

# Community-based antiretroviral therapy programs can overcome barriers to retention of patients and decongest health services in sub-Saharan Africa: a systematic review

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In sub-Saharan Africa models of care need to adapt to support continued scale up of antiretroviral therapy (ART) and retain millions in care. Task shifting, coupled with community participation has the potential to address the workforce gap, decongest health services, improve ART coverage, and to sustain retention of patients on ART over the long-term. The evidence supporting different models of community participation for ART care, or community-based ART, in sub-Saharan Africa, was reviewed. In Uganda and Kenya community health workers or volunteers delivered ART at home. In Mozambique people living with HIV/AIDS (PLWHA) self-formed community-based ART groups to deliver ART in the community. These examples of community ART programs made treatment more accessible and affordable. However, to achieve success some major challenges need to be overcome: first, community programs need to be driven, owned by and embedded in the communities. Second, an enabling and supportive environment is needed to ensure that task shifting to lay staff and PLWHA is effective and quality services are provided. Finally, a long term vision and commitment from national governments and international donors is required. Exploration of the cost, effectiveness, and sustainability of the different community-based ART models in different contexts will be needed.

**Keywords:** HIV, Antiretroviral therapy, Highly active, Health services accessibility, Task shifting, Community participation

## Introduction

In sub-Saharan Africa 23.2 million people live with HIV, and more than 10 million are in need of antiretroviral therapy (ART). With ART coverage in sub-Saharan Africa at around 50% of the need, health systems are faced with the dual challenge of having to increase the rate of enrollment for those still in need while at the same time continuing to care for the millions of people who are currently on treatment.<sup>1</sup>

There are considerable challenges to managing this ever growing caseload. A critical shortage of clinically qualified staff to provide clinical care places considerable pressure on the scarce medical workforce.<sup>2</sup> In rural Africa, the low geographical density of health structures creates a heavy burden on patients who may have to travel long distances to seek care, and patients may have to choose between cost of food and cost of transport fees to the ART clinic. In urban settings, competing activities such as work and social life interfere with time spent queuing in overburdened health facilities with large patient cohorts. Moreover,

long waiting times are a key driver of attrition among patients on ART.<sup>3</sup> A meta-analysis from over 17 countries in sub-Saharan Africa revealed that patient attrition on ART was 30% at 24 months and 35% at 36 months.<sup>4</sup> Attrition included patients who died or were lost to follow-up (LTFU) while on ART, and is the opposite of retention (i.e. 1 – attrition).<sup>4</sup>

One way to overcome the shortage of health staff is task shifting, which aims to obtain an optimal skill mix among the different professional categories within local health teams in order to increase capacity to deliver services.<sup>5,6</sup> Lay workers, communities and people living with HIV/AIDS (PLWHA) can also be engaged and deliver basic essential care functions to decrease the pressure on the scarce medical cadres.<sup>7</sup> In particular, treatment adherence strategies such as peer support and community participation in care can increase the autonomy for day-to-day decision making of patients and their families.<sup>8</sup>

Task shifting, coupled with community participation, has the potential to address the workforce gap and make effective HIV care more widely available and closer to the communities.<sup>5,7</sup> This

paper reviews the published evidence for approaches and impact of engaging lay people (including volunteers, community health workers (CHWs) and PLWHA in ART delivery, a strategy that has the potential to be expanded and sustained in the resource scarce context of sub-Saharan Africa.

## Methods

A search strategy was developed combining key terms associated with community-based ART (CBART) programs: 'HIV' OR 'Antiretroviral Therapy' AND 'Africa' AND 'Community' OR 'Communit\*' OR 'Self Care' OR 'Home' OR 'Volunteer\*' AND 'Treatment Outcome' OR 'CD4 Lymphocyte Count' OR 'HIV Infections/Mortality' OR 'Survival Rate' OR 'Patient Dropouts' OR 'Acceptability' OR 'Affordability' OR 'Cost' OR 'Patient Acceptance of Health Care' OR 'Social Stigma'. The Cochrane Collaboration and Pubmed databases were searched in February 2013. Moreover, websites of non-governmental organizations, such as Médecins Sans Frontières (MSF) and The AIDS Support Organization (TASO), were assessed to identify relevant documentation. Google scholar was searched with key words of the string, and reference lists of relevant papers were checked. No language or study design restrictions were used.

All retrieved abstracts were reviewed in duplicate (FR and TD). Articles were retrieved if they: reported original data on effectiveness, acceptability or cost of CBART, and engaged lay workers, volunteers or PLWHA in community ART delivery (ART defined as treatment with at least three antiretroviral medications).

Articles without original data on effectiveness, acceptability or cost of CBART were excluded. Articles documenting directly observed therapy (DOT) programs were excluded, as the DOT strategy is not compatible with the principles of empowerment and self-management for chronic disease care.<sup>8</sup> Moreover DOT has already been established by other reviews to offer little or no benefit over self-administered treatment.<sup>9</sup>

## Results

Our search identified 1133 records, among which 1091 were excluded after reading the title and/or abstract; 42 records were read in full, and 18 were retained for review (Figure 1). The 18 retrieved records published outcomes of six different programs from three countries (Table 1). All articles were published between 2006 and February 2013. The 18 records comprised two cluster randomized controlled trials (RCTs), 11 prospective or retrospective observational cohort studies, two qualitative studies, one cost-effectiveness study, one activity report from a non-governmental organization and one abstract.

The different models described in the literature can be divided in two categories: health service outreach to support home-based ART delivery by CHWs, peer CHW or volunteers, in Uganda and Kenya; and patient-led community ART dispensing, in Mozambique.

### Health service outreach to support home-based ART delivery

#### *Home-based ART delivery by CHWs in Uganda*

In Uganda, CHWs were engaged in three different CBART programs to deliver ART at home, provide adherence support, detect side effects and opportunistic infections, and refer sick patients to the

clinics. Each CHW was responsible for 35 to 40 PLWHA on ART. CHWs were lay people, and received 4–6 weeks training and a basic salary to provide simple standardized medical tasks. They were equipped with a motorbike, and had access to a cell phone to ask advice from health facility-based medical staff when needed. Questionnaires and checklists were used for guidance and monitoring. Patients were enrolled in the CBART program straight after ART initiation. Routine visits to the clinic were scheduled every six months, or not at all. During regular meetings with all stakeholders information was provided and difficulties were discussed, which resulted in the development of a partnership between the patients, the community and the service provider (Tables 1 and 2).<sup>10–19</sup>

In a first CBART program, in Jinja, Uganda, a cluster RCT compared outcomes at 12 and 36 months on treatment of a CBART cohort with a facility-based cohort, and found a viral load below 500 at 12 months in 84% of the CBART cohort, and 83% in the facility-based cohort. At 12 months mortality rates were 11% in both arms, LTFU was 1% in the CBART and 2% in the facility-based cohort.<sup>17</sup> After 36 months follow-up, mortality rates were 14% in the CBART and 13% in the facility-based arm.<sup>18</sup> Time and money spent accessing HIV care were reduced drastically as patients only invested to go to a clinic when sick.<sup>17</sup> Overall, CBART was found to be no more expensive than facility-based ART, as the costs of the home visits were offset by the savings from reduced health service utilization.<sup>17</sup>

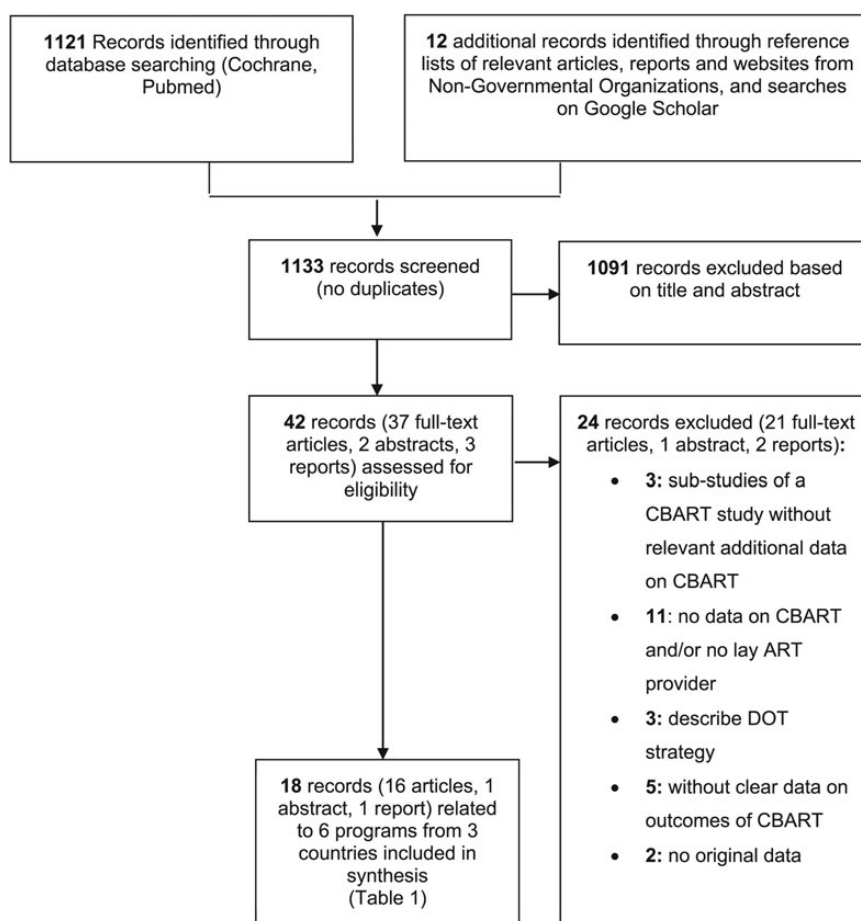
Prospective studies conducted at two other CBART programs sites in Uganda found similar results at 12 and 24 months.<sup>10,12,14,15</sup> Compared with no intervention, mortality decreased by 95% among PLWHA who accessed ART in the CBART program.<sup>12</sup> Program data reported 8.7% and 22.4% attrition respectively among 2155 patients in CBART and 1302 patients in the facility-based cohort.<sup>19</sup> CBART was associated with multiple positive social outcomes such as increased social support at community level and decreased discrimination.<sup>11</sup> Patients who before CBART had no access to HIV care were enrolled on ART together with multiple family members.<sup>10</sup>

#### *Home-based ART delivery by volunteers in Uganda*

Another study piloted a home-based ART delivery model, run by community volunteers. Volunteers had two days training. Each volunteer visited weekly no more than five PLWHA to deliver ART, support and monitor adherence, and refer sick patients to the clinic. The volunteers were motivated by social recognition and non-monetary incentives. During monthly meetings problems were reported and solutions sought. Out of the 41 volunteers 39 remained active over the entire study period.<sup>20–23</sup> A total of 185 patients on ART were enrolled in the CBART cohort, and 200 patients in the facility-based cohort. Treatment outcomes and response of the CBART cohort were comparable with the results of the facility-based cohort at 24 months of treatment, with 30% attrition in both arms, and respectively 7% and 13% viral suppression in the CBART and facility-based arm.<sup>23</sup> The mean physical and mental health among patients in CBART improved significantly after one year.<sup>21</sup>

#### *Home-based ART delivery by peer CHWs*

In Kenya, CHWs were recruited among PLWHA, and named community care coordinators (CCC).<sup>24,25</sup> CCCs received a 7-day



**Figure 1.** Flow of information through the different phases during the review of published work related to community-based antiretroviral therapy (CBART). DOT: directly observed therapy.

didactic training, followed by two months practicum. Each CCC is responsible for up to 20 clinically stable HIV positive adults and deliver ART, monitor adherence and refer patients if clinical problems arise. CCCs used personal digital assistants (PDAs), pre-programmed electronic devices that assist them in identifying and managing common problems and complaints. Routine clinic visits were scheduled every three months. Outcomes obtained were similar in both arms. At 12 months, of the 96 patients randomly assigned to the community-based arm, 5 (5%) were LTFU, 1 (1%) had died, and among those retained 89% had an undetectable viral load. Among the 112 patients in the health facility-based arm, 5 (5%) were LTFU, none had died and the viral load was undetectable for 86% among the retained.<sup>25</sup> The total number of health facility visits, including 3-monthly routine visits and unplanned visits, were reduced by 50% for the intervention arm.<sup>25</sup> CCCs were able to add their experience of living day-to-day with HIV to their professional skills which resulted in unexpected insights and practical solutions for adherence barriers and psychosocial problems.<sup>24,25</sup> Occasional reports on stigma-related events decreased after 16 months of implementation. Nevertheless, patients preferred to receive the peer CHWs in their homes than at public venues, to prevent stigma.<sup>24</sup>

### Patient-led community ART dispensing

In Mozambique, in Tete province, MSF and the district Ministry of Health proposed a series of practical solutions based on the concepts of peer support and self-management to improve retention in this highly resource-constrained environment. Driven by their own desire to improve their health, PLWHA agreed to self-form peer groups, named Community ART Groups (CAGs). PLWHA could join a CAG when more than six months on ART, clinically stable, and having a CD4 more than 200 cells/ $\mu$ l. CAGs had a maximum of six members, who participated in standardized care tasks such as ART distribution, adherence monitoring, outcome reporting and referral of sick members to the health facility, and supported each other socially. CAG members elected monthly a representative to fetch a drug refill at the clinic. When back in the community, the medication was delivered to the fellow members of the CAG.<sup>26</sup>

Joint decision making, regular dialogue and opportunities to give feedback were essential steps in the process of implementation of CAG. Early results showed an excellent retention of 97.5% (attrition 2.5%) among 1301 stable patients on ART (median follow-up time 13 months).<sup>26</sup> These early results have been sustained over time, with 95.7% of 5727 members still in care by

**Table 1.** Characteristics of the studies documenting CBART programs

Study, year	Study design	Country	CBART model and type lay ART provider	No. of participants	Contains data on
Weidle et al. 2006 <sup>10</sup>	Prospective cohort study	Uganda (Tororo and Busia districts)	Home-based ART delivery by CHW (field officer)	987 CBART	Treatment response Treatment outcomes
Apondi et al. 2007 <sup>11</sup>	Qualitative study			654 CBART	Social outcomes
Mermin et al. 2008 <sup>12</sup>	Prospective cohort study	Uganda		1045	Treatment response
Moore et al. 2011 <sup>14</sup>		(Tororo, Busia, and Mbale districts)		1094	Treatment outcomes
Mermin et al. 2011 <sup>15</sup>				1132	
Marseille et al. 2009 <sup>13</sup>	Cost-effectiveness study			all CBART 1045	Cost effectiveness of CBART
Amuron et al. 2007 <sup>16</sup>	Cluster RCT	Uganda (Jinja district)		Total 1453	Treatment response
Jaffar et al. 2009 <sup>17</sup>				859 CBART	Treatment outcomes
Amuron et al. 2011 <sup>18</sup>				594 FBART	Cost
Mpiima et al. 2012 <sup>19</sup>	Retrospective cohort study (activity report)			Total 3457	Treatment outcomes
				2155 CBART	
				1302 FBART	
Kipp et al. 2010, 2011, 2012 <sup>20,22,23</sup>	Prospective cohort study	Uganda (Kabarole district)	Home-based ART delivery by volunteers	Total 385	Treatment response Treatment outcomes
				185 CBART	
				200 FBART	
Alibhai et al. 2010 <sup>21</sup>	Qualitative study			130 CBART	Health related quality of life
Wools-Kaloustian et al. 2009 <sup>24</sup>	Cluster RCT	Kenya	Home-based ART delivery by peer CHW (CCC)	Total 208	Treatment response
Selke et al. 2010 <sup>25</sup>				96 CBART	Treatment outcomes
Decroo et al. 2011, 2012 <sup>26,27</sup>	Retrospective cohort study	Mozambique	Patient led community ART dispensing in peer groups (CAG)	1301 CBART	Treatment outcomes

ART: antiretroviral therapy; CAG: community ART group; CBART: community-based ART; CCC: community care coordinator; CHW: community health worker; FBART: facility-based ART; RCT: randomized controlled trial.

**Table 2.** Characteristics of described CBART models

CBART model and type lay ART provider	Training	Salary or other motivation	Equipment	Inclusion criteria clients CBART	No. of clients/lay provider	Frequency community distribution	Frequency clinic visits
Home-based ART delivery by CHW <sup>10-19</sup>	Four to six weeks theoretical training; Refresher courses	Salary	Motorbike Cellphone	From initiation ART; Positive adherence plan for some studies	35-40	Weekly or monthly	Range: no regular visits – every six months
Home-based ART delivery by volunteers <sup>20-23</sup>	Two day training and monthly meetings	Social recognition; Non-monetary incentive	Bicycle Boots Raincoat	From initiation ART; Willing to receive home visits	5	Monthly for ART; Weekly for other support	Every 6 months
Home-based ART delivery by peer CHW <sup>24,25</sup>	One week theoretical; Two months practical	Salary	Motorbike Cellphone Electronic device	3 months on ART; Clinically stable	11	Monthly	Every 3 months
Patient led community ART dispensing in peer groups <sup>26,27</sup>	6 monthly meetings	Health benefits; Peer support	No equipment	6 months on ART; Clinically stable	Peer groups (CAG) of 6	Monthly	Every 6 months

ART: antiretroviral therapy; CAG: community ART group; CCC: community care coordinator; CHW: community health worker.

December 2012, with a median follow-up time of 21 months (program data). Moreover CAG members are encouraged to bring children (below 15 years old) for counselling and testing and to start ART when eligible. Retention among 265 children of CAG members was 94.0% after a median of 13 months.<sup>27</sup> As CAG members send one representative to represent a maximum of six members, health facility visits were reduced, and the pressure on the medical workforce decreased. CAG members were perceived as partners in care, and as such the patient-provider relationship changed considerably. PLWHA who were part of community groups felt empowered to voice their concerns and were able to have a more active role in the management of their HIV.

## Discussion

This review identified 18 records documenting a variety of models for CBART (Tables 1 and 2). In all studies the responsibilities of the lay ART provider included ART delivery in the community, provision of adherence support and referral of sick people to the clinic. In most programs lay ART providers were remunerated CHW or peer CHW who deliver ART at the homes of PLWHA. However, two CBART programs engaged non-remunerated lay ART providers. One program in Uganda used community volunteers for ART home-delivery.<sup>20-23</sup> In Mozambique, community ART delivery was part of a peer group dynamic.<sup>26,27</sup>

There were substantial differences in patient populations and resources available across different studies. Nevertheless, all outcomes provided positive evidence in support of CBART. In all comparative studies, patients had similar outcomes than patients in facility-based care (Tables 3 and 4).<sup>17-20,22,23,25</sup> Attrition rates from observational cohort studies that reported only data on the CBART cohort compared favorably with those reported in a recent meta-analysis (Table 3).<sup>4,10,12,14,15,26,27</sup>

The few studies reporting data on cost found that provider costs were similar for facility-based ART and CBART,<sup>17,22</sup> and one study found that CBART was more cost-effective than estimates for facility-based ART.<sup>13</sup> Moreover, CBART was much cheaper for patients (Table 5).<sup>17,25</sup> Community interventions which are visibly associated with HIV care potentially impact on stigma. Only three studies reported data on the acceptability or social outcomes of CBART, and concluded that CBART is associated with more positive than negative social outcomes (Table 6).<sup>11,21,24</sup>

### Potential of community participation in ART delivery

CBART aims to overcome two major challenges related to ART initiation and retention: how to decongest health services, and how to sustain adherence for patients over the long-term. To increase the capacity of the health services and offer ART to increasing caseloads, strategies such as decentralization and task shifting have shared the workload over a larger number of health facilities and different levels of the medical workforce, including professionals without formal clinical training.<sup>5,6,28</sup> However, caseloads will increase progressively, and the growing queues at the health facilities will likely lead to inequities in which the most persistent and motivated patients receive care first. Without further adaptations in the model of care delivery, inclusion rates on ART risk to remain limited and attrition is expected to become even more problematic.<sup>3,7,29</sup>

To overcome these structural bottlenecks, CBART models aim to deliver a package of essential ART care functions beyond the clinic and in the community such as ART refills, monitoring of treatment adherence and outcomes, and detection of sick patients and rapid referral to care. This in turn frees up capacity within the clinic-based medical workforce to be able to focus on complicated tasks such as clinical care for sick patients, training and supervision of lower cadres, and management of health care services.<sup>7,17,25</sup> Moreover, CBART can serve communities beyond the reach of the formal health system.<sup>7,12,17,20,26</sup>

Provision of HIV care in the communities will also impact on the dynamic and quality of relationships between providers and patients, and can catalyze the social networking between peers. The intensified link between provider and beneficiary will make information more readily available for PLWHA, and will improve the understanding of the practical problems faced by PLWHA. In this way, care delivery can be expected to become more holistic and result in a relationship built on trust between the provider and the PLWHA. Delivery of HIV care in the social and living environment of PLWHA can activate social and peer support.<sup>30</sup>

### Role for PLWHA in CBART care

It will be important to pilot new studies, in different contexts, to compare the cost, acceptability, effectiveness and sustainability of the different models. To date, most CBART models function as clinical outreach programs, with professionals delivering services in the community. Few examples of voluntary engagement of PLWHA in the medical management of their condition have been described to date. In Mozambique, PLWHA self-formed a social network of peer groups, and became engaged in provision of ART.<sup>26</sup> In Thailand, PLWHA groups such as the Thai Network for PLWHA became engaged in planning of HIV care and provision of ART. PLWHA groups advocated for expanded access to treatment and promoted social normalization of HIV, a process which reduced social discrimination. When, by early 2006, ART became widespread available in Thailand, PLWHA assisted the health workers at the clinic as part of multidisciplinary teams, to provide psychosocial support and counseling, monitor CD4, and provide ART. The PLWHA volunteers were also involved in defaulter tracing. The engagement of PLWHA was one of the factors that made the HIV program of Thailand widely recognized as successful.<sup>31,32</sup>

The involvement of PLWHA in care functions is compatible with lessons learnt from chronic disease management. To sustain long-term adherence to daily treatment, patients need to be self-reliant within their living environment.<sup>33,34</sup> The level of self-reliance of each patient can be increased through acquirement of knowledge, sharing of treatment experiences among peers and practice of self-management skills.<sup>33,35</sup> Moreover, motivation to adhere to ART can be increased through social support.<sup>8</sup> Once informed and motivated, PLWHA can overcome barriers to daily adherence, and become experts in the daily management of their condition.<sup>7,30,33</sup>

### Implications of CBART for health systems

Community participation holds the potential of enabling countries to build sustainable, cost effective and equitable HIV care for populations in countries with a scarce health workforce. However, to achieve success some major challenges need to be overcome.

**Table 3.** Attrition on ART in CBART and FBART

CBART model and type lay ART provider	Study, year	Attrition (dead or LTFU) on ART				
		At 6 m	At 12 m	At 24 m	At 36 m	Per 100py
Home-based ART delivery by CHW	Weidle et al. 2006 <sup>10</sup>	NA	CBART: 7%	NA	NA	NA
	Mermin et al. 2008 <sup>12</sup>	NA	CBART: 7 %	CBART: 9%	NA	CBART: 5/100py <sup>a</sup>
	Moore et al. 2011 <sup>14</sup>					
	Mermin et al. 2011 <sup>15</sup>					
	Amuron et al. 2007 <sup>16</sup>	NA	CBART: 12%	NA	CBART: 14%	CBART: 6.3/100py
	Jaffar et al. 2009 <sup>17</sup> Amuron et al. 2011 <sup>18</sup>		FBART: 13%		FBART: 13%	FBART: 6.5/100py <sup>b</sup>
Home-based ART delivery by volunteers	Kipp et al. 2010, 2011, 2012 <sup>20,22,23</sup>	CBART: 25% FBART: 17%	NA	CBART: 30% FBART: 30%	NA	NA
Home-based ART delivery by peer CHW	Selke et al. 2010 <sup>25</sup>	NA	CBART: 6% FBART: 5%	NA	NA	NA
Patient led community ART dispensing in peer groups	Decroo et al. 2011 <sup>26</sup>	NA	NA	NA	NA	CBART: 2.3/100py <sup>c</sup>
Meta-analyses attrition in sub-Saharan Africa	Fox and Rosen <sup>4</sup>	14%	20%	30%	35%	NA

ART: antiretroviral therapy; CBART: community-based ART; CHW: community health worker; FBART: facility-based ART; LTFU: lost to follow up; NA: not available; py: person year.

<sup>a</sup>Mortality was 5/100py during an average follow-up time of almost 2 years since ART initiation. During first 16 weeks on ART mortality was 14/100py, afterwards 3/100py.

<sup>b</sup>Mortality during an average follow-up period of 2 years since ART initiation.

<sup>c</sup>Mortality and LTFU among patients clinically stable on ART, and more than 6 months on ART.

**Table 4.** Virological outcomes among patients in CBART and FBART

CBART model and type lay ART provider	Study, year <sup>a</sup>	Virologic rebound on ART			
		At 6 m	At 12 m	At 24 m	At 36 m
Home-based ART delivery by CHW	Weidle et al. 2006 <sup>10</sup> VL >1000 copies/ml	CBART: 2%	CBART: 4%	NA	NA
	Mermin et al. 2008, 2011 <sup>12,15</sup> VL >500 copies/ml	CBART: 4%		CBART: 4%	CBART: 6%
	Jaffar et al. 2009 <sup>17</sup> VL >500 copies/ml	NA	CBART: 16% FBART: 17%	NA	NA
Home-based ART delivery by volunteers	Kipp et al. 2010, 2011, 2012 <sup>20,22,23</sup> VL >400 copies/ml	CBART: 10% FBART: 11%	NA	CBART: 7% FBART: 13%	NA
Home-based ART delivery by peer CHW	Selke et al. 2010 <sup>25</sup> VL >400 copies/ml	NA	CBART: 10.5% FBART: 13.5%	NA	NA
Patient led community ART dispensing in peer groups	NA	NA	NA	NA	NA

ART: antiretroviral therapy; CBART: community-based ART; CHW: community health worker; FBART: facility-based ART; NA: not available; VL: viral load.

<sup>a</sup>Cut-off points used to define virological rebound: VL >400 copies/ml; VL >500 copies/ml; VL >1000 copies/ml

**Table 5.** Cost of CBART and FBART for the provider and the patients

CBART model and type lay ART provider	Study, year	Health-service costs		Patient costs	
		CBART	FBART	CBART	FBART
Home-based ART delivery by CHW	Marseille et al. 2009 <sup>13</sup>	Per patient-year: \$695	NA	NA	NA
	Jaffar et al. 2009 <sup>17</sup>	Per patient-year: \$793	Per patient-year: \$838	First patient- year on ART: \$29. Per patient-year after 1st year: \$18 (75% less clinic visits, with a median cost of \$2.3 per clinic visit)	First patient- year on ART: \$60. Per patient-year after 1st year: \$54
Home-based ART delivery by volunteers	Kipp et al. 2011 <sup>22</sup>	Program costs per patient-year: approx \$100	Program costs per patient-year: approx \$100	Average of 2 clinic visits per patient per year	Average of 12 clinic visits per patient per year
Home-based ART delivery by peer CHW	Selke et al. 2010 <sup>25</sup>	NA	NA	Average of 6.2 clinic visits per patient per year (50% less clinic visits)	Average of 12.4 clinic visits per patient per year
Patient led community ART dispensing in peer groups	NA	NA	NA	NA	NA

ART: antiretroviral therapy; CBART: community-based ART; FBART: facility-based ART; NA: not available.

First, community participation requires an approach which is contradictory to the dominant provider-driven development of health services, according to needs defined by health managers. Sustainable community participation is only possible when

community programs are driven, owned by, and embedded in the communities. Indicators that can measure the process of community participation are related to the quality of the partnership between community members and service providers and the



**Table 6.** Social outcomes of CBART

CBART model and type lay ART provider	Study, year	Data on positive social outcomes	Data on negative social outcomes
Home-based ART delivery by CHW	Apondi et al. 2007 <sup>11</sup>	Positive social outcomes (including family or community support and relationship strengthening) were significantly improved 3 months after joining CBART	Negative social outcomes (marriage break-up, discrimination, alienation by family) were not associated significantly with participation in CBART
Home-based ART delivery by volunteers	Alibhai et al. 2010 <sup>21</sup>	The mean physical and mental health improved significantly after one year CBART The largest increases were in physical, social, and role functioning. The perceived physical and mental health after one year CBART was similar to HIV negative woman observed in another study living in a similar context Overall a strong sense of appreciation of the support received from the volunteers.	15% (15/130) of patients in CBART experienced a decline in their overall wellbeing, which was not associated with clinical findings or lack of viral suppression. This decline could be caused by stress associated with poverty, concerns about uncertainty of drug supply in the future, and stigma.
Home-based ART delivery by peer CHW	Wools-Kaloustian et al. 2009 <sup>24</sup>	'Peer effect': The peer CHW were able to gain the trust of their clients, obtain unexpected insights into patient adherence, and identify and address psychosocial issues such as disclosure. The peer CHW linked the community with the clinic, and were perceived by the PLWHA as their advocates. Peer CHW addressed other than HIV related problems, such as domestic discord or alcohol abuse, and there was a willingness to address reproductive health issues.	Peer CHW presented themselves as health counselors, to avoid the AIDS label and prevent stigma. Patients preferred to receive the peer CHW in their homes than at public venues, to prevent stigma. Reports on stigma related events decreased after 16 months of implementation Expectations in the community were not only ART related. Some clients had unrealistic expectations such as provision of food or even money.
Patient led community ART dispensing in peer groups	NA (Qualitative study ongoing)	NA	NA

ART: antiretroviral therapy; CBART: community-based ART; CHW: community health worker.

level of ownership of the community program by the community members.<sup>36</sup> Community participation also requires an understanding and consideration of cultural factors such as gender inequalities, and traditional beliefs about health. Moreover, formal communication loops between representatives of the community and the providers need to be installed to assure mutual understanding.

Second, an enabling environment and supportive regulatory framework are needed to ensure that task shifting to lay staff and PLWHA is effective and quality services are provided. At country level health policies which embrace the concepts of task shifting and community participation need to be designed, defining the distribution of responsibilities and task packages among existent cadres, new cadres and actors in the communities. All relevant stakeholders need to participate in a process of collaborative planning. Standardized training, supportive supervision, supply

of equipment and functional referral systems are essential, and as such task shifting needs to be coupled with growth of the workforce, and investment in training, supervision and equipment.<sup>7,37,38</sup>

Finally, to achieve the above described redefinition of the landscape within the health workforce, a long term vision and commitment from national governments and international donors is required.<sup>37,38</sup> The global financial crisis threatens the achievements made and in times that HIV exceptionalism and vertical HIV funding are being questioned, efficiency of new interventions becomes more and more important. It is important to look for sustainable solutions, and 'to do more with the same', and increase coverage of ART at population level to decrease morbidity, mortality and new infections. From this perspective community-based strategies for HIV care can play an important role. However, they need to complement, rather than replace, functional health

systems, and as such sustained investments in health service improvements will be needed for some time to come.<sup>39</sup>

### Concerns with CBART models

Two potential concerns related to CBART are related to stigma and quality of care. First, the impact of the visibility of HIV related activities on stigma in the community needs further investigation.<sup>24</sup> However, studies have reported that only 3% of patients refused to participate in the community ART program due to stigma,<sup>17</sup> and it has even been suggested that involvement of CHWs in HIV care reduced stigma.<sup>11</sup> Being part of peer groups has been found to decrease the perception of social stigma.<sup>8</sup> Second, task shifting and community engagement may come at the cost of lower quality of care. Task shifting to CHWs and PLWHA is limited by the level of knowledge and skills required to exert defined medical tasks. However, the results of community-based models of care that bring care to populations that would not otherwise have had access should not be compared with results from conventional care.<sup>6</sup> Survival is the most important indicator for quality of care for patients with advanced AIDS, and provision of ART will always compare favorably with no treatment, as ultimately this is the only effective clinical intervention for reduction of mortality among PLWHA.<sup>40</sup> This was demonstrated in Uganda where a CBART program without scheduled routine clinic visits led to a reduction of mortality of 95% among PLWHA, and an 81% reduction of mortality among their dependent HIV uninfected children, in a population that otherwise would have had difficulty accessing HIV care.<sup>12</sup>

### Limitations of this review

Limitations of this review are related to the diversity of the set-up of the CBART models, and the observational design of most studies. The latter could have resulted in observation bias, and confounding bias when a comparison with a facility-based cohort was made. Moreover, in Mozambique the patients were able to choose between CBART and facility-based ART, which could have resulted in a selective enrolment of the fittest in CBART.<sup>26,27</sup> Another important bias is publication bias, as positive results tend to be more likely to be submitted and accepted for publication. Finally the limited number of rigorous studies means that more studies are needed to confirm whether the results of CBART can be sustained in different settings, including settings that are not supported by external agencies.

### Conclusions

The seemingly insurmountable challenge of bringing ART current global targets to provide 15 million people with ART by 2015 forces policy makers to consider redesigning the current model for HIV care to overcome structural bottlenecks, particularly in the resource-constrained context of sub-Saharan Africa. The results of this review suggest that community models serve to help overcome two major challenges. First, they can decongest health services to find space for new people and scale up ART. Second, they can support adherence and sustain retention of patients on ART over the long-term.

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### References

- 1 WHO. Global HIV/AIDS response. Epidemic update and health sector progress towards Universal Access: progress report 2011. Geneva: World Health Organization; 2011. [http://whqlibdoc.who.int/publications/2011/9789241502986\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789241502986_eng.pdf) [accessed 20 May 2012].
- 2 Kober K, Van Damme W. Scaling up access to antiretroviral treatment in southern Africa: who will do the job? *Lancet* 2004;364:103-7.
- 3 Govindasamy D, Ford N, Kranzer K. Risk factors, barriers and facilitators for linkage to antiretroviral therapy care: a systematic review. *AIDS* 2012;26:2059-67.
- 4 Fox MP, Rosen S. Patient retention in antiretroviral therapy programs up to three years on treatment in sub-Saharan Africa, 2007-2009: systematic review. *Trop Med Int Health* 2010;15(Suppl 1):1-15.
- 5 Callaghan M, Ford N, Schneider H. A systematic review of task-shifting for HIV treatment and care in Africa. *Hum Resour Health* 2010;8:8.
- 6 Fulton BD, Scheffler RM, Sparkes SP et al. Health workforce skill mix and task shifting in low income countries: a review of recent evidence. *Hum Resour Health* 2011;9:1.
- 7 Van Damme W, Kober K, Kegels G. Scaling-up antiretroviral treatment in Southern African countries with human resource shortage: how will health systems adapt? *Soc Sci Med* 2008;66:2108-21.
- 8 Wouters E, Van Damme W, van Rensburg D et al. Impact of community-based support services on antiretroviral treatment programme delivery and outcomes in resource-limited countries: a synthetic review. *BMC Health Serv Res* 2012;12:194.
- 9 Ford N, Nachega JB, Engel ME, Mills EJ. Directly observed antiretroviral therapy: a systematic review and meta-analysis of randomised clinical trials. *Lancet* 2009;374:2064-71.
- 10 Weidle PJ, Wamai N, Solberg P et al. Adherence to antiretroviral therapy in a home-based AIDS care programme in rural Uganda. *Lancet* 2006;368:1587-94.
- 11 Apondi R, Bunnell R, Awor A et al. Home-based antiretroviral care is associated with positive social outcomes in a prospective cohort in Uganda. *J Acquir Immune Defic Syndr* 2007;44:71-6.
- 12 Mermin J, Were W, Ekwaru JP et al. Mortality in HIV-infected Ugandan adults receiving antiretroviral treatment and survival of their HIV-uninfected children: a prospective cohort study. *Lancet* 2008;371:752-9.
- 13 Marseille E, Kahn JG, Pitter C et al. The cost effectiveness of home-based provision of antiretroviral therapy in rural Uganda. *Appl Health Econ Health Policy* 2009;7:229-43.
- 14 Moore DM, Yiannoutsos CT, Musick BS et al. Determinants of early and late mortality among HIV-infected individuals receiving home-based

- antiretroviral therapy in rural Uganda. *J Acquir Immune Defic Syndr* 2011;58:289–96.
- 15 Mermin J, Ekwaru JP, Were W et al. Utility of routine viral load, CD4 cell count, and clinical monitoring among adults with HIV receiving antiretroviral therapy in Uganda: randomised trial. *BMJ* 2011; 343:d6792.
- 16 Amuron B, Coutinho A, Grosskurth H et al. A cluster-randomised trial to compare home-based with health facility-based antiretroviral treatment in Uganda: study design and baseline findings. *Open AIDS J* 2007;1:21–7.
- 17 Jaffar S, Amuron B, Foster S et al. Rates of virological failure in patients treated in a home-based versus a facility-based HIV-care model in Jinja, southeast Uganda: a cluster-randomised equivalence trial. *Lancet* 2009;374: 2080–9.
- 18 Amuron B, Levin J, Birunghi J et al. Mortality in an antiretroviral therapy programme in Jinja, south-east Uganda: a prospective cohort study. *AIDS Res Ther* 2011;8:39. .
- 19 Mpiima D, Birungu J, Alwedo S, Luzze C. Successful community interventions to improve retention and reduce loss to follow up of patients taking antiretroviral therapy – The AIDS Support Organization (TASO). The AIDS Support Organisation (TASO), Uganda; 2012. [http://www.tasouganda.org/attachments/284\\_MPIIMA%20DE NNIS%20\[Read-Only\]%20\[Compatibility%20Mode\].pdf](http://www.tasouganda.org/attachments/284_MPIIMA%20DE NNIS%20[Read-Only]%20[Compatibility%20Mode].pdf) [accessed 20 February 2013].
- 20 Kipp W, Konde-Lule J, Saunders LD et al. Results of a community-based antiretroviral treatment program for HIV-1 infection in Western Uganda. *Curr HIV Res* 2010;8:179–85.
- 21 Alibhai A, Martin LJ, Kipp W et al. Quality of life of HIV patients in a rural area of western Uganda: impact of a community-based antiretroviral treatment program. *Curr HIV Res* 2010;8:370–8.
- 22 Kipp W, Konde-Lule J, Rubaale T et al. Comparing antiretroviral treatment outcomes between a prospective community-based and hospital-based cohort of HIV patients in rural Uganda. *BMC Int Health Hum Rights* 2011;11 Suppl 2:S12.
- 23 Kipp W, Konde-Lule J, Saunders LD et al. Antiretroviral treatment for HIV in rural Uganda: two-year treatment outcomes of a prospective health centre/community-based and hospital-based cohort. *PLoS One* 2012;7:e40902.
- 24 Wools-Kaloustian KK, Sidle JE, Selke HM et al. A model for extending antiretroviral care beyond the rural health centre. *J Int AIDS Soc* 2009;12:22.
- 25 Selke HM, Kimaiyo S, Sidle JE et al. Task-shifting of antiretroviral delivery from health care workers to persons living with HIV/AIDS: clinical outcomes of a community-based program in Kenya. *J Acquir Immune Defic Syndr* 2010;55:483–90.
- 26 Decroo T, Telfer B, Biot M et al. Distribution of antiretroviral treatment through self-forming groups of patients in Tete province, Mozambique. *J Acquir Immune Defic Syndr* 2011;56:39–44.
- 27 Decroo T, Mondlane V, Dos Santos N et al. Community ART groups support ART access and retention among HIV-positive dependent children in rural Tete, Mozambique. IAS Conference, Washington, USA, 22–27 July 2012.
- 28 Bemelmans M, Van Den Akker T, Ford N et al. Providing universal access to antiretroviral therapy in Thyolo, Malawi through task shifting and decentralization of HIV/AIDS care. *Trop Med Int Health* 2010;15:1413–20.
- 29 Lambdin BH, Micek MA, Koepsell TD et al. Patient volume, human resource levels and attrition from HIV treatment programs in central Mozambique. *J Acquir Immune Defic Syndr* 2011;57:33–9.
- 30 Decroo T, Van Damme W, Kegels G, Rasschaert F. Are expert patients an untapped resource for ART provision in sub-Saharan Africa? *Aids Res Treat* 2012;2012:749718.
- 31 Lyttleton C, Beesey A, Sitthikriengkrai M. Expanding community through ARV provision in Thailand. *AIDS Care* 2007;19(Suppl 1):S44–53.
- 32 Ford N, Wilson D, Cawthorne P et al. Challenge and co-operation: civil society activism for access to HIV treatment in Thailand. *Trop Med Int Health* 2009;14:258–66.
- 33 Gifford AL, Groessl EJ. Chronic disease self-management and adherence to HIV medications. *J Acquir Immune Defic Syndr* 2002;31(Suppl 3):S163–6.
- 34 WHO. Innovative care for chronic conditions: building blocks for action. Geneva: World Health Organization; 2011. [http://whqlibdoc.who.int/hq/2002/WHO\\_NMC\\_CCH\\_02.01.pdf](http://whqlibdoc.who.int/hq/2002/WHO_NMC_CCH_02.01.pdf) [accessed 11 May 2012].
- 35 Rueda S, Park-Wyllie LY, Bayoumi AM et al. Patient support and education for promoting adherence to highly active antiretroviral therapy for HIV/AIDS. *Cochrane Database Syst Rev* 2006;3:pCD001442.
- 36 Rifkin SB. Lessons from community participation in health programmes: a review of the post Alma-Ata experience. *International Health* 2009;1:31–6.
- 37 Hermann K, Van Damme W, Pariyo G et al. Community health workers for ART in sub-Saharan Africa: learning from experience – capitalizing on new opportunities. *Hum Resour Health* 2009;7:31.
- 38 Lehmann U, Van Damme W, Barten F, Sanders D. Task shifting: the answer to the human resources crisis in Africa? *Hum Resour Health* 2009;7:49.
- 39 Smith J, Whitside A. The history of AIDS exceptionalism. *J Int AIDS Soc* 2010;13:47.
- 40 Philips M, Zachariah R, Venis S. Task shifting for antiretroviral treatment delivery in sub-Saharan Africa: not a panacea. *Lancet* 2008;371:682–4.