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# The transition to living with HIV as a chronic condition: Working to create order and control on anti-retroviral therapy

Steven Russell & Janet Seeley

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## DEV Working Paper 18

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## Abstract

This paper analyses the productive activities of people living with HIV following their uptake of antiretroviral therapy (ART) in rural Uganda. It presents findings from qualitative longitudinal research with participants in an ART delivery programme. The thematic analysis is not focused on the economic effects of ART for individuals and their households *per se*, but on how their work facilitated an adjustment or 'transition' to living with HIV as a chronic condition. The term transition refers to a person's movement towards incorporating a long-term illness, treatment regimen and its various ramifications into his or her life. This transition is achieved by people taking action and making changes in various aspects of their lives and through reflective and spiritual endeavours. The narratives of work and related activities are interpreted to be adaptive strategies to achieve this transition: 'quests' to create order, regain control and independence, and to feel 'normal' again. The paper seeks to build an understanding of the transition process to living with HIV as a chronic illness in a rural African setting. It also considers the factors enabling or hindering the transition process in a resource-limited setting, notably circumstances of poverty and vulnerability. Better understanding of this transition process, the adjustment challenges people face and the support they need, is important for the success of ART programmes, because people who adjust are more likely to be 'responsible patients' and sustain the management of their chronic condition.


# Introduction

## Rationale and scope of paper

In parts of Sub-Saharan Africa antiretroviral therapy (ART) is allowing practitioners and people living with HIV to treat HIV as a manageable chronic condition rather than a terminal illness. Despite this very positive development, ART means people living with HIV must make numerous changes in their lives as they move from a situation of sickness, near-death and perhaps social isolation (Robins, 2005) to a new chance of living with HIV as a chronic condition. Following the earlier disruption caused by HIV, ART represents a second phase of change which requires people to incorporate both the disease and the treatment regimen into their lives.

Adjustment to a new life on ART, however, still poses significant medical, economic and social challenges, especially in a setting of poverty and treatment insecurity (Rhodes et al., 2009; Russell et al., 2007). People must take a daily treatment regimen, for the rest of their lives, and with the uncertainties of side-effects, resistance and long term availability. Adjustment to living with HIV as a chronic illness also requires changes in

people's economic and social lives. The challenges of rebuilding a livelihood, relationships and hope devastated by HIV are considerable.

In this paper the term transition is used to refer to a person's adjustment or movement towards incorporating the illness into their lives, within themselves (self), in their identity and interactions with others, in their daily routines and their future outlook (Kralik, 2002). Transition as a part of chronic illness experience, and also adjustment to living with HIV on ART, have been the subject of sociological research in industrial countries (Kralik, 2002). However to date there has been little social scientific research on people living with HIV and their new lives on ART in sub-Saharan Africa, their adaptive strategies, and their transition to living with HIV as a chronic condition.

This paper seeks to contribute to conceptual and empirical understanding about the nature and features of this transition process in a rural African setting, and the factors enabling or hindering transition. It presents qualitative findings from interviews with participants on an ART project in rural Uganda (hereafter referred to as the participants). It focuses on their work to rebuild their livelihoods, and related social and spiritual activities that were important to their productive projects. The analytic focus is not on the economic effects of ART for participants and their households. Rather, narratives of work and resource mobilisation are interpreted to be adaptive strategies that facilitated a 'transition' to living with HIV as a chronic condition: they were people's 'quests' to create order, regain control and independence, and to feel 'normal' again.

This transition process is important for individuals and the success of ART programmes because incorporating the virus and the treatment regimen into life is essential for people's long term management of the disease (Kralik et al., 2004), and more specifically, adherence to ART (Nam et al., 2008). People need to be leading meaningful economic and social lives to go on adhering to ART. They need to live with as well as manage their chronic illness, and the management will be affected by that 'living with' (Strauss, 1990).

## Chronic illness experience: disruption, transition and transformation

Disruption, transition and transformation are broad concepts that feature strongly in people's narratives of chronic illness experience and management, identified by sociological research predominantly undertaken in industrial societies (Conrad, 1990; Kralik et al., 2004; Strauss, 1990). These overarching concepts informed the research in

rural Uganda. Following the onset of chronic illness people may undergo a disruption to their life and an 'extraordinary' phase of distress, fear and uncertainty (Kralik, 2002). Disruption can affect numerous aspects of life: daily routines, work and leisure, relationships and identity may all need to be rearranged and reworked (Pierret, 2007). Disruption is clearly pertinent to narratives of HIV experience, notably because of stigma, and, before ART was available, shattered hope and assumptions about one's future (Davies, 1997; Ezzy, 2000; Pierret, 2007; Robins, 2005).

Some people make a transition following a phase of disruption. Transition, also labelled 'adjustment', does not just happen with the passing of time. It is achieved by people taking action and making changes in various aspects of their lives and through reflective and spiritual endeavours (Kralik, 2002; Pierret, 2007), for example going back to work, joining a social group, finding faith or living by a new philosophy, becoming an activist, as well as smaller activities or routines. These actions have been termed 'adaptive coping' or 'self-management' strategies (Kralik et al., 2004; Schussler, 1992): they are the work people do to gain a sense of order following disruption, to regain control over decisions, to build independence and rebuild meaningful relationships. Some people may not manage to make a transition following disruption, due to difficult social and economic circumstances, lack of support, or psychological factors. Some of these factors are explored in this paper through participants' narratives. The movement from disruption to transition can also be a non-linear process. People's 'quests' towards order, control and normalcy falter and new challenges can upset the progress and balance achieved, causing a shift back to a state of disruption and extraordinariness (Kralik 2002; Kralik et al., 2004).

Transition for some can involve a significant change to values, identity and activities that can be described in stronger terms than a return to 'normal'. The incorporation of illness into life is a more radical adjustment that is transformative. The illness is perceived as an opportunity to learn and live a better life, with a new outlook and set of personal aims and rules, a new approach to work or social life, giving one's new condition and identity meaning (Pierret, 2007; Robins, 2005).

# Methodology

## Sampling and data collection

The study setting is an ART project in rural Uganda. Subsistence agriculture is the main livelihood activity in the area, and fishing and cross-border trade are other

important activities for some sectors of the population. The majority of people in the area have not received education beyond primary school level. Women, particularly those over 40, are less likely to have been to school than men. The ART participants on the project came from The AIDS Support Organisation (TASO), a large non-governmental organisation operating at national level that provides counselling and support services for people living with HIV.

The findings presented here are from qualitative research that explored participants' lives and activities following the introduction of ART. The aim of the study was to build empirical and conceptual understanding about people's adaptive strategies, their incorporation of the disease and the new treatment into their lives, and so the transition process to living with HIV as a chronic illness. The difficulties and challenges of achieving this transition in a setting of poverty, vulnerable livelihoods and gender inequality were explored.

In the first phase of research (2005) a small sample of 12 people, six women and six men, were purposefully selected to capture a range of age groups that was typical of all the people receiving ART on the project. These participants and their families were visited once a month over a 12 month period. On each visit a loosely-structured interview was conducted with the participant and observations were made. The first interview used a life history instrument to gather data on changes to people's lives since the illness began to disrupt their lives and following the start of ART.

In the second phase (2006) an additional 58 participants were purposefully selected to explore key themes further, using gender and age criteria to capture a wide range of experiences considered typical of all the people receiving ART in the project. (Table 1). These people were visited twice.

The interviews were carried out by a team of 10 people, six men and four women. All were fluent in at least one of the seven local languages and trained in counselling as well as social science research methods. The interviewers participated in discussions about the central concepts guiding the research, as well as training in qualitative research methods. They were involved in sample selection, stratifying the sample by age and purposively sampling participants to ensure that the sample was typical of participants on the project. All of the selected participants and adult family members provided informed consent. The study received ethical approval from the Uganda Virus Research Institute and the University of East Anglia.

**Table 1: Age, marital status and sex distribution of the study sample**

| | Female N (%) | Male N (%) | Total N (%) |
|---|---|---|---|
| **Age range** | | | |
| 30 and under | 1 (3) | 1 (3) | 2 (3) |
| 31-40 | 14 (39) | 9 (26) | 23 (33) |
| 41-50 | 11 (30) | 14 (41) | 24 (34) |
| 51-60 | 7 (20) | 9 (26) | 17 (24) |
| 61 and over | 3 (8) | 1 (3) | 4 (6) |
| **Marital status** | | | |
| Married/co-habiting | 0 | 1 (3) | 1 (1) |
| Divorced/separated | 3 (8) | 9 (26) | 12 (17) |
| Widowed/single | 33 (92) | 24 (76) | 57 (82) |
| **Total** | 36 (100) | 34 (100) | 70 (100) |

### Analysis

Interviewers took notes during the interviews and afterwards wrote these up as detailed transcripts in English. The interviews were analysed as hard copies and with word processing software. A grounded theoretical approach was used, beginning with an intense reading of the transcripts and a provisional coding of themes and sub-themes. Researchers referred back to the theoretical literature, and considered the emerging conceptual insights arising from the data. A list of main themes and sub-themes was finalised and these make up some of the results presented here. The analysis was also sensitive to narrative analysis approaches that have been used to explore people's experiences of illness (Davies, 1997; Ezzy, 1990), noting that the way participants constructed their accounts of the past and the present would reveal aspects of their adaptive coping and transition experiences, for example the meaning that they attached to work and their new chance at life.

## Results

### Antecedents to ART: Disruption, loss and early adjustment to living with HIV

The severe disruption and traumatic experiences caused by HIV and AIDS were the antecedents that heavily influenced people's subsequent processes of transition and

transformation on ART. Narratives revealed three broad phases of experience before ART. The first was characterised by loss and disruption, involving the unexplained illness and death of a child or partner, uncertainty and rumour about the cause of these deaths, a growing fear of HIV, and intensifying anxiety about the future. The participants had found the courage to go for an HIV test, and following the shattering effects of a positive result they had to deal with the unfolding difficulties of disclosure, fear of being ostracised and anxiety about their children's future.

The second phase was characterised by adjustment with struggles. The majority of participants managed to accept their HIV status and make some adjustments to living with HIV. The data revealed three important factors enabling and supporting this adjustment process. First, the emotional and physical resilience of the participants: all had summoned the courage to get tested, disclose their status and seek support and treatment. They were the determined and demonstrated an inner control that enabled adaptive coping rather than dysfunctional coping. Second, joining TASO was an important step that gave them access to vital emotional and psychological support, medical treatment and food rations, which enabled improved health and *recovery of hope*. Third, they received a great deal of support from a few key individuals, usually close family members, without whom they would not be here today.

The third phase of experience before ART was characterised by an intensification of struggles. As the disease had progressed most participants faced increasing disruption to their working and social lives, struggled to cope, and the challenge to sustain an identity or feelings of being 'ordinary' had become overwhelming. The following clinical and social processes intensified disruption (with a few exceptions):

- Serious illness: bed-ridden for extended periods
- Giving up hope: the loss of meaning to life
- Disruption and disorder: inability to work, to continue parenting, impoverishment
- Loss of control over decisions
- Increasing dependence on others for food and care
- Extraordinariness and prejudice: being labelled 'already dead', the break-down of relationships, isolation and a process of 'social death' (Robins, 2005).

## Coming back from the dead: health and hope as bases of transition

Recovery of health on ART had profound implications for participants' identity and their social and economic lives, and was a fundamental pre-requisite to the transition to living with HIV as a chronic illness. Recovery of mental competence was as important

as physical health because one could re-engage with friends and family as a normal person who was doing normal things. The recovery of a normal body image was important to self-esteem and social identity.

One group of participants stated that they had recovered full health, expressed as *feeling and living like a normal person, feeling like they do not have HIV* and *feeling strong and able to work hard*.

> "'I can even fight' she tells me, clenching her fist and demonstrating how strong she is now, 'I can dig until the end of the day'" (42 year old woman).

Others, a smaller group, had regained health but had not fully recovered. Despite adherence to treatment, they had persistent health problems such as numbness in the feet or body aches, and some had been slow to recover because they had been very sick when they had started ART. Not recovering full health did not necessarily prevent transition. Transition was a process whereby participants accepted and managed their health status, took their medicine, ate a healthy diet and monitored their health:

> 'She has one persistent complaint of numbness which started at the onset of her AIDS symptoms. This numbness of the feet and hands has persisted since she has been on ARVs but she said it is much reduced... She has learnt to live with it, saying: "I think this is part of the virus and since HIV has no cure I just have to live with this pain."' (45 year old woman).

Participants' children's HIV status was also an important factor affecting transition because this affected their outlook for the future. A child who was not HIV-positive had, in the eyes of the participant, a future, and gave the participant a reason and meaning to use this second chance and work, save and invest. This effect of children for participants was gendered. Women renewed their role of caring for children as before, but because the norm is for women to perform this role (with a few exceptions), men expressed the need to find another wife to look after my children.

In contrast when a child was HIV-positive their future was shrouded in doubt, they faced health problems, and an important source of hope was dashed, posing additional challenges or disruptions to participants' work towards transition. Gender relations and patrilineal systems of inheritance mediated these transition processes. If a woman's HIV-positive child was the only boy, and she and her late husband's family felt that there was little hope of the boy surviving, there was pressure to have another male child with a member of the late-husband's family to protect her and her daughter's ability to stay on the land.

To differing degrees the participants had moved from a situation of lost hope to renewed hope for life and the future. They could aspire to things which they had thought had no prospect. Hope was evidence of transition to living with HIV as a chronic condition and a good indicator of well-being. However, hope was not just an outcome indicator of well-being. It also drove efforts and investments towards the future:

> 'He has hope of a fairly long life now he is on ARVs. Before he was less confident about whatever he was doing and most of the time he thought that he was going to die. However when he started ART his feelings began changing and he began seeing things positively. Worries reduced and hope got restored. One can live positively when one has hope. It is not just the ARVs. Counselling support and health education from TASO and the ART project also helped to restore his hope' (44 year old man).

Uncertainty about the future could not be entirely dispelled. The prospect of mortality remained because participants were aware that ART did not work for everybody and they had seen others die. The balance between hope and uncertainty was also precarious in a setting where there was no long-term guarantee of treatment. This affected participants to different degrees and at different times. Long term access to ART was not a prominent anxiety in their busy daily lives or immediate thinking, and uncertainty was rarely voiced but sat in the background of the narratives, cropping up more explicitly on some occasions:

> "Yes, I have been told that I have the assurance of receiving drugs for another three years; but what will happen after that? We are told these drugs are very expensive, so won't we just die like chicken?" he asked (34 year old man).

Uncertainties about treatment security were projected to a distant future and did not appear to undermine participants' present transition. More prominent were uncertainties relating to poverty: the 'normal uncertainties' people experience in this context.

## Working hard: the quest for order, control and independence

The recovery of a future presented new challenges. The most important work to be done, for the majority of participants, was to deal with a devastated household economy. Men and women had embarked on a range of productive 'projects', as well

as social activities, and prominent narratives were about being very busy, digging again and working very hard. This hard work can be interpreted as an economic necessity in a setting of poverty where subsistence agriculture contributes to a large proportion of household food. Single parents, who made up a considerable proportion of the sample, had to work hard in their gardens to ensure that children were fed and could go to school.

These narratives, however, also revealed the importance of hard work for transition. Work was part of the quest to restore or create order and control in their lives. Being hyperactive, with numerous 'projects' on the go, was portrayed as a positive mode of living:

> "On Mondays and Fridays she goes to shop for her merchandise (second hand clothes)…on Wednesdays and Thursdays she takes her merchandise to the local market, a distance of about five kilometres from her home… Local market days start in the afternoon at about two o'clock…she goes after she has attended to her garden work, cooked and had lunch at home. Household work such as cooking and cleaning is mainly done by the participant and her sister in law... Other activities like fetching water and collecting firewood are done by the participant…For leisure, the participant said she has almost no time" (36 year old woman).

The planning of productive activities was another prominent theme. Like hard work this was an economic necessity, but narratives of constant planning revealed it to be another form of 'work' done to incorporate HIV into a new life on ART. Planning was a self-management process to take back control over decisions that affected them, to manage change and look to the future. Most planning focused on investing in agricultural and small business activities that would increase income and *enable investment in children's future* (education, land), revealing a future orientation which motivated participants' efforts to work hard in the present.

Being busy and working and planning hard was explained in terms of making the most of a new chance at life, the need to get things done while I am still here, and investing in a sound economic base for the children's future.

Routine also featured in participants' narratives, and was a portrayal of a recovery of stability and order, of predictability and control, following earlier disruptions to routines. Routines also represented living a normal life by normative standards: the different work, rest and play that men or women did or were expected to do. Most participants were keen to describe their productive and social routines in detail:

> "The participant begins his day at 5:30am in the morning with garden work up to 12:00 noon. He then takes his animals… to graze. He gets back home in the afternoon and in case there is no water he collects some water, cleans himself and then takes a rest. In the evening he takes a walk to the nearby trading centre to pass time with his friends…." (57 year old man).

Better health and returning to work meant all participants had improved their economic situation to different degrees. Common observations or themes about productive achievements were; the garden is well worked and tidy, crops are growing; the compound is neat and well-swept; the house has been rebuilt or repaired or newly plastered. Asset accumulation, especially the process of 'multiplying livestock' (breeding smaller animals and exchanging for a larger animal), was a common strategy of investment and improvement. Many men and women were running a small business or trade of some sort in addition to cultivation.

These economic achievements were important for household food security and poverty reduction. They also had important psychological, social and aesthetic dimensions that contributed to people's adjustment to living with HIV as a chronic illness. Being more independent or less dependent on others for support was a theme of men's and women's narratives, an important part of forging a new life on ART and the 'quest' for order and control:

> "He is able to wake up every morning and plan for the day's work and actually to him the days are very short because he is always preoccupied in productive work which was not the case in the past…He believes in struggling hard for the betterment of his life because he experiences a lot of comfort when he is able to plan and work for himself and his family" (35 year old man)

Achievements were a source of pride and self-esteem, they gave life more meaning and motivated participants to continue working to the future:

> "During the years she has been on ARVs she has had a lot of economic development. She has a piggery with eight piglets per season, she rears chicken and she is involved in agricultural activities...She has millet, maize and groundnuts almost ready for harvest, and the home is surrounded with fruits. Her mood is always high and she loves to show people her projects, she says: "I want to tell the whole world my experience, it may help other people who are still struggling". (55 year old woman).

Achievements were evidence for the participant, and demonstrated to others, that they had competence again and could *work* like any other normal person. The appearance of a well-tended and successful garden, with crops in the field or laid out to dry in the compound, was a visible demonstration of a return to order, control and living by normative standards. The mud on participants' feet and shins and sweat on their faces from digging were common observations by interviewers as they arrived at participants' homes in the mid-morning. These scenes provided neighbours and the community with images of normalcy.

## Mobilising resources: taking action to achieve control

Taking action to mobilise resources, making the most of what was available, was another prominent theme of participants' quests to rebuild livelihoods and recreate order.

The material and emotional support provided by relatives and friends had been a critical factor in the survival of participants before ART, and continued to play an important role in many participants' lives. Resource mobilisation also involved an active engagement with civil society organisations. This process had started before ART when participants had joined TASO, post-test clubs and other community-based HIV support groups. Membership of these organisations enabled people to access emotional and psychological support, economic inputs such as credit, seeds and livestock, and spiritual strength. These resources were vital for motivating and enabling the rebuilding of economic livelihoods.

Women in particular had invested a lot of time with HIV support groups and other organisations, had built new relationships and transformed their social lives (see Seeley et al. 2009). Some had become social activists (see below). The depth and range of their networks had been increased:

> "She interacts with a lot more people, including friends, relatives, health providers, church members and fellow participants. Her husband used to refuse her permission to get involved in some community activities like women's groups that did savings and income generation" (35 year old woman)

Post-test clubs were the most frequently discussed source of support beyond the family. Participants were active in these small, local organisations, which were often supported by a larger organisation such as Plan International or TASO. Only a few participants appeared not to be attending a club. The clubs provide the opportunity to share

experiences, get encouragement to take medicine, and tackle challenges, and also offer tangible resources:

> "I joined in 2002…I started getting some help - soap, sometimes a kilo of beans and also just going and to chat with other people and sing, and dance; and hear other people's memories. I mean testimonies. You just come home cured instead of sitting here (*Said while chuckling*). And I also like going out to share – there are many people who are in sorrow like us…(59 year old woman).

Religiosity is widespread in this setting and churches and mosques are central organisations in people's lives, providing a social life and spiritual and social support. Faith itself, and the social networks of the church, were resources mobilised by participants that appeared to have played a profound role in their earlier resilience to disruption, and their determination in more recent efforts to incorporate the disease and its management into their new life. Faith provided reassurance, encouragement and strengthened their locus of control: the belief that the challenges ahead were surmountable if one took initiative and action. Faith therefore provided the energy for people's adaptive coping strategies:

> "He is a catholic by faith and socializes with his fellow Christians in the village and occasionally the religious leaders who support him…and that…encourages him to adhere to his ARV drugs" (35 year old man).

> (Participant had lost her husband and both her children) "At that time she felt increasingly troubled with thoughts about the loss of her two children. Whenever such thoughts came they would get stuck in her mind and make her depressed. So when a relative came and preached to her she got saved…She then accepted the Lord as her saviour and since then she has never had any worry that threatened her life as before. Salvation changed her life. She is never afraid of any situation." (50 year old woman).

Faith in god was also viewed to be a relationship with somebody who was part of a participant's social network, a contact with influence who could provide opportunities and make sure 'things work out':

> "She considers herself a very blessed person in the hands of god: "I have always been a lucky person in my life. Just when I think I have a very big challenge, an opportunity has always come my way". What does she think will happen to her when the project comes to an end? She is very optimistic another opportunity will come her way. God has always been good to her." (36 year old woman)

Participants referred to people who had rejected treatment on the grounds of their faith, who believed god rather than medication could heal them. The participants, however, were a group who had harnessed the energy of their faith alongside treatment. They knew the necessity of treatment for their survival, and attributed their better health to a combination of both ART and god. The two worked together: God had helped them find or be selected for the life-giving medicine: this was 'god's will' or "a blessing from god", and god had worked to keep them alive, working through the medicine.

## Transformation and empowerment

The profound disruption of HIV, followed by a new chance of life on ART, had for some of the participants motivated a transformation in their identity, priorities and social and economic activities. A common feature of men and women's narratives was a change in their identity within their community. The dramatic recovery of health and appearance, the accumulation of knowledge about HIV and ART, and links with organisations such as TASO meant that they had become or were perceived to be 'experts' in the community on HIV. People no longer shunned them: instead participants expressed that now they had recovered on ART, their experiences and knowledge had empowered them to become counsellors and advisors to family, friends and the wider community.

Social activism around HIV and AIDS was a transformation that had inspired and affected the lives of participants, especially women. Women played leadership roles in post-test clubs, other support or campaign groups, and local systems of collective work and savings. They worked hard for organisations doing community-outreach and HIV awareness campaigns. Women's stories of social activism revealed processes of empowerment: they had greater purpose and confidence in public activities, were involved in collective action to build HIV awareness and improve access to voluntary counselling and testing, and to push for change such as lobbying local government to provide more support. Through their organisations women had stronger links with social actors beyond their marriage and in-laws, and felt they had greater agency.

Men were members of community-based HIV organisations but fewer men were activists and fewer men's experiences could be described as transformative. Social activism as a part of transformation was a more prominent theme among women because HIV organisations gave women new opportunities to engage in civil society and the public sphere, opportunities that men had already had.

While all participants' economic situations had improved, HIV and ART had had transformative and empowering effects for many of the women's productive lives. Before the disruption of HIV many of the women had been less economically active and had relied on their husband and his family for resources. Membership of TASO and other organisations had enabled them to access livelihood inputs such as livestock, seeds and training, get involved in collective livelihood initiatives with other women, and to carry out their livelihood activities at home more independently:

> "Various organisations have played a prominent role in her life over the last 3-4 years. They have helped her along quite a bit…The Africa 2000 Network provides technical support in the area of agriculture, including the provision of improved varieties of crop seeds…and helped to set up 30 members in a "merry-go-round" system of agricultural activities based in each other's gardens: they would dig, sow, weed, and harvest depending on the work at hand" (59 year old woman)

Many widows on ART had become the household's main worker. They were digging again and often spending more time on agricultural activities, they were making more decisions about farming, and had achieved success. Others had also started businesses and discovered they were successful entrepreneurs. A process of empowerment was observable as women drew more resources from the public sphere, did new economic activities, and exerted greater agency in decision-making about work and use of its rewards:

> "Mary says she owned nothing then. Her husband would sell whatever he felt like selling. She had no say if he wanted to sell off livestock. It was not until she started living alone…The first goat she owned was given to her by the pastor. She together with her eldest son did casual labour from which money they bought another goat. From the sale of pancakes she also saved and bought a goat. These goats multiplied and she exchanged them for a cow. She now has 2 cows, a goat, 2 hens, a pig, 2 ducks and 5 ducklings" (36 year old woman)

Men's narratives gave less emphasis to this transformative effect of ART, for reasons similar to those noted above: men already held household positions of authority around production and the use of money. Men did have access to livelihood inputs through HIV-related organisations, but these were drawn on in attempt to restore their economic status and achievements, and were not transforming their identity or agency as productive workers. Men's narratives actually reported more frustration about the barriers to rebuilding their earlier economic status (see below).

## Transition dynamics and difficulties

Transition to living with HIV as a chronic illness was a difficult journey with ups and downs. There was a balance to be sustained between achieving a sense of order and a positive outlook, or falling back into a state of disorder and loss of hope. All participants encountered difficulties at times (this is why support was so important) but a few individuals struggled more than the others with their work towards transition. Their adjustment was more transient and susceptible to further disruption. Their narratives revealed that they felt less in control and were vulnerable to feelings of stress, uncertainty, isolation and a negative outlook. Processes underlying these 'transition dynamics' were clearly complex, related to psycho-social factors and emotional well-being, but here some more observable factors are examined: ill-health and the difficult economic circumstances of poverty and vulnerability that could undermine transition.

A specific vulnerability for some participants was their HIV status which had caused long-lasting ill-health or reduced their strength. Illness episodes could undermine self-management because they were disruptions that could trigger economic difficulties, a feeling of loss of control, a return to dependency on others, and increased uncertainty about the future. Children's ill-health, if serious, had a similar effect:

> "In the fifth month of the study she had been very ill with malaria. She had collapsed and had been helped to hospital. After discharge she remained weak and so could not do much agricultural work…ill-health was compounded by economic problems (lack of food) which contributed to her mood swings. She was doing subsistence agriculture, had a business, and was slowly improving her livelihood, but illness and drought undermined her investments and efforts" (40 year old woman).

As in many parts of rural Uganda poverty, lack of assets and vulnerability are widespread, and despite participants' access to land for cultivation and hard work in most cases, the majority had limited financial assets and income poverty persisted. Women were more asset vulnerable than men, especially with respect to accessing land, because patrilineal systems privilege men's ownership rights. Often widows' continued access to their husband's land was dependent on the goodwill of the husband's family and some participants recalled how their in-laws had tried and sometimes succeeded in removing them.

Lack of financial capital was a prominent theme, and men expressed more strongly than women the expectation or need to restore previous economic achievements and status.

This constraint had thwarted their plans and hopes to invest in farming or a business in order to rebuild their livelihoods following the earlier devastation caused by HIV.

> "He says there is nowhere he can see finances coming to him to revive meaningful agriculture…That is the reason his children spend time at his brother's homes, so they can get something to eat each day. The important change he has experienced recently is the improvement of his health. Nevertheless, he sees agriculture as his mainstay…He also mentioned that he depends a lot on the goodwill of people around him, who know what he used to be like and understand what he has gone through…He has no hope of restarting (his productive activities) unless he gets assistance." (46 year old man)

Participants were exposed to economic shocks that affected all the community, such as the death of livestock and adverse weather conditions. During the course of the year a prolonged period without rain (early 2006) and hail storms had adversely affected harvests, livestock and also undermined small businesses that sold commodities such as vegetables and fish. These shocks disrupted progress in rebuilding livelihoods, demoralised participants after their investments, forced them to dig deep for more energy and motivation to cope, and so threatened transition.

Income poverty was a widespread difficulty, often a legacy of earlier impoverishment caused by HIV. Subsistence farming and revenue from selling agricultural commodities or a small business could meet basic food needs but not at all times, and could not cover additional expenses for items such as school fees or transport to health facilities. Despite their economic achievements, many participants' remained partly dependent on relatives or agencies such as TASO for food support. A degree of 'beneficiary dependency' on these rations was evident among some participants in 2006, when they expressed anxiety about TASO withdrawing the rations from those on ART:

> "She said her life depends so much on the TASO porridge that she wouldn't know what she would do if she became one of those not getting food. When she doesn't take that porridge, she doesn't feel normal". (36 year old woman).

A new life on ART had, in effect, returned participants to the normal worries and struggles of poverty and making a living in this resource-poor setting.

## Discussion

This research has revealed different dimensions of transition to living with HIV as a chronic illness in rural Africa, focusing on people's productive work and resource mobilisation as ways to create order and control. ART, and earlier interventions to deal with opportunistic infections, underpin these stories of rebuilding and hope. But these stories involve much more change than just clinical indicators of improved CD4 counts and reduced viral loads. As Robins' (2005) work on ART and social reintegration in South Africa has shown, ART has stimulated people to take action, make changes in their lives and render new identities meaningful, in turn influencing changes in the wider community. These social and economic changes are not simply an 'outcome': they are also an 'input' into the success of ART programmes, changes that are necessary if ART is to 'make sense' for people in the long-run. Our study reveals that people's work and resource mobilisations were part of a 'quest' to regain order, control, independence and normalcy, following a period of disruption, disorder and extraordinariness (Kralik, 2002; Robins, 2005). People need to pursue meaningful economic and social lives if they are to incorporate HIV as a long-term chronic condition into their lives and adhere to treatment.

## The nature of transition

Transition experiences were complex, but several themes of transition identified by the narratives resemble features of transition found in industrial settings (Kralik, et al., 2004; Meleis et al., 2000). First, social actors were actively engaged in self-management and transition, working hard, planning hard, making links with groups and mobilising resources. Second, making changes - to priorities, one's outlook or activities - was important for transition. Change was not just necessary to help participants incorporate the daily treatment into their lives, but also the challenges of a new life with new plans. Third, transition was a non-linear process with difficulties that could precipitate a fall back to a sense of disruption, disorder or loss of control. Kralik (2002) has demonstrated this non-linearity of the transition process in industrial settings, and in the study setting economic difficulties were a notable cause of renewed disruption to transition.

In this resource-poor setting, renewed hope for the future was mixed with a degree of uncertainty, based on an understanding that access to ART was not guaranteed, an experience found elsewhere in settings of treatment insecurity (Rhodes et al., 2009). Consequently transition for participants was characterised by a mixed time orientation, combining what Davies (1997) calls "living with a philosophy of the present" (working hard now because of uncertainty about one's future) and "living in the future" (a more positive future time orientation, here derived from renewed health and hope).

Transition and transformation in individuals' lives had contributed to wider social processes. The earlier disruption of HIV, followed by a literal 'coming back from the dead' on ART, had led to a new social activism, people advising on HIV in their communities, and processes of empowerment (especially for women). A trajectory of intensifying stigma which had accompanied disease progression (Alonzo & Reynolds, 1995) had been halted and new positive identities were being formed in communities. This 'reincorporation' into the social world following a social death, with a new public status as an expert and adviser, is a transformative social process documented elsewhere (Robins, 2005).

Finally, the research also shows that transition can be conceptualised as the achievement of a set of functionings (Sen, 1999), the 'doings' and 'beings' central to quality of life and removal of deprivation. Improved health, when combined with meaningful social and economic lives, enabled participants to move from negative to positive functionings that constituted transition: health and hope (from sickness and despair); a sense of order (from disorder); control (from loss of control); independence (from dependence); normalcy and living by normative standards (from extraordinariness).

## Factors affecting transition

As other studies have shown, social and health system contexts mediated participants' adaptive strategies and transition processes (Pierret, 2007; Robins, 2005). Poverty and gender relations for example, were important structural contexts influencing people's ownership or access to resources and support systems. State provision was limited, but other resources came to the fore in this setting from close family and relatives, from community-based and non-governmental organisations, and the church. Without these support structures participants would have struggled to re-build their economic lives. The combined effects of these support systems were complex and synergistic: economic inputs could lead to achievements and increased self-esteem; emotional support enabled people to start working and take control again.

Locus of control is an inner and intangible resource that has perhaps been neglected by research on poverty or health in the South, but might be usefully applied here to understand participants' coping with the disruption of HIV and transitions (Schussler, 1992). A person with an inner or high locus of control sees the world and events around them as understandable, manageable and worth tackling. When an event such as the onset of illness occurs, it is seen a challenge that can be met using the resources

available, and there is a motivation and belief that these actions will be successful. In contrast people with an external locus of control conceptualise an illness as a challenge that cannot be overcome, and so not worth making commitments or efforts to cope. They are more likely to adopt maladaptive strategies, such as a denial, blaming oneself, loss of hope and giving up treatment (Schussler 1992). This exploratory study suggests that locus of control was an important 'resource' that had driven participants' early acceptance of HIV, and their work and determination to build a new life, and so affected their management of HIV and their desire to adhere to ART. Even before ART was made available the vast majority had made the first transition of accepting their HIV status: they had overcome immense fear and other barriers to seek a test, they had joined TASO, taken action to get treatment and unless they had become very sick they had continued to work for themselves and their children as best they could. They called themselves the survivors, and many had shown a determination to keep going. Support from TASO and close relatives, emotional, psychological and material, obviously played a crucial role in this first transition, but they had taken action to mobilise these resources. And only through their positive decision to join TASO were they given access to ART. Their access to ART, and their recovery of health, strengthened their determination, optimism and patience, and the sense that if one keeps working to stay well and meet challenges, something better will always come one's way. The sample is therefore unlikely to be representative of all those who have had HIV in this setting, because many do not go for a test, access treatment or survive.

Support structures and locus of control are likely to be inter-related: people striving to meet challenges are more likely to mobilise resources from social relationships, to construct and use networks more effectively. The support received can then build self-confidence and inner strength.

## Policy

Transition to living with HIV as a chronic condition is important for people's long term management of the disease (Kralik et al., 2004). Practitioners therefore need to understand the social and economic lives of people living on ART, their quests for order and control, the transition challenges that they face and the support that they need beyond medicine. With this support people can become active self-managers of their condition.

Counselling for participants on ART is clearly important for supporting adaptive coping strategies, and in resource limited settings should not be neglected (Meursing & Sibindi, 2000). Guidance and support must, however, take into account people's own

self-management perspectives and strategies, looking beyond the perspective of health professionals and simple adherence to medicine, to take into account patients' wider social and economic lives and the family and social contexts in which they are living with HIV (Kralik et al., 2004; Mitchell & Linsk, 2004). Guidance needs to take on board the meanings that people give to the work and changes they make to achieve control and order (Kralik et al., 2004). The study also showed that some people were struggling to cope, especially those with HIV-positive children and those in extreme poverty. ART programmes may therefore need to target certain categories of participant with additional counselling support.

Interventions to support participants' livelihood rebuilding strategies were also critically important measures in this setting for participants' adjustment to living with HIV on ART. As participants recovered their health they resumed the 'normal struggle' of poverty but faced particular hurdles: HIV had already caused catastrophic costs and impoverishment, and they had less capacity to cope with other shocks or rebuild their livelihoods, especially due to the loss of other adult family members. The study showed a remarkable range of livelihood support organisations for people living with HIV in this particular setting however, not everyone in need was reached by these interventions and better coordination might have provided consistent and fairer social protection coverage.

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