Evidence For Action
on HIV treatment and care systems

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New challenges faced by home-based caregivers in sub-Saharan Africa

Key Points

- Home-based care programmes are used across Sub-Saharan Africa to provide care for people living with HIV, and reduce the burden on the formal health system
- The scope of home-based care has expanded to include helping clients to access and adhere to ART in addition to their traditional roles
- Home-based care givers face challenges to carrying out this expanded role, including:
  - lack of regular training and supervision
  - lack of recognition and compensation
  - lack of psychosocial support

Introduction

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Home-based care (HBC) programmes for People Living with HIV (PLHIV) in Sub-Saharan Africa have evolved over the past two decades in response to the roll-out of antiretroviral therapy (ART). HBC programmes developed through the early 1990s, providing nursing and palliative care, as well as general support for households affected by HIV. As ART has become more widely available, many PLHIV have regained their physical health and strength, and resumed 'normal'levels of social and productive activity. Home-based care has become more medicalised as a result of the drive to initiate and sustain patients on ART. Home-based caregivers' roles and tasks are changing in important ways as they are drawn on to support the public sector ART roll-out in Southern Africa. However, they remain a vast and highly diversified group of lay workers whose contributions to HIV care have low visibility, and little or no formal recognition and compensation.

The purpose of this brief is to provide information on how home-based caregivers' roles and relationships with the public health system have changed, and guidance on how to address the new challenges that caregivers face in the light of expanded roll-out of ART programmes. It is intended for local and international policy makers, HBC programme implementers and researchers in the field of HBC.

The evidence presented originates from empirical studies and a literature review conducted as part of the Evidence for Action Research Consortium (see Further Reading).

The Role of Home Based Care in Sub-Saharan Africa

There is a major shortage of health care workers in Southern Africa. In this context, comprehensive HBC programmes are a popular strategy for ensuring a continuum of care and support to PLHIV outside of the health facility environment. HBC services can help to reduce the burden on health facilities by shifting certain tasks to patients' homes. They may prove more effective than providing alternative clinic-based services using formally trained healthcare workers.

Providing care within the household can overcome some of the barriers to accessing HIV care, including those that relate to the economic and opportunity costs incurred by patients if they have to travel to attend health facilities. HBC also has the potential to reduce the pervasive stigma that surrounds the illness, thus improving uptake of HIV testing, and access to care and support for those diagnosed with HIV.

The changing role of home based caregivers in the context of ART

The scope of HBC is increasingly defined by the demands of starting and adhering to ART. Caregivers continue to provide physical nursing care, psycho-social support, as well as help with household work but are additionally involved in supporting the formal health system: they identify and refer clients for testing and for treatment of co-infections; they accompany clients to the clinics, and they provide support for PLHIV on ART. HBC caregivers intervene at crucial steps of the care-seeking trajectory. They are often the first to recognise thresholds of ill health and distress and to encourage clients to test for HIV, to seek formal care, and to screen for other infections. These interventions can involve lengthy interactions with clients, client's relatives, and with the health services (Box 1).

Health care staff working in ART clinics have welcomed the new roles of HBC caregivers, reinforcing their central role as a sustained link between clients and ART centres. For front-line health providers, especially nurses, caregivers help to alleviate the burden of the daily workload by performing some of the basic administrative and baseline functions. These include treatment preparedness, filling of patients' records, collecting and recording client parameters such as temperature, height, weight and blood pressure readings.

Current challenges faced by home based care caregivers

A number of challenges face home-based caregivers in the current landscape of HIV care in Southern Africa. The lack of training, remuneration, and recognition of their support contribute to staff demotivation and poor retention.

Box 1: Interacting with clients and health services

"My [client's] household had serious food shortages; her husband did not care for her and the children were very young. If the sister [who lived abroad] did not send money, it became my responsibility to support them. One day I persuaded her to visit a doctor. I said: *Look, you are not getting any better; you may become bed-ridden...who will take care of your children? Let us go. I will speak to the doctor myself.* That day, I woke up at 5am, got my bicycle, picked her up and cycled towards the bus stop so we could board a bus to the hospital. When we met the doctor I said: *Doctor, [client] has not been allowed to start ART due to her low CD4 count. She is very sick. I am asking you to please just give the ARVs to her. If ART will worsen the situation, then let it be so.* The doctor heeded my request and put this client on ART."

Sophie, caregiver in Kabwe, Zambia

Lack of regular training and supervision

Training for home-based caregivers has not always evolved adequately to equip home-based caregivers with the skills required to support clients initiation and follow-up on ART, as well as other medical tasks, partly because of the lack of available funds or restrictions on their use. In addition, training of caregivers still remain adhoc and irregular. Inadequate training, lack of on-the-job mentorship, and inadequate supportive-supervision have constantly been cited by caregivers as key de-motivating factors that need to be addressed.

Lack of recognition and compensation

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 (Box 2). Additionally, caregivers receive little or no compensation for the work they do; many consider themselves volunteers although some receive small incentives (e.g. travel money, training per diems, T-shirts) that are often dependent on the donor organisations funding the programmes. The uneven distribution of incentives contributes to demotivation and tension among caregivers.

Lack of psychosocial support for home-based caregivers

Most caregivers come from low-income backgrounds and are not engaged in formal employment. In addition, they are often caring for someone living with HIV within their families. Some are also living with HIV themselves. They report high levels of emotional stress, usually arising from the increased burden of care, feelings of helplessness towards their clients, emotional attachment to their clients, and the lack of requisite logistical and supervisory support. The psychological burden on HBC volunteers is particularly high in programmes focusing on providing end-of-life care.

Box 2: Lack of formal status

"We do not have identities for health care staff to identify us as caregivers...we are not known by the health workers. If we had uniforms, it would help."

Raymond, caregiver in Lusaka, Zambia

Recommendations

Recommendations for Policy Makers

- Funding agencies should improve the coordination of technical and material assistance for home-based care programmes, support their integration and recognition by the district level health systems, and ensure involvement of local communities from the outset in planning strategies for home-based care.
- Standardised curriculum and manual for training and support of home-based caregivers in the in the context of ART should be developed, disseminated and implemented in-order to motivate caregivers while improving the quality of care they deliver.

Recommendations for HBC Program Implementers

- Home-based care programmes need to provide on-site supervision, regular on-job-mentorship and psychosocial and stress management support to home based caregivers.
- Home-based care programmes should develop appropriate 'exit strategies' for caregivers in parallel with adequate provision to train and support family members to assume responsibility of caring for their relatives living with HIV.

Recommendations for Researchers

- Further research is needed to document and systematically assess the potential impact that home-based caregivers can make in the health-seeking behaviours of persons living with HIV.

Credits

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Further Readings

1. Wringe A., Cataldo F., Fakoya A., Stevenson N., Delivering comprehensive home-based care programmes for HIV: a review of lessons learned and challenges ahead in the era of antiretroviral therapy. Health Policy Plan. 2010 Sep;25(5):352-62. Epub 2010 Feb 8. [Challenges and opportunities for scale up of ART within HBC]

2. Young T, Busgeeth K. Home-based care for reducing morbidity and mortality in people infected with HIV/AIDS. Cochrane Database Syst Rev. 2010 Jan 20;(1):CD005417: [A comprehensive review of evidence for Home Based Care]

3. Task Shifting. Global recommendations and Guidelines. Available athttp://whqlibdoc.who.int/unaids/2007/9789241596312_eng.pdf : [Recommendations from WHO on Task Shifting]

4. Cataldo F., Kielmann K., Musheke M., 2009 'New challenges for home-based care providers in the context of ART rollout in Zambia' [study report from project that is part of the Evidence for Action Research Consortium, funded by DFID]

5. For more information on the Home Based Care study visit http://bit.ly/hbcinfosheet and http://bit.ly/hbccasestudy

Evidence For Action 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

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

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