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Treatment retention and care transitions during and after the scale-up of HIV care and treatment in Northern Tanzania

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Abstract

Decentralization of HIV care is promoted to improve access to antiretroviral therapy in sub-Saharan Africa. This study describes care transitions among HIV-infected persons in Northern Tanzania during a period of rapid decentralization of HIV Care and Treatment Centers (CTCs) from hospitals to local health centers.

Between November 2008 and June 2009, 492 HIV-infected patients in established care at two referral hospitals in Moshi, Tanzania, and 262 persons newly diagnosed with HIV were selected for participation in a prospective cohort study entitled Coping with HIV/AIDS in Tanzania. Clinical records and participant self-reports, collected between June and November 2012, were used to describe retention in care and transitions between CTCs during the study period.

After a mean follow-up period of 3.5 years, 10 percent of participants had died, 9 percent were lost to follow-up, and 11 percent had moved. Of the remaining participants enrolled from CTCs, more than 90 percent reported at least one CTC visit during the previous six months, with 98 percent still in care at the CTC at which they were enrolled. Nearly 3 out of 4 newly diagnosed clients listed a referral hospital as their primary CTC. Fewer than 10 percent of participants ever

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sought care at another CTC in the study area; nearly 90 percent of those in care bypassed their closest CTC. Administrative data from all facilities in the study area indicate that new clients, even after the scale-up from 8 CTCs in 2006 to 21 CTCs in 2008, disproportionately selected established CTCs, and client volume at newly approved facilities was highly variable.

Despite the decentralization of HIV care and treatment in this setting, many patients continue to bypass their closest CTC to seek care at established facilities. Patient preferences for HIV care, which may inform optimal resource utilization, are largely unknown and warrant further investigation.

Keywords

HIV/AIDS; antiretroviral therapy; decentralization; treatment retention; Tanzania

BACKGROUND

Access to antiretroviral therapy (ART) in low- and middle-income countries (LMIC) has improved dramatically over the past decade (World Health Organization, 2013), facilitated in part by the decentralization and scale-up of the number of health facilities providing ART (El-Sadr et al., 2012; TACAIDS, 2012).

Decentralization of HIV care has been pursued by numerous sub-Saharan African (SSA) countries (see, e.g., Fayorsey et al., 2013; Pfeiffer et al., 2010; Topp et al., 2013; Uebel, Joubert, Wouters, Mollentze, & van Rensburg, 2013; World Health Organization, 2013) and is advocated by the President's Emergency Plan for AIDS Relief (PEPFAR) as a means of expanding coverage, co-utilizing services for HIV and other illnesses, and improving engagement and retention in care (PEPFAR, 2009; Gilks et al., 2006; Mulamba et al., 2010). While several implementation studies (Mutemwa et al., 2013; Topp et al., 2013; Uebel et al., 2013) described efficiency gains due to decentralization and integration of HIV care with care for other conditions, little is known about changes in patients' care-seeking behaviors in response to the availability of additional treatment options.

In 2008, near the beginning of a marked expansion of HIV care and treatment in Tanzania, the Coping with HIV/AIDS in Tanzania (CHAT) study prospectively enrolled cohorts of patients with established HIV infection and persons newly diagnosed with HIV, with the aims of identifying predictors of HIV treatment adherence and health outcomes in a SSA setting. Analyses of study participants' transitions between HIV care and treatment centers (CTCs) during the 3.5 year study period provide a unique opportunity to assess the effects of HIV care and treatment decentralization on care-seeking behaviors.

METHODS

CHAT is an observational cohort study designed to explore the relationships between psychosocial characteristics, treatment adherence, and health outcomes among HIV-positive individuals in Tanzania (Pence et al., 2012). The study was conducted in three districts in Kilimanjaro Region, Tanzania. During the past decade, the study area experienced a significant increase in the number of health facilities providing HIV care and treatment

services. In 2004, only one zonal referral hospital and one regional public hospital, both in the Region's capital, were operating as CTCs; by 2008, the number of CTCs had increased to 21 (Figure 1.)

Sample selection

Between November 2008 and June 2009, CHAT recruited 492 patients with established HIV infection from the region's two referral hospitals and 262 newly diagnosed individuals from four urban voluntary counseling and testing sites. Participants were ages 18–65 years at enrollment and had no plans to leave the study area. The detailed CHAT sampling and enrollment approach has been described previously (Pence et al., 2012) and is summarized in a supplemental online appendix.

Data collection

Surveys addressing varied domains, including demographic characteristics, HIV knowledge and risk behaviors, physical and mental health, and HIV medication adherence were administered twice annually by trained research interviewers in participants' native language, Kiswahili (Pence et al., 2012). At the 3.5 year follow-up assessment, participants were also asked to list all CTCs ever attended and to identify their primary CTC. GPS coordinates were obtained for all study area CTCs; participants' residences were linked to village centroids (OpenMicroData, 2013).

Ethical considerations

Study activities were approved by the Institutional Review Boards of Duke University, Kilimanjaro Christian Medical College and the National Institute for Medical Research in Tanzania.

Analysis

Student t-tests and chi-squared statistics were used to assess the statistical significance of differences between participants in established care and those newly diagnosed at enrollment. Distances from village centroids to study area CTCs were calculated using the shortest possible route along a known road network, plus straight line distances from each endpoint to the nearest road (ESRI, Redlands, CA).

RESULTS

Participants' demographic and clinical characteristics are summarized in Table 1. At baseline, nearly two-thirds of participants had experienced a WHO stage 3 or 4 event; the majority had a nadir CD4+ count below 200 cells/mm³; 82 percent of those in established care were on ART. More than half of the participants came from rural areas. On average, patients reported travelling more than 15km and spent more than 1 hour getting to the CTC.

After 3.5 years of follow-up, nearly 3 out of 4 newly diagnosed clients listed a referral hospital as their primary CTC, and 98 percent of participants enrolled at the two referral hospitals still considered these hospitals to be their primary CTC (Table 2). Only 5 percent of CHAT participants ever sought care at another facility in the study area.

Many patients bypassed multiple closer facilities for care at their self-identified primary CTC (Table 3). For both urban and rural participants the distance to their primary CTC was more than twice the distance to their closest CTC. One of 10 rural patients and 12 percent of urban patients sought care at their closest CTC; half of rural participants and two thirds of urban participants were in care at their respective closest hospital-based CTCs. Only 2 percent were in care at their nearest health center.

Administrative data from the study area also suggest limited utilization of many newly approved CTCs. Between 2009 and 2012, 3,291 new clients enrolled at the two referral hospitals (1,645 per facility); 2,435 at six other hospitals (406 per facility); and 2,332 at fourteen health centers (167 per facility; Figure 2). The variation in client enrollment at newly approved facilities was high.

DISCUSSION

This study describes treatment retention and care transitions among a cohort of HIV infected adults during a period of rapid HIV care and treatment scale-up in Northern Tanzania. After 3.5 years of follow-up, despite a near tripling of the number of CTCs in the study area, 98 percent of patients enrolled from the two referral hospitals remained in care at these facilities, and nearly three quarters of newly diagnosed study participants made a referral hospital their primary CTC. Despite concerted efforts to decentralize HIV care and treatment to smaller, local facilities, many patients continued to bypass their closest CTC, and the number of clients enrolled at newly approved CTCs was low and varied greatly across facilities.

While patients' familiarity with existing care providers may have played a role in limiting care transitions, a variety of characteristics, including concerns regarding quality of care, confidentiality, patient-provider interactions, cost, and the availability of medications, laboratory tests, and other services (T. Heckman et al., 1998; Ickovics & Meade, 2002; Meredith, Orlando, Humphrey, Camp, & Sherbourne, 2001; R. Whetten et al., 2006), influence patients' decisions to engage and remain in care at specific facilities.

A recent Cochrane review (Kredo, Ford, Adeniyi, & Garner, 2013) provided no evidence that decentralization from hospitals to more peripheral health facilities led to worse health outcomes, and in some settings loss to care was reduced. However, experiences from both wealthier and poorer nations suggest that the quality of HIV care varies greatly across diverse HIV treatment clinics (Halm, Lee, & Chassin, 2002; T. G. Heckman et al., 1998; Hogg et al., 1998; Shapiro et al., 1999). While some studies indicate that comparable quality can be provided at primary health facilities (Boyer et al., 2012; Fayorsey et al., 2013; Hansudewechakul et al., 2012; McGuire et al., 2012), others document a lack of laboratory facilities, medication shortages and limited drug options (Labhardt et al., 2012; Nyogea et al., 2012; Pasquet et al., 2010). Further, while some aspects of localized care, such as community-based support and increased tracing of defaulters, may appeal to some patients, others may perceive these activities as intrusive or stigmatizing (Humphreys et al., 2010).

While this study cannot ascertain the reasons for patients' treatment decisions, low rates of care transitions to smaller CTCs have significant implications for the cost-effectiveness of decentralization efforts and the potential success of further decentralization of HIV care. The push for decentralization of HIV care to rural areas in the United States in the 1990s was not as successful as hoped, largely due to concerns about the quality of care, confidentiality, and stigma (McKinney, 2002; Nguyen & Whetten, 2003; Reif, Golin, & Smith, 2005; K. Whetten & Pence, 2013; K. Whetten, Reif, Whetten, & Murphy-McMillan, 2008). Similar concerns affect care in rural areas of low and middle-income countries (Kahabuka, Kvåle, Moland, & Hinderaker, 2011; Kahabuka, Moland, Kvåle, & Hinderaker, 2012; Tran & Nguyen, 2012).

We acknowledge several limitations of this study. Rates of care transitions in this study may not be representative of all HIV patients in the area; no information was available on care locations among those who dropped out of the study; and treatment patterns may differ for different populations, including by gender. Further, the findings may not be generalizable to other areas that experienced similar scale-up of HIV care and treatment.

CONCLUSION

Despite intense efforts to scale-up and decentralize HIV care, many patients continue to bypass their closest HIV CTC to seek care at larger established facilities. With the effectiveness and cost-effectiveness of decentralization depending greatly on the ability of new CTCs to attract and retain a sufficiently large client base, further evidence is needed to understand the characteristics of care and treatment delivery that influence patients' care-seeking behaviors.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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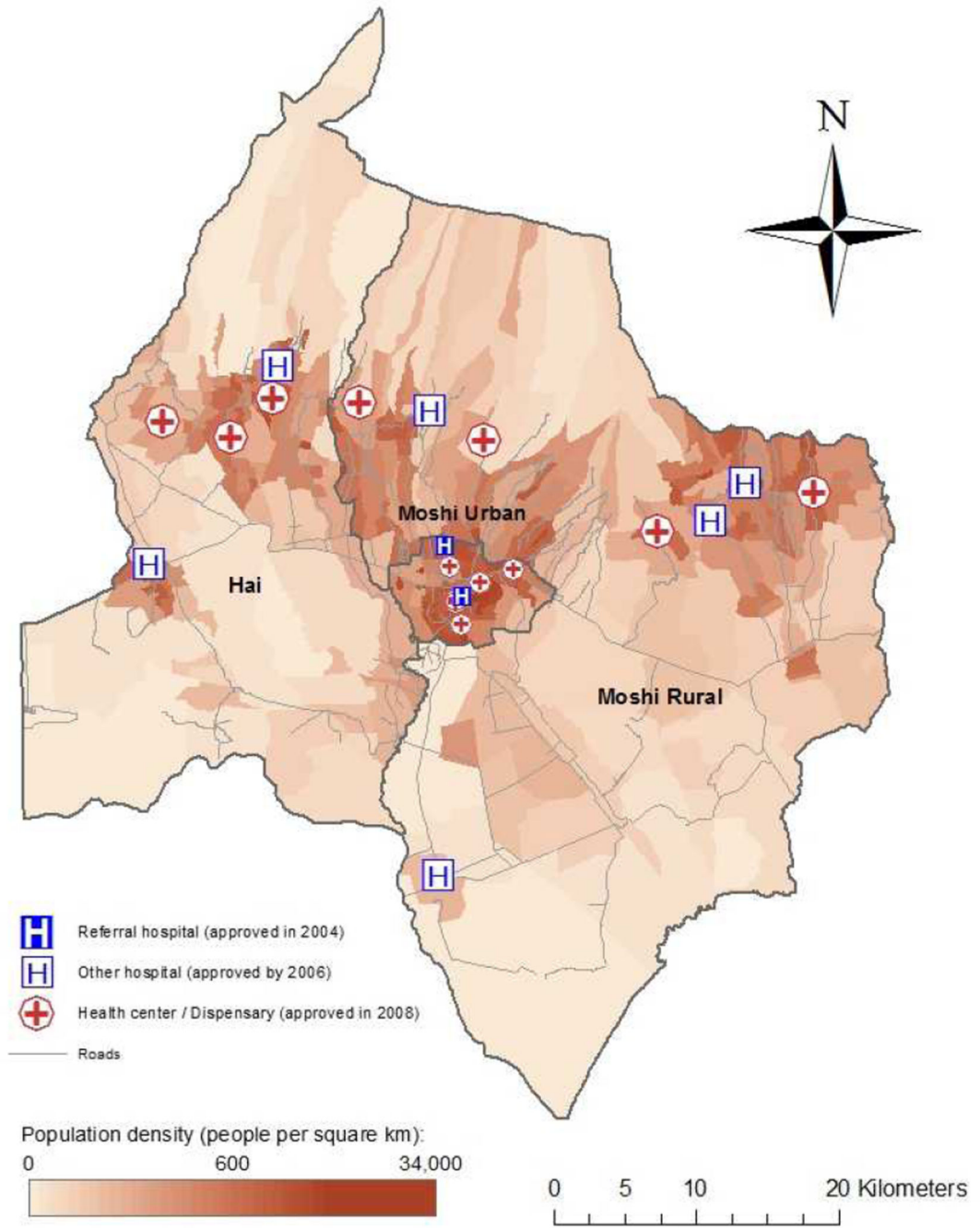


Figure 1.
 HIV care and treatment centers (CTCs) in the CHAT study area
 Note: Two proximal health center-based CTCs in Moshi Urban are indistinguishable in the figure.

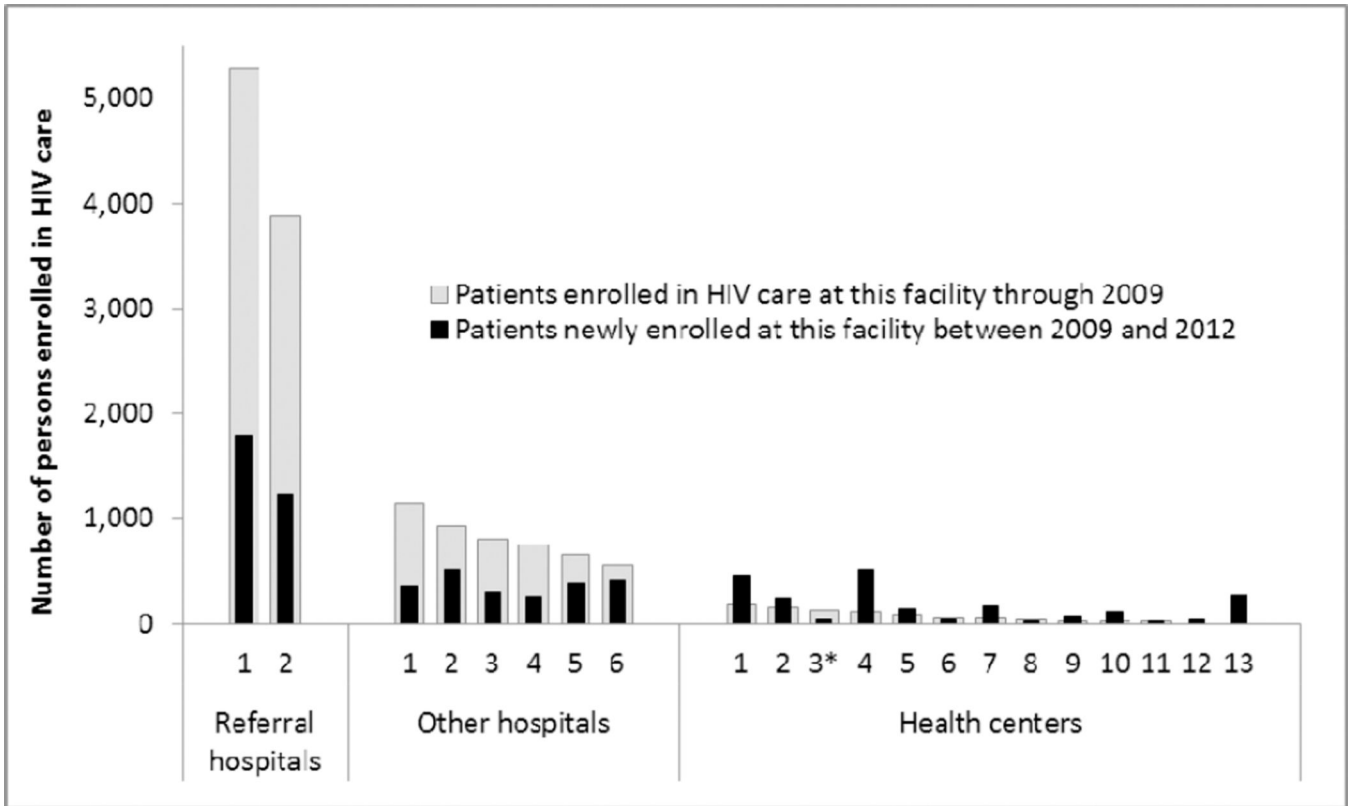


Figure 2.

Patient enrollment before and after CTC scale-up in the study area, 2009 through 2012

Source: Administrative data for the CHAT study area; sequential numbers identify individual CTCs in each category (referral hospitals; other hospitals; health centers), sorted by cumulative patient enrollment through September 2009. The cumulative number of clients ever enrolled at CTCs in the study area increased from 14,865 in 2009 to 22,874 in 2012. Correlation between pre- and post-2009 volumes: $\rho=0.9526$; $R^2=0.9075$.

*2011 data were used due to missing 2012 data for one facility.

Table 1

CHAT sample characteristics at baseline (N=754)

| | In established care | Newly diagnosed ¹ | |
|--|-----------------------------|------------------------------|----------------|
| Number of participants | 492 | 262 | |
| <i>Client characteristics</i> | Percent or mean (sd) | Percent or mean (sd) | p-value |
| Female gender | 68.1 % | 68.7 % | 0.863 |
| Age (years) | 41.8 (8.8) | 37.4 (9.0) | <0.001 |
| Married | 36.8 % | 37.8 % | 0.787 |
| Nadir CD4+ count < 200 cells/mm ³ | 63.0 % | 50.0 % | 0.107 |
| 200 to < 350 cells/mm ³ | 24.3 % | 26.7 % | |
| 350 to < 500 cells/mm ³ | 8.9 % | 15.0 % | |
| 500+ cells/mm ³ | 3.8 % | 8.3 % | |
| WHO stage 3 or 4 | 64.4 % | 60.0 % | 0.404 |
| Years since HIV diagnosis | 2.0 (1.7) | 0.0 (0.0) | <0.001 |
| On antiretroviral therapy | 82.4 % | 10.3 % | <0.001 |
| Rural residence | 57.6 % | 62.5 % | 0.206 |
| Time spent getting to the CTC (minutes) | 80.9 (46.9) | | |
| Patient-reported distance to CTC (km) | 15.7 (12.5) | | |
| Cost of getting to and from CTC (TSH) ² | 1749.2 (1352.0) | | |

¹Of newly diagnosed participants, 38% were enrolled immediately, 49 percent within one week of diagnosis; 13% more than one week after diagnosis.

²In 2008, the exchange rate of US Dollar to Tanzania shilling was approximately 1:1,200.

Table 2

HIV care and treatment among CHAT participants after 3.5 years of follow-up (N=525)

| | Participants enrolled from | | | Total N (%) |
|--|---------------------------------|---------------------------------|-----------------------------|----------------|
| | Referral hospital 1 N (%) | Referral hospital 2 N (%) | Newly diagnosed N (%) | |
| N at baseline | 223 | 269 | 262 | 754 |
| Died | 7 (3%) | 26 (10%) | 42 (16%) | 75 (10%) |
| Lost to follow-up | 8 (4%) | 16 (6%) | 46 (18%) | 70 (9%) |
| Moved during the study period ¹ | 24 (11%) | 24 (9%) | 36 (14%) | 84 (11%) |
| N at follow-up ² | 184 | 203 | 138 | 525 |
| At least 1 CTC visit in the past 6 months | 166 (90%) | 190 (94%) | 111 (80%) | 467 (89%) |
| Primary care location after 3.5 years | | | | |
| Referral hospital 1 | 181 (98%) | 1 (0%) | 8 (6%) | 190 (36%) |
| Referral hospital 2 | 0 (0%) | 198 (98%) | 94 (68%) | 292 (56%) |
| Other hospital | 0 (0%) | 1 (0%) | 3 (2%) | 4 (1%) |
| Health center | 2 (1%) | 2 (1%) | 16 (12%) | 20 (4%) |
| Out of the study area | 1 (1%) | 1 (0%) | 7 (5%) | 9 (2%) |
| Never sought care at a CTC | 0 (0%) | 0 (0%) | 10 (7%) | 10 (2%) |
| Total # of CTCs ever attended | | | | |
| 1 | 165 (90%) | 176 (87%) | 104 (75%) | 445 (85%) |
| 2 | 17 (9%) | 26 (13%) | 23 (17%) | 66 (13%) |
| 3 | 2 (1%) | 1 (0%) | 1 (1%) | 4 (1%) |
| # of CTCs in the study area ever attended | | | | |
| None | - | - | 13 (9%) | 13 (2%) |
| 1 | 171 (93%) | 188 (93%) | 112 (81%) | 471 (90%) |
| 2 | 12 (7%) | 15 (7%) | 13 (9%) | 40 (8%) |
| 3 | 1 (1%) | 0 (0%) | 0 (0%) | 1 (0%) |

¹ 84 participants who moved during the study period were excluded from analyses of treatment locations at follow-up because many of these participants moved out of the study area, and patients may have moved for their HIV care.

² All subsequent percentages refer to CHAT participants observed at both baseline and follow-up who did not move during the study period.

Table 3

Distances from participants' homes to HIV care and treatment centers, 2012 (N=502)

| | Rural | Urban | |
|--|--------------|--------------|--------|
| # of participants ^I | 265 | 237 | |
| # of active CTCs in the study area | 13 | 8 | |
| Estimated distance to the primary CTC (km) | 20.5 (11.6) | 5.5 (7.4) | <0.001 |
| Estimated distance to the closest CTC (km) | 9.5 (6.6) | 2.5 (4.2) | <0.001 |
| % of patients seeking care at: | | | |
| Closest HIV CTC | 10.2 % | 12.7 % | 0.384 |
| Closest hospital-based CTC | 46.0 % | 66.7 % | <0.001 |
| Closest health center-based CTC | 1.5 % | 2.1 % | 0.613 |
| # of urban CTCs bypassed for care | 2.9 (2.2) | 3.0 (2.3) | 0.713 |
| # of rural CTCs bypassed for care | 1.6 (1.8) | 0.2 (0.9) | <0.001 |
| Total # of CTCs bypassed for care | 4.5 (3.2) | 3.1 (2.6) | <0.001 |

^IExcludes 10 participants who never sought care at a CTC, 9 participants whose primary CTC is outside the study area, and 4 participants with missing data on residence or CTC location