

# BALANCING THE MEDICAL AND THE MORAL: HOME-BASED CAREGIVERS' INTERVENTIONS FOR PLHIV IN ZAMBIA

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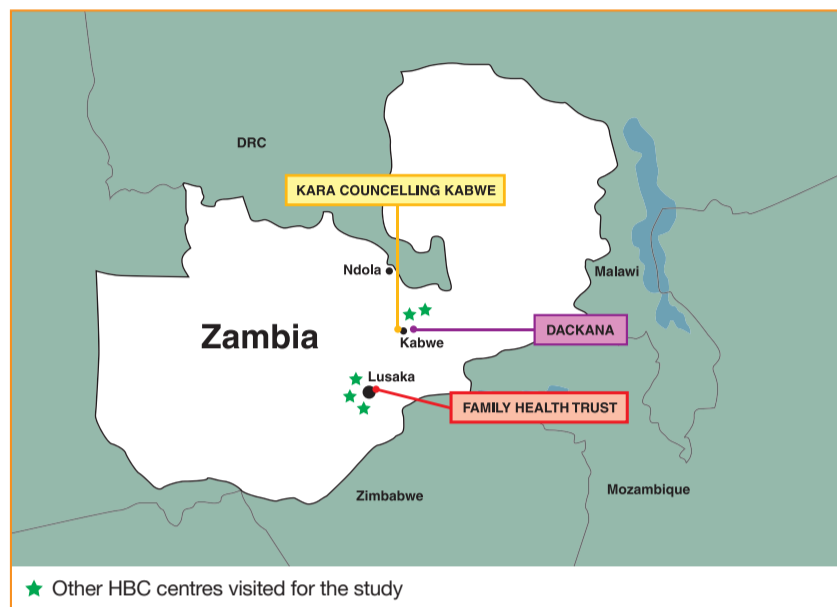
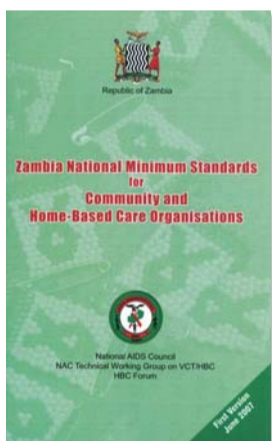
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## Background

- Formal health systems in sub-Saharan Africa (SSA) increasingly rely on home-based caregivers to support PLHIV (Persons Living with HIV) on antiretroviral therapy (ART).
- Home-based care (HBC) has become more task-oriented in relation to ART uptake and adherence.
- There is tremendous variation in formal training of caregivers and their relationships with clients.
- Little is known about the mechanisms through which caregiver interventions are making an impact on the health of PLHIV.

## HBC in Zambia

- One of the first countries in SSA to implement HBC programmes formally.
- NGOs, particularly faith-based organisations and health facilities began to provide HBC in the 1980s
- National AIDS Council (NAC) guidelines on minimum standards for community and home-based care in Zambia put in place in 2007.



## Medical Tasks

- Medicalisation of HIV care has 'formalised' caregiver tasks, however without formal recognition of status
- Formal health providers welcome the involvement of caregivers as alleviating their work burden
- Monitoring and surveillance roles are prescriptive and not always welcomed by clients.

"...within the policy of HBC, there is standardised training; a standardised home based care kit; there is also a standardised guide of client-to-caregiver relationships"

Programme staff, Dackana, Kabwe

## Moral Interventions

- Caregivers intervene at crucial steps of the health-seeking trajectory of PLHIV; they describe these interventions as *personal decisions* and *moral obligations*
- Interventions extend beyond the individual, involving wider therapy management groups
- Caregivers often rely on their personal resources and social networks to facilitate access to care.

"Caregivers are instructed to observe the client drink the medicine. (...) Some clients pretend to have swallowed the tablets yet haven't, they keep tablets under their tongue and wait for the caregiver to leave so that they can spit out. It is for this reason that we use a technique of interrogating the client immediately after taking their medicine to check whether they have swallowed."

Caregiver with Dackana, Kabwe

"One day I persuaded her (client): "Look, your sickness is not getting any better...you may become seriously ill and eventually die, no one will take care of your children... therefore let us go. I will speak to the doctor about your condition myself". That day, I woke up at 5am, I got my bicycle and went to her place, picked her up and cycled towards the bus stop so that we could board a bus to the hospital. When we met the doctor I personally explained to him: "Doctor, this person has not been allowed to start ART due to her low CD4 count and is becoming very sick (...) I am asking you to just administer the ARVs to her..."

Caregiver with Dackana, Kabwe

## Conclusion

The 'medicalisation' of home-based caregivers' tasks in relation to ART delivery has increased their accountability to the formal health system, yet created tensions in their role as community carers. In order to sustain community trust, medical monitoring is balanced with social solidarity and personal moral engagement – these are the mechanisms through which caregivers make a difference to PLHIV health-seeking trajectories.

## Key Recommendation

HBC organisations and policies must recognise and support the fundamentally social and moral nature of community care-giving:

- Delegation of 'new' medicalised tasks to caregivers is more likely to be successful if integrated with caregivers' social roles and relations within community
- Impact assessments of HBC need to consider caregivers' interventions at crucial thresholds of health-related decision making among PLHIV.

## Aim

To examine the impact of HBC on health-seeking trajectories of PLHIV from the perspectives of home-based caregivers and HBC recipients.

## Methodology

### Sites

- CBOs selected from a pool of HBC organisations in Lusaka, Central and Southern Provinces
- Providing HBC services for HIV related treatment; established ≥ 4 yrs
- Working with PLHIV currently on ART.

### Methods

- Key informant interviews with HBC programme and ART clinic staff
- In-depth interviews with a purposive sample of 48 home-based caregivers and 31 HBC recipients.

### Analysis

Thematic analysis of interview transcripts under broad headings, e.g.

- Experiences of giving and receiving care
- Relationships between caregivers and clients
- Relationships between caregivers and formal health system
- Perceived impact of home-based care.

## Results: Profile of Caregivers

- Mainly women (70%), over the age of 40 (85%)
- High number widowed, divorced, or separated (43%)
- Most had completed secondary school (91%)
- All from low-income backgrounds; very few formally employed (5%)
- Many had witnessed the illness and death of family/relatives due to HIV.

"When I find that she (client) is not feeling well, I accompany her child to school and help her with the house-work when she is bedridden. I once helped her go to the market, I stayed there from 8 in the morning until 19 hours."

Caregiver with Family Health Trust, Lusaka

## Social Relations

- Many caregivers have quasi-familial relationships with clients and their households
- They contribute to maintaining households through productive/reproductive activity
- These ties engender trust, but also create expectations and obligations

"When I am hungry and I don't have food, I normally go to her (caregiver's) place to ask for food and she gives some to me. If am in need of money, she also gives me money to buy a bag of charcoal."

HBC-Client, Kara Counselling, Kabwe