

Lay workers' vital roles in supporting ART rollout: Home-based care in Zambia

Summary

The International HIV/AIDS Alliance, LSHTM, ZAMBART and AIDS Alliance Zambia have completed work on a study on Home Based Care (HBC) in Zambia. The study, an example of a successful collaboration between Evidence for Action partners, generated new data on the new roles of frontline lay health workers in Sub-Saharan Africa.

The research focused on the changing role of home based care givers since antiretroviral therapy (ART) was introduced in Zambia. It found that the role of home-based caregivers has become more 'medicalised' since the introduction of ART.

In addition to care and support in households, lay caregivers are now more directly involved in enabling and sustaining access to ART for PLHIV through tasks including: identifying, referring, and accompanying patients for testing and initiation on to ART; treatment counselling, adherence support and monitoring patients on ART.

Home based care givers increasingly support the formal health system, and effectively create lasting linkages between PLHIV and the ART clinics.

The findings of this research were communicated in various ways to key stakeholders, including home based care organisations; policy makers in the Zambian health service, and international organisations. They provide recognition and strong evidence for the important role of home-based care providers – often underpaid and undervalued – in supporting formal health systems for ART delivery.

Description of the project

The study involved eight months of data collection with three NGOs providing HBC in Zambia. Interviews were conducted with key informants, caregivers and people living with HIV to understand the changes in scope, tasks and impact of HBC in the light of ART rollout.

Findings

Findings include in-depth case studies of the three NGOs, a cost analysis of HBC activities, and insights into the day-to-day operations of HBC, including the activities of caregivers and their relationships with households affected by HIV.

ART delivery has modified the power dynamics between caregivers, their clients and the formal health system: in their new roles as extensions of the formal health care system, HBC caregivers promote the 'medicalisation'



Dackana Home Based Care Centre in Kabwe, Zambia © F. Cataldo

Dackana are one of the organisations that took part in this study. They implement Home Based Care programmes, nutrition and income generation support for people living with HIV in around Kabwe.

of HIV-care outside of formal health services. Care practices are being standardised in relation to ART delivery. While this represents a move towards more rational HIV-care, it signifies a potential loss of a community ethic of care.

ART has brought about significant improvement in the health of PLHIV in Zambia, as reported by both PLHIV and caregivers. Care for PLHIV is

“ The Zambian formal health system increasingly relies on an army of lay health workers... These lay care-providers play a vital role in supporting formal systems, yet vary widely in their qualifications, experience, and remuneration for the tasks they are expected to do. ”



funded by:

DFID

Department for
International
Development

International
HIV/AIDS



increasingly defined by the demands of starting and adhering to ART.

HBC caregivers' activities can increasingly be differentiated between non-medical support and medical support to PLHIV. They actively support the formal health sector's activities in enrolling patients on ART and providing support for their clients to stay on ART, accompanying them to the clinic, and monitoring their adherence to treatment.

Home-based caregivers intervene at crucial steps of the care-seeking trajectory. They are often the ones to recognise thresholds of ill health and distress and to encourage clients to test for HIV, to seek formal care, and to seek care for co-morbidities.

ART clinic staff increasingly welcome and rely on the support of HBC caregivers to enable people to access and adhere to ART. HBC caregivers are often seen as an extension of the public sector programmes, fulfilling a monitoring and surveillance role.

Caregivers, however, feel that their increased responsibilities and accountability to the health system are not formally recognized. They express dissatisfaction that the acquisition of skills to support ART roll-out is not matched by a formal change in status.

What is the potential impact of the research?

These findings point to the need to strengthen the capacity, motivation, and rewards for caregivers who support ART rollout in direct ways – but also to carefully consider the impact their changing role has on their relationship with PLHIV and communities.

The study was designed to be of interest to various stakeholders, and results were disseminated locally to HBC organisations, the Zambian Ministry of Health, the National AIDS Council, and

the organisations that were approached during data collection. The study was also presented to international audiences more recently.

At the national level, it is hoped that the recommendations from the study will:

- inform the updating / creation of minimum standards, regulations and national policies on Home Based Care in Zambia
- renew recognition of the contribution of Home Based Care to the formal sector

The study results will also have an impact on community based organisations through:

- providing evidence of the importance of their role which can be used in fund raising and resource mobilisation activities
- documenting changes in their daily activities, allowing them to adapt their programme strategies and tailor specific interventions and training

Who worked on the study?

The lead researchers on this study were:

- Fabian Cataldo (International HIV/AIDS Alliance)
- Karina Kielmann (LSHTM)
- Maurice Musheke (ZAMBART)
- Ginny Bond (LSHTM & ZAMBART)



on HIV treatment and care systems

About Evidence for Action

Evidence for Action is an international research consortium with partners in India, Malawi, Uganda, UK and Zambia, examining issues surrounding HIV treatment and care systems.

The research is organised in four key themes:

1. What "package" of HIV treatment and care services should be provided in different settings?
2. What delivery systems should be used in different contexts?
3. How best should HIV treatment and care be integrated into existing health and social systems?
4. How can new knowledge related to the first three questions be rapidly translated into improved policy and programming?

Partners:

International HIV/AIDS Alliance, UK

Lighthouse Trust, Malawi

London School of Hygiene and Tropical Medicine, UK

Medical Research Council Uganda Research Unit on AIDS, Uganda

Medical Research Council Clinical Trials Unit / University College London, UK

National AIDS Research Institute, India

ZAMBART, Zambia

This document is an output from a project funded by DFID for the benefit of developing countries. The views expressed are not necessarily those of DFID.