


# “Most of what they do, we cannot do!” How lay health workers respond to barriers to uptake and retention in HIV care among pregnant and breastfeeding mothers in Malawi

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**To cite:** Topp SM, Carbone NB, Tseka J, *et al.* “Most of what they do, we cannot do!” How lay health workers respond to barriers to uptake and retention in HIV care among pregnant and breastfeeding mothers in Malawi. *BMJ Global Health* 2020;**5**:e002220. doi:10.1136/bmjgh-2019-002220

**Handling editor** Seye Abimbola

Received 10 December 2019  
Revised 6 May 2020  
Accepted 9 May 2020



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## ABSTRACT

**Background** In the era of Option B+ and ‘treat all’ policies for HIV, challenges to retention in care are well documented. In Malawi, several large community-facility linkage (CFL) models have emerged to address these challenges, training lay health workers (LHW) to support the national prevention of mother-to-child transmission (PMTCT) programme. This qualitative study sought to examine how PMTCT LHW deployed by Malawi’s three most prevalent CFL models respond to known barriers to access and retention to antiretroviral therapy (ART) and PMTCT.

**Methods** We conducted a qualitative study, including 43 semi-structured interviews with PMTCT clients; 30 focus group discussions with Ministry of Health (MOH)-employed lay and professional providers and PMTCT LHWs; a facility CFL survey and 2–4 hours of onsite observation at each of 8 sites and in-depth interviews with 13 programme coordinators and MOH officials. Thematic analysis was used, combining inductive and deductive approaches.

**Results** Across all three models, PMTCT LHWs carried out a number of ‘targeted’ activities that respond directly to a range of known barriers to ART uptake and retention. These include: (i) fulfilling counselling and educational functions that responded to women’s fears and uncertainties; (ii) enhancing women’s social connectedness and participation in their own care and (iii) strengthening service function by helping clinic-based providers carry out duties more efficiently and effectively. Beyond absorbing workload or improving efficiency, however, PMTCT LHWs supported uptake and retention through foundational but often intangible work to strengthen CFL, including via efforts to strengthen facility-side responsiveness, and build community members’ recognition of and trust in services.

**Conclusion** PMTCT LHWs in each of the CFL models examined, addressed social, cultural and health system factors influencing client access to, and engagement with, HIV care and treatment. Findings underscore the importance of person-centred design in the ‘treat-all’ era and the contribution LHWs can make to this, but foreground the challenges of achieving person-centredness in the context of an under-resourced health system. Further work to understand the governance and

## Key questions

### What is already known?

- ▶ In the era of treat-all policies for prevention of mother-to-child transmission of HIV (PMTCT) and antiretroviral therapy (ART), uptake but particularly long-term engagement in care are ongoing challenges.
- ▶ Current strategies for strengthening retention and engagement along the PMTCT service ‘cascade’ include community-facility linkage models that deploy lay health workers (LHWs) to support various aspects of service delivery in clinic and community settings.
- ▶ Malawi’s PMTCT programme is currently heavily supported by LHWs recruited under three non-government funded community-facility linkage models—Mentor Mothers, Expert Clients and Tingathe-Community Health Workers.

sustainability of these project-funded CFL models and LHW cadres is now urgently required.

## INTRODUCTION

In 2012, WHO published recommendations for the adoption of lifelong combination antiretroviral therapy (ART) for all pregnant and breastfeeding women living with HIV, regardless of their CD4+ cell count or clinical staging.<sup>1</sup> Coined Option B+ after initial implementation in Malawi, the recommendations represented an evolution from earlier WHO guidelines (that employed clinical algorithms for ART eligibility) and adopted a public health approach to ensure all pregnant and breastfeeding women living with HIV had access to lifelong ART immediately following HIV diagnosis. The dual aims were to save

## Key questions

**What are the new findings?**

- ▶ Across all three models, PMTCT LHWs carried out many ‘targeted’ activities that responded directly to a range of known barriers to ART uptake and retention—these included: (i) carrying out critical counselling and educational functions that addressed prevalent fears about treatment; (ii) enhancing social connectedness and patient participation in their own care; (iii) strengthening facilities capacity to deliver services effectively and efficiently.
- ▶ PMTCT LHWs also supported uptake and retention through foundational but often intangible work to strengthen community-facility linkage, including via efforts to strengthen facility-side patient centredness and responsiveness, and build community members’ recognition of and trust in services.

**How do the new findings imply?**

- ▶ Findings underscore the importance of person-centred design in the ‘treat-all’ era and the contribution LHWs can make to this, but also foreground the challenges of achieving such in the context of an under-resourced health system.
- ▶ Understanding in what ways PMTCT LHWs are supporting efforts to address known barriers to uptake and long-term engagement in ART—in both targeted and more systemic ways—should help inform decisions about strategic investments in both PMTCT and ART programming and core health system functions such as human resource capacity.

maternal lives and to ensure prevention of mother-to-child transmission of HIV (PMTCT).<sup>1 2</sup> Malawi was the first country in the world to introduce Option B+ with policy adoption driven by a combination of factors,<sup>3 4</sup> including desire to maximise ART coverage and eliminate paediatric HIV and the need to simplify clinical programming and better integrate ART and PMTCT guidelines in an under-resourced health system.<sup>4</sup>

Implementation of Option B+ produced impressive early results in Malawi. In the first quarter of Option B+ implementation alone, Malawi reported a 748% increase in the number of pregnant women living with HIV who started lifelong treatment.<sup>3</sup> Yet impressive programmatic and health gains were accompanied by a number of challenges. In 2014, Tenthani *et al* found that Malawian women who started ART via Option B+ were five times more likely to never return to care after their initial visit, and twice as likely to miss their first follow-up visit, compared with women who started ART through other channels, including self-referral via voluntary testing and counselling.<sup>5</sup> In 2015, Kim *et al* reported that although Option B+ dramatically improved rates of ART initiation, loss to follow-up of Malawian women living with HIV following the birth of their child increased from 5.8% before Option B+ to 11.2% after Option B+ was introduced.<sup>6</sup> The most recent Malawi national data showed that 26% of Malawian pregnant women became lost to follow-up within 12 months of starting treatment.<sup>7</sup>

Reflecting what is now a central challenge of opt-out test-and-treat models of HIV care in many settings, suboptimal retention among women initiated on ART in

PMTCT has been documented elsewhere in the region. A meta-analysis of sub-Saharan African PMTCT programmes demonstrates retention rates among those initiating care via Option B+ to be below those of the general adult population.<sup>8</sup> Results from pragmatic universal test-and-treat trials from high HIV-burden countries too, suggest that the issues with linkage to care and early care retention first observed with Option B+ may be not unique to PMTCT and that in the ‘treat all’ era we will likely require interventions to improve patient engagement along the entire HIV care continuum.<sup>9–12</sup> Such interventions may need to be differentiated based on the specific population and treatment setting of concern.

Barriers to uptake and long-term engagement in care for pregnant and breastfeeding women have been identified in a number of studies in sub-Saharan Africa, including some specific to women accessing ART via opt-out Option B+ services.<sup>13–15</sup> The literature points to the role of women’s knowledge of their HIV status, understanding of PMTCT services, disclosure status and male partner support as common factors affecting willingness and ability to start or remain in care. In relation to Option B+ specifically, McLean *et al* in a study of women from four countries, demonstrated how feeling ‘ready’ was central to pregnant women’s willingness to start treatment on the same-day, with degree of ‘readiness’ influenced by their previous knowledge of HIV status, interactions with health workers and their partners and a desire and sense of responsibility to protect their infants.<sup>16</sup> A rapidly evolving ‘engagement in care’ literature now documents how the interplay between social and relational factors, individual biological and psychological features and health system design and responsiveness all influence uptake and engagement outcomes.<sup>17</sup>

Various interventions have been developed to address PMTCT and ART retention challenges variously focused on clinic, community or both settings.<sup>18</sup> Recently, so-called ‘differentiated care’ models, trialling services not reliant on individual, clinic-based attendance, have shown some promising results. These include ART adherence clubs in Western Province South Africa,<sup>19</sup> community adherence groups in Tete, Mozambique<sup>20</sup> and the medication adherence clubs in Nairobi, Kenya.<sup>21</sup> Long standing earlier versions of ‘differentiated care’ for HIV services include task-shifting and community-facility linkage (CFL) using lay health workers (LHWs) in support of more traditional clinic-based services.<sup>22–26</sup> A feature of both PMTCT and adult ART programmes in Malawi among other sub-Saharan African countries,<sup>27 28</sup> these CFL approaches<sup>29</sup> train LHWs to support education, counselling and outreach services across both clinic and community settings.

In Malawi, CFL models using PMTCT LHWs are widespread.<sup>30 31</sup> At the time of this study (2017–19), three such models—Expert Clients, Mentor Mothers and Tingathe-Community Health Workers (hereafter *Tingathe-CHW*)—resourced and overseen by non-government partners, were providing support to Malawi’s PMTCT programme

across much of the country. Although anecdotally well accepted, little has been written about how the PMTCT LHWs mobilised under these models address Malawi's PMTCT and ART engagement challenges. Nested within a larger evaluative effort, this qualitative study set out to improve understanding of (i) what Mentor Mothers, Expert Clients and Tingathe-CHWs (hereafter collectively *PMTCT LHWs*) do and (ii) how they address barriers to uptake and retention in the Malawian context.

## METHODS

We conducted an exploratory qualitative study seeking to understand, from the perspective of multiple stakeholders, how PMTCT LHWs are responding to barriers to uptake and retention in Malawi's PMTCT and ART programmes. Qualitative research was deemed an appropriate approach as it helps to develop concepts that support stronger understanding of social phenomena *in situ*, and carries an emphasis on meaning, experience and the views of participants.<sup>32</sup> Our approach was enabled through collection of observational data as well as in-depth interviews (IDIs) and focus groups that used open-ended questions. Explorations of participants' responses used probes such as 'why', 'how' and 'what' to gain deeper understanding of participants' views and experiences of PMTCT LHWs and their activities. As a reference to local barriers to uptake and retention in ART in Malawi, we were guided by McLean's adaptation of Skovdal's ecological framework for engagement barriers, and their empirically derived framework of factors relating to pregnant women's 'readiness' to start ART.

### Study design & data collection

Using qualitative methods, we conducted eight<sup>8</sup> *in-depth 'site assessments'* to enable detailed exploration of different actors' experiences with PMTCT LHWs and their role in addressing barriers to uptake and retention in PMTCT and ART in 'paired' community and clinic settings. We also conducted seven<sup>7</sup> *rapid site assessments* to improve the robustness of the conclusions drawn about PMTCT LHW activities and their health service interface by broadening our observational data of day-to-day clinic and communities activities at additional sites. Site selection was purposive and designed to ensure a demographic mix of clinics and their surrounding catchment areas taking into account the major geographic regions (Northern, Central, Southern) and health zones of Malawi (Northern, Central Eastern, Central Western and South Eastern), the urban versus rural location, size and capacity (eg, hospital vs primary health centre) and the active presence of a PMTCT LHWs (table 1).

Data collection took place between January 2018 and April 2019. At all sites (in-depth and rapid assessment), we completed a closed-ended LHW Facility Survey to characterise activities conducted by LHWs under each of the models, and structured non-participant observations

to observe the flow and dynamics of service delivery activities in facilities and the surrounding communities. For in-depth site assessments only, we also: (1) conducted focus group discussions with the different types of PMTCT LHWs, Ministry of Health (MOH) professional health workers (ie, doctors, clinical officers, midwives and nurses), MOH LHWs (eg, Health Surveillance Assistants (HSAs) and clerks); (2) semi-structured interviews with a convenience sample of HIV-positive mothers; (3) conducted IDIs within each major region with key stakeholders such as members of MOH District Health Management Teams and PMTCT LHW managers and supervisors. A team of trained and experienced Malawian research assistants fluent in local languages carried out all data collection activities. The research manager lead daily debriefings, and the lead investigator debriefed with the team approximately every fortnight. Table 1 summarises data collection activities and participants across the sites.

### Patient and public involvement

Due to educational and capacity constraints in the study setting, this research was done without direct patient involvement in study design or dissemination. However, input on study design and implementation was obtained from a multidisciplinary Study Advisory Committee which included Malawian policy makers, health systems experts and service providers, and study findings were disseminated widely among these stakeholders.

Throughout the study, attention was paid to ensuring participants' anonymity. Each participant was given an ID number based on their type (client, provider, manager), and their demographic information, with a link log held on a secure file in a separate location. If participants identified themselves or others in the course of their interview, this was transcribed to aid cross-referencing during analysis, but redacted for purpose of any quotation in reports, presentations or manuscripts. To further reduce the risk of identification, quotations of frontline providers were linked to anonymised site numbers only (eg, site 1, 2, etc) and quotations of more senior participants (eg, district or NGO managers) identified by role only.

### Analysis

Thematic analysis was conducted. To identify major and minor themes, we took the following steps: (a) familiarisation through careful and repeat reading of transcripts and research memos, noting emergent themes; (b) performing open coding in which codes were created based on identified themes, codes were assigned to specific sections of transcripts, with double-coding conducted on a sample of data to promote intercoder reliability; (c) developing a codebook; (d) performing data reduction in which inventory was taken in relation to each given code, capturing the variation or richness of each theme and noting differences between individuals or among subgroups; (e) data display using matrices



**Table 1** Summary of qualitative data collection by site and type

Type of assessment	Region	Site	Focus group PMTCT LHWs* (participants)	Focus group professional HCW (participants)	Focus group HSA† (participants)	In-depth district/provincial stakeholder interview	Semi-structured interview with mothers	Observations	CFL facility survey‡
In depth	Central	1	3 (17)	1 (8)	1 (5)	8	6	2	1
		2	1 (6)	1 (5)	1 (8)		6	2	1
		3	1 (6)	1 (4)	1 (4)		6	2	1
		4	2 (10)	1 (4)	1 (4)		5	2	1
	Northern	5	1 (8)	1 (6)	1 (6)	2	6	2	1
		6	2 (11)	1 (5)	1 (5)	3	4	2	1
	Southern	7	2 (10)	1 (5)	1 (6)		6	2	1
		8	2 (7)	1 (8)	1 (5)		4	2	1
Rapid	Central	i	-	-	-	-	-	2	1
		ii	-	-	-	-	-	2	1
		iii	-	-	-	-	-	2	1
	Northern	iv	-	-	-	-	-	2	1
		v	-	-	-	-	-	2	1
	Southern	vi	-	-	-	-	-	2	1
		vii	-	-	-	-	-	2	1
Total activities			14	8	8	13	43	30	15
Total people involved			75	45	43	13	43	N/A	N/A

\*Some facilities had more than one LHW programme operating on site; where this was the case, a separate focus group was conducted with the LHW workers/providers of each model.

†These focus groups also occasionally included MOH-hired counsellors, clerical staff.

‡Completed by a study research assistant in conjunction with the facility in-charge or nominated proxy

CFL, community-facility linkage; HCW, healthcare worker; HSA, Health Surveillance Assistants; LHW, lay health workers; MOH, Ministry of Health; N/A, not available; PMTCT, prevention of mother-to-child transmission.

and tables and (f) interpretation by searching for relationships among themes or concepts identified and developing diagrams in order to map out relationships in the data. Two investigators (one additionally being the research manager), reviewed all qualitative data, independently identifying emergent themes and conferred to agree on final coding and findings.

## FINDINGS

### Overview

In the following, we first provide an overview of the approach and organisation of PMTCT LHWs for each of the three CFL models. In the subsequent section, drawing on multiple actors' accounts, we examine and distil key themes regarding the ways PMTCT LHWs are responding to ART uptake and retention barriers among pregnant and breastfeeding women in Malawi.

### Major features of three CFL models

The major features of the three CFL models investigated are summarised in tables 2 and 3. Table 2 provides an overview of the three models and table 3 summarises types of organisation of PMTCT LHW in each model.

Although with differing emphasis, all three models used a combination of facility-based and community-based strategies. Common facility-based strategies included bolstering pre-test and post-test psychosocial counselling; navigation and accompaniment through the clinic and administrative support. Tingathe-CHW alone were also trained and responsible for dried blood spot testing of exposed infants. Common community-based strategies across the three models included tracing and follow-up of mother-infant pairs disengaged from care; home-based counselling and education visits and establishment of various types of peer-to-peer networks. Differences in

**Table 2** Overview of three PMTCT lay health worker models operating in Malawi

Expert Clients	Mentor Mothers	Tingathe-CHW
<b>Management</b>	<b>Management</b>	<b>Management</b>
Expert Clients are recruited and overseen by several different non-government groups (EGPAF, mothers2mothers) and at least one District Health Office. In several districts, Expert Clients are no longer supervised by any organisation as project funds have run out. These Expert Clients work independently, relying on pre-existing relationships with MOH clinic staff and the community.	Mentors Mothers were recruited and overseen by the non-government organisation, mothers2mothers.	Tingathe-CHW are recruited and overseen by the Baylor Tingathe programme. These CHWs are distinct from Malawi's cadre of government employed community-based public health agents called HSAs.
<b>Recruitment and training</b>	<b>Recruitment and training</b>	<b>Recruitment and training</b>
Expert Clients could be either men or women, who are living with HIV, are virally suppressed and open to others about their HIV status. They must be confident and willing to discuss their own experiences with HIV and ART in both group and one-on-one settings. There is no age requirement. Typically, Expert Clients were meant to have a Junior Certificate, although exceptions were made for highly articulate individuals, provided they could read and write. Expert Clients tended to be volunteers, sometimes receiving a monthly stipend. They usually received an initial training of about 2 weeks.	Mentor Mothers are all women, living with HIV, who have been through the PMTCT cascade, so most of the mothers tend to be middle-aged. In order to be a Mentor Mother, a woman needed to disclose their status and be open to talking about living with HIV and living positively. All Mentor Mothers were required to have finished Form Four and be able to read and write. Mentor Mothers are recruited via advertisement and formal interviews by mothers2mothers staff. Prior to beginning their work, they undergo a 2-week intensive training workshop covering the MOH HIV guidelines, and all MOH tools and mothers2mothers tools.	Tingathe-CHWs can be men or women, who may or may not be living with HIV. Although there is no formal age requirement, interviews and observations suggested the programme targets younger recruits due to the travel requirements (frequently on bike) of the job. Tingathe-CHWs must have a higher level of education compared with Expert Clients and Mentor Mothers, received 6 weeks initial training and ongoing quarterly updates. Tingathe-CHWs are required to live within the communities, so that they are 'embedded' and accessible community members. Tingathe-CHW are formal employees, and provided daily supportive supervision.
<b>Activities and relationships</b>	<b>Activities and relationships</b>	<b>Activities and relationships</b>
Expert Clients work in both the clinic and community setting. In the community, Expert Clients are mobile, and visit clients in their homes or other settings with no restrictions on the distances travelled. In the clinic, Expert Clients are technically supposed to be based in both the ART and ANC departments. However, interview and observational data suggest that for various reasons (space, staff dynamics and relative time demand), Expert Clients are more usually based in ART, and visit ANC on a need-dependent basis.	Mentor Mothers play roles at both facilities and in communities. In the facilities, Mentor Mothers are predominately in ANC. They welcome women to antenatal and help women to navigate the different queues for those coming to antenatal for the visit time. Facility-based Mentor Mothers interact with all women coming for their first antenatal visit regardless of their HIV test result, providing pre-testing and post-testing support to all. While facility-based mentor mothers conduct home visits within a 5 km radius, some sites also have community-based mentor mothers, who work predominately in the communities surrounding the health facilities. The two types of Mentor Mothers work together, have linkage registers and have monthly meetings to ensure clients from the community are linked to the facility and vice versa.	Tingathe-LHWs work in both the clinic and community setting. In the clinic, Tingathe-CHWs tended to have their own (NGO-funded) offices. In their support work, they are based predominantly in the ART clinic, although were observed travelling around all clinical/hospital departments where the study observations took place. Reflecting their educational status, Tingathe-CHWs were observed to take on a number of higher-order coordination-style tasks in the facilities they worked in. In the community, Tingathe-CHW are highly mobile, visiting clients in their homes or other settings and they do not have any restrictions on the distances travelled. Most Tingathe-CHW active in the community had received a bicycle, improving their reach and efficiency.

ANC, antenatal care; ART, antiretroviral therapy; CHW, community health worker; HSA, Health Surveillance Assistant; MOH, Ministry of Health; NGO, non-governmental organisation; PMTCT, prevention of mother-to-child transmission.

**Table 3** PMTCT lay health worker organisation by model

	Parent NGOs	Eligibility to be a CFL provider*	Community involvement	Sex	HIV status and disclosure	PMTCT cascade requirement	Recruitment process	Training provided†	Paid or volunteer*‡	Job enablers
Tingathe-CHWs	Baylor Tingathe Programme	All required to have 2–4 years of secondary school and qualifying exams	Required to live within the communities	Male and female	No HIV status requirement	N/A	Advert and interview process	Six-week training plus quarterly follow-up training	83.3% are considered employees, but not all of those employed are paid; average monthly salary is ~US\$120.	Some but not all receive a uniform, bicycle and airtime.
Expert Clients	Various: mothers2mothers; Lighthouse; Partners in Hope—Project Equip; EGPAF; some volunteers through MOH	Some said no education requirement; others said 2 years of secondary school and exam is required	No requirement, but usually from the areas around the facility	Male and female	All are HIV positive and are open to discussing their status	No known requirement	Differs by organisation—some recruit from within facilities or communities	Typically 2-week training but can vary	50% are considered formally employed are paid; average monthly salary is ~US\$60.	Some but not all receive a uniform, bicycle, food pack and airtime.
Mentor Mothers	mothers2mothers	All required to have 2–4 years of secondary school and exams	No requirement, but usually from the areas around the facility	Female	All are HIV positive and have disclosed to at least one person	Completed PMTCT cascade	Advert and interview process	Two-week intensive workshop+3 months mentorship programme	All are paid employees of mothers2mothers; average monthly salary is ~US\$50.	Uniform, airtime, sugar and tea.

\*In Malawi, the Junior Certificate of Education is the examination taken mid-way through secondary school (after 2 years of secondary school); and the Malawi School Certificate of Education is the final examination at secondary school level in Malawi (after 4 years of secondary school).

†All models reported receiving formal introductory training before starting CFL activities (n=23) and all receive training on the national HIV guidelines (n=23)

‡Employee was defined as receiving a salary at regular intervals and salaries are calculated based on the averages reported in Malawi Kwacha.

CFL, community-facility linkage; CHW, community health worker; MOH, Ministry of Health; N/A, not available; NGO, non-governmental organisation; PMTCT, prevention of mother-to-child transmission.

the degree of resourcing and mode of management and oversight by the various non-government partners were apparent, but closer examination of these goes beyond scope of this study and will be described elsewhere. Overall, we found a substantial degree of ‘convergence’ across the three cadres, with one exception. Expert Clients and Mentor Mothers programmes explicitly recruited from among individuals living with HIV, with participants noting these individuals had distinctive ability to connect with, and act as role models to, vulnerable clients living with HIV.

### How do PMTCT LHWs address barriers to uptake and retention?

In this section, we organise findings to reflect four major themes regarding PMTCT LHWs contribution to addressing uptake and retention barriers, including: (i) addressing fear and uncertainty surrounding treatment; (ii) strengthening social connectedness and patient participation; (iii) enhancing frontline service function and (iv) improving CFL.

#### Addressing fear, stigma and uncertainty

PMTCT LHWs were described as, and observed to, carry out critical counselling and educational functions that responded to pregnant and breastfeeding women’s fears in relation to HIV and treatment initiation. At all sites, health workers and clients described the opt-out policy of Option B+ as producing uptake and retention challenges due often to the lack of ‘readiness’ among women.<sup>16</sup>

So they come here and they get tested and then they are told that: ‘You have HIV and because of that you are support to start medication straight away’. For that person, these are two new things; first of all, she did not expect to have HIV and secondly she did not expect to start medication. So, within the time period, that person is not stable and what happens is like we are forcing her. She does not accept whole-heartedly. (MOH lay worker, site 4)

Fears of pregnant and breastfeeding women included those relating to spousal abandonment and resulting destitution, shame and community stigma. For others, concerns about HIV being a ‘death sentence’ and their capacity to be productive family and community members were prominent as in one mother’s account below:

At the time when one has just found out their HIV status and start(-ed) treatment, (we) go through a stressful phase, thinking that life is over and (we) will be a sickly person. (Mother 060, site 4)

At all sites, participants described PMTCT LHWs as helping to mitigate those fears through a range of strategies but primarily including formal and informal counselling, in both clinic and community settings.

Those people help to counsel us to the point where (we) are encouraged and at peace. (Mother 060, site 4)

Mother: They help us not to lose heart.

Interviewer: What should you not lose heart over?

Mother: That I should not be afraid in taking the medication. That there is no future for our lives. (Mother 021, site 4)

A number of mothers interviewed for the study emphasised the educational role played by PMTCT LHWs who allayed fears regarding the nature of the disease, and the processes of care in non-threatening and easy-to-understand ways.

They are important because we would not know all this by ourselves. We are learning things from them teaching us. (And) they are very open with us compared to the nurses. We just go to the nurses to get the medication. But the (LHWs) explain to us. (Mother 086, site 5)

So when a person has just started receiving drugs, they don’t know anything. They don’t (know) how (treatment is) supposed to run. The (LHWs) help us understand. (Mother 012, site 2)

#### Strengthening social connectedness and patient participation

A second thematic finding was the role PMTCT LHWs played in enhancing social connectedness and patient participation in their own care. Many mothers in this study described their decisions about ART uptake and engagement as influenced by their immediate and broader social network. Spouses and family members were an important source of emotional and material support for some mothers, but for others, experiences or fear of stigma and discrimination prevented them from disclosing to their most important networks. Health workers and mothers described how PMTCT LHWs used counselling strategies to provide advice and support (often termed ‘encouragement’) to these relationships.

Yes, they (LHWs) are very important, because sometimes (we) are shy to come to the clinic in groups. But when they are conducting home visits, (LHWs) drive away shyness. (So that when) you come (to the clinic) and you see the group of your friends then you become free. To know you are not alone—we are so many! (Mother 035, site 2).

In addition, strategies to minimise those same mothers’ social isolation were invoked. In the case of Expert Client and Mentor Mothers, role modelling of specific coping strategies and their positive outcomes was also described. Reflecting on the links between women’s fears (above) and the potential for social isolation, several higher-level officials described the skill of the most effective PMTCT LHWs to evaluate clients’ psychosocial state and use appropriate strategies based on the (material, symbolic, relational or service-related) challenges affecting a given client. Some professional health workers noted that this type of in-depth and deeply interpersonal work was not something that they themselves were equipped or had time to carry out.

Most of what they do, we cannot do! (Professional health-care worker 1, site 4)

### Enhancing frontline services

A third thematic finding was the role PMTCT LHWs played in strengthening service function in primary care facilities. At all sites, and among all stakeholder groups interviewed, PMTCT LHWs were recognised as helping clinic-based providers carry out their duties more efficiently, and effectively. Improved human resource capacity, reduced workload and the consequent ability to deliver more comprehensive services were all noted outcomes of PMTCT LHW presence at the study sites:

Expert Clients and (MentorMothers) simplify our tasks as health workers [...] so it becomes easier for the clients and for us. (Professional healthcare worker 3, site 4)

They are a bridge to the ART, so if they were not available things would not be as effective. (MOH lay worker 6, site 7)

Tasks taken on by PMTCT LHWs that eased the load of professional workers and improved the efficiency of service delivery included: carrying out clinic-based and home-based counselling, completing documentation in registers, collecting dried blot spot samples (for Tingathe-CHW only) and providing patient accompaniment and navigation between clinic departments. At some study sites, PMTCT LHWs assumed complete (or near complete) responsibility for these tasks.

In multiple sites, the patient follow-up and outreach activities conducted by PMTCT LHWs were noted to overlap with the official remit of Malawi's government employed community health cadre, HSAs. Yet in focus group discussions, HSAs and other frontline providers noted that in part due to other human resource shortages HSAs had become so 'clinic-bound' in their responsibilities, that their outreach and tracing role had fallen by the wayside. Rather than being perceived as a professional threat, therefore, the relationship between PMTCT LHWs and government-employed staff was generally described as a positive one, as characterised in this account:

It is not one man's work. It means that if I am in testing, the clinician should send me the (client) and when am done (...), I send them back to the clinician. So, for us to achieve, we are only achieving because there is oneness. Everyone has their limits and everyone knows that 'this is where I stop and from here, this (other) person goes'. So, to cut it short, at this facility, our relationship is very good. (Tingathe-CHW 5, site 8)

### Community-facility linkage

A final important theme was the way PMTCT LHWs promoted stronger links between their community and facilities, and through this, improved ART uptake and retention. Beyond simply absorbing the workload of overburdened clinical professionals or providing counselling, education and outreach, LHWs were described by various participants as having a demonstrable and positive effect on broader service responsiveness.

Although less tangible in nature, the significance of more responsive service delivery was stressed by many, given a prevailing context of poor—or at least

impersonal—services. Mothers described this responsiveness citing examples of often simple, but material demonstrations of respect, often lacking in their experience of clinic services:

They are important because they greet you and serve you with priority (Mother 069, site 4)

Other health professionals emphasised the way PMTCT LHWs were 'links' or 'bridges' between themselves and their clients, and between the clinic and the community—carrying out work that extended, but just as importantly *enhanced* their services through interpretation (linguistic and procedural) and physical representation:

For example, I am a clinician, well trained. Maybe more (educated) than Mentor Mothers or Expert Clients. But maybe I am from a different district, different culture (and) they are closer to the patients because they are right there in the community and it is like they speak the same language. (Professional healthcare worker 2, site 4)

Us as health workers (...) our target is on the time. Depending on the amount of work that we have we may just decide to talk with (clients) for about five minutes and we are done (...) The Expert Clients, however, spend a lot of time with the person until they understand. (Professional healthcare worker 4, site 7)

In some sites, PMTCT LHWs explained how they were able to help clinicians advocate for change, such as one Expert Client who requested clinical staff to harmonise a patient's ART and antenatal care visit dates:

We go and talk to the nurse or even doctors and suggest that 'This person will come twice in the same month, is it possible to help her so she can only come once?' (Expert Client 3, site 4)

The knowledge (a form of 'intelligence') that PMTCT LHWs brought to bear on the work of clinic-based providers was also recognised at the next level of the health system. Both District and CFL programme managers reflected on the improved understanding of patient needs by clinical providers and higher level planners, and the potentially transformational impact of such understanding on their own responses and decisions:

For a long time, our programming has been focusing on care at the facility level. So as long as the patient comes to the facility, you give him ARVs, you give them an appointment date: 'You should come in two or three months' that was all. (So you) see them in the next two months and all you say is: 'How have you been taking medications?' But there are a lot of things that have been happening in the background. And this programme has given us useful information about those issues (...) You are able to interact with them at household level and you see a lot of challenges. And when you are able to deal with those issues from the community where they stay, you realise that the success of HIV care becomes more (complicated) than just giving them the medications and then expecting them to see them again after two months. (Doing it) that way you may not be able to appreciate most of the challenges our patients go through. (PMTCT LHW Programme Manager 1).



I would say in summary that there is that great rapport between patient and (PMTCT LHWs). They try to create that environment so that we (health professionals) can understand how (and) why is it that these people are falling out from the treatment. (District Official 2)

Many PMTCT LHWs acknowledged and expressed pride in this linking and bridging role, reflecting on how (if done well) it enabled them to build client and community trust that went beyond their PMTCT remit.

I am an Expert Client *and* a person that works at the facility. Most of the people in the community see us here at the facility and so there are those who approach us in the community to tell us of others (who) are very sick. They ask us to make time to visit these individuals (who) tell us their challenges, and we encourage them and assist them. [Expert Client 4, site 6]

## DISCUSSION

As ART and PMTCT programmes mature globally, and treatment scale up continues to accelerate in the ‘treat all’ era, the complexities of designing and delivering services to support pregnant and breastfeeding women living with HIV, and their children, to durably engage in care have become more evident. McNairy *et al*<sup>33</sup> note that suboptimal retention continues to threaten the achievements of PMTCT programming in many settings, stating that ‘no partial credit’ should be given for improvements in the upstream targets (eg, enrolment in treatment) when the complexities of ensuring effective engagement and retention for women and their infants over time remain unresolved. Improved understanding of whether and how interventions such as PMTCT LHWs are addressing known barriers to engagement and retention in the current ‘treat all’ era is therefore important. Findings from this study contribute to that knowledge base, by exploring how PMTCT LHWs operating under three prevailing models of non-government support in Malawi are directly and indirectly responding to such challenges.

Although all the PMTCT LHWs in this study were recruited and trained to address specific uptake and retention challenges in Malawi’s national PMTCT programme, study participants highlighted their less tangible work to promote community-facility linkage as one of their most important functions. On the service side, frontline providers and district-level planners linked these efforts to improved understanding of clients by providers, and improved facility responsiveness and person-centredness. In part, such impact could be viewed as a ‘positive externality’ of the improved human resource capacity in the clinics—as discussed further below. Yet study participants were at pains to describe something more distinctive; a cadre whose bridging role—“*I am an Expert Client and a person that works at the facility*”—systems knowledge, and moral authority enabled them to move beyond basic service functions to promote greater accountability among frontline staff through improved recognition, engagement with and response to client’s needs.<sup>26</sup>

On the client and community side, PMTCT LHWs were described as, and observed to be, builders of community trust in health services, operating in ways that transcended their tracing or follow-up role. PMTCT LHWs drew on relational—as well as technical—skills, to establish or strengthen relationships through conversations and visitation in non-threatening home and community environments. These relationships were leveraged to build trust when mothers (and others) returned to the facility, thereby promoting virtuous cycles of interaction.

Health systems and human resource for health literature well-document the potential of lay or community health workers to enhance CFL in the ways outlined above.<sup>34–38</sup> Indeed, over a decade ago in 2010, Schneider and Lehmann<sup>26</sup> observed:

the emergence of lay workers in South Africa does offer opportunities for improved access and quality of care. Harnessing this potential requires recognising their role as integral to the formal health system and as more complex than a one-way delegation of tasks [...]. If broader roles are accepted, a more formalised lay health worker infrastructure may lay the ground for new negotiated orders with local health services and a strengthening of primary healthcare.

Notwithstanding the different models under which they worked, our findings demonstrated PMTCT LHWs in Malawi are engaged in such a ‘negotiated order’, seeking to strengthen primary healthcare on a day-to-day basis by scaffolding connections between the formal health services, and community and social contexts, even while conducting more programme-specific activities.

In HIV-specific literature, despite early adoption and dependency on LHWs in ART programmes across sub-Saharan Africa,<sup>26 39 40</sup> discussion and debate about their role has tended to focus on the safety, quality, access gains and technical feasibility of deploying LHWs for specific services.<sup>25 26</sup> Much less has been said about the social and systems impact of LHWs, or, ‘*their role and location between the formal health services and communities*’.<sup>26</sup> This potentially reflects the disciplinary focus in the HIV field on individually oriented and programme-specific interventions. But for countries with a high-burden of HIV and in an era of declining external funding, ART and PMTCT programmes are increasingly grappling with the imperative to integrate at least some functions of ART and primary healthcare service. In doing so, they face the long-standing conundrum<sup>25 41</sup> of how to support ART uptake and retention outcomes within a broader health service environment that may not be resourced, or oriented to provide targeted support. Since the capacity to strengthen patient-centred care and responsiveness constitutes a core component of this struggle, the role of cadres such as Malawi’s PMTCT LHWs in such a context takes on renewed significance.

Supporting existing evidence demonstrating the targeted role PMTCT LHWs can play in strengthening ART uptake and retention,<sup>18 28 42</sup> PMTCT LHWs in all

three models in this study were described as helping allay clients' fears through psycho-social counselling support and role modelling, as well as health education to improve understanding of HIV and services options, including rapid initiation of lifelong treatment. Our findings also demonstrated how the PMTCT LHWs addressed social barriers to uptake and retention, by using role modelling, (confidential) home visitation and group based counselling or support groups that help women build alternative networks. These findings are intuitive, given the growing body of research from Malawi and elsewhere<sup>43</sup> documenting the multiple socio-cultural and gender-based barriers to uptake and retention in care<sup>30 31 44 45</sup> including prevalent concerns about spousal abandonment or community rejection.<sup>15 17 46</sup> Although the focus in this study was PMTCT LHWs' role in promoting uptake and retention from a systems perspective, rather than womens' readiness to start treatment per se, our findings align well with McLean's framework, which identifies women's previous knowledge of HIV status, their relationships with healthcare workers, relationships with partners and roles/responsibilities as a mother, as key factors influencing treatment choices.<sup>16</sup>

A final important, if instrumental, contribution of PMTCT LHWs to improved PMTCT and ART uptake and retention identified in this study, was their bolstering of frontline human resource capacity of primary care clinics. Malawi has long experienced chronic health worker shortages and empirical studies have demonstrated the additional health system pressures that were created by the scale up of Option B+. Phiri *et al*<sup>47</sup> describe 'severe pressure' on Malawi's health workers due to increased patient loads associated with Option B+ and reduced ability to deliver quality of care. Workload has been directly (although not exclusively) linked to provider disrespect and abuse of clients, with a substantial body of literature documenting the negative impact of disrespect and abuse in health services generally<sup>48 49</sup> and maternal healthcare in particular.<sup>50-53</sup> In a health system with recognised human resource shortages<sup>54</sup> and chronically overworked government employed healthcare providers,<sup>55 56</sup> the sometimes poor quality of services was acknowledged by many in this study. We found the presence of PMTCT LHWs—irrespective of which model—was universally welcomed by government-employed health workers who described a reduction in workload stress, improved ability to deliver quality care and overall improvements in workplace morale related to basic improvements in human resource capacity.

### Strengths and limitations

A strength of the study was the rich data set, drawing on multiple types of stakeholders from settings across Malawi. As it was nested within a broader study that sought to evaluate the programmatic impact of LHW models, there were some limitations on the design and scope of the qualitative component. We acknowledge the risk of social desirability bias, particularly in interviews

with women enrolled in PMTCT and among PMTCT LHWs themselves. We sought to minimise the risk of such bias through careful training of a core set of four qualitative research assistants who conducted all interviews for the study's duration. Although study procedures were designed to facilitate participant comfort and trust and all due care was taken during informed consent processes, research assistants reported interviews with a number of women enrolled in PMTCT to be difficult, with some accounts lacking the desired depth. This was potentially due to underlying concerns about study purpose.

### CONCLUSION

Drawing on client, health worker and policy makers' accounts, this study explores different actors perceptions of the way PMTCT LHWs are responding to barriers to ART uptake and retention barriers in Malawi. Study findings show that in the process of responding to client fears, strengthening social connectedness and improving facility function, PMTCT LHWs are directly addressing known individual, community and health service factors impacting uptake and retention in care. Analysis further demonstrates PMTCT LHWs are addressing uptake and retention barriers through less targeted but vitally important community-facility linkage functions that promote responsive and person-centred services. This analysis contributes to a burgeoning body of work demonstrating the hidden complexities of: i) achieving global targets such as UNAIDS' 95-95-95, in the context of highly resource-constrained health systems, and ii) the importance of health workforce and service design that enables providers to address often overlooked social, cultural and health system factors affecting client access to, and engagement with, PMTCT and ART services. Further work to understand the governance and sustainability of these project-funded non-government administered models is now urgently required.

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**Acknowledgements** The authors would like to thank the Malawian Ministry of Health, the three LHW programmes and all respondents for their time and generosity in participating in this study.

**Contributors** ST contributed to study design, provided oversight of data collection, led analysis and wrote the first draft of the manuscript. NC supervised data collection, contributed to analysis and provided critical edits to the manuscript. JS, LK and GB collected the data, contributed to analysis and provided critical edits. MH contributed to study design, provided overall study oversight, contributed to analysis and made critical edits to the manuscript.

**Funding** This work was supported by Project SOAR (Cooperative agreement AID-OAA-A-14-00060), made possible by the generous support of the American people through the United States President's Emergency Plan for AIDS Relief (PEPFAR) and United States Agency for International Development (USAID). MEH was also supported through the Fogarty International Centre at the National Institutes of Health (K01 TW010272). SMT is currently supported through a National Health and Medical Research Council (NHMRC) Investigator Grant (GNT1173004).

**Disclaimer** The contents of this paper are the sole responsibility of the authors and do not necessarily reflect the views of PEPFAR, USAID or the United States Government. The funders had no role in study design, data collection and analysis, decision to publish or preparation of the manuscript.

**Competing interests** None declared.

**Patient consent for publication** Not required.

**Ethics approval** Ethical Approval was provided by the Malawi National Health Sciences Research Committee (#17/05/1812), the Institutional Review Board of the University of North Carolina at Chapel Hill (#17-1114) and James Cook University's Human Research Ethics Committee (#1812).

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Some data are available on request. Respect for participant anonymity and consent which provided permission for use of data for this project only, mean qualitative data will not be available. De-identified quantitative survey data may be provided on request.

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