

Living with antiretroviral therapy: A qualitative study of the lives of people living with HIV who have been taking antiretroviral therapy for more than one year in Wakiso District, Uganda

Summary

The 'Living with ART' study was conducted with 10 men and 10 women who had been on ART for more than one year and aimed at documenting people's everyday life experiences over the time they were accessing ART to understand more about adjusting to life with HIV as a chronic condition. Working with a government hospital provided the advantage that participants could be traced even after they were transferred to a health centre where they could access ART closer to their homes. All the twenty participants were followed up once a month for a period of eight months and 12 (mainly females) completed all the scheduled visits. Due to the nature of their work, only three male participants completed the eight visits but each participant was visited at least five times.

A combination of qualitative methods were used e.g. in-depth interviews, life history calendars and observation to gain insights into the participants' background and provide an in-depth understanding of how PLHIV manage ART over a long period of time, and what the consequences of accessing ART are in relation to their personal experiences, relationships, social networks, livelihood, etc. The knowledge generated increases our understanding of the social factors that affect patient management of HIV as a chronic illness, and therefore the social contexts and processes that can undermine or support the success of ART delivery programs.

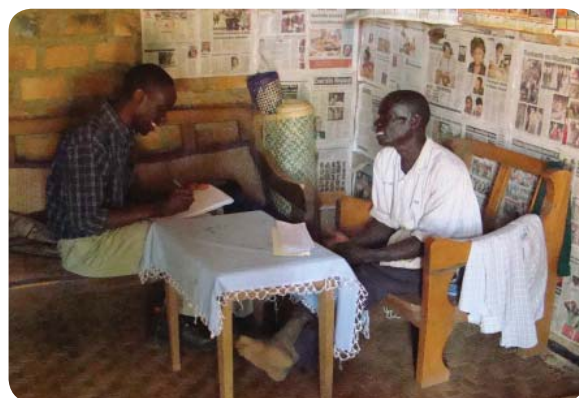
Description of the study

Background

The roll-out of ART has prolonged the lives of thousands of people living with HIV in sub-Saharan Africa. Restored health has enabled these people to work again, re-engage with family and participate in social and political activities. Health providers and PLHIV are able to treat HIV as a manageable chronic condition rather than a terminal illness. Adjustment to a new life on ART, and living with HIV as a chronic condition, poses significant medical, social and economic challenges for PLHIV, especially in settings of poverty, gender inequality and where the supply of ART is insecure.

Findings and interpretation

After ART initiation, participants gradually rebuilt their lives. This inevitably followed a process of self management and adjustment which also resulted from inclusive counselling by health care providers and reintegration with family and friends. Participants resumed work or engaged in new



income generating activities and many were able to lead a 'normal' life again. For instance, four participants had or expected a baby. Participants believed that they could live longer while on ART. Future plans included finding work, building a house, and educating their children. Disclosure of their status to spouses and family improved drug adherence and led to better health for most of the participants. As a result, stigma reduced considerably, and so did concerns about the drugs. In cases where they got drug reactions and reported to health care providers, they were changed to a different regimen or given more health education. However, a few people decided to stop taking Septrin without consulting the doctors.

“People on ART, whose health has been restored, wish to get on with their lives and forget that they are living with HIV; they don't want their life to be defined by a disease.”



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What is the potential impact of this?

We were able to use the study design and initial findings to inform the design of a larger study which focuses more on mental health and long-term ART use. This has been successfully funded by ESRC and MRC.

Analysis is on-going and we are providing emerging insights to colleagues involved in clinical trials related to ART. We will continue to do this and produce briefing papers and short notes to help ART providers understand some of the issues raised by the study.

The knowledge generated will inform empirical and conceptual understanding of the social factors that affect patient management of HIV as a chronic illness, and therefore the social contexts and processes that can undermine or support the success of ART delivery programs. It will feed into national and international policy debates on scaling up ART in resource-poor settings and inform future social research.

By highlighting challenges at a personal level related to the drug burden, compromised diet and accessibility of health centres; and also with the health care system, this will inform future interventions and lead to a comprehensive health care package which takes into consideration the unique needs of an HIV client. A good client–health care provider relationship is important for people ‘living with ART’ yet it is often compromised. Through enhanced self management, more patients are likely to adhere to HIV treatment and this will also increase uptake of HIV prevention messages and HIV information in general.

How is this research novel?

Social Science research, when it has been included in research programs on ART has often focussed on the same areas of bio-medical research, such as issues around ART adherence. This research was looking at the broader impact of ART on people’s lives and livelihoods; the obstacles that stand in the way of the transformation to a ‘normal life’ for the people accessing their drugs through Uganda government channels.

What made the research successful?

The participants were recruited from an existing cohort at a government hospital and the study team worked hand in hand with the health care providers. Participants were visited monthly for eight months which made them open up and volunteer information about their life histories and experiences while on ART. This would not have been achieved in a one-off interview. The team was trained and used a range of qualitative data collection methods like life history calendars, in-depth interviews and observation to obtain useful data and they used a gender sensitive approach.

Who has been involved?

- **Medical Research Council/Uganda Virus Research Institute (MRC/UVRI):** Prof. Janet Seeley, Flavia Zalwango, Prof. Heiner Grosskurth
- **International HIV/AIDS Alliance:** Dr. Fabiano Cataldo
- **HIV/AIDS Alliance in Uganda:** Dr. David Bitira
- **Entebbe Hospital:** Dr Herbert Kisamba
- **The AIDS Support Organization (TASO)**
- **Uganda Virus Research Institute:** Dr. George Miiro

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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

London School of Hygiene and Tropical Medicine, UK

Medical Research Council Uganda Research Unit on AIDS, Uganda

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

National AIDS Research Institute, India

ZAMBART, Zambia

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