**BALANCING THE MEDICAL AND THE MORAL: HOME-BASED CAREGIVERS’ INTERVENTIONS FOR PLHIV IN ZAMBIA**

Karina Kielmann¹, Fabian Cataldo², and Maurice Mushoke³

¹ London School of Hygiene and Tropical Medicine
² Evidence for Action on HIV Treatment and Care Systems, International HIV/AIDS Alliance, Brighton, UK
³ Zambia AIDS-Related Tuberculosis (ZAMBAR) Project, Lusaka, Zambia

**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.

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

**Methodology**
- **Participants**
  - 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 (45%)
- 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.

**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.

**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.

**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.

**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 care-givers. 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.

*For more information please contact Karina Kielmann
Karina.Kielmann@lshtm.ac.uk*