

# Do Community-Based Programs Help to Improve HIV Treatment and Health Outcomes? A Review of the Literature

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## Abstract

Increased availability of antiretroviral treatment for HIV makes the goal of universal access attainable. However, in most resource constrained settings where existing health systems are largely dysfunctional, major barriers to achieving this goal remain. While treatments with antiretroviral drugs (ART) are the focal point of HIV management, it is increasingly recognized that ART alone will not be sufficient to adequately deal with the lifelong consequences of the disease. In addition, the current global economic downturn will continue to impact on funding for HIV care and support, making the search for sustainable solutions more urgent. This article reviews the current evidence base on the impact of community-based programs on HIV/AIDS treatment and general health outcomes, as well as their contribution to ensuring sustained care for HIV-positive people. Our findings suggest that these programs overall have a positive impact on various dimensions of HIV treatment and care, and make a significant contribution to health and HIV outcomes. The authors argue that better use of community platforms for HIV treatment and care programs could be critical for attaining desired goals and should be prioritized at all levels of program design, implementation, and monitoring and evaluation.

## Keywords

HIV/AIDS, ARV Treatment, Care, Community-Based Programs

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## 1. Introduction

In this era of increased availability of antiretroviral therapy (ART) for treatment of HIV/AIDS, the World Health Organization's goal of universal access to comprehensive HIV prevention, treatment, and care seems attainable

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[1] [2]. However, realizing this goal will be challenging, particularly in resource-limited regions where existing health systems are fragmented and weak and there are insufficient operational resources for delivering required services. In these settings, and in addition to a range of biomedical matters to deal with, there are structural issues of program design and service delivery to be considered, as well as socio-cultural challenges including those related to targeting of key populations.

Overall, ART has transformed HIV from a fatal disease to a chronic illness. New HIV infections fell 21% worldwide between 1997 and 2010, and since 2001, the estimated number of people living with HIV has increased 17% to 34 million [3]. These statistics highlight the importance of addressing the entire trajectory of the disease over a person's lifetime, from diagnosis onward. Research shows that without support, adherence to treatment decreases, which in turn can lead to drug resistance [4] [5]. Beyond appropriate medical treatment, other services are required for achieving a successful continuum of care among HIV patients, including the provision of psychological care and support. This often comprises nonclinical, community-based services such as, but not limited to, spiritual, legal and economic support. While psychological care and support can come from staff at the health facility treating the patient, several studies have demonstrated that support is more effective when coming from a focused, on-going program in the community where the patient resides [6]-[9].

Just as support is needed for individual treatment adherence and retention in care, a re-evaluation of the entire health care system may be needed to ensure universal access to long-term care for HIV patients. As HIV has transitioned from being an acute disease to being a chronic illness, so too must the global HIV response transition from one guided by a predominantly medical model to one guided by a more interdisciplinary model of comprehensive care. ART is reaching more people than ever before. Yet in 2011 a total of 47% of people with HIV in need of ART did not have access to treatment [2], most of who lived in rural and hard-to-reach areas. In order to increase access, a paradigm shift in the way the global health community thinks about HIV/AIDS service provision may be necessary. There is a growing consensus that the conventional model of health care delivery is not sufficiently addressing the complex challenges of HIV prevention, treatment, and care [10] [11].

## A Call to Action

Funding constraints from the global economic crisis persist, and national governments and the international community are reassessing fiscal priorities. While treatment with antiretrovirals is the focal point of HIV management, it is increasingly recognized that treatment alone is not enough to adequately deal with the lifelong consequences of contracting HIV. Beyond the physical consequences of long-term ART, there is a growing body of literature that examines the role of community-based programs in addressing ART's long-term social and psychological consequences. Taking into account the changing needs of the epidemic, including increased survival rates for people living with HIV on ART, it has been estimated that by 2017, 1.5 to 3 times the current number of health care workers (depending on the world region) will be needed to provide 100% coverage to people living with HIV [12]. In 2006, 4.3 million additional trained health workers were needed globally [13]. Workforce shortfalls will likely be the greatest in the poorest countries. Therefore, developing innovative programs that leverage community assets while employing task-shifting for efficient use of resources may help governments to provide services for people previously considered out of reach.

Works by Brown *et al.* [14], Battles & Wiener [15], Ledie [16], and Domek [17] all attest to the positive and vital role that such programs can play in helping HIV-positive children make the kinds of psychosocial adjustments associated with the challenges of long-term survival of HIV. Increasingly researchers are arguing for a comprehensive package of treatment, care and prevention of onward transmission, implemented at the local level, as the most effective way to deal with the current and long-term needs of HIV patients. In spite of limited research in the form of randomized control trials, there is growing evidence that community-based programs can play an important role in improving treatment and health outcomes [18]-[24].

In this article, we review the literature to assess the current evidence on the role and impact of community-based programs on HIV/AIDS treatment and health outcomes for people living with HIV.

## 2. Methods

### 2.1. Search Strategy

In June 2012, the authors undertook a search of the following databases for articles on the relationship between

health outcomes and community-based practices related to HIV treatment, care and support: Medline, Academic Search Premier, PubMed, Family and Society Studies Worldwide, Global Health, CINAHL, ERIC, SocIndex, Google Scholar, and Social Work Abstracts. We set the search perimeters for a ten-year window from June 2002 to June 2012. The search terms included community-based/home-based/palliative care/community health worker\* / expert patient\*, and morbidity/adherence/retention/disclosure/stigma/health/outcomes, and HIV/AIDS. In the documents resulting from this search, we examined the references cited to identify additional research articles of value. We also looked at gray literature such as program evaluations, reports, and toolkits because they provide information about recent community-based projects.

The criteria for inclusion in the literature review were as follows: 1) the article was original research written in English; 2) the subjects were from low- and middle-income countries, categorized according to the World Bank system of classification; and 3) the study discussed HIV service provision regarding community-based programs and treatment outcomes for people living with HIV/AIDS on ART or those not yet eligible for HIV treatment but accessing treatment for opportunistic infections (OIs) and enrolled in care. Studies that incorporated elements of community-based programs but did not explicitly state this were also included.

Our research focused on low- and middle-income countries that, for the most part, have had to use innovative strategies to address the HIV epidemic. Unlike most reviews that focused solely on sub-Saharan Africa [25]-[27], we took a broader perspective, aiming to glean additional insight from multiple regional contexts. We reviewed research from Africa (n = 62), Asia (n = 8), Latin America (n = 5), and studies that included multiple countries (n = 12).

## 2.2. Analysis

The search yielded a total of 1569 articles referring to the subject matter. After sorting to identify the studies based on research conducted in low- and middle-income countries, 489 articles remained. Abstracts of these were reviewed and 74 met the inclusion criteria described above. An additional 11 articles were added from bibliographies, hand searches, and consultations with experts, yielding a total of 90 articles for review.

The researchers used a recognized appraisal tool, the *Johns Hopkins nursing evidence-based practice: research evidence appraisal tool* [28] to grade the 90 studies (See [Table 1](#)). Studies were then grouped by outcome measures and policy recommendations, with outcomes including the following: viral load, adherence to treatment, loss to follow-up, increased disclosure, stigma reduction, task shifting, and cost effectiveness. Concurrently, the review also examined the relationship between facility-based and community-based services. Without appropriate study designs or standardized outcome measures, statistical pooling of results was not possible; therefore, a formal meta-analysis was not undertaken.

## 3. Results

Literature on this topic remains limited. Due to the nature of the HIV/AIDS epidemic (which involves social stigma), randomized control trials (RCTs) are often not the ethical choice for use during an intervention that requires service provision to those in need while meeting rigorous data collection requirements [29] [30]. Our review indicated that the majority of studies used some form of sampling controls at the time of the intervention. Therefore, this review included a range of studies from RCTs to program evaluations. To mitigate concerns about scientific rigor, [Table 2](#) presents a synthesis of the research evidence showing quality and quantity of the studies, based on the weighed evaluation reflected in [Table 1](#).

Of the 90 articles reviewed six reported on the limitations of community-based HIV treatment programs [21] [31]-[35]. The vast majority of articles provided evidence on the positive role of the community in enhancing HIV care and treatment outcomes. Beyond posing the broad question “*do community-based programs impact the fight against HIV?*” we paid special attention to studies that revealed *in what ways* do community-based programs impact the health or wellbeing of people living with HIV.

### 3.1. Stigma and Disclosure

On the topic of community-level stigma, research has shown a strong correlation between disclosure of HIV status and retention in care [36] [37]. Studies reveal that disclosure increases as stigma is mitigated [38] [39]. Forty-two studies in the review argued that the community should be the main platform for addressing issues of

**Table 1.** Research evidence category appraisal tool.

<b>Level I:</b>	Randomized Controlled Trials (RCT); experimental studies; or systematic reviews of RCTs with or without meta-analysis
<b>Level II:</b>	Quasi-experimental studies; systematic reviews of a combination of RCTs and quasi-experimental studies or quasi-experimental studies only, with or without meta-analysis
<b>Level III:</b>	Non-experimental studies; qualitative studies; systematic review of a combination of RCTs, quasi-experimental and non-experimental studies or non-experimental studies, only with or without meta-analysis; systematic review of qualitative studies, with or without meta-synthesis
<b>Level IV:</b>	Opinion of respected authorities and/or reports of nationally recognized expert committees based on scientific evidence
<b>Level V:</b>	Evidence obtained from literature reviews, quality improvement documents, program evaluation, financial evaluations, case studies, or opinions of nationally recognized experts based on experimental evidence

Note: The research evidence categories are drawn from *Johns Hopkins Nursing Evidence-Based Practice: Research Evidence Appraisal Tool* (Dearholt & Dang, 2012).

**Table 2.** Quality rating based on quality appraisal tool.

<b>A—High Quality</b>	consistent, generalizable results; sufficient sample size for the study design, adequate control; definitive conclusions; consistent recommendations based on comprehensive literature review that includes thorough reference to scientific evidence
<b>B—Good Quality</b>	reasonably consistent results; sufficient sample size for the study design; some control; fairly definitive conclusions; reasonably consistent recommendations based on fairly comprehensive literature review that includes some references to scientific evidence
<b>C—Low Quality</b>	little evidence with inconsistent results; insufficient sample size for the study design; conclusions cannot be drawn

Note: The quality ratings are drawn from *Johns Hopkins Nursing Evidence-Based Practice: Research Evidence Appraisal Tool* (Dearholt & Dang, 2012).

stigma and disclosure. One study that examined the barriers to HIV service provision found that the main reason people do not access testing and treatment was fear of stigma and discrimination [40]. Three other studies found a strong correlation between social support structures that promote anti-stigma education and improved health outcomes for people living with HIV [36]-[38]. Clinical outcomes in these studies ranged from suppression of viral load to improved quality of life indicators.

### 3.2. Viral Load

Using the outcome of decreased viral load, one cohort study demonstrated that community-based ART programs could be an effective alternative model to facility-based HIV treatment. After two years, 86% of active patients in the study had a viral load of less than 400 copies per millilitre [41]. Twenty-one of the studies reported decreases in viral load associated with community-based programs. Of these, 15 are high quality RCTs or quasi-experimental studies and the remaining are high quality program evaluations. The 15 RCTs and quasi-experimental studies all provided quantitative outcome data.

### 3.3. Adherence

Treatment adherence is implicit for decreased viral loads throughout the continuum of care. Half of the articles reviewed ( $n = 45$ ) included some discussion of the importance of adherence to treatment protocols. The data indicate that increased community support correlates with improved adherence, which results in decreased loss to follow-up and mortality [8] [9] [18] [24] [42] [43].

However, in a number of articles ( $n = 14$ ) that discussed the two treatment modes (facility-based and community-based care) at length, some divergence was seen on recognition of improved health outcomes. There were varying suggestions as to the kind of relationship health facilities should have with the community. While most all of the evidence in this review pointed to the benefits of community support, an on-going question remains: To yield the best results, what is the optimal type and degree of collaboration between HIV treatment facilities

and community-based organizations [7] [8] [20] [44]-[46].

### 3.4. Cost-Effectiveness

Similarly, there is varying evidence on the cost-effectiveness of community-based versus facility-based treatment. Of the six articles that discussed the cost construct of community-based programming, four reported that community-based ART is the most cost-effective option in resource-limited settings [20] [45] [47] [48]. In contrast, an article by Babigumira, Sethi, Smyth, and Singer [31] concluded the opposite, that facility-based care is the most cost-effective option. However, Babigumira *et al.* also argue that community-based treatment programs result in the best health outcomes for patients.

## 4. Discussion

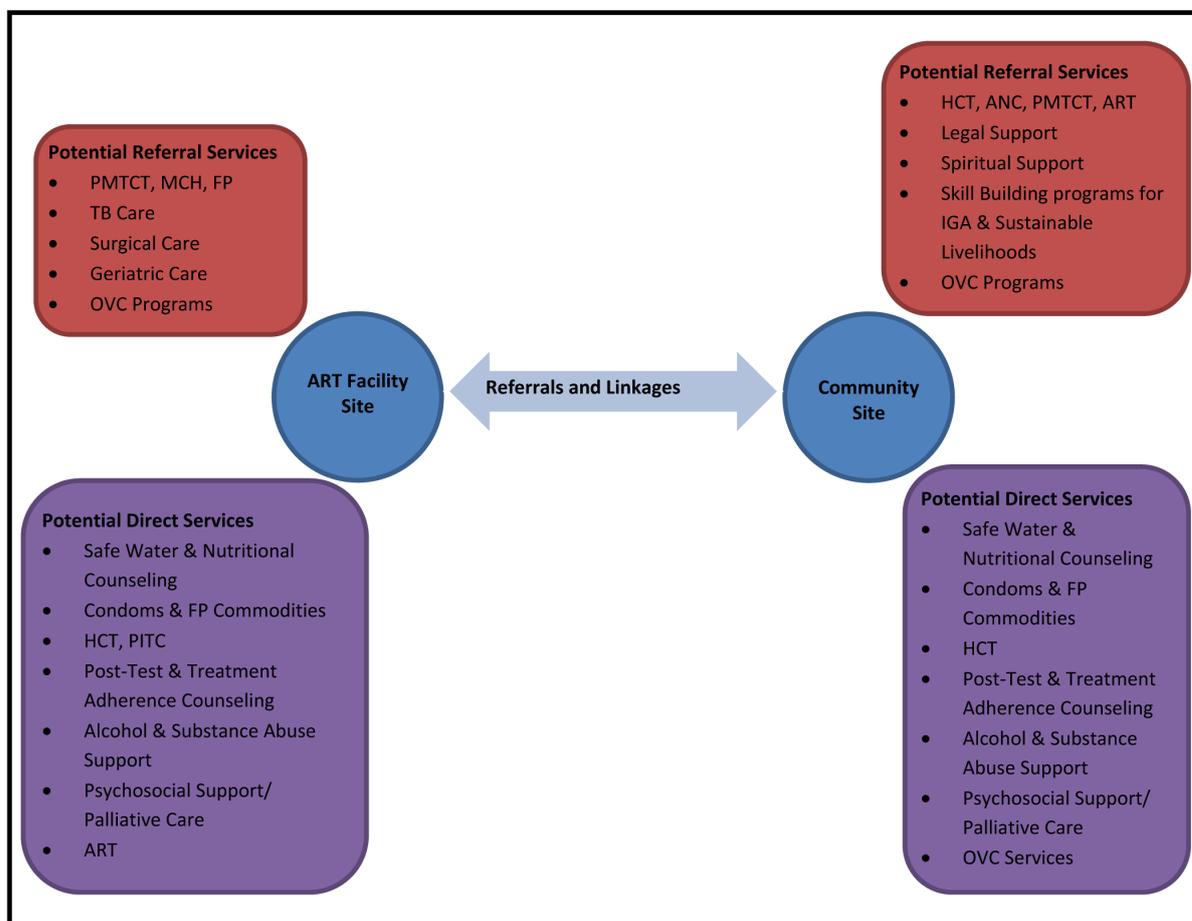
Our review of the existing literature indicates that the implementation of specific non-clinical/community-based interventions contribute to improved HIV treatment and health outcomes. This corroborates the findings from previous review studies on the topic such as that by Barnighausen *et al.* [12] and Wouters *et al.* [49]. Further research is required to ascertain more precisely which interventions are most effective in treating HIV in a community setting and which interventions best meet the needs of individual patients. For service providers, program developers, and policymakers, more research is needed to identify which components of a basic continuum of care, across clinical and community-based services best address patient needs in an integrated manner. It should be noted that none of the articles reviewed stated categorically that the facility setting or the community setting was better for providing HIV care. Programs that produced favourable HIV treatment and health outcomes were largely those where services were provided across both settings, as a continuum of care. A hallmark of these programs was a formally established affiliation between the facility-based programs and community-based programs whereby both worked together. These partnerships involved patients being enrolled in community-based support programs as well as strong facility treatment services [8] [9] [18] [24] [42]-[43].

While evidence for improved treatment outcomes in the context of formalized facility-community support structures is strong, it still appears to be the case that few facility-based programs have formalized linkages with community-based interventions [18] [20] [44]-[46]. The success of a formalized facility-community approach to the continuum of HIV care and treatment is mostly attributed to the strong working relationships between clinical and nonclinical programs. Through a formalized bi-directional referral system, people living with HIV and their caregivers would have access to a wider range of HIV services (see **Figure 1**). Additionally, by creating a comprehensive network of service provision, researchers argue that patients are less likely to be lost to follow-up and more likely to adhere to treatment regimens. Furthermore, as expanded public information messages about HIV prevention, treatment and care, as well as other education efforts reach people within the community, stigma toward HIV sero-positive status reportedly decreases and people living with HIV are more likely to seek out and take advantage of the available services.

The research evidence indicates a comprehensive continuum of care across health facilities and community-based programs may be the most sustainable way to improve treatment outcomes and quality of life for people living with HIV. This raises questions about the cost of long-term treatment and care for these patients. As this segment of the population lives longer with the aid of ART, the overall cost of treatment and care increases. Based on the studies reviewed, the majority of researchers found that community-based services are the most cost-effective option in resource-limited settings [20] [45] [47] [48]. For a sustainable community health infrastructure to succeed there would need to be willingness among funding entities (government agencies and donors) to invest in developing community-based systems and programs that complement the traditional health sector. Just as there is a focus on building strong institutional capacity for evidence-based practices, supportive supervision, and monitoring and evaluation for facility-based care, the same should be required for community-based care and services. By formalizing these support structures at both the facility level and the community level, countries could create a comprehensive, outcome-driven and sustainable service delivery system benefitting health care in general and HIV prevention, treatment, and care in particular.

### 4.1. Strengths

This article provided an overview of research to date examining the impact of community-based HIV programs



**Figure 1.** Continuum of care and support across facility and community settings.

on treatment and care outcomes. By analysing 90 articles, the authors were able to examine a broad range of service provision methods and country-specific examples. Similarly, by examining randomized control trials (RCTs), quantitative, qualitative, mixed methods, and program evaluation research approaches, the authors were able to determine the relationship between community-based programs and health outcomes, information that is useful for program planning and policy development at all levels. During the course of the review the authors did not come across a previous publication that looked specifically at how community-based HIV programs impact treatment outcomes; thus, this work is a contribution to that important topic.

#### 4.2. Limitations

It proved challenging to find relevant RCTs being conducted on the impact of community-based care on HIV treatment outcomes. Therefore, the review included evaluation research and program case studies not typically found in routine peer-reviewed literature. The authors did not include literature reporting on community-based activities in other HIV-related areas such as prevention. Because this review focused on treatment and care, the authors elected not to use a number of studies that showed successful outcomes when communities and facilities collaborate in prevention initiatives such as outreach programs that increase community awareness.

#### 5. Conclusions

The literature overwhelmingly attests to a positive relationship between community-based programs and improved HIV treatment outcomes in resource-limited settings. As healthcare for people living with HIV progresses to lifetime chronic care, it is vital that the global HIV community shift its focus from a predominantly facilities-based model of care delivery to one that is more decentralized and potentially more sustainable. Based

on the evidence provided by studies carried out in resource-limited settings—which account for the greatest burden of HIV globally—more emphasis needs to be placed on identifying suitable community platforms that can be leveraged to offer HIV services in the community setting. Partnering with existing facility-based structures, these platforms can provide cost-effective HIV services that meet the needs of people in the community. Formalizing the relationship between facility-based and community-based service provision through regulated supervision, outcome attainment, and monitoring and evaluation would help to strengthen such programs. Policy-makers and other stakeholders need to recognize the potential cost savings to be gained by engaging existing community-based structures in the delivery of HIV services in a locally monitored continuum of care. Policy reform is required to formalize and validate collaborative partnerships between health facilities and community platforms tasked with delivery of services to people living with HIV.

An ideal continuum of care would extend beyond the partnership of health facilities and communities to include relationships between communities, donor agencies, and the host country governments. Because each community setting has unique characteristics, we suggest three important factors to be taken into account for creating a basic care package to provide improved treatment outcomes for people living with HIV: 1) the specific sociocultural context, 2) the status of the formal health system, and 3) the community's knowledge, attitudes and practices regarding HIV and people living with HIV. In contrast to the “one-size-fits-all” minimum packages that are commonly promoted, countries planning to implement a continuum of care program for HIV patients would need to reach a consensus with all relevant stakeholders regarding tailoring for what to include in specific care packages.

Current evidence indicates that community-based care and support are a viable solution to addressing the complex problems associated with increased demand for HIV services resulting from people living longer with the disease. The evidence shows that such programs are cost effective and contribute to improved health outcomes in resource-limited settings. It is now up to the global HIV community to strategically support implementation of community-based HIV/AIDS programs that complement and synergize with clinical services, thereby ensuring increasingly sustained improvement in treatment outcomes.

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