BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (http://bmjopen.bmj.com).

If you have any questions on BMJ Open's open peer review process please email editorial.bmjopen@bmj.com

BMJ Open

Community cadres engaged to support retention in PMTCT Option B+: A multi country qualitative rapid appraisal

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-020754
Article Type:	Research
Date Submitted by the Author:	23-Nov-2017

Complete List of Authors:	Besada, Donela; South African Medical Research Council, Health Systems Goga, Ameena; Medical Research Council, Daviaud, Emmanuelle; South African Medical Research Council, Health Systems Rohde, Sarah; South African Medical Research Council, Health Systems Chinkonde, Jacqueline ; UNICEF Malawi Villeneuve, Susie ; United Nations Childrens Fund Cote d'Ivoire Clarysse, Guy; United Nations Childrens Fund Cote d'Ivoire Raphaely, Nika; MRC South Africa Okokwu, Steve; UNICEF Tumwesigye, NAthan; UNICEF; USAID's Regional Health Integration to Enhance Services in East Central Uganda (USAID RHITES-EC) Project, University Research Co., LLC, Daries, Nathalie ; United Nations Childrens Fund Cote d'Ivoire Doherty, Tanya; Medical Research Council, Health Systems Research Unit

Primary Subject Heading:	HIV/AIDS
Secondary Subject Heading:	Public health, Qualitative research, Health policy, Global health
Keywords:	PMTCT Option B+, Retention in Care, Community-facility linkages, Community based workers

SCHOLARONE™
Manuscripts

1
2
3 Community cadres engaged to support retention in PMTCT Option B+: A multi country qualitative rapid appraisal

Donela Besada[1§], Ameena Goga[1], Emmanuelle Daviaud[1], Sarah Rohde[1], Jacqueline Rose Chinkonde[2], Susie Villeneuve[3], Guy Clarysse[3], Nika Raphaely[1], Steve Okokwu[4], Nathan Tumwesigye[45], Nathalie Daries[6], Tanya Doherty[1]

Author affiliations:

1 Health Systems Unit, South African Medical Research Council, Cape Town, South Africa

2 HIV/AIDS, UNICEF, Lilongwe, Malawi

3 Regional Health, UNICEF West and Central African Office, Dakar, Senegal

4 Child Survival and Development, UNICEF, Kampala, Uganda

5 USAID's Regional Health Integration to Enhance Services in East Central Uganda (USAID RHITES-EC) Project, University Research Co., LLC, Kampala, Uganda

6 HIV /AIDS and Adolescent Section, UNICEF, Abidjan, Cote D'Ivoire

§Corresponding author: Donela Besada

South African Medical Research Council

Francie Van Zijl Drive

Parowvallei, Cape
PO Box 19070
7505 Tygerberg, South Africa
Tel: +27 21 938-0911; Cell: +27849773090

Email: donnela.besada@mrc.ac.za)

*These authors have contributed equally to the work.

Email addresses of authors:

DB: Donnela.Besada@mrc.ac.za

AG: Ameena.Goga@mrc.ac.za

ED: Emmanuelle.Daviaud@mrc.ac.za

SR: sarahrohde@me.com

JN: jnkhoma@unicef.org

SV: svilleneuve@unicef.org

GC: gclarysse@unicef.org

NR: Nika.Raphaely@mrc.ac.za

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

SO: sokokwu@unicef.org

NT: ntumwesigye@urc-chs.com

ND : ndaries@unicef.org

TD : Tanya.Doherty@mrc.ac.za

Word count: 4058

For peer review only

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

Abstract

Objectives

To explore the roles of community cadres in improving access to and retention in care for PMTCT services in the context of PMTCT Option B+ treatment scale-up.

Design: Retrospective qualitative study design using semi-structured in-depth interviews and focus group discussions

Participants: A range of individual interviews and focus group discussions with key stakeholders including Ministry of Health employees, Implementation partners, district management teams, facility-based health workers and community cadres.

Individual interviews were conducted with 7 females and 11 males in Malawi, 9 females and 19 males in Cote d'Ivoire, 9 females and 22 males in the DRC and 40 females and 43 males in Uganda. Mixed gender focus group discussions with 125 participants in Malawi, 61 in Cote d'Ivoire, 35 in DRC and 76 in Uganda.

Setting: Interviews were conducted on the offices of Ministry of Health Staff and Implementing partners, as well as district offices and health facility sites across Cote D'Ivoire, DRC, Malawi, and Uganda

Results

Community cadres either operated solely in the community, worked from health centres, or in combination and their mandates were PMTCT-specific or included general HIV support and other health issues. Community cadres included volunteers, those supported by implementing partners or employed directly by the Ministry of Health. Their complimentary roles along the continuum of HIV care and treatment include demand creation, household mapping of pregnant and lactating women, linkage to care, infant follow-up, and adherence and retention support.

Conclusions

Community cadres provide an integral link between communities and health facilities, supporting overstretched health workers in HIV client support and follow-up. However, their role in health systems is neither standardized nor systematic and there is an urgent need to invest in the standardization of and support to community cadres to maximize potential health impacts.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Strengths and limitations of the study

- Inclusion of four diverse countries in Southern, Central and West Africa, at different stages with implementation of PMTCT Option B+. The extent of involvement of community cadres in PMTCT in each country reflects this with Malawi and Uganda having more integrated and institutionalized approaches compared with the DRC and CdI, which are at an earlier stage of implementation.
- Key informant interviews and focus group discussions were undertaken with a wide range of stakeholders in the countries, from national to community level.
- A limitation is the field research by rapid appraisal during short country visits. Thus the impressions presented must be regarded as a snapshot, raising questions for further exploration, particularly regarding the impact of the identified strategies on increasing retention and their potential for scale-up.
- This study could not explore the perceptions of service users towards the strategies. These would be important to address in future research.

Introduction

In April 2012, the World Health Organization (WHO) recommended the use of lifelong triple antiretroviral treatment (ART) for all pregnant and lactating women living with HIV, regardless of CD4 cell count and/or clinical staging (PMTCT Option B+), to prevent mother-to-child transmission of HIV (PMTCT) and to keep mothers healthy [1, 2].

Lifelong treatment for pregnant and breastfeeding women living with HIV has also been advocated as a strategy to reduce transmission to HIV-negative partners.[3] The WHO further states that this approach would strengthen the effectiveness of the PMTCT programme, through improved linkages with ART programmes [1, 4-6].

These global recommendations have prompted rapid adoption of Option B+ guidelines across high-burden countries. The WHO identified 22 priority countries encompassing 90% of the world's population living with HIV and comprising 75% of women in need of PMTCT globally. In those countries, the proportion of women receiving treatment more than doubled between 2009 and 2015 [7]. These increases have been largely attributed to the adoption of Option B+, with all priority countries having implemented this approach by 2015 [8].

As more countries endorse lifelong treatment for all individuals living with HIV, health services should implement strategies to ensure good retention in care. Research in Malawi, the first country to implement Option B+, found lower retention in care for pregnant women living with HIV

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

initiated on lifelong ART compared with other adults.[9]. Uganda however, reported similar retention rates at 6 months for pregnant women (88%) and other non-pregnant adults (87%)[10]. A recent review of Option B+ roll out in Malawi, [11] demonstrated that while women receiving lifelong ART had a higher risk of dropout during the first two years following initiation than other adult cohorts, retention rates were similar as the programme matured. This emphasizes the need to focus efforts in the first years of implementation, when women are most likely to be lost to follow up.

While the literature around factors contributing to poor adherence and retention in HIV care is well known, [12-14] evidence around strategies to improve retention is limited. One of the serious constraints to scaling up HIV treatment and care is the critical shortage of health workers. With 3% of the global health work force [15] and a disproportionate share of people living with HIV, the sub-Saharan African region is increasingly focused on the potential for different community cadres to fill the gap [16-18].

This article presents qualitative findings from a rapid appraisal of the roles of community cadres in improving access to and retention in care for PMTCT in the context of treatment scale-up. This paper aims to highlight the different cadres and the wide range of activities they perform.

Methods

Study design

The research was part of an evaluation of the Optimizing HIV Treatment Access (OHTA) initiative for pregnant and breastfeeding women. The initiative, funded by the governments of Sweden and Norway through the United Nations Children's Fund (UNICEF), was undertaken in four countries (Malawi, Uganda, the Democratic Republic of Congo (DRC) and Côte d'Ivoire) between 2013 and 2017 in partnership with several international and local Implementing Partners (IPs).[19] The OHTA initiative aimed to support the transition to Option B+ for PMTCT in the DRC and Cote d'Ivoire and to optimize delivery and increase demand in Uganda and Malawi, [20]. To achieve its aims, OHTA focused among other objectives on strengthening community-facility linkages through establishing or strengthening community-based lay health worker cadres.

This descriptive qualitative study [21] used rapid appraisal methods [22] to explore the roles of community cadres in improving access to and retention in care for PMTCT services. This methodology was chosen as it would provide findings in a short period of time, which could inform planning for the completion of the OHTA initiative and handover of activities to the Ministry of Health and local implementing partners (IPs).

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Settings and Participants

Qualitative data were collected through desk review and individual interviews and focus group discussions (FGDs) during country fieldwork of 12 days per country (DRC, Cote d'Ivoire, Malawi, Uganda) between June-July 2015. Key informants were identified through a desk review process, with the support of UNICEF headquarters (HQ), Regional offices and country offices.

Semi-structured interview guides were developed for each category of respondent (Ministry of Health, IPs, district management teams, facility-based health workers and community cadres). The terms of reference excluded beneficiaries.

Research team

Eight researchers (all women) participated in the study as teams of 3-4 for each country visit. DB, TD, AG, NR and ED, SR had experience undertaking multi-country evaluations and have worked in the area of PMTCT but had no prior relationship with any of the participants.

Data collection

Each semi-structured interview and focus group discussion was conducted by one or more researchers at the interviewees' workplaces, and lasted 30-60 minutes, with the support of translators. Interviews were audio-recorded where permission was granted, and researchers took notes. Signed informed consent from literate participants and recorded verbal consent from illiterate participants were obtained by the interviewer.

Table 1 shows the numbers of interviews undertaken in each country.

Data analysis

We conducted a simple manifest analysis of the qualitative material [21, 23] and analysed the data both deductively and inductively [24]. Each country team reviewed country material, annotated reflections and came together to discuss, compare and critique insights. Data were then grouped (via word processor) into categories, whose results are reported in narrative form in this paper.

Ethics approval

This study received ethical approval from the South African Medical Research Council (EC014-4/2015) and received permission from each of the following authorities: Malawi: Director of the HIV & AIDS Department in the national Ministry of Health; Uganda: Higher degrees, research and ethics committee, College of Health Sciences, School of Public Health, Makerere University; Cote

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

d'Ivoire: President of the National Committee of Research and Ethics, Ministry of Health; DRC: Director, National AIDS Control Programme (PNLS), Ministry of Health.

Results

Types of community cadres

Interviews identified different community cadres, newly created or strengthened, to support PMTCT services. Table 2 summarizes the community cadres involved in the PMTCT response. These community cadres operated either solely in the community, worked from health centres, or in combination. Their mandates were PMTCT-specific or ranged across general HIV support and broader health issues. Community cadres included volunteers, such as the "Relais communautaires" in the DRC to the Village Health Teams of Uganda. Others were supported by IPs, such as the mentor mothers in Malawi, Uganda, and the DRC, while some were employed directly by the Ministry of Health, such as the Health Surveillance Assistants (HSAs) of Malawi. Some of these cadres, including the mentor mothers in Uganda or expert client/peer supporters in all four countries, were themselves living with HIV, and trained to provide counselling, psychosocial support and peer support to their peers.

Activities performed by community cadres

Acting as the interface between communities and health services, community cadres created awareness, generated demand, referred and followed up pregnant and lactating women living with HIV in the community, to ensure they received appropriate services and remained in care.

Figure 1 illustrates the roles of community cadres across the PMTCT care continuum.

Demand Creation

"*I am not paid anything. I joined this because I felt that the life of other people was very important to me. When I moved to the villages, my first role was to mobilize women. When I identified any pregnant women, I mobilized them to come to the hospital so that they test. When I send them, I follow them to make sure that they have reached the unit." (Expert client, Uganda)*

Cadres including the Agents de Santé Communautaires (ASCs) of Cote d'Ivoire, Relais communautaires of DRC, and the Expert clients and Village Health teams (VHTs) and committees of Uganda and Malawi, participated in community dialogues to increase service uptake and retention.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

"*They (community cadres) have contributed a lot to the health centre…because we as health workers don't have time to go into the community to sensitize them*" (facility-based health worker, Cote d'Ivoire)

Health workers reported that participating in an open dialogue with community members and getting the buy-in of leaders helped dispel myths and fears around HIV, and addressed challenges with stigma.

"Thanks to the support of the ASCs, they have been able to meet community leaders and women's associations, and explained to them transmission of HIV and … what women who are positive and pregnant can do" (Nurse, Cote d'Ivoire)

Furthermore, the male champions of Uganda and Malawi actively engaged men to promote increased partner participation in reproductive health, and addressed interpersonal barriers to retention including partner disclosure and domestic violence.

"*Male motivators and male study circles conduct door-to-door peer education to encourage fellow men to accompany their wives to ANC, couple HTC, delivery and post-natal checks. But during meetings organised by chiefs, they also take advantage to provide education on a topic*" (IP, Malawi)

Client follow-up and retention in care

"*Many people still don't believe in the HIV/AIDS. They still don't think they need to live, so you find many families are breaking because of HIV/AIDS and so these high levels of stigma is still causing treatment interruptions.* (MOH, Uganda)

Once clients are initiated into care, community cadres focused on counselling and psychosocial support, including formation of support groups and key activities to promote positive living and self-efficacy in HIV management. Community cadres who undertook home visits and followed up patients were perceived to play an integral role in this domain.

"So we have what we call active-plan follow-up. Every Friday there is a meeting at the facility. That meeting involves the facility mentor mothers and the health facility team, the midwife in charge and community mentor mothers. They map out and say, who are the women who are defaulted, and which parishes do they come from. So they come up with lists and distribute this. This is your woman, this is your woman." (IP, Uganda)

Concerns were highlighted about confidentiality and the use of the volunteer cadres for follow-up of individuals living with HIV.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

"There is also a challenge to work with VHTs with regards to HIV-positive mothers. They don't want VHTs to know their status, especially with retention. Mothers get very angry when VHTs go to do home visits" (Facility interview, Uganda)

Communities were often more accepting of these generalist community cadres for broad health promotion activities (such as ANC care, follow-up of mothers post-partum, and their children), while HIV-specific follow-up was preferred from peer supporters and lay counsellors. As many of these HIV-specific community cadres were living with HIV, they could share personal coping strategies, and demonstrate the positive impact of treatment adherence through their own experiences.

"*There is very good retention for Option B + and also good coverage for HIV testing and that in a way is attributed to the Mentor Mothers. Because these are the people who [have] gone through the experience of PMTCT or Option B +… and are able to share with other women, to help them provide some of the counselling, so that they can get the intended care*" (Malawi, IP)

Peer support was a commonly used role for community cadres in all four countries. Through support networks (treatment buddies, peer supports, mentor mothers, expert clients, support groups), mothers had access to emotional support and motivation, and were provided with a platform to share knowledge and experiences.

"*So even the peer clients, the peer mothers work with the village health team members, so they can follow-up their colleagues and bring them back. Then healthcare workers… can do physical follow-up but they also have a bit of issues around, you know, going through the community. And the community knows that, oh, they recognise that house, and there is something wrong with that woman there, you know, that kind of thing, yeah. But mostly the peer, that is where the peer mothers become very successful in following up."* (IP, Uganda)

Strategies to improve patient retention recognized the time and cost burdens for patients travelling monthly to facilities for ART refills. In Malawi, HSAs were trained to provide ART refills at rural health posts. In this model, clients obtained refills every three months, only visiting the clinic for screening every six months. Similarly, community ART distribution points in the DRC were run by People Living with HIV. One IP in the DRC piloted the use of an adherence group for HIV-positive women, with one patient responsible each month for picking up ART refills.

"We are piloting the GAAC model (groups to support community accession), which is an adherence group in the community. One person in the group goes every month to pick up drugs for the group.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

This is working well in certain areas. The group needs to know each other well for it to work" (IP, DRC)

Health facility-based activities

Some community cadres, including linkage facilitators in Uganda and community counsellors in Cote d'Ivoire, were based in facilities full-time, or divided their time between community and facility, to support staff with patient triage, educational talks, pre-test counselling and referrals to facility staff for HIV-testing. In Malawi, the HSAs performed HIV-testing and counseling after 28 days of formal training, and in Uganda lay counsellors conduct HIV testing.

One advantage of this system was that, by performing regular educational, counselling and administrative duties, these paid community cadres focused on guiding patients through the continuum of care and eased the non-clinical workload of midwifes and nurses:

"*They have lay counsellors at health centres permanently, who fill registers and records of pregnant women, and make appointments for treatment, and follow-up women who miss her appointment…..The ASCs also have a referral form. In addition to this, the NGO has designed some materials like diaries to monitor the appointments of pregnant women. And when they are completed at field level, they summarize this at the health facility, and then at the health facility they can know how many have been referred*" (Health worker, Cote d'Ivoire)

Uganda established *Family Support Groups* to encourage family participation in follow-up ART visits, to improve patient retention. These support groups were often facilitated by nurses, in conjunction with community cadres and mentor mothers. Encouraging women to bring their children ensured exposed children were also monitored, until their 18 months status was ascertained. Furthermore, these groups encouraged women to disclose their status to partners and included them as active participants in family health decisions. Group sessions included a health education talk, scheduled on-the same day as ARV drug pick up, to encourage adherence. Support groups on the same day as monthly ART pick-up dates were also occurring in the DRC, Cote d'Ivoire and Malawi.

"*So they support retention in that way, they support the health workers to coordinate family support groups, […] that have been institutionalised by Minister of Health. So in these family support groups, these HIV-positive mums come with their babies. We always insist that facilitators come with the baby and … in m2m we also do what we call a needs assessment, to ensure that, in addition*

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

to just getting the education and the testimonies and trying to make each other strong, we ensure that that's an opportunity to catch up with services that are due, like PCR." (IP, Uganda)

Patient tracking

In all countries, community cadres supported health workers with tracing women and children who missed appointments. Tools used for longitudinal follow-up varied across settings, generally including client appointment books, agendas to identify those missing appointments, and longitudinal facility registers. A combination of phone calls and home visits were used to track patients and re-connect them to services.

"*So when she's compiling her report, she has a paper-based report that shows loss of month one, loss of month two….and then missed appointments for that month. So as she sending the report to the central level, she's also thinking of what actions. I was expecting thirty mothers and got fifteen. So, she has to put down actions for the fifteen lost mothers. And then either use of community people or whatever, she has to make sure that she tracks them*" (National MOH, Uganda)

Limited access to accurate patient information caused a major barrier to finding patients lost to follow-up. In "*Mon Bip Mon Sauveur*" (My Beep My Savior) a Cote d'Ivoire initiative, facility staff or ASCs gave women a missed call immediately after they provided phone numbers, to ensure the number was correct. Since a large proportion of the population did not have access to mobile phones or formal addresses, another strategy ("*Cahier de Localisation*" or Location Book) described the area in which patients lived according to landmarks, and mapped them to allow easier tracking.

Challenges to the sustainability of community cadres

Concerns were expressed around community cadre remuneration that is mainly dependent on external support, and variability in payment schedules.

"*She is saying that these peers, they are widows, and they spend a lot of time here when there is no-one to do any other activities in their homes. And then, on top of that, they have their children who are at school. So they are worried where to get funds for their children. So they are saying, even their funds don't come in time, because she is saying like after three months, so they find that they are really broke*." (Health worker, Uganda)

Despite some financial support for community cadres undertaking HIV-related activities, these incentives did not amount to a living wage, and retention of these cadres was described as a challenge.

For peer review only

"For the village health teams, I will say allowance. When we work with them often, we give them some refreshment and some transport. Otherwise, paying them a stipend, like which is regular, no." (IP, Uganda)

"I am not married, so even though the money is little, it still helps me because I have children and it helps me to help them […]. I don't worry about anything, because I consider myself to have a job" (Expert Client, Malawi).

The mothers2mothers model in Uganda and Malawi, mentor mothers in the DRC and the HSAs in Malawi were amongst the only cadres receiving a regular salary:

"*Mothers to Mothers model, […], is not voluntarily at all, in all in the countries. So we don't believe in voluntarism. We have a component, one of objectives is empowering women who are living with HIV, and we realise that when you get the stipend and give it to them at the end of the month, it makes more meaning to them. They can be able to invest it, they can be able to do things with it*." (IP, Uganda)

"I think that professionalisation of these mums makes them feel maybe valued, and so it really makes a difference." (IP, Uganda)

Discussion

This paper highlights the range and characteristics of community cadres engaged to support PMTCT programmes across the four countries. The scale up of lifelong treatment, and investments in newly created cadres or capacity-building of existing cadres, have facilitated their engagement in promoting and supporting lifelong HIV treatment at community and facility level. While this paper, reflects a synthesis of a mid-term programmatic evaluation, and therefore does not make linkages between activity data and PMTCT-related health outcomes, the synthesis of qualitative investigations from key informant interviews demonstrate the interplay of these community cadres with facility based interventions in supporting PMTCT scale up. Investments in increasing community awareness around the benefits of HIV testing and treatment adherence, while addressing stigma and discrimination in the community through positive messaging and the use of peer supporters who openly disclose their status, have been shown in other studies to improve patient retention [25].

Once clients are linked to services, the HIV-specific community cadres, largely facility-based, support uptake of and retention in HIV services, through counselling, HIV-testing, home-based care, patient education, adherence counselling, patient SMS reminders and defaulter tracing.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Integrating peers into the health care team has resulted in positive patient outcomes, where peers motivate behavioural change in people living with HIV, to improve patient retention.[25] Furthermore, investments in facility-based lay cadres have eased the clinical workload of health workers, resembling task-shifting in other programmes [26]. Operationalising community cadres for the HIV response has to take into consideration interactions between established generalist community cadres covering a range of healthcare activities, and cadres created specifically for the HIV response.

The mothers2mothers programme is a successful example of peer-support in PMTCT services across several countries. It hires, remunerates, supervises and supports with external funding women living with HIV to serve as peers in PMTCT programmes. A recent evaluation in Uganda found improved outcomes across a range of health-related indicators, including significantly higher rates of 12-month ART retention (91 vs. 64 %), uptake of EID at 6-8 weeks (72 vs. 46 %), ART initiation in infants (61 vs. 28 %) and partner disclosure (82 vs. 70 per cent) in M2M supported sites [27].

Ongoing challenges with stigma, geographical access to health services, high levels of poverty and low male partner involvement in maternal and reproductive services, make women less likely to remain on treatment. Furthermore, high HIV-prevalence rates, coupled with high fertility rates in these countries, place an increasing burden on health systems for follow-up and support of a growing number of women on ART. It is therefore critical that PMTCT programmes make concerted efforts towards scaling up effective strategies to optimize retention.

With the rapidly increasing HIV care and treatment needs and the accelerating human resource crisis in many African countries, community-based cadres will remain a core feature of health systems. Effective inclusion of these cadres in the health team requires political and financial commitments, regulatory frameworks and mechanisms for supervision and mentoring [18, 28-30].

In the absence of formal recognition, these cadres will continue to be inadequately resourced and undervalued, undercutting their potential health impacts [31]. Community cadres interviewed highlighted a range of challenges for patient follow-up including lack of transport, phones or airtime, and insufficient money for transport. Furthermore, remuneration of community cadres is currently not standardized within countries, and has the potential to create tensions between cadres and to reduce motivation. These cadres are largely donor-supported and high turnover rates, inadequate job security, formal recognition or harmonization, threaten the sustainability of achievements. These well-established challenges affecting Community Cadre programmes have been reported for several decades [32]. The recent interest in and use of community cadres in

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

response to large-scale ARV roll-out appear to pay insufficient attention to these major determinants of success [33].

Conclusion

Community cadres can provide an integral link between communities and health facilities, supporting overstretched health workers in HIV client support and follow-up. There is a need to invest in country-specific standardization of and support to the range of community cadres, and adequate investment in training and supervision linked to scope of practice, to decrease turnover amongst community cadres and low motivation, in order to maximize the potential effectiveness of their activities. Further interrogations into the services, strategies and approaches most effective in improving outcomes along the continuum of care are required, with explicit investments in community cadres to deliver them. Such investments will extend healthcare interventions and their success beyond the confined walls of health facilities.

Competing interests

The authors have no competing interests to declare

Acknowledgements

The authors thank the Ministry of Health,UNICEF country office and implementing partners in Cote d'Ivoire, DRC Malawi, and Uganda for their assistance with the field visits. We thank all participants for sharing their insights and experiences with us.

Funding

The research was supported by UNICEF New York through a grant from the government of Sweden and the Norwegian Agency for Development Cooperation (Norad), and the South African Medical Research Council. The South African Medical Research Council supported the time of the authors to write the article. TD is supported by the National Research Foundation, South Africa.

Authors' contributions

TD, DB, SR, AG and ED conceptualized the study and developed the protocol and data collection materials. TD, AG, DB, NR, SR and ED participated in the country visits in 2015 and participated in the analysis of interview transcripts. DB and TD prepared the first draft of the paper. TD, DB, SR, AG, ED, JRC, SV, GC, SO, NT, ND, NR reviewed and contributed to subsequent drafts and approved the final version for publication.

Data sharing statement

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

The audio recordings and transcribed interviews are stored in a password protected system with the project team at the South African Medical Research Council office. The privacy of the data is maintained since participants did not consent for data to be shared beyond the research team. However, all data has been consolidated and written up for the purposes of the evaluation and reports published on the SAMRC website in addition to the development of peer reviewed publications.

References

1. (WHO). WHO: **Programmatic Update: Use of Antiretroviral Drugs for Treating Pregnant Women and Preventing HIV Infection in Infants.** In. Geneva: WHO; 2012.
2. (WHO) WHO: **Programmatic Update: Use of Antiretroviral Drugs for Treating Pregnant Women and Preventing HIV Infection in Infants.** In. Geneva: WHO; 2012.
3. Rayment M: **Prevention of HIV-1 infection with early antiretroviral therapy**. *Journal of Family Planning and Reproductive Health Care* 2012, **38**(3):193-193.
4. UNICEF BLC: **A Business Case for Options B and B+ to Eliminate Mother to Child Transmission of HIV by 2015.** . In.; 2012.
5. Board PEPfARPSA: **Recommendations for the Office of the US Global AIDS Coordinator: Implications of HPTN 052 for PEPFAR's Treatment Programs 2011.** . In. Washington: PEPFAR; 2011.
6. **PMTCT and Community: Updates and PEPFAR Perspectives. Presentations from the CCABA/UNICEF/UNAIDS/Global Fund/RIATT 'Road to Washington' meeting in London** [http://www.ccaba.org/wp-content/uploads/Bachman-and-Phelps-presentation.pdf]
7. Haroz D, von Zinkernagel D, Kiragu K: **Development and Impact of the Global Plan**. *Journal of acquired immune deficiency syndromes (1999)* 2017, **75**(1):S2-S6.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

8. UNAIDS: **On the Fast-Track to an AIDS-free generation.** . In.; 2016.

9. Tenthani L, Haas AD, Tweya H, Jahn A, van Oosterhout JJ, Chimbwandira F, Chirwa Z, Ng'ambi W, Bakali A, Phiri S *et al*: **Retention in care under universal antiretroviral therapy for HIV-infected pregnant and breastfeeding women ('Option B+') in Malawi**. *AIDS (London, England)* 2014, **28**(4):589-598.

10. Kieffer MP, Mattingly M, Giphart A, van de Ven R, Chouraya C, Walakira M, Boon A, Mikusova S, Simonds RJ, Forum ETD: **Lessons learned from early implementation of option B+: the Elizabeth Glaser Pediatric AIDS Foundation experience in 11 African countries**. *J Acquir Immune Defic Syndr* 2014, **67 Suppl 4**:S188-194.

11. Haas AD, Tenthani L, Msukwa MT, Tal K, Jahn A, Gadabu OJ, Spoerri A, Chimbwandira F, van Oosterhout JJ, Keiser O: **Retention in care during the first 3 years of antiretroviral therapy for women in Malawi's option B+ programme: an observational cohort study**. *The lancet HIV* 2016, **3**(4):e175-182.

12. Brinkhof MW, Pujades-Rodriguez M, Egger M: **Mortality of patients lost to follow-up in antiretroviral treatment programmes in resource-limited settings: systematic review and meta-analysis**. *PloS one* 2009, **4**(6):e5790.

13. Geng EH, Nash D, Kambugu A, Zhang Y, Braitstein P, Christopoulos KA, Muyindike W, Bwana MB, Yiannoutsos CT, Petersen ML *et al*: **Retention in care among HIV-infected patients in resource-limited settings: emerging insights and new directions**. *Current HIV/AIDS reports* 2010, **7**(4):234-244.

14. Hodgson I, Plummer ML, Konopka SN, Colvin CJ, Jonas E, Albertini J, Amzel A, Fogg KP: **A systematic review of individual and contextual factors affecting ART initiation, adherence, and retention for HIV-infected pregnant and postpartum women**. *PloS one* 2014, **9**(11):e111421.

15. Maddison AR, Schlech WF: **Will universal access to antiretroviral therapy ever be possible? The health care worker challenge**. *The Canadian journal of infectious diseases & medical microbiology = Journal canadien des maladies infectieuses et de la microbiologie medicale* 2010, **21**(1):e64-69.

16. Jerome G, Ivers LC: **Community health workers in health systems strengthening: a qualitative evaluation from rural Haiti**. *AIDS (London, England)* 2010, **24 Suppl 1**:S67-72.

17. Callaghan M, Ford N, Schneider H: **A systematic review of task- shifting for HIV treatment and care in Africa**. *Human resources for health* 2010, **8**:8.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

18. Rasschaert F, Philips M, Van Leemput L, Assefa Y, Schouten E, Van Damme W: **Tackling health workforce shortages during antiretroviral treatment scale-up--experiences from Ethiopia and Malawi**. *Journal of acquired immune deficiency syndromes (1999)* 2011, **57 Suppl 2**:S109-112.

19. Doherty T, Besada D, Rohde S, Torresi B, Goga A, Ramokolo V, Noveve N, Magasana V, Raphaely N, Daviaud E: **Report on the external mid-term, formative evaluation of the optimizing HIV treatment access (OHTA) for pregnant and breastfeeding women initiative in Uganda, Malawi, Ivory Coast and the Democratic Republic of Congo.** In. Cape Town: South African Medical Research Council; 2015.

20. **Optimizing HIV treatment access for pregnant and breastfeeding women. http://www.childrenandaids.org/partnership/optimizing-hiv-treatment-access.** [http://www.childrenandaids.org/partnership/optimizing-hiv-treatment-access]

21. Green J, Thorogood, N: **Qualitative Methods for Health Research**. London: Sage Publications; 2004.

22. USAID Center for Development Information and Evaluation: **Using Rapid Appraisal Methods**. In: *Perfomance Monitoring and Evaluation TIPS.* Washington: USAID; 1996.

23. Graneheim UH, Lundman B: **Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness**. *Nurse Educ Today* 2004, **24**(2):105-112.

24. Fereday J, Muir-Cochrane E: **Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development.** *International Journal of Qualitative Methods* 2006, **5**(1):80-92.

25. MSF: **Reaching 90 90 90**. In. Brussels: MSF; 2016.

26. MSF: **HIV/TB Counseling: Who is doing the job? Time for recognition of lay counselors**. In.; 2016.

27. Zikusooka CMK-M, D.; Bwanika, J.B.; Akena, D.; Kwesiga, B.; Abewe, C.; Watsemba, A.; and A. Nakitende: **External Evaluation of the m2m Mentor Mother Model as Implemented under the STAR-EC Program in Uganda.** In. Cape town: Mothers to Mothers; 2014.

28. 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.

29. Lehmann U, Van Damme W, Barten F, Sanders D: **Task shifting: the answer to the human resources crisis in Africa?** *Human resources for health* 2009, **7**(1):49.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

30. Hermann K, Van Damme W, Pariyo GW, Schouten E, Assefa Y, Cirera A, Massavon W: **Community health workers for ART in sub-Saharan Africa: learning from experience--capitalizing on new opportunities**. *Human resources for health* 2009, **7**:31.

31. Mwai GW, Mburu G, Torpey K, Frost P, Ford N, Seeley J: **Role and outcomes of community health workers in HIV care in sub-Saharan Africa: a systematic review**. *Journal of the International AIDS Society* 2013, **16**:18586.

32. Lehmann U, Sanders D: **Community health workers: What do we know about them? The state of the evidence on programmes, activities, costs and impact on health outcomes of using community health workers**. In. Geneva: World Health Organisation; 2007.

33. Hermann K, Van Damme W, Pariyo G, Schouten E, Assefa Y, Cirera A, Massavon W: **Community health workers for ART in sub-Saharan Africa: Learning from experience - Capitalizing on new opportunities**. *Human Resources for Health* 2009, **7**(1):31.

For peer review only

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Table 1: Summary of Participants

Malawi Data collection 15th to 24th June: Districts visited Lilongwe, Mzimba North, Zomba		
Type of interview	**Participant category**	**Number of interviewees/ focus group discussion participants**
Individual interviews	Implementing partner	2 female
	Ministry of Health	1 female, 2 male
	Multilateral agency	1 female, 1 male
	District management	5 male
	Facility-based health workers	2 female, 2 male
	Community-based health worker	1 female, 1 male
Focus Group Discussions	Implementing partner	7 female, 4 male
	Ministry of Health	1 female, 2 males
	Multilateral agency	2 female; 3 male
	District management	1 female, 3 male
	Facility-based health workers	7 female, 5 male
	Community-based health workers (health surveillance assistants, Male Study Circles, M2M mentor mothers, Community advisory board)	10 groups (average size 9 individuals, mixed gender)
Côte d' Ivoire Data collection 19th to 31st July: Three districts visited (Port-Bouet, Bouake Sud, Daloa)		
Type of interview	**Participant category**	**Number of interviewees/ focus group discussion participants**
Individual interviews	Implementing partner	4 female, 6 male
	Ministry of Health	1 female, 3 male
	Multilateral agency	3 female, 3 male
	District management	1 female, 6 male
	Facility-based health workers	1 male
Focus Group Discussions	Implementing partner	4 groups (average size 7, mixed gender)
	District management	1 group of 2 females and 4 males
	Facility-based health workers	1 group of 2 females and 1 male
	Community-based health workers	3 groups (average size 8, mixed gender)

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

	(scouts, lay counsellors, community health workers, traditional leaders)	
DRC Data collection 8th to 19th June 2015: 3 health zones in the Katanga Province (Kasenga, Kapemba, Kisanga).		
Type of interview	**Participant category**	**Number of interviewees/ focus group discussion participants**
Individual interviews	Implementing partner	6 male
	Ministry of Health	2 female, 6 male
	Multilateral agency	4 female, 6 male
	District management	1 female, 3 male
	Facility-based health workers	2 female, 1 male
Focus Group Discussions	Implementing partner	5 groups (average size 3, mixed gender)
	Facility-based health workers	1 group with 4 females
	Community-based health workers (Relais communautaires, mentor mothers, peer educator)	4 groups (average size 4, mixed gender)
Uganda 29th June to 19th July: Greater Kampala and 9 districts across three regions (Bugiri, Kamuli, Kaliro, Isingiro, Bushenyi, Ibanda, Moroto, Kotido, Abim).		
Type of interview	**Participant category**	**Number of interviewees/ focus group discussion participants**
Individual interviews	Implementing partner	6 female, 9 male
	Ministry of Health	2 female, 4 male
	Multilateral agency	2 male
	District management	30 female, 27 male
	Community-based health worker	2 female
Focus Group Discussions	Implementing partner	1 group with 2 females and one male
	Facility-based health workers	2 groups (average size 4, mostly female)
	Community-based health workers (scouts, lay counsellors, community health workers, traditional leaders)	13 groups (average size 5, mixed gender)

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Table 2 Community cadres involved in the PMTCT response

Health Worker	Country	Paid/ Volunteer	Formal Gov Structure/ Informal	Supervision	Facility/ Community based	HIV-Specific/ General	Domains		
							community engagement	Linkage to care	Longitudinal Follow up
Agents Sante Communautaire (ASCs)	Cote d'Ivoire	Not standardized – country embarking on CHW policy awaiting approval for their formalization	Formal	Supervised by cadres from OHTA IPs and by health centers nurses / midwives	Community	General	Participate in demand generation activities with work plans developed by responsible implementing partners, attend weekly review meetings organized by midwives/nurses where registers are reviewed and patients who require follow up through phones and home visits are identified and assigned to ASCs.		
							X	X	X
Assistants sociaux (social assistants)	DRC	Paid	Informal / NGO based	In addition to the IPS and health nurses, the executive committee and community facilitator	Facility	HIV-Specific	Provide psychosocial support to patients who test HIV-positive		
							X		
Community Counsellors	Cote d'Ivoire	Paid	Informal /NGO based	Supervised by cadres from OHTA IPs and by health centers nurses / midwives	Facility	HIV-Specific	Serve as the link between the ASCs and facility health workers in addition to providing psychosocial support to women who have tested positive; Manage the referral and counter referral process by consolidating information and monitoring clients' appointment dashboard.		
							X	X	X

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

Expert Clients/Peer educators (living with HIV)	Malawi, Uganda (expert clients) DRC, Cote d'Ivoire (peer educators)	Volunteer (compensation for transport/ food)	Informal /NGO based	Usually supervised by a health worker involved in the HIV prevention, care, treatment and support services at facility level. In DRC: In addition to the IPS and health nurses, the executive committee and community facilitator	Combination	HIV-Specific	Responsibilities at facility: client health education sessions; adherence assessment counselling and support; nutritional assessment; maintaining a client appointment system to help facilitate clinic visits and identify missed appointments; developing a search list for clients who miss appointments; following up patients through telephone calls and physical tracking of clients; and HIV post-test and pre-ART counselling. At the community level: follow up clients who miss appointments, continue to provide adherence counselling and support, and conduct home visits for sick patients or those struggling with treatment adherence.	X	X	X
Health Surveillance Assistants	Malawi	Paid	Formal	HSAs are supervised by senior HSAs who are mainly based out of the health centres. HSAs are also expected to come into the facility and provide supervised care to patients as a form of mentorship	Work out of Village clinics in community but report to facility	General	Health education talks, provision of immunisation services, integrated community case management of childhood illnesses (iCCM), home and market inspection, malaria screening, growth monitoring and nutrition education. HIV-related tasks include: HIV prevention, provision of HCT, opportunistic infection management and cotrimoxazole administration, defaulter tracing, and general support to ART clients.	X	X	X
Linkage	Uganda	Paid	Informal	Supervised by health	Facility	Not HIV-	Receive all the referrals from the community,			

For peer review only

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

Facilitator			/NGO based	facility staff and as members of the VHT also supervised by parish leaders		specific	help navigate clients to the services they require, consolidate all the referral information and ensure information is fed back to the community.		
								X	X
Male Champions	Malawi, Uganda	Volunteer	Informal /NGO based	NGO partners, health facility staff	Community	Not HIV-specific	Conduct door to door peer education and provide health education talks to mobilise men to accompany their partners to access MNCH services: promote increased couple HIV counselling and testing, and in the case of discordant relationships, facilitate partner disclosure and general partner support.		
							X	X	
Mentor mothers (living with HIV)	DRC, Malawi, Uganda	Paid	Informal /NGO based	Peer mentor mothers, PMTCT focal persons/health workers at facility level or M2M (NGO) staff	Combination	HIV-specific	Community level: conduct community health education talks on Maternal and Child Health (MNCH) and PMTCT topics, conduct household visits of pregnant and lactating women identified and referred by VHTS, conduct referrals and obtain the list of clients missing appointments and HIV-positive mother baby pairs for follow up Facility level: group education talks, client triage, HIV pre-test education at the ANC clinics, TB and nutrition screening services, individual and couple counselling sessions, active client follow up through phone calls and home visits (where community mentor mothers do not exist), and provide reminders to patients for their next visits. Mentor mothers also organize psychosocial support groups with the support of		

For peer review only

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

							health workers and expert clients, and participate in integrated outreach activities.		
							X	X	X
Relais communautaires	DRC	Volunteer	Formal	Feedback monthly activities to a local commmittee. This local committee then feeds the information to health committees (CODESA) and the social mobilization committee of the health zone. Community facilitators and nurses conduct supervision visits.	Community	General	Promote the use of reproductive health services including ANC attendance and family planning, conduct home visits, and carry out community sensitisation activities.		
							X	X	
Village Health Committees	Malawi	Volunteer	Formal	VHTs are linked to health units, there is a VHT focal person at the district and at the health facility. They are expected to come and meet regularly at least once a quarter, although preferably monthly.	Community	General	Conduct village health inspections and mobilize households to participate in immunization campaigns, child health days and other outreach activities.		
							X	X	
Village Health Teams	Uganda	Volunteer	Formal	Informal leaders at Parish level coordinate VHTs. These Parish leaders report to the HSAs	Community	General	Provide a range of health promotion, referral and linkage services. Some HIV-related responsibilities include sensitizing communities on HIV prevention, care and treatment, demand generation for MNCH/ PMTCT services and		

For peer review only

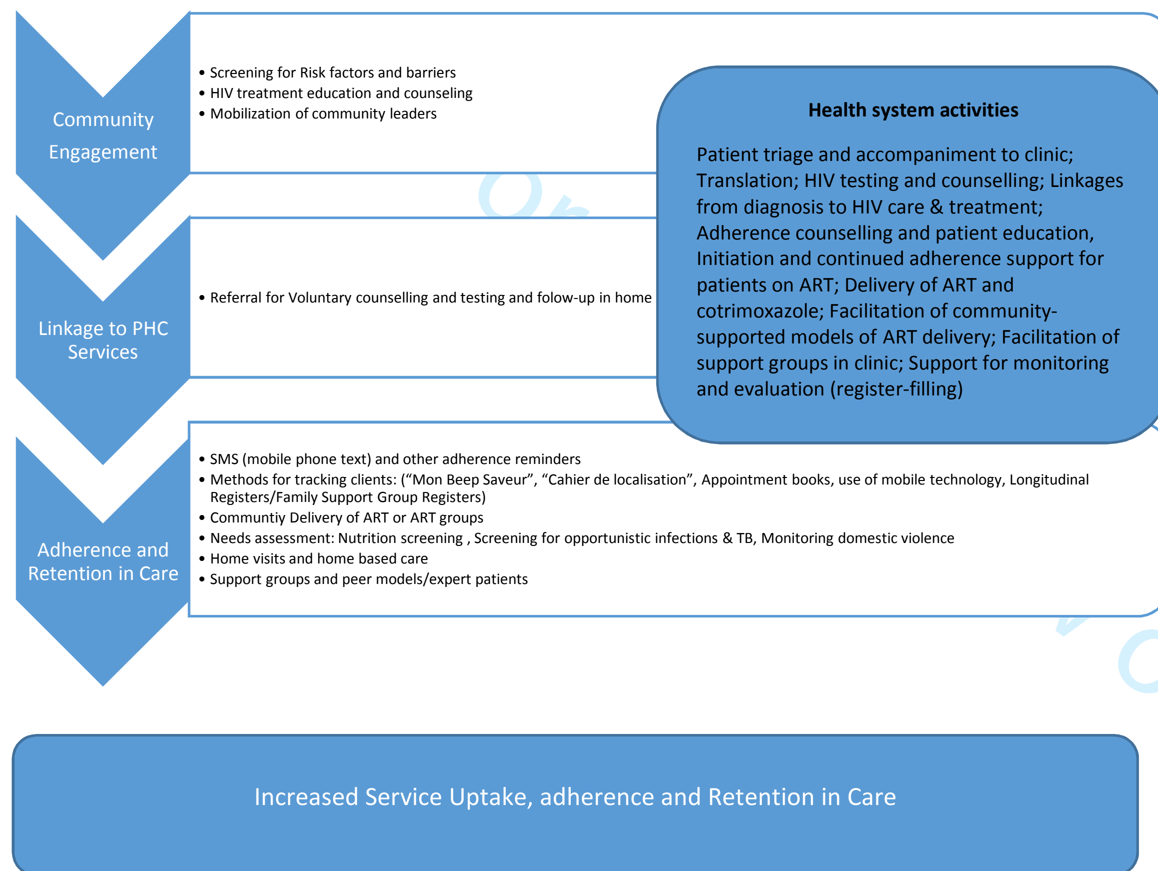
							referral for HIV counselling and testing (HCT).		
							X	X	

For peer review only

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Figure 1: Conceptual framework of community- and facility-based activities for increased service uptake and improved retention in PMTCT care



For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page/line no(s).
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	3

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4-5
Purpose or research question - Purpose of the study and specific objectives or questions	5

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	5
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	6
Context - Setting/site and salient contextual factors; rationale**	5
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	6
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	6
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	6

For peer review only

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	6
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	6 & 18-20
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	6
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	6
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	6

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	7-12
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	7-12

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	12-13
Limitations - Trustworthiness and limitations of findings	12

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	14
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	14

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

For peer review only

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388

For peer review only

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

BMJ Open

Roles played by community cadres to support retention in PMTCT Option B+ in four African countries: A qualitative rapid appraisal

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-020754.R1
Article Type:	Research
Date Submitted by the Author:	19-Jan-2018
Complete List of Authors:	Besada, Donela; South African Medical Research Council, Health Systems Goga, Ameena; Medical Research Council, Health Systems Daviaud, Emmanuelle; South African Medical Research Council, Health Systems Rohde, Sarah; South African Medical Research Council, Health Systems Chinkonde, Jacqueline ; UNICEF Malawi, HIV/AIDS Villeneuve, Susie ; United Nations Childrens Fund Cote d'Ivoire, Regional Health Clarysse, Guy; United Nations Childrens Fund Cote d'Ivoire, Regional Health Raphaely, Nika; MRC South Africa, Health Systems Okokwu, Steve; UNICEF , Child Survival and Development Tumwesigye, NAthan; UNICEF, Child Survival and Development; USAID’s Regional Health Integration to Enhance Services in East Central Uganda (USAID RHITES-EC) Project, University Research Co., LLC, Daries, Nathalie ; United Nations Childrens Fund Cote d'Ivoire, HIV /AIDS and Adolescent Section Doherty, Tanya; Medical Research Council, Health Systems Research Unit
Primary Subject Heading:	HIV/AIDS
Secondary Subject Heading:	Public health, Qualitative research, Health policy, Global health
Keywords:	HIV & AIDS < INFECTIOUS DISEASES, Public health < INFECTIOUS DISEASES, Human resource management < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PUBLIC HEALTH, community cadres

SCHOLARONE™
Manuscripts

1
2
3 Roles played by community cadres to support retention in PMTCT Option B+ in four African
4 countries: A qualitative rapid appraisal
5
6
7
8 Donela Besada[1§], Ameena Goga[2], Emmanuelle Daviaud[1], Sarah Rohde[1], Jacqueline Rose
9 Chinkonde[3], Susie Villeneuve[4], Guy Clarysse[4], Nika Raphaely[2], Steve Okokwu[5], Nathan
10 Tumwesigye[56], Nathalie Daries[7], Tanya Doherty[1,8,9]
11
12
13
14 Author affiliations:
15 1 Health Systems Research Unit, South African Medical Research Council, Cape Town, South
16 Africa
17
18 2. Health Systems Research Unit, South African Medical Research Council, Pretoria, South Africa
19
20 3 HIV/AIDS, UNICEF, Lilongwe, Malawi
21
22 4 Regional Health, UNICEF West and Central African Office, Dakar, Senegal
23
24 5 Child Survival and Development, UNICEF, Kampala, Uganda
25
26 6 USAID's Regional Health Integration to Enhance Services in East Central Uganda (USAID
27 RHITES-EC) Project, University Research Co., LLC, Kampala, Uganda
28 7 HIV /AIDS and Adolescent Section, UNICEF, Abidjan, Cote D'Ivoire
29
30 8 School of Public Health, University of the Western Cape, Cape Town, South Africa
31
32 9 School of Public Health, University of the Witwatersrand, Johannesburg, South Africa
33
34
35 [§]Corresponding author: Donela Besada
36
37 South African Medical Research Council
38
39 Francie Van Zijl Drive
40
41 Parowvallei, Cape
42 PO Box 19070
43 7505 Tygerberg, South Africa
44 Tel: +27 21 938-0911; Cell: +27849773090
45
46 Email: donnela.besada@mrc.ac.za)
47 *These authors have contributed equally to the work.
48
49 Email addresses of authors:
50
51 DB: Donnela.Besada@mrc.ac.za
52
53 AG: Ameena.Goga@mrc.ac.za
54
55 ED: Emmanuelle.Daviaud@mrc.ac.za
56
57 SR: sarahrohde@me.com
58
59
60

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

JN: jnkhoma@unicef.org

SV: svilleneuve@unicef.org

GC: gclarysse@unicef.org

NR: Nika.Raphaely@mrc.ac.za

SO: sokokwu@unicef.org

NT: ntumwesigye@urc-chs.com

ND : ndaries@unicef.org

TD : Tanya.Doherty@mrc.ac.za

Word count: 4219

For peer review only

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Abstract

Objectives

To explore the roles of community cadres in improving access to and retention in care for PMTCT services in the context of PMTCT Option B+ treatment scale-up in high burden low and lower-middle income countries.

Design/Methods: Qualitative rapid appraisal study design using semi-structured in-depth interviews and focus group discussions between 8th June and 31st July 2015

Setting and Participants: Interviews were conducted in the offices of Ministry of Health Staff, Implementing partners, district offices and health facility sites across 4 low and lower-middle income countries: Cote D'Ivoire, DRC, Malawi, and Uganda.

A range of individual interviews and focus group discussions with key stakeholders including Ministry of Health employees, Implementation partners, district management teams, facility-based health workers and community cadres. A total number of 18, 28, 31, and 83 individual interviews were conducted in Malawi, Cote d'Ivoire, DRC, and Uganda respectively. A total number of 15, 9, 10, and 16 mixed gender focus group discussions were undertaken in Malawi, Cote d'Ivoire, DRC and Uganda respectively.

Results

Community cadres either operated solely in the community, worked from health centres, or in combination and their mandates were PMTCT-specific or included general HIV support and other health issues. Community cadres included volunteers, those supported by implementing partners or employed directly by the Ministry of Health. Their complimentary roles along the continuum of HIV care and treatment include demand creation, household mapping of pregnant and lactating women, linkage to care, infant follow-up, and adherence and retention support.

Conclusions

Community cadres provide an integral link between communities and health facilities, supporting overstretched health workers in HIV client support and follow-up. However, their role in health systems is neither standardized nor systematic and there is an urgent need to invest in the standardization of and support to community cadres to maximize potential health impacts.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Strengths and limitations of the study

- Inclusion of four diverse countries in Southern, Central and West Africa, at different stages with implementation of PMTCT Option B+. The extent of involvement of community cadres in PMTCT in each country reflects this with Malawi and Uganda having more integrated and institutionalized approaches compared with the DRC and CdI, which are at an earlier stage of implementation.
- Qualitative data collection undertaken with a wide range of stakeholders in 4 diverse countries to capture implementation experiences and key roles and innovations introduced by community cadres operating within a complex health programme
- A limitation is the field research by rapid appraisal during short country visits. Thus the impressions presented must be regarded as a snapshot, raising questions for further exploration, particularly regarding the impact of the identified strategies on increasing retention and their potential for scale-up.
- This study could not explore the perceptions of women living with HIV and their families regarding the role of community cadres. These would be important to address in future research as the perspectives of patients and their families could differ from health care workers and managers.

Introduction

In April 2012, the World Health Organization (WHO) recommended the use of lifelong triple antiretroviral treatment (ART) for all pregnant and lactating women living with HIV, regardless of CD4 cell count and/or clinical staging (PMTCT Option B+), to prevent mother-to-child transmission of HIV (PMTCT) and to keep mothers healthy.[1]

Lifelong treatment for pregnant and breastfeeding women living with HIV has also been advocated as a strategy to reduce transmission to HIV-negative partners.[2] The WHO further states that this approach would strengthen the effectiveness of the PMTCT programme, through improved linkages with ART programmes.[1 3-5]

These global recommendations have prompted rapid adoption of Option B+ guidelines across high-burden countries. The WHO identified 22 priority countries encompassing 90% of the world's population living with HIV and comprising 75% of women in need of PMTCT globally. In those predominantly low and middle income African countries, the proportion of women receiving treatment more than doubled between 2009 and 2015.[6] These increases have been largely attributed to the adoption of Option B+, with all priority countries having implemented this approach by

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

2015.[7] Nonetheless, countries face challenges in reaching scale, while health systems and health workers face ever-increasing, complex demands.

Therefore, as more countries endorse lifelong treatment for all individuals living with HIV, health services should implement strategies to ensure good retention in care. Research in Malawi, the first country to implement Option B+, found lower retention in care for pregnant women living with HIV initiated on lifelong ART compared with other adults.[8] Uganda however, reported similar retention rates at 6 months for pregnant women (88%) and other non-pregnant adults (87%).[9] A recent review of Option B+ roll out in Malawi,[10] demonstrated that while women receiving lifelong ART had a higher risk of dropout during the first two years following initiation than other adult cohorts, retention rates were similar as the programme matured. This emphasizes the need to focus efforts in the first years of implementation, when women are most likely to be lost to follow up.

While the literature around factors contributing to poor adherence and retention in HIV care is well known,[11-13] evidence around strategies to improve retention is limited. One of the serious constraints to scaling up HIV treatment and care is the critical shortage of health workers. With 3% of the global health work force[14] and a disproportionate share of people living with HIV, the sub-Saharan African region is increasingly focused on the potential for different community cadres to fill the gap.[15-17] This article presents qualitative findings from a rapid appraisal with the objective to explore the roles of community cadres in improving access to and retention in care for PMTCT in the context of treatment scale-up. This paper aims to highlight the different cadres and the wide range of activities they perform.

Methods

<u>Study design</u>

The research was part of an evaluation of the Optimizing HIV Treatment Access (OHTA) initiative for pregnant and breastfeeding women. The initiative, funded by the governments of Sweden and

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

Norway through the United Nations Children's Fund (UNICEF), was undertaken in four countries (Malawi, Uganda, the Democratic Republic of Congo (DRC) and Côte d'Ivoire) between 2013 and 2017 in partnership with several international and local Implementing Partners (IPs).[18] The OHTA initiative aimed to support the transition to Option B+ for PMTCT in the DRC and Cote d'Ivoire and to optimize delivery and increase demand in Uganda and Malawi.[19] To achieve its aims, OHTA focused among other objectives on strengthening community-facility linkages through establishing or strengthening community-based lay health worker cadres.

We defined community cadres as any lay health workers (paid or voluntary) who: provide care and support for pregnant and breastfeeding women living with HIV; are trained on PMTCT but have received no formal professional or paraprofessional certificate or tertiary education degree (adapted from Lewin 2010.)[20]

This descriptive qualitative study[21] used rapid appraisal methods [22] to explore the roles of community cadres in improving access to and retention in care for PMTCT services.
Rapid Appraisal is an approach that draws on multiple data collection methods and techniques to quickly, yet systematically, collect data when time in the field is limited and research findings are needed in a timely manner for decision-makers. Qualitative methodology was chosen as it allows for direct engagement with participants within their social context and this qualitative approach is flexible and adaptive allowing for probing key aspects and multi-level factors experienced by the range of stakeholders involved in PMTCT service delivery.[23]

Settings and Participants

Qualitative data were collected through desk review and individual interviews and focus group discussions (FGDs) during country fieldwork of 12 days per country in the DRC, Cote d'Ivoire, Malawi and Uganda between June-July 2015 (table 1).

Sampling and Recruitment

In advance of the country visits, potential organisations and individuals for key informant interviews and FGDs were identified through a desk review process and were shared with and amended in collaboration with UNICEF headquarters and the UNICEF country offices. In compiling the list of potential participants, we gave consideration to gaining as wide a range of opinion as possible so as to ensure a fair representation of how the implementation of PMTCT Option B+ and particularly community involvement was experienced in the four settings.

The UNICEF country teams assisted with pre-scheduling appointments. Before engaging with participants, we explained in detail who we were, why we were visiting and why we wanted to

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

speak with them. When necessary in Uganda and Malawi, especially with community cadres and their supervisors, we used the services of a translator to explain our research aim and the consenting process, while in the DRC and Cote d'Ivoire all interviews were conducted in French through a translator. One of the research team members was a French national.

Ethics approval

This study received ethical approval from the South African Medical Research Council (EC014-4/2015) and received permission from each of the following authorities: Malawi: Director of the HIV & AIDS Department in the national Ministry of Health; Uganda: Higher degrees, research and ethics committee, College of Health Sciences, School of Public Health, Makerere University; Cote d'Ivoire: President of the National Committee of Research and Ethics, Ministry of Health; DRC: Director, National AIDS Control Programme (PNLS), Ministry of Health.

Research team

Eight researchers (all women) participated in the study as teams of 3-4 for each country visit. DB, TD, AG, NR and ED, SR had experience undertaking multi-country evaluations and have worked in the area of PMTCT but had no prior relationship with any of the participants.

Data collection

Semi-structured interview guides were developed for each category of respondent (Ministry of Health, IPs, district management teams, facility-based health workers and community cadres). The terms of reference excluded beneficiaries.

Each semi-structured interview and focus group discussion was conducted by one or more researchers at the interviewees' workplaces, and lasted an average of 45 minutes, with the support of translators. Interviews were audio-recorded where permission was granted, and researchers took notes. Signed informed consent from literate participants and recorded verbal consent from illiterate participants were obtained by the interviewer.

Table 1 shows the numbers of interviews undertaken in each country. The total number of interviews undertaken per country was determined by several considerations including the geographic scope of the OHTA support in each country, regional variations in health services and cultural diversity and ensuring fair representation of all categories of participants. The number of

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

interviews was largest in Uganda as the OHTA programme supported all four regions of the country.

Data analysis

Audio recorded interviews and focus group discussions were translated and transcribed into English, and field notes were summarized. We conducted a simple manifest analysis of the qualitative material[21 24] and analysed the data both deductively and inductively.[25] Deductively we sought to find answers to pre-defined questions (e.g. what role do community cadres play in delivery of PMTCT Option B+?). Inductively, we tried to understand what new insights could be gleaned from the interviews and our experiences in the field. The analysis was based on the typed interviews, field notes and desk review material (programme reports, policy documents and country plans). Country teams came together to discuss, compare and critique emerging themes and categories. Data were then grouped (via word processor) into final categories, whose results are reported in narrative form in this paper.

For peer review only

Results

Types of community cadres

Interviews identified different community cadres, newly created or strengthened, to support PMTCT services. Table 2 summarizes the community cadres involved in the PMTCT response. These community cadres operated either solely in the community, worked from health centres, or in combination. Their mandates were PMTCT-specific or ranged across general HIV support and broader health issues. Community cadres included volunteers, such as the “Relais communautaires” in the DRC to the Village Health Teams of Uganda. Others were supported by IPs, such as the mentor mothers in Malawi, Uganda, and the DRC, while some were employed directly by the Ministry of Health, such as the Health Surveillance Assistants (HSAs) of Malawi. Some of these cadres, including the mentor mothers in Uganda or expert client/peer supporters in all four countries, were themselves living with HIV, and trained to provide counselling, psychosocial support and peer support to their peers.

Activities performed by community cadres

Acting as the interface between communities and health services, community cadres created awareness, generated demand for PMTCT services (raising awareness about service availability and importance of seeking care), referred and followed up pregnant and lactating women living with HIV in the community, to ensure they received appropriate services and remained in care.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

Figure 1 illustrates the roles of community cadres across the PMTCT care continuum.

Community engagement and awareness raising

"*I am not paid anything. I joined this because I felt that the life of other people was very important to me. When I moved to the villages, my first role was to mobilize* (provide information and encouragement*) women. When I identified any pregnant women, I mobilized them to come to the hospital so that they test. When I send them, I follow them* (make a follow up home visit) *to make sure that they have reached the unit." (Expert client, Uganda)*

Cadres including the Agents de Santé Communautaires (ASCs) of Cote d'Ivoire, Relais communautaires of DRC, and the Expert clients and Village Health teams (VHTs) and committees of Uganda and Malawi, participated in community dialogues to increase service uptake and retention.

"*They (community cadres) have contributed a lot to the health centre…because we as health workers don't have time to go into the community to sensitize them*" (inform them of HIV treatment and prevention available). (facility-based health worker, Cote d'Ivoire)

Health workers reported that participating in an open dialogue with community members and getting the buy-in of leaders helped dispel myths and fears around HIV, and addressed challenges with stigma.

"Thanks to the support of the ASCs, they have been able to meet community leaders and women's associations, and explained to them transmission of HIV and … what women who are positive and pregnant can do." (Nurse, Cote d'Ivoire)

Furthermore, the male champions of Uganda and Malawi actively engaged men to promote increased partner participation in reproductive health, and addressed interpersonal barriers to retention including partner disclosure and domestic violence.

"*Male motivators and male study circles conduct door-to-door peer education to encourage fellow men to accompany their wives to ANC, couple HTC, delivery and post-natal checks. But during meetings organised by chiefs, they also take advantage to provide education on a topic.*" (IP, Malawi)

Client follow-up and retention in care

"*Many people still don't believe in the HIV/AIDS. They still don't think they need to live, so you find many families are breaking because of HIV/AIDS and so these high levels of stigma is still causing treatment interruptions* (because women drop out of care)*."* (MOH, Uganda)

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

Once clients are initiated into care, community cadres focused on counselling and psychosocial support, including formation of support groups and key activities to promote positive living and self-efficacy in HIV management. Community cadres who undertook home visits and followed up patients were perceived to play an integral role in this domain.

"So we have what we call active-plan follow-up. Every Friday there is a meeting at the facility. That meeting involves the facility mentor mothers and the health facility team, the midwife in charge and community mentor mothers. They map out and say, who are the women who are defaulted, and which parishes do they come from. So they come up with lists and distribute this (to the mentor mothers).*"* (IP, Uganda)

Concerns were highlighted about confidentiality and the use of the volunteer cadres for follow-up of individuals living with HIV.

"There is also a challenge to work with VHTs (Village health teams) *with regards to HIV-positive mothers. They don't want VHTs to know their status, especially with retention. Mothers get very angry when VHTs go to do home visits* (likely due to fear of HIV stigma)*"* (Facility interview, Uganda)

Communities were often more accepting of these generalist community cadres for broad health promotion activities (such as ANC care, follow-up of mothers post-partum, and their children), while HIV-specific follow-up was preferred from peer supporters and lay counsellors. As many of these HIV-specific community cadres were living with HIV, they could share personal coping strategies, and demonstrate the positive impact of treatment adherence through their own experiences.

"*There is very good retention for Option B + and also good coverage for HIV testing and that in a way is attributed to the Mentor Mothers. Because these are the people who [have] gone through the experience of PMTCT or Option B +… and are able to share with other women, to help them provide some of the counselling, so that they can get the intended care*" (Malawi, IP)

Peer support was a commonly used role for community cadres in all four countries. Through support networks (treatment buddies, peer supports, mentor mothers, expert clients, support groups), mothers had access to emotional support and motivation, and were provided with a platform to share knowledge and experiences.

"*So even the peer clients, the peer mothers work with the VHT members, so they can follow-up their colleagues and bring them back. Then healthcare workers… can do physical follow-up but they also have a bit of issues around, you know, going through the community. And the community*

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

knows that, oh, they recognise that house, and there is something wrong with that woman there, you know, that kind of thing, yeah. But mostly the peer, that is where the peer mothers become very successful in following up (to address problems with retention)*."* (IP, Uganda)

Such strategies to improve patient retention recognized the time and cost burdens for patients travelling monthly to facilities for ART refills. In Malawi, HSAs were trained to provide ART refills at rural health posts. In this model, clients obtained refills every three months, only visiting the clinic for screening every six months. Similarly, community ART distribution points in the DRC were run by People Living with HIV. One IP in the DRC piloted the use of an adherence group for HIV-positive women, with one patient responsible each month for picking up ART refills.

"We are piloting the GAAC model (groups to support community accession), which is an adherence group in the community. One person in the group goes every month to pick up drugs for the group. This is working well in certain areas. The group needs to know each other well for it to work" (IP, DRC)

Health facility-based activities

Some community cadres, including linkage facilitators in Uganda and community counsellors in Cote d'Ivoire, were based in facilities full-time, or divided their time between community and facility, to support staff with patient triage, educational talks, pre-test counselling and referrals to facility staff for HIV-testing. In Malawi, the HSAs performed HIV-testing and counseling after 28 days of formal training, and in Uganda lay counsellors conduct HIV testing.

One advantage of this system was that, by performing regular educational, counselling and administrative duties, these paid community cadres focused on guiding patients through the continuum of care and eased the non-clinical workload of midwifes and nurses:

"*They have lay counsellors at health centres permanently, who fill registers and records of pregnant women, and make appointments for treatment, and follow-up women who miss her appointment…..The ASCs also have a referral form. In addition to this, the NGO has designed some materials like diaries to monitor the appointments of pregnant women. And when they are completed at field level, they summarize this at the health facility, and then at the health facility they can know how many have been referred*" (Health worker, Cote d'Ivoire)

Uganda established *Family Support Groups* to encourage family participation in follow-up ART visits, to improve patient retention. These support groups were often facilitated by nurses, in conjunction with community cadres and mentor mothers. Encouraging women to bring their children ensured exposed children were also monitored, until their 18 months status was

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

ascertained. Furthermore, these groups encouraged women to disclose their status to partners and included them as active participants in family health decisions. Group sessions included a health education talk, scheduled on-the same day as ARV drug pick up, to encourage adherence. Support groups on the same day as monthly ART pick-up dates were also occurring in the DRC, Cote d'Ivoire and Malawi.

"*So they support retention in that way, they support the health workers to coordinate family support groups, […] that have been institutionalised by Minister of Health. So in these family support groups, these HIV-positive mums come with their babies. We always insist that facilitators come with the baby and ... in m2m we also do what we call a needs assessment, to ensure that, in addition to just getting the education and the testimonies and trying to make each other strong, we ensure that that's an opportunity to catch up with services that are due, like Polymerase Chain Reaction (PCR)*." (IP, Uganda)

Patient tracking

In all countries, community cadres supported health workers with tracing women and children who missed appointments. Tools used for longitudinal follow-up varied across settings, generally including client appointment books, agendas to identify those missing appointments, and longitudinal facility registers. A combination of phone calls and home visits were used to track patients and re-connect them to services.

"*So when she's compiling her report, she has a paper-based report that shows loss of month one, loss of month two….and then missed appointments for that month. So as she sending the report to the central level, she's also thinking of what actions. I was expecting thirty mothers and got fifteen. So, she has to put down actions for the fifteen lost mothers. And then either use of community people or whatever, she has to make sure that she tracks them*" (National MOH, Uganda)

Limited access to accurate patient information caused a major barrier to finding patients lost to follow-up. In "*Mon Bip Mon Sauveur*" (My Beep My Savior) a Cote d'Ivoire initiative, facility staff or ASCs gave women a missed call immediately after they provided phone numbers, to ensure the number was correct. Since a large proportion of the population did not have access to mobile phones or formal addresses, another strategy ("*Cahier de Localisation*" or Location Book) described the area in which patients lived according to landmarks, and mapped them to allow easier tracking.

Challenges to the sustainability of community cadres

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

Concerns were expressed around community cadre remuneration that is mainly dependent on external support, and variability in payment schedules.

"*She is saying that these peers, they are widows, and they spend a lot of time here when there is no-one to do any other activities in their homes. And then, on top of that, they have their children who are at school. So they are worried where to get funds for their children. So they are saying, even their funds don't come in time, because she is saying like after three months, so they find that they are really broke*." (Health worker, Uganda)

Despite some financial support for community cadres undertaking HIV-related activities, these incentives did not amount to a living wage, and retention of these cadres was described as a challenge.

"For the village health teams, I will say allowance. When we work with them often, we give them some refreshment and some transport. Otherwise, paying them a stipend, like which is regular, no." (IP, Uganda)

"I am not married, so even though the money is little, it still helps me because I have children and it helps me to help them […]. I don't worry about anything, because I consider myself to have a job" (Expert Client, Malawi).

The mothers2mothers model in Uganda and Malawi, mentor mothers in the DRC and the HSAs in Malawi were amongst the only cadres receiving a regular salary:

"*Mothers to Mothers model, […], is not voluntarily at all, in all in the countries. So we don't believe in voluntarism. We have a component, one of objectives is empowering women who are living with HIV, and we realise that when you get the stipend and give it to them at the end of the month, it makes more meaning to them. They can be able to invest it, they can be able to do things with it*." (IP, Uganda)

"I think that professionalisation of these mums makes them feel maybe valued, and so it really makes a difference." (IP, Uganda)

Discussion

This paper highlights the range and characteristics of community cadres engaged to support PMTCT programmes across the four countries. The findings of the paper provide important insights into the unique roles of community cadres and innovative strategies employed by them to support PMTCT. These include family support groups, community adherence groups and active follow up

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

which can have significant influence on the uptake and retention in HIV care in these low resourced contexts.

The scale up of lifelong treatment, and investments in newly created cadres or capacity-building of existing cadres, have facilitated their engagement in promoting and supporting lifelong HIV treatment at community and facility level. While this paper, reflects a synthesis of a mid-term programmatic evaluation, and therefore does not make linkages between activity data and PMTCT-related health outcomes, the synthesis of qualitative investigations from key informant interviews demonstrate the interplay of these community cadres with facility based interventions in supporting PMTCT scale up. Investments in increasing community awareness around the benefits of HIV testing and treatment adherence, while addressing stigma and discrimination in the community through positive messaging and the use of peer supporters who openly disclose their status, have been shown in other studies to improve patient retention.[26]

Once clients are linked to services, the HIV-specific community cadres, largely facility-based, support uptake of and retention in HIV services, through counselling, HIV-testing, home-based care, patient education, adherence counselling, patient SMS reminders and defaulter tracing. Integrating peers into the health care team has resulted in positive patient outcomes, where peers motivate behavioural change in people living with HIV, to improve patient retention.[26] Furthermore, investments in facility-based lay cadres have eased the clinical workload of health workers, resembling task-shifting in other programmes.[27] Operationalising community cadres for the HIV response has to take into consideration interactions between established generalist community cadres covering a range of healthcare activities, and cadres created specifically for the HIV response.

The mothers2mothers programme is a successful example of peer-support in PMTCT services across several countries. It hires, remunerates, supervises and supports with external funding women living with HIV to serve as peers in PMTCT programmes. A recent evaluation in Uganda found improved outcomes across a range of health-related indicators, including significantly higher rates of 12-month ART retention (91 vs. 64 %), uptake of EID at 6-8 weeks (72 vs. 46 %), ART initiation in infants (61 vs. 28 %) and partner disclosure (82 vs. 70 per cent) in M2M supported sites.[28]

Ongoing challenges with stigma, geographical access to health services, high levels of poverty and low male partner involvement in maternal and reproductive services, make women less likely to remain on treatment. Furthermore, high HIV-prevalence rates, coupled with high fertility rates in these countries, place an increasing burden on health systems for follow-up and support of a

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

growing number of women on ART. It is therefore critical that PMTCT programmes make concerted efforts towards scaling up effective strategies to optimize retention.

With the rapidly increasing HIV care and treatment needs and the accelerating human resource crisis in many African countries, community-based cadres will remain a core feature of health systems. Effective inclusion of these cadres in the health team requires political and financial commitments, regulatory frameworks and mechanisms for supervision and mentoring.[17 29 30]

In the absence of formal recognition, these cadres will continue to be inadequately resourced and undervalued, undercutting their potential health impacts.[31] Community cadres interviewed highlighted a range of challenges for patient follow-up including lack of transport, phones or airtime, and insufficient money for transport. Furthermore, remuneration of community cadres is currently not standardized within countries, and has the potential to create tensions between cadres and to reduce motivation. These cadres are largely donor-supported and high turnover rates, inadequate job security, formal recognition or harmonization, threaten the sustainability of achievements. These well-established challenges affecting Community Cadre programmes have been reported for several decades.[32] The recent interest in and use of community cadres in response to large-scale ARV roll-out appear to pay insufficient attention to these major determinants of success.[29]

Conclusion

Community cadres can provide an integral link between communities and health facilities, using innovative strategies to support overstretched health workers in HIV client support and follow-up. However, challenges remain including the need to invest in country-specific standardization of roles, responsibilities and remuneration for the range of community cadres in order to promote sustainability and maximize the potential effectiveness of their activities. Further research is needed to understand which services, strategies and approaches are most effective in improving outcomes along the continuum of care, including the perspectives of women living with HIV and their families.

For peer review only

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Competing interests

The authors have no competing interests to declare

Acknowledgements

The authors thank the Ministry of Health, UNICEF country office and implementing partners in Cote d'Ivoire, DRC Malawi, and Uganda for their assistance with the field visits. We thank all participants for sharing their insights and experiences with us.

Funding

The research was supported by UNICEF New York through a grant from the government of Sweden and the Norwegian Agency for Development Cooperation (Norad), and the South African Medical Research Council. The South African Medical Research Council supported the time of the authors to write the article. TD is supported by the National Research Foundation, South Africa.

For peer review only

Authors' contributions

TD, DB, SR, AG and ED conceptualized the study and developed the protocol and data collection materials. TD, AG, DB, NR, SR and ED participated in the country visits in 2015 and participated in the analysis of interview transcripts. DB and TD prepared the first draft of the paper. TD, DB, SR, AG, ED, JRC, SV, GC, SO, NT, ND, NR reviewed and contributed to subsequent drafts and approved the final version for publication.

Data sharing statement

The audio recordings and transcribed interviews are stored in a password protected system with the project team at the South African Medical Research Council office. The privacy of the data is maintained since participants did not consent for data to be shared beyond the research team. However, all data has been consolidated and written up for the purposes of the evaluation and reports published on the SAMRC website in addition to the development of peer reviewed publications.

Figure 1 illustrates the roles of community cadres across the PMTCT care continuum, which includes community engagement activities to sensitize the community around the need to test for HIV and access care; linkage to care in which community cadres inform the community around where to access services and refer to care; and adherence a strategies to ensure those living with

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

HIV are retained in care. The figure further illustrates the role of community cadres who operate partly out of the health facilities.

References

1. World Health Organization. Programmatic Update: Use of Antiretroviral Drugs for Treating Pregnant Women and Preventing HIV Infection in Infants. Geneva, 2012.(Accessed 15 November 2017).
2. Rayment M. Prevention of HIV-1 infection with early antiretroviral therapy. *Journal of Family Planning and Reproductive Health Care* 2012;38(3):193-93.
3. UNICEF Business Leadership Council. A Business Case for Options B and B+ to Eliminate Mother to Child Transmission of HIV by 2015. New York: UNICEF, 2012.(Accessed 5 January 2018).
4. Presidential Emergency Plan for AIDS Relief (PEPFAR) Scientific Advisory Board. Recommendations for the Office of the US Global AIDS Coordinator: Implications of HPTN 052 for PEPFAR's Treatment Programs 2011. Washington, 2011.(Accessed 10 December 2017).
5. Bachman G, Phelps B. PMTCT and Community: Updates and PEPFAR Perspectives. Presentations from the CCABA/UNICEF/UNAIDS/Global Fund/RIATT 'Road to Washington' meeting in London London: UNICEF; 2012 [Available from: http://www.ccaba.org/wp-content/uploads/Bachman-and-Phelps-presentation.pdf accessed 15 December 2017.
6. Haroz D, von Zinkernagel D, Kiragu K. Development and Impact of the Global Plan. *Journal of Acquired Immune Deficiency Syndromes (1999)* 2017;75(1):S2-S6.
7. UNAIDS. On the Fast-Track to an AIDS-free generation. Geneva: UNAIDS, 2016.(Accessed 10 January 2018).
8. Tenthani L, Haas AD, Tweya H*, et al.* Retention in care under universal antiretroviral therapy for HIV-infected pregnant and breastfeeding women ('Option B+') in Malawi. *Aids* 2014;28(4):589-98.
9. Kieffer MP, Mattingly M, Giphart A*, et al.* Lessons learned from early implementation of option B+: the Elizabeth Glaser Pediatric AIDS Foundation experience in 11 African countries. *J Acquir Immune Defic Syndr* 2014;67 Suppl 4:S188-94.
10. Haas AD, Tenthani L, Msukwa MT*, et al.* Retention in care during the first 3 years of antiretroviral therapy for women in Malawi's option B+ programme: an observational cohort study. *The lancet HIV* 2016;3(4):e175-82.
11. Brinkhof MW, Pujades-Rodriguez M, Egger M. Mortality of patients lost to follow-up in antiretroviral treatment programmes in resource-limited settings: systematic review and meta-analysis. *PloS one* 2009;4(6):e5790.
12. Geng EH, Nash D, Kambugu A*, et al.* Retention in care among HIV-infected patients in resource-limited settings: emerging insights and new directions. *Current HIV/AIDS reports* 2010;7(4):234-44.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

13. Hodgson I, Plummer ML, Konopka SN*, et al.* A Systematic Review of Individual and Contextual Factors Affecting ART Initiation, Adherence, and Retention for HIV-Infected Pregnant and Postpartum Women. *PloS one* 2014;9(11):e111421.
14. Maddison AR, Schlech WF. Will universal access to antiretroviral therapy ever be possible? The health care worker challenge. *The Canadian journal of infectious diseases & medical microbiology = Journal canadien des maladies infectieuses et de la microbiologie medicale* 2010;21(1):e64-9.
15. Jerome G, Ivers LC. Community health workers in health systems strengthening: a qualitative evaluation from rural Haiti. *Aids* 2010;24 Suppl 1:S67-72.
16. 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.
17. Rasschaert F, Philips M, Van Leemput L*, et al.* Tackling health workforce shortages during antiretroviral treatment scale-up--experiences from Ethiopia and Malawi. *J Acquir Immune Defic Syndr* 2011;57 Suppl 2:S109-12.
18. Doherty T, Besada D, Rohde S*, et al.* Report on the external mid-term, formative evaluation of the optimizing HIV treatment access (OHTA) for pregnant and breastfeeding women initiative in Uganda, Malawi, Ivory Coast and the Democratic Republic of Congo. Cape Town, 2015
19. UNICEF. Optimizing HIV treatment access for pregnant and breastfeeding women. http://www.childrenandaids.org/partnership/optimizing-hiv-treatment-access. New York: UNICEF; 2015 [Available from: http://www.childrenandaids.org/partnership/optimizing-hiv-treatment-access.
20. Lewin S, Munabi-Babigumira S, Glenton C*, et al.* Lay health workers in primary and community health care for maternal and child health and the management of infectious diseases. *Cochrane Database Syst Rev* 2010;3
21. Green J, Thorogood, N. Qualitative Methods for Health Research. London: Sage Publications 2004.
22. USAID Center for Development Information and Evaluation. Using Rapid Appraisal Methods. Perfomance Monitoring and Evaluation TIPS. Washington: USAID, 1996.
23. Sprague C, Scanlon ML, Pantalone DW. Qualitative Research Methods to Advance Research on Health Inequities Among Previously Incarcerated Women Living With HIV in Alabama. *Health education & behavior : the official publication of the Society for Public Health Education* 2017;44(5):716-27.
24. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse education today* 2004;24(2):105-12.
25. Fereday J, Muir-Cochrane E. Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. *International Journal of Qualitative Methods* 2006;5(1):80-92.
26. MSF. Reaching 90 90 90. Brussels: MSF, 2016.(Accessed 15 November 2017).
27. MSF. HIV/TB Counseling: Who is doing the job? Time for recognition of lay counselors. Brussels: MSF, 2016.(Accessed 15 November 2017).
28. Zikusooka CM, Kibuuka-Musoke D, Bwanika JB*, et al.* External Evaluation of the m2m Mentor Mother Model as Implemented under the STAR-EC Program in Uganda. Cape Town: Mothers to Mothers, 2014.(Accessed 15 November 2017).
29. 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. *Human Resources for Health* 2009;7(1):31.
30. Lehmann U, Van Damme W, Barten F*, et al.* Task shifting: the answer to the human resources crisis in Africa? *Hum Resour Health* 2009;7:49.
31. Mwai GW, Mburu G, Torpey K*, et al.* Role and outcomes of community health workers in HIV care in sub-Saharan Africa: a systematic review. *Journal of the International AIDS Society* 2013;16:18586.
32. Lehmann U, Sanders D. Community health workers: What do we know about them? The state of the evidence on programmes, activities, costs and impact on health outcomes of using community health workers. Geneva: World Health Organisation, 2007.(Accessed 9 January 2018).

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

For peer review only

1
2
3
4 **Table 1: Summary of Participants**

Malawi Data collection 15th to 24th June: Districts visited Lilongwe, Mzimba North, Zomba		
Type of interview	**Participant category**	**Number of interviewees/ focus group discussion participants**
Individual interviews (39% female; 61% male)	Implementing partner	2 female
	Ministry of Health	1 female, 2 male
	Multilateral agency	1 female, 1 male
	District management	5 male
	Facility-based health workers	2 female, 2 male
	Community-based health worker	1 female, 1 male
Focus Group Discussions (53% female; 47% male)	Implementing partner	7 female, 4 male
	Ministry of Health	1 female, 2 males
	Multilateral agency	2 female; 3 male
	District management	1 female, 3 male
	Facility-based health workers	7 female, 5 male
	Community-based health workers (health surveillance assistants, Male Study Circles, M2M mentor mothers, Community advisory board)	10 groups (average size 9 individuals, mixed gender)
Côte d' Ivoire Data collection 19th to 31st July: Three districts visited (Port-Bouet, Bouake Sud, Daloa)		
Type of interview	**Participant category**	**Number of interviewees/ focus group discussion participants**
Individual interviews (32% female; 68% male)	Implementing partner	4 female, 6 male
	Ministry of Health	1 female, 3 male
	Multilateral agency	3 female, 3 male
	District management	1 female, 6 male
	Facility-based health workers	1 male
Focus Group Discussions (53% female; 47% male)	Implementing partner	4 groups (average size 7, mixed gender)
	District management	1 group of 2 females and 4 males
	Facility-based health workers	1 group of 2 females and 1 male
	Community-based health workers	3 groups (average size 8, mixed gender)

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

	Participant category	
	(scouts, lay counsellors, community health workers, traditional leaders)	
DRC Data collection 8th to 19th June 2015: 3 health zones in the Katanga Province (Kasenga, Kapemba, Kisanga).		
Type of interview	**Participant category**	**Number of interviewees/ focus group discussion participants**
Individual interviews (29% female; 71% male)	Implementing partner	6 male
	Ministry of Health	2 female, 6 male
	Multilateral agency	4 female, 6 male
	District management	1 female, 3 male
	Facility-based health workers	2 female, 1 male
Focus Group Discussions (52% female; 48% male)	Implementing partner	5 groups (average size 3, mixed gender)
	Facility-based health workers	1 group with 4 females
	Community-based health workers (Relais communautaires, mentor mothers, peer educator)	4 groups (average size 4, mixed gender)
Uganda 29th June to 19th July: Greater Kampala and 9 districts across three regions (Bugiri, Kamuli, Kaliro, Isingiro, Bushenyi, Ibanda, Moroto, Kotido, Abim).		
Type of interview	**Participant category**	**Number of interviewees/ focus group discussion participants**
Individual interviews (49% female; 51% male)	Implementing partner	6 female, 9 male
	Ministry of Health	2 female, 4 male
	Multilateral agency	2 male
	District management	30 female, 27 male
	Community-based health worker	2 female
Focus Group Discussions (54% female; 46% male)	Implementing partner	1 group with 2 females and one male
	Facility-based health workers	2 groups (average size 4, mostly female)
	Community-based health workers (scouts, lay counsellors, community health workers, traditional leaders)	13 groups (average size 5, mixed gender)

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Table 2 Community cadres involved in the PMTCT response

Health Worker	Country	Paid/ Volunteer	Formal Gov Structure/ Informal	Facility/ Community based	HIV-Specific/ General	Domains		
						Community engagement	Linkage to care	Longitudinal Follow up
Agents Sante Communautaire (ASCs)	Cote d'Ivoire	Not standardized	Formal	Community	General	Participate in communtiy engagement activities with work plans developed by responsible implementing partners, attend weekly review meetings organized by midwives/nurses where registers are reviewed and patients who require follow up through phones and home visits are identified and assigned to ASCs.		
						X	X	X
Assistants sociaux (social assistants)	DRC	Paid	Informal/ NGO based	Facility	HIV-Specific	Provide psychosocial support to patients who test HIV-positive		
						X		
Community Counsellors	Cote d'Ivoire	Paid	Informal/ NGO based	Facility	HIV-Specific	Serve as the link between the ASCs and facility health workers in addition to providing psychosocial support to women who have tested positive; Manage the referral and counter referral process by consolidating information and monitoring clients' appointment dashboard.		
						X	X	X
Expert Clients/Peer educators (living with HIV)	All 4	Volunteer	Informal/ NGO based	Combination	HIV-Specific	Responsibilities at facility: client health education sessions; adherence assessment counselling and support; nutritional assessment; maintaining a client appointment system to help facilitate clinic visits and identify missed appointments; developing a search list for clients who miss appointments; following up patients through telephone calls and physical tracking of clients; and HIV post-test and pre-ART counselling.		

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

						<u>At the community level</u>: follow up clients who miss appointments, continue to provide adherence counselling and support, and conduct home visits for sick patients or those struggling with treatment adherence.	X	X	X
Health Surveillance Assistants	Malawi	Paid	Formal	Work out of Village clinics in community but report to facility	General	Health education talks, provision of immunisation services, integrated community case management of childhood illnesses (iCCM), home and market inspection, malaria screening, growth monitoring and nutrition education. HIV-related tasks include: HIV prevention, provision of HCT, opportunistic infection management and cotrimoxazole administration, defaulter tracing, and general support to ART clients.	X	X	X
Linkage Facilitator	Uganda	Paid	Informal/ NGO based	Facility	General	Receive all the referrals from the community, help navigate clients to the services they require, consolidate all the referral information and ensure information is fed back to the community.		X	X
Male Champions	Malawi, Uganda	Volunteer	Informal/ NGO based	Community	General	Conduct door to door peer education and provide health education talks to mobilise men to accompany their partners to access MNCH services: promote increased couple HIV counselling and testing, and in the case of discordant relationships, facilitate partner disclosure and general partner support.	X	X	
Mentor mothers (living with HIV)	DRC, Malawi,	Paid	Informal/ NGO	Combination	HIV-specific	<u>Community level:</u> conduct community health education talks on Maternal and Child Health (MNCH) and PMTCT topics, conduct			

For peer review only

	Uganda		based			household visits of pregnant and lactating women identified and referred by VHTS, conduct referrals and obtain the list of clients missing appointments and HIV-positive mother baby pairs for follow up Facility level: group education talks, client triage, HIV pre-test education at the ANC clinics, TB and nutrition screening services, individual and couple counselling sessions, active client follow up through phone calls and home visits (where community mentor mothers do not exist), and provide reminders to patients for their next visits. Mentor mothers also organize psychosocial support groups with the support of health workers and expert clients, and participate in integrated outreach activities.	X	X	X
Relais communautaires	DRC	Volunteer	Formal	Community	General	Promote the use of reproductive health services including ANC attendance and family planning, conduct home visits, and carry out community sensitisation activities.	X	X	
Village Health Committees	Malawi	Volunteer	Formal	Community	General	Conduct village health inspections and mobilize households to participate in immunization campaigns, child health days and other outreach activities.	X	X	
Village Health Teams	Uganda	Volunteer	Formal	Community	General	Provide a range of health promotion, referral and linkage services. Some HIV-related responsibilities include sensitizing communities on HIV prevention, care and treatment, demand generation for MNCH/ PMTCT services and referral for HIV counselling and testing (HCT).	X	X	

For peer review only

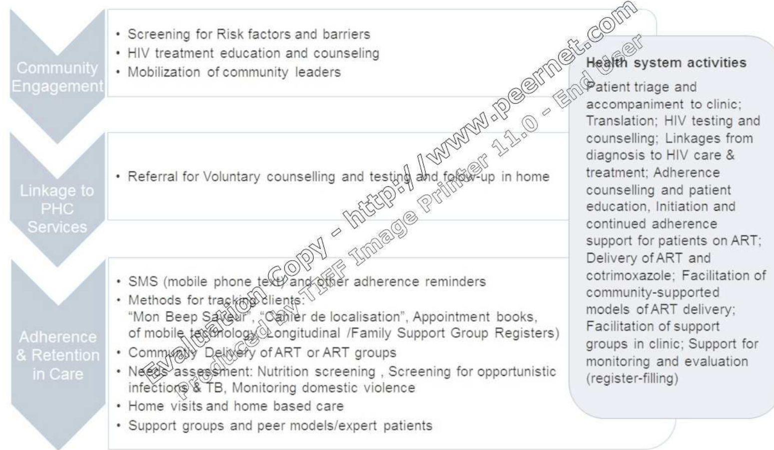
For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

For peer review only

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60



Evaluation Copy - http://www.peernet.com
Produced by TIFF Image Printer 11.0 - End User

Figure 1 illustrates the roles of community cadres across the PMTCT care continuum, which includes community engagement activities to sensitize the community around the need to test for HIV and access care; linkage to care in which community cadres inform the community around where to access services and refer to care; and adherence a strategies to ensure those living with HIV are retained in care. The figure further illustrates the role of community cadres who operate partly out of the health facilities

215x166mm (300 x 300 DPI)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page/line no(s).
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	3

Introduction

	Page/line no(s).
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4-5
Purpose or research question - Purpose of the study and specific objectives or questions	5

Methods

	Page/line no(s).
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	5
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	6
Context - Setting/site and salient contextual factors; rationale**	5
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	6
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	6
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	6

For peer review only

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	6
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	6 & 18-20
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	6
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	6
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	6

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	7-12
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	7-12

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	12-13
Limitations - Trustworthiness and limitations of findings	12

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	14
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	14

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388

For peer review only

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml