Coming back from the dead: living with HIV as a chronic condition in rural Africa

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Scaling-up of anti-retroviral therapy (ART) in resource-poor settings has dramatically reduced mortality and morbidity for those with access, but considerable challenges remain for people who are trying to live with HIV as a manageable chronic condition. A return to ‘normal life’ for people on ART depends on the assurance of an uninterrupted, affordable and accessible supply of medication. However, many poor people also require economic support to re-establish their livelihoods, particularly where productive and financial assets have been depleted because of long-term illness. ART programmes need to seek convergence with economic programmes that have expertise in livelihood support and promotion, and with social protection initiatives. The future for those on ART depends not only on the provision of medicine but also on economic and social support for rebuilding lives and livelihoods.

Keywords HIV, anti-retroviral therapy, chronic illness, normalization, Africa, Uganda

Introduction

Awino is a subsistence farmer in rural Uganda and sole provider today for four children. In 2001, she gave birth to a baby girl who died after only a few months. In February 2002, her husband, a fisherman, died of AIDS, leaving her HIV-infected and with no source of income. After her husband’s death she struggled to make money by selling cooked food, but that business failed when she became very sick and was taken to her parents’ home close to death. At this time in late 2003, with a CD4 count of 202 and a viral load of 56,000 copies per ml, Awino began taking anti-retroviral therapy (ART). By April 2006, her CD4 count was 611 and her viral load was undetectable. One of her sons, born in 1997, is HIV-infected and is now doing well on ART. Awino’s physical well-being has returned, but her poverty remains. She has no cash income to support herself and her children.

Awino’s story highlights some of the enormous contextual challenges of expanding anti-retroviral therapy (ART) for people living with HIV (PLWH) in the context of poverty in rural Africa. To date we have only had the resources to focus on the immediate requirements of increasing ART availability, including establishing drug distribution systems, training programmes, ART education and counselling, and monitoring systems. Longer-term visions for the expansion or scale-up of ART availability must consider questions of cost, health system capacity, long-term adherence and clinical management challenges. However, in the frenzy to scale-up ART, and within longer-term visions for ART scale-up in resource-poor settings, little attention has been paid to the social and economic realities of the lives of PLWH, people like Awino. The harsh realities of poverty and vulnerability may undermine people’s ability to live with and manage HIV as a chronic condition. This paper argues that a longer-term vision for ART scale-up must be broadened to go beyond medicine to incorporate economic and social interventions that support the rebuilding of people’s economic and social lives.

In industrialized countries, ART’s success in reducing mortality and morbidity means HIV is now cautiously treated as a manageable chronic condition rather than a terminal illness (Palella et al. 1998; Gifford and Groessl 2002). In resource-poor settings, ART has also achieved remarkable mortality and morbidity reductions, renewed hope and reduced stigma (Farmer et al. 2001; Castro and Farmer 2005). However, in settings of poverty and vulnerability, PLWH face particularly difficult social and economic challenges to managing and living with HIV as a chronic illness, challenges less commonly seen in more affluent settings. If people must struggle to pursue viable economic lives, then their management of their HIV infection is likely to be undermined. The limited evidence from rural Africa shows that people have to overcome enormous barriers to manage any chronic condition successfully (Epping-Jordan et al. 2001). Based on our experiences of people’s adjustments to living with HIV on ART in rural Uganda, we ask two related...
questions relevant to a longer-term vision of ART scale-up in rural Africa:

- For PLWH in resource-poor settings, what are the potential challenges to the normalization of HIV as a manageable chronic illness?
- What do these challenges mean for policies and programmes aiming to expand HIV access and care?

### Normalization of chronic illness

In industrialized settings, medical sociology research has explored the ways chronically ill people strive to manage and live with their condition, adjust to the disruption of ‘normal’ routines, and so ‘normalize’ their everyday lives, work and leisure activities, and relationships (Radley and Green 1987; Conrad 1990). Here we approach normalization from this patient-centred perspective, distinct from previous discussions of the need to normalize HIV at the public health policy level (Rosenbrock et al. 2000). Normalization does not imply that a person can return to their earlier life. People living with diabetes, for example, know that their new ‘normal’ life has changed because it is punctuated with taking medicine, attention to diet and exercise, and regular professional interventions. Living with chronic illness requires people to cope with the ‘medicalization’ of their life, making their strategies and daily work to normalize life all the more difficult (Conrad 1990).

Psychological, social and economic factors heavily influence people’s adjustments to living with and managing chronic illness (Conrad 1985; Drummond and Mason 2002). More serious conditions such as HIV can disrupt identity and one’s deeply embedded orientation towards future life course, which can have profound psychological effects and make normalization even more difficult (Davies 1997; Mitchell and Linsk 2004). ART is associated with toxicity, side effects and treatment failure for many people. ART resistance is increasing (Weidle et al. 2003), and treatment alternatives remain limited, so living with HIV is imbued with greater uncertainty about treatment success than many other chronic conditions. In addition, people’s efforts to live with chronic illness and normalize life require not only effective treatment regimens but also supportive economic and social conditions. Such conditions may not be available to poor PLWH in rural Africa.

### Challenges to normalization of HIV in resource-poor settings

#### Economic realities

Strategies to rebuild a sustainable livelihood for persons taking ART in resource-poor settings are hindered by the harsh economic realities of asset and income poverty, food insecurity and vulnerability. Many poor people live in these precarious settings and struggle to build sustainable livelihoods. However, PLWH face additional challenges because they know that illness can quickly come and undermine one of their most important assets, their physical labour. Many people in rural Africa rely on subsistence agriculture, and therefore their physical strength, to survive. Alternatively PLWH seeking to return to work may struggle to find a job in areas of high unemployment. The difficulty might be compounded by loss of strength or skill levels due to absence from work, and employer prejudices. Work activities in resource-poor settings often require mobility or migration which may be incompatible with ART adherence (Chesney et al. 2000; Seeley and Allison 2005). In addition, in communities with mature HIV epidemics, many economically active adults have already died. Productive and financial assets from an earlier livelihood have often been depleted to cover the income losses and expenditures incurred due to long-term illness (Russell 2004). Re-building these asset portfolios and returning to feasible livelihood strategies may be a daunting task and may not be possible without support.

For PLWH a euphoric return from near death to new life can be quashed by the struggle for work and lack of money and food. ART can treat one vulnerability, HIV, but it cannot address the failure of the maize crop due to drought, hunger, rising debt levels and the limited availability of credit.

#### Social and psychological realities

In sub-Saharan Africa, high AIDS-related mortality and stigma have changed many familial relationships and friendships. The difficulty of normalizing family life is compounded by the vertical transmission of HIV which has resulted in high child mortality in sub-Saharan Africa. People who regain their own health must live with painful memories about the loss of a child, or the devastation of learning that a child is also HIV-infected. Even if HIV becomes manageable for an individual adult, many families have multiple members infected, including children, which may increase the likelihood of treatment failure experiences and depression.

Among PLWH taking ART, the desire for a new intimate relationship is common as their health returns. However, new sexual relationships pose huge dilemmas for a person who knows they can still transmit the virus, and possibly a drug-resistant strain. Even if testing and disclosure within couples takes place, difficult choices have to be made about abstinence, condom use, and the risks associated with pregnancy and childbirth. In many African societies, social practices and norms relating to gender and kinship make these dilemmas particularly hard to resolve for both women and men. Motherhood is an important part of a woman’s identity and women face pressure from men to have children to strengthen the relationship and provide heirs (Barnett and Whiteside 2002).

### Developmental visions for longer term ART scale-up: beyond medicine

What do these challenges mean for a longer-term vision and course of action for the scale-up of ART delivery? The larger questions of sustained funding and health system strengthening are fundamental requirements. However, current funding initiatives for ART expansion in Africa are time-limited. While they may be extended or re-conceptualized, their shifting nature suggests that a long-term vision for ART funding and scale-up is uncertain and has not been widely embraced in the light of competing priorities and political changes. Even if donor support were guaranteed, health system weaknesses...
in many countries, including procurement and distribution systems, raise concerns about drug stock-outs, particularly in rural and unstable areas. The foundation upon which a return to normalcy depends—the assurance of an uninterrupted, affordable and accessible supply of medication and care—remains absent in many countries. Poor and vulnerable sections of the population will only be able to access ART on a long-term basis if it is provided free at the point of delivery and delivery systems are decentralized to ‘close-to-client’ levels of the health system, such as health centres, changes requiring substantial investments (Commission on Macroeconomics and Health 2002).

Even if difficult supply-side challenges to ART delivery are resolved, wider social and economic challenges remain. HIV and the onset of AIDS-related illnesses usually cause economic stress and impoverishment before people are eligible for or can access ART (Russell 2004). In general, HIV programmes need to pay more attention to these economic difficulties. With respect to ART programmes, PLWH who are recovering their health require economic and social support, in the form of food rations, livestock, other asset investments and small loans for micro-enterprises. Without this support, PLWH taking ART will face challenges in rebuilding their livelihood activities and economic security. These economic difficulties have the potential not only to undermine people’s ability to resume their earlier economic lives on ART, but may actually threaten their ability to adhere to treatment regimens (Chesney et al. 2000).

If PLWH are to survive with HIV as a chronic illness, international policy debates on ART roll-out must consider links with complementary livelihood and social support programmes in the longer term. However, implementing successful livelihood and poverty reduction programmes is not easy: food handouts, asset building and micro-credit programmes often fail. Lessons need to be learned from the numerous and often small-scale livelihood support programmes implemented in resource-poor settings by community groups, NGOs and governments which have helped PLWH sustain or rebuild their livelihood assets and activities, for example poultry production for households lacking able-bodied workers (Alders et al. 2005) and practical training in farming and life skills for young people affected by HIV (Djeddah et al. 2006).

ART programmes are not usually designed to deliver complementary livelihood support interventions, and indeed, staff involved with ART delivery may already be overstretched. ART programmes therefore need to seek partnerships with organizations, governmental and non-governmental, with experiences and comparative advantages in the provision of social protection (Pronyk et al. 2005).

Development agencies must ask what are the long-term obligations to people supported on ART in resource-poor settings? Will ART be guaranteed for life for the lucky minority who have gained access, regardless of the increased cost of different treatment regimens required if resistance develops? And should the boundaries of donor commitments be extended to economic and social interventions that are needed to support people’s efforts to normalize HIV as a manageable chronic condition, for example programmes that enable people to build assets, get enough food and clean water, pay for transport to clinics for drug re-supplies, and access advice and counselling? And will these commitments be extended to the even larger number of people without ART access?

ART has brought many people like Awino ‘back from the dead’. This is obviously positive in terms of their health and well-being and their ability to be active and work again. ART programmes might set targets that go beyond medical variables and monitor the proportion of clients who successfully return to their activities or work. This is because the sustainability of ART success in the long term depends on a broader vision that supports not only medicine, but also the rebuilding of lives and livelihoods. In the rush to scale-up ART delivery and achieve international development targets such as the Millennium Development Goals, there is a danger we may start to narrow the definition of ‘health’ to medication, forgetting broader notions of well-being. Have we initiated commitments which we have no long-term plan to meet, and are we creating a situation in which unmet expectations will shatter the fragile hope that ART has restored? The time has come for us to define a collective, long-term vision for the provision of ART.

**Ethical issues**

The ideas in this commentary paper are drawn from the authors’ wider experience and learning from the Home-Based Care Programme (HBAC) in Eastern Uganda funded by the Centers for Disease Control and Prevention (CDC). These ideas formed the basis for the design of a sub-study of the HBAC programme to explore the way people adjust to life on ART and live with HIV as a chronic illness in a context of rural poverty. That sub-study began in 2005 and is ongoing. Ethical approval was obtained for the research from the IRB of CDC, Atlanta, USA, and the Science and Ethics Committee of the Ugandan Virus Research Institute, Entebbe, Uganda.

The person case study of Awino presented in this paper is a fictional character used for illustrative purposes. The experiences and characteristics of this fictional character are a typical reflection of those encountered in the research currently being undertaken in Uganda.

**References**


