

# IMPACT OF ART ROLLOUT ON THE ACCEPTABILITY, ROLES AND RELATIONSHIPS OF HOME-BASED CARE PROVIDERS IN ZAMBIA

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## Background

- Zambia was one of the first countries in Sub-Saharan Africa to implement home-based care (HBC) for people living with HIV (PLHIV) in the early 1990s
- Alongside ART roll-out in the Zambian public health system, the paradigm of care is gradually shifting from nursing to ambulatory services
- The role of home-based caregivers and their relationships with clients and with formal health systems is currently evolving in the context of greater access to ART.

## Study Aim and Methodology

### Aim

To examine the current role and acceptability of home-based caregivers in relation to the public health roll-out of ART in Zambia.

### Study Design

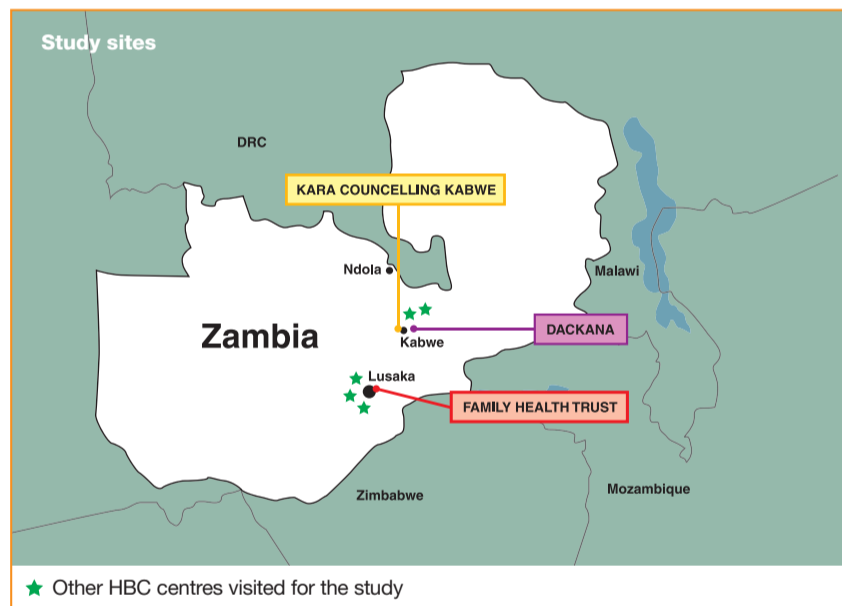
A one-year cross-sectional study using qualitative methods

### Setting

Three community-based organisations that provide HBC and ART related services in two districts of Zambia.

### Methods

- Key informant interviews (n=25) with ART staff in the health facilities and programme staff of the three local organisations
- In-depth interviews with home-based caregivers (n=48) and PLHIV (n=31)
- Daily observations on-site and recorded field notes.



## Key Findings

- In their new roles as extensions of the formal health care system, HBC caregivers promote the 'medicalisation' of HIV-care outside of formal health services
- Care practices are being standardised in relation to ART delivery. Whilst this represents a move towards more rational HIV-care, it signifies a potential loss of a community ethic of care
- ART delivery has modified the power dynamics between caregivers, their clients and the formal health system. Our data reveals tensions and new expectations between these different actors.

### 1. Recent changes in experiences of care in the era of ART

- ART has improved the health of PLHIV in Zambia, and care for PLHIV is increasingly defined by the demands of starting and adhering to ART
- The management of HIV as a long-term illness presents new challenges in the context of chronic poverty and continued social stigma around HIV.

*At first when they start to take the drug... it's very difficult. Some of the side effects are bad but they become fine again. So... yes that has changed and also now that there is ART, people have to eat when taking this medicine, so we caregivers, we sometimes give some of our own food [to them].*  
Caregiver with Family Health Trust, Lusaka

### 2. Evolution of the roles of home-based caregivers

- As HIV care has become more 'medicalised' HBC caregivers' activities are differentiated between non-medical support and medical support
- Home-based caregivers intervene at crucial steps of the care-seeking trajectory and they actively support the formal health sector's activities by enrolling and sustaining patients on ART.

*They alert us and make us know what is taking place out there in the community: Are patients adhering to the drugs? How many have stopped the drugs? How many have died? This data is very important for us.*  
ART clinic in-charge, Kabwe

- 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
- Many caregivers continue to perform their former tasks, such as providing pastoral care and material assistance to their clients and their families, despite lacking support themselves for providing this type of assistance.

### 3. Shifts in the relationships between caregivers, clients, and the formal health system

- HBC caregivers are seen as an extension of the public sector programmes, fulfilling a monitoring and surveillance role
- ART clinic staff welcome and rely on the support of HBC caregivers to enable people to access and adhere to ART
- Caregivers 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
- ART distribution has modified the power dynamics between caregivers, their clients and the formal health system. Caregivers place expectations on clients not only in terms of adherence to ART, but also with respect to health-seeking and lifestyle behaviours, whilst clients continue to demand physical and material support.

*[My role] has become more important because now we have to make sure that they [the clients] adhere to the medication they are taking.*  
Caregiver with Family Health Trust, Lusaka

*Nowadays our clients are even angry with us, they shout at us. They accuse us that we appropriate food and other material support meant for them. So we tell them to cool down and we tell them that we are not lying when we say that there is no material support that is provided any longer.*  
Caregiver with Family Health Trust, Lusaka.

## Recommendations

It is vital to consider how the changing roles of home-based caregivers and their relationships with clients and formal health staff impact on programmes in the context of ART delivery in Zambia and elsewhere.

### Policy Recommendations

- HBC caregivers have become extensions of the formal health system, but they do not receive standardised training. Efforts to develop training and a manual for HBC in the context of ART would contribute to a greater quality of care by HBC providers
- Care practices are being standardised in relation to ART delivery and the National AIDS Council (NAC) has developed National guidelines on minimum standards for HBC in Zambia, however these standards have not been widely disseminated or are not used by HBC programmes. Renewed efforts must ensure that these guidelines reach the relevant organisations throughout the country
- NGOs/CBOs and the NAC should ensure that caregivers are adequately equipped to carry out their tasks and receive enough support from their organisation in order to adhere to the set of guidelines and organisational practices set to deliver HBC in the context of ART
- Longer term commitment, adequate financial and material resources are required to ensure the continuous training of caregivers and access to material tools for the effective delivery of HBC.

### Programme Recommendations

- ART delivery has modified the power dynamics between caregivers, and HBC programmes should ensure that caregivers are equipped to deal with demands and expectations from both their clients and health system staff
- As the nature of the care provided is changing in the context of ART delivery, 'exit strategies' should be developed for caregivers in parallel to the training of family members to care for their relatives living with HIV
- "Caring for the carer": on-site psychosocial and stress management support must be given to caregivers
- More systematic assessments of the impact of HBC programmes on health-seeking behaviours and health outcomes of PLHIV are needed. The impact of caregivers interventions on client's health-seeking decisions, actions, and health outcomes need to be systematically assessed, both quantitatively and qualitatively.

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