

New challenges for home-based care providers in the context of ART rollout in Zambia

F. Cataldo¹, K. Kielmann², M. Musheke³, V. Bond³

¹International HIV/AIDS Alliance, Evidence for Action on HIV Treatment and Care Systems, Brighton, United Kingdom, ²London School of Hygiene and Tropical Medicine, Health Policy Unit, London, United Kingdom, ³Zambian AIDS-Related Tuberculosis Project (ZAMBART), Department of Medicine, University Teaching Hospital, Lusaka, Zambia

Summary

The scope of community-based HIV care is evolving in Zambia, as ART becomes more widely accessible. Professional Community HBC care-givers are expected to provide more comprehensive support for their clients on ART. HBC care-givers are increasingly involved in building linkages and directly supporting provision of care within the formal health system. The burden, benefits, and challenges of this expanded range of tasks remain to be explored.

Background

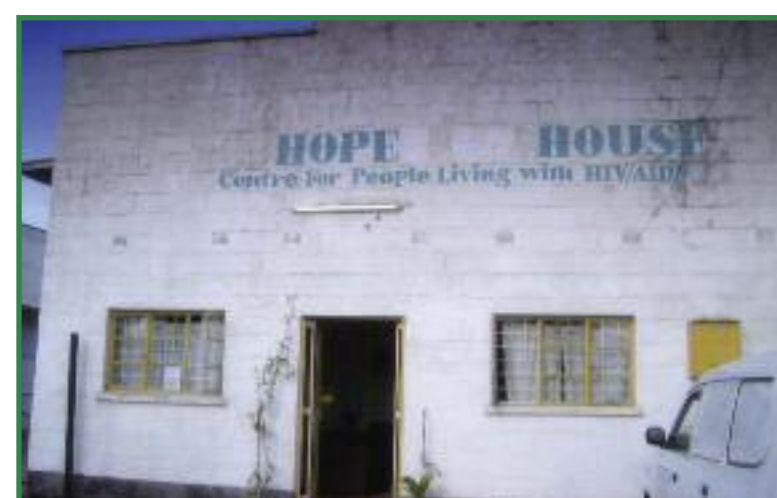
Zambia was one of the first countries in sub-Saharan Africa to implement **home-based care (HBC) for HIV/AIDS** as of the early 1990s. Until ART became more widely available from 2004 onwards, both faith-based and non-faith based NGOs provided counselling, nursing and palliative care.

As ART has become more widely available, the role of these organisations is evolving. HBC programmes are increasingly seen as an effective entry point for promoting uptake of testing, partner notification and referrals as well as treatment preparedness and adherence support.

Little is known about how the organisations, their staff and their clients are re-defining and responding to **new concepts of care and its delivery** through an expanded range of actors. We report from an on-going 12 month study in Zambia.



Dackana home based care centre, Kabwe, Zambia. © Fabian Cataldo 2008



Kara Counselling Kabwe, home based care centre, Zambia. © Fabian Cataldo 2008

Questions

- How have the **mandate, scope, and delivery** of services for HBC changed **in the context of ART roll-out** in Zambia?
- How have these changes affected the **relationships between NGOs providing HBC and other care providers**, including the formal public health system?
- How have the changes affected the **experience of HBC clients and their families**?
- What are the **operational costs** for delivering HBC in the age of ART?

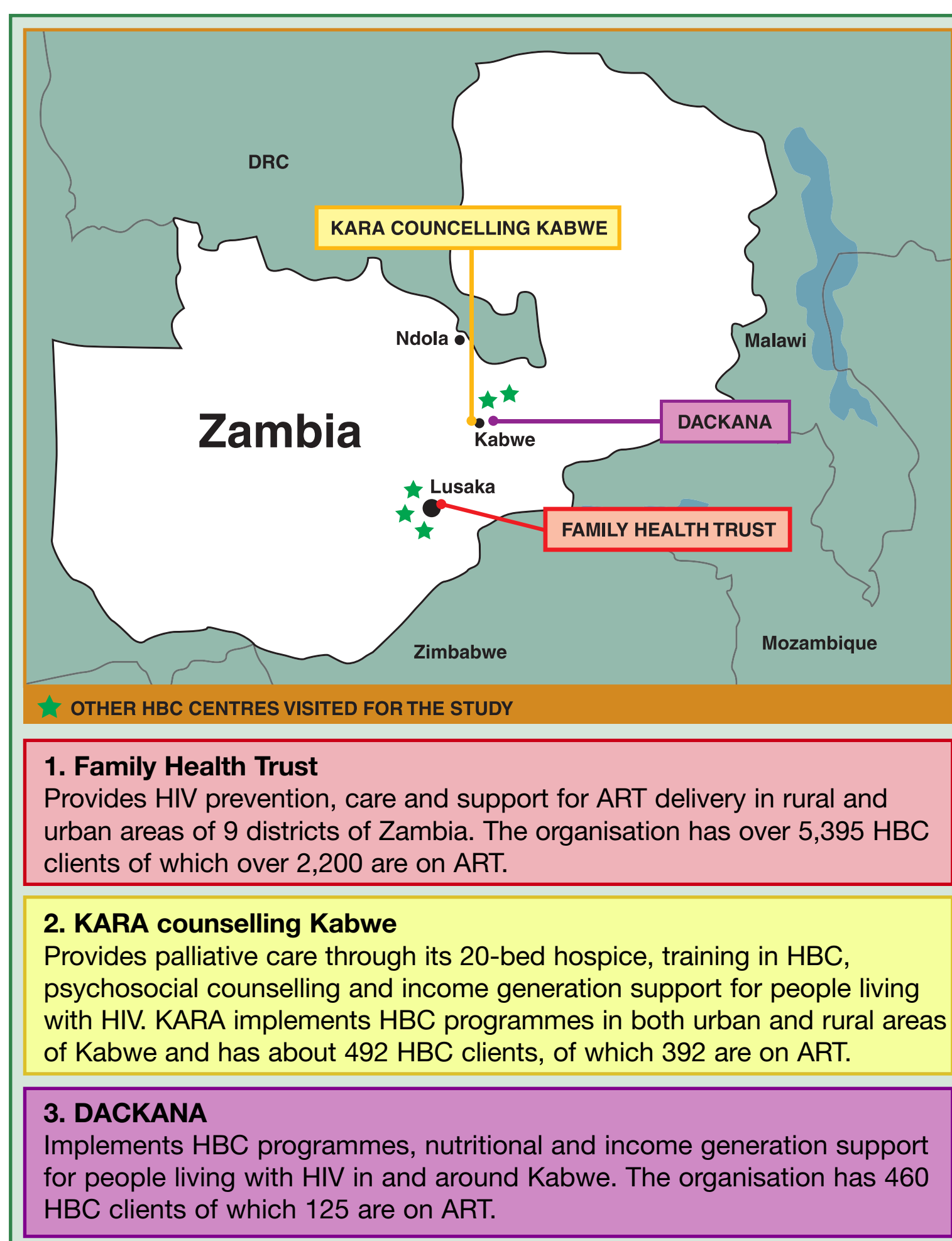
Methodology

Study design:

The project is cross-sectional and observational, drawing on qualitative methods and a cost analysis.

Study methods:

- Short **structured profiles** of 8 NGOs delivering HBC
- **Key informant interviews** with relevant stakeholders (health district managers, CBO directors, local HBC managers)
- **Case studies** of three organizations involving direct observations and participation in the daily life of these organizations
- **In-depth Interviews** with HBC providers, HBC clients and their families
- **Observations/documentation** of a 'day in the life of' HBC providers
- **Case studies and observations** within households of people living with HIV (PLHIV)
- **Cost analyses** of HBC



Preliminary findings

- ART has transformed the lives of people living with HIV; they look and feel healthier and are resuming economic, social and sexual activity. However, poverty and malnutrition remain a sustained reality for many people living with HIV on ART.
- NGOs providing HBC have expanded their scope of activities to include adherence and safer sex counselling, as well as support for nutritional supplementation and income generation.
- In addition to preventive and health promotion tasks, care-givers play an increasingly important role in seconding formal health services, by linking PLHIV to VCT and ART centres, collecting ARVs on behalf of their clients, serving as DOT supporters, and in some cases, becoming first line providers of treatment for opportunistic infections.
- Caregivers themselves are often poor, with limited knowledge or skills to undertake these new roles.

Emerging issues and relevance of study

ART roll-out in Zambia has improved the lives of many PLHIV significantly. However, structural barriers including poverty, unemployment and poor nutrition remain an enduring reality.

For NGOs delivering HBC, the challenge is how best to address the needs of clients who resume active lives on ART but may have difficulties accessing formal care, staying on treatment, and maintaining safer sexual behaviour.

Care-givers enter into new relationships with other care providers including the formal health system.

As we move forward with the study, we hope to answer emerging questions such as:

- How do care-givers relate to their clients in the light of changing roles?
- To what extent do they feel adequately equipped (and motivated) to take on these new roles?
- How does the formal health care system perceive and accommodate the expanded role of NGO-based care givers?

For more information about this research please contact:

Fabian Cataldo: fcataldo@aidalliance.org

Karina Kielmann: Karina.Kielmann@lshtm.ac.uk

www.aidalliance.org www.lshtm.ac.uk www.zambart.org www.evidence4action.org