund, et al., 2017; Hoddinott et al., 2018) but remains underappreciated in rural populations. Participants reported perceived or actual difficulties obtaining a formal transfer letter, without which, they could not access ART. Not unexpectedly, those formally transferring care are more likely to reengage and have better outcomes than those who are LTFU(Hickey et al., 2016). Furthermore, mobile populations may demonstrate greater risk behaviors(Camlin, Akullian, et al., 2018; Camlin, Cassels, & Seeley, 2018). Patients should be educated, regularly, about how to transfer care should the need arise.

Current systems are insufficient for providers to reconcile ART history if a patient presents without records(Camlin, Akullian, et al., 2018; Hoddinott et al., 2018; Myer et al., 2017).

Networked electronic records across health facilities would enable medication collection while away from their primary clinic(Clouse, Phillips, & Myer, 2017; Clouse, Vermund, et al., 2017). mHealth strategies have demonstrated effectiveness in improving chronic disease outcomes(Drake et al., 2017; Hirsch-Moverman et al., 2017; Nachega et al., 2016), and if widely implementable, may improve retention in rural areas.

Competing demands and economic concerns took precedence over appointments(Ware et al., 2013), exacerbated by dissatisfaction with traditional clinic-based care. Successful longitudinal ART requires adaptation of care models(Labhardt et al., 2018; Plazy et al., 2017). Expanding mobile clinics, dispensing sites, multi-month prescriptions, and community-based ART delivery are patient-centered strategies that could decrease the economic and time burden on PLWH and ease HCW workload.

We observed HIV-related stigma in both quantitative (Table 4) and qualitative (Table 5) responses. Though most had disclosed to a partner, PLWH were embarrassed, avoided community members or employers learning their status, and avoided being seen at the HIV clinic. At our public hospital, ART prescription mandates a different color clinic book and medication pickup from a distinct pharmacy than HIV-negative patients, making PLWH identifiable. Integration of HIV care into primary care services, underway in South Africa, will help address this, in addition to mobile clinics, HCW training, and community care models(Jones & Cameron, 2017; Loeliger, Niccolai, Mtungwa, Moll, & Sheno, 2016; Long et al., 2016).

Despite knowing others taking ART, disclosing their status, and family support, most reported lacking social support. This may reflect a distinction between support from trusted family members vs. stigma in the general community and requires further investigation. (Rueda S, 2016) Previously, ART initiation required a patient-selected treatment supporter, but is now not compulsory. Emphasis on patient-centered care, including resurrecting the requirement for a treatment supporter(Duwell et al., 2013), introducing community-wide stigma interventions, expanding support groups and adherence clubs(Dageid, 2014; Grimsrud, Lesosky, Kalombo, Bekker, & Myer, 2016; James et al., 2018), and ensuring dedicated staff for adherence support are evidence-based strategies to mitigate stressors associated with longitudinal HIV care.(Hu et al., 2018)

Surprisingly, we identified gap in knowledge about HIV treatment as prevention. As the motivation to protect partners may influence adherence and retention in care, strategies to address this critical gap include enhanced health care worker and counselor training as well as public health media campaigns.(Bavinton et al., 2016; Carter et al., 2015; Mooney et al., 2017)

Disengaged patients often resurface with advanced disease, resulting in high morbidity and mortality(Brinkhof, Pujades-Rodriguez, & Egger, 2009; Lahuerta et al., 2014; McNairy, Abrams, Rabkin, & El-Sadr, 2017; Wilkinson, Skordis-Worrall, Ajose, & Ford, 2015). Severe illness, particularly TB, was the most common reason for returning to care. Ongoing education about the consequences of discontinuing ART, possibly from peer educators, and expanding TB preventive therapy implementation, may be helpful.

We recognize several limitations. Participants represent a convenience sample of ambulatory patients resuming care, and results may not be generalizable to all LTFU. Additionally, lack of an established scale may undermine the HIV knowledge assessment.

## Conclusion

These findings highlight challenges faced by PLWH in rural resource-limited settings and inform potential interventions to facilitate longitudinal, patient-centered HIV care. Strategies include system-level facilitated transfer of care, multi-month ART prescriptions, expanding medication distribution sites, including community-based dispensing, integrating ART into primary care, and facilitating linkage to remote facilities when away from their home clinic. Lastly, HCW should be capacitated to identify patients' barriers to chronic care and intervene on those at high risk of LTFU.(Arnesen et al., 2017)

## Acknowledgements

The authors wish to thank the staff at Church of Scotland Hospital and Philanjalo NGO for their dedication to the Msinga community.

### Support:

The study was funded by Doris Duke Clinical Research Fellowship (AH, #2016178), NIAID (SS, #K23AI089260), Doris Duke/YCCI (SS, #2015216), Patterson Foundation (#14-001927), Irene Diamond Foundation (#2006078).

## Availability of data and material

The datasets generated and analysed during the current study are available in the Mendeley repository. It can be found at this link, <http://dx.doi.org/10.17632/rg27cvw69m.1>

## References

- Anand P, Springer SA, Copenhaver MM, & Altice FL (2010). Neurocognitive impairment and HIV risk factors: a reciprocal relationship. *AIDS Behav*, 14(6), 1213–1226. 10.1007/s10461-010-9684-1 [PubMed: 20232242]
- Arnesen R, Moll AP, & Shenoj SV (2017). Predictors of loss to follow-up among patients on ART at a rural hospital in KwaZulu-Natal, South Africa. *PloS one*, 12(5), e0177168. 10.1371/journal.pone.0177168 [PubMed: 28542309]
- Bartlett JA, Fath MJ, Demasi R, Hermes A, Quinn J, Mondou E, & Rousseau F (2006). An updated systematic overview of triple combination therapy in antiretroviral-naive HIV-infected adults. *Aids*, 20(16), 2051–2064. 10.1097/01.aids.0000247578.08449.ff [PubMed: 17053351]
- Bassett IV, Regan S, Chetty S, Giddy J, Uhler LM, Holst H, ... Losina E (2010). Who starts antiretroviral therapy in Durban, South Africa?... not everyone who should. *AIDS*, 24 Suppl 1, S37–44. 10.1097/01.aids.0000366081.91192.1c
- Bassett IV, Wang B, Chetty S, Mazibuko M, Bearnot B, Giddy J, ... Freedberg KA (2009). Loss to care and death before antiretroviral therapy in Durban, South Africa. *J Acquir Immune Defic Syndr*, 51(2), 135–139. [PubMed: 19504725]
- Bavinton BR, Holt M, Grulich AE, Brown G, Zablotska IB, & Prestage GP (2016). Willingness to Act upon Beliefs about 'Treatment as Prevention' among Australian Gay and Bisexual Men. *PloS one*, 11(1), e0145847. 10.1371/journal.pone.0145847 [PubMed: 26741143]
- Bradley EH, Curry LA, & Devers KJ (2007). Qualitative Data Analysis for Health Services Research: Developing Taxonomy, Themes, and Theory. *Health Serv Res*, 42(4), 1758–1772. 10.1111/j.1475-6773.2006.00684.x [PubMed: 17286625]

- Brinkhof MW, Pujades-Rodriguez M, & Egger M (2009). Mortality of patients lost to follow-up in antiretroviral treatment programmes in resource-limited settings: systematic review and meta-analysis. *PloS one*, 4(6), e5790. 10.1371/journal.pone.0005790 [PubMed: 19495419]
- Camlin CS, Akullian A, Neilands TB, Getahun M, Eyul P, Maeri I, ... Charlebois ED (2018). Population mobility associated with higher risk sexual behaviour in eastern African communities participating in a Universal Testing and Treatment trial. *J Int AIDS Soc*, 21 Suppl 4, e25115. 10.1002/jia2.25115 [PubMed: 30027668]
- Camlin CS, Cassels S, & Seeley J (2018). Bringing population mobility into focus to achieve HIV prevention goals. *J Int AIDS Soc*, 21 Suppl 4, e25136. 10.1002/jia2.25136 [PubMed: 30027588]
- Carter A, Lachowsky N, Rich A, Forrest JI, Sereda P, Cui Z, ... Hogg RS (2015). Gay and bisexual men's awareness and knowledge of treatment as prevention: findings from the Momentum Health Study in Vancouver, Canada. *J Int AIDS Soc*, 18(1), 20039. 10.7448/ias.18.1.20039 [PubMed: 26268817]
- Clouse K, Fox MP, Mongwenyana C, Motlathledi M, Buthelezi S, Bokaba D, ... Vermund SH (2018). "I will leave the baby with my mother": Long-distance travel and follow-up care among HIV-positive pregnant and postpartum women in South Africa. *J Int AIDS Soc*, 21 Suppl 4, e25121. 10.1002/jia2.25121 [PubMed: 30027665]
- Clouse K, Phillips T, & Myer L (2017). Understanding data sources to measure patient retention in HIV care in sub-Saharan Africa. *Int Health*, 9(4), 203–205. 10.1093/inthealth/ihx024 [PubMed: 28810667]
- Clouse K, Vermund SH, Maskew M, Lurie MN, MacLeod W, Malete G, ... Fox MP (2017). Mobility and Clinic Switching Among Postpartum Women Considered Lost to HIV Care in South Africa. *J Acquir Immune Defic Syndr*, 74(4), 383–389. 10.1097/qai.0000000000001284 [PubMed: 28225717]
- Council, H. S. R. (2018). HIV impact assessment summary: The Fifth South African National HIV Prevalence, Incidence, Behaviour and Communication Survey, 2017.
- Creswell JW (2014). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches* (4th ed.). CA: Thousand Oaks: Sage Publications.
- Cunningham CO, Buck J, Shaw FM, Spiegel LS, Heo M, & Agins BD (2014). Factors associated with returning to HIV care after a gap in care in New York State. *J Acquir Immune Defic Syndr*, 66(4), 419–427. 10.1097/qai.0000000000000171 [PubMed: 24751434]
- Dageid W (2014). Support groups for HIV-positive people in South Africa: who joins, who does not, and why? *Afr J AIDS Res*, 13(1), 1–11. 10.2989/16085906.2014.886601 [PubMed: 25174510]
- Dalal RP, Macphail C, Mqhayi M, Wing J, Feldman C, Chersich MF, & Venter WD (2008). Characteristics and outcomes of adult patients lost to follow-up at an antiretroviral treatment clinic in johannesburg, South Africa. *J Acquir Immune Defic Syndr*, 47(1), 101–107. 10.1097/QAI.0b013e31815b833a [PubMed: 17971708]
- Drake AL, Unger JA, Ronen K, Matemo D, Perrier T, DeRenzi B, ... John-Stewart G (2017). Evaluation of mHealth strategies to optimize adherence and efficacy of Option B+ prevention of mother-to-child HIV transmission: Rationale, design and methods of a 3-armed randomized controlled trial. *Contemp Clin Trials*, 57, 44–50. 10.1016/j.cct.2017.03.007 [PubMed: 28315480]
- Duwell MM, Knowlton AR, Nachega JB, Efron A, Goliath R, Morroni C, ... Chaisson RE (2013). Patient-nominated, community-based HIV treatment supporters: patient perspectives, feasibility, challenges, and factors for success in HIV-infected South African adults. *AIDS Patient Care STDS*, 27(2), 96–102. 10.1089/apc.2012.0348 [PubMed: 23373664]
- Fox M, Bor J, MacLeod W, Maskew M, Brennan A, Stevens W, & S., C. (2016). Is Retention on ART Underestimated Due to Patient Transfers? Estimating System-Wide Retention Using a National Labs Database in South Africa. 21st International AIDS Conference, Durban, Abstract TUAB0205.
- Fox MP, & Rosen S (2010). Patient retention in antiretroviral therapy programs up to three years on treatment in sub-Saharan Africa, 2007–2009: systematic review. *Trop Med Int Health*, 15 Suppl 1, 1–15. 10.1111/j.1365-3156.2010.02508.x

- Gardner EM, McLees MP, Steiner JF, Del Rio C, & Burman WJ (2011). The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clin Infect Dis*, 52(6), 793–800. 10.1093/cid/ciq243 [PubMed: 21367734]
- Geng EH, Nash D, Kambugu A, Zhang Y, Braitstein P, Christopoulos KA, ... Martin JN (2010). Retention in care among HIV-infected patients in resource-limited settings: emerging insights and new directions. *Curr HIV/AIDS Rep*, 7(4), 234–244. 10.1007/s11904-010-0061-5 [PubMed: 20820972]
- Grimsrud A, Lesosky M, Kalombo C, Bekker LG, & Myer L (2016). Implementation and Operational Research: Community-Based Adherence Clubs for the Management of Stable Antiretroviral Therapy Patients in Cape Town, South Africa: A Cohort Study. *J Acquir Immune Defic Syndr*, 71(1), e16–23. 10.1097/qai.0000000000000863 [PubMed: 26473798]
- Hammond R, & Harry TC (2008). Efficacy of antiretroviral therapy in Africa: effect on immunological and virological outcome measures -- a meta-analysis. *Int J STD AIDS*, 19(5), 291–296. 10.1258/ijsa.2007.007248 [PubMed: 18482957]
- HB, G. V. a. K. (2015). Patient Perspectives on Leaving, Disengaging, and Returning to HIV Care. *AIDS Patient Care STDS*, 29(7), 400–407. 10.1089/apc.2015.0001 [PubMed: 26065908]
- Hickey MD, Omollo D, Salmen CR, Mattah B, Blat C, Ouma GB, ... Geng EH (2016). Movement between facilities for HIV care among a mobile population in Kenya: transfer, loss to follow-up, and reengagement. *AIDS Care*, 28(11), 1386–1393. 10.1080/09540121.2016.1179253 [PubMed: 27145451]
- Hirsch-Moverman Y, Daftary A, Yuengling KA, Saito S, Ntoane M, Frederix K, ... Howard AA (2017). Using mHealth for HIV/TB Treatment Support in Lesotho: Enhancing Patient-Provider Communication in the START Study. *J Acquir Immune Defic Syndr*, 74 Suppl 1, S37–s43. 10.1097/qai.0000000000001202 [PubMed: 27930610]
- Hoddinott G, Myburgh H, de Villiers L, Ndubani R, Mantantana J, Thomas A, ... Reynolds L (2018). Households, fluidity, and HIV service delivery in Zambia and South Africa - an exploratory analysis of longitudinal qualitative data from the HPTN 071 (PopART) trial. *J Int AIDS Soc*, 21 Suppl 4, e25135. 10.1002/jia2.25135 [PubMed: 30027687]
- Hu J, Geldsetzer P, Steele SJ, Matthews P, Ortblad K, Solomon T, ... Barnighausen T (2018). The impact of lay counselors on HIV testing rates: Quasi-experimental evidence from lay counselor redeployment in KwaZulu-Natal, South Africa. *Aids*. 10.1097/qad.0000000000001924
- James S, Martin CE, Moalusi B, Beery M, Pahad S, & Imrie J (2018). Integrated access to care and treatment (I ACT) support groups for adolescents living with HIV in public healthcare facilities in South Africa: feasibility and acceptability for scaling up. *AIDS Care*, 1–7. 10.1080/09540121.2018.1478384
- Jones M, & Cameron D (2017). Evaluating 5 years' NIMART mentoring in South Africa's HIV treatment programme: Successes, challenges and future needs. *S Afr Med J*, 107(10), 839–842. 10.7196/SAMJ.2017.v107i10.12392 [PubMed: 29022525]
- Kaplan SR, Oosthuizen C, Stinson K, Little F, Euvrard J, Schomaker M, ... Meintjes G (2017). Contemporary disengagement from antiretroviral therapy in Khayelitsha, South Africa: A cohort study. *Plos Med*, 14(11), e1002407. 10.1371/journal.pmed.1002407 [PubMed: 29112692]
- Hall Katharine, Ebrahim Amina, De Lannoy Ariane, & Makiwane M (2015). Youth and mobility: Linking movement to opportunity South African Child Gauge. Cape Town: Children's Institute, University of Cape Town.
- Kranzer K, Govindasamy D, Ford N, Johnston V, & Lawn SD (2012). Quantifying and addressing losses along the continuum of care for people living with HIV infection in sub-Saharan Africa: a systematic review. *J Int AIDS Soc*, 15(2), 17383. 10.7448/ias.15.2.17383 [PubMed: 23199799]
- Kranzer K, Lewis JJ, Ford N, Zeinecker J, Orrell C, Lawn SD, ... Wood R (2010). Treatment interruption in a primary care antiretroviral therapy program in South Africa: cohort analysis of trends and risk factors. *J Acquir Immune Defic Syndr*, 55(3), e17–23. 10.1097/QAI.0b013e3181f275fd [PubMed: 20827216]
- Kranzer K, Zeinecker J, Ginsberg P, Orrell C, Kalawe NN, Lawn SD, ... Wood R (2010). Linkage to HIV care and antiretroviral therapy in Cape Town, South Africa. *PloS one*, 5(11), e13801. 10.1371/journal.pone.0013801 [PubMed: 21072191]



- Labhardt ND, Ringera I, Lejone TI, Klimkait T, Muhairwe J, Amstutz A, & Glass TR (2018). Effect of Offering Same-Day ART vs Usual Health Facility Referral During Home-Based HIV Testing on Linkage to Care and Viral Suppression Among Adults With HIV in Lesotho: The CASCADE Randomized Clinical Trial. *JAMA*, 319(11), 1103–1112. 10.1001/jama.2018.1818 [PubMed: 29509839]
- Lahuerta M, Wu Y, Hoffman S, Elul B, Kulkarni SG, Remien RH, ... Nash D (2014). Advanced HIV disease at entry into HIV care and initiation of antiretroviral therapy during 2006–2011: findings from four sub-saharan African countries. *Clin Infect Dis*, 58(3), 432–441. 10.1093/cid/cit724 [PubMed: 24198226]
- Layer EH, Beckham SW, Ntogwisangu J, Mwampashi A, Davis WW, Kerrigan DL, and Kennedy CE. (2014). “I Pray That They Accept Me Without Scolding:” Experiences with Disengagement and Re-Engagement in HIV Care and Treatment Services in Tanzania. *AIDS Patient Care STDS*, 28(9), 483–488. 10.1089/apc.2014.0077 [PubMed: 25093247]
- Loeliger KB, Niccolai LM, Mtungwa LN, Moll A, & Shenoi SV (2016). Antiretroviral therapy initiation and adherence in rural South Africa: community health workers’ perspectives on barriers and facilitators. *AIDS care*, 28(8), 982–993. 10.1080/09540121.2016.1164292 [PubMed: 27043077]
- Long LC, Rosen SB, Brennan A, Moyo F, Sauls C, Evans D, ... Fox MP (2016). Treatment Outcomes and Costs of Providing Antiretroviral Therapy at a Primary Health Clinic versus a Hospital-Based HIV Clinic in South Africa. *PLoS One*, 11(12), e0168118. 10.1371/journal.pone.0168118 [PubMed: 27942005]
- Massyn N, Peer N, English R, Padarath A, Barron P, & Day C. (2016). *District Health Barometer 2015/16*. Durban: Health Systems Trust.
- McNairy ML, Abrams EJ, Rabkin M, & El-Sadr WM (2017). Clinical decision tools are needed to identify HIV-positive patients at high risk for poor outcomes after initiation of antiretroviral therapy. *PLoS Med*, 14(4), e1002278. 10.1371/journal.pmed.1002278 [PubMed: 28419097]
- Meintjes G, Black J, Conradie F, Dlamini S, Maartens G, Manzini TC, ... Wilson D (2015). Southern African HIV Clinicians Society adult antiretroviral therapy guidelines: Update on when to initiate antiretroviral therapy. *South Afr J HIV Med*, 16(1), 428. 10.4102/sajhivmed.v16i1.428 [PubMed: 29568598]
- Mooney AC, Gottert A, Khoza N, Rebombo D, Hove J, Suárez AJ, ... Lippman SA (2017). Men’s Perceptions of Treatment as Prevention in South Africa: Implications for Engagement in HIV Care and Treatment. *AIDS Educ Prev*, 29(3), 274–287. 10.1521/aeap.2017.29.3.274 [PubMed: 28650225]
- Myer L, Iyun V, Zerbe A, Phillips TK, Brittain K, Mukonda E, ... Abrams EJ (2017). Differentiated models of care for postpartum women on antiretroviral therapy in Cape Town, South Africa: a cohort study. *J Int AIDS Soc*, 20(Suppl 4), 21636. 10.7448/ias.20.5.21636 [PubMed: 28770593]
- Nachege JB, Skinner D, Jennings L, Magidson JF, Altice FL, Burke JG, ... Theron GB (2016). Acceptability and feasibility of mHealth and community-based directly observed antiretroviral therapy to prevent mother-to-child HIV transmission in South African pregnant women under Option B+: an exploratory study. *Patient Prefer Adherence*, 10, 683–690. 10.2147/ppa.s100002 [PubMed: 27175068]
- Massyn Naomi, Padarath Ashnie, Peer Nazia, & Day C (2017). *District Health Barometer 2016/17*. Durban, South Africa: National Department of Health.
- Ndiaye B, Ould-Kaci K, Salleron J, Bataille P, Bonnevie F, Cochonat K, ... Yazdanpanah Y (2009). Characteristics of and outcomes in HIV-infected patients who return to care after loss to follow-up. *AIDS*, 23(13), 1786–1789. 10.1097/QAD.0b013e32832e3469 [PubMed: 19531927]
- Palella FJ Jr., Delaney KM, Moonman AC, Loveless MO, Fuhrer J, Satten GA, ... Holmberg SD (1998). Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. HIV Outpatient Study Investigators. *N Engl J Med*, 338(13), 853–860. 10.1056/NEJM199803263381301 [PubMed: 9516219]
- Plazy M, Perriat D, Gumede D, Boyer S, Pillay D, Dabis F, ... Orne-Gliemann J (2017). Implementing universal HIV treatment in a high HIV prevalence and rural South African setting - Field experiences and recommendations of health care providers. *PLoS one*, 12(11), e0186883. 10.1371/journal.pone.0186883 [PubMed: 29155832]

- Prentiss D, Power R, Balmes G, Tzuang G, & Israelski DM (2004). Patterns of marijuana use among patients with HIV/AIDS followed in a public health care setting. *J Acquir Immune Defic Syndr*, 35(1), 38–45. [PubMed: 14707790]
- Rosen S, & Fox MP (2011). Retention in HIV care between testing and treatment in sub-Saharan Africa: a systematic review. *PLoS Med*, 8(7), e1001056. 10.1371/journal.pmed.1001056 [PubMed: 21811403]
- Rueda S, MS, Chen S, Gogolishvili D, Globerman J, Chambers L, Wilson M, Logie CH, Shi Q, Morassaei S, Rourke SB., (2016). Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. *BMJ open*, 6(7), e011453. 10.1136/bmjopen-2016-011453
- Shenoi SV, Moll AP, Brooks RP, Kyriakides T, Andrews L, Kompala T, ... Friedland G (2017). Integrated Tuberculosis/Human Immunodeficiency Virus Community-Based Case Finding in Rural South Africa: Implications for Tuberculosis Control Efforts. *Open Forum Infect Dis*, 4(3), ofx092. 10.1093/ofid/ofx092 [PubMed: 28695145]
- Somma D, Thomas BE, Karim F, Kemp J, Arias N, Auer C, ... Weiss MG (2008). Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia. *Int J Tuberc Lung Dis*, 12(7), 856–866. [PubMed: 18544216]
- South African Department of Health. (2007). HIV & AIDS Strategic Plan for South Africa 2007–2011. Retrieved from [http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/externaldocument/2007/20070604\\_sa\\_nsp\\_final\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/externaldocument/2007/20070604_sa_nsp_final_en.pdf).
- South African Department of Health. (2013). South Africa ART Guidelines 2013. Retrieved from <http://www.sahivsoc.org/upload/documents/2013%20ART%20Guidelines-Short%20Combined%20FINAL%20draft%20guidelines%2014%20March%202013.pdf>.
- Statistics South Africa. (2017). Msinga. from Stats SA [http://www.statssa.gov.za/?page\\_id=993&id=msinga-municipality](http://www.statssa.gov.za/?page_id=993&id=msinga-municipality)
- Thompson MA, Mugavero MJ, Amico KR, Cargill VA, Chang LW, Gross R, ... Nachega JB (2012). Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV: evidence-based recommendations from an International Association of Physicians in AIDS Care panel. *Ann Intern Med*, 156(11), 817–833. 10.7326/0003-4819-156-11-201206050-00419 [PubMed: 22393036]
- UNAIDS. (2018). Country progress report - South Africa, Global AIDS Monitoring 2018.
- Ware NC, Wyatt MA, Geng EH, Kaaya SF, Agbaji OO, Muyindike WR, ... Agaba PA (2013). Toward an understanding of disengagement from HIV treatment and care in sub-Saharan Africa: a qualitative study. *PLoS Med*, 10(1), e1001369; 10.1371/journal.pmed.1001369 [PubMed: 23341753]
- Wilkinson LS, Skordis-Worrall J, Ajose O, & Ford N (2015). Self-transfer and mortality amongst adults lost to follow-up in ART programmes in low- and middle-income countries: systematic review and meta-analysis. *Trop Med Int Health*, 20(3), 365–379. 10.1111/tmi.12434 [PubMed: 25418366]
- World Health Organization. (2013). Global Health Observatory Data Repository, WHO African Region: South Africa statistics summary (2002 - present). Retrieved Dec 23, 2013, from <http://apps.who.int/gho/data/node.country.country-ZAF>

**Table 1:**

Characteristics of respondents previously disengaged from antiretroviral therapy returning to care in rural South Africa (n=102)

Characteristic	n (%)
Female Gender	54 (53)
Marital status (n=82)	
Single	37 (45)
Partner	27 (33)
Married	13 (16)
Widowed	5 (6)
Median Age (years)	36 (IQR 28–44)
Nearest clinic <30 min away	51 (50)
Travel to clinic using Taxi	74 (73)
Median clinic travel cost (one way)	R14 (IQR R10–20); (approx. \$1.17 USD)
Receive Monthly grant	85 (83)
Not Employed	84 (82)
Completed Secondary School	58 (57)
Electricity	69 (68)
Pit latrine Toilet	99 (97)
Median time defaulted ART	9 months (IQR 4–22mo)
>1 year on ART before disengaging	60 (63)
No prior TB treatment	56 (55)
No prior household member on TB treatment	77 (79)
No prior IPT	71 (74)
Know other people with HIV	80 (78)
Know other people on ART	78 (81)
Disclosed HIV status to a partner (n=84)	69 (82)
Partner living with HIV (n=70)	56 (80)
Children living with HIV	21 (21)
No adverse effects from HIV treatment	76 (77)

**Table 2:**

HIV knowledge among people living with HIV who previously disengaged from antiretroviral therapy (n=102)

Question	No N (%)	Yes N (%)	Unknown N (%)
<i>HIV knowledge questions (n=15)</i>			
What causes HIV?			
A virus	4 (4)	<b>94 (92)</b>	4 (4)
Witchcraft	<b>96 (94)</b>	4 (4)	2 (2)
Drinking alcohol	<b>93 (91)</b>	5 (5)	4 (4)
Smoking cigarettes	<b>95 (93)</b>	4 (4)	3 (3)
Being poor	<b>95 (93)</b>	5 (5)	2 (2)
Punishment from God	<b>92 (90)</b>	6 (6)	4 (4)
Punishment from the ancestors	<b>96 (94)</b>	3 (3)	3 (3)
How is HIV spread?			
Unprotected sex	0 (0)	<b>102 (100)</b>	0 (0)
Sharing clothes	<b>90 (88)</b>	5 (5)	7 (7)
Mother during childbirth	10 (10)	<b>76 (75)</b>	16 (16)
Breastmilk	9 (9)	<b>81 (79)</b>	12 (12)
Eating food prepared by a person with HIV	<b>93 (91)</b>	4 (4)	5 (5)
Getting pricked by needle that has HIV infected blood	7 (7)	<b>92 (90)</b>	3 (3)
HIV treatment can prevent me from giving HIV to my partner	51 (50)	<b>34 (33)</b>	17 (17)
Using condoms can prevent HIV spread	1 (1)	<b>97 (95)</b>	4 (4)
HIV is treatable	11 (11)	<b>85 (83)</b>	6 (6)
HIV is curable	<b>76 (75)</b>	11 (11)	14 (14)
ART reduces the risk of getting sick from TB	18 (18)	<b>49 (48)</b>	35 (34)
If you have HIV, there is a high risk of getting TB	5 (5)	<b>71 (70)</b>	26 (25)
If you take ART you will not get sick with TB for some time	18 (18)	<b>27 (26)</b>	57 (56)

Correct answers noted in **bolded** font.

**Table 3:**

Healthcare seeking behaviors among people living with HIV who previously disengaged from antiretroviral therapy (n=102)

Health care options and preferences		n (%)
All sources of care (n=102)	Clinic	99 (97)
	Hospital	95 (93)
	Private doctor	65 (63)
	Relative	41 (40)
	Pharmacist	37 (36)
	Traditional Healer	26 (25)
First point of care preference (n=81)	Clinic	61 (75)
	Traditional healer	9 (11)
	Relative	6 (7)
	Hospital	3 (4)
	Other	2 (2)
Second point of care preference (n=81)	Hospital	32 (40)
	Clinic	23 (28)
	Relative	8 (10)
	Pharmacist	7 (9)
	Other	11 (14)
Reasons to not seek care at the clinic (n=45)	Clinic is too expensive	11 (24)
	Clinic is too far away	10 (22)
	Clinic waits are too long	9 (20)
	Seek care elsewhere	9 (20)
	Cannot miss work	9 (20)
	I only go when I am very sick	7 (16)
	Too many responsibilities	4 (9)
	Clinic staff are rude	4 (9)
	I don't want to be hospitalized	4 (9)
	I am treated badly at the clinic	4 (9)

**Table 4:**

Stigma amongst people living with HIV who previously were lost to follow up (n=102)

Response	n (%)
I feel I may die from HIV	55 (54)
I have to stay healthy to take care of my family	101 (99)
I am embarrassed that I have HIV	40 (39)
I would not be afraid to deal with doctors and clinic visits	95 (93)
I can get to the clinic for the refill every month	96 (94)
Traveling to the clinic is too expensive (n=61)	11 (18)
My fear of side effects would prevent me from taking the medications	26 (26)
Life is so busy, I do not have time for medicine	13 (13)
Clinic appointments are more trouble than they are worth	25 (25)
My family would support me taking ART	92 (90)
Others would think better of me if I took ART	75 (74)
I have told someone that I have HIV	77 (74)
I could share information to others about why I'm taking medicine for HIV	89 (87)
I do not like to go to the clinic because the clinic staff treats me badly (n=45)	4 (10)

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Table 5:

## Reasons for disengaging from HIV care among people living with HIV in rural South Africa

Mobility	<ul style="list-style-type: none"> <li>• “I went to look for a job in Durban, and I forgot to ask for the transfer letter from the clinic. I did not find a job and then did not have money to come back to the clinic.”</li> <li>• “I had not fully accepted my status. I worked far from home and had no money to come back for my appointments. I tried to get a transfer but it took time and I lost my job during that time making it more difficult.”</li> <li>• “I work for a contract company and my working days did not allow me to travel and get my ART. On the days I was off I had no money to come.”</li> <li>• “I worked in Joburg, .... I lost my job and had no financial support. I had however requested a transfer but I did not get one at the clinic to be able to get my pills in Joburg.”</li> <li>• “I was working away from home and I requested the caregiver to get my pills for me. The nurses refused to give her my treatment. My family is poor and I have 4 children. The money I had went into getting food for my children. I could not travel to the clinic. I got frustrated with the nurses at clinic and stopped going completely because they refused to understand the situation.”</li> <li>• “I had a family emergency and I had to go to Durban. My grandmother was raped and I went to go look after her. I ended up staying 4 months there and I did not carry my blue book.”</li> </ul>
Lack of money to come to the clinic	<ul style="list-style-type: none"> <li>• “I have no work, not even enough for food and I had no money to go to the clinic, so taking my medication was too much for me.”</li> <li>• “I had no transport money to go and fetch my medicine at the clinic, the person who supported me financially passed away.”</li> </ul>
Lack of social support	<ul style="list-style-type: none"> <li>• I was not treated well in Joburg by my son’s father. I ended up having no support or a place to stay.</li> <li>• When I found out about my HIV status I told my husband and he was in denial about the matter and said I should not take ARVs. I did not take them because he was angry when I did. I tried to hide them from him but it was difficult because we live together.</li> </ul>
HIV Stigma	<ul style="list-style-type: none"> <li>• “I was still in denial and afraid to be seen going to clinic to take ARV’s.”</li> <li>• “I was scared to go to the clinic because I might come across people who know me. I was ashamed of having HIV.”</li> <li>• “I got a job and I was afraid to tell my manager that I’m taking ARVs. I was scared of losing my job.”</li> <li>• “I was afraid that my family members would know that I’m HIV-positive when they see me taking the medication.”</li> <li>• “When I am at school, the other kids have a habit of opening my backpack and they see my blue book and sometimes my pills and they make fun of me. I then felt embarrassed and did not bring my blue book to my [clinic] appointment and could not collect my pills. The clinic is closed during the weekends so I cannot collect them on a day that I do not have school. I stopped collecting them because the other kids know the ARV container. I felt embarrassed.”</li> <li>• “My husband said he tested negative but refused to show me the results. When I insisted on seeing the results he said he tore them up. Our child fell ill and was tested again in Joburg and when he saw the results for our child (positive) he agreed for the child to take them but not me.”</li> </ul>
Adverse effects of medication	<ul style="list-style-type: none"> <li>• “I felt very sick and I also had bad dreams.”</li> <li>• “HIV medicines made me very hungry, and I did not have money to buy to food.”</li> </ul>
Did not want to take medication anymore	<ul style="list-style-type: none"> <li>• “I just got tired of taking my medication and stopped collecting it since last year.”</li> <li>• “I have been taking ARVs for far too long so I thought taking a break on my medication. I was busy sometimes so I would forget taking my pills. When I feel depressed I don’t feel like doing anything even drinking my medicine.”</li> </ul>
Participant did not feel sick anymore	<ul style="list-style-type: none"> <li>• “I felt that I was not sick anymore, therefore I saw no need to continue with medication.”</li> </ul>
Other	<ul style="list-style-type: none"> <li>• “I was confused because my wife tested negative several times and we don’t condomise every time we have sex so <i>I didn’t know if I was positive.</i>”</li> <li>• “I was <i>incarcerated.</i>”</li> <li>• “I was addicted to <i>alcohol.</i> I felt it was not important to take my medication.”</li> <li>• “I started using other <i>traditional medicines</i> that I was told they can cure HIV completely.”</li> <li>• “I cannot see properly and find it hard to travel to the clinic. I usually ask neighbors to get the medication for me if they go to the clinic. At times there is no one going or they forget.”</li> <li>• “I was writing my grade 12 <i>exams</i> and the mobile clinic only comes on Tuesdays.”</li> </ul>

**Table 6:**

Reasons for returning to HIV care among people living with HIV in rural South Africa

Patient became severely ill	<ul style="list-style-type: none"> <li>• “I felt weak and came to the hospital, not the clinic. The doctor then re-initiated me after I told him I stopped taking my ART.”</li> <li>• “I became very sick, so went to the clinic and they told me that I will not be okay anytime soon because I was not taking my treatment anymore.”</li> </ul>
To take responsibility for themselves or children	<ul style="list-style-type: none"> <li>• “I realized that this is my life that I am not taking care of, I started to be sick again and I thought I was going to die and leave my children.”</li> <li>• “I realized that defaulting on the ARV treatment was a huge mistake, most of the time I felt sick. This was why I started my treatment again.”</li> </ul>
Previous barriers resolved	<ul style="list-style-type: none"> <li>• “I found a job and I was able to provide food for myself.”</li> <li>• “My job is finished, so I wanted to restart my medication before getting sick.”</li> </ul>
To avoid getting sick in the future	<ul style="list-style-type: none"> <li>• “My family told me that it is important to take my medicine daily to avoid getting sick.”</li> </ul>
Clinic Staff convinced patient to re-initiate	<ul style="list-style-type: none"> <li>• “The sister in charge of the clinic reached out to her when she saw she was not coming to clinic. I explained why I hadn’t been coming. The clinic now lets me leave my blue book at the clinic and I can put her pills in a plastic bag so they do not make the noise that they make in the pill bottle.”</li> </ul>
Accepted HIV diagnosis	<ul style="list-style-type: none"> <li>• “It because I am now ready and have admitted the situation.”</li> </ul>