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"Living by the hoe" in the age of treatment: perceptions of household well-being after antiretroviral treatment among family members of persons with AIDS

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"Living by the hoe" in the age of treatment: perceptions of household well-being after antiretroviral treatment among family members of persons with AIDS

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This paper considers the effects of antiretroviral treatment on the households of person with AIDS in western Uganda. Interviews were carried out with 110 co-resident "treatment partners" of people receiving treatment. We discuss these family members' accounts of the impact of sickness, followed by treatment, on their household's livelihood, defined as the activities needed to obtain and process the resources required to sustain the households. The household's ability to muster labour for subsistence agriculture was of paramount concern when family members considered what treatment meant for the households. While they were very happy with the treatment, they said that households have not yet recovered from the shock of AIDS sicknesses.

Keywords: antiretroviral treatment; HIV/AIDS; Uganda; households; recovery

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Introduction

Antiretroviral (ARV) treatments for AIDS have a reputation as miracle drugs which raise people with AIDS from death's door and set them back on the path to a normal health and life. Slowly, these drugs are filtering across the worst-hit regions of the world, as unit costs continue to 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, 115,000 Ugandans are currently on treatment out of 350,000 HIV-positive Ugandans in need of treatment, and a total HIV-positive population of approximately 940,000 (UNAIDS/WHO, 2008).

Most studies of ARV treatment focus on individuals receiving drugs. In addition to clinical studies documenting the revival of the immune system, the impact of side effects from the drugs and the effects of different regimens, behavioural studies have focused primarily on adherence to the dosing regimen and on behavioural changes related to transmission of AIDS, such as sexual partnering practices and condom use. However, to date no one has examined the impact of these drugs on the people who surround the one actually taking the pills – the people 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 households. We focus primarily on livelihood questions – psychosocial and relation issues will be addressed in future papers – and use subjective accounts of what treatment has meant for the household's well-being, rather than objective, quantitative accounts of changes in production, consumption and transaction, studies of which will be forthcoming from economists associated with this treatment programme.

The programme

The data are from a community-based ARV distribution programme in Kabarole district, western Uganda. AIDS prevalence in Kabarole is officially estimated at 11.6%, although local opinion holds that it is much more common (Bedingfield, 2008). The programme is supported by the Ugandan government's ARV distribution network, and provides free treatment to 187 people with AIDS in rural districts west of Kabarole. Of particular salience to this paper, 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, the majority of people on treatment chose someone they live with to be their TP, and these co-resident TPs, rather than the patients themselves, are the source of the information presented here.

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In medical terms, the programme has been extremely successful. Adherence to the dosing regime was 97% (i.e., 97% of all doses for all patients were taken as directed). Most notably, the mean CD4 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, Banjenja, Karamagi, & Tindyebwa, 2007). In addition, 90.2% of the patients had a viral load of less than 400 copies per millilitre of blood, effectively an undetectable viral load (Alibhai, 2008). In this paper, we seek to go beyond 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. The survey component was carried out with all co-resident TPs of people who were receiving ARVs through the programme – that is, not the patients themselves, but their spouses, parents, children and siblings, who lived with the patient and who were directly affected by changes in household production and consumption resulting from AIDS in the family. The patients had begun treatment between March 2006 and May 2007, and their TPs were surveyed between August 2007 and August 2008, with the intent of surveying TPs roughly 14 months after their patient had begun treatment, in order to hold constant the duration of time on treatment at the time of the interview. This was not always possible, due to weather, logistical constraints and competing demands on interviewers' time. In total, 110 out of 136 co-resident TPs[1] had been surveyed, and 25 were unreachable, were no longer acting as TPs, or had left the programme.

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 2008 survey instrument. For this paper, we will consider the results only from the livelihood section.

Thirty interviewees were chosen by the first author from a list of all co-resident TPs, initially by choosing every sixth name, and then by adding and substituting additional TPs in order to ensure that the interview sample approximated the survey population as closely as possible, with respect to genders, ages and relationships to the client. The interviews were conducted in March and April 2008 in TPs' homes by two experienced female interviewers, 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 a more open-ended fashion, enabling the participants to expand, digress from, or substantiate their accounts of their experiences. Interview transcripts were analysed 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, Uganda and the Ethical Review Committee of the School of Public Health, Makerere University, Kampala, and 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, as were 62% of the clients (Alibhai, 2008). The TPs had many relationships to their patients, the most common of which were child TP/parent patient[2] (27%) and spouse TP/spouse patient (30%), with the rest being siblings, aunts/uncles and in-laws. It is noteworthy that the majority of TPs were describing situations in which the person with AIDS was someone on whom they were normatively expected to be dependent, such as a parent or a husband. Almost all the TPs had been caregivers for their patient during the worst days of AIDS sicknesses, to the extent that "TP" and "caregiver" were virtually synonymous.[3]

In this paper, we discuss how TPs perceived changes in their households' means of obtaining and processing the resources needed to secure the continued viability of the household, which we refer to as livelihood. They discuss how first AIDS, and then treatment, impacted household livelihoods, with emphasis on 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, including 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., Bachmann & Booysen, 2006; Baylies, 2002; Bryceson & Fonseca, 2006; Collins & Leibbrandt, 2007; Gregson, Mushati, & Nyamukapa, 2007; Hosegood et al., 2007; Johnson et al., 2002; Kipp, Tindyebwa, Karmagi, & Rubaale, 2006; Lawson, 2004;

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Lawson, Mckay, & Okidi, 2005; Nkosi, Kipp, & Laing, 2006; Urdang, 2006). In the interests of space, we will omit a full review of these studies, assuming that readers are familiar with the impoverishment and household destabilisation that attends the crises of AIDS sicknesses.

However, the existing literature on the household impact of AIDS does not describe what happens (or what household members perceive to be happening) when the afflicted household member is restored to a state of health, or near-health. The accounts here begin to fill that gap. This paper is not an authoritative, objective account of verifiable shifts in livelihood in the wake of first AIDS and then ARVs. However, it offers insight into how the family members perceive these shifts and how they understand the household-level implications of treatment.

This discussion 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 analysing households in the social-scientific literature on AIDS, but as feminist critics and others have pointed out, it obscures the internal disparities within household, particularly along lines of gender but also along lines of age and relational status. In further papers, we hope to seek out the internally differentiated consequences of ARV treatment for different household members.

Second, it 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, by counting assets and asking about expenditure and income of all sorts, is in progress. However, retrospective accounts are also important, as people's motivations and decisions concerning treatment are influenced by what they believe themselves to have experienced, whether these experiences can be verified by an "objective" observer or not. Public opinion on treatment is strongly influenced by what the intimates of those on treatment believe they have experienced.

Digging: "We live by the hoe"

In their interviews, 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.[4] In interviews, only three of the 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 25% of TPs said that anyone in their household worked for money.[5] For the rest, the degree of involvement in cash transactions varied across the sample of TPs, 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.[6] 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 from these family members were sporadic usually in response to a direct request for help with a specific expense and were not reliable sources of income. Only 9% of survey respondents said that friends or relatives assisted them financially, but in the interviews many TPs described non-monetary assistance from friends and neighbours during the period of sickness, 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, the interview discussions of livelihood were dominated by "digging" – the planting, hoeing, weeding and other tasks necessary for subsistence farmers to successfully cultivate bananas, beans, groundnuts, maize, avocados and other staples.[7] In the survey, 77% of respondents said they grew "all" or "most" of the food they ate. When asked how their households obtained money for the necessities which they could not produce, 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.

Ravnborg et al. (2004, p. 30) found that 51% of their sample of Kabarole households owned between 0.5 and 1 hectare of land, and 30% were effectively landless, and survived by renting land or various forms of sharecropper arrangements. These renting/sharecropping arrangements are regarded as stigmatising and as a source of poverty, according to Ravnborg et al.'s wealth ranking exercise, in which "having to work for others as a casual labourer was unanimously mentioned as an indicator of the lowest level of well-being" (p. 33). Although in the interviews many TPs mentioned hiring themselves out for this sort of work, only 2% said that they were employers of such casual labour, compared to 30% in Ravnborg et al.'s study, suggesting that AIDS-afflicted households are poorer than average.[8]

"Digging" even functioned as an index of health, eclipsing medical parameters such as CD4 counts or viral loads (even though conversations with TPs indicated that they were conversant with these medical concepts). In interviews and in the survey, a person was 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 graded her client's sickness in terms of digging:

> I [Interviewer]: When she started getting sick, that time she was sick, was she very sick?
>
> R [Respondent]: No.
>
> I: That time she started medication?
>
> R: 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.

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Digging and loss of labour from AIDS

The ability to dig dwindled as the client became gradually weaker with AIDS. TPs described this debility as a loss of strength, affecting the amount of time that a person could spend in the field. Those who were not bedridden would go to the field as usual in the mornings but, according to TPs, they would have to return to rest before noon, even as early as 9 or 10 in the morning. This loss of labour was the single biggest crisis for families with someone in the later stages of AIDS. Their reduced ability to produce food for consumption or for sale, coming as it did at the same time as increased need for money and for caregiving time resulted in a downward spiral of impoverishment for many, though not all, families. The speed and trajectory of the spiral varied according to various factors – the existence of assets which could be sold off to smooth new demands for cash, the presence of unutilised labour which could be harnessed to replace the sick person, or the accessibility, both financial and geographical, of medical resources to help with opportunistic infections. However, the most important element shaping this trajectory was the physical condition of the person with AIDS.

For households which were already extremely poor, such as those headed by women whose husbands had already died or deserted, there simply wasn't much further into poverty they could fall when AIDS hit. For other households, the way downwards could be measured incrementally, as was the case with one family in which one child was taken out of school each year, the area planted was gradually reduced year by year, and the household furniture was sold off piecemeal, so that the interview took place in the shell of what had once been a relatively prosperous rural home.[9]

Some households were able to compensate for the labour deficit 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, which could not be replaced by labour from other family members:

> I: When your mother got sick, did farming in your home reduce?
>
> R: Yes. 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.

A second factor complicating subsistence farming was the reduction or diversion of family finances as a consequence of AIDS. Several household did not own land but rented gardening plots, which had to be paid for in cash:

> I: Did you find difficulties in digging when your husband was sick?
>
> R: When he got sick, we could not dig.
>
> I: Why? Was it because he was the one who dug the most [before sickness]?
>
> R: Now you know this land is for renting, now if he does not get money and rent land somewhere, where would you dig?
>
> I: So you have to get money and rent land. Did you have any way of getting money and renting?
>
> R: No.

Selling: "We get some small money somehow"

AIDS also affected livelihoods in ways beyond digging, notably by shifting the ways that families earned

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cash. For families who had ongoing money-making assets, AIDS might force the disposal of these assets. For instance, one man with AIDS 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 at the live market. 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.

Another TP, who was himself on ARV treatment, had to switch out of small-scale trading in order to divert money to his and his wife's treatment:

> I: Now that time before your wife got sick and now, how is your trading faring?
>
> R: That is obvious, when one gets sick things have to change. Of course the things we were trading in reduced because we did not have strength and manpower to do it. When I was okay and could still do hard work with my wife helping me [we could trade] but when she got sick, I had to use all the money for her hospital and food.

As seen from the three examples above, AIDS did not affect households' involvement in market transactions in a straightforward linear fashion. Some families, such as the one in which the cattle were liquidated, had to withdraw from market transactions when they no longer had anything to sell, or when they could no longer afford the opportunity cost of time spent selling. Others, such as the one in which bananas were sold rather than eaten, intensified their involvement in markets exchanges in order to meet increased needs for money. In yet other cases, such as the quote directly above, the market activity continued, albeit on a reduced scale, but the money thereby earned was diverted.

Despite the battering that household livelihoods took as a result of AIDS, TPs said that they and their families did not go completely without food, even during the clients' health crises. They mentioned not having the means to buy luxury items such as sugar, or having 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, absolute hunger was kept at bay.[10] These accounts are consistent with Bridge, Kipp, Raine, and Konde-Lule (2006b), who found that children in AIDS-afflicted households in Kabarole were no more likely to experience malnutrition than children in non-afflicted households (although they were more likely to consume low-quality starches).

Treatment partners (TPs) and antiretrovirals (ARVs)

As clients began treatment on ARVs, the livelihood practices of their households began to shift, albeit slowly and only partially. The most immediate impact of treatment, interestingly, was felt by TPs, rather than by clients. 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 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 the form of time foregone from productive activities:

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

Another 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, every day to the hospital. 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.

TPs believed it was necessary to remain in close physical proximity to their clients, and as gardens were often located up to several hours' walk away this precluded intensive digging. Wealthier families could

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hire labour to replace the caregiver's time, but for most families, AIDS meant the loss of two workers, not one:

> R: For almost a month, I did not go to the garden – I stayed at home taking care of him, cooking and washing ...
>
> I: Were there any other activities you had to forego?
> R: Digging, grazing the cows, all of that [was very difficult for me]. All I did was wash, sweep and cook.

An elderly TP, caring for his grandson, said that he and his wife were unable to harvest any crops for several seasons because one of them always needed to be with their grandson, and that the family only survived because other relatives brought them food.

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:

> I was in Senior Four, but 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 who is in Primary Seven, 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 ability to work rebounded to pre-sickness levels once the clients were stabilised 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. As we will discuss in a later paper, increased mobility also meant that TPs could initiate and maintain involvement with social networks and organised activities, such as church, which, although not directly implicated in livelihood, enabled them to accumulate the social capital which could be drawn on in later times of need.

Expenditures and antiretrovirals (ARVs)

In addition to freeing up more household labour, ARV treatments also shifted expenditure patterns significantly. For most households, the arrival of severe symptoms of AIDS precipitated a scramble to secure enough money to feed, transport the client, such that existing sources of cash had to be diverted into client care, and new sources had to be created, whether by entering into new market activities, or, more frequently, by selling off assets. Households were thus pushed further into a cash economy, in which subsistence farming was not enough to meet their new needs. TPs cited transport, hospital care, medicines and special foods as the main expenditures when the client was severely debilitated. Compared to pre-illness household expenditures, episodes of illness appear to have precipitated an increase in expenditure and consumption.[11] The extent of these expenditures depended on the client's condition, so that households in which the client had been sick for years had experienced greater burdens then families in which the client's illness, though equally severe, had not persisted for as long.

Longer illnesses also meant more hospitalisations, and 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 had to incur 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:

> Mmm, I moved [around the district]. 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 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, as discussed above. One man described how he had saved up 230,000 shillings to buy furniture with, but spent only 30,000 on a mattress and used up the rest on his wife's treatment. Others used money which had been set aside for children's secondary school fees. Another man sold his land for 300,000 shillings, then used up all that money on his grandson's treatment and had to be bailed out by his own children. Yet another, who had been well-off before he developed AIDS, has gradually sold off the various properties he had rented out, until he along with his wife and children were left living in the last remaining property, a decrepit one-room unit in an overcrowded courtyard. Selling land and real property, however, was a last resort, and more respondents talked of selling off sheep, pigs and goats instead.[12]

The advent of 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 prioritised over all other productive activities, so that food could be eaten by the family rather than sold, as described in this study. TPs linked treatment to the ability to replenish assets, especially livestock. One talked of "the goats and pigs I sold to treat her" and expressed hope that "if we dig and harvest much, we can be able to buy them and have animals at home again". Another described the changes in his household after treatment as his children being able to keep, rather than sell, the goats and chickens. 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.[13]

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 ... Before she was trading in markets, but now she buys and trades goats, and takes them to the village and there they sell them for her, and in that way she gets money ... 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 the house we are living in.

In addition to major investments in future prosperity, such as land and school fees, the money saved could also be used for small purchases that improved morale and the quality of life for members of the households. Salt, sugar, soap and lotions were among these small but significant home comforts. 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 (ARVs)

ARVs have the potential to restore strength and return labour power, but according to TPs, they could not always restore household members to their former pre-AIDS strength. At first glance, TPs appeared to be confident that their clients had recovered. Fifty-nine percent of survey respondents said that their clients' health was "much better" since treatment began, and 37% 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 (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".[14] In interviews, this ambiguity was even more pronounced. Although all TPs were very happy with the ARV distribution programme, roughly half said that their clients experienced weakness and lack of strength which had not been present before they got sick.

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In addition to ambiguity about the physical state of their clients, TPs were also ambivalent about the state of their household livelihood. On one hand, survey respondents said that their clients were able to engage in a wide range of household activities which had been impossible when the client was sick. Eighteen percent said that their client had gone from being too sick to do any household work, including digging, meal preparation, housework, child care or obtaining money to being able to take part in at least some of these activities, and another 66% said their client had expanded the range of household activities that he or she was able to undertake.

On the other hand, although clients' health improved, assets and finances which had been lost during the period of sickness were not so easy to reclaim. For instance, another former market trader had to revert to digging as the only means of subsistence, according to her TP:

> 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 like I told you, 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] and ever since she stopped working in the market, even sugar has become scarce for us ... 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 saving money to buy 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 the interviewer's last few visits, since the client had begun treatment. The goats had been sold during a crisis in the patient's illness, and were not likely to come back. Land in particular was considered hard to regain, once it had been sold.

Participants reported that their households' ability to secure resources was still compromised, even after clients got better. 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.[15] One TP described this loss of energy as a global phenomenon, affecting many sources of livelihood:

> 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.

This persistent debility also affected households' ability to engage in market transactions, as they could no longer produce surpluses to sell, but only enough for their own consumption. One TP described her sister-in-law's nostalgia for the days when she could purchase luxury items like meat for her family:

> R: [Before she got sick] she would really dig [a great deal] and sell the produce from her own garden so that she is not in need of anything, she was self-reliant. But right now, she can be in need of something, but she doesn't have that money. Sometimes when she sees me going to the trading centre she says "I wish I had money, I would have sent you to buy me some meat there from the trading centre". You can see that she is in want which she never felt before when she was healthy and doing her own work, because [then] she could get money from the gardens she dug.

Household members also reported that 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:

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> 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.

Some TPs speculated that AIDS had damaged their clients' bodies in ways which could not be undone by ARVs (as distinct from the side effects of ARVs, which were rarely mentioned). While the drugs could control the more overt manifestations of AIDS, such as diarrhoea or rashes, they could not change the body in more fundamental ways:

> Before he became sick he had a good life, he did all his work properly, but when he became sick he became weak, his body changed and he stopped doing heavy work, he was always seated at home and he did not work at all ... Now that he is on drugs there is a difference from when he had not yet started on the treatment ... His body that had got spoilt [by AIDS], the rashes normalized and he regained strength to do some work, but for a short while. He doesn't spend a lot of time working.

In addition to bodily weakness, changes in the relations surrounding garden production also characterised 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, one TP, who became ill herself, at the same time that her patient became healthy enough to work in the garden, recounted that 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

The vast majority of respondents were extremely happy with the treatment programme, and their only concern was whether they could count on it to be sustained over the long term. They also 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 issue. 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 41% 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.

We have attempted to draw out some common themes in the slow changes to households subsequent to the end of the immediate AIDS crisis. 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. TPs, 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 had plugged 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 the ability to do 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 treatment in the interviews. Focusing on this particular benefit may provide fodder for encouraging adherence to ARVs, and for encouraging family and community support for the people taking them. Agricultural labour is both an engine of household revitalisation and a strong selling point for the virtues of treatment.

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Notes

1. The other TPs did not reside with the patients – they were usually neighbours or friends.
2. The great majority of these parents were mothers, especially mothers whose husbands or male partners had died or abandoned them, leaving the mother in charge of a single-parent household.
3. Although almost all TPs had provided care to patients, they were not necessarily the only caregivers. As Bedingfield (2008) demonstrates caregiving duties were often shared out among various family members, meaning that the impact of caregiving was also shared.
4. 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 & Leibbrandt, 2007).
5. This dependence on farming is consistent with Bridge et al.'s (2006a) 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" (p. 621).
6. Interestingly, although other studies of rural Ugandan life (e.g., Bird & Shinyekwa, 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 stigmatised activity, or whether brewing is less common in this district than in others.
7. As noted above, 25% of TPs said that someone in their household worked for money. Among the minority who did, the most frequent job description was "digging". The predominance of digging over other forms of labour was also remarked by Ravnborg et al. (2004, p. 47), who found that especially among the less wealthy households "only a minority are . . . engaged in non-agricultural income generating activities such as beer brewing, charcoal burning, brick-making, running businesses, etc.".
8. Ravnborg et al. (2004, p. 38) reported that 29% of their Kabarole sample hired labour for agricultural tasks.
9. At the time of the interview, all three children were back in school, although each of them was at least one year behind their former peers.
10. However, Barnett and Whiteside (2006, p. 204) note that retrospective accounts impoverishment will 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 Kabarole, but certainly interview participants described "closed houses", from which all family members had disappeared, and lineages which had been completely annihilated by AIDS.
11. This apparent rise in expenditures differs from the impact of illness episodes in contexts where pre-illness expenditures were generally higher than in rural Kabarole (owing to a larger amount of circulating cash in the community), so that AIDS brought on a net decrease in expenditure (e.g., Bachman & Booysen, 2006).
12. Although Ravnborg et al. (2004, p. 36) found that 30% of Kabarole households own cattle, none of the TPs mentioned them (we should explore this further with our staff in Ft. Portal), which may be an indicator of the relative poverty of AIDS-hit households.
13. Kabarole district has also had one of the highest population growth rates in Uganda since the 1970s (Mulley & Unruh, 2004, p. 201). The current population density is greater than 60 people per square kilometre, above the average for Uganda (http://www.unep.org/depi/rainwater/Maps/Uganda_population.pdf). The inevitable consequence is an increasing scarcity of land.
14. 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 (Ravnborg et al., 2004, p. 43).
15. These statements might be seen as reflecting a general nostalgia for the better days before AIDS hit the family, but respondents were quite specific about the parameters of decline. Rather than simply saying "My client is weaker than s/he used to be" or "we don't have as big a garden as we used to", TPs often gave specific comparative quantities, whether in terms of area planted "we used to cultivate two hectares but now we can only manage one" or time worked "s/he used to work until sunset, but now s/he has to stop at noon", suggesting that these declines were actually observed, and are not nostalgic artefacts.

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