Beyond the Lazarus effect: Social impacts of antiretroviral treatment on patients' family members in western Uganda

Amy Kaler
University of Alberta
akaler@ualberta.ca[1]

Session 133: Contextual factors influencing HIV testing and treatment

XVI IUSSP International Population Conference

Marrakech, Morocco, September 2009

Introduction

Antiretroviral treatments (ARVs) have a reputation as miracle drugs, able to raise AIDS sufferers from death's door and set them back on the path to normal life. Slowly, these drugs are filtering across central and eastern Africa, as unit costs drop and the political will to expand treatment grows (driven in part by the remarkable recoveries of most people on treatment). In Uganda, the focus of this paper, 250 000 are currently on treatment, out of an HIV-positive population of approximately 2.4 million (WHO/UNAIDS 2008).

Most studies of ARV outcomes focus on individuals. In addition to clinical studies documenting the revival of the immune system, the impact of side effects from

---

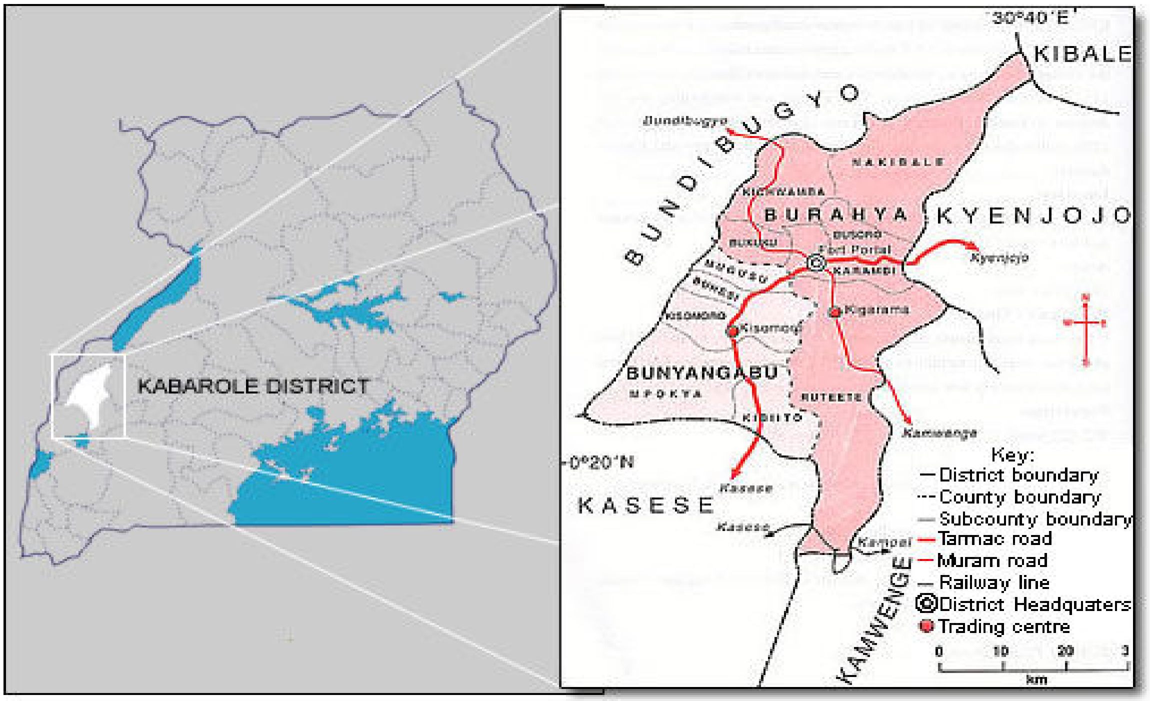
[1] A portion of this paper will be published in a different form as Amy Kaler, Arif Alibhai, Walter Kipp, Tom Rubaale and Joseph Konde-Lule (2010) " 'Living by the hoe' in the age of treatment: Perceptions of household well-being after antiretroviral treatment among family members of persons with AIDS". Forthcoming in *AIDS Care.*

the drugs, and the effects of different regimens, behavioral studies have focused primarily on adherence and on behavioral changes related to transmission of AIDS, such as sexual partnering and condom use. However, to date no one has examined the outcomes for the people who surround the one actually taking the pills – those who make up the webs of family, friends, neighbours and co-workers in which people with AIDS are embedded.

In this paper, we attempt to fill this gap. From a community-based treatment project in western Uganda, we use the accounts of people who share a home with a person receiving treatment to shed some light on what happens for the intimates of people on treatment. We focus primarily on livelihood issues here, and use subjective accounts of what treatment has meant for the household's well-being, rather than quantitative accounts of changes in production, consumption and transaction, studies of which will be forthcoming from economists associated with this project.

The programme

The data is drawn from a community-based antiretroviral distribution programme in Kabarole district, western Uganda (see map). AIDS prevalence in Kabarole is officially estimated at 11.6%, although local opinion holds that it is much more common (Kabarole District 2007; Bedingfield 2008).



The programme is part of the Ugandan government's ARV distribution network, and provides free treatment to 187 people with AIDS in rural districts west of Kabarole, using a network of health volunteers to liaise between recipients and medical staff. Every person on treatment must designate a "treatment partner (TP)" – someone who will monitor them swallowing their pills twice a day, and will sign their treatment card daily. Because of this requirement for daily monitoring, most clients chose someone they live with to be their TP; and these co-resident TPs are the source of the information presented here.

In medical terms, the programme has been extremely successful. Adherence was 97% (that is, 97% of all doses for all patients were taken as directed). Most notably, the mean CD-4 cell count (a measure of the strength of the immune system had risen from 134 at the initiation of treatment to 318, well above the clinical threshold for active AIDS, a CD4 count of 200 or less (Kipp et al. 2007). In addition, 90.2% of the patients had a viral load of less than 400 copies per milliliter of blood, effectively an undetectable viral load (Alibhai et al 2008). In this paper, however, we seek to go beyond the programme's success at the level of the individual body to inquire into what this has meant for the people connected to that individual in webs of affection and interdependence.

Methods

This study is based on interviews and surveys with TPs, whose clients had begun treatment between March 2006 and May 2007. All TPs were surveyed between September 2007 and May 2008, with the intent of surveying TPs roughly 14 months after their patient had begun treatment. This was not always possible, due to weather, logistical constraints and competing demands on interviewers' time. At the time of writing, 110 out of 136 coresident TPs had been surveyed. The survey instrument itself was developed from the results of an earlier round of surveys in 2006, which elucidated the broad domains of life which TPs said had been most affected by HIV in the household (Kaler 2008). These three domains – livelihood, psychosocial wellbeing, and household ecology – formed the basis of the current survey instrument. For this paper, we consider the results from the livelihood section.

Thirty-one TPs were chosen for extended qualitative interviews. They were chosen by the first author from a list of all coresident TPs, initially by choosing every sixth name, and then by adding and substituting additional TPs to ensure that the interview sample approximated the survey population as closely as possible. The interviews were conducted in March and April 2008 in TPs' homes by two experienced female interviewers, carried out in either Rutooro or Rukiga, depending on the TP's preference, and taped, translated and transcribed in Uganda. The first author was present for roughly a third of the interviews during March and April. The interview guide hewed closely to the topics covered by the survey, but was set up in an open-ended fashion, enabling the participants to expand, digress from, or substantiate their accounts of their experiences. Interview transcripts were analyzed in Canada by the first author, using N*Vivo software. This work was covered by ethics approval from the University of Alberta, the Uganda National Council for Science and Technology, and the Ethical review Committee of the School of Public Health, Makerere University, Uganda. The study was supported by funds from the Canadian Institutes of Health Research.

The survey population and the interview sample had a definite feminine skew, as 64% of the co-resident TPs were women. They had a variety of relationships to their patients, the most common of which were child TP/parent patient (generally child/mother) (39%) and spouse TP/spouse patient (25%), with the rest being siblings, aunts/uncles and in-laws. Almost all the TPs had been caregivers for their patient during the worst days of AIDS sicknesses, so that "TP" and "caregiver" were virtually synonymous[2].

In the interviews, TPs discussed how they perceived changes in their households' means of obtaining and processing the resources needed to secure the continued viability

---

[2] Although almost all TPs had provided care to patients, they were not necessarily the only caregivers. As Bedingfield (2008) demonstrates, in Kabarole caregiving duties were often shared out among various family members, meaning that the impact of caregiving was also shared.

of the household, which we refer to as livelihood. They emphasized the increased need for cash (as distinct from resources obtained through subsistence farming, barter or other non-market activities), and concomitant shifts in forms of economic activities; the burden of health care costs for the afflicted individual, often necessitating the liquidation of household assets; the loss of labour; and the opportunity costs for caregivers. These themes are consistent with other longitudinal and cross-sectional studies of the household-level impacts of the AIDS epidemic in Kabarole district; in Uganda; and in the rest of southern and eastern Africa (e.g. Hosegood et al. 2007; Collins and Leibbrandt 2007; .Gregson et al 2007; Bachman and Booysen 2006; Bryceson and Fonseca 2006; Kipp et al 2006; Lawson, Mckay and Okidi 2006; Nkosi et al. 2006; Urdang 2006).

However, our discussion of livelihood change is limited in two significant ways. First, it treats the household as a homogenous unit with uniform needs and interests. This is the most common way of analyzing households in the social-scientific literature on AIDS, but as feminist critics and others have pointed out, it obscures the internal divisions and disparities within household.

Second, this discussion is based on subjective retrospective accounts, which may not map onto objective changes in livelihood. A second household survey, which attempts to quantify changes in livelihood at three-month intervals, in in process. However, subjective accounts are important as people’s motivations and decisions concerning treatment are influenced by what they believe themselves to have experienced, whether or not these experiences are verified by an outside surveyor.

Digging: “We live by the hoe”

TPs described a matrix of ways to secure resources for their households in which working for cash played a relatively small role; and subsistence farming a very large one[3]. Only three TPs said that they or their clients worked in the formal economy, two as elementary school teachers and one as a guide on a nature preserve; and in the survey, only 19% of TPs said that anyone in their household worked for money[4]. For the rest, the degree of involvement in cash transactions varied across households, and within individual households, the intensity of cash transactions varied across time.

The most common means of earning cash was hiring oneself out as a contract labourer on other household's fields (although this labour was sometimes compensated by payment in food or by sharecropping arrangements); and by selling surplus produce in the informal markets. Other less commonly mentioned activities included buying livestock for retail, selling secondhand clothes, and retailing firewood, also in the informal markets[5]. These selling activities fluctuated according to the season, the stage in the agricultural cycle, the availability of money to use to purchase goats, firewood or clothes up front, and the time availability and stamina of family members to spend the day in the market. Several TPs said they had family members, most often children, who worked in the cities, usually in the informal sector, but remittances were sporadic, usually in response to a direct request for help, and were not reliable sources of income. Only 9%

---

[3] This situation differs from that in other AIDS-hit areas, where a much greater proportion of the population depends on either regular wage income or on income replacement, such as government support (e.g. Collins and Leibbrandt 2007).

[4] This dependency on farming is consistent with Bridge wt al. (2006) survey of AIDS-afflicted and non-afflicted families in the same district, in which 85% of participants were classified as subsistence or "low-level" farmers, who "occasionally [sold] agricultural products on the market" (621).

[5] Interestingly, although other studies of rural Ugandan life (e.g. Shinyekwa and Bird 2002) have identified beer-brewing and home distillation of *waragi*, a cane or molasses-based drink, as an important source of income for poor people, especially widows and those who do not have access to sufficient land, none of the TPs mentioned brewing. It is not clear whether this is because brewing is a stigmatized activity, or whether brewing is less common in this district than in others.

of survey respondents said that friends or relatives assisted them financially, but many TPs described non-monetary assistance, such as help with fetching water, escorting the sick household member to the hospital, or contributing beans and bananas from their own gardens.

Given the unpredictability of cash income, discussions of livelihood were dominated by "digging" – the planting, hoeing, weeding and other tasks necessary for subsistence farmers. In the survey, 77% of respondents said they grew "all" or "more than half" of the food they ate. When asked how their households obtained money for the necessities which they could not produce themselves, 87% of respondents said they sold crops. In such circumstances, a household member's ability to dig could mean the difference between hunger and survival. "We live by the hoe", said one TP, and the importance of farm labour cannot be overstated.

"Digging" even functioned as an index of sickness – TPs described a client as sick to the extent that he or she could not dig, and healthy to the extent that he or she was able to work in the garden once again. For instance, one woman described the degree of her client's sickness in terms of digging:

> I: When she started getting sick, that time she was sick, was she very sick?
>
> R: No. … She didn't get very sick, you could say not very sick, she would get her hoe and go to dig. She was still digging, and you could not recognize that she has this disease.

Digging and loss of labour from AIDS

The ability to dig dwindled as the client became gradually weaker with AIDS. This loss of labour was the single biggest crisis for families with someone on treatment. Their reduced ability to produce food for consumption or for sale, coming as it did at the same time as increased needs for money and for caregiving time resulted in a downward spiral of impoverishment for many, though not all, families. Some household could compensate by hiring labour or renting out their land to others and using the rent to purchase food, but most lived too close to the margin of survival to use these strategies, and instead saw their land “return to bush” for lack of labour, as one respondent put it.

One child described the reduction in labour power in his household when his mother was sick:

> I: When your mother got sick, did farming in your home reduce?
>
> R: Yes.
>
> I: How did it reduce?
>
> R: It reduced because for her she is the one who would be digging at the gardens all day for us. When she got sick, some work would be left undone. Now it was us [children] who would dig a little bit when we came back from school in the evening. So a whole portion [of the garden] was left because we would come to dig a small portion like this and for a little time, [then] it became dark and we would leave. The gardens became small, and we got little for eating.

Selling: “We get some small money somehow”

AIDS also affected livelihoods in ways beyond digging, notably by shifting the ways that families earned cash. For families who had money-making assets to earn money, AIDS might force the disposal of these assets. For instance, one man who had made a living by buying cattle, butchering them and selling the meat lost the strength to manage the cattle herd, and sold off all the cows. Another TP had to downgrade her family's nutritional status by selling the bananas she grew rather than taking them home to eat:

> R: I would only grow a few things like beans to eat, but I would not dig a big garden. I could not manage alone that time [when her husband was sick] because I was also pregnant. If there were bananas, I would forego eating them and sell them to meet our needs …
>
> I: You said you sold the bananas, did you sometimes not eat because you had sold the bananas for money?
>
> R: [Laughs] No … maybe I would sell the banana and buy something else like posho [maize meal] and use the other money to buy for the client what he wanted, so we did not have to look to some other person to help us.

Despite the battering that household livelihoods took as a result of AIDS, TPs said that they and their families did not go entirely without food. They could not buy luxury items such as sugar, and had to switch to lower-quality and less desirable staples (for instance, switching from plantain porridge to millet), but perhaps due to the great fertility of the local soil, severe hunger was kept at bay[6]. These accounts are consistent with Bridge et al (2006), who studied children's diets in the same district, and found that children in AIDS-afflicted households were no more likely to experience malnutrition than children in non-afflicted households (although they were more likely to consume low-quality starches).

TPs and antiretrovirals

As clients began treatment on antiretrovirals, the livelihood practices of their households began to shift. While clients experienced a limited increase in their own ability to work, TPs experienced a more dramatic revival of labour power. Clients recovered gradually and, as discussed below, often did not appear to have gotten back their full strength at the time of the interview, but for TPs, the changes in terms of their own availability for labour and their household's expenditure patterns was dramatic.

Almost all TPs reported that during their clients' illness, much of their time was diverted into caregiving during the client's illness, exacting a very large opportunity cost in time foregone from productive activities. Households lost the productive labour of two workers – the sick person and the one who gave care to him or her.

> R: I had to forego many activities – for example I could not leave the client alone in the house to go out and weed the beans. I had to leave [the beans]. I would

---

[6] However, Barnett and Blaikie (2006:204) note that retrospective account of the impoverishing effects of AIDS are likely to understate the true extent of household immiseration. They point out that the worst-hit households are likely to disperse, disintegrate or simply disappear at the lowest points of their crises, and thus are not around to talk about their experiences later. We do not know the extent to which this happened in this particular site, but certainly interview participants did describe "closed houses", from which all family members had disappeared, and lineages which had been completely annihilated by AIDS.

> think what if I left and maybe he needed some water, who could he send [to fetch water]? So I stayed home.

One woman who sold produce in the informal market said that her selling was constantly interrupted by medical crises:

> We used a lot of money. Sometimes I would be in the market and I hear people calling to me, “Eh, go and find your client [who has been taken to] the hospital”. And if you had a little money [for hospital costs] you would take it to the hospital, there was no peace. We [went] to the hospital every day, it was like our home... I used to dig far away, and whenever I saw someone coming I would know they [were coming to] collect me [because the client was in the hospital], but now we are okay.

For children, the opportunity costs of caregiving took the form of missing school. Even when AIDS-affected households were able to pay school fees, the need to look after an ailing parent meant that some children had to drop out. According to one child who had both parents sick at the same time

> Whenever they were sick there was no one at home to take care of them, so I would miss school taking care of them. And sometimes I would be with either Mummy or Daddy in the hospital, and all this while school was going on, so I could not perform well [at school]. … My sister, she also used to miss [school] –

> we took turns, sometimes she would stay home to take care of Mummy and I would then go to school.

However, TPs said that their own productive ability rebounded to pre-sickness levels once the clients were stabilized on drugs. As one woman said

> We are all okay at home now because I can now go and dig peacefully and do my other activities when I am not worried about my client. But before, when she was sick and when she started on drugs, I could not do any work. Now I can work and get enough food for home consumption [and] I am able to raise some money for school fees.

In addition, TPs' mobility also increased once clients began to regain their health. Instead of being tethered to the homestead or the hospital, TPs could now move around, whether to dig, to find markets for their produce, or to work in other ways. Mobility was also facilitated by the release of money which had been used to take the client to and from hospitals and clinics and which could now be used to transport other members of the family. This meant that TPs get involved with social networks and organized activities such as church which, though not directly implicated in livelihood, enabled them to accumulate forge the social bonds which could be drawn on in later times of need.

Expenditures and antiretrovirals

For most households, the arrival of full AIDS had precipitated a scramble to secure enough money to feed, transport the client. Households were pushed further into a cash economy, in which subsistence farming was not enough to meet their new needs. Compared to pre-illness household expenditures, episodes of illness precipitated an increase in expenditure and consumption[7].

Several TPs described a cycle by which clients would go to hospital, get marginally healthier, return home, and then need to go back to the hospital only weeks later. This meant that in addition to hospital costs, households also incurred repeated transport expenses, especially if the client was too sick to travel alone. One TP described the endless search for treatments for her husband's opportunistic illnesses:

> We first went to that hospital over there, and I think there we spent around 100 000 shillings, they gave him injections, but [his health did not improve]. Then they told us that he has typhoid, he took the pills, but no improvement. So we went to the herbalist, and even there things did not work out, but he went there and we paid a lot of money, buying litres of herbal medicine in bottles and jerry-cans. … Then Rwimi, even there we paid them money, we had a goat and we sold it for his treatment. But he went there just one day. And we paid money there, and that is when we decided to go to Fort Portal.

Several respondents said that they spent most of their money before they knew their clients had AIDS, when they still had hopes that the illness was something that could be

---

[7] This apparent rise in expenditures differs from the impact of illness episodes in contexts where pre-illness expenditures are higher than in rural Kabarole, so that AIDS brings on a net decrease in expenditure (e.g. Bachman and Booysen 2006).

cured by conventional treatment, if they could only find the right doctor and medicine. As one woman said

> We spent a lot of money because we didn't know what the problem was, so when he became sick we ran to clinics treating the disease. We didn't know [that it was AIDS]. We went to Kabarole, to Virika – we didn't know what he was suffering from, and he couldn't get cured, so we had a lot of expenses.

Households found the funds in various ways. One man had saved up two hundred thirty thousand shillings to buy furniture with, but spent only thirty thousand on a mattress and used up the rest on his wife's treatment. Another man sold his land for three hundred thousand shillings, then used up all that money on his grandson's treatment and had to be bailed out by his own children. Selling land, however, was a last resort, and more respondents talked of selling off sheep, pigs and goats instead.

Treatment meant that money could be re-diverted back into household costs, rather than spent on a single individual. It also meant that getting money no longer needed to be prioritized over all other productive activities, so that food could be eaten by the family rather than sold. TPs linked treatment to the ability to replenish assets, especially livestock. Among those who had sold land, however, no such optimism was expressed that they would be able to reclaim the lost farm plots and move out of the ranks of renters[8].

---

[8] Kabarole district has also had one of the highest population growth rates in Uganda since the 1970s (Mulley and Unruh 2004:201). The current population density is greater than 60 people per square kilometer, above the average for Uganda (http://www.unep.org/depi/rainwater/Maps/Uganda_population.pdf). The inevitable consequence is an increasing scarcity of land.

One TP said that the savings from being on treatment enabled his mother to start up another business:

> Before [AIDS], when she had money she would buy some things for us, but when she started getting sick she would spend all her money on drugs, that is before she knew what she was sick with and before she started taking medication. … The drugs she is getting now, she is not buying them, and so she uses the money to buy other things … now she buys and trades goats, and takes them to the village and there they sell them for her. … It has helped us, after selling those goats she gets money and when I ask her for school fees she gives it to me and I go to school.

Another TP, whose patient was one of the few who had employment, said that savings from treatment managed to get their family back on the track of upward mobility.

> I: Do you think your family's standard of living will get better if he is recovered?
> R: Yes, because he has now managed to save part of his salary and he bought a plot of land because there were many problems [when] all the money was spent on sickness – he was always sick. [Now] he bought a plot of land and is now planning to build [a house]. At the moment we are just renting..

In addition to investments in future prosperity, the money saved could also be used for small purchases that improved morale for household members. One TP recounted that after her husband started on treatment, she was able to buy a new dress for the first time since he had become sick. Most poignantly, another TP indicated the wooden couch frame on which the interviewer and first author were sitting, and told us that this furniture had been purchased since her husband had started treatment, and that she was no longer ashamed to have visitors come to her house because she could now offer them a place to sit other than the floor

The limits of antiretrovirals

Antiretrovirals could restore strength and return labour power, but according to TPs, they could not always return household members to their former strength. One hand, TPs believed clients were better off. Sixty-four percent of survey respondents said that their clients' health was "much better" since treatment began, and 38% said their clients' health was "a little bit better". However, when asked to describe their client's state of health the last time they saw him or her (and given that TPs resided with their clients, they had seen the client on the same day as the survey), 59% said that their client either "did not feel well" or "was very sick"[9]. In interviews, this ambiguity was even more pronounced, as roughly half said that their clients experienced weakness and lack of strength which had not been present before they got sick.

Even though clients' health had improved, assets and finances which had been lost during the period of sickness were not so easy to reclaim. For instance, a former market trader had to revert to digging as the only means of subsistence:

---

[9] It should be noted, however, that ill-health is relatively common in Kabarole, where 24% reported that somebody in the households suffers from TB, AIDS/HIV, anaemia or chest diseases, or is disabled" (Ravnsborg et al. 2004:43).

> R: When she was still trading in the market [pre-AIDS] she had her money, she was getting everything that we needed and that she needed. But now she doesn't have the money to go back to trading, we are only depending on digging, which takes a long time to yield [a profit]. … Life has gone down, and even the weight she had before, it is not the same, she has lost weight … Now she doesn't have money for the things she used to sell in the market, she doesn't sell anymore.

Lack of cash for inputs also meant that farming did not rebound easily to pre-AIDS levels. This produced a vicious cycle – spending money on sickness meant that there was no money to buy seeds to grow crops to sell, which in turn meant that no money was earned from sales, so there would be no money to buy seeds the following year.

> R: Now we harvest very little food from the gardens [compared to] before. Even right now we have very few beans, we planted only half a kilogram. It is easy to grow maize because we have the seed, but beans and groundnut [seeds] are expensive. Right now we have planted two things, maize and beans, but little beans. We have no money to buy the seed for planting.

Other TPs said that they were having difficulty buying back assets that had been dispersed during the illness, and were resigned to a lower standard of living. One TP, for instance, asked the interviewer (rhetorically) whether she had seen any goats around the homestead on her last few visits - the goats had been sold during a crisis in the patient's illness, and were not likely to come back.

While 87% of survey respondents said the standard of living of their household at the time of the survey was "much better" or "a little better" than it had been at the time the client began treatment, in the interviews, TPs said that they had not regained their pre-AIDS standard of living because clients were not able to work as they had before they got sick. This loss of energy affected many different tasks:

> I: In general, the work she used to do before she got sick, is it the one that she still does now?
>
> R: It is what she still does, but less than before. … She used to dig, but now she cannot even lift a hoe [high], and also fetching water, she cannot hold any heavy things at all. She does tailoring, but now in one day she could make two clothes, when she could make ten clothes [in a day] before she got sick. … The land she grows her crops on is small. Like before [her sickness] she could rent two hectares, but because of the little strength and the lack of money, she rents perhaps half a hectare, and the things grown there will not be like before on two hectares.

TPs also said clients were husbanding their strength, fearful of overworking and relapsing into sickness. Combined with persistent weakness, this meant that households had not yet regained their full labour power. One man described this combination of factors affecting his wife's ability to dig:

> I: Did the drugs improve her health in any way?

> R: Yes, she is now strong. I don’t let her work so hard because of fearing she might fall sick again, so when she has some work digging I help her so we can finish easily and quickly. She can now dig, though not [for a long time] – before she was sick she would dig form morning until evening, now she digs from around eight o’clock in the morning to one o’clock in the afternoon.

In addition to bodily weakness, changes in the relations surrounding garden production also characterized the immediate post-treatment period. When patients were sick, their work was taken over (where possible) by other family members or by hired labour. For some, this meant that their authority over farming was also taken over by others. When patients began recovering, and started asserting themselves as the legitimate owners of certain plots or crops, tensions could surface. For instance, in one household, this patchwork of labour led to arguments over who the garden really belonged to.

> We one day picked a quarrel over the garden. First of all I was the one who had paid for digging the garden where we had planted maize and beans and by then I was sick. We agreed together that for her she will harvest maize and for me I will take beans because I was the one who had paid someone to dig the garden. But she refused and got annoyed with me because she wanted the whole garden to be hers. After the harvest, I told her to leave my garden.

Conclusions

In surveys, respondents overwhelmingly reported that they were happy their patient had gotten treatment, and that they were the better for it. Exactly how much better, however, is a tricky question. Certainly the dramatic returns to immunological health apparent in the clinical records of the project do not map directly onto returns to health in other areas.

Among survey respondents, 8% said their households' "difficulties in getting food and money to support [them]selves" had gotten "much better", while 51% said that these difficulties had gotten "a little bit better" since their client had gone on treatment, and 42% said their households' difficulties had remained the same or gotten "a little bit worse". This ambiguous perception of household well-being following treatment may solidify into a more definite sense of improvement as family members on treatment regain more of their health and strength. Alternately, it is possible that the ground that was lost during the period of sickness with AIDS is impossible to make up, even when household members are returned to health, money is no longer diverted to caring for the sick, and both patients and caregivers are freed to return to productive labour.

Treatment frees up time, labour and mobility for the all-important tasks of gardening, as well as secondary livelihood activities such as selling or hiring oneself out as a labourer. Treatment partners, almost all of them former caregivers, experienced the biggest change in time availability, while those actually on treatment were perceived as being still too debilitated to work as they had before they became sick. Given the time frame of this study, this perception of debility could be a transient phenomenon which will disappear as more time on treatment goes by, or it could be a permanent artifact of the "new normal" created by treatment. Households experienced difficulty returning to pre-AIDS standards of living, whether because the full labour power of the household had not been restored, or because the measures that had been taken to deal with the crisis phase of AIDS sickness, such as selling off land, were very difficult to undo. Nonetheless, the provision of treatment plugs the major hole through which money flowed out of the family, and into medical care and transport for the sick person, so that redirection of expenditure was now possible. Taken together, all these factors suggest a slow, and perhaps truncated, return to full productive capacity and to the higher standard of living that goes with the ability to produce for consumption and market.

The importance of agricultural labour as an index of health (or lack thereof) cannot be overstated. Even when the return to health and strength was only partial, the ability to work in the garden dominated discussion of the benefits of ARVs in the interviews. Focusing on this particular benefit may provide fodder for encouraging adherence to antiretrovirals, and for encouraging family and community support for the people taking them. Agricultural labour, both as an engine of household revitalization and as a strong selling point for the virtues of treatment, is at the heart of the success of antiretroviral programmes.

References

Alibhai, Arif. 2008. “Community-based versus hospital-based antiretroviral treatment in western Uganda”. Lecture presented at University of Alberta, January 2008.

Bachmann, M O; F Booysen. 2006. "Economic causes and effects of AIDS in South African households." *AIDS* 230:1861-1867.

Barnett, T; A Whiteside (2006) *AIDS in the twenty-First Century: Disease and Globalization*. New York: Palgrave

Baylies, Carolyn. 2002. "The impact of AIDS on rural households in Africa: A shock like any other?" *Development and Change* 33:611-632.

Bedingfield, N. 2008. “The impact of highly active antiretroviral therapy on patients and caregivers in western Uganda: A qualitative study”. MPH thesis, School of Public Health, University of Alberta

Bird, K; I Shinyekwa. 2006. "Multiple shocks and downward mobility: learning from the life histories of rural Ugandans." in *CPRC Working Papers*. Kampala, Uganda: Centre for Chronic Poverty Research, Makerere University.

Bridge, A; W Kipp, K Raine and J Konde-Lule. 2006. "Nutritional status and food consumption patterns of young children living in western Uganda." *East African medical journal* 83:619-625.

Bridge, A; W Kipp; G Jhangri; L Laing; J Konde-Lule. 2006. "Nutritional status of young children in AIDS-affected households and controls in Uganda." *American journalof tropical medicine and hygiene* 74:926-931.

Bryceson, Deborah Fahy; Jodie Fonseca. 2006. "Risking death for survival: peasant responses to hunger and HIV/AIDS in Malawi." *World Development* 34:1654-1666.

Collins, D. L., and M. Leibbrandt. 2007. "The financial impact of HIV/AIDS on poor households in South Africa." *AIDS* 21 Suppl 7:S75-81.

Gregson, S; P Mushati; C Nyamukapa. 2007. "Adult mortality and erosion of household viability in AIDS-afflicted towns, estates and villages in eastern Zimbabwe." *Journal of Acquired Immune Deficiency Studies* 44:188-195.

Johnson, Saul; Russell, Bev; Gill Schierhout; Malcolm Steniberg; Hall, Katherine; Morgan, Jonathan. 2002. "AIDS in the household." Pp. 203-216 in *South African Health Review 2002*, edited by Petrida Ijumba. Johannesburg: Health Systems Trust.

Kaler, Amy. 2008. “My Heart Settled in Its Right Place”: Psychosocial Dimensions of AIDS Treatment In Rural Ugandan Households: Some Preliminary Findings”. Lecture presented at University of Alberta, January 2008.

Kipp, Walter; Denis Tindyebwa; Ednah Karmagi; Tom Rubaale. 2006. "Family caregivers to AIDS patients: the role of gender in caregiver burden in Uganda." *Journal of International Women's Studies* 7:1-13.

Kipp, Walter; Ellen Banjenja; Ednah Karamagi; Denis Tindyebwa. 2007. "AIDS-related stigma: perceptions of family caregivers and health volutneers in western Uganda." *World Health and Population* 9:1-9.

Lawson, David. 2004. "The influence of ill health on chronic and transient poverty: evidence from Uganda." No. 37 in the series *Chronic Poverty Research Centre working papers*. Manchester: University of Manchester.

Lawson, David; McKay, Andy; Okidi, John. 2005. "Poverty persistence and transitions in Uganda: A combined qualitative and quantitative analysis." No. 33 in the series *Global Research Poverty Group*. Manchester: University of Manchester.

Collins, D. L., and M. Leibbrandt. 2007. "The financial impact of HIV/AIDS on poor households in South Africa." *AIDS* 21 Suppl 7:S75-81.

Mulley, Brad G and John D Unruh. 2004. "The role of off-farm employment in tropical forest conservation: labor, migration and smallholder attitudes towards land in western Uganda." *Journal of environmental management* 71:193-205.

Nkosi, T; W Kipp; L Laing; J Mill. 2006. "Family caregiving for AIDS patients in the Democratic Republic of Congo." *Healthcare quarterly* 9:94-101.

Ravnborg, HM; J Boesen, A M Sorenson; Z Akello; B Bashasha; M Kidoido; V Wabukawo. 2004. "Gendered district poverty profiles and poverty monitoring: Kabarole, Masaka, Pallisa, Rakai and Tororo Districts, Uganda." In the series *Danish Institute for International Studies Working Papers*. Copenhagen: Danish Institute for International Studies.

UNAIDS/WHO. 2008. *Epidemiological fact sheet on HIV and AIDS: Uganda*. http://www.who.int/globalatlas/predefinedReports/EFS2008/full/EFS2008_UG.pdf

Urdang, Stephanie. 2006. "The care economy: Gender and the silent AIDS crisis in southern Africa." *Journal of Southern African Studies* 32:165-177.