

# Population mobility: challenges for universal HIV testing and treatment

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#### EDITORIAL

### Bringing population mobility into focus to achieve HIV prevention goals

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The ambitious UNAIDS '90-90-90' targets, aiming to end the AIDS epidemic by the year 2030 [1], are a response to the profound therapeutic and preventive benefits of HIV treatment. Universal voluntary HIV counselling and testing followed by prompt initiation of antiretroviral therapy (ART) for all those diagnosed HIV-infected, an approach known as Universal Test and Treat (UTT), is now seen as the primary means through which the 90-90-90 targets can be achieved. Beyond the targets, the recently emergent concept of a prevention cascade [2] also recognizes the imperative of "coverage" for achieving population-level effects of HIV prevention interventions, which are needed together with the expansion of treatment to end the epidemic [3].

Perhaps nowhere else in the world is more momentum required to bring HIV treatment *and* prevention to all who need it than in Africa. The HIV epidemic on the continent has been concentrated in eastern and southern Africa, where an estimated 19.4 million adults are living with HIV [4]. Despite substantial progress in recent years, only approximately 60% of people living with HIV (PLHIV) in the region were receiving ART in 2016 [4]; an estimated 45% had a suppressed viral load as a result of their successful engagement in care in 2015 [5].

These estimates reflect tremendous successes of HIV prevention and care initiatives towards accelerating ART coverage for sub-Saharan African populations, and many successful efforts to reach key populations—yet also the sobering reality that what has been achieved to date has been achieved in easier to reach populations. A focus by UNAIDS and global leadership on harder to reach, key populations, that are particularly important for further scale-up, is laudable; but to date, inadequate attention has been paid to population mobility, a major force that challenges the HIV care cascade and threatens the promise of "treatment as prevention" particularly in high HIV prevalence, resource-limited regions. Ultimately, strategies to attain the 90-90-90 targets that do not account

for the complex dynamics of mobility in specific settings will fail to engage successfully with the magnitude of populations necessary to end the epidemic [6].

There is an urgent need to deepen our understanding of population mobility, its heterogeneous forms and gender dimensions in high HIV prevalence areas, its effects on sexual behaviour and sexual networks, HIV testing and engagement in HIV care and treatment, and on HIV acquisition and onward transmission, even as widespread HIV prevention interventions are underway—indeed, *especially* in contexts in which interventions such as UTT are underway. To understand whether and how mobility attenuates the effectiveness of HIV prevention and care initiatives is a vital first step towards identifying the full set of solutions, inclusive of mobile populations, that will be needed to end the epidemic.

Historically, the spread of HIV in sub-Saharan Africa followed the corridors of population movement, as people moved to expanding urban areas and other places of employment opportunity [7-10]. Today, mobility continues to place individuals at great risk of HIV acquisition as well as onward transmission [11-13]. The highly gendered nature of that linkage is well-documented, yet rarely commented upon. Forms of mobility in sub-Saharan Africa are diverse and complex relative to those of other regions, and men's and women's patterns of movement significantly differ, with women increasingly participating in mobility [14-18], as has been seen elsewhere [19-22]. While transcontinental migration from Africa is low [23], the intra-sub-Saharan African emigration rate represents the largest south to south movement of people in the world [24]. Data for the study of internal migration have been limited; however, data from Demographic Surveillance Sites show that 7% to 20% of local populations in surveillance areas, often over 30% of young adults, have migrated annually in recent years [14,25]. Rural to urban migration flows do not predominate in all settings [26]; rather, counter-urbanization [27] and circulation between rural areas, semi-urban towns, and rural

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perimeters of cities are common [14]. Mobility has positive benefits for development and is a key driver of economic growth in southern and eastern Africa: from 50% to 80% of rural households have at least one migrant member [24], and the "sending" of a female migrant has been particularly advantageous to the poorest households [23,28,29].

Despite its importance, research on the effects of mobility in sub-Saharan Africa on HIV care engagement, and on effectiveness of ART as treatment and as prevention, is in its nascency. Existing literature mostly from the global north has shown that mobility can break bonds between individuals and HIV care systems [30], thus leading to disengagement from care, treatment interruption and poor health outcomes. Research on mobility and care engagement in sub-Saharan African settings is relatively scarce; thus there are key questions about the extent to which mobility is contributing to the gap that exists between the remarkable promise of ART for large-scale prevention [31-33], and actual engagement in care [34].

Recent meta-analyses in sub-Saharan African populations have shown that 30% to 60% of people living with HIV are lost to follow-up at each step after HIV diagnosis [35-37]. People repeatedly exit and re-enter the care cascade at various points [38,39]. Greater attention to the contextual factors that shape HIV treatment experiences, engagement and outcomes has recently emerged in social science research on HIV [40], revealing the complex social realities underlying "bottlenecks" in the cascade [40]. Yet data have been limited for investigating the role of mobility in these care cascade shortfalls.

Several meta-analyses and systematic reviews of the literature examining factors associated with care entry, engagement and retention [35,37,41-43] show that optimal lifelong engagement in HIV care can be threatened by a range of factors at the individual, social, and structural levels. Mobility affects many of the factors found to contribute to delayed entry or lapses in care, including psychological factors (e.g. seeking care away from home because of stigma) [39,44,45]. clinic characteristics (e.g. waiting times) [46,47] and structural barriers [44,48] such as distance to clinic and transportation costs [44,47,49,50]. Yet the direct impact of mobility, and the pathways for this impact, have not been examined in depth [30,51]. Better measures and methods are needed to understand how mobility affects the ability of individuals to successfully navigate the HIV care cascade. This is especially urgent for sub-Saharan Africa, where levels of mobility are high and forms of mobility are complex and dynamic. The effects of mobility on initiatives designed to extend the reach of primary HIV prevention interventions in these settings are, to date, unknown— a glaring gap in the literature.

The articles in this supplement of the *Journal of the International AIDS Society* focus on crucial questions regarding the forms and dimensions of mobility and the impact on HIV prevention and care initiatives—particularly in Southern and Eastern Africa, but also in the 'receiving' nations in the global north of sub-Saharan African migrants. This volume includes contributions from each of the large-scale UTT studies in five African countries [52], which include HPTN 071 Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART), Sustainable East Africa Research in Community Health (SEARCH); the MaxART (Early Access to ART for All)

implementation study; and the ANRS 12249 Antiretroviral Treatment as Prevention (TasP) trial. It also includes contributions from studies outside UTT trial settings on the impacts of mobility on care engagement. The authors of the papers use different methods and approaches to identify emergent themes, key problems and gaps in the study of mobility and HIV prevention and care and point to potential solutions. The collection includes quantitative research that advances approaches towards measurement of diverse forms of mobility and its impacts, and also highlights the value of qualitative research for understanding the meaning of factors driving linkage to HIV treatment and prevention in the context of migration and mobility.

We observe four major themes across the contributions to this volume: first, the spatial and temporal dimensions of mobility are important, because mobility is inherently linked to time exposed to interventions and services within geographies: secondly, types of mobility in different populations and settings are diverse and highly gendered, and this heterogeneity across contexts should inform HIV prevention and treatment approaches in specific settings; thirdly, while mobility is intertwined with other factors that affect engagement in HIV care and prevention, it often sets into motion a "chain of events" that leads to disengagement; and fourth, the period following resettlement in new destinations is one of instability, in which risk is heightened, disrupting engagement and leading to 'missed opportunities' for progress along the prevention and care cascades. Such missed opportunities must be addressed through health systems- and policy-level actions. In sum, this collection speaks to a need for reconfiguration of programs and services to respond to the challenges to HIV care and prevention engagement that are presented by the mobility of populations.

Speaking to the dynamic nature of mobility and the importance of temporality, Larmarange and colleagues [53] present findings from the ANRS 12249 Antiretroviral Treatment as Prevention (TasP) trial, that highlight the effect of population mobility on temporality of and geographic exposure to the UTT intervention in rural KwaZulu-Natal, South Africa. The TasP cluster-randomized trial failed to show a reduction in HIV incidence at population level when ART was proposed regardless of CD4 count. The authors describe a dynamic cascade of various degrees of exposure to the trial interventions, using both calendar (population) and exposure (individual) time approaches in their analyses, and show that the structural effects of mobility diluted the impact of the UTT strategy. In a context of high HIV incidence, the circulation of newly infected individuals in and out of communities slowed down TasP efforts to increase ART coverage and population viral suppression, ultimately attenuating any population-level impact on HIV incidence.

In their study of population mobility embedded within the SEARCH trial in rural populations in Kenya and Uganda, Camlin and colleagues [54] describe significant heterogeneity in mobility across regions in Kenya and Uganda, which correlated with heterogeneous levels of risk behaviour and HIV prevalence observed across the regions: communities with higher proportions of mobile residents tended to also have higher HIV prevalence. Mobility may undermine UTT interventions in high prevalence areas if mobile populations are spending time exposed outside of their communities and indeed they were

as follows: both migration and also localized short-term mobility were associated with higher risk sexual behaviour, especially among women. Livelihoods requiring mobility for women, such as market trading, and the fish trade in particular, were strongly associated with their higher risk sexual behaviour. In contrast, men's labour-related mobility was not associated with higher risk behaviour; their travel for other purposes (e.g. attending funerals, seeking care, visiting family), was. This work highlights the need for gender-specific interventions among mobile populations.

The links between mobility and livelihoods that affect engagement in HIV care and prevention services and interventions also figure prominently in two contributions from the PopART trial. Bond and colleagues [55] used longitudinal qualitative data focused on the lives of six people living with HIV in urban Zambia to show the challenges of juggling household responsibility, livelihood mobility and HIV management. For five of the six, ongoing engagement in treatment could not be sustained because of travel. The authors highlight the need for differential care options which can adjust more to clients' temporal and spatial realities. Hoddinott and colleagues [56] used ethnographic and participatory research to describe patterns of 'household fluidity' in the Western Cape of South Africa, and explored how movements in and out of households to ensure livelihoods and social support shape HIV service access. With their conceptualization of 'fluidity', the authors challenge conventional sociological concepts of households, that is, they are not static, contained or bounded as the typical measures would suggest. Echoing the recommendations of Bond and colleagues, the authors call for "responsive, flexible health service delivery systems designed to support continuity in care across many shifts in client circumstances."

Shabalala and colleagues [57] present findings from a mixed methods study to improve understanding of care retention among ART clients in the MaxART implementation study in Swaziland. The authors examined associations between socio-demographic characteristics and retention, and conducted in-depth interviews with clients who were lost-tofollow-up from the study to explore their reasons for leaving care. Mobility, particularly relocations to another community far from the facility where the client initially obtained ART, was described by study participants as the first step in a complex chain of events that affected retention in care. Several often-intersecting reasons for discontinuing ART also mattered, including "harsh treatment by health care workers", ART side effects, stigma, and food insecurity. These findings provide further evidence in support of Ware's conceptualization of care disengagement as a process through which missed visits, and ensuing reluctance to return, can erode patients' feelings of connectedness to care over time [39]. They also expand upon this conceptualization by documenting how migration events can trigger the chain of events that leads to disengagement.

Expanding upon this theme, studies conducted outside of UTT trial contexts highlight how the period following resettlement in new destinations is a period of instability in which behavioural risks of HIV acquisition are heightened, and engagement in care and prevention is disrupted, leading to missed opportunities for improving the prevention and care cascades. Fakoya and colleagues [58] present findings from a study of care engagement among migrants living with HIV in

Europe. Using data from 57 HIV clinics in nine countries, the authors investigated the barriers and facilitators to HIV testing, and assessed the current treatment and healthcare needs of migrants living with HIV in Europe. Noting that immigrants are overrepresented in the European HIV epidemic, the authors present evidence suggesting that exposure to HIV after migrating accounts for a substantial proportion of infections among migrants, and that opportunities for HIV prevention are being missed. They call for a greater attention to the HIV prevention needs of immigrants to Europe, including interventions to reduce HIV acquisition among migrant gay and bisexual men, and to expand HIV testing opportunities for migrant heterosexual men and women.

Two articles in this volume examine women's migration in the context of pregnancy. Clouse and colleagues [59] present findings from a mixed methods study to identify drivers and types of mobility among pregnant and postpartum women living with HIV in the Johannesburg area in South Africa. They examine long-distance travel of mothers and infants before and after delivery, finding that the frequent mobility in the peripartum period "underscores the challenge of ensuring a continuity of HIV care in a fragmented health care system that is not adapted for a mobile population." In another setting in South Africa (Cape Town), Phillips and colleagues [60] also examined the mobility of women attending an integrated antenatal-ART clinic. Using routine electronic health data (including laboratory testing, ART dispensing and clinic visits) to measure the movements and access points of pregnancy and postpartum women, the authors show that a substantial proportion of women do not link to postpartum care, and among those who do, long-term retention remains a challenge as women move to a wide variety of facilities locally and nationally.

Vearey [61] offers a Commentary that speaks to a need for improving the policy environment to address better the HIV prevention and care needs of mobile populations. She explores challenges and strategic opportunities for "re-setting" the policy agenda on migration and HIV in southern Africa, specifically in the policy environment of the Southern African Development Community (SADC) - a region associated with high levels of migration, and home to the largest population of people living with HIV globally. Drawing upon policy review, empirical data, and on-going participant observation within local, regional and global policy processes, Vearey shows how current policy processes have the potential to undermine efforts to improve the global responses to migration and HIV. She argues that, "without mainstreaming migration, HIV programmes will continue to struggle, and key health targets will not be met."

Lastly, in our Viewpoint, the editors have expanded on two specific organizing concepts that have emerged from our work on this volume: the time scales of mobility, and migrants' sexual networks. Temporal scales of population mobility are complex, sexual risk behaviour can change in relation to the timing of migration, and timing of migration can interact with timing of, and exposure to, HIV prevention efforts. Additionally, the timing, sequence and spatial scale of migrant's sexual networks can mitigate intervention effectiveness. Cassels, Camlin and Seeley [62] argue that focusing on temporal patterns of mobility and network characteristics will not only help to explain why population mobility presents a challenge for HIV

prevention and care, but can be leveraged to improve future interventions

The collection of articles in this volume contribute to framing a future policy and research agenda. Treatment access is a key area of concern: how can migrants sustain their care in the myriad destinations to which they travel? What interventions, policies, or health systems improvements are needed to maximize the engagement of mobile individuals in HIV care? Recognising the need for approaches that are responsive to diversity, that risk and opportunities for care may be affected by gender, age, sexual identity and ethnicity, is essential if hard to reach populations are to be reached by UTT. What possibilities exist for reconceptualising care delivery to address these challenges?

Mobile populations may be among those who stand to benefit the most from new models of differentiated care or differentiated service delivery, which aim to simplify and adapt HIV services across the cascade to better meet the needs of PLHIV and reduce burdens on health systems [63]. These models include patient-led community adherence groups, healthcare worker-managed groups known as adherence clubs, fast-track or multi-month scripting, mobile outreach, and community drug distribution points. To the extent that these models can be informed by an understanding of the needs of mobile women and men living with HIV, they hold promise for engaging and retaining these populations who struggle to fit their needs to the requirements of clinic-based HIV care systems.

In addition, mobile populations stand to benefit from improved therapeutic technologies such as long-acting ART as well as longer-acting formulations of biomedical prevention technologies such as Pre-Exposure Prophylaxis (PrEP), and expansion of the delivery of these technologies beyond clinic settings into communities and key migration destinations and transit hubs. Structural and behavioural interventions to facilitate demand are needed to complement these 'supply side' interventions [2]. Without such innovations, migrants will continue to be left behind in the quest to end the AIDS epidemic. We hope that this collection stimulates focus and commitment towards meeting this critical public health challenge.

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#### **COMPETING INTERESTS**

The authors have no competing interests to declare.

#### **AUTHORS' CONTRIBUTIONS**

CC, SC, and JS conceptualized the main messages. CC drafted the manuscript; SC and JS provided critical reviews. All authors read and approved of the final manuscript.

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#### RESEARCH ARTICLE

# The impact of population dynamics on the population HIV care cascade: results from the ANRS 12249 Treatment as Prevention trial in rural KwaZulu-Natal (South Africa)

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#### **Abstract**

**Introduction:** The universal test and treat strategy (UTT) was developed to maximize the proportion of all HIV-positive individuals on antiretroviral treatment (ART) and virally suppressed, assuming that it will lead to a reduction in HIV incidence at the population level. The evolution over time of the cross-sectional HIV care cascade is determined by individual longitudinal trajectories through the HIV care continuum and underlying population dynamics. The purpose of this paper is to quantify the contribution of each component of population change (in- and out-migration, HIV seroconversion, ageing into the cohort and definitive exit such as death) on the HIV care cascade in the context of the ANRS 12249 Treatment as Prevention (TasP) cluster-randomized trial, investigating UTT in rural KwaZulu-Natal, South Africa, between 2012 and 2016.

**Methods:** HIV test results and information on clinic visits, ART prescriptions, viral load and CD4 count, migration and deaths were used to calculate residency status, HIV status and HIV care status for each individual on a daily basis. Position within the HIV care continuum was considered as a score ranging from 0 (undiagnosed) to 4 (virally suppressed). We compared the cascade score of each individual joining or leaving the population of resident adults living with HIV with the average score of their cluster at the time of entry or exit. Then, we computed the contribution of each entry or exit on the average cascade score and their annualized total contribution, by component of change.

**Results:** While the average cascade score increased over time in all clusters, that increase was constrained by population dynamics. Permanent exits and ageing into the people living with HIV cohort had a marginal effect. Both in-migrants and outmigrants were less likely to be retained at each step of the HIV care continuum. However, their overall impact on the cross-sectional cascade was limited as the effect of in- and out-migration balanced each other. The contribution of HIV seroconversions was negative in all clusters.

**Conclusions:** In a context of high HIV incidence, the continuous flow of newly infected individuals slows down the efforts to increase ART coverage and population viral suppression, ultimately attenuating any population-level impact on HIV incidence. **Clinical Trial Number:** NCT01509508 (clinicalTrials.gov)/DOH-27-0512-3974 (South African National Clinical Trials Register).

**Keywords:** HIV care continuum; Public health; Structural drivers; Migration; Cross-sectional cascade; Rural South Africa; Population dynamics

Additional Supporting Information may be found online in the Supporting information tab for this article.

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#### 1 | INTRODUCTION

Early antiretroviral treatment (ART) of HIV-positive patients has been shown to prevent transmission of HIV [1], in addition to individual benefits in terms of reducing morbidity and mortality [2,3]. The universal test and treat (UTT) strategy was developed by extending this idea to the population level

under the hypothesis that HIV testing of all adult members of a community, followed by immediate ART initiation of nearly all HIV-positive individuals, regardless of immunological or clinical staging, will prevent onward transmission and reduce HIV incidence in the community. This strategy is supported by modelling work suggesting that such an approach, if successfully implemented, could eliminate HIV transmission in South

Africa [4], and in a large population-based cohort from rural KwaZulu-Natal, South Africa, demonstrating a strong inverse association between ART coverage and HIV acquisition [5].

The implementation of any UTT strategy involves improving all steps of the "cascade of HIV care" [6,7], as set out by UNAIDS in their 90-90-90 targets to be reached by 2020, that is 90% of all people living with HIV (PLWHIV) being diagnosed, 90% of those being in care and receiving ART and 90% of those on ART with viral suppression [8]. This type of HIV care cascade is measured by a population-based and cross-sectional set of indicators estimating the proportion of HIV-positive individuals diagnosed, in care, on ART and virally suppressed among all PLWHIV residing within a certain geographical area at a specific time point, although alternative longitudinal measurements of the cascade exist [9].

The evolution over time of a cross-sectional HIV care cascade is determined by two elements: (i) the journey of HIV-positive individuals through the care continuum (longitudinal care trajectories), and (ii) the changes in the underlying population of resident PLWHIV (population dynamics, i.e. in- and out-migration, HIV seroconversion, ageing into the cohort and definitive exit such as death).

Migration is one component of population dynamics. It has been shown in rural South Africa that even relatively short-distance migration events confer substantial additional risk of HIV acquisition [10]. More generally, mobility is associated with increased risk of ART non-adherence, lost to follow-up, deterioration in CD4 count, HIV-related death, development of drug resistance and general non-continuity of HIV care [11].

Beyond the understanding of individual trajectories through the HIV care continuum (sometimes referred as longitudinal cascade [12]), it is also important to quantify the structural effect of the dynamics of the PLWHIV population and its impact on the cross-sectional HIV care cascade.

The ANRS 12249 Treatment as Prevention (TasP) trial implemented a UTT strategy in rural KwaZulu-Natal to test the impact of universal ART on population HIV incidence. The objectives of this analysis are: (i) to document the dynamics of the PLWHIV population in the trial area over time, distinguishing the different components of population change; (ii) to identify the position within the HIV care continuum of individuals joining or leaving the PLWHIV population at the time of entry or exit; (iii) to compare their care position with the average care position of the local PLWHIV population; and finally, (iv) to quantify the contribution of each component of population change on the cross-sectional HIV care cascade.

#### 2 | METHODS

#### 2.1 Study setting and design

The TasP trial was a phased two-arm cluster-randomized trial implemented by the Africa Health Research Institute (AHRI) in Hlabisa sub-district, northeast KwaZulu-Natal, South Africa, in a rural area with approximately 28,000 isiZulu-speaking resident adults. Adult HIV prevalence in the sub-district was around 30% [13,14]. Hlabisa sub-district is characterized by frequent migration [15,16], low marital rates and late marriage [17]. On average, one adult in ten in the trial area is employed [18].

The trial aimed to investigate whether immediate ART initiation offered to all HIV-positive individuals, identified through home-based HIV testing will reduce HIV incidence in the area. Trial protocol and study procedures have previously been reported in detail [19,20].

The trial was implemented from March 2012 to June 2016 using a phased approach: four clusters opened in 2012, six additional clusters opened in 2013 and 12 in 2014. All 22 clusters (2  $\times$  11) were followed until mid-2016. Each cluster was designed to correspond to an average of about 1,000 resident adults.

The UTT strategy tested in TasP trial had two main components: (i) repeat home-based HIV testing (both arms) and (ii) immediate ART initiation (intervention arm).

In both trial arms, HIV counsellors visited all local households and enumerated, with the household head or another adult household member, all resident adult (16 years and above) household members (initial census during the first survey round). Residency was defined in trial protocol as spending at least four nights per week within the homestead (de jure household members at the survey date). At each subsequent home-based survey round, conducted six-monthly, newly identified households and all previously registered households were (re)visited and the list of resident adult household members was updated. Exits (including deaths and out-migration from trial area) were documented as reported from another household member.

Eligible individuals providing written informed consent in isi-Zulu responded to a socio-demographic and sexual behaviour questionnaire and gave a finger prick sample collected as a dried blood spot (DBS), used for HIV incidence estimation. HIV counsellors also offered individuals point-of-care rapid HIV counselling and testing. Participants identified HIV-positive through DBS but who refused HIV rapid test at a specific survey round were not notified of their DBS result. However, they were re-invited to test for HIV in a subsequent survey round. All trial participants identified as HIV positive (through rapid HIV test or self-report) were referred to a local trial clinic set up by the trial and situated in the trial cluster in which they lived, located at less than 45 minutes walking distance. From May 2013, support for linkage to trial clinics through phone calls and home visits by a dedicated trial team was offered to individuals not linked to care within three months after referral.

In the trial clinics of the control clusters, HIV-positive adults were offered ART according to national guidelines (initially CD4 count ≤350/µL, then ≤500/µL from January 2015). In the trial clinics of the intervention clusters, all HIV-positive adults were offered the opportunity to begin ART immediately regardless of CD4 count or clinical staging. The trial area was also served by three local governmental primary care clinics of the department of health providing HIV testing, HIV care and ART according to national guidelines only [21]. HIV-positive participants of both arms could opt to receive HIV care in primary care clinics or transfer to a trial clinic.

The Biomedical Research Ethics Committee (BREC), University of KwaZulu-Natal, South Africa (BFC 104/11) and the Medicines Control Council of South Africa approved the trial. The trial was also registered on ClinicalTrials.gov: NCT01509508 and South African National Clinical Trials Register: DOH-27-0512-3974.

#### 2.2 | Sources of data

The main data source for this analysis was the trial database, which provided information on trial registrations and trial exits; uptake and results of home-based rapid HIV testing; third generation ELISA HIV serological results from DBS; and clinic visits, ART prescription and viral loads of PLWHIV seen in trial clinics.

Two additional data sources were used to capture information from PLWHIV seen in local governmental clinics: (a) viral loads and CD4 counts from National Health Laboratory Service (NHLS); and (b) ART clinic visits and ART prescriptions from the AHRI clinical database (ACCDB) which is managed by the Hlabisa Department of Health and AHRI. Both NHLS and the ACCDB database contain data from Hlabisa primary care clinics since 2004 [21]. Linkage between trial, NHLS and ACCDB database used a probabilistic score based on first name, last name, date of birth, South African ID number and cell phone number. Matching of the databases was approved by the BREC in March 2013 (Protocol Amendment 4).

#### 2.3 Daily statuses

Residency, HIV status and HIV care status (if resident and HIV-positive) were estimated daily for all individuals registered within the trial.

Out-migration and permanent exits were documented through trial exits. In-migration and ageing into the cohort (16th birthdays) were derived from the resident household members lists updated at every round. Dates of in-migration events were randomly imputed using a random point approach (uniform distribution) between the last home visit where individuals were known as non-resident and the first home visit where they were considered as resident. An individual could contribute several migration events, for example if he/she out-migrated from the trial area and re-entered the trial area at a later date.

HIV status was identified using multiple sources: repeat DBS, repeat rapid tests, HIV-positive self-reports and HIV clinic visits in trial and/or local governmental clinics, providing information on HIV status at specific dates. A case-by-case investigation (including additional laboratory analysis) was performed to solve any inconsistent data. An individual was considered as HIV-negative before the last known negative status and as HIV-positive after the first known positive status. For those in whom a negative status was followed by a positive one, date of seroconversion was imputed using a random point approach (uniform distribution). For individuals entering the trial cohort, the first opportunity for the trial team to ascertain their HIV status occurred de facto after their entry. For some, a previous record was found in NHLS and/or in ACCDB database. For the others, we imputed if and when a potential unobserved HIV seroconversion occurred using the observed incidence within the same cluster and for people of the same sex. A similar approach was used to impute a possible seroconversion before the end of trial follow-up for those whose last observed HIV status was negative, assuming they remained undiagnosed until the end of trial follow-up. Individuals with no observed HIV status (i.e. with no data on HIV status) were excluded from the analysis.

HIV care statuses were defined as: (i) undiagnosed; (ii) diagnosed but not actively in care (i.e. never in care or lost to

follow-up); (iii) actively in care but not on ART; (iv) on ART but not virally suppressed (undocumented viral load or viral load over 400 copies/ $\mu$ L); and (v) in care, on ART and documented viral suppression. Position within the HIV care continuum was considered as a score ranging from 0 (undiagnosed) to 4 (virally suppressed). We note  $S_{i,t}$  the score of an individual i at time t.

An individual was considered as being diagnosed if he/she had at least one positive rapid test, one self-report as HIV-positive or had visited a primary care clinic. Date of HIV diagnosis was defined as the date of home-based HIV testing for individuals newly diagnosed by the trial counsellors. For those already diagnosed when they were interviewed, we considered the date of the first record in NHLS or ACCDB database, if any. It should be noted that for individuals tested in primary care clinics, a CD4 count is performed the same day in case of positive result, resulting in a record in NHLS database. For the few individuals self-reporting being HIV-positive but with no previous record in NHLS/ACCDB, we considered as a proxy of the diagnosis date the date of the self-report.

Being actively in HIV care in a trial clinic was defined as not being >90 days late of a scheduled clinic appointment date [22] (visits were scheduled monthly if on ART, six-monthly if not yet eligible for ART in control arm). Due to the nature of the data available in NHLS and ACCDB database with neither database being exhaustive (some individuals recorded in one database were not found in the other, in particular pre-ART patients not covered by ACCDB), we were not able to use the same definitions regarding being actively in HIV care in primary care clinic. For patients matched with ACCDB database, being actively in HIV care was defined as having a clinic visit recorded in the last four months (one month for next appointment, this database being limited to ART patients supposed to visit clinics monthly, +3 months late). For patients matched with NHLS database (which contains only laboratory test results), it was having a CD4 count or a viral load recorded in the previous 13 months, CD4 count and viral load data being considered a proxy for clinic visits, following the approach proposed by Lessel et al. [23].

Being on ART was defined as having an ART prescription recorded in the trial or the ACCDB database in the previous 3 months or as having an undetectable viral load (<400 copies/ $\mu$ L) recorded in the last 13 months in the NHLS database, an undetectable viral load being considered here as a proxy for being on ART for HIV patients recorded in NHLS database but not found in ACCDB.

Viral suppression was defined as a viral load fewer than 400 copies/ $\mu$ L. The viral load at a given date was estimated by linear interpolation using all results recorded in the trial and the NHLS database. The viral load was considered as undocumented before the first available record.

#### 2.4 Components of population change

We broke down change of the resident PLWHIV population into five components: (i) ageing into the cohort; (ii) HIV sero-conversion; (iii) in-migration to the cluster; (iv) out-migration from the cluster; and (v) permanent exits (deaths or loss of the ability to provide an informed consent, e.g. due to illness). Dates of out-migration and permanent exit events were collected by a specific form, while dates of in-migration, ageing

into the cohort and HIV seroconversion were estimated (see previous section). A same individual could have experienced several events over the course of the trial.

#### 2.5 | Statistical analysis

As all clusters were not open at the same time, and have therefore different observation periods, we performed the statistical analysis per cluster, from the end of the initial population census to the beginning of the last survey round (Figure 1). In addition, this allows us to see if the impact of population dynamics on the HIV care cascade is uniform or heterogenous between clusters.

For a given cluster c, the average cascade score  $\mu_{c,t}$  at time t is equal to  $\Sigma_i S_{i,t} / n_{c,t}$  where  $n_{c,t}$  corresponds to the number of PLWHIV aged 16 years or older, residing within the cluster c at the date t. This average score is a summary statistic of the cascade distribution.

We computed, per cluster, rates of each population change component from the resident HIV-positive population per person years of residency.

To compare the cascade score of a specific individual i joining or leaving the PLWHIV population with the average score of their cluster at the time te of entry/exit, we computed  $\delta_{i,te}$  as  $S_{i,te} - \mu_{c,te}$ . We used Student's t-test to test if the mean of  $\delta_{i,te}$  by type of population movement differed significantly from zero.

The contribution  $C_e$  of a specific event e on the change in the average cascade score at cluster level depends on the PLWHIV population size and could be defined as  $\delta_{i,te}/n_{c,te}$  for an entry event and  $-\delta_{i,te}/n_{c,te}$  for an exit event. For a given

cluster c, the sum of all event contributions, that is  $SC_e = \Sigma_e$   $C_e$ , provides the total contribution of population change on the average cascade score over time. As all clusters were not observed for the same amount of time, we annualized these total contributions for comparing clusters:  $aSC_e = SC_e/T_c$ , where  $T_c$  is the observation period for cluster c.

All analyses were performed using R version 3.4.1 [24].

#### 3 | RESULTS

Overall, 28,419 adults were registered over the course of the trial. 338 individuals exited the trial area before the end of the initial census or were registered during the last survey round. Among the remaining 28,081 individuals: HIV status was undocumented for 2,582 (9.2%); and 16,994 (60.5%) remained HIV negative over the analysis period; thus, 8,505 individuals were part of the resident population of PLWHIV over the analysis period and included in the analysis.

The population HIV care cascade improved over time: the proportion of PLWHIV in care, on ART and virally suppressed increased from approximately 30% to 45% to 50%, while the proportion of PLWHIV not in care (diagnosed or undiagnosed) decreased from approximately 50% to 35% to 40%, depending on the duration of trial follow-up in each cluster (Figure 2). Although the level of the average cascade score differs between clusters, trends present a similar pattern of increase in all clusters (Figure 3).

The PLWHIV population is characterized by a high turnover over the study period: the overall annual exit rate is 22.6%

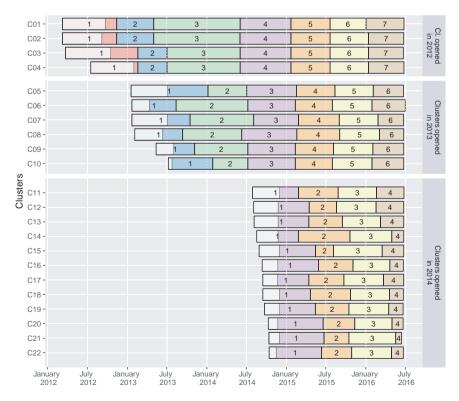


Figure 1. Dates of home-based survey rounds activities by clusters, ANRS 12249 TasP trial (2012 to 2016). The light areas in round 1 indicate the time required to complete the initial census of the resident population.

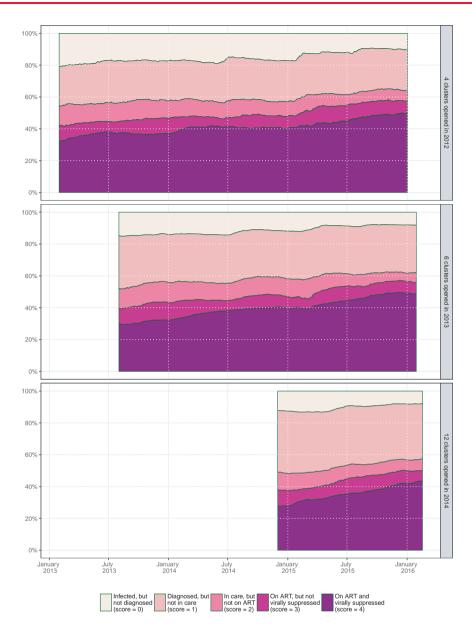


Figure 2. Evolution over time of the population cross-sectional HIV care cascade per group of clusters, ANRS 12249 TasP trial (2012 to 2016).

(2,979 exits for 13,180 person years) and the overall annual entry rate 22.4% (2,948 entries for 13,180 person years). Population dynamics were mainly due to out- and in-migration (annual rate, respectively, of 21.0% and 17.3%). New HIV infections accounted for a 4.8% annual increase in the PLWHIV population (625 events: 510 observed seroconversions and eight estimated unobserved seroconversions before the first observed positive status and 117 after the last negative one). The annual rate of permanent exits was 1.6% (216 events: 186 deaths and 30 individuals who lost their ability to consent). Finally, we observed 29 participants already HIV positive when they reached 16 years of age during the trial. The distribution of population change by component is similar between clusters, although the overall net growth is negative for 14 clusters and positive for the other 8 (Figure 4). Basic socio-demographic characteristics of PLWHIV entering/exiting the resident population are provided in supplementary materials (Table S1).

The average cascade score by cluster could be considered as a good summary statistic of the cross-sectional cascade as it is highly and significantly (p < 0.0001) correlated (Figure S2) with the proportions of diagnosed individuals (score  $\geq$  1), individuals in care (score  $\geq$  2), individuals on ART (score  $\geq$  3), and individuals virally suppressed (score = 4).

HIV seroconverters, who were undiagnosed at the date of seroconversion (Figure 5), had a lower cascade score compared to PLWHIV in the same cluster and at the same date (mean difference: -2.278, p < 0.0001, Figure 6). Half of the young people turning 16 years old and already infected by HIV were undiagnosed and only a fifth were on ART at that time (mean difference: -1.039, p = 0.0007). Permanent exits had on average a similar score to the rest of PLWHIV in their



Figure 3. Trends of the average cascade score per cluster over time, ANRS 12249 TasP trial (2012 to 2016). Each line represents a different cluster. All clusters did not open at the same time (cf. Figure 1): 4 clusters opened in 2012, 6 in 2013 and 12 in 2014.

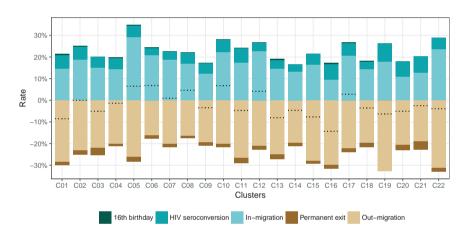


Figure 4. Annual growth rates of the resident PLWHIV population, by population change components and per cluster, ANRS 12249 TasP trial (2012 to 2016). Dotted lines indicate the sum of all rates, i.e. net annual population growth rate.

cluster (mean difference: 0.030, p=0.7541), two-thirds being actively in care at the date of the exit. Most migrants had a lower position compared to their cluster population, the difference being higher for in-migrants (mean difference: -0.630, p<0.0001) than out-migrants (-0.429, p<0.0001): 26% of out-migrants were on ART and virally suppressed at the date they out-migrated compared to 19% among in-migrants at arrival.

In all clusters (Figure 7), in-migration contributed negatively to the cluster average cascade score (from -0.210 to -0.043, median: -0.093) while out-migration contributed positively (from +0.046 to +0.255, median: +0.108). Because out-migrants had a lower score compared to local HIV residents, when they left their cluster, it mechanically increased the average cascade score of the population left behind. In- and out-migration compensated each other: the total contribution of migration was negative in 10 clusters and positive in the other 12, and close to zero in several clusters (from -0.099 to +0.154, median: +0.002). The contribution of permanent

exits (from -0.019 to +0.032, median: +0.001) and 16th birthdays (from -0.012 to +0.005, median: -0.004) was marginal with no clear pattern between clusters. HIV seroconversion had a negative contribution to the cascade in all clusters (from -0.182 to -0.072, median: -0.117), resulting in a total contribution of all events being negative almost everywhere (from -0.190 to +0.032, median: -0.112).

The imputation of potential unobserved HIV seroconversions had a marginal effect. Re-analysing the data without considering imputed seroconversions (Figure S3) did not change the results substantively, and the annualized total contribution of all components on the cluster average score ranged from -0.174 to +0.069 (median: -0.098).

#### 4 | DISCUSSION

Our results demonstrate that the turnover of the PLWHIV population residing in our trial area was high, more than

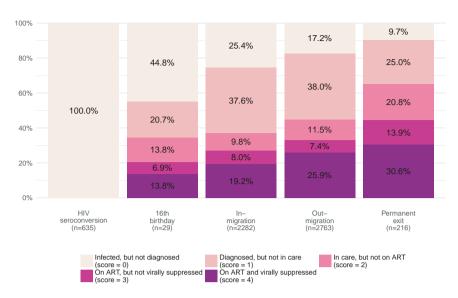


Figure 5. Position within the HIV care continuum at the date of entry/exit, by population change component, ANRS 12249 TasP trial (2012 to 2016).

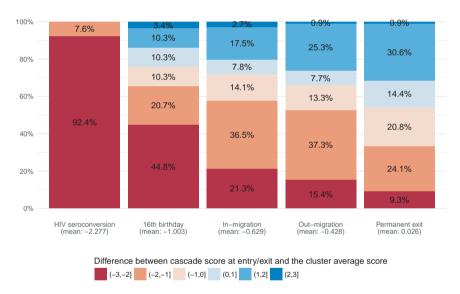


Figure 6. Distribution of the differences between HIV care cascade score at entry/exit and the cluster average score at the same date, by population change component, ANRS 12249 TasP trial (2012 to 2016).

one-fifth being replaced every year. While the average HIV care cascade score increased over time in all clusters, that increase was limited due to population dynamics, the total contribution of all entries and exits being systematically negative, and it was mainly due to new HIV infections.

In-migrants joined the PLWHIV population at earlier stages of the cascade and lowered the cluster average score. Even if out-migrants usually left at a slightly higher position in the cascade than in-migrants when they arrived, there were also at earlier stages compared to the rest of the resident population. Although this could be counterintuitive, at the population level, it had a positive effect on the cluster average score. As a result, out- and in-migration had a balanced impact on the cross-sectional cascade, both effects cancelling out.

Data collected through the ANRS 12249 TasP trial constitute a unique opportunity to make a fine description of individual trajectories over time through HIV services, on a daily basis, which can be done only in very few settings. However, to fully understand our results, it is crucial to understand the limitations of the data. Due to the nature of available data sources, different definitions and assumptions were required to estimate individual statuses. First, in-migration events were not directly collected by TasP fieldworkers and have therefore been derived by comparison of resident household members lists between survey rounds. Second, while HIV care statuses were measured precisely within trial clinics, we had to use proxy indicators (based on laboratory data in particular) for being in HIV care and being on ART in local governmental clinics. Measurement of

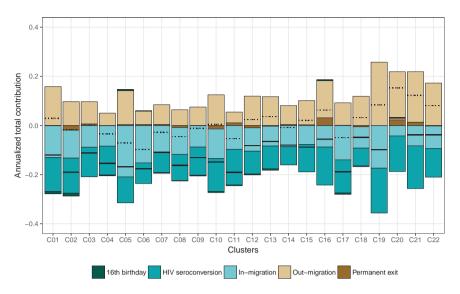


Figure 7. Annualized total contribution of population change on cluster average cascade score, by component of population change and per cluster, ANRS 12249 TasP trial (2012 to 2016). Dotted lines indicate the sum of the total contribution of in- and out-migration. Black lines indicate the sum of total contribution of all events. Examples of reading: in cluster C01, in-migration events reduced annually the cluster average cascade score by 0.127 while out-migration events increased it by 0.161. Therefore, the overall contribution of migration is +0.034 per year.

entry into care is generally robust because a CD4 count and/or a viral load is almost associated with first clinic visit. However, the identification of individuals exiting care is delayed for individuals matched only to NHLS database. In addition, considering our matching algorithm, the probability that a trial participant was wrongly associated with a record in ACCDB or NHLS (type-I error) is relatively small. However, some patients who resided in the trial area could not be matched (type-II error), for reasons such as data entry errors or use of different names in different settings [25]. Third, we did not have any data on individuals receiving HIV care in the private sector or in primary care clinics located outside the Hlabisa sub-district, potentially resulting in an underestimation of population progression through the HIV care cascade. Our estimates of the proportion of PLWHIV being in care should be considered as lower bounds. Finally, 9.5% of trial participants had an undocumented HIV status (because the fieldworkers were not able to contact them at least once or because they systematically refused rapid HIV tests and to provide a DBS) and were excluded from the analysis. A sensitivity analysis (unpublished yet) suggests that it is not affecting the observed trends of the population HIV care cascade. However, we could expect higher migration rates and a higher HIV incidence in that group. Therefore, our estimates of the contribution of population change on the cascade could thus be seen as conservative estimates.

The ANRS 12249 TasP trial did not demonstrate a significant difference in cumulative incidence by arms [18], due in particular to a low level of linkage to care [26], resulting in a limited increase of ART coverage over time and the absence of differentiation between arms. At the beginning of the trial, population ART coverage among all HIV-positive adults living in the study area was estimated at 29.6% in intervention arm and 33.7% in control arm. ART coverage rose to 53.4% (+23.8) in the intervention arm and 52.8% (+19.1) in the control arm by 1 January 2016, with the difference between arms not statistically significant (p = 0.67) [18].

In our context of high HIV incidence, delays in HIV diagnosis is a key barrier to progress through the population HIV care cascade. Within the ANRS 12249 TasP trial, one-third of individuals who seroconverted remained undiagnosed after one year, one-third discovered their HIV-positive status but did not enter care and one-third linked to an HIV clinic [27]. Overall, with only 17% initiating ART within 12 months after seroconversion, we are far from the 81% expected by the model of Granich and colleagues [4] to eliminate HIV transmission in South Africa. The HIV care trajectories were clearly suboptimal in seroconverters despite the introduction of UTT services and a trial environment, contributing to a continuous transmission of HIV within the population.

Migrants in general had a lower position within the continuum of HIV care than the average population: this group needs specific interventions to link and retain into care over time. This very mobile population is not living separately from the rest of the local population. In this rural area with few job opportunities, people come and go and are still part of local sexual networks. In this trial, around 40% of participants reported having a sexual partner located outside of the trial area, some as far as major cities outside of KwaZulu-Natal [18]. In this paper, we did not analyse migration patterns and their associated factors (in particular gender), such topic needed to be explored further. More generally, the dynamics between migration, the HIV epidemic and care trajectories through the health system require additional investigations.

#### 5 | CONCLUSIONS

Migrants face specific vulnerabilities that limit their retention at each step of the HIV care continuum and coordination to facilitate continued access to care when people move should be developed. In a context of high HIV incidence, the continuous flow of newly infected individuals who are less likely to

link to HIV care and to initiate ART, slows down efforts to increase overall ART coverage and population viral suppression, ultimately attenuating any population-level impact on HIV incidence. Identifying specific interventions to reach newly infected people as early as possible is a crucial step on the way towards the end of the epidemic.

#### **COMPETING INTERESTS**

CI received honoraria for consulting services rendered to Gilead Sciences. All other authors declare that they have no conflicts of interest.

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#### **AUTHORS' CONTRIBUTIONS**

CI, JOG, FT, DP and FD designed and implemented the ANRS 12249 TasP trial. JL, JOG and NM developed the research question addressed in this paper. JL and MHD did the statistical analysis. JL wrote the first draft of the manuscript with the support of JOG. All authors contributed to the interpretation and presentation of the findings. All authors approved the final version of the manuscript for submission.

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#### SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

**Table S1.** Socio-demographic characteristics of individuals who entered or exited the resident PLWHIV population, by population change component, ANRS 12249 TasP trial (2012 to 2016) **Figure S2.** Correlation between the average cascade score and proportions of all resident PLWHIV being diagnosed, in care, on

ART or virally suppressed at cluster level, ANRS 12249 TasP trial (2012 to 2016)

**Figure S3.** Sensitive analysis: comparison of annualized total contribution of population change on cluster average cascade score, by component of population change and per cluster, with **(A)** and without **(B)** imputation of potential unobserved seroconversions.



#### RESEARCH ARTICLE

# Population mobility associated with higher risk sexual behaviour in eastern African communities participating in a Universal Testing and Treatment trial

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#### Abstract

**Introduction:** There are significant knowledge gaps concerning complex forms of mobility emergent in sub-Saharan Africa, their relationship to sexual behaviours, HIV transmission, and how sex modifies these associations. This study, within an ongoing test-and-treat trial (SEARCH, NCT01864603), sought to measure effects of diverse metrics of mobility on behaviours, with attention to gender.

**Methods:** Cross-sectional data were collected in 2016 from 1919 adults in 12 communities in Kenya and Uganda, to examine mobility (labour/non-labour-related travel), migration (changes of residence over geopolitical boundaries) and their associations with sexual behaviours (concurrent/higher risk partnerships), by region and sex. Multilevel mixed-effects logistic regression models, stratified by sex and adjusted for clustering by community, were fitted to examine associations of mobility with higher-risk behaviours, in past 2 years/past 6 months, controlling for key covariates.

**Results:** The population was 45.8% male and 52.4% female, with mean age 38.7 (median 37, IQR: 17); 11.2% had migrated in the past 2 years. Migration varied by region (14.4% in Kenya, 11.5% in southwestern and 1.7% in eastern and Uganda) and sex (13.6% of men and 9.2% of women). Ten per cent reported labour-related travel and 45.9% non-labour-related travel in past 6 months—and varied by region and sex: labour-related mobility was more common in men (18.5%) than women (2.9%); non-labour-related mobility was more common in women (57.1%) than men (32.6%). In 2015 to 2016, 24.6% of men and 6.6% of women had concurrent sexual partnerships; in past 6 months, 21.6% of men and 5.4% of women had concurrent partnerships. Concurrency in 2015 to 2016 was more strongly associated with migration in women [aRR = 2.0, 95% CI(1.1 to 3.7)] than men [aRR = 1.5, 95% CI(1.0 to 2.2)]. Concurrency in past 6 months was more strongly associated with labour-related mobility in women [aRR = 2.9, 95% CI(1.0 to 8.0)] than men [aRR = 1.8, 95% CI(1.2 to 2.5)], but with non-labour-related mobility in men [aRR = 2.2, 95% CI(1.5 to 3.4)].

**Conclusions:** In rural eastern Africa, both longer-distance/permanent, and localized/shorter-term forms of mobility are associated with higher-risk behaviours, and are highly gendered: the HIV risks associated with mobility are more pronounced for women. Gender-specific interventions among mobile populations are needed to combat HIV in the region.

Keywords: HIV; universal test and treat; population dynamics; geographic mobility; sexual behaviour; sub-Saharan Africa

Additional Supporting Information may be found online in the Supporting information tab for this article.

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#### 1 | INTRODUCTION

Despite substantial progress in HIV treatment and prevention in sub-Saharan Africa, highly mobile populations are proving challenging to engage in these gains. The significance of mobility in the HIV epidemic is clear: the early epidemic spread along major transportation routes [1-4], mobile populations are faced with numerous individual- and structural-level barriers to HIV diagnosis, treatment and prevention [5-8], and may disproportionately contribute to onward transmission [9]. However, there exist significant knowledge gaps concerning the complex forms of mobility emergent in sub-Saharan Africa,

their relationship to sexual behaviours, HIV acquisition and risk of onward transmission, as well as how sex modifies these associations. These knowledge gaps hinder the development and delivery of tailored interventions to successfully engage mobile persons in recent advances in HIV treatment and prevention.

Previous research into the relationships between mobility, sexual behaviours and HIV has been limited by measures that are broad, simplistic in their range and complexity, and has failed to take into account the significant heterogeneity of mobility by sex [10,11]. There are few data sources and metrics for population-based estimates that are reflective of the complex forms of mobility emergent in sub-Saharan Africa. This has precluded meta-analytical summaries [11-13], and resulted in contradictory and inconclusive results in studies of the links between mobility, sexual behaviour and HIV [11].

The lack of adequate depth and breadth in current measures and dimensions of mobility is particularly problematic for research on HIV and mobility in sub-Saharan Africa, where populations are highly mobile: sub-Saharan Africa's intra-continental emigration rate (65%) represents the largest south to south movement of people in the world [14]. Levels of mobility in the region have risen dramatically in recent decades, in tandem with rapid social transformations, including the world's fastest rate of urbanization (from 23% urban in 1970 to 40% in 2005.[15]) Forms of mobility in sub-Saharan Africa are diverse and complex relative to other regions: the paradigmatic rural-to-urban migration flow does not predominate in all settings [16]; rather, counter-urbanization [17] and circulation between rural areas, semi-urban towns and the rural perimeters of cities are common [10,18-21], particularly among women. The temporary, localized forms of mobility, for example, frequent movements among several homesteads, are more common in women, but difficult to measure [21].

To overcome these previous research gaps, we leveraged an ongoing large scale, population-level community cluster randomized trial of 334,512 persons in eastern Africa evaluating a test-and-treat strategy for HIV epidemic control, to embed a detailed sub-study of mobility, sexual behaviours and HIV. In this sub-study, we apply newly developed, high-resolution measures of mobility and sexual relationship history to enhance our understanding of the behavioural and social pathways through which patterns of mobility may contribute to HIV acquisition and sustain onward transmission.

#### 2 | METHODS

#### 2.1 Study Setting

This mobility study is embedded within the *Sustainable East Africa Research in Community Health (SEARCH)* trial (NCT# 01864603), which seeks to test the effectiveness of the test and treat strategy for reducing population-level HIV incidence [22,23]. SEARCH is a community cluster-randomized controlled trial in 32 communities in one region in Kenya and two regions in Uganda. All communities received a census and population-wide HIV testing at baseline. The SEARCH intervention used a hybrid mobile HIV testing approach, in which 2-week, mobile, multi-disease community health campaigns were followed up by home-based testing of campaign non-participants [22]. In the 16 intervention communities, all

individuals diagnosed as HIV-seropositive were then referred for immediate anti-retroviral therapy (ART) within a streamlined model of care that is patient-centred and designed to reduce patient-level barriers and maximize health system efficiency [24]. The ongoing study of mobility within the trial (R01MH104132) is being conducted in 12 of the SEARCH trial communities. In the embedded mobility study, we are conducting original data collection using novel classifications and quantifications of mobility in individuals in the 12 communities in order to more fully understand the impact of mobility on sexual HIV risk behaviours, HIV prevalence and incidence, engagement in the HIV care continuum and components of the universal HIV testing and treatment intervention strategy. This analysis describes significant forms of mobility and their associations with sexual behaviours at study baseline.

#### 2.2 | Study sample

Our study enrolled 2750 adults aged 16 and older (with a consent rate of 98.3% to derive the cohort), of whom n=480 simultaneously were enrolled in an embedded cohort of n=240 couples. Individual-level analyses were conducted with n=2308 individuals who were not exclusively in the couples' cohort (including n=2270 who were exclusively in the individuals' cohort and n=38 who were in both cohorts). The analyses for this article were further restricted to n=1919 sexually active individuals, defined as individuals reporting any sexual partnerships since January 2011. The dataset therefore excluded n=389 individuals, among whom n=76 reported not ever having had any sexual partners and n=313 reported having been sexually active in the past but not since January 2011.

A multi-level stratified random sampling design (region, intervention arm, HIV status, mobility status, gender) was used to select the sample of individuals from the census-enumerated adult population of each of 12 SEARCH communities, composed of eight roughly equally sized groups of HIV-positive and HIVnegative, mobile and residentially stable men and women. The 12 communities, balanced by SEARCH study arm, were selected purposively to reflect underlying heterogeneity in forms of mobility across communities in SEARCH, and were composed of three communities each from the two regions of Uganda, along with three inland, and three Lake Victoria shoreline communities in Kenya. Baseline mobility for sampling purposes was defined on the basis of census data collected by the SEARCH trial on household presence in past 12 months (mobile = 'away from household 6 months or more in past 12 months', and/or "fewer than half of nights spent in household in past 4 months"). HIV-positive individuals and mobile individuals were oversampled to achieve the desired sample size in each stratum. In communities with low total numbers of a stratum, all individuals were sampled in the stratum, a scenario that was common in communities with low HIV prevalence and low levels of mobility.

Sampling weights were generated based on the proportional representation of each of eight strata in the population census enumeration of the 12 communities. Sampling weights for stratum i in community  $j(w_{i,j})$  were calculated by dividing the expected number of individuals within each stratum (based on population proportions) by the observed number of individuals actually sampled in each stratum, as follows:

$$w_{i,j} = \frac{\text{Expected}_{i,j}}{\text{Sampled}_{i,i}} = \frac{\binom{N_{i,j}}{N_j} \times n_j}{n_{i,j}}$$

Where  $N_{i,j}$  is the population size of stratum i in community j,  $N_j$  is the total population size of community j,  $n_j$  is the sample size of community j, and  $n_{i,j}$  is the sample size of stratum i in community j.

#### 2.3 Inclusion/exclusion criteria

Inclusion into the study was restricted to individuals in these 12 SEARCH communities, aged 16 and older, for whom baseline HIV serostatus and census-defined mobility status was ascertained. As described in detail elsewhere [22], the SEARCH trial ascertained individuals' HIV status via rapid, finger-prick blood based HIV antibody testing and counselling using ministry of health test kits and testing algorithms.

#### 2.4 Data collection

Mobility survey data were collected during one visit with study participants between February and November 2016. Data were collected in households or in another location preferred by the participant; research assistants, trained in research ethics and qualitative and survey interview techniques, conducted data collection in participants' preferred local language. Research teams were gender-balanced and gender-matched to participants, to maximize rapport and reduce social desirability bias. Survey data were collected using programmed tablets and took about one and one-half hours to complete; topics included demographics, migration histories, work and non-work related travel in the past six months, and reasons for mobility. For HIV-positive participants, additional data were collected about disclosure, experiences of stigma, and HIV care engagement.

#### 2.5 Measurement of sexual behaviour

A Relationship History Calendar module, adapted from an instrument previously used in the region and shown to reduce social desirability bias to improve the reporting of sexual relationships and behaviour [25], was used to collect information about sexual behaviour and partnerships since January 2011. The calendar survey is a fold-out grid with units of time in months and years noted across the top of the grid. The survey records information in monthly intervals rather than years, because many relationships survive for <1 year; we measured changes in relationship dimensions and behaviours over the course of each sexual relationship in the preceding approximately five years from the time of the survey (i.e. since January 2011). Use of the calendar survey enabled us to clearly identify sexual partner concurrency and its overlap with mobility over time.

The calendar was used to collect month-by-month data on partnerships, including relationship type and co-residence and mobility of partners; durations; frequency of sex, contraceptive and condom use; and the exchange of gifts and/or money within each partnership. "High risk partner" refers to a sexual partnership with a casual partner, commercial sex worker or client, one night stand, or inherited partner/inheritor. Sexual partnership concurrency is occurrence of two or more sexual

partnerships within any one month over a given time period. Occupation types, detailed in Table 1, are grouped into the categories "informal low risk", "formal" and "informal high risk" on the basis of underlying HIV prevalence levels within those livelihood categories.

#### 2.6 | Measurement of mobility

The baseline mobility survey captured participants' histories of migrations over their lifetime, by asking participants to tell us their birthplace and the names of places they lived (with county/district/nation recorded by the interviewer) along with their age at change of residence, in childhood through to the present. Reasons for moves were collected for the five most recent changes of residence. These data were used for measures of migration. Migration was defined as a movement of people across a specified geopolitical boundary for the purpose of establishing a new permanent residence. Migration between countries was classified as international; migration within countries, as internal migration. We used high-resolution metrics in order to differentiate between shorter-distance and longer-distance internal migration; we recorded inter-district/sub-county (i.e. across district) as well as intra-district/subcounty (i.e. within district) changes of residence. Districts in Uganda, and sub-counties in Kenya, are the geopolitical units that are most equivalent in population size and area.

After a set of questions about livelihoods, interviewers asked about mobility in the past six months. Participants were asked first about labour-related mobility: "The next questions are about the travelling that you do for business/to earn money. This includes travel to look for a job, and for farming/food production. Do you ever travel away from your home area for these purposes? (For this question, I'm talking about travel that requires your sleeping away from your main residence.)" If participants answered yes, interviewers then probed to ask the names of ALL locations where participants travelled in past six months. Interviewers recorded the county/district of the location, the number of trips to the location, the length of nights spent on each trip to the location, where participants stayed, and the reasons for the trip(s) to the location. Interviewers then asked participants about non-labour-related mobility: "Did you travel to any other places for other purposes (other than work) in the last six months?" If participants answered yes, interviewers then probed to ask the names of ALL locations where participants travelled in past six months for reasons other than work, and recorded all subsequent information as described about frequency, duration and reasons. These data were used for measures of mobility: Mobility was defined as travel involving time spent away from primary places of residence, without any intention to change residence (locations and movements between multiple homes that are considered to be main residences are also recorded). This excluded commuting, as mobility is recorded only if the travel involved sleeping one or more nights away from primary residence(s). Labourrelated mobility was defined as travel "for business/to earn money", including travel to look for a job, and for farming/food production. Non-labour-related mobility was defined as travel for all other purposes. Numbers of trips taken, and number of nights spent on each trip, by location, are collected for the previous 6 months before the visit date; a total number of nights was tallied over time periods by travel purpose.

Table 1. Sociodemographic characteristics, by region and sex.

			Region				Sex	
Characteristic	Overall	Kenya	Uganda E	Uganda SW	р	Men	Women	р
Weighted n	1898.1	1045	364	489.1		869.1	1029	
Region					NA			0.910
Kenya-Western	1045.0 (55.1)	1045.0 (100.0)	0.0 (0.0)	0.0 (0.0)		479.4 (55.2)	565.5 (55.0)	
Uganda-Eastern	364.0 (19.2)	0.0 (0.0)	364.0 (100.0)	0.0 (0.0)		167.2 (19.2)	196.8 (19.1)	
Uganda-South Western	489.1 (25.8)	0.0 (0.0)	0.0 (0.0)	489.1 (100.0)		222.4 (25.6)	266.7 (25.9)	
10-year age band					0.038			0.017
16 to 24	405.2 (21.3)	226.8 (21.7)	72.4 (19.9)	106.0 (21.7)		175.5 (20.2)	229.7 (22.3)	
25 to 34	616.6 (32.5)	320.5 (30.7)	133.1 (36.6)	162.9 (33.3)		250.6 (28.8)	366.0 (35.6)	
35 to 44	423.8 (22.3)	240.5 (23.0)	83.3 (22.9)	100.1 (20.5)		202.5 (23.3)	221.3 (21.5)	
45 to 54	207.6 (10.9)	105.7 (10.1)	53.7 (14.8)	48.2 (9.9)		93.4 (10.8)	114.2 (11.1)	
55 to 64	149.3 (7.9)	96.7 (9.3)	17.8 (4.9)	34.9 (7.1)		83.0 (9.6)	66.3 (6.4)	
65 and older	95.5 (5.0)	54.8 (5.2)	3.7 (1.0)	37.0 (7.6)		64.1 (7.4)	31.5 (3.1)	
Marital status					< 0.001			0.022
Divorced, separated, widowed, missing	155.2 (8.2)	108.3 (10.4)	4.5 (1.2)	42.5 (8.7)		26.8 (3.1)	128.4 (12.5)	
Currently married	1543.8 (81.3)	815.7 (78.1)	345.2 (94.8)	382.9 (78.3)		734.1 (84.5)	809.7 (78.7)	
Currently single	199.1 (10.5)	121.0 (11.6)	14.3 (3.9)	63.8 (13.0)		108.2 (12.4)	90.9 (8.8)	
Education level					< 0.001			0.007
No Schooling	193.8 (10.4)	41.2 (4.0)	68.4 (19.1)	84.2 (17.3)		61.0 (7.2)	132.8 (13.1)	
Primary/Secondary	1587.4 (85.0)	953.3 (93.2)	274.1 (76.5)	360.0 (74.1)		747.7 (88.0)	839.7 (82.6)	
Post-secondary	85.3 (4.6)	27.8 (2.7)	16.0 (4.5)	41.4 (8.5)		41.1 (4.8)	44.1 (4.3)	
Household wealth: Poorest	256.3 (13.5)	113.1 (10.8)	56.5 (15.5)	86.6 (17.7)	0.018	133.5 (15.4)	122.7 (11.9)	0.120
quantile								
Occupation								
Informal sector (low risk)					0.239			< 0.001
Farming/livestock	1037.5 (58.6)	461.0 (47.8)	302.8 (85.5)	273.6 (60.8)		441.2 (54.2)	596.3 (62.4)	
Student	22.1 (1.2)	22.1 (2.3)	0.0 (0.0)	0.0 (0.0)		21.2 (2.6)	0.9 (0.1)	
Construction/artisanal labour	65.8 (3.7)	41.6 (4.3)	0.0 (0.0)	24.2 (5.4)		65.1 (8.0)	0.7 (0.1)	
Shopkeeper/market vendor	272.4 (15.4)	160.0 (16.6)	23.7 (6.7)	88.8 (19.7)		87.7 (10.8)	184.8 (19.3)	
Household worker/housewife	5.7 (0.3)	5.0 (0.5)	0.0 (0.0)	0.6 (0.1)		3.4 (0.4)	2.3 (0.2)	
Informal sector (high risk)								
Fishing/fish trade	188.5 (10.7)	184.1 (19.1)	3.1 (0.9)	1.4 (0.3)		96.3 (11.8)	92.2 (9.7)	
Hotel/restaurant/bar worker	35.1 (2.0)	13.7 (1.4)	5.5 (1.6)	15.8 (3.5)		17.5 (2.2)	17.5 (1.8)	
Transport driver/tourism	41.4 (2.3)	30.4 (3.2)	0.0 (0.0)	11.0 (2.4)		39.4 (4.8)	2.1 (0.2)	
Formal sector								
Gov't/military/teacher/ healthcare	95.7 (5.4)	42.1 (4.4)	19.1 (5.4)	34.5 (7.7)		38.9 (4.8)	56.8 (6.0)	
Factory worker/mining	4.7 (0.3)	4.6 (0.5)	0.0 (0.0)	0.1 (0.0)		3.1 (0.4)	1.5 (0.2)	

Weighted frequencies and column percentages shown.

Informal sector occupations categorized as "high risk" or "low risk" are defined on the basis of associations with underlying HIV prevalence in the SEARCH trial.

#### 2.7 Data analysis

Statistical analyses with individual-level survey weights were used to describe population characteristics and test for their bivariate associations with sexual partnership concurrency and with higher risk partnerships over the period 2015 to 2016 and in the six months prior to the survey date, and implemented in the R statistical language version 3.2.2 using the

survey package [26]. Multilevel mixed-effects logistic regression models, adjusted for clustering by community, were fitted using Stata statistical software (version 14.2) [27] to examine associations of measures of mobility with sexual behaviour measures, in past two years and in past six months respectively, controlling for key covariates (region, sex, age, marital status, occupation, and household wealth.) Subsequent models were fitted to test for interactions between sex and measures

of mobility on sexual behaviour. We then estimated model-adjusted risks [28] to compare predicted sexual behaviour outcomes: using Stata post estimation procedures ("margins, dydx"), we obtained average marginal effects of selected mobility metrics (dichotomous independent variables) from the fitted logistic regression models, summarized in Tables 6. The average marginal effect is the difference in the adjusted predictions for the two groups, or risk difference [28], from which adjusted marginal relative risks are obtained using the conversion method [29].

#### 2.8 | Ethical approval

Ethical approvals for this research were received from the University of California San Francisco Committee on Human Research (14-15058), Ethical Review Committee of the Kenya Medical Research Institute (KEMRI/SERU/CMR/3052), Makerere University School of Medicine Research and Ethics Committee (2015-040), and Uganda National Council for Science and Technology (HS 1834).

#### 3 | RESULTS

#### 3.1 Migration by Region and Sex

Tables 1 and 2 describe characteristics of the study population and their mobility and sexual behaviours by region and sex. Over half of the sample (50.6%) had at least one migration as an adult; nearly all of these were internal migrations (49.5%). A higher proportion of internal migrations occurred across district or sub-county lines (38.3%), compared to intradistrict/sub-county (23.6%) migrations. Over 20% had migrated in the past five years, 11.2% in the past two years, and 7.5% in the past year. International migration was rare, undertaken by men only, and almost exclusively intra-continental (not shown). Levels of migration varied across regions, and were most prevalent in Kenya, with 27% having migrated in past five years, and 14.4% in past two years. The only exception: a higher proportion of southwestern Ugandans (18%) than Kenyans (12.3%) undertook inter-district/sub-county migration in the previous five years (and in past two years, 11% vs. 4.6% respectively.) Higher proportions of men than women migrated in past five (22.4% vs. 18.2%) and two years (13.6% vs. 9.2%). However, women predominated in the more localized intra-district/sub-county migrations (25.6% vs. 21.2%) overall, with higher but non-statistically significant differences in levels of intra-district moves in the past five, two and one years.

#### 3.2 Recent mobility by region and sex

Overall, 10% undertook any labour-related travel, and 45.9% undertook travel for other reasons, in the previous six months. The mean number of labour-related trips was higher than for non-labour related trips, and the mean number of nights spent away was higher on labour-related trips (16.5) than on non-labour related (11.9). Levels of mobility of all types were significantly lower in eastern Uganda, comparable between southwestern Uganda and Kenya, but somewhat higher in Kenya for some forms of mobility. For example, 58.6% of Kenyans versus 48.5% of southwestern Ugandans undertook non-labour related travel in the prior six months. Types of mobility

by purpose varied significantly by sex: while 18.5% of men versus 2.9% of women undertook labour-related travel ( $p \le 0.001$ ), 57.1% of women versus 32.6% of men undertook travel for other purposes (p = 0.001) in the past six months. The mean number of nights spent away for labour-related travel was 21.5 for men versus 9.9 for women (p = 0.008); in contrast, women spent 13.7 nights away and men spent 9.0 nights away on average on non-labour-related travel (p = 0.022) in past six months.

### 3.3 | Sex and regional differences in reasons for mobility

Participants were asked about the reasons for trips taken in the prior six months; these were significantly patterned by region and sex, as shown in Table 3. The predominant reasons men travelled for work were "artisanal labour (e.g. construction)" in Kenya (33.6%), and "market trading" in eastern (45.9%), and southwest Uganda (58.3%). The predominant reasons women travelled for work were "market trading" in Kenya (83.5%), and "looking for work" in southwest Uganda (77.3%) (in eastern Uganda fewer than five women travelled for livelihoods). Mobility in fishing communities figured predominantly in Kenya, where 27.9% of men and 11.1% of women travelled for livelihoods in the fish trade. The predominant reasons for non-labour-related mobility among men were for "attending funerals" in Kenya (42.4%), "holidays and visiting family" in south eastern Uganda (60.6%), and "care-giving or care-seeking" in southwest Uganda (58.5%). Among women, these were "attending funerals" in Kenya (50.1%) and eastern Uganda (85.7%), and "care-giving or care-seeking" in southwest Uganda (55.4%).

#### 3.4 Sexual risk behaviour

The mean number of lifetime sexual partners was 5.2 overall, significantly higher in Kenya (6.5) than in southwest (4.2) or eastern Uganda (3.0) ( $p \le 0.001$ ), and higher in men (7.8) than women (3.0) ( $p \le 0.001$ ) (Table 2). Similarly, measures of sexual partnership concurrency varied by region and sex. For example, 15% reported overlapping sexual partnerships in any month over the period 2015 to 2016; concurrency was highest in Kenya (19.5%), followed by southwestern (11.6%) and eastern Uganda (6.6%) ( $p \le 0.001$ ). A higher proportion of men (24.9%) than women (6.6%) reported sexual partnership concurrency ( $p \le 0.001$ ). Figure 1 shows the prevalence of concurrency by age and sex in 2015 to 2016. As shown, prevalence peaked in women in the youngest age band, declining thereafter; in contrast, prevalence of concurrency peaked in men aged 55 to 64. Condom use was rare, with only 9.8% always using condoms within a one-month period. In 2015 to 2016, 11.9% had partnerships classified as higher risk (including casual partners and "one night stands", commercial sex workers or clients, or inherited partners/inheritors), a proportion higher in Kenya (16.7%) than southwestern (10.4%) and eastern Uganda (0.1%) ( $p \le 0.001$ ); sex differences were nonsignificant. Finally, prevalent HIV infection in the baseline year of the SEARCH study among this sample was 13.7% overall; 20.9% in Kenya, 6.8% in southwest and 2.5% in eastern Uganda ( $p \le 0.001$ ), and 15.4% in women versus 11.8% in men ( $p \le 0.001$ ).

Table 2. Mobility and sexual behaviour, by region and sex.

			Region	u			Sex	
Characteristic	Overall	Kenya	Uganda E	Uganda SW	d	Men	Women	d
Weighted n	1898.1	1045	364	489.1		869.1	1029	
Any adult migration	959.9 (50.6)	733.9 (70.2)	41.6 (11.4)	184.4 (37.7)	<0.001	473.8 (54.5)	486.1 (47.2)	0.119
Any adult internal migration	938.7 (49.5)	716.2 (68.5)	41.6 (11.4)	180.9 (37.0)	<0.001	453.2 (52.1)	485.5 (47.2)	0.335
Intra-district/sub-county	447.8 (23.6)	445.2 (42.6)	0.2 (0.0)	2.4 (0.5)	<0.001	184.4 (21.2)	263.4 (25.6)	0.003
Inter-district/sub-county	727.1 (38.3)	505.6 (48.4)	41.5 (11.4)	179.9 (36.8)	<0.001	399.3 (45.9)	327.8 (31.9)	0.003
Any adult international migration	74.3 (3.9)	66.2 (3.5)	0.1 (0.0)	8.1 (0.4)	<0.001	61.2 (3.2)	13.1 (1.0)	<0.001
Past 5 years: Any migration	382.0 (20.1)	282.1 (27.0)	8.0 (2.2)	91.9 (18.8)	<0.001	194.5 (22.4)	187.4 (18.2)	0.028
Past 5 years: Any internal migration	377.5 (19.9)	280.3 (26.8)	8.0 (2.2)	89.2 (18.2)	<0.001	190.1 (21.9)	187.4 (18.2)	0.056
5-year Intra-District/Sub-county	192.8 (10.2)	191.7 (18.3)	0.0 (0.0)	1.1 (0.2)	0.054	77.9 (9.0)	115.0 (11.2)	0.076
5-year Inter-District/Sub-county	224.4 (11.8)	128.1 (12.3)	8.0 (2.2)	88.3 (18.0)	0.004	137.3 (15.8)	87.1 (8.5)	900:0
Past 5 years: international migration	8.2 (0.4)	4.1 (0.4)	0.0 (0.0)	4.2 (0.9)	0.471	8.2 (0.9)	0.0 (0.0)	0.032
Past 2 years: Any migration	212.9 (11.2)	150.4 (14.4)	6.2 (1.7)	56.3 (11.5)	0.004	117.8 (13.6)	95.1 (9.2)	0.002
Past 2 years: Any internal migration	211.5 (11.1)	150.4 (14.4)	6.2 (1.7)	54.9 (11.2)	0.003	116.3 (13.4)	95.1 (9.2)	0.003
2-year Intra-District/Sub-county	106.9 (5.6)	105.9 (10.1)	0.0 (0.0)	1.0 (0.2)	0.104	42.7 (4.9)	64.2 (6.2)	0.138
2-year Inter-District/Sub-county	107.9 (5.7)	47.8 (4.6)	6.2 (1.7)	53.9 (11.0)	0.001	76.4 (8.8)	31.5 (3.1)	0.009
Past 2 years: international migration	2.6 (0.1)	0.0 (0.0)	0.0 (0.0)	2.6 (0.5)	0.827	2.6 (0.3)	(0.0) 0.0	0.121
Past 1 year: Any migration	142.5 (7.5)	99.2 (9.5)	2.0 (0.5)	41.3 (8.4)	0.005	79.4 (9.1)	63.1 (6.1)	0.016
Past 1 year: Any internal migration	140.1 (7.4)	99.2 (9.5)	2.0 (0.5)	38.9 (8.0)	0.004	77.0 (8.9)	63.1 (6.1)	0.029
Past year intra-district/sub-county	67.9 (3.6)	67.0 (6.4)	0.0 (0.0)	1.0 (0.2)	0.120	27.6 (3.2)	40.3 (3.9)	0.409
Past year inter-district/sub-county	74.2 (3.9)	34.3 (3.3)	2.0 (0.5)	37.9 (7.8)	0.001	51.0 (5.9)	23.2 (2.3)	0.034
Past year international migration	2.4 (0.1)	0.0 (0.0)	0.0 (0.0)	2.4 (0.5)	0.835	2.4 (0.3)	(0.0) 0.0	0.135
Short-term mobility								
Past 6 months mobility (≥1 nights away)								
Any labour-related travel, past 6 month(%)	190.0 (10.0)	132.0 (12.6)	3.0 (0.8)	55.1 (11.3)	0.019	160.5 (18.5)	29.5 (2.9)	<0.001
No. labour-related trips (mean (SD))	1.05 (9.27)	1.54 (12.00)	0.07 (1.39)	0.77 (5.02)	0.034	1.89 (12.25)	0.33 (5.39)	0.046
No. nights away, labour-related travel (mean (SD))	3.08 (16.49)	3.13 (16.79)	0.50 (7.17)	4.94 (20.24)	0.020	5.42 (21.51)	1.06 (9.87)	0.008
Any non-labour-related travel, past 6 month (%)	871.0 (45.9)	612.9 (58.6)	20.8 (5.7)	237.3 (48.5)	<0.001	283.3 (32.6)	587.7 (57.1)	0.001
No. non-work trips (mean (SD))	0.95 (1.80)	1.32 (2.08)	0.13 (0.67)	0.80 (1.51)	<0.001	0.59 (1.15)	1.27 (2.17)	0.007
No. nights away, non-work travel (mean (SD))	4.29 (11.87)	5.47 (12.39)	0.89 (5.83)	4.37 (13.58)	<0.001	2.61 (9.01)	5.75 (13.73)	0.022
Past 1 month: Recent mobility (≥1 nights away)								
Any labour-related travel, past 1 month (%)	108.3 (5.7)	80.3 (7.7)	3.0 (0.8)	25.0 (5.1)	0.015	91.2 (10.5)	17.1 (1.7)	<0.001
No. labour-related trips (mean (SD))	0.21 (1.68)	0.31 (2.18)	0.02 (0.38)	0.13 (0.84)	0.035	0.38 (2.26)	0.06 (0.90)	0.040
No. nights away, labour-related travel (mean (SD))	0.50 (3.06)	0.62 (3.38)	0.08 (1.16)	0.58 (3.30)	0.008	0.94 (4.12)	0.13 (1.57)	0.026
Any non-labour-related travel, past 1 month(%)	407.4 (21.5)	253.8 (24.3)	20.8 (5.7)	132.8 (27.2)	<0.001	127.1 (14.6)	280.3 (27.2)	0.001
No. non-work trips (mean (SD))	0.27 (0.59)	0.31 (0.64)	0.09 (0.45)	0.31 (0.55)	0.002	0.19 (0.52)	0.34 (0.64)	0.011
No. nights away, non-work travel (mean (SD))	0.94 (3.41)	0.91 (2.98)	0.58 (3.20)	1.28 (4.28)	0.134	0.83 (3.56)	1.04 (3.28)	0.244

Table 2. (Continued)

			Region	u.			Sex	
Characteristic	Overall	Kenya	Uganda E	Uganda SW	d	Men	Women	d
Sexual behaviour								
Lifetime number of sexual partners (mean (SD))	5.2 (8.3)	6.5 (9.8)	3.0 (2.6)	4.2 (7.1)	<0.001	7.8 (11.1)	3.0 (3.6)	<0.001
Number of sexual partners, 2015 to 2016					0.005			<0.001
0 or 1	1605.3 (84.6)	832.9 (79.7)	340.1 (93.4)	432.3 (88.4)		645.2 (74.2)	960.1 (93.3)	
2	228.3 (12.0)	165.1 (15.8)	17.6 (4.8)	45.7 (9.3)		168.2 (19.4)	60.1 (5.8)	
3 or more	64.4 (3.4)	47.0 (4.5)	6.4 (1.8)	11.0 (2.3)		55.7 (6.4)	8.8 (0.9)	
Number of sexual partners, past 6 months					0.001			<0.001
0 or 1	1553.3 (85.7)	800.5 (80.8)	333.9 (94.1)	418.8 (89.4)		644.1 (76.5)	909.2 (93.6)	
2	206.7 (11.4)	149.5 (15.1)	17.1 (4.8)	40.1 (8.6)		150.8 (17.9)	56.0 (5.8)	
3 or more	53.3 (2.9)	40.2 (4.1)	3.7 (1.0)	9.4 (2.0)		47.3 (5.6)	5.9 (0.6)	
Sexual partnership concurrency								
Any concurrent sex partnerships, 2015 to 2016	284.6 (15.0)	203.9 (19.5)	24.0 (6.6)	56.7 (11.6)	<0.001	216.6 (24.9)	(9.9) (8.9)	<0.001
Any concurrent sex partnerships, past 6 months	234.1 (12.9)	171.4 (17.3)	20.8 (5.9)	41.9 (8.9)	0.002	181.5 (21.6)	52.5 (5.4)	<0.001
Condom use, most recent month and partner					<0.001			
N/A (No sex)	203.3 (11.6)	87.4 (9.1)	19.6 (5.7)	96.3 (20.9)		75.7 (9.1)	127.6 (13.7)	0.061
Always	171.3 (9.8)	139.1 (14.6)	11.1 (3.2)	21.1 (4.6)		89.8 (10.8)	81.5 (8.8)	
Most of the time	40.2 (2.3)	26.9 (2.8)	11.9 (3.5)	1.3 (0.3)		30.7 (3.7)	9.5 (1.0)	
Sometimes	119.7 (6.8)	103.7 (10.9)	6.8 (2.0)	9.1 (2.0)		43.0 (5.2)	76.7 (8.3)	
Very rarely	11.0 (0.6)	1.9 (0.2)	0.1 (0.0)	9.0 (1.9)		5.6 (0.7)	5.4 (0.6)	
Never	1213.0 (69.0)	596.3 (62.4)	292.6 (85.5)	323.7 (70.3)		584.1 (70.5)	628.6 (67.6)	
Higher risk sexual partnerships								
Any higher risk sex partners, 2015 to 2016 (%)	225.9 (11.9)	174.8 (16.7)	0.3 (0.1)	50.8 (10.4)	<0.001	126.7 (14.6)	99.2 (9.6)	0.063
Any higher risk sex partners, past 6 month (%)	184.0 (9.7)	142.5 (13.6)	0.1 (0.0)	41.4 (8.5)	<0.001	98.9 (11.4)	85.1 (8.3)	0.199
HIV infection	260.1 (13.7)	217.9 (20.9)	8.9 (2.5)	33.3 (6.8)	<0.001	102.2 (11.8)	158.0 (15.4)	<0.001

Weighted frequencies and column percentages shown. Informal sector occupations categorized as "high risk" or "low risk" are defined on the basis of associations with underlying HIV prevalence in the SEARCH trial. "High risk partner," = casual partner, commercial sex worker or client, one night stand, or inherited partner/inheritor. Sexual partnership concurrency is occurrence of 2 or more sexual partnerships within any 1 month over a given time period.

Table 3. Reasons for labour and non-labour related mobility (among those reporting any mobility), by region and sex.

Most common reported reason		Me	en			Wom	en	
for travel	Kenya	Uganda E	Uganda SW	р	Kenya	Uganda E	Uganda SW	р
Weighted n (weighted %)	479.4	167.2	222.4		565.5	196.8	266.7	
Non-labour-related travel				< 0.001				0.018
Holiday/Visiting family	9.6 (4.7)	7.4 (60.6)	15.2 (21.8)		35.8 (8.7)	0.6 (6.4)	16.0 (9.5)	
Funeral	85.5 (42.4)	0.8 (6.7)	9.0 (12.9)		205.9 (50.1)	7.4 (85.7)	36.4 (21.7)	
Care-giving/Care-seeking	68.5 (34.0)	0.8 (6.7)	40.7 (58.5)		107.2 (26.1)	0.6 (6.7)	93.1 (55.4)	
Other	33.4 (16.6)	3.2 (26.1)	0.5 (0.7)		60.7 (14.8)	0.1 (1.2)	18.3 (10.9)	
Schooling	4.6 (2.3)	0.0 (0.0)	4.2 (6.0)		1.7 (0.4)	0.0 (0.0)	4.0 (2.4)	
Labour-related travel				0.070				NA
Artisanal labour (e.g. construction)	20.2 (33.6)	1.0 (33.8)	6.5 (19.6)					
Farming (own or others' plots)	2.2 (3.7)	0.2 (8.3)	6.4 (19.1)		1.0 (5.1)	0.0 (NA)	1.0 (11.7)	
Fish trade	16.7 (27.9)	0.1 (3.7)	1.0 (2.9)		2.3 (11.1)	0.0 (NA)	0.0 (0.0)	
Looking for work	2.7 (4.5)	0.2 (8.3)	0.0 (0.0)		0.1 (0.3)	0.0 (NA)	6.8 (77.3)	
Market trading (incl. buying stock)	18.2 (30.3)	1.4 (45.9)	19.4 (58.3)		17.1 (83.5)	0.0 (NA)	1.0 (11.0)	

Weighted frequencies and column percentages shown.

### 3.5 | Characteristics associated with higher risk sexual behaviours, by sex

The distribution of sex-stratified population characteristics by concurrent sexual partnerships, and higher risk sexual partnerships, is shown for 2015 to 2016 (Table 4) and in the six months prior to survey (Table 5). Measures of mobility in the two tables differ in order to be temporally aligned with outcomes, with migration in 2015 to 2016 shown in Table 4, and past six-month mobility shown in Table 5. Compared to those without concurrent sexual partners in 2015 to 2016, men and women who had any concurrent sexual partners were more likely to be Kenyan (p = 0.006), HIV infected

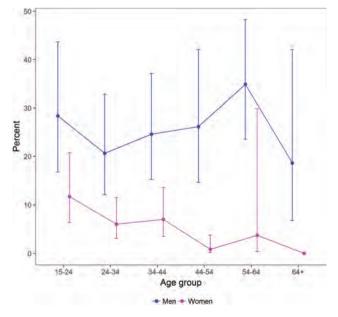


Figure 1. Prevalence of concurrent sexual partnerships in 2015 to 2016 among Sexually Active Adults, by 10-year Age Band and Sex.

(p=0.004), and migrated in 2015 to 2016 (p=0.003). Concurrency also differed by age and marital status in women, and by occupation in men (Table 4); in addition, concurrency was associated with age and marital status in women, and with occupation in men. Women with concurrent partners in 2015 to 2016 were more likely to be younger (39.6%, vs. 21.1% of those without concurrency were ages 16 to 24) (p=0.035), and single (26.2%, compared to 7.6% of those without concurrent partners) (p=0.013).

Concurrency was disproportionately higher among those in 'informal high risk' occupations: 33.5% of men and 13.6% of women with concurrent partners had these occupations (vs. 15.6% of men and 10.8% of women without concurrent partners in these occupations); these associations were highly significant in men but only approached significance in women (p=0.090). Concurrency was more prevalent than not among women who were fish traders (14.1% vs. 9.4%), market traders (14.1% vs. 18.9%), and hotel/restaurant/bar workers (19.4% vs. 18.9%); and among men who were fishermen (19.4% vs. 18.9%), transport drivers (19.4% vs. 18.9%) and hotel/restaurant/bar workers (19.4% vs. 19.4%), transport drivers (19.4% vs. 19.4%) (not shown).

Participation migration in 2015 to 2016 was elevated in those with concurrent partners in 2015 to 2016. Among women, 30% of those in concurrent partnerships reported having migrated in 2015 to 2016 (vs. 7.8% not in such partnerships)(p=0.003), and the respective differences were especially pronounced for migrations across district/subcounty boundaries (16.5% vs. 2.1%) ( $p \le 0.001$ ). In men, 20.6% of those in concurrent partnerships (vs. 11.2% not in such partnerships) migrated in 2015 to 2016 (p=0.011); there was no statistically significant association between concurrency and inter-district/sub-county migration. Figure 2 illustrates the associations of past migration in 2015 to 2016 with prevalence of sexual concurrency in the same time period for both men and women.

In women, engagement in higher risk sexual partnerships over 2015 and 2016 was significantly associated only with Kenyan residence and with marital status: women with higher

Table 4. Characteristics associated with concurrent and higher risk sexual partnerships in 2015 to 2016, by sex.

		Women			Men	·		Women			Men	
	Concurrent so	Concurrent sexual partnerships	hips	Concurrent	Concurrent sexual partnerships	ships	Higher	Higher risk partnerships	ips	Higher	Higher risk partnerships	S
Characteristic	No	Yes	d	No	Yes	d	No	Yes	d	No	Yes	d
Weighted n	961.0	0.89		652.5	216.6		929.8	99.2		742.4	126.7	
Region	517.4 (53.8)		900.0			<0.001			<0.001			<0.001
Kenya - Western		48.1 (70.7)		323.7 (49.6)	155.8 (71.9)		487.4 (52.4)	78.2 (78.8)		382.8 (51.6)	96.6 (76.3)	
Uganda - Eastern	196.5 (20.4)	0.3 (0.4)		143.6 (22.0)	23.7 (10.9)		196.7 (21.2)	0.0 (0.0)		167.0 (22.5)	0.3 (0.2)	
Uganda - South Western	247.0 (25.7)	19.6 (28.9)		185.3 (28.4)	37.1 (17.1)		245.7 (26.4)	21.0 (21.2)		192.6 (25.9)	29.8 (23.5)	
Age Band			0.035			0.240			0.145			<0.001
16 to 24	202.7 (21.1)	27.0 (39.6)		125.7 (19.3)	49.8 (23.0)		211.1 (22.7)	18.6 (18.8)		109.3 (14.7)	66.2 (52.3)	
25 to 34	343.9 (35.8)	22.1 (32.5)		198.9 (30.5)	51.7 (23.9)		338.1 (36.4)	27.9 (28.1)		219.0 (29.5)	31.5 (24.9)	
35 and older	414.4 (43.1)	18.9 (27.8)		327.9 (50.3)	115.1 (53.2)		380.6 (40.9)	52.7 (53.1)		414.1 (55.8)	29.0 (22.9)	
Marital Status			0.013			0.340			<0.001			<0.001
Divorced, Separated,	121.0 (12.6)	7.4 (10.9)		22.0 (3.4)	4.8 (2.2)		77.2 (8.3)	51.3 (51.7)		16.9 (2.3)	9.9 (7.8)	
Widowed, Missing												
Currently married	766.9 (79.8)	42.8 (62.9)		557.2 (85.4)	176.9 (81.7)		780.4 (83.9)	29.3 (29.5)		669.9 (90.2)	64.2 (50.7)	
Currently single	73.1 (7.6)	17.8 (26.2)		73.2 (11.2)	35.0 (16.1)		72.2 (7.8)	18.7 (18.8)		55.6 (7.5)	52.5 (41.5)	
Education level			0.287			0.653			0.475			0.007
No Schooling	129.8 (13.7)	3.0 (4.5)		49.4 (7.8)	11.6 (5.4)		121.5 (13.2)	11.3 (11.6)		59.3 (8.2)	1.7 (1.3)	
Primary/Secondary	775.5 (81.7)	64.2 (95.5)		556.4 (87.4)	191.2 (89.7)		753.3 (82.0)	86.4 (88.4)		626.3 (86.6)	121.4 (96.2)	
Post-secondary	44.1 (4.6)	0.0 (0.0)		30.8 (4.8)	10.4 (4.9)		44.1 (4.8)	0.0 (0.0)		38.0 (5.2)	3.2 (2.5)	
Household wealth: Poorest	112.2 (11.7)	10.6 (15.5)	0.533	106.7 (16.4)	26.8 (12.4)	0.334	105.0 (11.3)	17.7 (17.9)	0.112	108.7 (14.6)	24.9 (19.6)	0.479
quantile												
Occupation			0.094			<0.001			0.254			<0.001
Informal sector: low risk	738.2 (76.8)	45.9 (67.5)		480.2 (73.6)	117.1 (54.1)		709.8 (76.3)	74.3 (74.9)		538.1 (72.5)	59.2 (46.7)	
Formal sector	56.5 (5.9)	1.9 (2.8)		32.9 (5.0)	9.1 (4.2)		55.6 (6.0)	2.7 (2.8)		38.5 (5.2)	3.5 (2.8)	
Informal sector: high risk	103.5 (10.8)	9.3 (13.6)		101.8 (15.6)	72.6 (33.5)		94.7 (10.2)	18.0 (18.1)		127.0 (17.1)	47.4 (37.4)	
HIV infection	139.8 (14.5)	18.2 (26.8)	0.004	65.5 (10.0)	36.7 (16.9)	0.001	122.9 (13.2)	35.1 (35.4)	0.005	84.1 (11.3)	18.1 (14.3)	0.394
Migration in 2015 to 2016: Any	74.7 (7.8)	20.4 (30.0)	0.003	73.0 (11.2)	44.8 (20.7)	0.011	81.7 (8.8)	13.4 (13.5)	0.334	80.8 (10.9)	37.0 (29.2)	0.004
Any internal migration	74.7 (7.8)	20.4 (30.0)	0.003	71.7 (11.0)	44.7 (20.6)	0.008	81.7 (8.8)	13.4 (13.5)	0.334	79.5 (10.7)	36.9 (29.1)	0.003
Intra-District/Sub-county	55.0 (5.7)	9.2 (13.5)	0.023	19.4 (3.0)	23.3 (10.8)	900.0	55.6 (6.0)	8.7 (8.7)	0.509	22.3 (3.0)	20.3 (16.0)	0.004
Inter-District/Sub-county	20.3 (2.1)	11.2 (16.5)	<0.001	53.4 (8.2)	23.0 (10.6)	0.324	26.3 (2.8)	5.2 (5.2)	0.356	59.3 (8.0)	17.1 (13.5)	0.027
Any international migration	NA	∀ Z	ΝΑ	2.3 (0.4)	0.3 (0.1)	0.205	NA	NA	₹ Z	2.3 (0.3)	0.3 (0.2)	0.665

Data are weighted; column percentages shown; missing data excluded for education level and occupation.

Table 5. Characteristics associated with concurrent and higher risk sexual partnerships in past 6 months, by sex.

		Women			Men			Women			Men	
	Concurrent se	Concurrent sexual partnerships	ips	Concurrent	Concurrent sexual partnerships	ships	Higher	Higher risk partnerships	bs	Higher	Higher risk partnerships	S
Characteristic	No	Yes	р	No	Yes	d	No	Yes	d	No	Yes	d
Weighted n Region	918.6	52.5	0.078	9.099	181.5	<0.001	943.9	85.1	0.001	770.2	6'86	<0.001
Kenya-Western	490.6 (53.4)	37.6 (71.6)		328.3 (49.7)	133.8 (73.7)		498.1 (52.8)	67.4 (79.2)		404.4 (52.5)	75.1 (75.9)	
Uganda-Eastern	193.4 (21.0)	0.1 (0.1)		140.6 (21.3)	20.7 (11.4)		196.7 (20.8)	0.0 (0.0)		167.2 (21.7)	0.0 (0.0)	
Uganda-South Western	234.6 (25.5)	14.9 (28.3)		191.7 (29.0)	27.0 (14.9)		249.0 (26.4)	17.6 (20.7)		198.6 (25.8)	23.8 (24.0)	
Age Band			0.652			0.008			0.081			<0.001
16 to 24	207.9 (22.6)	15.7 (29.9)		112.3 (17.0)	45.6 (25.1)		213.3 (22.6)	16.4 (19.3)		118.3 (15.4)	57.2 (57.8)	
25 to 34	337.1 (36.7)	18.9 (36.1)		212.0 (32.1)	34.9 (19.2)		343.4 (36.4)	22.6 (26.6)		231.3 (30.0)	19.2 (19.4)	
35 and older	373.6 (40.7)	17.9 (34.0)		336.3 (50.9)	101.0 (55.6)		387.2 (41.0)	46.1 (54.2)		420.6 (54.6)	22.5 (22.7)	
Marital status			0.027			0.005			<0.001			<0.001
Divorced, Separated,	78.0 (8.5)	5.6 (10.7)		21.4 (3.2)	1.6 (0.9)		84.4 (8.9)	44.1 (51.8)		18.8 (2.4)	8.0 (8.1)	
Widowed, Missing												
Currently married	775.6 (84.4)	33.4 (63.7)		579.5 (87.7)	149.8 (82.5)		783.4 (83.0)	26.3 (30.9)		694.6 (90.2)	39.5 (39.9)	
Currently single	65.0 (7.1)	13.5 (25.7)		59.6 (9.0)	30.1 (16.6)		76.1 (8.1)	14.8 (17.4)		56.8 (7.4)	51.4 (51.9)	
Education level			0.452			0.623			0.421			0.002
No Schooling	113.6 (12.5)	3.0 (5.8)		50.8 (7.9)	9.5 (5.3)		124.9 (13.4)	8.0 (9.5)		(0.8) 0.09	1.0 (1.0)	
Primary/Secondary	751.8 (82.9)	48.7 (94.2)		563.6 (87.3)	158.6 (89.0)		764.0 (81.9)	75.7 (90.5)		653.2 (86.9)	94.5 (96.1)	
Post-secondary	41.7 (4.6)	0.0 (0.0)		30.9 (4.8)	10.1 (5.7)		44.1 (4.7)	0.0 (0.0)		38.2 (5.1)	2.9 (3.0)	
Household wealth: Poorest	108.9 (11.9)	8.7 (16.6)	0.505	109.3 (16.5)	20.3 (11.2)	0.218	105.3 (11.2)	17.4 (20.5)	0.061	114.0 (14.8)	19.5 (19.7)	0.562
quantile												
Occupation			0.312			900.0			0.205			0.004
Informal sector: low risk	706.6 (76.9)	38.6 (73.4)		484.7 (73.4)	105.0 (57.8)		722.3 (76.5)	61.8 (72.5)		553.1 (71.8)	44.2 (44.7)	
Formal sector	54.6 (5.9)	1.0 (1.8)		30.5 (4.6)	8.5 (4.7)		55.6 (5.9)	2.7 (3.2)		39.1 (5.1)	3.0 (3.0)	
Informal sector: high risk	98.7 (10.7)	6.6 (12.5)		112.1 (17.0)	50.2 (27.7)		95.7 (10.1)	17.1 (20.1)		139.0 (18.1)	35.4 (35.8)	
Missing	58.6 (6.4)	6.4 (12.2)		33.4 (5.1)	17.8 (9.8)		70.3 (7.4)	3.6 (4.2)		38.9 (5.1)	16.4 (16.6)	
HIV infection	129.7 (14.1)	12.1 (23.0)	0.065	67.0 (10.1)	32.3 (17.8)	0.001	128.4 (13.6)	29.6 (34.8)	0.007	89.0 (11.6)	13.2 (13.3)	0.572
Mobility in Past 6 months												
Any labour-related travel,	22.8 (2.5)	4.7 (9.0)	0.103	110.7 (16.7)	45.7 (25.2)	0.018	21.3 (2.3)	8.3 (9.7)	0.015	140.3 (18.2)	20.2 (20.4)	0.742
past 6 months												
No. nights away, labour-	0.79 (8.68)	5.72 (21.66)	0.326	4.33 (17.99)	9.37 (30.88)	0.036	0.50 (5.96)	6.91 (26.68)	0.131	5.03 (20.64)	8.34 (27.12)	0.387
LOSCO C. CON C.	(0 7 7 7 7 0 )	(0/2///0/		100001	(0 / 7) (0 / 0)	700	6047 (660)	(7 17) 0 17	7000	(1,00) 1,200	(0 /5 / 0 / 5	7000
Any non-labour-related travel, past 6 months	512.2 (55.8)	40.4 (77.0)	0.022	178.7 (30.1)	81.3 (44.8)	0.024	526.7 (55.8)	0 T.O (/ T./)	0.030	220.1 (27.4)	(8.75) 7.76	0.00
No. nights away, non-	1.24 (2.19)	1.76 (1.70)	0.086	0.53 (1.09)	0.80 (1.33)	0.013	1.24 (2.21)	1.53 (1.67)	0.325	0.53 (1.10)	1.02 (1.43)	0.023
WOIR LIAVE												

**Table 5.** (Continued)

		Women			Men			Women			Men	
	Concurrent so	Concurrent sexual partnerships	ips	Concurrent	Concurrent sexual partnerships	ships	Higher	Higher risk partnerships	sdi	Higher	Higher risk partnerships	sd
Characteristic	°N	Yes	d	No	Yes	d	N <sub>o</sub>	Yes	d	<sup>o</sup> N	Yes	d
Sexual behaviour, Past 6 months	ıths											
Any concurrent sex							23.5 (2.6)	29.1 (34.1)	<0.001	<0.001 120.2 (16.2)	61.4 (62.0)	<0.001
partners, past												
6 months												
Any high risk sex	56.1 (6.1)	29.1 (55.3)	<0.001	37.5 (5.7)	61.4 (33.8)	<0.001						
partners, past 6 month												
Number of sexual			<0.001			<0.001			<0.001			<0.001
partners, past												
6 months												
0 or 1	909.2 (99.0) 0.0 (0.0)	0.0 (0.0)		644.1 (97.5)	0.0 (0.0)		853.3 (96.3)	55.9 (65.7)		608.8 (81.9)	35.3 (35.7)	
2	9.3 (1.0)	46.7 (88.9)		16.6 (2.5)	134.2 (73.9)		29.0 (3.3)	26.9 (31.6)		115.9 (15.6)	34.8 (35.2)	
3 or more	0.1 (0.0)	5.8 (11.1)		0.0 (0.0)	47.3 (26.1)		3.7 (0.4)	2.3 (2.7)		18.6 (2.5)	28.8 (29.1)	

Data are weighted; column percentages shown; missing data excluded for education level and occupation

risk partners were disproportionately divorced/separated/widowed (51.7% vs. 8.3%) or single (18.8% vs. 7.8%)( $p \le 0.001$ ). In men, having higher risk sexual partners was associated with Kenyan residence, younger age group, middle education level, informal high-risk occupation, and past two-year internal migrations of all types. Over 29% of men who had higher risk partners from 2015 to 2016 (vs. 10.9% without such partners) had migrated during the same time period (p = 0.004).

In the six-month period prior to survey (Table 5), concurrency was disproportionately more prevalent among women not currently married (p = 0.027), and women who had undertaken any non-labour-related travel (77% in concurrent relationships vs. 55.8% not in such relationships) (p = 0.022). In men concurrency was disproportionately more prevalent among those who were Kenyan ( $p \le 0.001$ ), older (p = 0.008), not currently married (p = 0.005), in informal sector employment (p = 0.006), and who had undertaken past six-month mobility of all types (for example, 25.2% in concurrent relationships vs. 16.7% not in such relationships had travelled for work) (p = 0.018). In women, having higher risk sexual partners in the past six months was more prevalent among those who were Kenvan (p = 0.001), unmarried (p < 0.003), and travelled for work (9.7% with higher risk partners vs. 2.3% without such partners) (p = 0.015). For men, higher risk partnerships were more prevalent among men who were younger and unmarried ( $p \le 0.001$ ), and in informal sector employment (p = 0.004), and who travelled for non-labour-related reasons (57.8% with higher risk partners vs. 29.4% without such partners) (p = 0.006). Figure 3 illustrates the association of any past six-month mobility with prevalence of sexual concurrency in the past six months for both men and women. A Supplemental Figure S1, displays the same associations, but by the types of past six month mobility.

### 3.6 | Multivariate relationships between mobility and higher risk sexual behaviours

Table 6 shows summary mobility metrics (with model-adjusted relative risks of outcomes) from multilevel mixed effects logistic regression models fitted on four outcomes, sequentially: concurrency in 2015 to 2016, and in the past six months, and higher risk sexual partnerships in 2015 to 2016, and in the past six months. Models were adjusted for clustering at the community level, controlled for region, age group, marital status, occupation, and HIV status, and stratified by sex (full output of the models is shown in supplementary Tables S3, S4.) Having undertaken any migration in 2015 to 2016 was associated with concurrency in 2015 to 2016 among women  $[aRR = 1.99, 95\% \ CI \ (1.08 \ to \ 3.68)]$  and men [aRR = 1.47,95% CI (1.00 to 2.16)]. Intra-district/sub-country migration in 2015 to 2016 was not associated with concurrency in 2015 to 2016 in either men or women, but inter-district migration was, in women only [aRR = 2.93, 95% CI (1.18 to 7.28)]. Having undertaken any labour-related travel in the past six months was associated with concurrency in the past six months in women [aRR = 2.86, 95% CI (1.03 to 7.96)] and men [aRR = 1.75, 95% CI (1.24 to 2.49)]. Non-labour-related travel in the past six months was associated with concurrency in the past six months in men only [aRR = 1.40, 95% CI (1.01 to 1.94)]. Migration in 2015 to 2016 was not associated with having higher-risk partnerships in 2015 to 2016, in adjusted

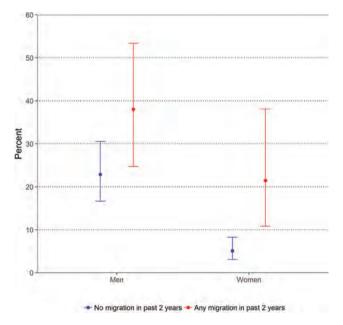


Figure 2. Prevalence of Sexual Partnership Concurrency in 2015 to 2016, by Sex and Migration in 2015 to 2016.

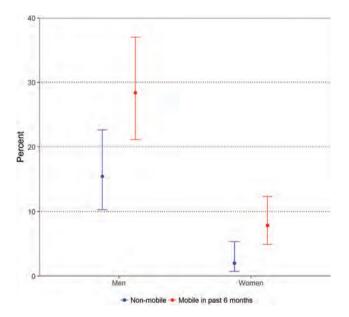


Figure 3. Prevalence of Sexual Partnership Concurrency in past 6 months, by Sex and Mobility.

models, but there were associations between mobility and higher risk partnerships in the past six months: having higher risk partners was associated with labour-related travel in women [aRR = 2.32, 95% CI (1.01 to 5.33)] and non-labour-related travel in men [aRR = 2.33, 95% CI (1.45 to 3.43)]. Tests for interactions between sex and key mobility metrics yielded null findings, but were suggestive; the coefficient for the interaction between sex and migration for the prediction

of concurrency in 2015 to 2016 was non-significant at p = 0.07.

#### 4 | DISCUSSION

The findings of this study in rural populations in Kenya and Uganda underscore the highly gendered nature of mobility and its influence on higher-risk sexual behaviour. There was significant heterogeneity in mobility (movements to and from households of primary residence) and migration (moves to change residence, across geopolitical boundaries) across regions in Kenya and Uganda, which correlated with heterogeneous levels of risk behaviour and HIV prevalence observed across the regions. As we [10] and others [30-32] have previously documented in rural settings in South Africa, Uganda and Kenya, while men overall are more mobile than women. associations between population mobility and sexual risk behaviour were observed to be stronger in women compared to men. Levels of concurrency are elevated among both men and women who migrated or travelled compared to their more residentially stable counterparts, but the differences in levels of risk behaviour were greater for women than for men. For example, even though lower proportions of women (9.2%) than men (13.6%) migrated in the past 2 years, that migration was associated with a markedly higher risk of sexual partnership concurrency among women (aRR 2.0), than in men (aRR 1.5). Similarly, women were less likely (2.9%) than men (18.5%) to travel away from home for labour-related purposes in the prior six months, but women who did had a higher risk of sexual partnership concurrency in that period (aRR 2.9) than did men who travelled for those reasons (aRR 1.8). Our findings support evidence that the pathway linking mobility to HIV acquisition and transmission in sub-Saharan Africa is through higher risk sexual behaviour, and that these relationships are especially pronounced in women; longitudinal data will be required to confirm these findings.

Our study builds on a growing theoretical framework for empirical research on mobility and HIV (including key work by Cassels et al.[33]), by including high-resolution measures inclusive of both men's and women's forms of and motivations for mobility. A unique contribution of this study to that literature is the finding that sex differences in the behavioural HIV risks associated with mobility are influenced by the underlying purposes of that mobility. The findings also show that not all markers of higher risk sexual behaviour are equivalent: whilst concurrency was associated with multiple measures of migration and mobility among both men and women, having higher risk partnerships was associated with certain types of mobility that differed by sex: having higher risk partners was associated with labour-related travel in women (aRR = 2.3) and non-labour-related travel in men (aRR = 2.3). Labour-related mobility was associated with concurrent partnerships in both women (aRR 2.9) and men (aRR 1.8), yet it conferred risk of higher risk partnerships only in women (aRR 2.3); that mobility was conducted primarily for livelihoods associated with market trading and the fish trade in women in Kenya. For men, non-labour-related mobility was associated with having concurrent (aRR 1.4) and higher risk partnerships (aRR 2.2); and that mobility was undertaken for more varied reasons including attending funerals, in Kenya, and care-seeking or

1.95

0.75

0.430

1.21

5.33

1.01

0.049

2.32

1.85

0.82

0.308

1.23

2.49

1.24

0.002

1.75

7.96

1.03

0.044

2.86

2.57

1.33

0.000

1.85

Any labour-related

travel, past 6 month 3.43

1.45

0.000

2.23

2.43

0.87

0.157

1.45

2.65

1.38

0.000

1.91

1.94

1.01

0.043

1.40

2.30

0.65

0.531

1.22

1.87

1.05

0.022

1.40

Any non-labourrelated travel, past 6 month 1.01

0.99

0.763

1.00

1.03

1.00

0.017

1.01

1.01

1.00

0.303

1.00

1.01

1.00

0.001

1.01

1.02

1.00

0.195

1.01

1.01

1.00

0.000

1.01

labour-related

1.02

0.99

0.747

1.00

1.02

0.99

0.815

1.00

1.01

0.99

0.623

1.00

1.02

0.99

0.282

1.01

1.02

1.00

0.100

1.01

1.02

1.00

0.036

1.01

No. nights away,

Table 6. Associations of measures of mobility with concurrent and higher risk sexual partnerships over a 2-year period (2015 to 2016) and in past 6 months.

		Adjust	Adjusted risk ratio, any concurrent	ratio, ar	Jy conc		sexnal	partner	ship, 2	sexual partnership, 2015 to 2016	2016	 	Adju	sted risk ratio	, any hi	gher ris	Adjusted risk ratio, any higher risk sexual partnership, 2015 to 2016	nership,	2015 t	0 2016
	₹					Women	nen			Men	c			All		×	Women		Σ	Men
Mobility metric	aRR	d	95% CI	S CI	aRR	d	95% CI	ID :	aRR	þ	95% CI	I aRR	R p	95% CI	aRR	d i	95% CI	aRR	d	95% CI
Past 2 years: any	1.58	1.58 0.006 1.14 2.18 1.99 0.027	1.14	2.18	1.99	0.027	1.08	3.68	1.47 0.049	0.049	1.00 2.16	16 1.32	2 0.119	9 0.93 1.88	88 1.07	7 0.835	0.56 2.03	3 1.53	0.061	0.98 2.40
Past 2 year internal		1.60 0.005 1.15 2.23 1.99 0.027	1.15	2.23	1.99	0.027	1.08	3.68	1.50	1.50 0.042 1.01	1.01 2.21	21								
migration Past 2 year inter- district/sub-co.	1.63	1.63 0.020 1.08	1.08	2.45	2.45 2.93 0.021	0.021	1.18	7.28	1.43	0.126	0.90 2.25	25								
migration Past 2 year intradistrict/sub-co	1.38	1.38 0.174 2.95 11.63 1.35 0.443	2.95	11.63	1.35	0.443	0.63	2.92	1.43 0.228		0.80 2.56	26								
migration																				
		Adjuste	Adjusted risk ratio, any concurrent	atio, an	y conc	urrent s	exual p	artner	thip, pa	sexual partnership, past 6 months	onths		Adjus	ted risk ratio	, any hig	gher risk	Adjusted risk ratio, any higher risk sexual partnership, past 6 months	nership,	past 6	months
	Ā					Women	en	,		Men	_	ļ		All	ļ	Wo	Women		Σ	Men
Mobility metric	aRR	d	95% CI		aRR	р	95% CI		aRR	ф	95% CI	aRR	d	95% CI	aRR	d	95% CI	aRR	d	95% CI

Results in Table 6 are from multilevel mixed-effects logistic regression models adjusted for clustering at community level and controlling for region, age group, marital status, occupation, and HIV status. aRRs calculated using a linear prediction of average adjusted individual marginal effects of selected mobility metrics (1 vs. 0) from models. Models of mobility metrics beyond any past 2 year migration not fitted for prediction of higher risk sexual partnerships because of null findings in the initial model.

care-giving or travelling for holidays to visit family in Uganda. For both men and women, higher risk sexual behaviour cooccurred with the type of mobility that was less common for their sex (18.5% of men vs. 2.9% of women travelled for labour-related purposes; 57.1% of women vs. 32.6% of men travelled for other purposes in the past six months).

Our prior research has documented the ways in which women's labour-related mobility in Kenya—the livelihoods that women engage in that require their mobility—often involve sexual behaviour that can increase HIV acquisition and onward transmission risks [19]. The circumstances that drive migration (e.g. widowhood) may increase HIV risk at the community of origin, and social contexts at destinations and transit points facilitate multiple and higher risk sexual partnerships. We found higher HIV prevalence among female market traders (25.6% in 2013) relative to a comparable population of women of reproductive age from a household survey in Kisumu in western Kenya (15.3% in 2013) [34]. Our qualitative research has revealed that the more mobile market traders (in contrast to those who did not travel) often supplemented their low and sporadic earnings from market trading with transactional sex; the practice was common enough that the phrase "she mixes her business" was used, we were told, to describe this practice. Women's travel away from home communities, and away from the social monitoring of their sexual behaviour that occurs within kinship networks (especially the "prying eyes" of mothers-in-law with whom women often reside), facilitated opportunities for such exchanges [19].

That men's labour-related mobility was not associated with higher risk sexual behaviour reflects the social reality that for most men in our study communities, higher risk sexual behaviour is not embedded within livelihood strategies as it is for many women. Men's non-labour-related mobility, often associated with travel that is highly social and even familial (attending funerals, seeking care, visiting family), was associated with higher risk behaviour and this perhaps reflects the greater cultural acceptance of men's extramarital sexual behaviour. Prior research from Tanzania found that men living apart from their wives did not report more extramarital sex than men who co-resided with their wives, but the opposite was true for women, among whom those living apart reported extramarital sex more often [35]. Normative masculinities in these settings are such that men's extramarital affairs, while often leading to marital strife, are common and even valorised [36]. In Kenya, funerals are multi-day gatherings of friends and family at the home of the deceased, accompanied by music and dancing; these are also occasions in which casual, transactional unprotected sex is common [37].

The findings presented here also confirm our prior research documenting high levels of mobility and HIV risk in communities on the shores of Lake Victoria: fishermen follow the fish over great distances, and female fish traders, who buy, process, transport and retail the fish in local markets, are also highly mobile [38,39]. Moreover, a lakeside transactional sexual economy known as "sex-for-fish", or "jaboya", contributes to the continued spread of HIV in these communities [38,40] and those effects are likely to be amplified through women's mobility necessary to access fish and to sell in local and distant markets.

Reduced to its simplest message, this study's findings show that in predominantly rural eastern African settings, both

migration and also localized short-term mobility—whether labour-related travel, or travel for other purposes—are associated with higher risk sexual behaviour, and that types of mobility and their relationship to sexual behaviours are strongly influenced by gender.

Our findings are of significant importance for understanding the context of the larger test and treat intervention trial in which this study is embedded. SEARCH demonstrated the effectiveness of its model for high HIV "cascade coverage", and demonstrated an increase in virologic suppression rates from 45% to 81% among intervention communities [23]. As of the time of this publication, measurement of the impact of the "test and treat" intervention on community-level HIV incidence is underway. The impact of mobility on the efficacy of "test and treat" is not yet known, but mathematical modelling of its potential effect has suggested that the movement of individuals in and out of communities and care systems may substantially attenuate the gains of test and treat [41] and other HIV prevention interventions. We have recently argued [9] that even strategies that successfully meet or exceed the 90-90-90 targets will leave up to 27% of people living with HIV/ AIDS virally non-suppressed, and that the sexual behaviour. mobility, and network connectedness of this "missing 27%" must be better characterized to fully evaluate the effectiveness of and barriers to the universal test and treat strategy. Moreover, even demonstrated effectiveness in one setting does not ensure that these strategies will work everywhere. Understanding the potential effects of mobility on sexual behaviours and engagement in HIV prevention and treatment interventions could be critical for settings where mobility is common and on the rise.

Our study has several limitations. First, the data are crosssectional, serving as a baseline characterization of a cohort being followed longitudinally. The direction of causality between mobility and sexual risk cannot therefore be conclusively determined. Higher risk sexual behaviour may precede mobility, follow it as a consequence, or an unmeasured "predisposition to risk-taking" may underlie both mobility and risk behaviour. Second, we cannot fully ascertain the pathways between mobility, risk and HIV prevalence in the region. That being said, the strength and consistency of relationships seen in this study can provide significant evidence in support of hypotheses that can be longitudinally investigated and confirmed in future study. There are strong associations between mobility and baseline HIV infection observed in this and other settings and plausible causal pathways leading from mobility to infection and in the other directions can be made. Prior research has shown that marital instability following HIV infection can lead to migration [42], and that people living with HIV are known to move to seek better care [43]. Lastly, data for understanding the dynamics of mobility and sexual risk behaviour at the couple level was not available for this analysis. Future dyadic analyses, and longitudinal data, will be necessary to answer important research questions concerning relationship dynamics and links between mobility and HIV in these settings.

#### 5 | CONCLUSIONS

In rural eastern African settings, both long-distance and permanent, and localized, short-term forms of mobility were

associated with higher-risk sexual behaviour. Types of mobility, and their influence on sexual behaviour were found to be highly gendered and while overall men are more mobile than women, the behavioural risks associated with mobility are more pronounced for women than for men. Taken together, our research has significant implications for the design and evaluation of HIV prevention and treatment interventions that need to address the strong links between mobility and sexual HIV risk behaviours. Moreover, this work highlights the need for gender-specific interventions among mobile populations to combat the ongoing HIV epidemic in sub-Saharan Africa.

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#### **AUTHORS' CONTRIBUTIONS**

CSC, TBN and EDC designed the study, with contributions from MG, CRC, MRK and EAB. CSC and AA conducted the statistical analysis; TBN and MG contributed to data analysis and interpretation. CSC took primary responsibility and EDC and AA secondary responsibility for writing the manuscript. MG, PE and IM oversaw data collection and curation. All authors were involved in review, critiquing and editing of the manuscript.

#### **COMPETING INTERESTS**

The authors have no competing interests to declare.

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#### SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

**Table S1.** Characteristics Associated with Number of Sexual Partnerships in 2015 to 2016, by Sex.

**Table S2.** Characteristics Associated with Number of Sexual Partnerships in Past 6 months, by Sex.

**Table S3.** Associations of Measures of Mobility with Concurrent Sexual Partnerships Over a 2-year Period (2015 to 2016) [Full model output].

**Table S4.** Associations of Measures of Mobility with Higher Risk Sexual Partnerships Over a 2-Year Period (2015 to 2016) [Full model output].

**Figure S1.**Prevalence of Sexual Partnership Concurrency in Past 6 Months, by Sex and Mobility in Past 6 Months, by Type of Mobility.



#### RESEARCH ARTICLE

# Spinning plates: livelihood mobility, household responsibility and anti-retroviral treatment in an urban Zambian community during the HPTN 071 (PopART) study

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#### Abstract

**Introduction:** Qualitative data are lacking on the impact of mobility among people living with HIV (PLHIV) and their decision-making around anti-retroviral treatment (ART). We describe challenges of juggling household responsibility, livelihood mobility and HIV management for six PLHIV in urban Zambia.

**Methods:** Six PLHIV (three men and three women, aged 21 to 44) were recruited from different geographic zones in one urban community drawn from a qualitative cohort in a social science component of a cluster-randomized trial (HPTN071 PopART). Participants were on ART (n = 2), not on ART (n = 2) and had started and stopped ART (n = 2). At least two in-depth interviews and participant observations, and three drop-in household visits with each were carried out between February and August 2017. Themed and comparative analysis was conducted.

**Results:** The six participants relied on the informal economy to meet basic household needs. Routine livelihood mobility, either within the community and to a nearby town centre, or further afield for longer periods of time, was essential to get by. Although aware of ART benefits, only one of the six participants managed to successfully access and sustain treatment. The other five struggled to find time to access ART alongside other priorities, routine mobility and when daily routines were more chaotic. Difficulty in accessing ART was exacerbated by local health facility factors (congestion, a culture of reprimanding PLHIV who miss appointments, sporadic rationed drug supply), stigma and more limited social capital.

**Conclusions:** Using a time-space framework illustrated how household responsibility, livelihood mobility and HIV management every day were like spinning plates, each liable to topple and demanding constant attention. If universal lifelong ART is to be delivered, the current service model needs to adjust the limited time that some PLHIV have to access ART because of household responsibilities and the need to earn a living moving around, often away from home. Practical strategies that could facilitate ART access in the context of livelihood mobility include challenging the practice of reprimand, improving drug supply, having ART services more widely distributed, mapped and available at night and weekends, and an effective centralized client health information system.

Keywords: Zambia; Livelihood Mobility; HIV; ART; Time-Geography; Household responsibility

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#### 1 | INTRODUCTION

In 2016, Zambia had an estimated 59,000 new HIV infections and approximately 21,000 AIDS-related deaths. There were 1,200,000 people living with HIV (PLHIV) among whom 65% had access to antiretroviral therapy (ART) and an estimated 58% had attained viral suppression [1]. Reaching universality of testing and treatment for HIV in all populations in Zambia requires addressing patterns of mobility including those common to the day-to-day experiences of PLHIV. Data in sub-Saharan Africa show mobility as a risk factor for acquiring HIV

[2] and a reason for not engaging with care [3]. In this paper, we use qualitative data to illustrate how the convergence of livelihood mobility, household responsibility and HIV creates time and space challenges for ART access that were, or could be, reduced by adjustments made both by individual PLHIV and the health system.

The most prevalent form of mobility in Zambia is linked directly to livelihoods. In the absence of a comprehensive welfare system, economic survival is often dependent on the ability to trade in assorted goods, casual work in construction and mines, charcoal making and more seasonal trading in fish and

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maize. Mobility patterns linked to these economic activities involve four types of movement: rural-rural, rural-urban, urban-rural and urban-urban, labelled by Bruijn et al. "the rural-urban dichotomy" [4]. For PLHIV who are dependent on mobile livelihoods, immediate economic survival can come at a cost to their long-term health needs [5]. When PLHIV weigh up the relative costs and benefits of various courses of action in their daily life and choose the course that provides "the best return" [6 p1469], earning money can be prioritized over frequent clinic appointments [7,8]. The need to prioritize livelihood needs intensifies with deepening social obligations, particularly for the head of the household and in the wake of deaths or lower productivity due to HIV [9].

Individuals living with HIV with frequent livelihood commitments and many social-network orientated responsibilities have "compressed temporal and spatial windows" [9 p853]. Harvey's concept of "time-space compression" [10], which refers to any alteration in the quality and relationship between space and time, helps convey how ART constrains PLHIV pursuing economic activities. PLHIV, for example, are often expected to collect ART on a routine basis from a specific HIV service close to their main residence but their household livelihood needs may require time, more movement and flexibility [11-16].

Takahashi et al. [9] proposed a time-space typology of rigid, flexible and chaotic daily routines to illustrate the challenge of fitting ART obligations alongside multiple obligations [9 p861]. A systematic review by Mills et al. [17] on patient reported barriers to adherence, identified disruptions in routine or having a chaotic schedule, and difficulties coordinating adherence with work, family, or caregiving responsibilities as barriers to adherence. There is no smooth, static "fit" between the competing needs of raising money and managing HIV successfully, and poverty and temporal and spatial compression exacerbate the tensions between the two [9-11,16,18-20].

Quantitative data in sub-Saharan Africa have shown mobility as a risk factor both for acquiring HIV [2] and a reason for not engaging or disengaging from care [3]. Few qualitative data exist on access to care and treatment to provide a deeper understanding of how PLHIV and their households navigate different priorities [9,21,22].

Focusing on an urban community of 37,034 people (18,517 aged 18 and over) and 8484 households with a HIV prevalence of 14% [23], we use six case-studies of adult residents living with HIV (LHIV) to illustrate the dilemmas posed by livelihood-related mobility and the obligations of anti-retroviral treatment (ART). Drawing on the considerations of time and space that deliberate the impact of geographic mobility on time to access HIV health services [9,24], we illustrate PLHIV juggling to balance livelihood mobility, household responsibilities and their health, using an analogy of spinning plates.

#### 2 | METHODS

Data are drawn from the social science component of HIV Prevention Trials Network (HPTN) 071 (Population Effects of Antiretroviral Therapy to Reduce HIV Transmission, PopART) study, a cluster randomized trial (HPTN071) measuring the impact of a combination HIV prevention package (including

Universal HIV Testing and Treatment [UTT]) on population level HIV incidence 2014 to 2017 [25]. For the intervention, a cadre of local community lay workers employed by the trial provided a broad package of HIV services at household level, referring clients to the local government health facility for ART [26]. The HPTN071 (PopART) social science component runs from the start of the trial to the end of follow up (2012 to 2018). This includes a qualitative cohort (2016 to 2017) using participatory and ethnographic approaches to explore responses to HIV testing and treatment over time and across different social groups, contexts and HIV outcomes in the final year of the intervention. The qualitative cohort data collection with adults was carried out in four Zambian HPTN071 (PopART) communities selected for representing different intervention packages and geographical areas. A total of 39 adult participants (19 men and 20 women) were purposefully selected to represent different HIV pathways, geographical locations and gender and age groups. Twenty-one were LHIV (out of whom nine were on treatment, eight had defaulted and four had not started treatment). No participant was selected based on mobility type.

This analysis focuses on qualitative cohort data from six of these participants in one of these four Zambian communities. The community (referred to as "Zx" in this manuscript) was selected because the universal treatment intervention was in place and for demonstrating (due to location and a dominant lower socio-economic class) salient livelihood mobility patterns that are typical of the Zambian informal economy. We focus on the six adult participants LHIV (three men, three women aged 21 to 44 years) who, at recruitment, had either not started ART (n = 2), were on ART (n = 2) or had started and stopped ART (n = 2). The purpose of selecting these six adult participants is to provide illustrative and detailed case material [27] which address the influences of livelihood and mobility and household responsibilities on decisions to start and stay on ART. The competing priorities of providing for the household and managing HIV was a broader theme apparent in the communities [28]. Adopting a case study approach allows the complexity of livelihoods, mobility and health systems to be conveyed in detail, while acknowledging the uniqueness and particularity of each case [29].

In February 2017, the six participants were recruited from different geographic zones in Zx using the knowledge and introductions of community lay workers. Data were collected by a Zambian social scientist supported by a local research assistant using in-depth interviews (IDIs) and participant observation during visits every three months, with additional monthly drop-in visits to maintain contact. By August 2017, at least two IDIs with two observations and three research assistant drop-in visits had been carried out with each participant and their household. Interview discussion guides focussed on questions around family and kinship; understandings of mobility, place and space; HIV and household livelihood; HIV, gender relations and stigma; and lastly, sex, love, marriage and HIV. Interviews took three hours on average and were usually carried out around daily tasks of participants, taking breaks when necessary or coming back another day to finish. The mobility of participants and the absence of incentives extended time in the field, with repeated visits often necessary. Observations were carried out in the households at the same time as both interviews and other visits, and carried out

for one day at the local health facility, observing client flow from early in the morning to the afternoon. Drop-in visits by research assistants furnished details on the whereabouts, health and details of the household of the participant using a structured check list. IDIs were recorded with participants' consent, and handwritten notes were taken. Field notes and sketches were made during observations.

Social science team debriefings after each block of fieldwork aided discussions around emerging themes. Notes and summaries of each interview were written up and IDIs transcribed by the researchers. Comparative, themed analysis was carried out inductively and manually on the raw data by the first authors. Once the juggling between livelihood mobility, household responsibility and HIV emerged, all the data supporting these themes was identified and collated, and analysed for each individual case-study and across the six case-studies. The analysis was led by the two first authors and findings were also discussed with other social scientists who carried out the qualitative cohort fieldwork in the other three sites.

#### 2.1 | Ethical approvals

The Biomedical Research Ethics Committee of University of Zambia, the London School of Hygiene and Tropical Medicine Ethics Committee and the Zambian government approved this research. Participants were asked to participate on a voluntary basis without receiving any incentives, and written informed consent was obtained before the start of the first research activity. Staff members in charge of the health facility were asked for permission before carrying out the health facility observation. Informed consent and interviews were conducted in local languages chosen by participants. The community name is anonymized and pseudonyms used for participants in this manuscript to protect participant identity.

#### 3 | RESULTS

#### 3.1 Intervention context

Data from the trial showed high rates of mobility in the eight intervention Zambian communities [23,28,30,31]. This mobility was both within communities and in and out of communities, and made it hard to reach mobile individuals for testing (especially men) and undermined uptake of treatment in more communities where mobility was more prominent [31-33], and linkage of mobile PLHIV into care. Zx is a densely populated unplanned settlement on the outskirts of a district town [Bond, Simuyaba et al. Narrative Report 2013, internal technical report, Zambart, Lusaka]. Livelihood mobility in Zx included residents moving for trading and other casual work within the community (3 to 15 km), moving into a nearby town centre (5 to 20 km) and/or fishing camp (90 km) either using public mini-buses, bicycles or by foot, and travelling some distance (usually 200 to 500 km) to other provincial centres, rural areas and markets using buses and lorries.

The one government health facility within Zx had an ART clinic. Two other options for accessing ART in or near Zx were a Non-Governmental Organization (NGO) centre within and a renovated government health facility just outside the community boundary. The NGO centre was a small health facility about 12 km from the local government health facility which

provided daily HIV services (testing and ART) with the mandate and supplies of the government. Further afield there were other options, including a district hospital.

At Zx health facility, one day a week was allocated for review (follow-up) appointments, but new clients could be registered and obtain ART on the same day. Challenges during 2017 included sporadic low stocks of anti-retroviral drugs (ARVs); in August 2017, clients were rationed to a two-week drug supply. Power cuts undermined data entry and laboratory tests. Laboratory Staff members said they sometimes experienced a shortage of reagents. Congestion and long waiting times, especially at registration, and difficulties retrieving client files were also observed. PLHIV arrived from 6.00 am onwards and by the time the clinician started seeing clients at approximately 9.30 am, the ART clinic was crowded with about 50 to 80 clients. Any PLHIV who had missed a prior appointment was attended to last. The pharmacist gave transient PLHIV from outside 7x who had run out of ART a twoweek drug supply. Health staff members said that factors that had helped with clinic congestion included the re-opening of the government facility near the community boundary, conducting CD4 tests every day, registering PLHIV daily and the assistance of community lay workers (CLWs).

#### 3.2 Description of case-study participants

All but one of the participants were middle-aged (36 to 44 years). One was a 21-year-old woman. Four of the six participants were heads of the household (see Table 1). Two participants owned their plots of land, three of them lived on family plots and one rented. None of them lived in concrete brick houses or had water or electricity in their house. They used near-by communal water points, candles for light and charcoal for cooking. Three had their own pit latrine, the others utilized communal pit latrines. The smallest household had four members and the largest thirteen. Two participants were married, two widowed, another divorced and the other effectively separated. Being a single parent was experienced as a "struggle" by three participants. All the women spoke about being physically abused by their husbands, and two of the men were open about "beating up" their wives when drunk. Three participants (two men, one woman) regularly drank alcohol, and one struggled with binge drinking. Many of the children were under the age of 18, three households had adult children aged 19 to 21 of whom two contributed to household expenses. Three households had at least one child of school age who they could not afford to send to school. Only one participant could support higher education funding requests. Three households were noticeably food insecure, usually having two meals a day. All households got assistance from neighbours, church members and other relatives, sometimes reciprocating this assistance when they could.

All six participants were long-term residents of Zx, with strong ties to rural areas (where they were brought up and/or traded) and two also spent long periods working in Lusaka. They all had strong local social networks. Relationships with spouses or sexual partners were often tenuous for women, with gender-based violence and HIV heightening these tensions.

The participants and their households reflected the typical circumstances of many Zambians. They were reliant on the

Table 1. Demographic profile and livelihood mobility of the six participants (names are pseudonyms)

Participant						
Name	Age	ART status	HH role	HH composition	HH location (estimate)	Livelihood mobility
Ronny (Male)	36	Defaulter Restarted ART	HH head Married	6 HH members: participant, wife, 4 children (ages: 15, 12, 7, 7); 2 in primary school but repeated grades; 2 of school age but not yet enrolled	Main road – 1.2 km Health facility – 11 km NGO ART centre – 1 km Water points – 100 m Market – 12 km	Urban-urban and urban rural Commuted to work in town as tailor + seasonally migrated to trade/barter maize for clothes in rural farms during harvest (four months). Casual work in rural mine during rains (three months). Wife helped with tailoring in town & rural area
Molly (Female)	44	Defaulter	HH head Widowed	4 HH members: participant, 3 children (ages: 19, 17, 10), eldest stopped school in grade 9, others at secondary and primary schools. HH head's husband died in 2006. 19-year-old son moved out for a short time	Main road – 1 km Health facility – 1 km NGO ART centre – 12 km Water point – 500 m Market – 1 km	Within local urban area.  Moved about selling assorted fruits within community and in town; travelled outside town to attend church meetings and funerals. Son gave sporadic support & started to pool capital with mother to buy and sell fruit
Denny (Male)	38	ART	Dependent Widowed	8 HH members: participant, brother (HH head), brother's wife and 5 children (ages: 16, 13, 8, 5, 1) – 2 in primary school, 1 of school age but not enrolled. Wife's mother & sister lived on plot. Participant's wife died in 2013, he has 2 children (ages: 6, 9) in village with wife's mother	Main road — 1.2 km Health facility — 1.2 km NGO ART centre — 11 km Water point — 10 m Market — 3 km	Within local urban area and urban- rural Security guard in Lusaka until very sick. This year moved around within community helping in household & with two market stalls. Brother promised start-up capital to assist with trading in maize. In June moved to rural area to work in cousin's shop
Pretty (Female)	41	ART	HH head Divorced	10 HH members: participant, 5 children (14, 8, 6, 4, 2), young sister and spouse, 1 brother and 1 sister in college. 2 children in school, 1 re- enrolled in school with help of boyfriend. HH head divorced husband in June 2016	Main road — 1.3 km Health facility — 9 km NGO ART centre - 7 km Water point 500 m Market — 15 km	Urban-rural.  Travelled outside town to border town to trade in fish, and to rural area to buy maize and wild caterpillars. In last year, travelled away six times for a week to trade. Young sister & husband contributed to household

Table 1. (Continued)

Participant							
Name	Age	ART status	HH role	HH composition	HH location (estimate)	Livelihood mobility	
Simba (Male)	44	Non-linker	HH head Married	11 HH members: participant, wife, father, 8 children (19, 16, 13, 9, 6, 4, 3, 3mths), 4 children in school	On main road  Health facility –  12 km  NGO ART – centre  3 km  Water point – 25 m  Market –15 km	Urban-rural.  Migrated to fishing camp for two to four months at a time and then to fish markets for over two weeks.  Rested for one month in-between at home & during the fish ban (December to March). Fish stocks low, "we used to make good money, now it is quite hard." Wife traded in fruits, routinely travelled away to buy fruit and returned to sell	
Mutinta (Female)	21	Non-linker	Dependant Married	13 HH members: participant, mother, stepfather (HH head), participant's 2 daughters (ages: 4, 2), 5 stepsisters (ages: 15, 7, 6, 3, 4), stepfather's nephew (young adult), stepfather's 2 nieces in school. Children in school. Participant's husband absent since May 2016; in jail for assault since November 2016. Never lived together	Main road – 3 km Health facility – 4 km NGO ART centre – 13 km Water point 25 m Market – 2 km	Within local urban area and urbanurban.  Moved about selling groundnuts within community and in town centre. In town from 7 am to 5 pm when selling. Travelled outside town to ask for money from relatives, met boyfriends in town & at their homes	

informal economy [17] and they were close to or beneath the poverty line (based on location, food expenditure, average meals a day, access to water, toilets and energy, housing type) [18]. Despite the stability given to them by families and long-term residence and some improvements in road and energy infrastructure, their poverty (coupled with rising costs of living) meant that their lives were precarious, and they were used to relying on their own efforts to survive.

#### 3.3 | The spinning plates

Household responsibilities, livelihood mobility and health/HIV experiences converged and were experienced daily alongside each other (see Tables 1–3).

#### 3.4 Household responsibility

All six participants carried household responsibilities: four were household heads and accountable for food security, water and firewood, school fees for children and providing shelter. The two participants (Denny and Mutinta) who were not household heads had two children each to support and contributed to their household's daily needs.

Denny was a 38-year-old widower whose wife died of HIV in 2013. Although he had also been sick due to HIV, he started ART in 2016 within a week of being diagnosed and regained health. He had two children who were living with his mother in-law. At the time of the first visit, he was living with his elder brother's family in a two-room house. Due to limited employment opportunities in Zx, he repeatedly said he would travel out of town as soon as he fully recovered to search for employment so that he could meet his needs as well as those of his two children. Although he was not living with his children, his mother-in-law required him to support his children (providing food, clothes and school fees). By the third visit, Denny had travelled to a farm in a rural area near Zx to work in a cousin's shop and hoped to also do some farming piecework. There were no ART services in this rural area, and he was dependent on family members collecting ART from the health facility in Zx

Table 2. Health and HIV profiles of six participants

#### **Participant** Health of participant History of HIV testing Contact and/or contemplation of ART services Ronnv 2013 very sick, "felt like a paper HIV Testing: Disbelief when Started, stopped, started ART. Livelihood mobility weight," "no balance," "body tested HIV negative twice and household responsibility influenced this weakness." Moved to Zx from before testing HIV positive with pattern. Started ART: December 2014, started ART Lusaka. Felt much better after HPTN071 community lay starting ART (2014). After workers (HPTN071 CLWs). within a week although CD4 "ok" defaulting, experienced (2014). "I was so sick I never Stopped ART: In 2016 ran out of drugs while out constipation, malaria, headache, loss thought I could be HIV of town for petty mining and farmed for over of appetite and weight. One week negative." Discordant with wife. three months. Took one week's worth of drugs into re-starting ART said he was Children all tested HIV with him but away for longer than intended. Took doing well negative. Ronny was the only remaining drugs when returned home. Lost ART one LHIV in his household. Wife card. Reluctant to restart for fear of being continuously retested herself & reprimanded by HCW who "look down on him" found it hard to believe she is and "reprimand so much" HPTN071 (CLWs). HIV negative encouraged him to find card and restart. Advocated taking ART, but also says that some PLHIV "would rather die than live like this taking ART." Claimed that some PLHIV take ART with alcohol but "not me" Restarted ART: April 2017, restarted ART from NGO health facility located much closer to his home. Ronny said he was also avoiding the queues at the main clinic. August 2017, in rural area with no ART services but planned to cycle back to collect ART once his 2-week supply runs out, leaving wife there to run business Molly Frequently fell ill in 2015. Suffered HIV testing: Husband HIV positive Started, stopped ART. Household responsibility and died in 2006. Tested HIV from muscle pains, headache, influenced this pattern stomach aches and sores on her positive at ante-natal in 2007 Starting ART: After falling sick in 2015, told to "private parts." Felt better once she when pregnant. 10-year-old start "regardless of CD4." Said that "all the pain started ART. In October 2016 daughter tested HIV positive reduced" and infection in her "private parts" developed chest pains and coughed with HPTN071 (CLWs) & was disappeared when she was on ART. In November 2016 diagnosed with TB ("coughed out blood") up blood. Diagnosed with TB. informed of her status by child Struggled with side-effects of counsellor at clinic and put on TB medication which made her "black medications and stopped all out and weak." CLWs told her to continue taking medication. She said, "now I only drugs and humiliated her (see main text) feel pain in my heart" (emotional Stopping ART: Decided to stop taking both TB pain). In February, she "feels well" and ART after being humiliated. "Bad reception but by August 2017, she made me stop taking ART," she repeatedly stated. complained of fatigue, body pains & Initially she seemed to consider re-starting ART if nightmares which she managed she fell sick again, but is also put off by the long with sleep, warm water, massage queues, side-effects, and needing to make a and prayer living. "I need to use that waiting time to sell to fend for my children," Molly explained. Her 10year-old daughter did not start ART either despite the advice of health workers. Molly does not want her to start at Zx health facility because of the "bad reception." The daughter said

she will start when she wants to, "maybe" once

she reaches 12 years

Table 2. (Continued)

Participant	Health of participant	History of HIV testing	Contact and/or contemplation of ART services
Denny	Ill in 2015 with stomach pains and STI; treated with traditional medicine. Fell extremely sick late 2016 with "stomach pains" and lost weight and strength. Regained strength and stomach pains go away on ART. In April 2017 suffered from malaria and is weaker. By May 2017 his health seemed restored although food is short in the household. Participant disclosed to his younger and older brothers, to a close friend, and to his sister and mother	HIV testing: Tested HIV negative early in 2017 while very sick in Lusaka. After moving to his brother's house in Zx, his brother intercepted HPTN071 (CLWs). on the road and asked them to test Denny. This time he tested HIV positive. His brother and family repeatedly tested with HPTN071 (CLWs). and his young sister is LHIV	Started ART. Livelihood mobility and household responsibility influenced decision to move away from easier access to ART, making him more vulnerable to stopping ART  Starting ART: After four days of being diagnosed with HIV, he started ART at Zx health facility.  Recalled skipping one dose which he forgot to take when watching football and had to wait untithe next day to take ART at a prescribed time.  Advocated taking ART early because "delaying makes the condition worse"  Considered consuming too much alcohol and being on ART "a problem," although was told he could drink alcohol and take ART as long as he did not get drunk  After three months on ART, he moved away to a rural area to work. According to family, there were no ART services where he had moved to and his brothers and cousin collected ART for him from Zx health facility and took it to him
Pretty	Before she started ART she used to feel weak and said she was "not well" when she tested for HIV. In 2017, she felt like she has "much energy." When she found out she had HIV, she was "very sad" but said the HPTN071 (CLWs) really helped her "to accept." She talked about HIV with two friends who are also LHIV. Participant disclosed to her ex-husband, young sister, her best-friend and another two friends LHIV, her boyfriend, a young sick widow and everyone in her household. The latter reminded her to take her drugs		Started ART. Adjusted livelihood mobility to ART access.  Starting ART: Since 2014 when pregnant had taken ART "consistently" from another health facility which was closer to where she lived. She always collected her ART herself and had her "vitals" done. When she travelled away for trading, she limited her time away (from one to three weeks), moved with all her drugs ("I do not carry and leave some. No!") and disclosed to a colleague she travelled with just in case of health complications. Complained of long queues at the health facility and said the "professional" healthcare workers were "harsh" but said she "always makes time" to collect her drugs
Simba	Suffered from TB in the past. Said he "feels strong" but on second visit complains of headache, stomach ache and coughing. Wife also not well at second visit; she looked frailer. Participant disclosed to his wife, and friend/colleague fisherman	HIV testing: Tested by HPTN071 (CLWs), at home with wife in 2014; both tested HIV positive	Not started ART. Livelihood mobility and household responsibility influenced this decision Referred twice by HPTN071 (CLWs) to Zx health facility. Told by HPTN071 (CLWs). that he should "go through investigations if I do not want to start ART." Went once but did not find HPTN072 (CLWs) so came home. Had not yet gone back because "still feeling strong" and prompted to start ART "only if sick often." Heard about "immediate ART" recently and believed that "drugs work" and that "health workers are fine." No ART services in swamp (where he fished)

although "a lot of people on ART there." Wife said she will start ART when husband starts or when he gets sick. They would go to a health facility closer to their home if they started ART

Table 2. (Continued)

Participant	Health of participant	History of HIV testing	Contact and/or contemplation of ART services
Mutinta	Complained of stomach aches, painful feet and pain under the breasts. Active and looked well. Mutinta disclosed to her mother, mother-inlaw and close childhood friend	and family planning clinics from 2012 onwards. In August 2016, HPTN071 (CLWs). tested almost everyone in her household and Mutinta tested positive. Did not know the HIV status of anyone else in the household. Re-tested elsewhere outside Zx after two months to re-confirm	Not started ART. Deference to position in the household and livelihood mobility influenced this decision  Put on Septrin (cotrimoxazole) for three months. Her mother-in-law wanted her to wait for her husband to come out of prison and re-test with him, so they can start ART together. Felt this was "unfair." She stated there is "nothing to fear" about taking ART, that if you "wait to get sick you risk dying" but "when you start there is no stopping. Once you stop taking the drugs this gives problems." Said that she would "go on Monday" to another health facility but never went during period of visiting her. Occupied with trading and long queues at ART clinic took time away from livelihood activities. She was also concerned of involuntary disclosure due to location of ART clinic. She said she might start ART when spouse gives permission when he gets released from jail

and bringing to him. Reflecting on his dependency on others, he said that regaining health would allow him to pick up his responsibilities as a father and move elsewhere to earn a living and find his own shelter.

Five of the six participants had made providing for their households and their dependents a priority over their own health, taking decisions to delay, miss or stop taking treatment to make ends meet for their households. Molly, for example was a 44-year-old widow living with HIV who had three teenage children. Her youngest child was perinatally infected with HIV. The oldest child was forced to stop school due to financial constraints and started travelling to Zambia's capital to buy fruit which Molly resold by walking around the community and in the town centre. In 2015, after frequently falling sick and being diagnosed with HIV, Molly started ART. In 2017, she was diagnosed with tuberculosis (TB) but taking drugs for both HIV and TB made her feel very sick and she could not walk around to sell her commodities. A decision to stop taking TB and HIV drugs was influenced by these factors coupled with being fed up with long queues at the health facility and a stigmatizing incident there. "I need to use that waiting time to sell to fend for my children," she explained. She also felt she needed to increase her income to improve her diet to take ART:

I will start ART again, first [,] I want my business to stabilize because business has been hard for me of late...Besides I need to work to earn money so that I will be able to buy food such that as I take the medication I do not get sick, it is not okay to take strong drugs without good food or poor nutrition.

#### 3.5 | Livelihood mobility

The main reason for mobility was to raise money for household basic needs (food, education, shelter, water, laundry, soap), as well as for capital needed for business ventures, recreational pursuits and social obligations. For two participants, poor health was a major motivation for moving from Lusaka back to family in Zx to be looked after. Their decisions around HIV (including starting treatment and routinely accessing drugs) were directly affected by the livelihood demands that involved urban-urban and urban-rural mobility.

One routine urban-urban mobility pattern was moving within Zx to the market and around the community and outside Zx to a nearby town centre. Molly and Mutinta used "small capital" (US\$10-15) for mobile businesses which entailed buying groundnuts or fruit for resale door-to-door, in markets and town centre streets, selling from 7 am to 5 pm during the week. Small profit margins, long days and geographical distances (into town and back and around the community) undermined their motivation to take ART. For example, Mutinta was occupied with trading and increasingly used transactional sex in the town centre to survive and said that the long queues at the health facility took time away from her business which was "not doing well."

Bigger returns were made by travelling further afield to urban and rural areas demonstrating urban-rural mobility patterns. Three participants routinely left Zx to make a living. Ronny was a tailor working within Zx, in the town centre and in a rural area, shifting to a temporary shelter in a rural area around the harvest season for four months to barter making or mending clothes for maize grain, which he would then

Table 3. Spinning plates

Name	Household responsibility and daily routine type	Livelihood mobility	HIV management	Balance/topple
Ronny	Mostly flexible daily routine, sometimes chaotic.  Extensive social networks & binge drinker, 4 younger children, renting house, mostly food secure, married, relationship with HIV negative - wife up and down, had other sexual partners.  Sometimes he & his wife absent at the same time	Mainly tailoring & bartering skills and although travelled away for up to four months, mostly predictable mobility to regularly visited places until took on casual work in mines which was chaotic	Has experienced extreme illness, started, stopped & started ART. Wife & HPTN071 (CLWs). prop up his health. Limited time to access ART; collecting drugs by biking from rural area to Zx proved challenging	Recent past saw topple in livelihood mobility & then Health/HIV. By August 2017, a delicate balance between all three
Molly	Mostly rigid daily routine.  More limited social network but strong church membership, 2 older & one younger child (latter LHIV), family plot, housing poor, food insecure, widowed, no sexual partners, elder son contributed to household, elder daughter gave emotional support	Initially selling ripe fruit locally & with small returns & capital. Son's support for her business could improve returns. Her role was to sell	Health improved on ART but bad experience of side-effects of TB medication & in Zx health facility pushed her away from bio-medicine (and off ART) towards faith-healing and self-management. Frail health by August 2017 & selling exhausted her	Health/HIV vulnerable to toppling in August 2017 by not resuming ART. Although poor, other "plates" propped up by church and adult children
Denny	Mostly flexible routine at first which became more chaotic when shifted household & location again. More limited social network as moved back to area & adult dependent, brothers were very supportive but brother also struggled financially, family plot, food insecure, widowed, no sexual partners, could not afford to have his children live with him	Tried to learn new livelihood options & assisted where he could with help of cousin & brothers. Moved to rural area to work in cousin's shop. Not independent so vulnerable to being moved around	Had experienced extreme illness but once on ART regained strength. However, reliance on his close family to collect ART and bring it to him deepened his dependency on others. Drinking and smoking habits and low selfesteem threatened his ART adherence	Past few years have seen all three plates topple and fall. Propped up by close family & a hard working personality, but any one plate vulnerable to toppling
Pretty	Mostly <b>flexible routine.</b> Extensive social network, 5 younger children, owns plot & reasonable house, food secure, divorced, boyfriend LHIV, responsible for siblings in college, adult sister & husband stayed with her & contributed to household. Shift to boyfriend's house more unpredictable	Routine & relatively predictable travel every couple of months for one to three weeks for trading in fish and/or maize. Travelled with woman companion	Health much better since started ART in 2014 and very pragmatic and organized with her management of HIV. Portrayed a sense of therapeutic citizenship. Sensitive to what her boyfriend thinks of her HIV status	Until August 2017, she had good balance across plates. However, shift to her boyfriend's house could make her household responsibility a bit more unstable, but plates still felt steady and balanced over all

**Table 3.** (Continued)

Name	Household responsibility and daily routine type	Livelihood mobility	HIV management	Balance/topple
Simba	Flexible daily routine becoming more chaotic. Extensive social network, one adult & 7 younger children, owned plots, married, HIV positive wife very supportive, food insecure. He & his wife often absent at the same time. Had some land assets & a resourceful personality	Routine and relatively predictable extended periods away in fishing camps (up to nine months) & travelled far to sell fish. Fish stocks low. Wife also routinely travelled to buy fruits to sell locally	Not yet linked to ART & time was very compressed to access ART. No ART services in fishing camp. Health was getting frailer, and a fishing accident in 2015 was another setback for his health. Wife also not well and not on ART	Health/HIV plate felt the most likely to topple, and this would make the livelihood mobility very challenging and his household responsibilities were extensive. Livelihood mobility plate also more off balance with low fish stocks leading to longer periods in the camps
Mutinta	More <b>chaotic daily routine</b> .  Extensive social network but dependent and young with small children and living in a large household, mother and mother-in-law supportive, mother's household food secure, sexual partners	Little control over livelihood and accompanying mobility, took up opportunities where she can (groundnuts, sexual exchange, asking relatives for money)	Well-informed but not yet started ART, partly because her mother-in-law asked her to wait for her estranged husband to get out of prison.  Health seemed stable.  Did not use condoms in sexual relationships or inform partners of her status	Her future seemed quite unpredictable, and her household and livelihood plates the most likely to topple

resell in Zx. During the rains, he had also taken on three months casual work in a rural mine. Pretty travelled for a week at a time roughly every two months either to national border posts or to rural areas to trade in dried fish and maize. She supplemented her household income with contributions from her younger sister and fisherman brother-in-law (who stayed with her).

Fishing was the main occupation of Simba. He spent about nine months a year fishing in the swamps and travelling to border posts and main towns to sell fish and this affected his access to HIV services since there was nowhere to access ART in the fishing camps. His wife, who was also LHIV and not on treatment, travelled to buy fruit from a distant town to resell in Zx, and was often away for two weeks a month. Simba explained that they will start ART with each other when one of them falls sick. In the meantime, he needed to prioritize household needs:

If I start now, where I go it is far and there is no ART centre. What happens when I run out of drugs? It is better I use my body to feed my family when I am still feeling strong.

Simba's predicament was echoed in Ronny's experience of stopping treatment for a period of six months because he ran out of drugs when he travelled from Zx to work in an informal copper mine. On his return to Zx, he further delayed resuming ART because he worried that health workers would reprimand him. Eventually he decided to access ART from the local NGO. He narrated:

I lost my ART identification number, and where I went there are no ART services, and I fear going to a public health ART centre because they would tell me off for treatment disruption.

#### 3.6 | Health and HIV

It was usually frequent illnesses, and for two participants, extreme illness, that prompted a decision to test for HIV (see Table 2). Most had found out they were LHIV within the last three years by testing at home with HPTN071 Staff members. The exception is Molly who found out in 2007 through antenatal care services. Simba, Denny and Molly have other family members LHIV that they stay with (a wife, an adult sister and a 10-year-old daughter respectively). All participants had disclosed to at least one other person in the household.

Although not all were on ART, all believed in ART, advocating taking it early and "consistently." ART was acknowledged as improving health and pushing illness away. Of the three participants not on treatment by August 2017, two (and one of their spouses) were not well. Denny had started on treatment recently when extremely ill and was frail, although slowly regained strength.

Worries about being seen accessing ART at Zx health facility were experienced either as a personal apprehension of participants or as something others worried about. Opting for "quieter" health facilities outside the Zx boundary with shorter queues was one strategy to avoid "being seen." Simba recalled PLHIV being made fun of for taking ART, and Molly said she was ridiculed by volunteers at Zx health facility when she fell

sick with TB while on ART. She recollected, "they said that even the air they breathe has been polluted due to the high viral load I have...they said I have infected a lot of people."

Experience with the HIV services at Zx health facility were chequered. Participants' complaints included long queues, rigid opening hours and/or health workers starting work late and blood results being lost. Although one participant said the healthcare workers were "fine," three others recalled being reprimanded and treated "harshly." One of the main reasons for being reprimanded was missing review appointments. However, Ronny's wife understood the frustrations of health workers faced with clients who do not come for their review appointment. She commented, "I think when they reprimand the patients it is to encourage them about their health, to look after your family."

After the difficult experience at Zx health facility, Molly relied on faith-healing and good nutrition which she found "more convenient" and "flexible." She explained how she can now "sell" from Monday to Friday, and still attend evening prayers: "When I attend church, I am even able to do my business because time is flexible than when I have to go and queue up at the clinic eating into my business time." At church on Sunday, she "benefits" not only from faith but also from testimonies on faith-healing and a counselling group for PLHIV.

Pretty, who travelled regularly but for limited periods (one to three weeks), travelled with all her drugs and with a woman trader companion who knew her HIV status. She "always makes time" to collect her drugs, choosing to access them from another health facility which was closer to her home. Explaining how she managed to stay on treatment both at home and when travelling away from home, she said:

My children remind me to take medicine when I forget, and when I am travelling or away to sell my commodities my friend reminds me because I disclosed to her. She is also HIV positive but not on ART. I also make sure I collect enough drugs for the period I am away.

When Denny shifted to work in a rural area with no ART services, his brother and cousin said they would collect his drugs and take them to him. But, this arrangement did not always work. He lamented that:

My cousin stopped going to town frequently, missed on collection of my drugs and my brother was out of town for a long time so my treatment was disrupted.

Ronny, faced with the same issue of residing (temporarily) in a rural area, resolved to cycle from the rural area to collect his drugs, leaving his wife to manage the business when he was away.

#### 4 | DISCUSSION

The case-studies of six Zambian PLHIV demonstrate how time to access ART was compressed by household responsibilities and the need to earn a living moving around, often away from home. At the health facility, lengthy waiting times, routine appointments, stigma linked to health facility space and health worker attitudes affected access. Using the typology of rigid,

flexible and chaotic routines [9] and the spinning plate analogy shows how each participant could not afford to focus on health and HIV exclusively (see Table 3). Each "plate" of household responsibility, livelihood mobility and HIV-management needed to be in balance; the tendency was to focus on the "plate" most vulnerable to toppling at the expense of the others. More chaotic and varied routines limit the time to access ART and rigid routines can be both oppressive and/or facilitate ART [9].

Intervening to support household responsibility and livelihood options is challenging. There is no comprehensive welfare support system in place in Zambia, although the government is planning to introduce a social cash transfer scheme [34] which aims to provide small bi-monthly cash payments to households experiencing severe poverty. We argue in this context that health service delivery needs adjustment to allow ART adherence, since livelihood mobility is an unalterable "temporal and spatial reality" [24 p862]. One area of intervention therefore could be in alternative health delivery methods. Based on the time-geography of PLHIV in California, Takashashi et al. [9 p862] suggest that service providers "make efforts to explore the daily routines of ...and restructure their organizational strategies and practices to take account of these temporal and spatial realities." As Taylor et al. [24 p293] state, based on patterns of mobility among Dominicans LHIV and on ART in New York City, "finding novel approaches to combat mobility-induced barriers to care, will be critical to the success of treatment programmes for HIV."

Leading precarious and mobile daily lives is a poor fit with the structure of HIV services [2,9,11] that require strict adherence and predictable routines, creating challenges both for PLHIV and health workers responsible for ART delivery. In Zambia, there are HIV delivery initiatives allowing travelling PLHIV (and family members) [35] to collect extra supplies of ART and access ART from a local NGO or outside the community boundary. However, the health worker practice of reprimand [20,36,37] towards those who miss review appointments, also noted by others in Zambia [37,38] and Kenya [11], intermittent drug stock shortage (and resulting rationed supply of drugs to clients), limiting ART provision to particular days and the lack of ART services in rural areas [3,39,40] and fishing camps indicate areas that require practical space and time strategies.

#### 4.1 Limitations

The data are limited by the small number of participants. However, the granular analysis and case-study approach provide detail on prevalent mobility patterns. A longitudinal approach, extending the period of fieldwork, would have illustrated the spinning plate analogy more comprehensively.

#### 5 | CONCLUSIONS

Given the inescapable role of livelihood mobility in the lives of many Zambians LHIV, the most promising interventions for sustained ART access and health are more client-centred care through a combination of changes that allow for mobility and flexibility and greater understanding between health workers and clients. ART services need to be in closer proximity to where livelihood activities take place [40] and open in the

evenings and at weekends. Providing clients with a map of where they can access ART if they run out of drugs when travelling, giving more long-term supplies of ART, an effective centralized client health information system and not restricting ART provision to a particular week day could be other practical strategies to address the needs of PLHIV on ART [41,42]. Health services need to adjust and adapt programming and service delivery to the "every day geographies" [9 p861] of many people living with HIV (PLHIV) in Zambia and their different degrees of inescapable routine mobility.

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#### COMPETING INTERESTS

There are no conflicts of interest for any authors.

#### **AUTHORS' CONTRIBUTIONS**

FN and VB were both involved in the design of the qualitative cohort data collection process, FN collected the data in this analysis, VB and FN analysed the data together and VB led on the drafting and analysis frame of this manuscript with close support from FN. AT assisted with the literature review and revised and reviewed manuscript drafts. MS was involved in the qualitative cohort data collection process, conducted and wrote up earlier data on the same community and reviewed the content of this manuscript. GH led in the design of the qualitative cohort and supported the analysis and content of this manuscript. JS gave technical support to the qualitative cohort at all stages and supported the analysis approach and editing for this manuscript. HA, RH and SF designed the HPTN071 intervention and have oversight of all research activities.

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#### RESEARCH ARTICLE

# Households, fluidity, and HIV service delivery in Zambia and South Africa – an exploratory analysis of longitudinal qualitative data from the HPTN 071 (PopART) trial

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Clinical Trial Number: NCT01900977.

#### **Abstract**

**Introduction:** Population distributions, family and household compositions, and people's sense of belonging and social stability in southern Africa have been shaped by tumultuous, continuing large-scale historical disruptions. As a result, many people experience high levels of geographic and social fluidity, which intersect with individual and population-level migration patterns. We describe the complexities of household fluidity and HIV service access in South Africa and Zambia to explore implications for health systems and service delivery in contexts of high household fluidity.

**Methods:** HPTN 071 (PopART) is a three-arm cluster randomized controlled trial implemented in 21 peri-urban study communities in Zambia and South Africa between 2013 and 2018. A qualitative cohort nested in the trial included 148 purposively sampled households. Data collection was informed by ethnographic and participatory research principles. The analysis process was reflexive and findings are descriptive narrative summaries of emergent ideas.

**Results:** Households in southern Africa are extremely fluid, with people having a tenuous sense of security in their social networks. This fluidity intersects with high individual and population mobility. To characterize fluidity, we describe thematic patterns of household membership and residence. We also identify reasons people give for moving around and shifting social ties, including economic survival, fostering interpersonal relationships, participating in cultural, traditional, religious, or familial gatherings, being institutionalized, and maintaining patterns of substance use. High fluidity disrupted HIV service access for some participants. Despite these challenges, many participants were able to regularly access HIV testing services and participants living with HIV were especially resourceful in maintaining continuity of antiretroviral therapy (ART). We identify three key features of health service interactions that facilitated care continuity: disclosure to family members, understanding attitudes among health services staff including flexibility to accommodate clients' transient pressures, and participants' agency in ART-related decisions.

**Conclusions:** Choices made to manage one's experiential sense of household fluidity are intentional responses to livelihood and social support constraints. To enhance retention in care for people living with HIV, policy makers and service providers should focus on creating responsive, flexible health service delivery systems designed to accommodate many shifts in client circumstances.

**Keywords:** HIV testing; antiretroviral therapy (ART); adherence; southern Africa; mobility; household residence; membership

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#### 1 | INTRODUCTION

An estimated 65% of people living with HIV (PLHIV) in Zambia and 56% in South Africa [1] are currently on antiretroviral therapy (ART). Both countries have committed to scaling up their ART programmes to all PLHIV [2,3]. However, multiple social, historical, economic, and health service challenges make this aim difficult to achieve [4]. Optimal implementation of ART programmes requires predictable progression of clients

through the sequential steps of the HIV care continuum [5,6]. In southern Africa, high levels of population mobility and what we term "household fluidity" create significant challenges for stability along the care continuum [7,8]. The concept of household fluidity emerges from anthropological studies that recognize the "problem of domestic group pliancy and labile household compositions ... where both individuals and households seemed to move about almost continuously" [9]. Households are not limited to one geographic location or social

network. Social networks are often geographically diffuse. We define household fluidity as an aggregate property of the person's experiential sense of their social networks' security, stability and reliability. This experience is on a continuum that ranges from stasis to chaotic unpredictability. The person's sense of household fluidity manifests in their experiences of belonging in a space with contemporary and historical dynamics and places parameters on their identity maintenance in that space. People seek a balance of stimulation/novelty/unpredictability to stability/routine/security in their social networks. The experience of household fluidity can therefore prompt mobility as people move towards their optimum balance. In addition, mobility causes changes in the experience of household fluidity both by imposing geographic barriers and by changing the interpersonal dynamics between household members. While individual and population mobility are active processes, we suggest that household fluidity is an inherent characteristic of everyday life that requires constant manage-

Population distributions, family and household compositions, and people's sense of belonging and social stability in southern Africa have been shaped by tumultuous, interwoven, and continuing large-scale historical disruptions at multiple levels of political and social geography [10-12]. In contemporary Zambia, the country's geographic position - sharing national borders with eight other countries - and its role as a hub for regional trade routes have led to particularly high patterns of mobility. In South Africa, apartheid-era policies formalized iniguitous place boundaries based on racial and ethnic classification and further distorted patterns of mobility and family and household structures [13-18]. These processes have shaped contemporary experiences of social inequity, including unequal burdens of disease and political and social marginalization. Many southern Africans are angry, mistrustful and disenchanted by the unequal distribution of land ownership and socio-economic opportunities that perpetuate poverty and serve as a reminder of their disempowerment [19,20].

Demographic categorizations of population mobility prioritize a distinction between long-term resettlements which change the population denominator, and short-term in- and out-flows of people through places. Much research has been dedicated to describing and explaining patterns of mobility that recur with cyclical regularity [9,21-25]. Other research has focused on the influences of household structure and interpersonal politics on individual-level drivers of intermittent mobility [26-30]. More recently, social scientists have proposed a reframing of mobility to also take account of how mobility intersects with processes of household fluidity and social instability [31-34]. In HIV research, there has also been an increasing focus on mobility highlighting how mobile populations are both at increased risk of HIV infection [35] and are more likely to fall out of the HIV care continuum [36]. High rates of mobility amongst particular groups or at specific life stages can create discontinuities along the care continuum. For example, young people, who are a key priority group for HIV service delivery [37], often experience mobility events as they transition from school learner to job seeker. Further, their household composition can change significantly as caregivers move in and out of the home, particularly in households affected by HIV [38,39]. Similarly, sub-groups within geographic communities – including sex workers [40], truck

drivers [41], and people living with disabilities [42] – experience different household mobility patterns, which shape their HIV risk and access to services.

To explore these dynamics, we suggest household fluidity as an analytic lens through which we aim to (1) describe patterns of household membership and residence in 13 study communities in South Africa and Zambia; (2) explore participants' narratives about why these patterns come about; and (3) describe key features of client/health service relationships that can enable continuity of care in the context of high levels of household fluidity. We discuss how more responsive, context-specific service delivery models can maintain continuity in the context of fluidity.

#### 2 | METHODS

#### 2.1 Study design and period

HPTN 071 (PopART) is a three-arm cluster randomized controlled trial implemented between 2013 and 2018 in 21 periurban study communities – 12 in Zambia and nine in South Africa [43]. Geographically, study communities were defined as the catchment area of a primary health facility. The communities ranged in size from approximately 15,000 to 100,000 adult residents and were typical of high-burden, low-resource places in the region. A nested social science evaluation includes a qualitative cohort of households. In Zambia, participants for this cohort were recruited between January and March 2017. In South Africa, some participants were recruited in an exploratory phase between August and December 2015, while the majority were recruited between March and July 2016. The cohort closed in both countries by March 2018.

#### 2.2 | Sample

In total, the qualitative cohort includes 148 households in Zambia and South Africa recruited in four of the Zambian study communities and all nine South African study communities. The study communities in Zambia were purposively sampled for geographical and study arm representation. Participants were sampled purposively to ensure diversity by trial arm, proximity to local health facility, HIV pathways (including self-reported HIV status and having tested HIV-negative or not tested for HIV), age, gender and household structure. In South Africa, the sampling approach also followed the principle of extreme cases to include people at greater risk of HIV acquisition and who are more socially marginalized - including cisgender female sex workers, men who have sex with men, transgender women, people living with disabilities, and young people aged 15 to 24. Finally, participants were sampled to ensure that at least half of the total households included at least one member who self-reported living with HIV.

#### 2.3 Data collection processes

Data collection was informed by ethnographic and participatory research principles. The researchers recorded their discussions with voice recorders and semi-structured field notes and took pictures of relevant activities. All interactions with

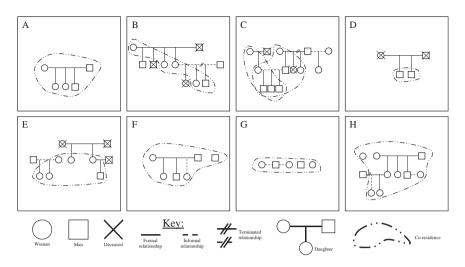


Figure 1. Patterns of household membership and residence.

participants happened in situ in the study communities - usually in their home, but also often as they moved about the study community completing their daily activities. Researchers interacted with households for several hours per interaction and multiple times over the course of the data collection period. Data collection was structured into six modules implemented sequentially but with flexibility to iterate between topics – (1) household, kin, and relational networks, (2) place and space, (3) getting by, (4) sex, love, and romance, (5) HIV service access, and (6) horizons, ambitions, and fears. We draw primarily on the first two of these modules for this analysis, supplemented by our experiences implementing the cohort overall. Participatory research activities in these two modules included: kinship mapping, community mapping, historical narratives of households' movement into the study community, and timelines of household members' weekly activities.

#### 2.4 Data analysis processes

The data analysis process was reflexive and included routine, structured written reflections by data collectors, monthly analytic workshops of country social science teams, and a targeted review of all primary data by the first five co-authors. The findings are descriptive narrative summaries of key emergent ideas with illustrative case examples. All interpretations of data were discussed with the country social science teams and expert reviewers as a sense checking mechanism.

#### 2.5 Ethical considerations

The trial – including all nested social science – was approved by the London School of Hygiene and Tropical Medicine, University of Zambia, and Stellenbosch University research ethics committees. All participants signed written informed consent per guidance of the in-country research ethics committee. Household participation was by consensus of all household members. All data are stored securely and reported on using pseudonyms to protect participant confidentiality. Participants did not receive any cash incentive. However, in South Africa research staff had discretionary allowances of

approximately 6 USD per day and in Zambia were able to claim back reimbursement for field expenses to contribute to shared meals and other costs of living with participant households.

#### 3 | RESULTS

## 3.1 | Thematic patterns of household membership, residence, and associated fluidity

We identified eight thematic patterns of household membership and residence with implications for fluidity (see Figure 1 as illustrative representations of each pattern). These patterns are changeable and overlapping and should therefore not be reified as diagnostic categories. We present them here as cross-sectional illustrations of diversity in household membership and residence arrangements common in the study communities. Further, they serve as a context within which to understand study community members' experiences of fluidity.

The simplest pattern of household membership and residence identified in our sample is a stable household consisting of two parents and one or more children (see Figure 1A). Although many participants identify this social grouping (the nuclear family) as defining their most immediate family, very few share consistent, stable residence with all members of their nuclear family in households without other residents. More commonly, household residence is spread across generations (see Figure 1B). These households are generally structured around grandparents - often grandmothers - their adult daughters and their daughters' children. Many of these households are multi-nodal, with sets of grandparents that are stably resident in physical structure but children and grandchildren who move between such nodes (see Figure 1C). The proximity of physical structures and household networks can range from being a few doors down the road to neighbouring provinces. There is often an enduring link of kinship or family membership between these places which encourages movement of household members - especially children and younger adults. In contrast, some participants live in very isolated households with limited membership networks, or even sometimes alone (see Figure 1D). These adults – usually men – had often moved recently into the community or from another household in the same community. Residents of these smaller, less stable households are particularly mobile, moving between work and recreational activities like visiting taverns and other social networks.

Participants identified these first four patterns of household residence as extensions of biological ties between family members. Other household patterns illustrate adaptations to these four patterns to include non-biologically related members. For example, a small group of adult women - who may be biological sisters or cousins, but often are not – cohabitate to pool resources to care for their children (see Figure 1E). Commonly, households with more stable resources foster additional members (see Figure 1F). The household members who are fostered are often new "girlfriends"/wives of young men who remain resident in their parents' home, children from the extended family or neighbourhood, or people who are chronically ill or living with disabilities (particularly in South Africa where people with disabilities receive a government grant equivalent to 140USD per month). Some households are also arranged to support an intentional survival venture or common goal (see Figure 1G). Often these activities are clandestine (such as selling sex, unlicensed alcohol, or drugs). Lastly, over time households' membership and residence dynamics change and represent a complex and shifting combination of patterns with internal tensions between members (see Figure 1H).

A household member's fluidity is an outcome of the overall type of household membership and residence pattern of their household(s). For example, households like "A" are generally experienced as more stable than households like "G" (see Figure 1) because familial bonds are often more enduring than enterprise-associated bonds. Further, households like "G" are experienced as more fluid than "A" because of the contingent and informal nature of associations between members of the household and their other family and social networks outside the residence.

## 3.2 | Participants' explanatory narratives about fluidity

Overall, we found that households are extremely mobile, with various people moving in and out on a daily, monthly and yearly basis. People move within their local neighbourhoods but also across much wider areas of the local town, city, and country. We identified six categories of reasons people provided to explain these movements (see Table 1). This mobility creates dynamic processes where participants spend multiple nights outside of their primary residence over the course of a month. Further, their mobility means that residents consider themselves members of multiple households over the course of a year. The main explanations participants offered for high levels of mobility were economic survival/seeking work or opportunities, seeking shelter and safety, fostering interpersonal – often romantic – relationships, observing cultural, traditional, religious, or familial gatherings and otherwise maintaining a social life, being institutionalized, and maintaining patterns of substance use. Participants pointed out that these dynamics are often very unpredictable as life circumstances change rapidly and new demands for mobility arise.

Further, participants described how high mobility creates an abiding sense of fluidity, disturbing their attempts to maintain a sense of belonging and social stability. This sense of fluidity must be understood in the context of an implicit moral responsibility to share socio-economic support with family and community members. Fulfilling this responsibility was interrelated with how strongly participants felt they belonged in the place and part of the social network. The participants' sense of their household fluidity related directly to how much they felt they could rely on relationships during times of instability - for example, ending romantic partnerships, shifts in childcare responsibilities, limited economic opportunities, or simply when needing a place to stay. Short- and long-term movements were also oftentimes the result of interpersonal conflict between household members or romantic partners that disturbed the person's household fluidity equilibrium. One example of these dynamics relates to a South African family in which the teenage daughter became pregnant and left school, souring the relationship with her mother. As a result, the daughter now moves between her boyfriend, her grandparents, and her biological father and struggles to manage shifts in her identity – as a girlfriend, grandchild and estranged child - in these spaces. She experiences her household as threateningly fluid (field notes, 27 October 2016; 31 October 2016; 24 November 2016).

South African participants often expressed a general dissatisfaction about life in their communities that informed their sense of not belonging to particular spaces. Some participants considered communities other than where they are resident to be "home." One example of this is a family who has experienced high levels of crime and violence. The field worker explains, "In times of trouble, the family would relocate to another province. Her family finds solace there. Where they currently live [SA16]<sup>a</sup> is perceived as a place of suffering" (field notes, 09 November 2016). Participants in Zambia expressed a stronger sense of belonging to their communities, and also usually described them as peaceful. Dissatisfaction was usually expressed towards particular spaces well known for criminal activity, the sale of drugs and alcohol. Friendship networks revolved around neighbours who were mostly described as supportive.

## 3.3 | Examples of care continuity in contexts of fluidity – key features

Experiencing one's household as highly fluid made it difficult for many participants to access HIV services consistently. However, in study communities with multiple avenues for HIV testing – including at facilities, in community venues, and door-to-door – participants indicated that they were more likely to find at least one option that suited their requirements.

For study participants living with HIV, fluidity created three inter-related challenges to continued ART access. Firstly, moving between households to manage fluidity meant that physical distance and associated travel costs to health facilities were often changing. Secondly, disruptions to ART continuity as a result of strategies to manage fluidity impacted negatively on PLHIV's relationships with health facility staff and led to experiences of shame related to being labelled as "defaulters." Thirdly, changes in social networks destabilized fluidity

	Examples
Economic survival/seeking work or opportunities	Participants talked about household members that migrated outside the community for work: "My father spends days away from home when he goes for business outside the country." (Z10³_man_17 yrs)  J (SA19_woman_43 yrs) lives under a bridge 6.6 km outside of SA19, together with her daughter and son. J and the other residents there go out on Mondays and Wednesdays to "scurry." They "scratch in the bins for boxes and plastic and things like that" (SA19_woman_25 yrs). Sometimes, they find packages of food intentionally left out by residents of homes. Through these movements, participants reported that they were able to ensure they have enough to eat.  Young people, especially in Zambian study communities, mentioned that they are also mobile to support the family
	business. "I go to sell groundnuts in town," one woman explained (Z6_woman_17 yrs)
Seeking shelter and safety	F is a transgender woman who sells sex and shares a garage with others behind a house. She explains how her living arrangements have changed over the last few years: "Back then I didn't stay here [in this garage] I lived there in this road. From there I moved further up to where I lived previously. And then I started sleeping here in the bush, me and another [transgender] girl and then I met S and I asked her if I could sleep [here in the garage]." (SA14_woman_30 yrs)
	L is a young man living with HIV from Z6, who was staying with his aunt before he was incarcerated. After his release from prison his aunt asked him to look for a house to rent. He relocated from his aunt's house in a low density area to Z6 (his aunt pays his house rentals). (Z6_man_18 yrs)
	J is a woman who had recently moved with her family to another part of the community. She explained this as a choice they had to make to escape gangsters who were endangering the community, saying "There we didn't even stay a year, because they broke in a lot." (SA18_woman_37 yrs)
Fostering inter-personal – often romantic – relationships	One woman explained that she moved out of her parents' house to go stay with her boyfriend with whom she had a child because, "We follow that tradition that children don't sleep together with a boyfriend under the roof with the parents." (SA21_woman_22 yrs)  N is a young man living with HIV who has been in his maternal uncle's foster care ever since the death of his
	parents. He says "growing up, I have never known my biological parents. I was told they died when I was still a baby, I have never seen themThree of my brothers are not here they live in Zimbabwe with my father's relatives but I only met them [my brothers] once." (Z7_man_22 yrs)
	Another woman described how her social world and physical residence shifted when she separated from her husband, "that time when my ex-husband and I were separated." Financial constraints forced her to move: "so then couldn't afford the rent anymore and had to move." (SA18_woman_37 yrs)
Observing cultural, traditional, religious, or familial gatherings and	A young man says that he travels to his parents/extended family's home in a neighbouring province multiple times a year for gatherings and for traditional observances. "In December 2013 I went to Eastern Cape for my circumcision ceremony." (SA13_man_21 yrs)
maintaining a social life	Young people in Zambia mentioned regularly going to other parts of the community outside their residential area for entertainment: "as for me the places where I'm usually found are X, Y, Z they are many except here in K [place of residence] and the reason why I like those places is because there is more entertainment. Here in K you will never see someone mingling around they'd say, 'ah no, we are not in the ghetto." (Z7_woman_17 yrs).
Being institutionalized	J is a 22 year old man who was staying with his girlfriend in a two bedroom wooden shack in SA19. He went to prison in March 2016 and was released a few months later. His girlfriend had started a new relationship and he no longer had a place to stay.
	A is a 19 year old young woman living with HIV in Z10 who had to relocate (within Z10) to take care of her aunt's house and business while her aunt was ill in hospital for slightly over two months. After her aunt's death, she moved back to her previous home.
Maintaining substance use	Many of the households, especially in South Africa, include household members connected to drug use. These individuals smoke <i>tik</i> (methamphetamine) together on a daily basis and build networks around their drug use that involve regular movements to acquire and share drugs. B, his sister, his brother, and his brother's girlfriend, along with friends and acquaintances, all in their late teens and twenties, spend large parts of their day in a derelict

house that his father owns. They move around the community looking for things to sell or steal to support their habit. When the research team asks B about his weekly routine he replies "Every day is like our Mondays. Yes, we

have our priority and responsibility like that, but the main thing is all about drugs." (SA19\_man\_29 yrs)

 $<sup>^{\</sup>rm a}\text{Study}$  communities are lettered Z (Zambia) or SA (South Africa), and numbered 1 to 21.

#### Table 2. Case descriptions of care continuity in contexts of fluidity

#### Case description

Managing geographic and social distance to access antiretroviral therapy (ART)

- N is a gay man who sells sex in SA18. He was diagnosed as living with HIV in 2007 and has been on ART since 2013. N lives in SA18 but he chooses not to access ART at the local health facility <3 km from his home. Instead, he travels 30 km to access ART at a specialized men's health clinic close to Cape Town CBD. N explains his choice with reference to his lack of connection and sense of safety in his community of residence. N prefers not to socialize with other residents of SA18, nor does he work locally. While N enjoys a night out, he does not visit any taverns in SA18 because he is afraid he will be assaulted for his sexual orientation.
  - Despite his decision to access ART far from his place of residence, N has devised various ways to ensure continuous adherence to ART. When he does not have taxi fare, N stows away on the train and walks 40 min from the station to the clinic. N has an arrangement with the clinic to collect his ART early in case he cannot arrive on an appointment date. He also receives additional months' supplies over the annual festive season so that his ART is not interrupted by travel in December to January for annual holidays in the neighbouring province.

Ensuring treatment continuity in shifting settings

P is a young man who lives alone in Z6. He is married to a 16 year old wife who recently gave birth. Both mother and child are HIV negative. P's wife is living with her mother's family while the baby is young. Both of P's parents are deceased. When he was younger, his parents had him sent to prison for stealing their money and because, he says, "they wanted to teach him a lesson." P is a trader, travelling to the swamps for months at a time to buy fish and meat to resell in the community. When he is not trading he is drinking at the bar in the market. P learned that he is living with HIV when he was in prison. He started on ART a week later. He says that at the time the health staff were well-educated and explained the seriousness of missing doses and the importance of eating well. They told him that if he took his medicines and ate appropriately, he would regain lost weight and be healthy. P has only disclosed his status to his wife and close relatives. Now that he is out of prison, he accesses ART at the local clinic. He says he feels safe there because everyone is there for the same reason – accessing ART. When P knows that he will not be available for a subsequent clinic appointment he asks for his ART to be dispensed in advance. When something unplanned arises, his wife is able to collect his ART on his behalf.

Balancing treatment and economic/work-related requirements through social support S is a woman who sells sex along a regional road. She used to live with Z in a neighbouring community, but has since moved in with a friend, whom she calls a sister, in SA14. S learnt that she is living with HIV when she was 18 years old after the birth of her child. She has disclosed to her family and to colleagues in different houses where she has worked selling sex. She says a local sex worker advocacy NGO motivated her to start ART in 2015. In 2016, she experienced a treatment interruption because she says the ART caused her to gain weight – implicitly jeopardizing her livelihood. In early 2017 she began taking her ART again alongside an exercise regime to maintain her ideal weight. Her co-resident friend reminds her to take her ART and she has fostered a positive relationship with health workers at her local health facility who understand the importance of her maintaining her weight.

equilibriums and created new challenges related to the management of disclosure, care and support. Despite these challenges, some participants living with HIV are able to maintain ART continuity even in the context of fluidity. The three vignettes summarized in Table 2 illustrate the many challenges PLHIV in highly fluid contexts experience in maintaining ART continuity. The vignettes also demonstrate three key features that enable these participants to overcome these challenges: disclosure to close family members, understanding attitudes and flexibility among health services staff, and participants' agency to decide on what terms they will be on ART. For N, being on ART means escaping the homophobic restrictions of SA18, for P it is about being a young married man and providing for his young family, and for S it is about looking good to stay economically independent. In each instance, fluidity is not a barrier to their ART continuity. Rather it is just another feature of the context of their lived experiences.

#### 4 | CONCLUSIONS

We described the complexity of household membership and residence in 13 study communities. We showed the interlinked reasons why choices about managing household fluidity are both ubiquitous and intentional responses. We further explored features of the interactions between clients, their social systems, and health services that facilitate continuity of HIV-related services access even in contexts of high fluidity. Further, by describing people's household contexts, their reasons for moving, and the continuity of social links even after moving, we are able to begin to explore opportunities to

manage the impacts of fluidity and HIV services more efficiently. Health services that are fixed and geographically static create challenges for managing continuity of care in these contexts [44]. Some gains have been made through community-based [45], door-to-door [46,47], and mobile [48] HIV service delivery, but gaps in the stability of the care continuum remain. In contexts of high fluidity, it is the granular adaptability of health services to client needs that enables care continuity. The paper contributes to a growing body of literature that aims to develop a more nuanced conceptualization of household fluidity in the context of HIV [49-51]. This manuscript is about understanding the inherent fluidity in the lives of people living in the highest HIV prevalence region of the world and how this fluidity intersects with their engagements with HIV services. One intersection is that a fixed/static health service system necessarily experiences patient fluidity as a challenge to manage. As illustrated in the vignettes, some participants are able to effectively manage threats to continuity of HIV service access that result from fluidity pressures. These threats include unstable social forms, physical and social distance, HIV and identity-related stigmas, and the difficulties of maintaining livelihoods in contexts of constraint. However, those who manage to receive consistent quality care do so with difficulty in a system that is not designed to accommodate their often unpredictably fluid life experiences.

It is important to acknowledge that choices around management of household fluidity are often intentional and necessary responses to ensure livelihoods and social support in contexts of social and economic constraint. Health services should thus focus on creating responsive, flexible health service delivery systems that are designed explicitly to support continuity across many shifts in people's everyday life circumstances — including place-based and support network shifts. Integrated, flexible systems would enable clients to interact continuously with the same health system network rather than stepping between different systems and falling through the gaps.

Increasing efforts to train health workers to be more sensitive to patients' fluidity will likely foster greater trust and build better relationships with patients that may in turn enable improved collaborative management of fluidity. Similarly, additional resources through counselling and facilitated disclosure processes will likely empower patients to mitigate the influence of social support network fluidity on their care continuum. However, in either case, such interventions are addressing the symptoms and not the underlying cause of fluidity-related interruptions to the care continuum. We argue for a broader re-imagining of the health service-patient interface throughout the health system.

Fundamentally, strategic frameworks for primary health service delivery in southern Africa must integrate responsiveness to granular, everyday shifts in clients' social and geographic worlds as part of the interpretation of differentiated models of care responsive to experiences of fluidity. One starting point for such a shift requires implementation of existing technologies for ensuring that patient record systems are integrated across health service centres and community-based health service delivery platforms. Further, clinic forms, patient information management systems, and staff training must be redesigned to work towards the core goal of ensuring continuity of care by offering multiple service options from which patients may choose as suits their fluid life demands. Once

these fundamentals are in place there are multiple avenues for optimizing continuity of care. For example, routinely dispensing ART at shifting intervals, according to time periods defined according to patients' shifting life schedules. Effectively accounting for and working with fluidity, rather than trying to work around it, can potentially create opportunities to tap into wider patient geographies and social networks that support access to continuous care. For example, designing patient indexing systems to see each home as an additional point of contact with that patient.

In HIV policy and implementation, "mobility" has for too long been understood as a barrier to be overcome or as an excuse for poor patient outcomes. In addition, conceptions of mobility that ignore the linked, but discrete, experiential sense of household fluidity, are inadequate to formulate effective HIV service delivery plans in southern Africa. Instead, we propose embracing the resourcefulness of patients and health workers to manage experiences of fluidity to ensure HIV service continuity. The time has come for stability and care continuity through matched fluidity in the health system itself.

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#### **COMPETING INTERESTS**

The authors have no competing interests to declare.

#### **AUTHORS' CONTRIBUTIONS**

GH led the design of the qualitative cohort data collection process, supervised the analytic team, and led the drafting of this manuscript. HM participated in data collection, led the analysis of observational data, and supported the development of the conceptual heuristic. LdV, RN, JM and MM participated in data collection and led the analysis of interview/discussion data. AT supported drafting the introduction. HA, PB, KS, JH and JS provided expert review to interpret the findings relative to the PopART intervention package and HIV service delivery in Zambia and South Africa. VB led the design of the social science evaluation of HPTN 071 (PopART) and supervised the data collection team in Zambia. LR supported the design of the qualitative cohort data collection process, offered expert oversight for the analytic design and conceptualization of this paper, and provided detailed revisions of the paper itself. All co-authors participated in the interpretation of data and reviewing the manuscript at different stages.

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#### RESEARCH ARTICLE

### Understanding reasons for discontinued antiretroviral treatment among clients in test and treat: a qualitative study in Swaziland

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#### Abstract

**Introduction:** Retention on antiretroviral therapy (ART) is critical for the successful adoption of the test and treat policy by sub-Saharan African countries, and for realizing the United Nations programme on HIV and AIDS target of 90-90-90. This qualitative study explores HIV positive clients' reasons for discontinuing ART under the *Max*ART test and treat implementation study in Swaziland.

**Methods:** Clients identified as lost to follow-up (LTFU) in the programme database, who had initiated ART under the intervention arm of the *Max*ART study, were purposively selected from two facilities. LTFU was defined as stopping ART refill for three months or longer from the date of last appointment, and not being classified as transferred out or deceased. Semi-structured face-to-face interviews were conducted with nine clients and one treatment supporter between July and August 2017. All interviews were conducted in the local language, audio-recorded, summarized or transcribed and translated to English for thematic analysis.

**Results:** Respondents described mobility as the first step in a chain of events that affected retention in care. It was entwined with precarious employment, care delivery, interactions with health workers, lack of social support, anticipated stigma and ART-related side-effects, including the exacerbation of hunger. The chains of events involved several intersecting reasons that occurred one after the other as a series of contiguous and linked events that led to clients' eventual discontinuation of ART. The individual accounts of step-by-step decision-making revealed the influence of multi-layered contexts and the importance of critical life-events.

**Conclusions:** Clients' reasons for abandoning ART are a complex, inextricably interwoven chain of events rather than a single occurrence. Mobility is often the first step in the process and commonly results from precarious economic and social circumstances. Currently the health system poorly caters to the reality of people's mobile lives. Interventions should seek to increase healthcare workers' understanding of the chain of events leading up to discontinuation on ART and the social dilemmas that clients face.

Keywords: ARV; Retention; Linkage to care; Intervention; Swaziland; Test and Treat

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#### 1 | INTRODUCTION

Between 2000 and 2015, the number of people living with HIV (PLHIV) who access antiretroviral therapy (ART) saw a thirty-fold global increase: from 250,000 to more than 17 million [1,2]. With increasing evidence of the benefit of "early" ART initiation in reducing morbidity, mortality, and onward transmission of HIV [3-5], the World Health Organization's (WHO) 2015 consolidated treatment guidelines recommended "test and treat": ART for all people diagnosed with HIV, regardless of CD4 cell count or disease stage.

With countries across sub-Saharan Africa (SSA) adopting test and treat, there is a renewed need to ensure long-term

retention on ART. Across Africa, the retention of clients in HIV care remains a challenge, with continent-wide retention estimated to be 65% at 36 months [6]. The high attrition rates mainly result from loss to follow-up [7-9]. This is of concern because interrupting or discontinuing ART leads to suboptimal clinical outcomes, higher risks of opportunistic complications, loss of income, and death [10,11]. Reasons for loss to follow-up include a lack of food, religious and family influences, use of traditional or alternative medicine, enacted and/or perceived stigma, poor client-provider relationships, improvement in health status and treatment fatigue [8,11,12]. Stemming high loss to follow-up rates is key to sustaining gains made against the HIV epidemic.

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In Swaziland, with a reported prevalence of 30.5% among 18-49 year-olds, HIV is the leading public health concern [13]. Although HIV incidence reduced from 2.5% in 2011 to 1.4% in 2016, prevalence has remained stable [13,14]. By December 2016, 171,266 (of the estimated 220,000) Swazi PLHIV had initiated ART, representing a coverage of 78% [15]. Among PLHIV in Swaziland, the 2016 retention at 36 months was 85% [15], indicating relatively high retention in care. Little is known, however, about the reasons for disengagement from care among the remaining 15%.

In general, the population of Swaziland is extremely mobile, within and across borders, and this has been a key driver of the HIV epidemic [16]. In 2010, almost half of 946 surveyed Swazi clients identified as lost to follow-up (LTFU) could not be traced because of their high mobility [17]. It is crucial to understand how mobility – absence from one's place of residence for a prolonged period of time – is linked to other reasons for discontinuing ART to design effective interventions to improve retention in care under test and treat. Drawing on interviews with clients identified as lost to follow-up in two public health facilities, this article explores their reasons for discontinuing ART. Ultimately, the aim is to use these data to inform an assessment tool to proactively identify clients likely to discontinue ART and offer them stepped-up counselling and support.

#### 2 | METHODS

#### 2.1 Study setting

Data were collected as part of the social science component of MaxART, a multidisciplinary implementation study in Hhohho Region, Swaziland, which examined feasibility, acceptability, affordability, and scalability of test and treat [18]. The MaxART study protocol is described in detail elsewhere [18]. The MaxART study population included all consenting adult (above 18 years) PLHIV and ART-naive clients. Pregnant and breastfeeding mothers and/or unable/refusing to consent were excluded. The MaxART clinical database included all study participants and was frequently updated with data from the 14 participating public health facilities. The data presented herein were collected at a regional referral hospital and a rural clinic, purposively selected because they were high-volume sites and reported the highest number of LTFU clients in the MaxART database.

Ethical approval was obtained from the Swaziland National Health Research Review Board.

#### 2.2 Data collection

In the MaxART database, clients who stopped ART refill for three months or longer from the date of last appointment and were not registered as either deceased or transferred out from the two sub-study sites were classified as LTFU. All LTFU clients from the selected sites were contacted using their mobile phone numbers obtained from the MaxART database. The calling researcher explained the purpose of the study to potential participants over the phone and verified whether they had difficulties with taking ART. Potential respondents who confirmed they had stopped treatment were asked whether they were willing to be interviewed about their experiences. An appointment was set with those who agreed

and a day before the agreed date respondents were called again to confirm their availability. Before the interview took place, the study purpose was explained again to the participants and written or verbal informed consent was obtained according to the participant's preference. Anonymity and confidentiality were maintained throughout the study.

Clients who were not reachable through their mobile phone number were traced through their listed treatment supporters. For those who could still not be reached, the treatment supporter was interviewed if he or she was aware of the client's HIV status. Among those successfully traced, eleven clients were confirmed as LTFU. All eleven clients (three males and eight females), and one treatment supporter were approached for an interview. One client refused, another evaded the researchers, not keeping four consecutive appointments. In one case, although the client could not be traced, her treatment supporter was interviewed. The findings are therefore based on face-to-face interviews with nine LTFU clients and one treatment supporter. Using a semi-structured topic guide, trained and experienced social scientists carried out the interviews that explored their reasons for discontinuing ART.

Consistent with an inductive approach, interviews were designed to be flexible, following a general, topic-oriented structure. The interview guide contained open questions on reasons for and experiences with discontinuation of ART, HIV testing, meaning of positive results, disclosure, availability (or lack) of a support system at home, the health facility and the community, and intentions to restart ART in the future. All interviews were conducted in the local language (siSwati) and audio-recorded upon consent from clients. Most audio recordings were transcribed verbatim and as data started to become saturated, and no new themes emerging, the final audio recordings were summarized. All transcripts/summaries were translated to English for analysis.

#### 2.3 Data analysis

In consultation with co-authors, FS manually analysed the data, using a data-driven inductive thematic approach to steer cross-case comparison. According to Thomas [19], the general inductive approach "allows research findings to emerge from the frequent, dominant, or significant themes inherent in raw data collected, without the restraints imposed by structured methodologies." A narrative approach was also used to elicit in-depth understanding of the individual contexts in which decisions were made. This was combined with constant comparison as described by Glaser and Strauss [20]. Combining cross-case analysis and within-case analysis helps to maintain the contextual richness of individual experience [21]. During analysis, emerging patterns were shared and discussed with EV and RR. Initial findings were discussed with all co-authors.

#### 3 | RESULTS

#### 3.1 Respondent characteristics

All clients enrolled in *Max*ART, who initiated ART between January 2014 and October 2016 and were classified as LTFU were eligible for inclusion. From the two selected facilities, 145 clients were identified as LTFU: 81% (n = 118) were

Table 1. Outcome of contact tracing of the initial LTFU selection

LTFU client categories	Total (N=145)
Unable to contact	93 (64%)
Contacted	52 (36%)
Confirmed LTFU <sup>a</sup>	11 (21%)
Active on ART <sup>b</sup>	26 (50%)
(Self)Transferred Out	14 (27%)
Died	1 (2%)

<sup>&</sup>lt;sup>a</sup>Clients who had stopped ART for 90 or more days from the last clinic appointment date

aged 25 to 39 years, 58% (n = 84) were female, and 57% (n = 83) initiated ART with CD4 < 350 cells/mL. Of the 145 clients, 93 (64%) could not be reached when called because their mobile numbers were either not available, unknown to the person answering or the call was unanswered. Clients (or the treatment supporters of those that could not be reached) were called five times on average.

Fifty-two clients (36%) were contacted by phone. Of these, 26 were actively attending the facility but records had not been updated, 14 had transferred out from the ("mother") facility where the client initiated ART to a new one, and one person had died. During the call, eleven clients (three males and eight females) confirmed having discontinued ART (Table 1).

## 3.2 | The chain of events leading to discontinued ART

Initially most respondents reported mobility – relocating residence – as the main reason for discontinuing ART. Further probing revealed more complex circumstances: sub-optimal care from health care providers, severity and prolonged medication side effects, fear of stigma, lack of food and social networks were entwined in the process that leads to loss to follow-up. In-depth analysis of individual cases revealed several intersecting reasons that occurred consecutively, as a "chain of events" [22]. Thus, a series of contiguous and linked events led to their eventual discontinuation of ART. The individual accounts of step-by-step decision-making revealed the influence of multi-layered contexts and the importance of critical life-events.

## 3.3 | Mobility as the first step to discontinuation of treatment

For over half of the respondents, the first step in the chain of events towards stopping ART was relocation to another town or community far from the health facility where HIV treatment was obtained. Life events, such as caring for a loved-one residing in another area or changes in employment, often prompted relocation.

I went to Mankayane to look after my brother who was sick... I took the pills with me and left my card thinking that I would not stay long. But the pills were finished while I was still there. (Female client, LTFU 05).

I had just started working after a long time without a job. Continuing with the pills would have meant I had to ask for a day off every month to go to the clinic. I have children to take care of... My husband died four years ago so I am their [children] only provider. I feared that if I continued with the pills my employer would fire me... I couldn't risk that... Also I quit treatment because I tested when I was still staying at home which is at [name of residential area]. When I found a job in Mbabane, it became too far for me to fetch the tablets at [name of health facility]. (Female client, LTFU 03).

As the previous quote illustrates, the mobility that leads to loss to follow up is related to precarious social and economic living circumstances which led some respondents to choose (continuation of) employment over continuation of treatment. Economic motives were prominent in respondents' explanation of why they stayed away from their place of residence for prolonged periods of time. In some cases, the distance to the mother facility, or a clash in working hours at the facility and those of respondents' jobs made it difficult for clients to continue to access ART. Jobs involving travel, such as driving a taxi or employment far from home made accessing care more difficult. Often, however, mobility alone did not necessarily threaten continued treatment; rather it became a problem in the context of the organization of HIV care in the public health system.

#### 3.4 The health system response to mobility

An immediate consequence of mobility was that clients had to (re)gain access to care. Returning after temporary absence meant regaining access to one's previous clinic. Negative experiences with healthcare providers sometimes became intertwined in the process that led to discontinuing ART. A participant who relocated because of her brother's sickness describes:

I went to the nurses at the ART clinic with the pill container to ask them to at least give me a few pills and explained my situation. But they refused and told me they needed the card to dispense the pills and write on it. I even asked one of the lodgers to go with me to plead with the nurses but they refused. Because I did not have money to go to [the facility where she gets ART] I stopped. After my brother's discharge from hospital I went back to my clinic, but they reprimanded me for skipping the pills for three weeks...The lady who wears maroon told me I was not serious and I am wasting their time. She took me to the counsellor who also shouted at me... So I told myself I will not go back there. (Female client, LTFU 05).

Perceived lack of attention or empathy from healthcare providers came to the fore in several accounts. These respondents mentioned that they decided to stop ART after they could not get the assistance they sought. Respondents reported being spoken to "roughly", "shouted at" or feeling that the clinic staff "didn't care". Such harsh treatment left clients feeling hurt, angry, and humiliated. One such client abandoned care due to poor care for her child by the HCWs, when she sought their assistance:

<sup>&</sup>lt;sup>b</sup>Clients who reported that they were still on ART at the same facility where they were reported as LFTU

My child had problems but they did not want to listen, instead they shouted at me. (Female client, LTFU 09).

Others did not like that they had to "retell their story" to new HCW:

I have thought about going there [nearest facility in the new residence] but eish, you know I thought now I have to retell my story again. So I thought, eish, I will see as time goes on...That was six months ago. (Female client, LTFU, 09).

For some respondents, the experience of side-effects became intertwined in the process of stopping treatment. As part of initiating ART, clients were informed about the possibility of side effects and assured that they will resolve over a few days or weeks. However, the experience of severe side effects coupled with a perceived lack of attention or empathy from HCWs resulted in some respondents stopping ART:

I was tired of taking [the tablets] because they also distorted my body shape. It became bad, I started to develop a hump at the back, and my belly was big... [HCWs] told me that the pills were the cause of that... I reported that the pills were giving me problems but they did not do anything about it. They kept telling me it will be better with time but it didn't. It's like they just didn't listen or care about me... So I stopped. I just stopped the pills. (Female client, LTFU 01).

The complex processes resulting in clients abandoning ART also influenced their decisions to re-engage in HIV care. Fear of reprimand by HCWs was a prime reason for respondents' reluctance to re-engage in care.

## 3.5 | Economic and social circumstances underlying mobility

Uncertain economic circumstances and unemployment led respondents to seek jobs elsewhere and to food insecurity, which was compounded by the feelings of hunger respondents associated with ART:

You know my sister, these pills are very good but, ey, they demand that you eat a lot. Because I am not employed and do not have money to buy food I decided to stop taking them. Maybe I will go back when I get a job and are able to buy food. (Male client, LTFU 07).

Others mentioned that ART made them fall ill, which meant lost income or unemployment:

When I started taking the pills I experienced abdominal pains and diarrhoea. They also caused bile... I was very sick and bedridden... I left my workplace to go home because of the sickness caused by the pills... I decided to stop them... I feel ok now [after stopping the ARVs], so I see no reason for returning to start the treatment again, especially because they made me very sick when I took them. (Male client, LTFU 10).

Mobility also disrupted the stability of or accessibility to support networks. A treatment supporter described how the influence of her granddaughter's peers led to her running away from home and abandoning treatment. For one respondent, whose job required him to spend weeks away from home, being abandoned by his wife, who acted as his treatment supporter, led to him stopping HIV treatment:

When she left I had no one [to fetch the ARVs]... Okay, I missed my appointment but the tablets were still there. Then the tablets got finished and as time went by I just thought that there was nothing to do. Then I said let the will of God be done, if I die then I'll die... I reached a time that I gave up since I felt I am no longer a person in my family. They don't like me. I think if I can die maybe. I think I have two or three weeks still deliberating about this... So I am nothing at home so that is why I thought if only it was possible for God to take me, let him take me because I can't commit suicide since it is a sin... (Male client, LTFU 08)

For this man, the negative psychological impact of family troubles became intertwined in the chain of events that led to disengagement from care. But his story also highlights how harmonious social relations (e.g. a supportive partner) may mitigate or compensate for mobility related challenges to continuing antiretroviral treatment.

#### 3.6 Negative emotions as a cross-cutting theme

Psychological factors were mentioned by most participants, with negative emotions (e.g. anxiety, fear) shaping decisions about care. As mentioned, nurses' lack of understanding about the circumstances that caused clients' mobility and complicated adherence led to feelings of hurt and anger. Anticipated stigma also featured prominently: concerns about stigma made respondents reluctant to disclose their HIV-status and they sometimes felt continuing treatment could lead to unintentional disclosure. Anxieties about unintended disclosure were related to the risk of partner violence or abandonment, losing a job, or social marginalization and, for some, became an added reason for discontinuing ART. This was particularly the case for women who are economically and socially dependant on male partners:

I found a partner and I couldn't bring myself to tell him. I did not tell him in the beginning [when we met] so it became hard to continue taking the tablets because he would find out... So I thought what if he became violent, or leave me, something like that. So I decided not to tell him. (Female client, LTFU 01).

For some respondents, a positive health outcome combined with fear of stigma became the final reason to discontinue ART. Having lied to their partners about the pills they were taking while visibly sick, made it difficult to continue taking them when they looked well again. Rather than risking being "caught" by her partner, one respondent opted to stop taking treatment:

My partner could see that I was now alright. So, if I continued taking the pills how could I explain that? So I stopped... He will leave me if I tell him [about my HIV status]. (Female client, LTFU 06).

Mobility figured as a primary trigger in some narratives about loss to follow-up, but ultimately it was respondents' navigation of the precarious social, economic *and* medical land-scape that led to disengagement from care. In this chain of events, decisions were shaped by practical reasoning and emotional appraisals.

#### 4 | DISCUSSION

The interviews with LTFU clients in Swaziland reveal how mobility can trigger a chain of events that leads to disengagement from care. In the process that leads to loss to follow-up, mobility is often entwined with precarious employment, care delivery, interactions with health workers, lack of social support, anticipated stigma and ART-related side-effects, including the exacerbation of hunger.

Reasons for discontinuing ART have been typically described as complex [22,23]. The thematic analysis revealed similar reasons for disengagement from care to those described by Ware et al. who identified competing social and economic demands, violence, lack of family or community support, and dissatisfaction with care [22]. Several studies have identified HIV-related stigma as a barrier to accessing ART or retention in care [24,25]. Fear of violence and/or rejection by a partner is commonly reported as a barrier to accessing HIV care, particularly for women. Extensive research highlights the relationship between HIV status and intimate partner violence following disclosure by women [26-28], including in Swaziland [25,29]. In a similar way to stigma, violence can be anticipated or enacted. Across SSA, most women who disclose their HIV status report supportive reactions from their partners, whereas a few experience partner violence and abandonment [30]. Similarly, in this study, no female respondents described violence; rather they feared that intentional or accidental disclosure of their HIV status would lead to violence. Other studies have also described fear of losing one's job because of HIV [31,32].

The narrative analysis revealed how a chain of events had triggered step-by-step their decisions to discontinue treatment. In this process, reasons became intertwined in complex and individualized ways. Respondents initially described relocation or mobility as their main reason, but closer scrutiny of their accounts shows that mobility resulted from complex individual navigations of precarious and specific life circumstances and was often triggered by critical life-events. The death of one's spouse, a brother's serious illness, the marriage breakup of a migrant labourer, or the lack of freedom to refuse mobile employment or a job far from home, are experienced and presented as highly individualized events pertinent to the micro scale of everyday life.

In Swaziland, these events typify the insecure living conditions for the majority and are intrinsically linked with macrolevel processes. Respondents who explained their financial predicament and the difficult choices about balancing their responsibility to their own health and caring for others, are victims of a precarious economy affected by the HIV epidemic.

Health policies that steer the procedures for patient transfers from one clinic to another are meso-level structural processes that do not align with the mobile lives of Swazis. Respondents' negative appraisals of their treatment by health staff, and the need to retell their illness trajectories over and

over again speak of health providers' frustrations and challenges with structural health system issues – specimen transportation and additional administrative tasks of test and treat – beyond their control. This also pertains to the difficulties of healthcare staff to respond to clients' need for food and medication without the side-effects that undermine their quality of life.

In resource-limited, high-HIV-prevalence settings, the influence of contextually embedded everyday practices and structures means that engagement with HIV services must be considered in relation to other social practices [23]. Ultimately, for Swazi clients, chains of events that complicate such engagement take shape in a context of dynamic and emotionally charged relationships with partners, families, peers and colleagues. Fear of stigma, violence and/or being rejected, and psychological distress related to loss can be the proverbial straw that breaks the camel's back.

The findings suggest that policy interventions to prevent loss to follow-up should be comprehensive, multifaceted, and address the organization of healthcare as well as be tailored to the situations and needs of individual clients. At health system level, policy makers and implementation scientists should pay attention to how referral systems and inter-facility communications can be improved to support healthcare workers to provide care to mobile clients who need temporarily access to HIV care in different localities. Interventions to prevent disengagement from care must consider the varied, complex and processual nature of factors involved in individuals' care trajectories, and recognize the key issues around re-engaging with care.

Because such trajectories are largely unconnected to clients' specific characteristics, but are rather linked to specific occurrences in their lives, healthcare providers must recognize such events as risks to disengagement from care, understand how they accumulate, and be able to effectively intervene. Healthcare providers need (knowledge, attitude and skills) training to help clients overcome difficulties to staying in treatment or to facilitate re-engagement in care of those who temporarily abandon treatment. Health staff must be informed of the social and economic challenges that LTFU clients face, plus their reasons for stopping ART. They also need an in-depth understanding of clients' efforts to re-engage with care. Training is also needed to strengthen healthcare workers' ability to reflect on their feelings (of disappointment, failure, anger, prejudice) when faced with clients who (temporarily) abandon treatment, to avoid these (understandable) feelings becoming a factor in the process leading to clients discontinuing treatment.

Finally, healthcare workers must be trained to identify signs of disengagement from care and to intervene at any point in the chain of events to help clients re-engage with care. A concise and practical (decision-making) tool that would help staff to attend more closely to clients' dilemmas and needs and identify solutions is needed. Mobility, as a potential starting point for a chain of events that leads to loss to follow-up, should be a focus in this instrument.

#### 4.1 Strengths and limitations

This is the first study in Swaziland to explore – from clients' perspectives – reasons for discontinuation of ART under test and treat in a context of high mobility. Combining in-depth thematic and narrative analysis highlighted the complex

sequential intertwinements of reasons for disengagement. Using qualitative methods, this study revealed the importance of social and psychological ramifications of critical life-events and structural issues often overlooked in quantitative studies of decision-making. More interviews are needed to establish typical first events and chains of events that lead to disengagement from care. The data reflects the perspectives of clients who had disengaged from care and additional interviews with HCWs, family members, and employers would have been beneficial. A systematic comparison with the narratives from people confronted by similar events and circumstances while continuing treatment would foster understanding of resilience to disengagement from care. Another limitation is that respondents were enrolled in a large intervention study with quality and ethics of care potentially superior to the norm in other facilities.

#### **5** | CONCLUSIONS

In Swaziland, there have been remarkable achievements in terms of the rates of HIV testing and ART initiation. Disengagement from HIV care however threatens this success. Swazi clients' reasons for abandoning ART are a complex, inextricably interwoven chain of events rather than a single occurrence. During these processes, clients take action to navigate the challenges they face before deciding to stop ART. Mobility – temporary or permanent relocation far from the health facility where HIV treatment was obtained – is often the first event in such a process. Mobility commonly results from complex deliberations weighing economic, social and other circumstances, and becomes a problem because the health system poorly caters to the reality of people's mobile lives.

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#### COMPETING INTERESTS

The authors declare that they have no competing interests.

#### **AUTHORS' CONTRIBUTIONS**

EV and RR conceived the sub-study; FS and SK designed the sub-study protocol; NS and NM conducted the interviews under the supervision of FS and SK; FS conducted data analysis in consultation with SK, EV and RR. FS, EV and RR drafted the manuscript; CL, DS, BC and SK critically revised the manuscript for intellectual content. All authors read and approved the final manuscript.

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#### RESEARCH ARTICLE

## HIV testing history and access to treatment among migrants living with HIV in Europe

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#### Abstract

**Introduction:** Migrants are overrepresented in the European HIV epidemic. We aimed to understand the barriers and facilitators to HIV testing and current treatment and healthcare needs of migrants living with HIV in Europe.

**Methods:** A cross-sectional study was conducted in 57 HIV clinics in nine countries (Belgium, Germany, Greece, Italy, The Netherlands, Portugal, Spain, Switzerland and United Kingdom), July 2013 to July 2015. HIV-positive patients were eligible for inclusion if they were as follows: 18 years or older; foreign-born residents and diagnosed within five years of recruitment. Questionnaires were completed electronically in one of 15 languages and linked to clinical records. Primary outcomes were access to primary care and previous negative HIV test. Data were analysed using random effects logistic regression. Outcomes of interest are presented for women, heterosexual men and gay/bisexual men.

Results: A total of 2093 respondents (658 women, 446 heterosexual men and 989 gay/bisexual men) were included. The prevalence of a previous negative HIV test was 46.7%, 43.4% and 82.0% for women, heterosexual and gay/bisexual men respectively. In multivariable analysis previous testing was positively associated with: receipt of post-migration antenatal care among women, permanent residency among heterosexual men and identifying as gay rather than bisexual among gay/bisexual men. Access to primary care was found to be high (>83%) in all groups and was strongly associated with country of residence. Late diagnosis was common for women and heterosexual men (60.8% and 67.1%, respectively) despite utilization of health services prior to diagnosis. Across all groups almost three-quarters of people on antiretrovirals had an HIV viral load <50 copies/mL.

**Conclusions:** Migrants access healthcare in Europe and while many migrants had previously tested for HIV, that they went on to test positive at a later date suggests that opportunities for HIV prevention are being missed. Expansion of testing beyond sexual health and antenatal settings is still required and testing opportunities should be linked with combination prevention measures such as access to PrEP and treatment as prevention.

Keywords: HIV; migrants; HIV serodiagnosis; primary healthcare; health services accessibility

Additional Supporting Information may be found online in the Supporting information tab for this article.

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#### 1 | INTRODUCTION

The HIV epidemic in Europe is characterized by a disproportionate number of infections among migrants. Although foreign citizens only made up 7% of the population of the European Union (EU) in 2014 [1], an estimated 37% of new HIV diagnoses in the EU/European Economic Area (EEA) in 2015 were among migrants [2]. Late diagnosis is a feature of the HIV epidemic among migrants; European surveillance data indicate

that some migrant groups are more than twice as likely to be diagnosed late than nonmigrants [3].

There are several reasons why migrants are at increased risk of HIV in Europe. Migrants from countries with a generalized HIV epidemic obviously have an increased risk of acquiring HIV before migration, but this risk remains as individuals migrate into, and become sexually active within, migrant communities where the HIV prevalence is higher than the receiving country population [4]. Estimates of post-migration HIV

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acquisition are as high as 62% in some populations [5]. In addition, social inequalities associated with migration (e.g. low income, unemployment, poor housing) [6], HIV-related stigma and discrimination, and changes in sexual behaviour may increase the risk of late diagnosis or HIV infection [7-10].

Controlling the HIV epidemic within Europe is dependent on ensuring that migrants have prompt access to HIV testing, antiretroviral therapy (ART) and ongoing healthcare [5,11,12]. Migrant populations are, of course, heterogeneous making it difficult for policymakers and HIV prevention specialists to provide interventions and services targeted at specific migrant sub-groups. Often research in this area focuses on one migrant population (e.g. Central and Eastern Europeans [13]) or migrants in one country [14]. Most of the available research has been conducted with heterosexual migrants from Sub-Saharan Africa [15]. While this reflects the global HIV epidemic, the heterogeneity of migrants living with HIV in Europe [3] rationalizes researching other population groups, particularly migrant gay and bisexual men. In this study we present the results of the first collaborative European survey examining the key socio-demographic, behavioural and structural factors associated with HIV testing and primary care utilization among migrants living with HIV in Europe. We examine how these factors differ across gender-related group and present recommendations for targeted health promotion and intervention development.

#### 2 | METHODS

#### 2.1 Study design

Full details of the methods used in the aMASE (advancing Migrant Access to health Services in Europe) Study have been described elsewhere [16]. A convenience sample was recruited within 57 clinics across the EuroCoord European Network of Excellence on HIV Research (www.eurocoord.net). Data collection took place in nine countries (Belgium, Germany, Greece, Italy, The Netherlands, Portugal, Spain, Switzerland and the United Kingdom) between July 2013 and July 2015. Patients were eligible for inclusion if they were (1) HIV positive, (2) aged 18 years and over, (3) foreign-born and resident in the country of recruitment for six months or more, (4) diagnosed within five years of the study date and (5) able to complete, either alone or supported, a computer-assisted self or personal interview in any one of the 15 languages available (Amharic, Arabic, Dutch, English, French, German, Greek, Italian, Polish, Portuguese, Russian, Turkish, Tigrinya, Spanish and Somali). In Switzerland, migrants from neighbouring Austria, France, Germany and Italy were excluded.

Eligible participants were identified through clinic records and asked to participate by clinicians or recruitment researchers. Most participants completed within-questionnaire "tick box" informed consent; participants in Belgium, Switzerland, Greece and Germany completed additional separate consent forms required by local research ethics committees.

The survey instrument was developed by an expert panel made up of experienced epidemiologists and community representatives and covered: socio-demographic characteristics (including migration history); sexual and HIV risk behaviour; health service use and experiences of living with HIV. Questionnaires were matched to clinical records (CD4 cell counts,

viral loads, viral clades, HIV testing history, co-infections, AIDS-defining illnesses, treatment initiation) using a unique study number.

The target sample size was 2000 participants (1000 men and 1000 women) from all clinics. Participants were recruited from a minimum of two clinics in each of the nine countries, with each clinic forming a discrete cluster. We assumed the intra-cluster correlation would be relatively weak (e.g. 0.005), at least after adjustment for country of residence and other variables selected into our statistical regression models. Assuming an average cluster size of 50 participants, the design effect for the study is 1.25 and hence an overall effective sample size of approximately 1600. With this effective sample size outcomes within each gender are estimated to be within 3.5% across Europe based on a 95% confidence interval, and to be within 10% for each country (even if the assumed underlying prevalence is 50%, which would minimize precision).

#### 2.2 Ethics

Ethical approval was obtained separately in each participating country. See Additional file 1 for full details.

#### 2.3 Outcomes and variables of interest

The primary outcome measures were access to primary care and a previous negative HIV test. Primary care represents integration into healthcare services, beyond attendance at HIV clinics. Access to primary care was defined as possession of a health card (Italy/Spain), regular follow up with the Infectious Diseases Unit (Greece) or registration with a general practitioner (GP) or family doctor (all other countries) at the time of survey completion. Participants were asked if they had ever had a negative HIV test (year and country) and where possible missing self-reported data were replaced by data from clinical records. Previous HIV testing was used as a marker of access to HIV prevention opportunities (e.g. how well messages promoting frequent HIV testing are reaching migrants before diagnosis) and analysis of this variable was restricted to those diagnosed post-migration.

Data are presented by three gender-related groups (women, heterosexual men and gay/bisexual men) as it was assumed that the three groups were all likely to be different with regard to HIV testing history and sexual behaviour. Individuals who identified as transgender were assumed to form a distinct group and were subsequently excluded from analysis due to low numbers.

Participants were grouped according to region of birth based on United Nations Statistics Division geographic regions and sub-regions classifications [17].

Individuals were classified as diagnosed "late" if they were diagnosed with a CD4 cell count <350 cells/mm<sup>3</sup> (<200 cells/mm<sup>3</sup> for "very late") and without serological evidence (e.g. avidity testing) of recent seroconversion.

#### 2.4 | Statistical analysis

We undertook statistical analysis using Stata (version 14.1). We accounted for the clustering of participants at clinic and the country level by declaring countries to be strata and

clinics to be primary sampling units using the complex survey functions. In descriptive analysis proportions were compared using a design-based chi-square equivalent test and linear regression used to compare means.

Associations between the primary outcomes and socio-demographic/behavioural factors were analysed using logistic regression, with a random effect for clinics. Initial analysis showed that access to primary care was unexpectedly very high in some countries for some gender-related groups (e.g. 100% of women in Italy and The Netherlands). Consequently, for each group, associations are only explored in countries where less than 95% of respondents reported access to primary care.

Factors were first analysed individually (see tables in the results section for variables included in univariate analysis) and those factors found to have significant associations with the primary outcomes ( $\alpha$ =0.05) were incorporated into a regression model using backwards selection from a hierarchy of groups. That is, covariates were arranged into logical groupings (e.g. socioeconomic, sexual behaviour etcetera) with factors considered least important tested for possible removal first. Covariate groupings not significant at the 5% level were discarded (see Table 1). In all models, a priori factors (country of residence, age, region of birth, years since migration, immigration status) were included. Sensitivity analyses were conducted (1) including years since HIV diagnosis as a predefined factor in the models and (2) excluding respondents who had migrated from another country in Europe (if that was not the country of birth). Associations are reported as odds ratios (OR) and adjusted OR (aOR) with 95% confidence intervals. Tests for interaction were performed.

#### 3 | RESULTS

Of 3794 patients registered on enrolment logs, 3251 eligible HIV-positive migrants were invited to participate and 2209 (68%) accepted and completed the survey. Participation was higher in men (75%) than in women (64%, p < 0.001), and decreased with age (83% in people aged 18 to 24 years and 62% in those aged over 64 years, p = 0.04). Those born in Oceania and North America (Rest of World) were most likely to participate compared with those born in Africa or Europe (91.3% vs. 62.4% vs. 64.4%, respectively, p < 0.001).

In total, 2117 respondents (658 women, 1435 men and 24 transgender) with matching clinical records were available for analysis. The 24 transgender participants were excluded from analysis leaving a final sample of 2093 subjects. Respondents were from 152 different countries: 35.1% Africa; 31.6% Latin America & Caribbean and 23.0% Europe (Table 2. See Figures S1 and S2 in Additional file 2 for full data). A large proportion of the sample were men (1435/2093; 68.6%) of which 68.9% (989/1435) were men who described their sexual orientation as gay or bisexual; there were differences between the three gender-related groups in nearly all demographic characteristics (Table 2). The majority of women and heterosexual men were born in Africa compared with gay/bisexual men (63.1% vs. 57.0% vs. 7.4%, p < 0.001) who were more likely to have been born in Latin America/Caribbean (18.2% vs. 16.1% vs. 46.1%, p < 0.001). Median times in Current Country of Residence (CCOR) were 7, 10 and 9 years for women, heterosexual men and gay men respectively. Other notable socio-demographic differences were in education level, employment status, income and immigration status with

Table 1. Covariate groupings of factors significant in univariate analysis for each primary outcome, tested in multivariate analysis in decreasing order of importance (1 = most important)

#### Previous negative testing for HIV

#### Women

- 1. Country of residence, Age, Region of birth, Years in current country of residence, Immigration status<sup>a</sup>
- 2. Antenatal service attendance in the 2 years prior to diagnosis\*children
- 3. Number of lifetime sexual partners & Diagnosed with STI before HIV diagnosis
- 4. Education level

#### Heterosexual men

- 1. Country of residence, Age, Region of birth, Years in current country of residence, Immigration status<sup>a</sup>
- 2. Number of children cared for in the home

#### Gay/Bisexual men

- 1. Country of residence, Age, Region of birth, Years in current country of residence, Immigration status<sup>a</sup>
- 2. Number of sexual partners in current country of residence
- 3. Diagnosed with an STI before HIV diagnosis
- 4. Sexual orientation
- 5. Employment & Income

#### Access to primary care

- Country of residence, Age, Region of birth, Years in current country of residence. Immigration status<sup>a</sup>
- 2. Employment
- 3. Any health service attendance in two years before diagnosis
- 1. Country of residence, Age, Region of birth, Years in current country of residence, Immigration status<sup>a</sup>
- 2. Employment
- 3. Experience of hunger in past 4 weeks
- Country of residence, Age, Region of birth, Years in current country of residence, Immigration status<sup>a</sup>
- 2. Currently on ART
- 3. Any health service attendance in 2 years before diagnosis
- 4. Employment & Income

<sup>&</sup>lt;sup>a</sup>Preselected covariates included in all models. Groupings and order of importance based on a priori assumptions informed by expert insight.

Table 2. Socio-demographic characteristics of survey respondents, by gender (men separated by sexual orientation)

	Women	Heterosexual men	Gay/bisexual men	p value
Total number of respondents n (row %)	658 (31.4)	446 (21.3)	989 (47.3)	
Median age in years (IQR) <sup>a</sup>	37 (30.9 to 44.6)	41 (34.3 to 48.4)	35 (29.4 to 41.6)	
Region of birth <sup>a</sup>				< 0.001
Africa	415 (63.1)	254 (57.0)	73 (7.4)	
Latin America/Caribbean	120 (18.2)	72 (16.1)	456 (46.1)	
Rest of World	32 (4.9)	39 (8.7)	146 (14.8)	
Europe	91 (13.8)	81 (18.2)	314 (31.7)	
Mean age in years at migration (SD)	29.3 (9.9)	30.1 (10.0)	26.3 (8.7)	< 0.001
Median years in CCOR (IQR) <sup>a</sup>	7 (4.1 to 12.7)	10 (6.1 to 15.0)	9 (4.8 to 13.9)	
Ethnicity (n = $1881$ ) <sup>b</sup>				< 0.001
Black African/Caribbean	334 (59.5)	205 (51.8)	51 (5.5)	
White European	92 (16.4)	69 (17.4)	296 (32.0)	
Latin American/Hispanic	39 (7.0)	26 (6.6)	177 (19.2)	
Mixed Ethnicity	44 (7.8)	30 (7.6)	204 (22.1)	
Other	52 (9.3)	66 (16.7)	196 (21.2)	
Education: upper secondary or more <sup>a</sup>	322 (48.9)	228 (51.1)	802 (81.1)	< 0.001
Employment status: working full/part time <sup>a</sup>	276 (41.9)	217 (48.7)	666 (67.3)	< 0.001
Relationship status <sup>a</sup>				0.005
Married/Cohabitating	273 (41.5)	195 (43.7)	352 (35.6)	
Single	302 (45.9)	170 (38.1)	513 (51.9)	
Living apart relationship/marriage	83 (12.6)	81 (18.2)	124 (12.5)	
Has children <sup>a</sup>	474 (72.6)	301 (69.2)	97 (9.9)	< 0.001
Religion of those who attend services $(n = 1165)^a$				< 0.001
Christian (All denominations)	428 (85.8)	235 (76.1)	306 (85.7)	
Muslim	48 (9.6)	67 (21.7)	13 (3.6)	
Other	23 (4.6)	7 (2.3)	38 (10.6)	
Sexual orientation (n = $2076$ ) <sup>a</sup>				< 0.001
Gay/Lesbian	12 (1.8)	0 (0.0)	843 (85.2)	
Heterosexual	616 (94.5)	417 (95.9)	0 (0.0)	
Bisexual	14 (2.1)	0 (0.0)	146 (14.8)	
Other	10 (1.5)	18 (4.1)	0 (0.0)	
Monthly income compared to national minimum wage $(n = 1975)^a$				< 0.001
More or a lot more	65 (10.6)	60 (14.3)	430 (45.6)	
About the same	82 (13.4)	70 (16.7)	167 (17.7)	
Less than minimum wage	215 (35.0)	126 (30.1)	189 (20.1)	
Own wage not earned	236 (38.4)	148 (35.3)	140 (14.7)	
Not known	16 (2.6)	15 (3.6)	16 (1.7)	
Moderate/severe household hunger in past 4 weeks $(n = 2006)^a$	136 (21.8)	112 (26.8)	124 (12.8)	< 0.001
Immigration status $(n = 2078)^a$	, , ,	, , , , ,	, , , ,	< 0.001
Permanent residency permit	335 (51.5)	258 (58.4)	777 (78.8)	
Temporary residency permit	238 (36.6)	147 (33.3)	152 (15.4)	
Asylum seeker/Refugee status	77 (11.8)	37 (8.4)	57 (5.8)	
Unknown	58 (8.9)	23 (2.2)	48 (4.9)	
Travelled back to country of birth in past year	191 (29.0)	133 (29.8)	497 (50.3)	<0.001

Data are n (%), median (Inter-quartile range) or mean (Standard Deviation). N = 2093 unless otherwise stated.

gay/bisexual men more likely to report paid work, higher earnings, higher levels of education and more than three-quarters (78.8%) reporting permanent residency compared with 51.5% of women and 58.4% of heterosexual men (Table 2).

#### 3.1 Access to testing and care pre-diagnosis

Table 3 shows HIV testing history and clinical characteristics of respondents at the time of diagnosis. Late (or very late)

<sup>&</sup>lt;sup>a</sup>Tested as an independent predictor in univariate analysis for both outcomes.

<sup>&</sup>lt;sup>b</sup>Excludes Portugal due to restrictions on data collection. CCOR=Current Country of Residence.

Table 3. Characteristics of survey respondents by gender (men separated by sexual orientation) at time of diagnosis

	Women	Heterosexual men	Gay/bisexual men
Median age in years at diagnosis (IQR)	34 (28.4 to 41.8)	38 (31.7 to 45.7)	34 (28.4 to 41.8)
Median CD4 cell count at diagnosis (IQR) (n = 15) <sup>a</sup>	277 (124 to 438)	240 (85 to 409)	450 (276 to 639)
Late diagnosis (n = 1815) <sup>a,b,c</sup>			
Diagnosed <350 cells mm <sup>3</sup>	293 (50.0)	227 (56.9)	248 (29.8)
Diagnosed <200 cells mm <sup>3</sup>	173 (29.5)	148 (37.1)	110 (13.3)
Median years between migration to CCOR and diagnosis (n = 1859) <sup>a</sup>	5 (1 to 10)	8 (3 to 13)	7 (3 to 12)
Diagnosed in CCOR (n = 2081) <sup>c</sup>	598 (91.7)	416 (93.9)	864 (87.6)
AIDS defining illness within 3 months of diagnosis (n = 1997)	101 (16.0)	86 (20.5)	63 (6.7)
<1 year between negative test and diagnosis (n = 1315)	21 (6.8)	18 (9.5)	181 (22.2)
Attended health services in the 2 years prior to diagnosis (n = 1878) <sup>a,c</sup>	423 (70.7)	310 (74.5)	717 (83.0)
Can recall mention of HIV testing at health service before	105 (24.8)	81 (26.3)	279 (38.9)
diagnosis (n = 1448) <sup>a,c</sup>			
Place where offered HIV test before diagnosis <sup>a</sup>			
Antenatal (n = 55)	26 (49)	_	_
Inpatient (n = 255)	24 (29.6)	13 (22.4)	24 (27.9)
Emergency (n = $322$ )	5 (5.7)	5 (6.9)	13 (8.0)
Sexual health clinic or HIV testing clinic (n = 257)	14 (66.7)	16 (69.6)	156 (73.2)
Outpatient (n = 317)	15 (15.2)	15 (23.8)	35 (22.6)
GP/family doctor (n = 690)	23 (11.4)	32 (21.3)	97 (28.6)
Other services ( $n = 143$ )	14 (22.6)	9 (33.3)	13 (24.1)
Place of diagnosis $(n = 1878)^{a,c}$			
Antenatal service	74 (12.4)	3 (0.7)	3 (0.3)
Hospital service, e.g. Emergency/Inpatient/Outpatient	240 (40.1)	196 (47.2)	171 (19.8)
Sexual health clinic or HIV testing clinic	75 (12.5)	66 (15.9)	376 (43.5)
GP/Family Doctor	105 (17.5)	95 (22.9)	201 (23.3)
Private clinic	17 (2.8)	7 (1.7)	43 (5.0)
Other	88 (14.7)	48 (11.6)	70 (8.1)
Tested because unwell/health problems <sup>c</sup>	261 (39.7)	230 (51.6)	256 (25.9)
Tested because of perceived risk <sup>c</sup>	128 (19.5)	77 (17.3)	384 (38.8)
Previous self-reported negative HIV test (n = 2028) <sup>d</sup>	294 (46.7)	183 (43.4)	801 (82.0)
Country of previous negative test (n = 1258)			
Current country of residence	128 (44.3)	95 (54.0)	524 (66.1)
Country of birth	145 (50.2)	67 (38.1)	218 (27.5)
Other country	16 (5.5)	14 (8.0)	51 (6.4)

Data are n (%), median (Inter-quartile range) or mean (Standard Deviation). CCOR=Current Country of Residence. N = 2093 unless otherwise stated.

HIV diagnosis was a feature in all groups (50.0% of women, 56.9% of heterosexual men and 29.8% of gay/bisexual men were diagnosed late); most respondents were diagnosed postmigration, with median times to diagnosis five, eight and seven years for women, heterosexual men and gay men respectively (Table 3). Health service attendance in the two years prior to diagnosis was high (>70%) in all groups but less than a quarter of women, 26% of heterosexual men and 38.9% of gay/bisexual men recalled HIV testing being mentioned/discussed at that time. Of those who had visited a GP before being diagnosed, only 11.4% of women, 21.0% of men and 28.6% of gay/bisexual men recalled being offered an HIV test. Recollections of provider-initiated HIV test discussions in sexual health

clinics were higher: 66% of women, 69.6% of heterosexual men and 73.2% of gay/bisexual men. Less than half of women recalled being offered a test in antenatal care (Table 3).

There were high rates (82.8%) of previous negative testing among migrant gay/bisexual men, but less than half of women and heterosexual men (46.9% and 43.9%, respectively) reported ever having had a negative test (Table 3).

Among women, those who received antenatal care in CCOR (post-migration) were three times as likely to have had a previous negative test (aOR 3.21 95% CI 1.55 to 6.66) than parous women who had not received antenatal care post-migration (Table 4). Multivariable analysis among heterosexual men found previous negative testing was significantly

<sup>&</sup>lt;sup>a</sup>Individuals diagnosed in current country of residence only.

<sup>&</sup>lt;sup>b</sup>Individuals diagnosed with serological evidence of seroconversion (e.g. avidity testing) excluded.

<sup>&</sup>lt;sup>c</sup>Tested as an independent predictor in univariate analysis.

<sup>&</sup>lt;sup>d</sup>Data missing from self-report supplemented from clinic records.

Table 4. Factors associated with self-reported previous HIV-negative test<sup>a</sup>, among women, heterosexual men and gay or bisexual men living with diagnosed HIV post-migration and attending HIV clinics in Europe

	% (n/N)	OR	AOR	95% CI	p value
Women (N = 565)					
Current country of residence (CCOR)					0.233
Belgium	53.8 (50/93)	1.59	1.49	0.72 to 3.10	
Greece	29.5 (18/61)	0.57	0.68	0.30 to 1.53	
Germany	66.7 (6/9)	3.19	3.21	0.68 to 15.18	
Italy	26.1 (6/23)	0.48	0.59	0.19 to 1.86	
Netherlands	50.0 (10/20)	1.37	1.79	0.61 to 5.27	
Portugal	50.0 (38/76)	1.40	1.49	0.74 to 3.02	
Spain	42.3 (60/142)	1.00	1.00	_	
Switzerland	44.9 (22/49)	1.04	1.41	0.63 to 3.20	
United Kingdom	58.7 (54/92)	1.96	1.76	0.90 to 3.45	
Age					0.154
18 to 24	35.1 (13/37)	0.57	0.71	0.32 to 1.57	
25 to 34	49.5 (100/202)	1.00	1.00	_	
35 to 44	48.4 (90/186)	0.96	0.85	0.54 to 1.33	
45 to 54	48.5 (48/99)	0.93	0.81	0.47 to 1.41	
55+	31.7 (13/41)	0.47	0.36	0.16 to 0.80	
Region of birth					0.305
Africa	50.6 (176/348)	1.00	1.00	_	
Latin America/Caribbean	44.5 (49/110)	0.78	0.79	0.46 to 1.36	
Rest of World	28.0 (7/25)	0.38	0.42	0.15 to 1.17	
Europe	39.0 (32/82)	0.62	0.73	0.41 to 1.30	
Years resident in country	, ,				0.050
≤2	41.9 (18/43)	0.70	0.57	0.26 to 1.25	
3 to 5	38.0 (57/150)	0.56	0.48	0.28 to 0.82	
6 to 10	49.1 (80/163)	0.92	0.82	0.52 to 1.31	
>10	52.2 (109/209)	1.00	1.00	_	
Immigration status	, ,				0.327
Permanent residency	50.7 (151/298)	1.00	1.00	_	
Temporary residency	41.7 (70/168)	0.69	0.72	0.46 to 1.13	
Refugee/Asylum seeker/Unknown	43.4 (43/99)	0.76	0.77	0.44 to 1.32	
Has children	,				0.006
No children	44.7 (67/150)	1.04	1.00	0.64 to 1.54	
Has children, no antenatal care in CCOR	43.9 (161/367)	1.00	1.00	_	
Has children, received antenatal care in CCOR	75.0 (36/48)	3.88	3.21	1.55 to 6.66	
Heterosexual men (N = 379)	(**************************************				
Current country of residence (CCOR)					0.106
Belgium	57.1 (28/49)	1.78	2.51	1.14 to 5.52	
Greece	32.0 (16/50)	0.63	0.68	0.30 to 1.55	
Germany	25.0 (2/8)	0.44	0.43	0.08 to 2.42	
Italy <sup>b</sup>	0.0 (0/15)	_	_	_	
Netherlands	52.6 (10/19)	1.48	2.24	0.79 to 6.33	
Portugal	40.0 (16/40)	0.89	0.92	0.42 to 2.04	
Spain	42.9 (48/112)	1.00	1.00	_	
Switzerland	53.5 (23/43)	1.53	1.41	0.65 to 3.06	
United Kingdom	51.7 (30/58)	1.42	1.55	0.76 to 3.14	
Age (years)	(,,				0.092
18 to 24	30.0 (3/10)	0.39	0.36	0.08 to 1.56	
25 to 34	50.5 (47/93)	0.92	0.88	0.50 to 1.56	
35 to 44	50.7 (73/144)	1.00	1.00	-	
	39.4 (37/94)	0.65	0.58	0.33 to 1.00	
45 to 54	37.4 (37/94)	(),()	(), 1()	(7.33 ED LOG	

 Table 4. (Continued)

Region of birth Africa Latin America/Caribbean Rest of World	44.2 (91/206)				
Africa Latin America/Caribbean	44.2 (91/206)				0.578
		1.00	1.00	_	
Rest of World	48.4 (31/64)	1.26	1.32	0.69 to 2.52	
	38.2 (13/34)	0.82	1.10	0.48 to 2.54	
Europe	50.7 (38/75)	1.35	1.55	0.81 to 2.97	
Years resident in country	(**************************************				0.428
≤2	50.0 (5/10)	0.98	1.96	0.47 to 8.22	
3 to 5	45.5 (25/55)	0.90	1.25	0.60 to 2.60	
6 to 10	51.4 (56/109)	1.34	1.54	0.90 to 2.64	
>10	42.4 (87/205)	1.00	1.00	_	
Immigration status					0.013
Permanent residency	50.0 (117/234)	1.00	1.00	_	
Temporary residency	33.7 (29/86)	0.42	0.41	0.23 to 0.75	
Refugee/Asylum seeker/Unknown	45.8 (27/59)	0.80	0.55	0.27 to 1.15	
Gay or bisexual men (n = 780)	,				
Current country of residence					< 0.001
Belgium	83.1 (49/59)	1.13	0.65	0.27 to 1.60	
Greece	44.4 (20/45)	0.15	0.12	0.05 to 0.29	
Germany	50.0 (3/6)	0.26	0.17	0.02 to 1.28	
Italy <sup>b</sup>	0.0 (0/4)	1.00	1.00	-	
Netherlands	90.3 (56/62)	1.75	1.33	0.48 to 3.69	
Portugal	91.1 (41/45)	1.72	3.41	1.11 to 10.50	
Spain	83.8 (299/357)	1.00	1.00	_	
Switzerland	78.4 (29/37)	0.66	0.63	0.24 to 1.67	
United Kingdom	89.3 (151/169)	1.71	1.06	0.53 to 2.13	
Age (years)	07.0 (101, 107)	11, 1	1.00	0.00 to 2.10	0.045
18 to 24	70.6 (48/68)	0.54	0.43	0.22 to 0.85	
25 to 34	83.8 (269/321)	1.00	1.00	_	
35 to 44	83.6 (219/262)	0.99	0.90	0.54 to 1.51	
45 to 54	90.3 (93/103)	1.61	1.87	0.82 to 4.25	
55+	73.1 (19/26)	0.57	1.10	0.33 to 3.62	
Region of birth	(=., ==,				0.292
Africa	76.9 (40/52)	0.67	1.36	0.54 to 3.40	
Latin America/Caribbean	83.3 (319/383)	1.00	1.00	_	
Rest of World	81.3 (87/107)	0.84	1.17	0.55 to 2.51	
Europe	84.9 (202/238)	1.02	1.84	0.97 to 3.50	
Years resident in country	· ··· (===,===,				0.128
≤2	90.7 (39/43)	1.65	3.71	1.09 to 12.66	
3 to 5	80.3 (118/147)	0.87	1.79	0.90 to 3.53	
6 to 10	82.8 (212/256)	0.98	1.13	0.67 to 1.91	
>10	83.5 (279/334)	1.00	1.00	_	
Immigration status	(=: :, == :,				0.125
Permanent residency	85.4 (527/617)	1.00	1.00	_	
Temporary residency	78.1 (89/114)	0.63	0.72	0.38 to 1.37	
Refugee/Asylum seeker/Unknown	65.3 (32/49)	0.35	0.44	0.20 to 0.99	
Number of sexual partners in current country of resi					0.008
0 to 5	81.3 (109/134)	0.33	0.41	0.18 to 0.93	2.000
6 to 10	72.6 (61/84)	0.18	0.32	0.14 to 0.74	
11 to 20	81.4 (79/97)	0.33	0.41	0.18 to 0.93	
21 to 50	73.4 (94/128)	0.21	0.24	0.12 to 0.49	
51 to 100	86.0 (104/121)	0.46	0.46	0.21 to 1.02	
More than 100	93.1 (201/216)	1.00	1.00	0.21 (0 1.02	

Table 4. (Continued)

	% (n/N)	OR	AOR	95% CI	p value
Diagnosed with STI before HIV diagnosis					<0.001
No	75.2 (354/471)	1.00	1.00	_	
Yes	95.1 (294/309)	6.42	4.41	2.42 to 8.03	
Sexual orientation					0.002
Gay	85.4 (568/665)	1.00	1.00	_	
Bisexual	69.6 (80/115)	0.37	0.43	0.25 to 0.74	

OR, odds ratio; AOR, adjusted odds ratio; 95% CI, 95% confidence interval; ART, antiretroviral therapy; STI, sexually transmitted infection.

associated with immigration status, with those with temporary residency significantly less likely to have had a previous test than those with permanent residency (aOR 0.41 95% CI 0.23 to 0.75; Table 4) after adjusting for CCOR, age, region of birth and years since migration. Among gay/bisexual men, negative testing was significantly associated with: CCOR, age, total number of sexual partners in CCOR, previous diagnosis with a sexually transmitted infection and sexual orientation with bisexual men being less likely (aOR 0.43 95% CI 0.25 0.74) to have had a previous negative test than gay men (Table 4). Sensitivity analyses did not indicate that including the number of years since HIV diagnosis would improve the multivariable models and did not affect the associations of the other factors. Sensitivity analysis excluding respondents who had migrated from another country in Europe (n = 188) did not appreciably alter the findings.

#### 3.2 | Access to treatment and ongoing care

Most participants in all groups were on antiretroviral treatment and 77.2% of women, 75.9% of heterosexual men and 77.9% of gay/bisexual men on treatment had an undetectable viral load (<50 copies/mL: Table 5). Most of those not on treatment reported this was because of their doctor's advice or because they were newly diagnosed. Around a third of women (32.2%) had experienced difficulties with health services since migration, a third of whom cited long waiting times in clinics, 22% did not trust GP confidentiality while 19.9% said they were unclear of their legal rights to access care (Table 5). Slightly fewer men of either sexual orientation group reported difficulties overall. Among gay/bisexual men, long waiting times were a problem for 40.1% who reported difficulties, whereas 25.3% were unclear of their rights to access care. For heterosexual men who reported problems, language barriers presented difficulties for 27.7% and a quarter (25.3%) were unclear of their rights to access care.

Travel expenses and prescription costs presented additional barriers for those who funded this element of their care. The cost of prescriptions (for all medication, not just Antiretrovirals) resulted in delaying or forgoing medications for 8.3% of women, 8.8% of heterosexual men and 4.9% of gay/bisexual men. Around one in ten women (11.9%), 15.1% of heterosexual men and 6.9% of gay/bisexual men reported missing appointments due to travel costs (Table 5).

Access to primary care was varied across countries. In Greece, Germany, Italy, the Netherlands and United Kingdom

>95% of respondents in one or more gender-related group reported having a primary care physician or access to an infectious disease unit (Table 6). In multivariable analysis, access to primary care was associated with CCOR and immigration status in all three groups. In addition, years since migration and being on antiretroviral therapy remained significantly associated with access to primary care among gay/bi-sexual men.

There were no significant interactions between CCOR or country of birth and any of the factors in the models selected for any group (data not shown).

#### 4 DISCUSSION

This study provides valuable data about the barriers and facilitators to secondary HIV prevention and accessing primary care for different migrant groups living with HIV in Europe. In addition, we have shown that for migrant women and heterosexual men, structural factors related to child-bearing or immigration status have a strong association with access to HIV testing. For migrant gay/bisexual men barriers to testing are mainly related to sexual behavioural factors with bisexual men and those with fewer partners less likely to have a previous negative test. Access to primary care, an indicator of integration into health services, was found to be strongly associated with current country of residence in all groups and immigration status among women and gay/bisexual men.

#### 4.1 | Policy Implications

Our findings suggest that for migrant women and heterosexual men, interventions that target sexual behaviour or other individual-level lifestyle factors might not be particularly successful in increasing the uptake of HIV testing. Rather, interventions that aim to address structural barriers could achieve more in the effort to increase access to earlier and regular testing. Large numbers in each group had attended primary care in the two years prior to diagnosis, however, attendance was not associated with the probability of having a negative test before diagnosis, or was it associated with late diagnosis (data not shown). The low proportion of individuals offered an HIV test before diagnosis suggests that there are continued missed opportunities for HIV testing, particularly in primary care. Policies advocating opportunistic provider-initiated testing, as provided in antenatal services in much of Europe, have

<sup>&</sup>lt;sup>a</sup>After final model selection. All models adjusted for factors listed in the model.

<sup>&</sup>lt;sup>b</sup>Excluded from multivariable analysis because of perfect prediction (separation).

Table 5. HIV treatment characteristics of aMASE clinic survey respondents, by gender (men separated by sexual orientation)

	Women	Heterosexual men	Gay/bisexual men
Most recent CD4 cell count ≥350 cells mm3 (n = 2011)	494 (76.8)	282 (65.4)	814 (86.9)
Undetectable viral load (<50 copies/mL) (n = 1540) <sup>a</sup>	409 (77.2)	290 (75.9)	489 (77.9)
Currently not on HIV treatment (n = 2090) <sup>b</sup>	105 (16.0)	40 (9.0)	312 (31.6)
Reason not on HIV treatment ( $n = 457$ )			
Doctor's advice or newly diagnosed	90 (85.7)	33 (82.5)	276 (88.5)
High cost or otherwise inaccessible	3 (2.9)	0 (0.0)	15 (4.8)
Fear of side effects or other difficulties taking medication	9 (8.6)	5 (12.5)	25 (8.0)
Other reason	7 (6.7)	3 (7.5)	16 (5.1)
Access to primary care (n = 2076)	552 (85.1)	369 (83.5)	833 (84.6)
Government-funded HIV treatment and care $(n = 972)^{b,c}$	244 (78.2)	162 (78.6)	319 (70.3)
Experienced difficulties with health service in CCOR (n = 2093)	211 (32.3)	132 (29.9)	272 (27.7)
No GP/Health card/insurance (n = 628)	33 (15.3)	18 (13.1)	58 (20.9)
Unclear of rights to access medical care (n = 629)	43 (19.9)	35 (25.5)	70 (25.3)
Long waiting times for an appointment/in the clinic ( $n = 628$ )	72 (33.3)	29 (21.2)	111 (40.1)
Does not trust the GP confidentiality (n = 628)	48 (22.2)	31 (22.6)	37 (13.4)
Difficulty communicating with staff because of language differences (n = 628)	55 (25.5)	38 (27.7)	38 (13.7)
Difficulty negotiating healthcare system (e.g. finding GP, payment, travel) (n = 629)	22 (10.2)	13 (9.5)	31 (11.2)
Missed clinical appointments because of travel expenses (n = 2071)	77 (11.9)	66 (15.1)	68 (6.9)
Delayed/forwent medication because of prescription costs ( $n = 2078$ ) <sup>d</sup>	54 (8.3)	39 (8.8)	48 (4.9)

Data are n (%).CCOR, Current Country of Residence.

been successful in increasing HIV testing and diagnosing women at earlier stages of infection [18] and a similar approach could work in primary care. Previous studies have shown that the introduction of routine, rapid or point-of-care testing in primary care is feasible and acceptable, especially among migrant or black and minority ethnic communities [19-22]. In addition, there may still be missed opportunities for testing in antenatal care as less than half of those who attended recalled HIV being mentioned during their visit. It is possible that women were unaware of routine opt-out testing. However, as multivariable analysis indicated that previous negative testing was associated with post-migration antenatal care these findings are difficult to interpret.

Missed opportunities are also likely to shape the HIV epidemic among migrant gay and bisexual men. Findings from this study support others that suggest that health promotion specialists may wish to consider targeted HIV testing interventions with men who identify as bisexual or who have low numbers of sexual partners [23-26]. Although the vast majority of gay/bisexual men had previously tested negative for HIV, over half had seroconverted within two years of their last negative test. This suggests there remain unmet HIV prevention needs, particularly about safer sex and condom use in this group, as highlighted by other studies [23-27]. Policymakers might need to expedite access to biomedical interventions such as Pre-exposure Prophylaxis (PrEP) that have been shown to be highly effective in European contexts [28,29] for migrant MSM and focus combination prevention efforts on this group in an effort to reduce seroconversion. Incorporating migration status with transmission risk in national surveillance data will enhance the ability to monitor and address HIV prevention needs for migrant MSM. In this study, we have shown that the main barriers to accessing ongoing healthcare are similar to those expressed by patients living with other chronic conditions, for example, long waiting times and difficulties with appointments [30,31]. This is perhaps to be expected as the mechanisms of accessing care are well documented as barriers, particularly among migrants who have competing interests which deprioritize health concerns [10].

Immigration legislation differs across Europe and changes to health policy affecting migrants frequently occur [32,33]. While all countries in this survey currently provide free ART for at least some migrants, only the United Kingdom provides all migrants with free ART regardless of their immigration status (see OptTest for more details [33]). However, even in the United Kingdom such affordable healthcare does not extend to other health conditions, which may present challenges for migrants living with multimorbidities.

Within this survey a substantial proportion of respondents were not taking ART, possibly because the data from this study were collected before updated European HIV Treatment Guidelines recommended immediate ART initiation irrespective of CD4 count [34]. The impact of the new guidelines on the uptake of ART in this population cannot be known from this study and further research is needed to establish if there remains a substantial (16 to 31%) deficit in uptake of ART, particularly among migrant gay and bisexual men, and whether high treatment costs are a barrier to ART initiation or

<sup>&</sup>lt;sup>a</sup>Only those on antiretroviral therapy (ART).

<sup>&</sup>lt;sup>b</sup>Tested as an independent predictor in univariate analysis.

<sup>&</sup>lt;sup>c</sup>Excludes co-pays.

<sup>&</sup>lt;sup>d</sup>Includes medicines other than antiretroviral therapy.

Table 6. Factors associated with access to primary care<sup>a</sup> among women, heterosexual men and gay/bisexual men living with diagnosed HIV and attending HIV clinics in Europe

	% (n/N)	OR	AOR	95% CI	p value
Women (N = 409)					
Current country of residence					< 0.001
Belgium	81.5 (88/108)	0.38	0.42	0.17 to 1.04	
Greece <sup>b</sup>	98.5 (65/66)	_	_	_	
Germany <sup>b</sup>	80.0 (8/10)	_	_	_	
Italy <sup>b</sup>	100.0 (35/35)	_	_	_	
Netherlands <sup>b</sup>	100.0 (20/20)	_	_	_	
Portugal	54.8 (46/84)	0.10	0.09	0.04 to 0.21	
Spain	92.1 (140/152)	1.00	1.00	_	
Switzerland	66.2 (43/65)	0.17	0.22	0.09 to 0.56	
United Kingdom <sup>b</sup>	98.2 (107/109)	_	_	_	
Age (years)	,				0.129
18 to 24	71.4 (20/28)	0.69	0.47	0.17 to 1.28	
25 to 34	78.4 (120/153)	1.00	1.00	_	
35 to 44	80.0 (108/135)	1.10	1.04	0.54 to 1.98	
45 to 54	81.5 (53/65)	1.21	1.24	0.52 to 2.95	
55+	57.1 (16/28)	0.37	0.39	0.14 to 1.08	
Region of birth					0.420
Africa	74.5 (190/255)	1.00	1.00	_	0.120
Latin America/Caribbean	86.9 (86/99)	2.26	0.90	0.39 to 2.06	
Rest of World	61.5 (8/13)	0.55	0.35	0.09 to 1.34	
Europe	78.6 (33/42)	1.25	0.66	0.25 to 1.70	
Years resident in country	7 0.0 (00) 12)	1.20	0.00	0.23 to 1.70	0.252
≤2	62.8 (27/43)	0.26	0.40	0.14 to 1.12	0.232
3 to 5	71.7 (91/127)	0.39	0.45	0.20 to 1.03	
6 to 10	79.3 (88/111)	0.59	0.60	0.27 to 1.35	
>10	86.7 (111/128)	1.00	1.00	-	
Immigration status	00.7 (111/120)	1.00	1.00		0.028
Permanent residency	84.0 (178/212)	1.00	1.00	_	0.020
Temporary residency	68.1 (81/119)	0.41	0.41	0.22 to 0.79	
Refugee/Asylum seeker/Unknown	74.4 (58/78)	0.55	0.56	0.26 to 1.21	
Heterosexual men (N = 271)	7 1.1 (30/70)	0.55	0.50	0.20 to 1.21	
Current country of residence					0.004
Belgium	63.3 (38/60)	0.25	0.34	0.14 to 0.85	0.001
Greece <sup>b</sup>	96.3 (52/54)	-	-	-	
Germany <sup>b</sup>	100.0 (9/9)	_	_	_	
Italy <sup>b</sup>	100.0 (23/23)	_	_	_	
Netherlands <sup>b</sup>	90.5 (19/21)	_	_	_	
Portugal	72.1 (31/43)	0.37	0.24	0.09 to 0.61	
Spain	87.4 (104/119)	1.00	1.00	0.07 to 0.01	
Switzerland	65.3 (32/49)	0.27	0.22	0.09 to 0.56	
United Kingdom <sup>b</sup>	95.3 (61/64)	-	- -	-	
Age (years)	73.3 (01/04)	_	_	_	0.211
18 to 24	625 (5/0)	0.56	0.44	0.08 to 2.40	0.211
25 to 34	62.5 (5/8) 80.0 (56/70)	1.33	1.40	0.61 to 3.21	
35 to 44		1.33	1.40	0.01 (0 3.21	
45 to 54	75.0 (75/100)	0.77	0.56	0.26 to 1.22	
	69.7 (46/66)			0.26 to 1.22	
55+	85.2 (23/27)	1.92	1.72	0.49 to 6.04	

 Table 6. (Continued)

	% (n/N)	OR	AOR	95% CI	p value
Region of birth					0.572
Africa	68.9 (104/151)	1.00	1.00		
Latin America/Caribbean	83.3 (50/60)	2.26	1.27	0.52 to 3.09	
Rest of World	71.4 (10/14)	1.13	1.07	0.28 to 4.00	
Europe	89.1 (41/46)	3.71	2.18	0.72 to 6.57	
Years resident in country					0.879
≤2	64.3 (9/14)	0.38	1.11	0.28 to 4.45	
3 to 5	57.4 (27/47)	0.29	0.72	0.28 to 1.88	
6 to 10	77.4 (65/84)	0.72	0.87	0.39 to 1.95	
>10	82.5 (104/126)	1.00	1.00		
Immigration status					0.040
Permanent residency	84.9 (135/159)	1.00	1.00		
Temporary residency	67.7 (44/65)	0.26	0.40	0.18 to 0.88	
Refugee/Asylum seeker/Unknown	55.3 (26/47)	0.22	0.34	0.13 to 0.92	
Gay/bisexual men (N = 913)					
Current country of residence					< 0.001
Belgium	75.6 (65/86)	0.40	0.31	0.11 to 0.86	
Greece <sup>b</sup>	96.4 (53/55)	_	_	_	
Germany <sup>b</sup>	100.0 (12/12)	_	_	_	
Italy <sup>b</sup>	100.0 (5/5)	_	_	_	
Netherlands	94.9 (74/78)	2.38	1.62	0.43 to 6.12	
Portugal	52.9 (27/51)	0.14	0.06	0.02 to 0.16	
Spain	88.6 (365/412)	1.00	1.00	_	
Switzerland	59.0 (36/61)	0.19	0.08	0.03 to 0.21	
United Kingdom	87.1 (196/225)	0.87	0.55	0.24 to 1.26	
Age					0.334
18 to 24	72.6 (61/84)	0.66	0.69	0.36 to 1.30	
25 to 34	80.0 (308/385)	1.00	1.00	_	
35 to 44	86.0 (257/299)	1.53	1.03	0.62 to 1.70	
45 to 54	94.3 (115/122)	4.11	2.11	0.85 to 5.26	
55+	95.7 (22/23)	5.50	1.34	0.16 to 11.34	
Region of birth					0.255
Africa	83.3 (55/66)	1.06	2.36	0.95 to 5.88	
Latin America/Caribbean	82.4 (371/450)	1.00	1.00	_	
Rest of World	85.7 (114/133)	1.28	1.49	0.74 to 3.00	
Europe	84.5 (223/264)	1.16	1.13	0.63 to 2.01	
Years resident in country					< 0.001
≤2	59.8 (58/97)	0.15	0.17	0.09 to 0.35	
3 to 5	72.6 (127/175)	0.27	0.44	0.24 to 0.82	
6 to 10	89.6 (250/279)	0.89	1.21	0.66 to 2.22	
>10	90.6 (328/362)	1.00	1.00	_	
Immigration status					< 0.001
Permanent residency	88.0 (639/726)	1.00	1.00	-	
Temporary residency	70.2 (92/131)	0.33	0.48	0.28 to 0.85	
Refugee/Asylum seeker/Unknown	57.1 (32/56)	0.15	0.21	0.10 to 0.45	
Currently on ART					0.001
No	79.9 (231/289)	0.69	0.42	0.26 to 0.70	
Yes	85.3 (532/624)	1.00	1.00	_	

OR, odds ratio; AOR, adjusted odds ratio; 95% CI, 95% confidence interval; ART, antiretroviral therapy.

<sup>&</sup>lt;sup>a</sup>After final model selection.

<sup>&</sup>lt;sup>b</sup>Excluded from multivariable analysis because of perfect prediction (separation) or small numbers. All models adjusted for factors listed in the table.

adherence for migrants who are not entitled to free ART. To highlight the benefits of HIV treatment, clinicians and policy-makers should consider the enhanced promotion of campaigns such as "Undetectable = Untransmittable" to migrants have not received accurate and up-to-date information about the risks of sexual transmission of HIV for those successfully on ART [35.36].

Migration-specific barriers, such as language barriers and difficulties understanding the legal rights to accessing healthcare, presented a problem for 20 to 25% of participants who experienced difficulties, although this finding is likely to have been underestimated (see below). These barriers may present challenges to physicians providing complex ongoing HIV healthcare. For example, language barriers could lead to poor health literacy among patients and consequently impact on the initiation of—and adherence to—ART as well as potentially facilitating onward transmission [37]. While it is beyond the scope of this survey to ascertain whether uncertainty surrounding the legal rights to access care leads to poor clinic attendance or adherence, other studies have shown that fear of deportation has prevented individuals from seeking care [10]. In addition, as some healthcare providers seek to normalize HIV by shifting care aware from specialist services to general practice, this study presents a timely understanding of some of the potential barriers to such policies.

Finally, this study found that poverty may influence access to ongoing care, with a substantial proportion of all groups reporting missing clinic appointments due to travel expenses and delaying or foregoing medication due to prescription costs. Poverty was especially prevalent among heterosexual men with over 20% reporting moderate or severe household hunger in the past four weeks. Poverty is well recognized as being associated with poorer engagement in care [38-41]. While tackling the overall problem of economic inequality is beyond the capacity of service providers, these impediments to care need to be recognized and where possible support offered to help mitigate this barrier.

#### 4.2 | Limitations

This study is not without its limitations [16]. The clinics and the countries were not selected at random and as such this is a convenience sample and therefore some of the prevalence estimates may have been over- or underestimated. In particular, it is likely that access to primary care was overestimated in some countries, as by including "health cards" and "infectious disease units" in our definition of primary care we may not have been able to sufficiently distinguish between family doctors/GPs and specialist care for HIV; therefore, caution is urged when using these estimates in health service planning. The proportions of respondents experiencing difficulties accessing health services are likely to have been underestimated, as those who experienced the greatest difficulties would not have been available in clinic to be recruited to the survey. It was assumed that those without a previous negative HIV test had experienced barriers to HIV testing up until the point of diagnosis. It is possible that some individuals had tested for the first time immediately after being exposed to HIV risk. However, given that a large proportion of participants were diagnosed late, it is likely that this previous negative testing is a suitable proxy for access to HIV testing.

#### 5 | CONCLUSION

Migrants are accessing healthcare in Europe prior to HIV diagnosis. While many migrants had previously tested negative for HIV, missed opportunities for earlier diagnosis persist among all migrant groups. In gay and bisexual migrant men many of who initially tested HIV negative in the receiving country went on to acquire HIV at a later date. Interventions to further expand testing outside of sexual health and antenatal settings are still required and these opportunities should be linked with combination prevention measures such as access to PrEP and treatment as prevention.

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#### **COMPETING INTERESTS**

The authors of this manuscript have no competing interests to declare.

#### **AUTHORS' CONTRIBUTIONS**

JDA and FB initiated this project. All authors and contributors in acknowledgements section were involved in data collection and exchange. IF carried out the data analyses and drafted the initial manuscript. FB, JDA and AC were also involved in analysis interpretation and contributed to the discussion and conclusions. AC also provided statistical support. All authors contributed to the design of the study, commented on the manuscript and approved the final draft.

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#### **APPENDIX**

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#### SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

**Additional File 1.** Ethical approval for the aMASE (advancing Migrant Access to Health Services in Europe) studies in each participating country.

#### Additional File 2.

**Figure S1.** Current country of residence of male and female respondents to the aMASE Clinic Survey. N = 2093 from 57 clinic sites (min, max patients 1, 148): Belgium 255, 4 clinics (27, 148; Germany 31, 2 clinics (14, 17; Greece 175, 8 clinics (1, 60) Italy 63, 2 clinics (20, 43); Netherlands 119, 3 clinics (28, 51); Portugal 179, 7 clinics (5, 54); Spain 693, 18 clinics (9, 141); Switzerland 177, 6 clinics (5, 42); United Kingdom 401, 7 clinics (21, 106).

**Figure S2.** Country of birth of male and female respondents to the aMASE clinic survey. N = 2093 from 152 countries. Brazil 146; Colombia 107; Nigeria 96; Ecuador 74; Cameroon 59; Ghana 58; Venezuela 57; Romania 56; Italy 52; Guinea-Bissau 49; Albania 43; Peru 39; Cuba 37; Argentina 36; Dominican Republic 36; Congo (Kinshasa) 35; Portugal 35; Poland 34; Russia 33; Spain 32; France 31; Guinea 30; Angola 28; Equatorial Guinea 27; Morocco 27; Ukraine 26; Cote

d'Ivoire 25; Zimbabwe 25; Cape Verde 24; United States of America 23; Bulgaria 22; Eritrea 22; Ethiopia 20; United Kingdom 20; Georgia 19; Rwanda 19; Togo 19; Bolivia 17; Mozambique 17; South Africa 17; Kenya 16; China 15; Paraguay 15; Thailand 15; Germany 14; Mexico 14; Suriname 13; Burundi 12; Philippines 12; Sierra Leone 12; Turkey 12; India 11; Chile 9; Malaysia 9; Serbia 9; Uruguay 9; Australia 8; Canada 8; Honduras 8; Hungary 8; Malawi 8; Netherlands 8; Senegal 8; Tanzania 8; Tunisia 8; Uganda 8; Benin 7; Burkina Faso 7; Czech Republic 7; Iran 7; Jamaica 7; Lebanon 7; Pakistan 7; Armenia 5; Belgium 5; Cyprus 5; Indonesia 5; Kazakhstan 5; Liberia 5; Nicaragua 5; Sweden 5; Switzerland 5; Uzbekistan 5; Finland 4; Greece 4; Hong Kong 4; Mali 4; Mauritius 4; Moldova 4; Nepal 4; Sao Tome and Principe 4; Trinidad and Tobago 4; Zambia 4; Austria 3; Congo (Brazzaville) 3; Egypt 3; Estonia 3; Gambia, The 3; Ireland 3; Israel 3; Japan 3: Latvia 3: Netherlands Antilles 3: Sri Lanka 3: Sudan 3; Vietnam 3; Afghanistan 2; Antigua and Barbuda 2; Bangladesh 2; Bosnia and Herzegovina 2; Botswana 2; Denmark 2; Gabon 2; Guatemala 2; Iraq 2; Kosovo 2; Macedonia 2; Madagascar 2; New Zealand 2; Norway 2; Panama 2; Seychelles 2; Slovakia 2; Slovenia 2; Somalia 2; Taiwan 2; Algeria 1; Azerbaijan 1; Bahamas, The 1; Barbados 1; Belarus 1; Burma 1; Central African Republic 1; Comoros 1; Croatia 1; Djibouti 1; Dominica 1; El Salvador 1; Guyana 1; Haiti 1; Laos 1; Libya 1; Lithuania 1; Mauritania 1; Niger 1; Oman 1; Swaziland 1; Syria 1; Tajikistan 1; Timor-Leste 1; Turkmenistan 1; United Arab Fmirates 1.

#### Additional File 3

**Table S2.** Sociodemographic characteristics of survey respondents, by gender (men separated by sexual orientation)

**Table S3.** Characteristics of survey respondents by gender (men separated by sexual orientation) at time of diagnosis

**Table S4.** HIV treatment characteristics of aMASE clinic survey respondents, by gender (men separated by sexual orientation)



## RESEARCH ARTICLE

# "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

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#### **Abstract**

**Introduction:** It is common in urban African settings for postpartum women to temporarily return to family in distant settings. We sought to explore mobility among peripartum HIV-positive women to understand the timing and motivation of travel, particularly vis-à-vis delivery, and how it may affect healthcare access.

**Methods:** Using the same mobility measurements within three different studies, we examined long-distance travel of mother and infant before and after delivery in three diverse clinics within greater Johannesburg, South Africa (n = 150). Participants were interviewed prior to delivery at two sites (n = 125) and after delivery at one (n = 25). Quantitative and qualitative results are reported.

**Results:** Among 150 women, median age was 29 years (IQR: 26 to 34) and 36.3% were employed. Overall, 76.7% of the participants were born in South Africa: 32.7% in Gauteng Province (Johannesburg area) and 44.0% in other South African provinces, but birthplace varied greatly by site. Almost half (44.0%) planned to travel around delivery; nearly all after delivery. Median duration of stay was 30 days (IQR: 24 to 90) overall, but varied from 60 days at two sites to just 7 days at another. Participants discussed travel to eight of South Africa's nine provinces and four countries. Travel most frequently was to visit family, typically to receive help with the new baby. Nearly all the employed participants planned to return to work in Johannesburg after delivery, sometimes leaving the infant in the care of family outside of Johannesburg. All expressed their intent to continue HIV care for themselves and their infant, but few planned to seek care at the destination site, and care for the infant was emphasized over care for the mother.

**Conclusions:** We identified frequent travel in the peripartum period with substantial differences in travel patterns by site. Participants more frequently discussed seeking care for the infant than for themselves. HIV-exposed children often were left in the care of family members in distant areas. Our results show the frequent mobility of women and infants in the peripartum period. This underscores the challenge of ensuring a continuity of HIV care in a fragmented healthcare system that is not adapted for a mobile population.

Keywords: HIV/AIDS; mobility; pregnant; postpartum; retention; South Africa

Additional Supporting Information may be found online in the Supporting information tab for this article.

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#### 1 | INTRODUCTION

South Africa is home to the world's largest public antiretroviral therapy (ART) programme [1]. This ambitious treatment programme has brought about historic gains in life expectancy [2], but is challenged by suboptimal retention in care [3,4]. The recent policy shift to a universal test-and-treat strategy [5] will increase the numbers of individuals on treatment but requires innovative approaches to initiate and retain all its estimated 7

million HIV-infected adults and children on lifelong ART [6].

To address this high rate of attrition, pregnant, HIV-positive women will require special attention, as they have been shown to be at high risk of disengagement from HIV care, particularly after delivery [7-11]. In a Johannesburg cohort of women diagnosed with HIV during antenatal care, just under half were lost to HIV care within six months of delivery [10]; a Cape Town study found that disengagement was more than twice as frequent in the postpartum period than during

antenatal care [11]. South African guidelines recommend five antenatal visits, two postpartum visits for the mother and child together, and then a return to routine ART care for HIV-positive women [12]. Retention through these multiple steps is a known challenge [13,14].

One important reason that postpartum women have such high rates of attrition relates to mobility. Postpartum women are highly mobile for a number of reasons. South Africa has a long history of temporary labor migration as a legacy of apartheid [15,16]. Population mobility remains high today in democratic South Africa, and the most typical pattern is of internal migrants moving within South Africa from rural or peri-urban areas to urban, but keeping strong ties to the origin [15]. Migrants in general are able to return home much more frequently than in the past [17]. Women migrate frequently too, are more likely than men to send remittances home, and may turn to family and neighbourhood networks to support children in their absence [16,17]. Postpartum women in South Africa often return to a rural home after delivery to receive care from family member [8,17,18], but the geospatial elements of this mobility are poorly characterized and their impact on retention in HIV care is unknown. The specific details of postpartum short-term migration that could illuminate health services planning include the reasons for travel, the timing of departure in relation to delivery, the duration of this stay, and any attempts or obstacles to continuing care in the rural location or at the original clinic.

South Africa's health facilities are not linked through electronic medical records, so it is difficult to ascertain if a patient who is lost from one clinic seeks care at another [19]. We recently investigated continued HIV care among women considered lost to follow-up after initiating ART during pregnancy and found evidence that over one-third had continued their HIV care at other clinics, both within the same city and throughout the country [20]. The goal of the current study was to characterize mobility among peripartum (pregnant and postpartum) HIV-positive women to understand the timing and motivation of travel, particularly vis-à-vis delivery, and how it may affect women's healthcare access.

#### 2 | METHODS

Data were collected by nesting the same mobility-related questions in data collection tools of three separate studies with diverse study objectives. Table S1 provides additional information on each study; all studies were related to understanding and improving engagement in HIV care among peripartum women. We enrolled 150 adult (age  $\geq$  18 years) peripartum participants at three study sites in Johannesburg, South Africa; activities and participant eligibility varied slightly at each site according to the objectives of each parent study.

Site one is a public health clinic operated by the City of Johannesburg that serves the Ivory Park region of eastern Johannesburg. Care is provided free of charge [21]. Site one participants were recruited during routine antenatal care if they were pregnant, HIV positive, and able to speak and understand English. From May 2015 to March 2016, we enrolled 100 participants and conducted a one-time questionnaire at enrolment.

Site two is a large primary healthcare clinic operated by a non-governmental organization based in Fourways in northern Johannesburg; clinic visits cost R110 (USD~8.50), but fees may be waived if clients are unable to pay. Site two participants were recruited during routine antenatal care and eligible for enrolment if pregnant and HIV positive; we enrolled 25 participants from October 2016 to April 2017.

Site three is an academic research clinic located within Chris Hani Baragwanath Hospital in Soweto, on the south-western edge of greater Johannesburg. Participants were already enrolled in a longitudinal maternal health cohort. Study visits are free and participants receive R150 (USD~11.60) for every completed visit. Women at site three were eligible for the present study if they were postpartum (gave birth 6 to 18 months prior to enrolment), HIV positive, and exhibiting a metabolic disorder (e.g. gestational diabetes). Interviews were conducted from August to December 2016. At sites two and three, we conducted a one-time, in-depth interview at enrolment based on a semi-structured questionnaire guide. All interviews were conducted by a female trained research coordinator in the local language preference of the participant.

The residential areas served by site one and two's patient populations were developed in the 1990s [22,23]; both are densely-populated areas with vast formal and informal settlements. By comparison, site three serves the population of a township that was formally established in 1963 [24]. The three diverse urban sites and mix of postpartum HIV-infected women enabled us to examine migration patterns for diverse clients of a government clinic, a clinic run by an NGO, and a clinic run by an academic medical centre that aided women with metabolic disorders.

Study questions are presented in Table S2. At all sites, participants were asked similar initial yes/no questions regarding travel outside of the Johannesburg area before and after delivery. For participants at sites one and two, we asked about intended travel, while we asked about actual travel for the postpartum women enrolled at site three. If travel was noted, we recorded details of the duration, reason, and plans for travel. The questionnaire used at site one collected categorical, short answer, and some open-ended responses. At sites two and three, in-depth interviews explored experiences of travel and pregnancy. At site one, questionnaire data were captured on paper forms, then entered into a REDCap (Research Electronic Data Capture) electronic database [25]. At sites two and three, interviews were recorded and transcribed.

When reporting the timing of travel, travel that was indicated to begin during pregnancy and end after delivery was marked as travel both before and after delivery. For example, if a pregnant participant reported planning to travel prior to delivery and staying through three months post-delivery, both "before delivery" and "after delivery" travel would be noted for the same participant. All participants provided written informed consent prior to interviewing, and study activities were approved by the institutional review board of Vanderbilt University Medical Center, Boston University (site one), and the Human Research Ethics Committee of the University of the Witwatersrand.

#### 2.1 Data analysis

SAS<sup>®</sup> 9.4 (SAS Institute, Cary, NC, USA) was used for statistical analysis of quantitative data. Cohort characteristics are

described using counts and proportions for categorical variables, and medians and interquartile ranges (IQR) for continuous data. Mobility within and outside of South Africa was mapped using ArcMap<sup>®</sup> 10.3.1 (Esri, Inc., Redlands, CA, USA).

For the analysis of open-ended data, coding, analysis, and reporting was completed by following the COREQ guidelines [26]. Responses to questions related to mobility during the peripartum period (see list Table S2) were consolidated in REDCap and exported for hand-coded analysis. Quotes were sorted by category, frequency distributions were examined, then quotes were read in detail to identify higher-order themes and relationships. The analysis was rooted in the theoretical framework proposed by Phillips and Myer [27], which is an adaptation of the Social-Ecological Model [28], and asserts that multi-level factors interact to determine engagement in HIV care among pregnant and postpartum women. We report the themes identified – staying with family, child-care and children separated from the mother, and plans for continuing care – and highlight key, illustrative quotes.

#### 3 | RESULTS

#### 3.1 | Participant characteristics

Participant characteristics are summarized in Table 1. Overall median age at enrolment was 29 years (IQR: 26 to 34), but varied across site, with the youngest participants at site one (median 28, IQR: 24 to 31), and the oldest at site three (median 36, IQR: 32 to 40). Median gestational age at enrolment was 26.7 weeks (IQR: 18.8 to 33.1); among the postpartum women at site three, the median time between delivery and

interview was 10.7 months (IQR: 8.2 to 13.9). At site one, 28.0% of the participants were pregnant for the first time; at site two, 8.0% had never been pregnant before the current pregnancy. At both sites, among the majority who already had children, the median number of children was two (IQR: 1 to 2). Data on previous children were unavailable at site three. All participants were on lifelong, combination ART.

Overall, 76.7% of the participants were born in South Africa, with substantial variability between sites. Of the 23.3% of participants born outside of South Africa, most were from Zimbabwe (77.1%). Of those participants born in South Africa, more were born outside of Gauteng Province – where Johannesburg and all three clinics are located – than within, again with site variability, notably at site three. All women reported currently living Johannesburg, in communities near their respective study site.

Over one-third of women were currently employed (36.3%), however at site two, this was as high as 84.0%. Of women currently working, the most common profession was cleaning/domestic work and median monthly salary was R3150 (USD~245 [IQR: 2450-3900, USD~190-300]).

#### 3.2 | Frequency and duration of travel

Intended (site one and two) and actual (site three) travel outcomes are displayed in Table 2. At site one and two, nearly all participants planned to deliver their baby at a healthcare facility in Johannesburg; at site three, all participants gave birth at a hospital in Johannesburg. Overall, nearly half of participants reported travel around the time of delivery (44.0%); this varied from 36.0% at site one to 60.0% at sites two and three.

Table 1. Characteristics of the study participants at time of study enrolment (n = 150).

Participant characteristics	Site one (n = 100)	Site two (n = 25)	Site three (n = 25)	Total
Age in years, median (IQR)	28 (24 to 31)	33 (26 to 34)	36 (32 to 40)	29 (26 to 34)
Age, n (%)				
18 to 24 years	26 (26.0%)	4 (16.0%)	1 (4.0%)	31 (20.7%)
25 to 34 years	61 (61.0%)	16 (64.0%)	10 (40.0%)	87 (58.0%)
35 years and older	13 (13.0%)	5 (20.0%)	14 (56.0%)	32 (21.3%)
Current pregnancy is first pregnancy	28 (28.0%)	2 (8.0%)	Unavailable	30 (24.0%) <sup>a</sup>
Number of living children among those with 1+ children, median (IQR)	2 (1 to 2)	2 (1 to 2)	Unavailable	2 (1 to 2)
Participant reports a current partner, n (%)	99 (99.0%)	24 (96.0%) <sup>b</sup>	22 (88.0%) <sup>c</sup>	145 (96.7%)
Participant lives with partner	48 (48.0%)	14 (58.3%) <sup>b</sup>	9 (40.9%) <sup>c</sup>	71 (48.6%)
Duration of partnership (months), median (IQR)	46 (27 to 88)	45 (24 to 84)	48 (36 to 60)	48 (27 to 86)
Birthplace, n (%)				
South Africa	79 (79.0%)	14 (56.0%)	22 (88.0%)	115 (76.7%)
In Gauteng Province (where clinics located)	33 (33.0%)	1 (4.0%)	15 (60.0%)	49 (32.7%)
Outside Gauteng Province	46 (46.0%)	13 (52.0%)	7 (28.0%)	66 (44.0%)
Outside of South Africa	21 (21.0%)	11 (44.0%)	3 (12.0%)	35 (23.3%)
Employed, n (%)	31 (31.0%)	21 (84.0%)	7 (28.0%)	59 (39.3%)

IQR, interquartile range

Participants at sites one and two were pregnant at the time of enrolment; at site three, participants were postpartum.

<sup>&</sup>lt;sup>a</sup>Data on prior pregnancies not collected at site three; denominator here is 125.

<sup>&</sup>lt;sup>b</sup>Missing 1 response at site two (n = 24).

 $<sup>^{</sup>c}$ Missing 3 responses at site three (n = 22).

Table 2. Participant travel outcomes (n = 150).

	Site one (n = 100)	Site two (n = 25)	Site three (n = 25)	Total
Intended or actual delivery in Johannesburg, n (%)	92 (92.0%)	24 (96.0%)	25 (100.0%)	141 (94.0%)
Travel outside of Johannesburg before or after delivery, n (%)	36 (36.0%)	15 (60.0%)	15 (60.0%)	66 (44.0%)
Travel before delivery <sup>a</sup>	9 (9.0%)	4 (16.0%)	3 (12.0%)	16 (10.7%)
Travel after delivery <sup>a</sup>	27 (27.0%)	14 (56.0%)	13 (52.0%)	54 (36.0%)
Median duration of stay (days), median (IQR)	60 (30 to 90)	60 (21 to 120)	7 (3 to 30)	30 (24 to 90)
Travel location (among those who planned to travel)				
In Gauteng Province, but out of Johannesburg	1 (2.8%)	$O_p$	2 (13.3%)	3 (4.6%)
In South Africa, but out of Gauteng Province	29 (80.6%)	11 (78.6%) <sup>b</sup>	10 (66.7%)	50 (76.9%)
Outside of South Africa	6 (16.7%)	3 (21.4%) <sup>b</sup>	3 (20.0%)	12 (18.5%)

<sup>&</sup>lt;sup>a</sup>An individual participant could travel before and after delivery, thus responses may exceed the total here. At sites one and two, pregnant women discussed intended travel; at site three, postpartum women discussed actual travel.

Travel was three times more common after delivery than before. Median duration of stay during travel (before or after delivery) was 30 days (IQR: 24 to 90), but varied from 60 days at site one and two to seven days at site three. Two participants (1.3%) indicated that the move would be permanent. Location of travel is visually displayed in Figure 1. The majority of travel around delivery at all sites was to a different province in South Africa (76.9%), most frequently neighbouring Limpopo Province. Of the 18.5% of women reporting international travel, 66.7% reported travel to Zimbabwe, with Lesotho, Mozambique, and Nigeria mentioned by the remaining one-third.

#### 3.3 Themes emerging from open-ended responses

In the open-ended responses, we identified three distinct themes: staying with family, childcare and children separated from the mother, and the plans for continuing care. Quotes selected as particularly illustrative of these themes are highlighted in Table 3. Those who were born outside of Johannesburg described a cycle of frequent travel between urban Johannesburg and a distant area considered "home." Life in Johannesburg, as reported, involved working or looking for work; after delivery of a baby, concerns grew about childcare and security. They reported a lack of social support in the urban environment – of "no one who can look after me" – and stressed the importance of relying on extended family outside of Johannesburg for support and childcare.

A prominent theme in participants' reported experiences was travelling to stay with family. Nearly all participants who travelled during the peripartum period said they did so to visit family, most commonly their mother or mother-in-law. "There is no one here who can help me with the baby, so I want to be home with my mother," one participant reported, demonstrating how mothers at "home" were portrayed as comforting, supportive, and knowledgeable about baby care. Relying on family for help with the new baby and their own postpartum recovery was the most frequent reason for staying with family. This was especially noted among first-time mothers who described turning to mothers and grandmothers for learning. By comparison, one participant who reported family outside of Johannesburg described anticipating a different experience

with her current pregnancy, her second: "I don't feel like going home. The first one I delivered at home; now I want...to do it myself so that I can learn and take responsibility."

Childcare was a pressing concern for respondents who were employed or looking for work. Nearly all of the employed participants planned to return to work after delivering their baby, and travel was planned to coordinate with maternity leave. Even those respondents who did not plan to travel reported difficulty in coordinating working hours with childcare and paying for day care. Participants who reported travel often acknowledged leaving the infant in the care of the child's grandmother outside of Johannesburg so that the mother could return to work in Johannesburg. Similarly, respondents sometimes referred to their other children who live full-time at the family home outside of Johannesburg. One employed participant living in an informal settlement described the relative safety of her family's home outside of Johannesburg for raising a child, stating, "It is not safe in the shack for a small baby." Of note, no participant at site three mentioned leaving the baby at a location outside of Johannesburg.

All women expressed their plan to continue seeking healthcare in Johannesburg for themselves and their child after delivery. However, very few respondents who travelled planned to seek care at the new location. Some participants described alerting the clinic in Johannesburg in advance of their travel to ensure that they would have sufficient ART, and also timing the travel as to not interfere with upcoming clinic visits. Quotes like, "I will take the baby [home outside of Johannesburg] once I have finished everything here at the clinic," demonstrate how some participants anticipate their travel and manage their clinic visits accordingly. Others cited concern with the quality of care at clinics outside of Johannesburg as a reason for continuing care in Johannesburg. Nearly all participants who intended to seek care elsewhere did so only for the infant, not for themselves. Some participants noted seeking care for the baby at the new location, but preferring to continue regular, adult HIV care in Johannesburg to avoid disruption. While some participants noted adhering to the newborn immunization schedule while travelling, others described only accessing care while travelling only in the event of illness.

<sup>&</sup>lt;sup>b</sup>One participant at site two reported her intention to travel but did not know her location plans at the time of the interview.

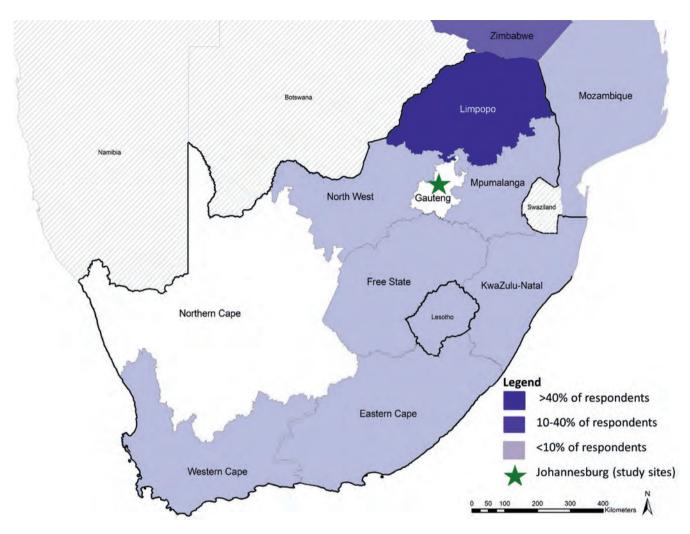


Figure 1. Distribution of destinations (n = 65) among the 44% of participants who reported travel around the time of delivery. Not pictured: Nigeria (1 participant; 1.5%)

#### 4 | DISCUSSION

To our knowledge, this is the first study to explore characteristics and motivations for long-distance travel among peripartum, HIV-positive women in sub-Saharan African. The impact of frequent mobility on engagement in care, particularly lifelong HIV care, is an emerging concern. Studies of migration and health usually focus on international migration, instead of circular, internal movement, which is prominent in sub-Saharan Africa. Earlier studies have noted that mobility among peripartum women may interfere with engagement in HIV care [8,18,29,30]. Through this study, we sought to understand the timing and motivation of travel around delivery, and how it impacts women's choices about healthcare. We found very high frequency of internal migration and subsequent travel, particularly at two of our study sites. Travel patterns showed movement throughout South Africa, covering eight of the country's nine provinces. In addition, we also found substantial international migration, particularly to and from Zimbabwe, and most notably at site two, and short-term travel to four countries during the peripartum period.

A strength of this study is that we report data from three different study sites in Johannesburg, and indeed, we noted substantial differences in the patient mobility at each site, reflecting the diversity of urban patient populations. Anecdotally, we had been told to expect less migration at site three, given that is an older and more well-established community than the areas served by sites one and two, and indeed our data reflect this. Our findings are consistent with a 2013 survey within the City of Johannesburg that found 32% of respondents had moved from elsewhere in South Africa and 13% from outside of South Africa [31]. At site three, far more participants were born nearby than seen at sites one and two. Travel during the peripartum period reflected this, with participants at site three less likely to report a lengthy stay outside of Johannesburg. At site three, short-term travel often was due to attending funerals, rather than to seek help from relatives after delivery, as was the case at the other two sites. The median length of stay away for respondents at site three was only seven days.

Respondents reported their intention to return to their Johannesburg clinic to resume their HIV care after delivery, with some reporting alerting their Johannesburg clinics of

#### Table 3. Illustrative quotes related to specific themes identified in open-ended responses.

Staying with family

Childcare and children

separated from the mother

- "It's my home place. I frequently visit my family." Participant 5, site one
- "I will have maternity leave for four months and I will go home...just to see people." Participant 103, site two
- "Before I delivered yes, I would go to Pretoria...then after I delivered I went to the Free State. [I went] To see...my in-laws in the Free State and in Pretoria was to see my husband, the father of my children. When I am in the Free State it can take a month for me being there, and then I come back. In Pretoria, I would stay about 2 or 3 months then I come back. Participant 129, site three
- "I want my mother to look after me and the baby after delivery." Participant 19, site one
- "Going down to KwaZulu-Natal [Province], because here I may not have anyone else to take care of me. At home I have my sisters. They will be able to take care of me." Participant 123, site two
- "This is my first child so I want my grandmother to teach me some other things about the baby." Participant 25, site one
- "Here there is no adult...and this is my first child; I don't know anything" Participant 107, site two
- "My problem is that I knock off [leave work] at night. The shop closes at eight. Just imagine where the baby will be at eight?...That's why I say I don't know; I'm not sure what I'm going to do." Participant 118, site two
- "I think will find someone to look after my baby. A small baby cannot go to crèche [daycare] because I will be working and knocking off [leaving] at nine. I don't want to...trouble the baby. But at least the baby will be comfortable." Participant 112, site two
- "I will go back to work after delivery so I will leave the baby with my mother." Participant 88, site one
- "After four or five months, maybe I will take it [the infant] to my mother then, because I'm working...because my salary can't afford to pay crèche." Participant 101, site two
- "I just want to see my other child and my mother." Participant 15, site one
- "I want to show my mother the baby and see my other kids." Participant 74, site one
- "My mother and my father are in [Limpopo Province], and my second-born child. In a year, I go there three times." Participant 114, site two
- "And the children, the other two, are in Zimbabwe... like April, I go to see them; December I go to see them [twice a year]... if I go there in April, I stay for one week, when I go in December, I stay for three weeks." Participant 105, site two

Plans for continuing care

- "I will come to the [study] clinic, I'll tell them I want to travel, then they give me the medication and everything; then I make sure that the next appointment, I have to be back." Participant 111, site two
- "No, I did not go to the clinics in those locations; I travelled with my medication." Participant 133, site three
- "I will come to the [study] clinic first before I leave." Participant 112, site two
- "For the baby, I can still go there [outside Johannesburg]. But for me if they gave me a date [appointment], I will come on that date. I prefer to attend clinic this side [here]...It is because if I keep changing clinics and go here and there I won't get the same treatment there that I get here, so I prefer that I continue with the way I am getting treatment now." Participant 112, site two
- "I will have maternity leave for four months and I will go home. But I will not go home around the time to take my child or me to the clinic. They said I must bring the baby when its two weeks old and then again after ten weeks if I haven't forgotten. So I will wait to do all those things because at home I cannot do that...I am HIV positive and I know it. So they say the situation at the clinics back home is poorer than what I see here... So I can take the baby home after I have the two weeks visit; so they see it at home and then come back here and wait for the ten weeks visit." Participant 103, site two
- "I only took him when it was his date to get immunized, I took him to...a clinic in Free State [Province] for him to be immunized." Participant 129, site three
- "Yes, I did [visit a new clinic], because my baby contacted malaria...in Nigeria." Participant 130, site three "The child was taken to the grandparents in Limpopo [Province]. Yeah, no [I didn't seek care for the child]. He [the infant] was OK. He did not get any sickness or anything." Participant 135, site three

their intended travel plans to ensure they would have sufficient ART. When participants did talk about visiting a clinic while travelling, it was almost exclusively for the baby, particularly to adhere to the immunization schedule. Our earlier work has shown a trend of mothers taking ART through pregnancy to protect the baby, but failing to see the importance of

continued care for themselves [32]. It is possible that respondents were presenting an optimistic scenario about continuing their care after delivery in order to appeal to the interviewer, a limitation of self-reported data. We recently found evidence of women continuing HIV care elsewhere in South Africa after initiating ART in Johannesburg, [20] so women may indeed

visit a clinic in their "home" area, particularly if their stay is extended. South Africa has a fragmented healthcare system, and the lack of national, networked electronic medical records means that a patient presenting at a new clinic cannot access her records from the first. Thus, the healthcare system in South Africa – and many neighbouring countries in sub-Saharan Africa – is not equipped to adequately care for a highly mobile population.

South Africa Labour Law mandates that pregnant women are eligible for four months of unpaid maternity leave [33]. While only 39% of our participants overall were employed, we found that mobility in our study very much revolved around employment. Most notably at site one and two, women moved to Johannesburg pursuing employment. At site two, 84% of women were employed, a far higher proportion than at site one and three. Still, current employment and job seeking was raised frequently in our interviews at all sites. When employed, time off work for holidays is often spent back in the other home, visiting family, including other children. This means that time off may be used for travel instead of visiting the clinic. Time in Johannesburg, according to participant accounts, focused on finding and keeping a job as a top priority.

Particularly at sites one and two, we found continued strong ties to "home" areas outside of Johannesburg. Participants noted that they often moved to Johannesburg alone and frequently identified a lack of social support in the city and safety concerns. We identified a reliance on family in distant areas, especially mothers and mothers-in-law for help with the baby, even going so far as to leave the baby in the care of distant family members so that the mother can return to work in Johannesburg. This was an alarming finding since all of their infants are HIV exposed. Leaving the baby behind was a frequently expressed option for both the current pregnancy, as well as for their earlier children. Even children who are HIV negative, but HIV exposed, are at increased risk of mortality compared to HIV-unexposed children [34]. Further research is needed to explore extended family members' knowledge of HIV and caring for HIV-exposed children, and to explore the outcomes of HIV-exposed children raised by extended family members

Our study has several limitations. First, all of our clinics were based in Johannesburg. While this is the largest city in South Africa, and one of the largest on the African continent, it does not necessarily reflect the mobility seen within other urban areas in South Africa. As our findings show, mobility patterns can vary substantially even within different areas of the same city. Additional research is needed to confirm our findings in different settings. Second, it is possible that women who were already travelling before delivery were omitted from the sample in site one and two. Third, the data were collected from three different studies; while this is a strength of the study, increasing population diversity and generalizability of the findings and the questions were consistent across sites, it is possible the lack of consistency in our participant population may alter our findings, distorting the generalizability of our results. Intended travel may have differed from actual travel. Reporting engagement in HIV care and ART adherence outcomes was beyond the scope of this analysis, so we are unable to report the actual loss from care among these participants. Lastly, it is possible that our sample size (n = 150) prohibited us from achieving full representation; however, it allowed for meaningful dialogue and facilitated analysis. Ultimately, we think the utility of our study is to alert HIV care providers in all plausibly similar African settings of the possibility of loss to follow-up of postpartum women who travel after delivery and to encourage them to consider interventions that may positively impact highly mobile postpartum women.

Our finding of frequent mobility during the brief peripartum period has potentially important public health implications. While this study did not measure engagement in care, we identified frequent long-distance travel among a population at high risk of dropping out of ART care. Continuous engagement in care is particularly important for HIV patients since HIV requires lifelong treatment with high treatment adherence; patients who stop and restart ART increase their risk of drug resistance, treatment failure and ultimately, death [35,36], and the postpartum period is associated with increased viremia [37]. Even those who remain in care but miss multiple ART appointments within the first six months of initiation are at increased risk of poor CD4 responses and failure to achieve viral suppression [38], a key consideration within the context women initiating ART during pregnancy. Our results suggest that public healthcare systems in South Africa and beyond should anticipate a mobile population, particularly around pregnancy, and adapt to improve care. An easy start is to ask a patient if she anticipates upcoming travel, discussing duration and a plan to ensure continuous care for herself and the baby, including adequate ART supply. The amount provided to patients varies depending on patient characteristics and clinic policy, but often is just 30 days. Numerous interventions to improve postpartum retention overall have drawn recent attention [39]; our findings particularly support those that improve patient tracking and two-way communication between patients and facilities.

#### 5 | CONCLUSIONS

In our study of HIV-positive, pregnant and postpartum women in care in Johannesburg, South Africa, we found high levels of movement from areas within South Africa, and other countries, that largely was driven by employment aspirations. At two of our sites, we found evidence of long-distance travel lasting a median of two months, and at all sites, a reliance upon family members for care and comfort after having a baby. In addition, we found ample evidence of women leaving their HIV-exposed children with family members outside of Johannesburg in order to return to work. Our results highlight the frequent mobility of women in the peripartum period and help to inform our understanding of loss to follow-up among HIV-positive, postpartum women. Our findings support healthcare system improvements that will facilitate care across multiple facilities to adapt and accommodate a mobile population.

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#### **AUTHORS' CONTRIBUTIONS**

K.C. conceived of the study, coded and analysed the data, and wrote the first draft of the manuscript. M.P.F., C.M., M.M., S.B., D.B., S.N. and J.B. facilitated data collection. M.P.F., M.N.L, D.M.A. and S.H.V. provided content expertise. All authors reviewed and contributed to the final manuscript.

#### COMPETING INTERESTS

The authors declare no competing interests.

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#### SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

**Table S1.** Description of three parent studies in Johannesburg, South Africa, providing data for the present analysis

**Table S2.** Mobility-related data measurements used at three sites



## RESEARCH ARTICLE

# Linkage to care, mobility and retention of HIV-positive postpartum women in antiretroviral therapy services in South Africa

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#### Abstract

**Introduction:** Linkage to care and mobility postpartum present challenges to long-term retention after initiating antiretroviral therapy (ART) in pregnancy, but there are few insights from sub-Saharan Africa. We aimed to describe postpartum linkage to care, mobility, retention and viral suppression after ART initiation in pregnancy.

**Methods:** Using routine electronic data we assessed HIV-specific health contacts and clinic movements among women initiating ART in an integrated antenatal care (ANC) and ART clinic in Cape Town, South Africa. The local care model includes mandatory transfer to general ART clinics postpartum. We investigated *linkage to care* after leaving the integrated clinic and *mobility* to new clinics until 30 months on ART. We used Poisson regression to explore predictors of linkage, *retention* (accessing care at least once at both 12 [6 to <18] and 24 [18 to <30] months on ART), and *viral suppression* (HIV viral load [VL]  $\leq$ 50 and  $\leq$ 1000 copies/mL after 12 months on ART).

**Results:** Among 617 women, 23% never linked to care; 71% and 65% were retained at 12 and 24 months on ART respectively, with 59% retained in care at both times. Those who linked (n = 485) accessed HIV care at 98 different clinics and 21% attended ≥2 clinics. Women >25 years, married/cohabiting or presenting early for ANC were more likely to link. Younger and unemployed women were more likely to attend ≥2 clinics (adjusted risk ratio [aRR] 1.10 95% confidence interval [CI] 1.02 to 1.18 and aRR 1.06 95% CI 0.99 to 1.12 respectively). Age >25 years (aRR 1.17 95% CI 1.02 to 1.33) and planned pregnancy (aRR 1.20 95% CI 1.09 to 1.33) were associated with being retained. Among 338 retained women with VL available, attending ≥2 clinics reduced the likelihood of viral suppression when defined as ≤50 copies/mL (aRR 0.81 95% CI 0.69 to 0.95). Distance moved was not associated with VL.

**Conclusions:** These data show that a substantial proportion of women do not link to postpartum ART care in this setting and, among those that do, long-term retention remains a challenge. Women move to a variety of clinics and young women appear particularly vulnerable to attrition. Interventions promoting linkage and continued retention for women initiating ART during pregnancy warrant urgent consideration.

Keywords: antiretroviral therapy; postpartum; mobility; transfer; linkage; retention; viral suppression; South Africa

Additional Supporting Information may be found online in the Supporting information tab for this article.

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#### 1 | INTRODUCTION

Population movement has received much attention in the context of the HIV epidemic [1,2]. Migration and mobility may be associated with HIV acquisition and providing HIV care to mobile populations presents particular challenges [3-6]. In South Africa, movement between rural and urban areas for employment, education, healthcare, cultural and family reasons occurs frequently, involving all demographic groups, including women of reproductive age [7-9].

Antiretroviral therapy (ART) during pregnancy and breast-feeding, and associated viral suppression, reduces mother-to-child transmission (MTCT), improves maternal health, and reduces sexual transmission [10]. However, these benefits hinge on women initiating ART, adhering to treatment, and remaining in care in the long term. Postpartum retention is a major challenge and there is an urgent need to understand how mobility may contribute to this [11-15].

In urban South Africa as well as other settings in sub-Saharan Africa, pregnant HIV-positive women who are not yet on ART start treatment during pregnancy in integrated clinics providing antenatal care (ANC) and HIV care including ART. Time in the integrated clinic after delivery varies, but ultimately women must transfer their HIV care and link to general ART clinics postpartum. Additional movement between healthcare facilities also occur due to relocation and patient choice. These movements may introduce challenges to the continuum of HIV care and maternal health services [3,4,16]. In South Africa, a recent analysis found that 38% of postpartum women who were considered lost to follow-up (LTFU) at the clinic of ART initiation were in care elsewhere, and 33% received care outside of the province where they started ART [13]. However, there are few data on the mobility of women with mandatory movement of ART care postpartum, and there is a need to understand the specific challenges related to linkage to care and mobility after delivery in these settings.

To address this, we explored continuity of care including linkage, geographic mobility and retention in care in a cohort of women who initiated ART in an integrated ANC-ART clinic. The objectives were (i) to describe linkage to care after leaving the integrated clinic and additional mobility after linking and (ii) to explore whether frequency or distance of clinic movement were associated with outcomes of retention in care and, in a subset of women, viral suppression.

#### 2 | METHODS

#### 2.1 | Setting

This is a secondary analysis of women enrolled into the Maternal & Child Health – Antiretroviral Therapy (MCH-ART) study, which investigated optimal ART services for pregnant and postpartum women (ClinicalTrials.gov NCT01933477). This study was conducted at a large primary healthcare clinic in Cape Town, South Africa in an area with high rates of unemployment and poverty [17]. ANC coverage is high (approximately 95%) and the antenatal HIV seroprevalence is approximately 30% [18]. The clinic serves over 4000 women annually from a wide catchment area. Women from neighbouring areas of Cape Town as well as from other provinces are known to access services here [19].

ART initiation and follow-up are provided with ANC by nurse-midwives throughout pregnancy. During the study period, ART eligibility was based on local public-sector guidelines (WHO stage III/IV disease or CD4 count ≤350 cells/µL until June 2013, and thereafter universal ART for pregnant women regardless of disease stage). All women initiated a fixed-dose combination of efavirenz, emtricitabine and tenofovir, and initiation usually occurred within a week of presentation for ANC. Per local standard of care, all women were transferred out to general ART services after delivery. They were provided with up to 3 months' supply of ART and a transfer letter to their new clinic, chosen based on preference or proximity to where a woman lived. Women were instructed to attend the new clinic before the end of her ART supply but no additional support for linkage occurs in this setting.

#### 2.2 Data sources

Data for this analysis came from multiple sources. Retrospective data from available routine electronic data sources were

assembled for all enrolled women through a minimum of 30 months on ART. Additional baseline data for all women, and for a subset of women additional prospectively collected data, were obtained from the parent study. The data sources are described in detail below.

The parent study methods have been described previously [20]. Briefly, between April 2013 and June 2014, 628 ART-eligible pregnant women were consecutively enrolled when they presented for ANC at the integrated clinic. Study measurement visits occurred prospectively through one month postpartum in all women and through 18 months postpartum in a subset of breastfeeding women (n = 471). Mandatory transfer out of the integrated clinic occurred at six weeks postpartum for most women per local standard of care. By study design, 233 women remained in the integrated clinic for up to 12 months postpartum (median 7 months, IQR 2 to 12). Data from the parent study provided details on baseline demographics, timing of ART initiation, delivery outcomes and last visit in the integrated clinic.

As part of the parent study, routine electronic health data were abstracted retrospectively through at least 30 months after ART initiation for all women (final data point December 2016). Data were abstracted from the National Health Laboratory Services (NHLS) database, which provides laboratory data for public health facilities in all provinces of South Africa. In addition, electronic data on pharmacy dispensing and clinic contacts, including facility recorded deaths were obtained from the Provincial Health Data Centre (PHDC) of the Western Cape Department of Health. These data are linked with a unique patient identifier and include all public health facilities in the Western Cape Province. Contacts at hospitals and other non-HIV services were excluded.

#### 2.3 Measures

We brought together the above data sources to measure the following constructs. First, we defined linkage to care after leaving the integrated clinic based on evidence of at least one HIV-specific contact (routine ART clinic visit, antiretroviral (ARV) pharmacy refill or a CD4 cell count or HIV VL laboratory test) between the last visit at the integrated clinic and 30 months after ART initiation. Second, we assessed mobility, by determining the location and counting each clinic attended after leaving the integrated clinic. This was analysed as a binary variable of one versus ≥2 different clinics. Third, we created a global measure of retention in HIV care based on evidence of at least one HIV-specific contact at both 12 (6 to <18) and 24 (18 to <30) months after ART initiation at any clinic (including the integrated clinic for any women who linked to care prior to 30 months on ART but had not been transferred out of the integrated clinic by 12 months on ART). In sensitivity analyses we also examined evidence of HIV-specific contact at only 24 (18 to <30) months after ART initiation and at 18 (12 to <24) months postpartum. A 12-month window was used in all definitions as, although routine ART visits and ARV dispensing are expected more regularly, routine HIV laboratory results (our only nationally available data source) are only expected annually in this setting. Fourth, among women considered to be retained in HIV care, we investigated HIV viral suppression based on any HIV RNA VL taken nearest to 24 months on ART and at least 12 months after ART

initiation. These were primarily routine care VL results from the NHLS database. However, if no routine VL was found, available VL results from the MCH-ART study were used. VLs were found for 338 women; 61% from NHLS. VL thresholds of ≤50 and ≤1000 copies/mL were used to define suppression based on definitions of suppression and flags for treatment failure in the South African National ART guidelines [21].

#### 2.4 | Analysis

Analyses were conducted in STATA 14 (STATA Corporation, College Station, TX). Descriptive analysis used frequencies and proportions, means with standard deviations (SD) or medians with interquartile ranges (IQR) with chi squared tests, Fisher's exact test, t-tests or rank sum tests as appropriate. ArcMap 10.3.1 (Esri, Inc., Redlands, CA, USA) was used to describe the spatial distribution of continued care after the integrated clinic. Multivariable Poisson regression models with robust standard errors were used to estimate the relative risk of each outcome [22]. Covariates that reached p < 0.10 in bivariate analyses were included in model building using a step-wise approach. Although the parent MCH-ART trial intervention was not the focus of this analysis, the MCH-ART intervention did impact retention in HIV care at 12 months postpartum in the primary trial analysis [23] and some differences were seen for the retention outcomes in this analysis (Table S6). To account for differences in subgroups of women who received continued prospective follow-up and/or delayed transfer out

of the integrated clinic as part of the MCH-ART study, all multivariable models were adjusted for design status in the MCH-ART study in. Results are presented as crude or adjusted relative risks (RR or aRR) with 95% confidence intervals (CI). In this exploratory secondary analysis which may not have had sufficient power to detect small associations, all associations reaching p < 0.10 were discussed.

#### 2.5 Ethics

All women included in this analysis completed written informed consent that included consent to review their routine medical records. Ethical approval was obtained from both the University of Cape Town Human Research Ethics Committee and the Columbia University Medical Centre Institutional Review Board.

#### 3 | RESULTS

Among 628 women who initiated ART in pregnancy, eight women were found to have died and three to have relocated out of South Africa during the study period (up to 30 months on ART). These women were excluded from further analysis. Of the remaining 617 women, the mean age was 29 years (SD 5.3), 41% were married/cohabiting, 38% were employed and 26% had completed high school (Table 1). More than half the women (54%) were newly diagnosed with HIV in the

Table 1. Description of 617 HIV-positive women who initiated ART during pregnancy, by linkage to HIV care after leaving the integrated clinic. Presented as n (%) unless specified

	Linked to care	Did not link to care	All women	p-value
Number of women	485 (79)	132 (21)	617 (100)	
Median (IQR) months from ART initiation until last evidence of accessing care	28 (22 to 29)	4 (2 to 8)	26 (12 to 29)	<0.001
Characteristics at enrolment				
Mean age (SD)	29 (5.4)	28 (5.3)	29 (5.3)	0.015
Age ≤25	122 (25)	48 (37)	170 (28)	0.011
Married/cohabiting	216 (45)	37 (28)	253 (41)	0.001
Completed secondary school	124 (26)	39 (30)	163 (26)	0.358
Employed	182 (38)	52 (39)	234 (38)	0.695
First pregnancy	83 (17)	29 (22)	112 (18)	0.199
Intended pregnancy	146 (30)	35 (27)	181 (29)	0.422
Diagnosed with HIV in this pregnancy	255 (53)	81 (61)	336 (54)	0.072
Mean weeks gestation (SD)	21 (7.4)	23 (7.8)	21 (7.5)	0.005
Presented for ANC before 20 weeks gestation	231 (48)	47 (36)	278 (45)	0.014
Median (IQR) CD4 cell count at presentation for ANC ( $n = 601$ )	342 (235 to 509)	386 (253 to 555)	345 (236 to 513)	0.110
Characteristics at delivery				
Place of delivery $(n = 597)$				0.624
Delivered in primary care	190 (41)	56 (43)	246 (41)	
Delivered at tertiary hospital	277 (59)	74 (57)	351 (59)	
Delivery outcome				0.253
Live birth	464 (96)	131 (99)	595 (96)	
Stillbirth	11 (2)	1 (1)	12 (2)	
Miscarriage	6 (1)	O (O)	6 (1)	
Unknown	4 (1)	0 (0)	4 (1)	

incident pregnancy and 45% presented for ANC at ≤20 weeks gestation.

#### 3.1 | Linkage to care

Figure 1 describes the flow of access to HIV care after leaving the integrated clinic and Table 1 describes the characteristics among women who did and did not link to a new clinic after their last visit in the integrated clinic. There were 132 women (21%) with no evidence of linking to HIV care during the follow-up period. Of these, nine women were not seen after their first ANC visit. Among the 485 women who did link to care, 384 (79%) had evidence of attending one clinic, 85 (18%) linked to two and 16 (3%) linked to three different clinics (Figure 1). There were 20 women who moved and linked to a new ART clinic while still pregnant, while the remaining 465 women linked to a new clinic after delivery.

Women who did not link to care during the follow-up period were slightly younger (mean age 28 vs. 29), less likely to be married/cohabiting (28% vs. 45%) and more often diagnosed with HIV in this pregnancy (61% vs. 53%), compared to women who did link to care (Table 1). They also presented for ANC later (mean gestation 23 vs. 21 weeks). The associations between successful linkage and age >25 years (aRR 1.11 95% CI 1.00 to 1.23), being married/cohabiting (aRR 1.13 95% CI 1.04 to 1.23) and presentation for ANC  $\leq$ 20 weeks gestation (aRR 1.11 95% CI 1.02 to 1.20) persisted in multivariable models (Table 2).

#### 3.2 Mobility

After leaving the integrated clinic, women accessed care at 98 different clinics across South Africa, excluding the integrated clinic. The median distance moved for initial linkage was 1 kilometre (km) (IQR <1 to 3, maximum 1271 km) and 95% of clinics initially linked to were in the Western Cape Province. After linkage, an additional 117 movements were observed and the distance between clinics increased with additional

Table 2. Poisson regression model (n = 617) predicting whether a woman linked to HIV care at any other clinic after the integrated clinic. Presented as unadjusted (RR) and adjusted (aRR) risk ratios with 95% confidence intervals (CI)

	Crude			Adjusted
	RR	95% CI	aRR	95% CI
Age >25	1.13	1.02 to 1.26	1.11	1.00 to 1.23
Married/cohabiting	1.16	1.07 to 1.25	1.13	1.04 to 1.23
Diagnosed with HIV in this pregnancy	0.93	0.85 to 1.01	-	
Presented for ANC ≤20 weeks	1.11	1.02 to 1.20	1.11	1.02 to 1.20

moves. The median distance of second (n = 101) and third (n = 16) move was 3 km (IQR 1 to 108) and 413 km (IQR 1 to 945) respectively, with 23% of the second and 25% of the third move being out of the Western Cape Province.

Overall, 270 women (56%) remained within the integrated clinic health district (clinics <5 km away), 157 (32%) moved out of the district but stayed in the Cape Town Metropole, 12 (2%) moved out of the region but stayed in the Western Cape and 46 (9%) accessed care in other provinces (Table S1). Figure 2 shows the geographic spread of clinics accessed (A) within the Cape Town Metropole, and (B) across South Africa.

Of 485 women who successfully linked to care after the integrated clinic, 101 women (21%) moved to  $\geq$ 2 clinics (maximum 3) during 30 months of follow-up (Figure 1, Table S1). Younger age and being unemployed were associated with moving to  $\geq$ 2 clinics (aRR 1.10 95% CI 1.02 to 1.18 and aRR 1.06 95% CI 0.99 to 1.12 respectively) (Table S3). Total follow-up time from ART initiation to the last available clinic visit did not differ by movement frequency (median 28 months in

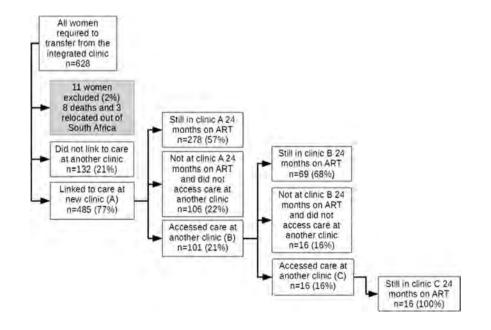


Figure 1. Flow of mobility for routine HIV care after leaving the integrated clinic through to 30 months after ART initiation.



Figure 2. Maps of clinics attended for HIV care after leaving the integrated clinic (A) within the Cape Town Metropole and (B) within South Africa.

both groups, p=0.787). However, women found at  $\geq 2$  clinics were more likely to ever access care outside of Cape Town (38% vs. 5%) and had a greater maximum distance between clinics (median 4 km vs. 1 km) compared to women who did not move again after linking.

#### 3.3 Mobility, retention and HIV VL

Of the 485 women who did have evidence of successfully linking after the integrated clinic, 438 (90%) and 398 (82%) women had evidence of being retained at 12 (6 to <18) and 24 (18 to <30) months after ART initiation respectively (Table S1). Evidence of retention at both 12 and 24 months was found for 363 women (75% of women who linked) (Table 3). When combining those who did not link to care after transfer (n = 132) and those who linked but were subsequently LTFU (n = 122), 71% (n = 438) and 65% (n = 398) of women were retained at 12 and 24 months after ART initiation respectively; 59% (n = 363) of women were retained in care at both time points.

Retention in care at both 12 and 24 months after ART initiation was associated with attending only one clinic, being >25 years old, being married, being employed, being multigravida, having a planned pregnancy and early presentation for ANC. The association with having a planned pregnancy (aRR 1.20 95% CI 1.09 to 1.33), age >25 years (aRR 1.17 95% CI 1.02 to 1.33) and presenting for ANC ≤20 weeks (aRR 1.10 95% CI 0.99 to 1.21) persisted in multivariable models (Table S3). In sensitivity analyses, having a planned pregnancy was similarly predictive of retention at 24 months after ART initiation and at 18 months postpartum, and the association between being multigravida and being retained maintained a similar effect size but reached statistical significance (Table S3). Distance moved was not associated with being retained in care.

VL measures at least 12 months after ART initiation were available for 338 of 363 women (93%) who were retained in HIV care at both 12 and 24 months after ART initiation (Table S4). There were 273 (81%) and 294 (87%) women who were virally suppressed  $\leq$ 50 and  $\leq$ 1000 copies/mL respectively (Tables S4 and S5). Attending  $\geq$ 2 clinics reduced the likelihood of having a VL  $\leq$ 50 copies/mL in multivariable models (aRR 0.81 95% CI 0.69 to 0.95); this association was not statistically significant for VL  $\leq$ 1000 copies/mL (Table 4). Being diagnosed with HIV in the current pregnancy was associated with having a VL  $\leq$ 50 and  $\leq$ 1000 copies/mL at least 12 months after ART initiation. Age >25 years predicted VL  $\leq$ 50 copies/mL, and being married/cohabiting or employed were predictive of having a VL  $\leq$ 1000 copies/mL in multivariable models (Table 4).

#### 4 | DISCUSSION

This unique study describes outcomes over 30 months of follow-up for a cohort of women who initiated ART in an integrated ANC and ART clinic and who were required to transfer ART clinics after delivery. Overall, 20% of women did not link to a new clinic within 30 months of ART initiation and an additional 21% were subsequently LTFU after linking. Cumulatively, 41% of women were not retained in care at both 12 and 24 months after ART initiation. Younger women emerged as consistently at risk for not linking to care, non-retention, non-suppression and attending ≥2 different clinics.

Our findings add to the limited literature on retention of postpartum women in Africa beyond 12 months on ART [15]. Overall retention at 12 and 24 months after ART initiation (71% and 65% respectively) were broadly comparable to reports from other parts of sub-Saharan Africa. A recent study from Malawi, using a more stringent definition of retention,

Table 3. Description of 485 HIV-positive women who linked to care after leaving the integrated clinic, by whether they were retained in HIV care at both 12 and 24 months after ART initiation. Presented as n (%) unless specified

	Retained	Not retained	All women	p-value
Number of women	363 (75)	122 (25)	485 (100)	
Characteristics at enrolment				
Mean age (SD)	29 (5.4)	28 (5.2)	29 (5.4)	0.025
Age ≤25	81 (22)	41 (34)	122 (25)	0.013
Married/cohabiting	173 (48)	43 (35)	216 (45)	0.017
Completed secondary school	93 (26)	31 (25)	124 (26)	0.963
Employed	144 (40)	38 (31)	182 (38)	0.093
First pregnancy	56 (15)	27 (22)	83 (17)	0.089
Intended pregnancy	124 (34)	22 (18)	146 (30)	0.001
Diagnosed with HIV in this pregnancy	184 (51)	71 (58)	255 (53)	0.151
Mean weeks gestation (SD)	20 (7.2)	23 (2.6)	21 (4.4)	0.001
Presented for ANC ≤20 weeks	184 (51)	47 (39)	231 (48)	0.020
Median (IQR) CD4 cell count at presentation for ANC (n = 474)	336 (235 to 499)	346 (242 to 537)	342 (235 to 509)	0.269
Characteristics at delivery				
Place of delivery (n = $467$ )				0.694
Delivered in primary care	141 (40)	49 (42)	190 (41)	
Delivered at tertiary hospital	210 (60)	67 (58)	277 (59)	
Delivery outcome				0.042
Live birth	349 (96)	115 (94)	464 (96)	
Stillbirth	7 (2)	4 (3)	11 (2)	
Miscarriage	6 (2)	O (O)	6 (1)	
Unknown	1 (<1)	3 (2)	4 (1)	
Characteristics postpartum				
Median (IQR) months from ART initiation until last evidence of accessing care	29 (27 to 29)	15 (9 to 22)	28 (21 to 29)	<0.001
Number of clinics after the integrated clinic				0.015
Attended 1 clinic	278 (77)	106 (87)	384 (79)	
Attended ≥ 2 clinics	85 (23)	16 (13)	101 (21)	
Median furthest distance (km) moved between clinics	1.07 (0.69 to 3.23)	1.07 (0.01 to 7.87)	1.07 (0.69 to 3.23)	0.868
Area moved after integrated clinic				0.252
Same health district	207 (57)	63 (52)	270 (56)	
Cape Town Metropole	117 (32)	40 (33)	157 (32)	
Western Cape Province	10 (3)	2 (2)	12 (2)	
Out of the Western Cape Province	29 (8)	17 (14)	46 (9)	

found that 77% and 71% of women were retained at 12 and 24 months on ART respectively [11]. In data from Zimbabwe and Mozambique, only 68% and 42% of women were still receiving ART 12 months after ART initiation [24,25]. A recent systematic review found a pooled estimate of 76% retained at 12 months on ART in African cohorts [15]. Reported retention in HIV care is often facility specific. Individuals who are transferred to new clinics are often considered retained in care, censored at the time of transfer or excluded from analyses [26,27]. In contrast, our results are from a cohort where all women were required to transfer care and access to HIV care was traced to any routine primary healthcare clinic in South Africa. It is of concern that, even after tracing women's movement to different clinics, 41% of women were not retained through 12 and 24 months after ART initiation. Importantly, women who never linked to care

after the integrated clinic accounted for half the LTFU seen in our cohort. This highlights the need to incorporate support for linkage to care where movement between ART clinics after delivery is required.

Current infant feeding guidelines recommend that HIV-positive women breastfeed their children for up to 24 months postpartum, making continued postpartum retention critical not only for maternal health and sexual transmission, but also to prevent MTCT in the breastfeeding period [21,28]. Breastfeeding status and access to routine child health services, although not indicators readily available in routine data systems, may impact maternal mobility and engagement in HIV care. In addition, routine child health services are very well attended in many settings and could provide opportunities to re-engage mothers who fail to link or are LTFU from HIV care.

Table 4. Poisson regression model among 338 women who were retained in care and had a VL available at least 12 months after ART initiation, predicting (A) VL  $\leq$ 50 copies/mL at least 12 months after ART initiation, and (B) VL  $\leq$ 1000 copies/mL at least 12 months after ART initiation (n = 325 with data complete). Presented as unadjusted (RR) and adjusted (aRR) risk ratios with 95% confidence intervals (CI)

	Crude			Adjusted
	RR	95% CI	aRR	95% CI
(A) VL ≤50 copies/mL at least 12 months after ART init	iation			
Attended ≥2 clinics after the integrated clinic	0.80	0.68 to 0.94	0.81	0.69 to 0.95
Age >25	1.18	1.01 to 1.38	1.17	1.01 to 1.36
Completed secondary school	1.11	1.00 to 1.23	_	
Married/cohabiting	1.10	0.99 to 1.21	_	
Planned pregnancy	1.09	0.99 to 1.21	1.10	0.99 to 1.21
Presented for ANC <20 weeks gestation	1.06	0.96 to 1.18	_	
Diagnosed with HIV in this pregnancy	1.15	1.03 to 1.27	1.15	1.04 to 1.28
Employed	1.13	1.02 to 1.25	1.08	0.98 to 1.19
(B) VL ≤1000 copies/mL at least 12 months after ART	initiation			
Attended ≥2 clinics after the integrated clinic	0.91	0.81 to 1.02	0.92	0.82 to 1.03
Age >25	1.14	1.00 to 1.29	1.10	0.97 to 1.24
Completed secondary school	1.08	0.99 to 1.17	_	
Married/cohabiting	1.14	1.05 to 1.23	1.14	1.06 to 1.24
Planned pregnancy	1.10	1.02 to 1.19	_	
Presented for ANC <20 weeks gestation	1.08	0.99 to 1.17	_	
Diagnosed with HIV in this pregnancy	1.08	0.99 to 1.17	1.10	1.01 to 1.19
Employed	1.13	1.04 to 1.22	1.12	1.04 to 1.21

Despite concerning retention levels, these results showed reassuring levels of viral suppression among women who were retained in care in this cohort. Our results suggest that increased clinic movement could be associated with increased risk of viraemia. However, we were unable to ascertain viral load outcomes for women who were not retained in care and therefore cannot conclusively determine the impact of mobility on HIV viral load. Younger age was a shared risk factor for not linking to care, more frequent mobility, non-retention and raised VL. This adds to the substantial evidence indicating that younger HIV-positive women are often at increased risk for poor treatment outcomes [15,29-33]. Although associations were small, younger age, timing of presentation for ANC and relationship status could flag women requiring additional support to link to care postpartum. Primigravity and unplanned pregnancy, previously linked to adverse maternal and child outcomes [34,35], may also flag women requiring targeted retention interventions. Although the impact of pregnancy intention on long-term ART outcomes is not clear, optimizing family planning services for both HIV-positive and negative women remains a vital component of strategies to prevent MTCT and improve maternal and child health. Importantly, interventions are needed not only at ART initiation facilities but also beyond the facility to promote continued retention in care when mobility is necessary.

Women accessed care at a variety of different clinics. Although some clinics provide combined appointments for HIV-positive mothers and their children, many require different appointments for maternal ART and routine child health and quite often these services are offered at different clinics. We

were unable to systematically assess each model of care but this should be a consideration in future work. The clinic movement seen in this analysis has further implications for linking mother-child pairs and monitoring long-term child and maternal outcomes. In both routine programmes and research cohorts, retention in ART care is frequently based on whether an individual is still receiving care from the clinic at which they started treatment [36-38]. A review of studies in low- and middleincome countries that actively traced patients to ascertain their status, showed a pooled estimate of 19% of adults considered LTFU were continuing care at other clinics [39]. Although the most recent World Health Organization recommendations for monitoring include using unique patient identifiers to allow linkage across health services, this is not a reality in many settings [40]. Availability of facility-linked data and the choice of data sources used will impact the ability to monitor long-term outcomes of women on lifelong ART and their children [41].

The results of this analysis should be interpreted with the following additional caveats in mind. Although a strength of this study is the availability of diverse data sources throughout the Western Cape Province and nationally for evaluating evidence of engagement in care, not all contacts with the health system are captured into routine electronic databases which could lead to underestimation of retention. Attempts were made to ascertain vital status using clinic records but unknown deaths may contribute to non-linkage and non-retention. Both a strength and limitation is that these results are applicable to a cohort of women required to transfer their ART care after delivery. We were unable to classify additional

mobility after linkage and outcomes may vary between formal clinic transfers and patient-initiated mobility.

Another important limitation of this analysis is that the same data sources were used to define mobility and retention in care and the mobility patterns among women who were not observed to be in care cannot be known. Surprisingly, employment was not strongly associated with mobility or any of the outcomes in this study [2,42]. This is likely a limitation of the measure which only assessed employment status at entry into ANC. Women may have returned to or started work after delivery with possible impacts on both mobility and HIV care access. Studies which can assess mobility independently from access to routine health services and which can assess changing risk factors such as employment and relationship status over time, will be required to further understand postpartum mobility and the impact on ART outcomes.

These data add important insights regarding mobility and retention in care in postpartum women up to 30 months after ART initiation in pregnancy. The step of moving care between clinics is a vulnerable step in the HIV care continuum and even women who manage to link successfully, particularly vounger, unmarried women and those who present late for ANC, remain vulnerable to subsequent LTFU and viraemia. Models of care to provide ART to pregnant and postpartum women need to accommodate women's mobility and where they choose to access care. Facility-based interventions may not be sufficient to support postpartum retention. For example, South African differentiated models of care and mHealth interventions are starting to provide non-facility based support for mothers [43,44]. Further consideration is needed on how continuous support for engagement in care can be provided as mothers living with HIV continue with their daily lives after delivery.

#### 5 | CONCLUSIONS

We found that less than two-thirds of women who started ART in an integrated ANC-ART clinic were retained in care at both 12 and 24 months after ART initiation. Losses occurred at the initial mandatory postpartum transfer and after successful linkage to care. Women who linked to care attended a wide range of facilities creating challenges for monitoring postpartum outcomes. Based on these data there is a clear and urgent need for interventions that extend outside of health facilities to help support postpartum women, and young mothers in particular, to remain engaged in lifelong ART care.

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#### **COMPETING INTERESTS**

The authors declare no competing interests.

#### **AUTHORS' CONTRIBUTIONS**

TP conceived the design, conducted the analysis and drafted the manuscript. KC contributed to the study design and analysis. AZ, CO, EJA and LM contributed to the study design and manuscript writing. All authors read and approved the final manuscript.

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#### SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

- **Table S1.** Description of 485 HIV-positive women, who had evidence of linking to care after leaving the integrated clinic, by the number of different clinics attended up to 30 months after ART initiation
- **Table S2.** Poisson regression model among 485 women who linked to care after the integrated clinic, predicting whether women moved to more than one additional clinic
- **Table S3.** Poisson regression model among 485 women who linked to care after the integrated clinic, predicting (A) retention in care at 12 and 24 months after ART initiation, (B) retention in care at 24 months after ART initiation, and (C) retention in care at 18 months postpartum
- **Table S4.** Description of 338 HIV-positive women with viral load (VL) ≤50 and >50 copies/mL who were retained at both 12 and 24 months after ART initiation and had a VL available at least 12 months after ART initiation
- **Table S5.** Description of 338 HIV-positive women with viral load (VL) ≤1000 and >1000 copies/mL who were retained at both 12 and 24 months after ART initiation and had a VL available at least 12 months after ART initiation
- **Table S6.** Description of study outcomes by the design of follow up received in the parent MCH-ART study



### COMMENTARY

# Moving forward: why responding to migration, mobility and HIV in South(ern) Africa is a public health priority

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#### **Abstract**

**Introduction:** Global migration policy discussions are increasingly driven by moral panics – public anxiety about issues thought to threaten the moral standards of society. This includes the development of two Global Compacts – agreed principles to guide an international response – for (1) "Refugees" and (2) "Safe, Regular and Orderly Migration." While the need to address migration and health is increasingly recognized at the global level, concerns are raised about if this will be reflected in the final Compacts. The Compacts focus on securitization, an approach that aims to restrict the movement of people, presenting potentially negative health consequences for people who move. Globally, concern is raised that migration-aware public health programming initiatives could be co-opted through a global health security agenda to further restrict movement across borders. This is particularly worrying in the Southern African Development Community (SADC) – a regional economic community associated with high levels of migration and the largest population of people living with HIV globally; this case is used to explore concerns about the health implications of the Global Compacts.

**Discussion:** Current HIV responses in SADC do not adequately engage with the movement of healthcare users within and between countries. This negatively affects existing HIV interventions and has implications for the development of universal HIV testing and treatment (UTT) programmes. Drawing on literature and policy review, and ongoing participant observation in policy processes, I outline how Global Compact processes may undermine HIV prevention efforts in SADC.

**Conclusions:** The global health imperative of developing migration-aware and mobility-competent health responses must not be undermined by moral panics; the resultant international policy processes run the risk of jeopardizing effective action at the local level. Globally, migration is increasingly recognized as a central public health concern, providing strategic opportunities to strengthen public health responses for all. Without mainstreaming migration, however, health responses will struggle. This is particularly concerning in SADC where HIV programmes – including UTT initiatives – will struggle, and key health targets will not be met. Globally, contextually appropriate migration-aware responses to health are needed, including and a specific focus on HIV programming in SADC.

Keywords: migration; mobility; HIV; southern Africa; Global Compact; SADC

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#### 1 | INTRODUCTION

While health has long been considered an essential component of human and economic development, the health of migrants has remained in the shadows of key global health, migration, and development dialogues and processes, and many migrants still lack access to affordable health services. (IOM, 2017: p. 4)

In spite of recent calls at the global level to improve responses to migration and health, and the development of a global research agenda to support this [1-4], the "unfinished agenda of migrant health for the benefit of all" [5,6] remains a glaring gap in current global, regional and national policy

discussions. To further complicate this situation, attempts to develop interventions on migration and health – at all levels – may be undermined by the global migration policy terrain. Following the 2016 "New York Declaration on Refugees and Migrants" [7], two Global Compacts are due to be finalized and released in the second half of 2018 – the "Global Compact on Refugees," and the "Global Compact on Safe, Regular and Orderly Migration." Global Compacts refer "to an agreement between states on matters of common interest of concern," and provide opportunities for determining how member states will "conduct themselves in the future" – in this case in relation to the management of migration [8]. Two discrete motivations for engaging with migration at a global level currently exist – one from a right to health, wellbeing, and public health perspective [1,3], and the other from a securitization and restriction of

movement approach [8,9]. The resulting tensions within the global community present multiple challenges for the development of improved responses to migration and health.

In this commentary, I explore the implications of the current global migration policy terrain for the Southern African Development Community (SADC), a regional economic community made up of 15 member states that is associated with high levels of both internal (within country) and cross-border (between country) migration and a high communicable disease burden, including the largest population of people living with HIV globally [10-13]. With the aim of offering suggestions for ways to mobilize a regional response to migration and HIV in SADC, I outline the challenges – and strategic opportunities – that result from the current global migration policy terrain. This is done by drawing on a review of research and policy associated with migration and HIV in SADC (13 and Table 1) and my ongoing participant observation within various global, regional and national policy processes.

#### 2 | DISCUSSION

#### 2.1 A global policy crisis?

As evidenced by the current Global Compact processes, we find ourselves in a world increasingly concerned with securitizing national borders and restricting the movement of people between nation states. Much of this focus on security is driven by moral panics – public anxiety about issues thought to threaten the moral standards of society - associated with migration, including human trafficking and the independent movement of women [9], and the so-called "Migration Crisis" in Europe [14-16]. Internationally, discussions on migration tend to ignore long-established population movements within Global South contexts where forced migration and movement in search of improved livelihood opportunities are commonplace and outnumber similar movements in the Global North; the Southern African region is no exception [17]. The current global discourses surrounding population mobility - that are fuelling morally panicked policy discussions - have negative impacts both for those who move, and for the development of improved responses to migration and health. Centrally, this includes the implementation of increasingly restrictive immigration policies, including further securitization of the borders of nation sates. In relation to health and wellbeing, historical perceptions of the migrant as the "diseased body"; as a carrier and transmitter of infectious diseases, particularly HIV; and, consequently, as a burden on the welfare state of receiving countries, are reemerging [18-21]. We need to remain vigilant and ensure that the re-emergence of this discourse is not used to support securitization agendas as health status may (once again) be used to mediate the ability to legally cross national borders. Particularly worrying is that this may include an unwelcome return to a focus on the HIV status of people crossing borders.

The "draft zeros" of the two Global Compacts were released in early 2018 [22,23] and, while they do acknowledge health, concerns remain that health – and other social justice issues – will be left off the final agenda [9,24]. As a result, the final Global Compacts run the risk of calling for actions that ignore – or may even be in contravention of – existing approaches aimed at improving health for all, including the Sustainable Development Goals (SDGs) [25,26] and the Global Compact

for Universal Health Care [27]. Table 1 summarizes the key international policy processes that have been engaging with migration and health, and the more recent processes associated with the Global Compacts. From a review of these processes, participation in both the 1st and 2nd Global Consultations on Migration and Health in 2010 and 2017 [3,28], and more recent engagement in global migration and health research initiatives, it becomes apparent that the progressive agenda being developed around migration and health stands the risk of being undermined by the Global Compacts process. With a clear focus on securitization and the restriction of movement, health-related issues are being side-lined in current global discussions. In addition, and particularly important for SADC, concerns have been raised that the loudest voices - those associated with the anti-immigrant agendas of northern Europe, are driving the Global Compact processes, resulting in a global agenda calling for further restrictions on international migration which will be detrimental to other regions of the world, including the African continent [29-31]. To this end, the African Union developed a draft Common African Position, that involved regional dialogues - including within SADC – in an attempt to ensure that the contextual realities of the continent are engaged with in the finalization of the Global Compacts [32]. This Position paper - which makes reference to the importance of ensuring access to healthcare for migrants - was presented in draft form at the international preparatory meeting on the Global Compacts held in Mexico in December 2017, and has since been finalized and approved [33]. How effective these interventions are, and whether health-related concerns are emphasized in the final Compacts, remains to be seen.

#### 2.2 | Migration, mobility and HIV

In spite of the SADC region being associated with a long history of diverse population movements, current public health responses to HIV still fail to adequately engage with migration and the movement of healthcare users - both within and between countries [10-12]. The result is a range of negative outcomes with serious implications for population health and HIV prevention, including challenges in initiating treatment, ensuring treatment continuity, and the associated risks for defaulting and drug resistance [34]. In addition, the absence of evidence-informed and migration-aware responses to HIV has led to the continued scapegoating of migrants - particularly non-nationals - as the carriers of HIV; the "diseased" migrant body is a long-standing trope, and one that conjures up the idea of the migrant as a disease vector, whose movements are solely responsible for the spread of new HIV infections [18]. Such imaginings conveniently absolve the state from its own shortcomings in terms of inadequate healthcare, health promotion and HIV prevention strategies. Rather, the state and their healthcare institutions blame internal and cross-border movements for placing an excessive burden on the state.

Globally – and in SADC – key population groups currently targeted for HIV prevention initiatives are often highly mobile, including sex workers and men who have sex with men [13]. Recent UNAIDS Gap Reports make the case for developing migration-aware responses to HIV, acknowledging the importance of developing cross-border initiatives and mainstreaming migration into national HIV strategic plans [13,35-37]. This

Table 1. An overview of key global and regional migration and health policy processes (expanded on from [3,12])

Year	Process
2003	WHO publishes International Migration, Health and Human Rights [54]
	International Organization for Migration (IOM) Position Paper on Psychosocial and Mental Well-Being of Migrants [55]
2004	Migrant health for the benefit of all MC/INF/275 [56]
2006	African Union Executive Council. 2006. African Common Position on Migration and Development [32]
	African Union Executive Council. 2006. The Migration Policy Framework for Africa [57]
2009	Draft 2009 declaration on population mobility and communicable diseases and associated financing model (Southern African
	Development Community (SADC)) [40] (Oxford Policy Management, unpublished work)
2008	WHA Resolution 61.17 on the Health of Migrants [58]
2010	2010 1st Global Consultation: The Health of Migrants – the Way Forward Madrid, Spain, 3 to 5 March 2010 [28]
	SADC HIV Cross Border Initiative [41]
2012	TB in the Mines (TIMS) [59] and SADC TB in the mines [42]
2015	IOM 106th Council Session: 26th Nov 2015, Geneva, Switzerland
	<ul> <li>Advancing The Unfinished Agenda Of Migrant Health For The Benefit Of All – C/106/INF/15 [5]</li> </ul>
	High-level Panel Discussion on Migration, human mobility and global health: a matter for diplomacy and intersectional
0047	partnership [6]
2016	UN GENERAL ASSEMBLY: 9th May 2016 – High-level Meeting on Addressing Large Movements of Refugees and Migrants
	• Report of the Secretary-General: In Safety and Dignity: Addressing Large Movements of Refugees and Migrants [60]
	69th World Health Assembly: 27th May 2016
	Technical Briefing on Migration and Health [61]  Provided the Control of
	Promoting the Health of Migrants. Report from the Secretariat [62]      The Company of the Migrants of the Company of the
	UN General Assembly High-level Meeting to Address Large Movements of Refugees and Migrants: 22nd Sept 2016
	Side Event Report – Health in the Context of Migration and Forced Displacement [63]
	3rd October 2016: New York Declaration for Refugees and Migrants Resolution adopted by the General Assembly
	on 19 September 2016 [7]
2017	Leaving no one behind: the imperative of inclusive development Report on the World Social Situation 2016 [64]
2017	January 2017 – 140th Session of the WHO Executive Board of the World Health  Noted the WHO Secretariat report on Promoting the health of migrants [62]
	Adopted Decision EB140 [9] – Promoting the health of refugees and migrants [65]
	February 2017: 2nd Global Consultation – Health of Migrants: Resetting the Agenda [3]
	17th May 2017:
	WHO Input to the 70th World Health Assembly – Draft framework of priorities and guiding principles. A70/24 [66]
	70th World Health Assembly – 30th May 2017
	Adoption of WHA Resolution 70.15 Promoting the Health of Refugees and Migrants [67]
	Global Compact Process
	IOM Thematic Paper: The Health Of Migrants: A Core Cross-Cutting Theme [68]
	IOM Migration Health Division – Thematic Paper Series
	MIGRATION HEALTH IN THE SUSTAINABLE DEVELOPMENT GOALS: "Leave No One Behind" in an increasingly
	mobile society [25]
2018	142nd WHO Executive Board Meeting
	71st World Health Assembly
	109th IOM Council Global
	Compact on Refugees
	Global Compact on Safe, Regular and Orderly Migration
2019	144th WHO Executive Board session
	72nd World health Assembly
	WHO Draft Global Action Plan on the Health of Refugees and Migrants to be submitted for consideration
2030	UN 2030 Agenda for Sustainable Development [26]

has implications for the development and implementation of effective HIV prevention programming, including universal HIV testing and treatment (UTT) and pre-exposure prophylaxis

(PreP). A key challenge relates to how to do this: migration is a politically sensitive issue – associated with anti-foreigner and xenophobic rhetoric, in spite of internal mobility being far

more prevalent- and HIV (and health more broadly) is also a politically sensitive concern. Bringing together the interconnected concerns and agendas relating to migration and HIV is challenging and innovative approaches to this are required; migration is a central public health concern that - if approached carefully – can provide a strategic opportunity to strengthen responses to HIV for the benefit of all. For example, framing the development of responses to migration and HIV as a key entry point to improving health for all, for addressing health inequities, and for working towards universal health coverage, could assist in obtaining the political support needed to fund and support migration-aware responses to HIV in SADC. This will have further positive impacts, namely in supporting activities for achieving global health targets, including the SDGs [26] and the UNAIDS 90-90-90 targets [38].

However, a key challenge exists - evidence suggests that SADC remains poorly equipped to initiate and manage the political discussions within and between member states that are required to develop appropriate regional responses to migration, mobility, and HIV [11,39]. This is partly due to the historical preference for the development of individual bilateral agreements between member states rather than regional responses [39]. However, as presented in Table 1, some regional processes have been initiated. For example, the SADC Framework for Population Mobility and Communicable Diseases was developed in 2009 [40] but remains in draft form with several member states refusing to ratify the Framework. The associated exercise to explore financing mechanisms – at the request of member states – was eventually completed by SADC in 2015, but remains unpublished (Oxford Policy Management, unpublished work). In 2010, the "SADC HIV and AIDS Cross Border Initiative" was awarded funding from the Global Fund to establish a regional cross-border HIV programme involving the establishment of 32 clinics offering HIV testing and treatment, alongside primary care, in border areas and along transit routes to serve migrant and mobile populations, and local migration-affected communities; 12 mainland member states signed Memorandums of Understanding (MoUs), agreeing to participate [41]. However, progress is painfully slow: phase 1 involved just 12 clinics being opened, and the second phase - with a further 20 clinics due to open - was initiated at the end of 2017, with the anticipation that all 32 clinics will be handed over to member states in the first half of 2018. The slow process and challenges associated with this give a good indication of the challenges faced - both political and logistical - in developing and implementing crossborder, migration-aware HIV interventions at a regional level. The only regional health and migration policy process that has been implemented is the 2012 Declaration on Tuberculosis in the Mines [42]; ratification of this Declaration happened quickly, and appears to be the result of any associated financial burden being the responsibility of the private sector, and not member states who are unwilling to commit to regional responses associated with migration and health.

# 2.3 A local lens: South Africa's engagement with migration and health

Within the SADC region, South Africa is the recipient of the largest number of cross-border migrants (most of whom come

from other SADC states), has a long history of internal migration, and a continued high prevalence and incidence of HIV [11,13]. However, responses to HIV that engage with population mobility are noticeably absent, in spite of calls being made for migration-aware responses to HIV [10,12,43,44]. In addition, South Africa has not ratified the 2009 "Draft SADC Framework on Population Mobility and Communicable Diseases" - in spite of the development of financing models to support equitable cost-sharing for regional responses to HIV. At a local level, some state-led responses are in place, a notable example is the sub-district of the Musina Municipality. Bordering Zimbabwe and home to the busiest border crossing in South Africa, Musina is a transit point for many. Local interventions include: mobile clinics providing antiretroviral therapy (ART) to migrant farmworkers; the Vhembe District Migrant Health Forum (MHF); and, Cross-Border Forums on HIV and TB that involve partnerships with the Musina Municipality and their counterparts in Beitbridge - on the Zimbabwean side of the border [34,69] (J Vearey and J Anderson, unpublished work).

Civil society and international organizations have attempted to step in to provide migration-aware responses in spaces where the state is absent, including through HIV interventions supported by the International Organization for Migration (IOM) (J Vearey and J Anderson, unpublished work) [45-47,69] and Medecins sans Frontiers [34]. In addition, MHFs networks of civil society, academic and government stakeholders - have been established in several areas of the country [48]. Three national migration and health consultations have been held, in partnership between IOM, the National Department of Health and the University of the Witwatersrand [49-51]. During the 2016 National Consultation, it was agreed that a National Migration and Health Forum needed to be established but, to date, no progress has been made [51]. In 2014, a task team was established to explore HIV, migration and mobility within the National Strategic Plan for HIV, STIs and TB. However, responses to migration in the national HIV plan remain limited – and no framework has been developed for their implementation [12]. South Africa is in the process of developing a National Health Insurance (NHI) which – in many ways - is a progressive development. However, current iterations of the NHI present a possible regression in the rights of non-nationals to access healthcare, including ART [52].

#### 3 | CONCLUSIONS

There is an urgent need to develop migration-aware [13] and mobility-competent [3] responses to health globally. Particular concerns are raised around the need to develop appropriate responses to migration and HIV in SADC. While gains have been made in the response to HIV in SADC, multiple challenges remain – particularly in the era of UTT – as current responses do not adequately engage with migration and the movement of healthcare users [13,53]. HIV prevalence and incidence remain high, and it has been suggested elsewhere that it is the lack of migration-aware programming that has undermined HIV prevention efforts at the regional level, where diverse internal and cross-border population movements are prevalent [13]. Currently, public healthcare systems in the southern African region are not designed to ensure continuity of care for migrant and

mobile populations and prevailing xenophobic and anti-foreigner sentiments present additional barriers to cross-border migrants [11,12,34]. The development of increasingly securitized migration management initiatives results in some crossborder migrants struggling to access the documentation required to be in a country legally – which is often required to access healthcare [12]. As a result, people moving both within countries and across national borders face barriers when trying to access HIV prevention, treatment and care [12,53]. The established evidence is clear: delayed testing and/or treatment initiation has negative impacts for infected individuals and for the populations with which they interact [34]. By not engaging with migration, programmes currently designed to support HIV testing, antiretroviral treatment initiation and treatment continuity are jeopardized, with potentially, devastating consequences for HIV prevention programming - particularly in relation to UTT initiatives.

Concerns about how the Global Compact processes may undermine efforts to improve responses to health and migration globally should not be taken lightly. Vigilance is required to ensure that migration-aware public health programming is not co-opted to support securitization agendas that place the health and wellbeing of people on the move at risk. Globally, contextually appropriate migration-aware responses to health are required; migration is a central public health imperative that provides a strategic opportunity to strengthen public health responses for all - including universal healthcare coverage [10,12]. In the SADC context, HIV prevention and treatment programmes will continue to struggle if migration is not mainstreamed, and key health targets will not be met [12]. There is an urgent need to implement a regional strategy for the development of contextually appropriate migration-aware responses to HIV in SADC, particularly in the UTT era. Efforts must be made to ensure that local-level health programming - including HIV programming in SADC is not undermined by current global moral panics, and resultant policy discourses.

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#### **COMPETING INTERESTS**

The author has no conflicts of interest to declare.

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### VIEWPOINT

# One step ahead: timing and sexual networks in population mobility and HIV prevention and care

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#### 1 | INTRODUCTION

Population mobility comes in heterogeneous forms and is triggered by many drivers. The diverse contexts of mobility can significantly influence the effectiveness of HIV prevention and care, as the contributions to this volume highlight. Nevertheless, some fundamental concepts are common across various forms of mobility. Two such concepts are time and sexual networks: mobility occurs in a space-time continuum, and migrants are situated within social and sexual networks. In this viewpoint, we argue that a closer examination of how (1) time scales of mobility and (2) sexual network characteristics of migrants present challenges to effective HIV prevention can help to optimize interventions.

#### 2 | TIME

We must consider time as well as space when conceptualizing and examining how migration might affect HIV prevention and care, including Universal Test and Treat (UTT) interventions. Forms of population mobility, especially in sub-Saharan Africa, are complex and often characterized by multiple rounds of travel, seasonal migration [1] or movement events in time [2-5]. Circular migration, where migrants leave home to work (or for other reasons) but frequently return home before leaving again, is also common, especially in South Africa [6, 7]. Sexual risk behaviour of circular migrants vary over time as well: before migrating, while away and after returning home [8,9].

Basic concepts of epidemiology will predict an association between migration and the effect of an intervention if we assume a dose-response relationship: the more the exposure to an effective HIV intervention, the larger the response. Thus, the timing of migration and chances of exposure to interventions matter for effective outcomes. For example, during a community trial of UTT, a circular migrant will not be exposed to the same level of messaging and linkage to care efforts

compared with non-migrants in their place of origin [10]. Additionally, treatment and prevention services may not reach migrants arriving in a new destination. Campaigns to increase HIV testing may miss new arrivals; they may not know where to get tested in an unfamiliar place, or may face political and structural barriers to care, such as those related to legal documentation status [11].

A recent longitudinal study in Uganda [12] found that HIV incidence decreased for permanent residents over time and scale-up of combination prevention efforts, but the same decline was not observed for migrants who had recently arrived. Similar evidence emerged in fishing villages in Uganda, where individuals who had been in the community for less than five years showed higher rates of seroconversion than longer term residents [13].

Migrants often exhibit riskier sexual behaviour while away from home compared with non-migrants [14-16], possibly due to an enabling environment. Moreover, behaviours of migrants vary with respect to *timing* of migration events as well, and seemingly converge to levels of risk behaviour of non-migrants over time [12]. Therefore, the timing of engagement into HIV care for migrants may be doubly important. Because of the non-linear nature of HIV transmission dynamics and potential for engagement in risky behaviour, a migrant disengaged from HIV care could contribute to a disproportionate amount of ongoing HIV transmission over space and time [17].

Time is also important when considering the particular stage of a person's life in which migration takes place. Following a life-course approach [18], a younger woman may be confronted by challenges to prevention and care that are different from those of an older woman, or indeed a man of any age. A migrant's life is situated within social relationships, and the social timing of mobility, such as moving when a single woman, a parent or a widow, impacts behaviour. For example, a single woman may face particular challenges because being seen as alone and available; travelling as a mother without her children, she may be anxious about their care and safety. If

she travels with children, she will need to find safe accommodation and time to care for them. Mobility is also situated in historical time: when someone moves, it exposes that person to constraints and opportunities that may differ from those of someone moving to the same place a decade earlier or later (this is termed, in demography, a "cohort effect"). Finally, there are variations in the extent people can influence the course of their life through the choices they make about mobility, sexual behaviour, prevention and care. If a young woman is struggling to find work in a place she has moved to, she may turn to transactional sex to gain access to food or shelter; this may make her vulnerable to sexually transmitted infections, violence and abuse. Human agency can be influenced by many factors: gender, age, socio-economic status, where one comes from and where one moves [19,20].

#### 3 | SEXUAL NETWORKS

Sexual transmission of HIV occurs within structured sexual networks [21-23] and the characteristics of sexual networks can influence the effectiveness of UTT. For migrants, the period after migration is often associated with instability and detachment from family, friends and previous community, with fewer constraints from social norms governing sexual behaviours [24,25]. The structure and context of migrant sexual networks are critical for understanding risks of HIV transmission [26] and the effectiveness of prevention interventions: the location (place) and timing of sexual ties can interrupt or dilute the effectiveness of interventions such as UTT. Migrant networks can bridge otherwise separate places and contribute to ongoing HIV transmission by engaging in sex acts in different places or maintaining relationships with sexual partners who live in different places [27]. The reverse is also possible, but less examined: migration can bridge places with different UTT coverage and interrupt the effectiveness of interventions. For example, large flows of migrants arriving in a new destination could reduce the proportion of a population on antiretroviral therapy below a critical threshold so that HIV could continue to circulate. Therefore, public health surveillance needs to account for both permanent and temporary migration flows.

The timing and sequence of migrant's sexual partnerships is also an important factor in anticipating and mitigating the effects of mobility on HIV prevention and care. Typically, individuals choose sexual partnerships with people who are similar to them (e.g. age, race/ethnicity) [28]. Sexual partners of mobile individuals may also be migrants or people living outside their home community (assortative mixing by migration status) [14,27]. Therefore, a migrant's partners may lack exposure to the same level of HIV treatment and prevention, and thus have higher rates of HIV infection. The spatial and temporal structure of sexual networks may result in a lower impact (e.g. population-level incidence) given the same amount of effort/intervention.

#### 4 ONE STEP AHEAD

As evidenced by the articles in this supplement, population mobility is complex. Nevertheless, there exist some fundamental concepts that we can rely on to understand when and why mobility presents challenges for HIV prevention and care, and

how to improve interventions. Since timing of mobility can influence the effectiveness of HIV prevention efforts, the rollout of interventions needs to account for time and potential missing populations. For example, seasonal patterns of mobility can be used to strategize and optimize interventions. For example, in Niger, seasonal migration patterns were estimated with satellite imagery in order to predict the most effective time for a measles vaccination campaign [29]. Second, spatial and temporal characteristics of migrant sexual networks may reduce intervention effectiveness, but a network perspective can be leveraged to improve or broaden interventions as well. For instance, mobile individuals can distribute HIV self-tests or deliver antiretroviral drugs to partners, possibly obtaining a broader coverage of testing or treatment as prevention than otherwise possible with individual interventions. Knowledge of the mobility of specific populations in specific settings can be used to inform, fine-tune, and thus amplify the potential effectiveness of differentiated care models as well as HIV prevention interventions. Such interventions are urgently needed to enable migrants to maintain their health and that of their sexual partners [30].

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