

Research article

Community-based approaches for prevention of mother to child transmission in resource-poor settings: a social ecological review

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Abstract

Introduction: Numerous barriers to optimal uptake of prevention of mother to child transmission (PMTCT) services occur at community level (i.e., outside the healthcare setting). To achieve elimination of paediatric HIV, therefore, interventions must also work within communities to address these barriers and increase service use and need to be informed by evidence. This paper reviews community-based approaches that have been used in resource-limited settings to increase rates of PMTCT enrolment, retention in care and successful treatment outcomes. It aims to identify which interventions work, why they may do so and what knowledge gaps remain.

Methods: First, we identified barriers to PMTCT that originate outside the health system. These were used to construct a social ecological framework categorizing barriers to PMTCT into the following levels of influence: individual, peer and family, community and sociocultural. We then used this conceptual framework to guide a review of the literature on community-based approaches, defined as interventions delivered outside of formal health settings, with the goal of increasing uptake, retention, adherence and positive psychosocial outcomes in PMTCT programmes in resource-poor countries.

Results: Our review found evidence of effectiveness of strategies targeting individuals and peer/family levels (e.g., providing household HIV testing and training peer counsellors to support exclusive breastfeeding) and at community level (e.g., participatory women's groups and home-based care to support adherence and retention). Evidence is more limited for complex interventions combining multiple strategies across different ecological levels. There is often little information describing implementation; and approaches such as "community mobilization" remain poorly defined.

Conclusions: Evidence from existing community approaches can be adapted for use in planning PMTCT. However, for successful replication of evidence-based interventions to occur, comprehensive process evaluations are needed to elucidate the pathways through which specific interventions achieve desired PMTCT outcomes. A social ecological framework can help analyze the complex interplay of facilitators and barriers to PMTCT service uptake in each context, thus helping to inform selection of locally relevant community-based interventions.

Keywords: PMTCT; community approaches; retention in care; social ecological framework.

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Introduction

Elimination of vertical transmission of HIV is a global priority, yet progress remains marred by severe disparities across regions. While it is almost a reality in developed country settings, in many resource-poor settings, only an estimated 15% to 30% of eligible women complete the prevention of mother to child transmission (PMTCT) cascade [1]. Weak health systems, unreliable infrastructure, breakdowns in supply chains and lack of health staff contribute to insufficient service coverage, but it is increasingly clear that many barriers to achieving universal access for PMTCT occur outside of formal health services [2].

Each setting will have its own specific mix of barriers to PMTCT uptake, adherence and retention that reflect prevailing behavioural norms, cultural beliefs and the policy environment [3]. Understanding context-specific barriers is

the first step to addressing them, followed by design of interventions that are informed by the evidence base yet tailored to each setting. This paper presents work commissioned by the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) that aimed to identify and synthesize research findings on community-based approaches used in developing country settings to overcome barriers to PMTCT enrolment, retention and successful outcomes. The goal was to identify which interventions work, why they may do so and what knowledge gaps remain, focussing on the following four priority outcomes within the EGPAF Community Initiative:

1. Increased uptake of HIV care and treatment services among pregnant women and vertically infected children;

2. Improved retention of individuals enrolled in prevention for vertical transmission and care and treatment programmes;
3. Enhanced adherence of pregnant and lactating women, their partners and children to ARV prophylaxis and/or antiretroviral treatment (ART) and/or other care regimens;
4. Strengthened psychosocial wellbeing of pregnant and lactating women and children enrolled in care and treatment programmes.

Barriers to PMTCT uptake and retention

The four priority outcomes indicate progress along a treatment continuum or “cascade,” commonly used in the literature to depict an individual’s trajectory from before HIV diagnosis, through each stage of successful enrolment in treatment and care, to measurable improvements in physical and mental health (Fig. 1) [4–6]. Due to barriers between each stage, a steady reduction occurs in the successful achievement of each successive step [7]. The treatment cascade can be made specific to PMTCT by defining each stage to reflect WHO programmatic guidelines.

Losses at each stage have been well-documented, and as suggested by the concept of a cascade, a consistently diminishing proportion of people transition between each step [7]. There is now an extensive literature on the barriers faced along the cascade, including in developing country settings due to rapid growth in provision of ART in recent years [8,9]. This section summarizes some of the most commonly cited barriers to set the backdrop to our review of intervention approaches used to overcome them. As studies documenting barriers specific to preventing vertical transmission are limited, lessons can be drawn from related programmes, such as HIV counselling and treatment (HCT), general provision of ARV and efforts to improve rates of skilled attendance at delivery (for all women, regardless of HIV status). The same barriers can operate at more than one stage of the cascade and may interact or reinforce each other at different times, depending on an individual’s evolving circumstances, so that even if a person is able to take up treatment early on, she/he may find it difficult to maintain levels of retention and treatment compliance.

The identified barriers are as follows:

Risk perception: While HIV-related knowledge is now widespread, individuals need to perceive themselves to be at risk to seek HCT. Widespread association of HIV with promiscuity and illicit sex (i.e., with sex workers or extra-marital partners) creates a false sense of security for some. Women in monogamous marriages, for example, may consider themselves at low risk [10] and may not present for testing early enough in a pregnancy for optimal initiation of PMTCT.

Motivation/self-efficacy: Even when pregnant women are concerned about their status, they may lack motivation or

self-efficacy to undergo testing, particularly if they need to make complicated logistical arrangements or explain their absence from home. Fear of receiving a positive result has been found to be a disincentive to HIV testing during pregnancy [11].

Health status: Poor mental and physical health also affect care-seeking. Depression has been linked to lower ARV adherence [12,13] while episodes of ill-health compromise ability to maintain appointments [14].

Family relationships: Household inequities in access to resources can mean women rely on others to decide whether or not they initiate PMTCT [15,16]. Male partners play a significant role; some women refuse HCT or do not collect their results, fearing partner disapproval [2,17]. Threats of intimate partner violence (IPV) also reduce enrolment in PMTCT [18] and studies have shown that women living with HIV can experience higher levels of IPV than others [19]. Where male partners are involved in HIV testing and antenatal care, on the other hand, women are statistically more likely to accept ARV prophylaxis [20–22], deliver in a facility [23] and attend follow-up care [24].

Disclosure of HIV status: Pregnant women’s disclosure to partners is positively associated with service use, while those who keep their status secret find it challenging to store and take medications [25]. Disclosure to partners also makes it more likely that HIV-positive mothers will follow infant feeding recommendations [26].

Social support: Anticipating and receiving social support proves important for programme retention and is associated with drug adherence [27,28], while pressure from family members, particularly mothers and mothers-in-law, discourages HIV-positive women from departing from traditional breastfeeding and weaning patterns [29,30].

Travel: Distance to facilities and cost of transportation affect testing, collection of results and health-seeking behaviours [31].

HIV stigma: A five-country comparative study found a statistically significant relationship between perceived stigma and neglecting to take all prescribed pills [32]. Several other reviews of barriers to treatment [27,33,34] confirm the importance of anticipated stigma, as well as perceptions of poor service quality (i.e., unfriendly staff, long waiting times and fear of stock-outs).

Social networks: Qualitative studies examining adherence in Botswana and Tanzania found that, when clients do not have strong social networks in the community, motivation to remain in treatment is reduced [35,36].

Health and religious beliefs: Prevailing norms and traditional world views shape how people engage with services. If HIV is believed to result from bewitchment or spiritual forces, alternative treatments may be sought [37,38]. Traditions related to pregnancy care, delivery and breastfeeding interact with advice received from health



Figure 1. Basic HIV treatment cascade.

professionals, affecting willingness to comply with PMTCT requirements [39–41].

Gender roles: Accepted power dynamics between men and women determine how scarce resources are allocated and often do not prioritize women's health. Gender norms also affect male partners' behaviour, and expectations of male and female responsibilities pose barriers to male involvement in pregnancy and infant care [42,43].

Policy environment: Provision of social welfare or insurance schemes, health systems' functioning and a country's economic and political stability will all affect service use and health outcomes across the continuum [44,45].

Although not an exhaustive list, the barriers summarized above were felt to capture the majority of challenges confronted by on-the-ground PMTCT programmes, such as those offered by EGPAF and its partner organizations.

Theoretical approach

Health outcomes are increasingly recognized as being shaped less by individual behaviour and more by the wider environments in which people live and make choices, influenced by family and peers, local beliefs and values, cultural norms and practices and political and economic circumstances [46–49]. The use of social ecological frameworks illustrates inter-relationships between proximate and distal determinants of health [50–53] and have been found useful in understanding HIV treatment adherence and programme retention [6,54]. They demonstrate the way in which an individual's behaviours and health outcomes are nested within different levels of social organization, visually depicted as overlapping concentric circles, through which pathways of influence can take multiple routes [50,51,55].

Social ecological framework for barriers to PMTCT

Figure 2 illustrates the social ecological framework that we developed to guide our literature review, in keeping with recent approaches used to identify and synthesize available evidence driven by theoretical models rather than specific research questions [56,57]. Each of the barriers to seeking, obtaining and remaining in PMTCT care, as summarized previously, has been situated at the level of social influence where it is most likely to operate. Individual pregnant women remain at the core of the framework, but their choices are embedded within multiple layers [58].

We used this framework to develop our review strategy for identifying community-based approaches implemented in developing countries to address one or more barriers along the PMTCT care continuum. Similar conceptually driven reviews have been conducted to understand determinants of access to services for sexual and reproductive health [59,60]. Our aim was to consider interventions at each level, although we chose to focus on the three middle circles of the framework (peer and family influences, community context and the sociocultural environment) as these seemed most amenable to being addressed through existing partnerships between biomedical service providers and civil society organizations, yet went beyond activities targeted at individual knowledge, attitudes and behaviours.

Community-based approaches

Extensive consultation with EGPAF staff throughout the organization, particularly in country-level programmes, as well as with other stakeholders, for example, partner institutions, civil society organizations, researchers in the field of paediatric HIV/AIDS care and representatives from donor agencies, led to adoption of the following working definition of community-based approaches to PMTCT: strategies and interventions to improve health behaviour and outcomes that are delivered outside of formal health settings including primary, secondary and tertiary medical facilities.

These could have a range of aims (e.g., increasing contact with individuals or empowering whole communities) but needed to explicitly target community members, their local civil or traditional authorities/leaders or traditional health providers outside the formal health sector. There was some ambiguity surrounding interventions where clinical services expanded to provide outreach, support or non-medical assistance (such as food supplementation) into the community. We decided to define activities delivered outside facilities as "community-based" regardless of how they were administered but not those where community members had to attend a clinic or health centre in order to receive the additional support.

Methods

As our interests covered four broad health outcomes and a wide range of barriers to achieving them, we considered a systematic literature review inappropriate to our needs. Instead, we developed a theory-driven search strategy guided by our social ecological framework to identify and synthesize up-to-date evidence on community-based interventions that work to increase uptake, retention, adherence and positive psychosocial outcomes in PMTCT programmes and in other areas of public health with direct relevance to PMTCT.

A series of literature searches was conducted using databases including PubMed, Medline, Web of Science, ClinicalTrials.gov and the Cochrane collection. Each search was guided by the social constructs in the social ecological framework and the review's four thematic areas. Primary search terms included HIV treatment, ART, PMTCT, retention, adherence, combined with community, intervention and evaluation. A matrix of secondary key terms was established for different outcomes along the care cascade (related to testing, enrolment, initiation, follow-up and psychosocial wellbeing) and their known determinants (social support, stigma and delivery practices). For example, the search for interventions to improve HIV testing rates among pregnant women utilized Boolean combinations of full, abbreviated and truncated versions of the following terms: HCT, VCT, PITC, HIV testing, antenatal care, prenatal care, uptake, PMTCT, intervention, evaluation, operations research and systematic review.

As agreed with EGPAF in advance, studies were included if they were published through a peer-reviewed process and available from scientific journals, databases of trial protocols or systematic reviews and internet-based reports from multilateral research or policy-setting institutions (e.g., WHO, research consortia and international task forces).

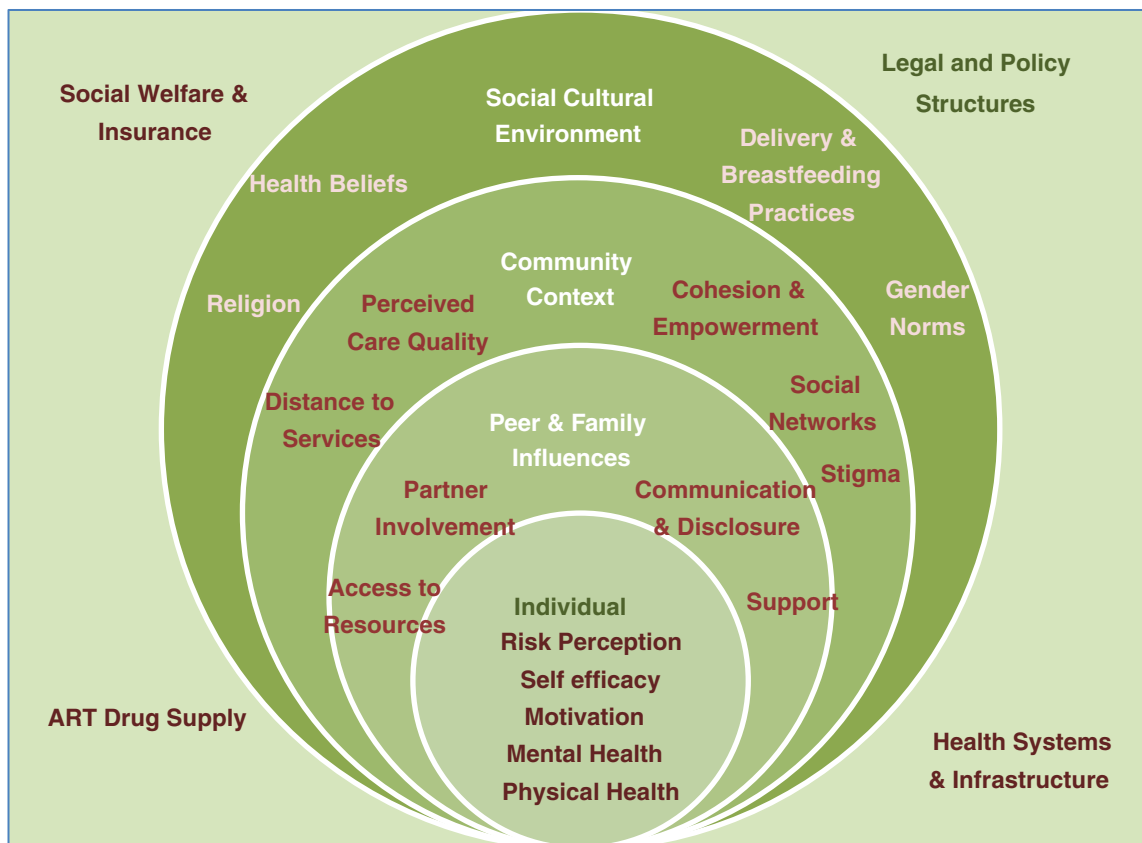


Figure 2. Social ecological framework for determinants of uptake, adherence and retention in PMTCT.

A start date of 2000 was applied to reflect the lack of prior availability of routine ART provision in most developing country settings (particularly in sub-Saharan Africa). September 2011 was the last month during which papers could have been published online to have been included in this review. Searches prioritized studies on implementation of PMTCT programmes; but where there was scant evidence, evaluations of community-based approaches from the field of HIV/AIDS treatment more generally, as well as examples from other related health conditions, were included. Examples include the use of women’s groups and community mobilization to reduce maternal and neonatal mortality, provision of conditional cash transfers to increase facility-based deliveries and peer counselling to extend periods of exclusive breastfeeding. In these cases, the cut-off year of 2000 did not apply.

Both quantitative and qualitative studies were included, although the emphasis was on identifying existing systematic and narrative reviews, and studies with rigorous evaluation designs prioritized in the following order: randomized controlled trials (RCTs), quasi-experimental designs, prospective cohort studies with historical controls and before-after comparisons without controls but with multiple-point time-series data to demonstrate trend [61,62]. Papers that were solely descriptive were not included.

Analysis consisted of reading eligible studies and determining which level of the social ecological framework the interventions targeted and subsequently extracting informa-

tion on how the described intervention attempted to facilitate uptake or reduce barriers to retention in care. Interventions were then grouped according to shared components or similarities of approach within each of the three community-based levels. Searches continued until “theoretical saturation” was achieved for each of the barriers included in the social ecological framework. This means that, if existing reviews, meta-analyses or rigorously designed evaluation studies were available for a particular barrier, these were reviewed and their findings synthesized, with no subsequent effort to locate weaker study designs when no new findings emerged. If, however, there were barriers on which little research has been conducted, additional search terms were added and attempts made to identify studies with at least a “before-after” comparison or historical controls in order to fully populate the framework.

Results

Findings are presented by the level of the social ecological framework of barriers that each community-based intervention attempts to overcome. Where an intervention works to address more than one social barrier to uptake and retention in care, such as in multilevel programmes, it is classified at the *highest* level of social influence targeted. Community health workers (CHWs), for example, may spend much of their time visiting households and working with family members to support health-seeking and adherence, but as

they are also often tasked with strengthening support networks, empowering groups and disseminating health-related practices at community level, they are described in the section on community context.

Family and peer level

There has been an increase in “family centred” PMTCT programmes, based on the observation that HIV is experienced as a family illness and all members can be affected physically, emotionally and economically [63]. Activities include offering HCT and treatment to partners and other family members alongside pregnant women, involving male partners in antenatal care and breastfeeding guidance, and peer counselling for HIV-positive pregnant women. These interventions aim to increase risk perception and awareness of HIV status, catalyze positive attitudes among male partners and increase social support for PMTCT.

Two models for community-based HCT have been evaluated: (1) house-to-house testing and (2) mobile testing sites. A cluster RCT in Uganda comparing home-based and clinic testing [64] found 93% of community members agreed to test in home sites, and 54.6% of HIV infections were identified compared to 27.3% in villages with clinic-based HCT. Another RCT in Tanzania, Zimbabwe and Thailand analyzed the effect of providing HIV testing through mobile testing outlets on testing uptake [65]. After 3 years, the number of people receiving their first HIV test was three times higher in intervention over control sites in Thailand, ten times higher in Zimbabwe and four times higher in Tanzania. However, pregnant women were more likely to be diagnosed in fixed-site clinics during antenatal appointments, making community-based testing less effective for identifying additional pregnant women, although it seems to be successful for recruiting higher-risk and low-income community members [66].

Involving male partners in pregnancy care is based on evidence from studies showing associations between HIV-positive pregnant women’s progression through the treatment cascade and their male partners’ awareness, support and participation [67]. Partner involvement is hypothesized to strengthen communication, disclosure and support between spouses. Men are invited to HCT alongside their partners, provided with couple counselling and given information on PMTCT and infant feeding. Two literature reviews have considered effectiveness of these interventions. The first found a strong association between spousal communication and men’s acceptance of HCT, and furthermore, when male partners test for HIV, pregnant women are more likely to accept PMTCT prophylaxis and adhere to breastfeeding guidance. Most studies were cross-sectional or prospective cohorts, thus results could be confounded by partnership characteristics (e.g., couples with good spousal communication are likely to differ in several ways that might affect health-seeking behaviour) [63]. The second review [67] concluded that issuing letters of invitation to men for couple testing, targeting men with community-based education on HCT and using mass media to publicize couple testing are all independently associated with improved PMTCT uptake.

Recently, two RCTs have tested methods to increase male engagement in their partner’s treatment during pregnancy, delivery and during follow-up. In South Africa, 1000 pregnant women were randomly allocated to receive a letter for their male partner that invited him to attend either VCT at the woman’s next scheduled ANC appointment (intervention) or a pregnancy information session, also during ANC (control) [68]. Although all the women agreed to deliver the letters, only 30% returned with a male partner. However, this was 35% among the women whose partners were offered VCT compared to 26% for those coming for an information session. At the end of the trial, 32% of male partners in the intervention arm received HIV testing compared to 11% in the control arm. Results were statistically significant, although no measures were provided for pregnant women’s uptake of PMTCT.

A similar study was conducted in Uganda with 1060 pregnant women participating [69]. In this study, women received letters for their partners that either invited the partner to attend ANC (intervention) or provided men with basic literature on pregnancy (control). At the end of the trial, there were no significant differences in the proportions of women attending ANC with a male partner (16.2% in the intervention group and 14.2% among controls) nor in male HCT uptake. However, the authors note that both groups exhibited an increase of over 10% from the baseline rate of 5% male partner attendance in ANC, suggesting that receipt of any formal information from ANC services has potential impact on male involvement. They also give a possible explanation for the different results between the RCTs, pointing out that the intervention in South Africa was preceded by information campaigns and community sensitization activities to promote male engagement more widely.

Peer counselling schemes have been developed to counteract feelings of isolation and provide support and assistance to pregnant women. The use of peers is theorized to be acceptable to people living with HIV, who might prefer advice from others who have undergone similar challenges. Peer counselling is often provided in clinics but increasingly incorporates house-to-house visits [70]. A quasi-experimental study of “mentor mothers” showed reductions in depression, increases in disclosure of HIV status and improvements in coping strategies, clinic attendance and breastfeeding among the intervention group, although there were no differences in women’s use of single-dose nevirapine, which was the recommended regimen at the time [70]. A systematic review of peer counselling for infant feeding outcomes concluded that community-based peer counsellors improve breastfeeding initiation, duration and exclusivity [71]. In Bangladesh, a RCT of peer counsellors promoting exclusive breastfeeding resulted in 70% exclusive breastfeeding in the intervention at 5 months compared to just 6% among the control group [72]. This study was replicated in sub-Saharan Africa (Uganda, Burkina Faso and South Africa) with similar success, although in South Africa, some participants did not trust counsellors’ motivations, feared loss of confidentiality and did not accept them as “peers” [73].

Community context

Interventions targeting the community context include strengthening linkages between health facilities and clients, home-based care (HBC) programmes and training community members (including traditional birth attendants (TBA)) to promote care initiation and retention.

Formalized links between clinics and the community try to increase perceived service "friendliness" and maintain regular contact with clients. Approaches include volunteers' accompanying clients to health facilities and observing ingestion of pills [74], hiring "meet and greet" staff to guide patients through hospital appointments [36], patient tracking systems to reduce attrition [75] and mobile phone message reminders [76]. There have been few evaluations of formalized linkages, although the use of mobile phones to sustain adherence was tested through an RCT in Kenya; weekly text reminders resulted in 53% of the intervention group, compared to 40% of controls, achieving 90% drug adherence [76]. Also in Kenya, a patient tracing system contacted PMTCT clients who did not return for appointments by phone, home visits or through nominated friends/relatives in the community. After 1 year, attempts had been made to contact 269 PMTCT clients, resulting in 60.2% returning to the clinic [75].

Home-based care programmes were introduced prior to widespread ARV availability, and the role of providers has evolved over time to encompass adherence support, HCT promotion within families, referrals to other services and, most recently, ART itself. HBC programmes have been subject to numerous reviews and evaluations. A cluster RCT in Uganda demonstrated that HBC programmes could be as clinically effective as facility-based treatment, measured by virological failure rates [77]. Furthermore, health service and patient costs related to transportation, missed time at work and childcare were significantly lower in the HBC group. While expanding HBC to support treatment access and adherence has proved feasible, inadequate attention has been given to operational challenges and threats to sustainability, particularly under pressure for "scaling up" [78].

Community health workers are trained lay persons who conduct health promotion, visit households for prevention and treatment and make referrals to higher levels of care. CHW are theorized to build local capacity, strengthen social networks and empower communities [79]. Interest in CHW has been reinvigorated in recent years due to the task-shifting agenda [80,81]. CHW differ in role, recruitment criteria and how they are compensated and supervised. While some schemes are managed through the government's formal health system (as in Ethiopia), many are not and have been implemented by community-based organizations (CBO) or evolve out of support groups for people living with HIV. Variations on CHW include lay health workers (LHWs), adherence support workers, lady health workers, health surveillance assistants, health extension workers and community health volunteers or caregivers (if unpaid). In relation to HIV, their tasks are varied and, in some cases, resemble those of HBC providers, while in others, they focus on adherence and peer support. CHW have also been used to promote behaviour

relevant to PMTCT such as facility-based delivery, exclusive breastfeeding and postnatal follow-up [79].

Several systematic and narrative reviews address the applicability of CHW to HIV treatment. A recent Cochrane Collection review [82] of LHWs' delivery of maternal and child health interventions concluded there is "moderate quality" evidence that LHW's interventions increase breastfeeding (including exclusive breastfeeding over 6 months). Another systematic review [79] found that CHW could increase facility-based delivery and skilled attendance, reduce maternal mortality through birth preparedness and provide counselling for postnatal depression and psychosocial support.

Some evidence of CHW effectiveness for adherence comes from a pre- and postintervention comparison in Zambia, in which peers of HIV-positive clients were trained as adherence support workers to provide home-based counselling on treatment guidelines [83]. After 12 months, responsibilities had shifted from health workers to peer CHW without compromising quality; loss to follow-up decreased. In Uganda, peer health workers (community-nominated HIV+ role models with good ART adherence) were trained to support new treatment initiators through regular home visits, information and counselling and provide wider psychosocial support through peer networks [84]. The cluster RCT results showed no effect on adherence or virologic failure between study arms during the first 18 months, although the intervention did appear to help sustain treatment in the longer term (≥ 96 weeks).

Traditional birth attendants are one type of community health worker, who have considerable influence over local practices. Pilot programmes have recruited TBA into tasks related to PMTCT. In Cameroon, trained TBA have been providing pre- and post-test counselling, rapid HIV tests and administering single-dose nevirapine during labour and to the newborn since 2002 [85]. In Tanzania, TBA have promoted VCT to pregnant women, observed ARV ingestion during home deliveries and referred postnatal mothers to infant HIV care [86]. Programmes that integrate TBA into PMTCT have not yet been rigorously evaluated.

It is difficult to generalize findings on CHW due to considerable heterogeneity across programmes. Success depends on levels of remuneration, supervisory structures, training and accreditation and relationship with clinical services [87,88].

Sociocultural environment

Interventions targeting the sociocultural context attempt to change social norms and create an enabling environment. Because these activities are removed from individual behaviour and operate through complex pathways of change, attributing impact is difficult, leading to calls for detailed process evaluations [89].

Based on theories of empowerment, social action and diffusion, community mobilization builds local ownership of HIV interventions [90,91]. A wide range of activities comprise community mobilization: engaging traditional leaders, organizing public discussions and theatrical events, peer education and participatory methods to involve community members. The social constructs targeted include social networks, gender

relations, behavioural norms and belief systems. Such interventions incorporate multiple components that can be difficult to disentangle through conventional evaluation designs, particularly as, by definition, mobilization requires flexibility.

A cluster RCT of community mobilization (Project Accept) has been implemented in Zimbabwe, South Africa, Tanzania and Thailand. Forty-eight communities were randomized to receive the Project Accept intervention or standard clinic-based HIV testing and care services. Intervention sites introduced (1) community working groups, (2) working with peer leaders in social networks as “change agents,” (3) outreach workers to promote VCT, (4) community volunteers encouraging testing and treatment and (5) post-test psychosocial support. Mobile testing has also been provided in intervention areas. Preliminary findings from three countries (Tanzania, Thailand and Zimbabwe) show testing uptake to be three times higher in intervention compared to control sites and suggest good levels of adherence among those taking up ARV [92].

A second community mobilization evaluation was conducted in South Africa, Lesotho, Namibia and Botswana. Local organizations underwent participatory planning to identify ways in which they might contribute to comprehensive social support services for people living with HIV and identified local adaptations as required. Testing was widely promoted and individuals diagnosed with HIV could opt to receive psychosocial support, a “treatment buddy,” home-based care, support groups, childcare, treatment literacy education, food supplements and income generation schemes. In the first year, uptake was highest for home-based care (61% of participants) and food supplementation (40%). The study found median CD4 counts increased more quickly and exhibited a significantly greater increase (207 vs 170 cells/mm³) among community members who received HBC or food supplements compared to those who did not [93]. After 12 months, adherence to ARV was 67.0% in people receiving home-based care or food vs 58.2% among those who did not use support services, a statistically significant difference. As a prospective cohort, however, the study was unable to attribute observed differences in health outcomes to the community-based support activities, as allocation of programme components was not random and reflected different levels of motivation or need.

Another approach is the organization of participatory women’s groups. Meetings are facilitated in which community members go through an analytical cycle: (1) problem identification and prioritization, (2) strategic planning, (3) strategy implementation and (4) impact assessment [94]. During strategic planning, groups select ways to overcome barriers (such as lack of transportation during an obstetric emergency) and put action plans into place. Participatory groups to improve maternal and neonatal health have been rigorously evaluated in trials throughout South and Southeast Asia, and found to significantly reduce both neonatal mortality and moderate maternal depression [95–97]. An ongoing cluster randomized trial is underway in Malawi that will help determine the applicability of this approach for sub-Saharan African contexts [98].

Finally, conditional cash transfers address socio-economic inequalities and provide a social safety net. Payments are disbursed to individuals or families in return for specific health behaviours or outcomes. For example, payments have been given to girls who remain enrolled in school, to young people who do not contract STI or HIV and to women if they collect test results, attend antenatal appointments or deliver their babies in health facilities [1,99]. Cash transfers can increase use of services; a Malawian study tested the use of financial incentives for collection of HIV test results and found an overall improvement of 27% in return visits compared to controls who received no incentive [100]. Although cash transfers have been used to increase skilled attendance at delivery, they have not been explicitly tested for PMTCT outcomes [101].

Discussion

Barriers to optimal PMTCT uptake that occur outside healthcare settings are well documented and seriously hamper current efforts to eliminate vertical transmission of HIV. Organizing these barriers within a social ecological framework illustrates how they can work individually or in combination with each other, through multiple pathways across overlapping levels of social influence. To identify ways to overcome these, we used the conceptual framework to guide a review of the literature on community-based approaches that can work at different levels. While some approaches are specific to PMTCT, many will need to be adapted from more general HIV testing and treatment programmes or drawn from the maternal and child health field.

There is a great deal of evidence that strategies targeting individuals within their families and peer groups, such as providing home-based and family HIV testing, and training peer volunteers to support others, improve outcomes related to testing, treatment uptake and adherence, all of which are relevant to preventing vertical transmission. While efforts to engage male partners are based on data showing the role played by good couple communication and male support in PMTCT uptake, to date, interventions to increase their involvement remain limited although show some positive signs. On the other hand, many other family members are likely to be influential in decision making; but this review was unable to identify interventions targeting parents, in-laws and other household members for PMTCT.

There is also good evidence that interventions operating at the community level, including provision of home-based care and community health worker schemes, can also increase retention in care and engage family members. These are often not adequately integrated into wider health systems, nor provided with sustained supervision. Furthermore, unless effective referral mechanisms are in place, HIV-positive women do not always receive HBC until late in the pregnancy or after delivery. Models in which HBC providers or CHW extend household testing so as to identify pregnant women early in gestation could be tried to tailor them to the specific needs of PMTCT. Once women are enrolled in care, linking facilities to community members more proactively, through accompaniment to appointments, mobile phone

messaging and household-based contact tracing, appear to be simple ways to support adherence and retention.

At the wider sociocultural level, the evidence emerging from participatory community groups that facilitate strategic health-seeking behaviour (e.g., for obstetric emergencies) is of particular interest due to the overlap between the PMTCT care cascade and other key maternal and child health services (antenatal care, facility-based deliveries and return for postnatal appointments). Participatory community groups have been comprehensively evaluated, although most studies have been conducted in Asia, and it is unclear to what extent findings can be applied to African countries.

For more “upstream” approaches, however, evidence is more difficult to interpret, particularly as complex interventions combine multiple strategies. Where evidence exists, there is often little information describing implementation, and components such as “community mobilization,” “empowerment” and “engagement” remain poorly defined and vary across settings. Lack of consistency in the content of these interventions is inevitable, as local ownership over programme design is part of the approach’s theoretical underpinning, making the outcomes of each possible permutation almost impossible to determine through traditional evaluation methods.

Given scarce resources, it is important to ensure that intervention packages use the most cost-effective combination of activities, which may differ according to setting and target audience (e.g., reaching pregnant women for PMTCT vs mobilizing high risk men to reduce sexual risk behaviour). Thus, even successful interventions can be difficult to replicate in new settings if they have not been tested for PMTCT-related outcomes.

Conclusions

This paper summarizes how social factors limit progress across the HIV treatment cascade, many of which are applicable to PMTCT, and reviews the emerging body of literature on the different approaches used by programmes to mitigate the causes of attrition at community level. There is now a need to fill gaps in understanding the mechanics of these approaches so that they can be adapted to eliminate new paediatric infections and keep HIV-positive mothers alive in different settings. Programme planners could benefit from using a social ecological framework to guide selection of context-specific interventions as well as to identify particular barriers or levels of influence that have not yet been addressed. Many interventions have focused on individuals, often ignoring how people’s behaviours are embedded within ever-widening social structures. Understanding the pathways to health-seeking behaviour can lead to greater appreciation or the need for broader normative and structural change.

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Competing interests

We declare that we have no competing interests.

Authors’ contributions

JB conducted the literature review on which this paper is based and drafted the manuscript. DW and AH conceived the original idea, commissioned the review and commented on all drafts of the text. LK, RS and DM served on the technical advisory group for the research, commented and reviewed the original conceptual framework and early drafts. AG, SL and CSP advised on the review’s aims and scope and reviewed paper drafts.

Abbreviations

CBO, community-based organizations; CHWs, Community health workers; EGPAF, Elizabeth Glaser Pediatric AIDS Foundation; HBC, home-based care; HCT, HIV counselling and treatment; IPV, intimate partner violence; LHWs, lay health workers; PMTCT, prevention of mother to child transmission; RCTs, randomized controlled trials; TBA, traditional birth attendants.

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