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ARVs and cash too: caring and supporting people living with HIV/AIDS with the Malawi Social Cash Transfer

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Abstract

OBJECTIVES The Malawian Social Cash Transfer Scheme (SCT) is a social protection programme for ultra poor and labour-constrained households, including people living with HIV/AIDS (PLWHA). We aimed to gain insight into respondents' circumstances prior to becoming transfer beneficiaries and to examine how PLWHA used transfers to support themselves and their families.

METHODS We conducted 24 semi-structured qualitative interviews with PLWHA who were also SCT beneficiaries and living in villages where the scheme was operational in 2008.

RESULTS Respondents were destitute and lacked food and basic necessities prior to the transfer. As cash recipients, the majority of respondents reported positive impacts on health, food security and economic well-being as well as an improved ability to care for their families.

CONCLUSION Important unanswered programmatic questions persist, such as 'What is the appropriate transfer level?' And 'Should recipients graduate from the scheme?' Moreover, the scheme's long-term sustainability is still unclear. Nevertheless, this analysis presents evidence describing how PLWHA used cash transfers to improve their situation and mitigate the impact of HIV/AIDS on families.

keywords cash transfer, social protection, impact evaluation, economic situation, Africa

Introduction

Globally, an estimated 33 million people are living with HIV/AIDS (PLWHA) and 67% are living in sub-Saharan Africa (UNAIDS 2009). Malawi, one of the nine countries with the highest HIV prevalence rates clustered in Southern Africa, has a population of 13 million people (Government of Malawi 2008), a GDP of \$310 per capita (World Bank 2009), and an HIV adult prevalence rate of 11% (Joint United Nations Programme on HIV 2009). More than half of the Malawian patients in need of anti-retroviral treatment (ARV) receive it, resulting in a ten-fold increase in the number of PLWHA on treatment from 2004 to 2009 (Medecines San Frontieres 2010).

Still, many PLWHA in resource poor countries have additional needs, including economic support, complementary healthcare and improved nutrition (Topouzis 1999; UNAIDS 2006; Bukusubali *et al.* 2007). For example, according to international guidelines, PLWHA should increase energy intake by 10–30% over the requirement of non-HIV infected persons and meet standard protein and micronutrient requirements to increase drug efficacy and adherence, reduce negative side effects, slow disease progression, and limit further negative impacts of HIV on nutritional status (Castleman *et al.* 2003).

Many PLWHA experience financial constraints because of reduced household labour supply and increased demand for healthcare and nutrition (Barnett & Whiteside 2007; Adato & Bassett 2008). Family members of PLWHA may face negative impacts as the disease imposes an economic toll on families (Adato & Bassett 2008; Barnett & Whiteside 2007). Households cope by eating fewer preferred foods, cutting portions, skipping meals and selling assets (Adato & Bassett 2008; Barnett & Whiteside 2007). Poverty in the households of PLWHA has been linked to poor ARV adherence as the cost of travelling to clinics can be a barrier to treatment (Posse *et al.* 2008).

In response, one of the priority areas outlined in the UNAIDS Outcome Framework 2009–2011 is enhanced social protection for people affected by HIV to reduce the negative effects of HIV (UNAIDS 2010). Social protection is defined as a set of public measures that support society's poorest and most vulnerable members (Holzmann & Jorgensen 1999). The 'Social Protection Floor Initiative' is a policy concept developed to advocate for 'a basic set of rights and transfers that enables all members of a society to access a minimum of goods and services' (UNAIDS 2010; Holzmann & Jorgensen 1999). From policy to programme, cash schemes have emerged as a social protection strategy to support PLWHA because transfers

provide economic assistance when people are unable to work (UNAIDS 2006; International Labour Organization (ILO) 2009; Richter 2010; Handa & Webb 2008). Moreover, African governments, armed with evidence of transfer impacts from Latin America, are pursuing cash transfers because of a growing awareness that (i) traditional market-based interventions fail to reach the poorest households; (ii) governments have a duty to fulfil human rights; and (iii) social and economic development positively influences health.

Using an asset-based social protection framework Adato and Bassett (2008), describe how transfers can help secure basic consumption needs (i.e. food, medicine); reduce fluctuations in consumption which lead to harmful coping mechanisms; enable people to save, invest, and accumulate assets; and reduce access constraints to healthcare or other essential services. Despite the theoretical consensus around social protection for PLWHA, there is a dearth of empirical evidence demonstrating how social protection in the form of cash transfers supports people affected by HIV/AIDS. In this study, we examine how PLWHA use transfers to aid in the care and support of themselves and their families. This analysis is based on 24 qualitative interviews among PLWHA who were transfer beneficiaries in Mchinji, Malawi. We conducted interviews in November 2007 and asked respondents to describe their lives prior to and since receiving the transfer.

The Malawi social cash transfer

The Malawi Government acknowledges that the wider needs of PLWHA must be met and that poverty reduction and HIV/AIDS programming must be integrated (Government of Malawi Office of the President and Cabinet, National AIDS Commission 2005; Government of Malawi 2009). The National Social Support Policy calls for programmes to meet the economic and support needs of ultra poor and vulnerable populations. Thus, in 2006, the Social Cash Transfer Scheme was developed by the Malawi Government, in partnership with UNICEF, as an inclusive social protection tool, to reduce poverty and hunger in ultra poor and labour-constrained households, which often contain PLWHA (Schubert & Kambewa 2006).

The Social Cash Transfer Scheme (SCT) provides monthly income grants to the poorest 10% of households that are labour constrained and identified by Community Social Protection Committees (Schubert & Kambewa 2006; Miller *et al.* 2010a). Ultra poor households consume only one meal per day and own no valuable assets. Labour-constrained households have a chronically ill, elderly or a child head-of-household, and no other adults aged 19–64 who are fit for work, or have an unfavourable dependency

ratio of >3. The SCTS does not specifically target households affected by HIV/AIDS, but does include them. On average, beneficiaries receive MK 2000 (US\$ 14) per month depending on the household size and the number of school-aged children (an MK 200 top-up is paid for primary school-aged children and MK 400 for secondary school-aged youth).

The SCT is implemented at the district level. In 2011, the Malawi Government made an annual commitment of US\$ 4.6 million, and in 2010, the German Government committed US\$ 18.6 million to fund transfers through 2013. The scheme operates in 7 of 28 districts and reaches 24 306 households. At scale, the SCT would cover approximately 300 000 families or 10% of households and cost US\$68 million per year (Schubert & Kambewa 2006). One-third of these households contain a PLWHA.

Methods

Sample

This analysis is one part of a larger mixed-method evaluation of the cash transfer (Miller et al. 2010a,b). For this study, we conducted qualitative interviews with PLWHA in Mchinji District, where the SCT was first piloted in 2008. We asked local leaders to create a list of recipients who were PLWHA. Generally, in Mchinji, if a PWLHA receives ARVs, their HIV status is widely known. In fact, many transfer recipients were targeted by Community Social Protection Committees to receive the transfer because of their status and poverty level (Miller et al. 2010c). The sample generated by local leaders was small, comprised of several households per village. We made visits to all listed households in several villages and invited the household head to participate in an interview. There may have been additional PLWHA in the villages whose HIV status was unknown or were not receiving the transfer.

This study was approved by the Boston University Institutional Review Board and the Malawi National Health Research Council.

Qualitative interviews

We developed semi-structured questionnaires to understand how PLWHA use transfers. Research assistants were trained and participated in mock and pilot interviews, and reflective discussions. The field staff obtained informed consent and took handwritten notes of all interviews in Chichewa which were later transcribed into English. Field supervisors observed the interviewers and reviewed all Chichewa and English transcripts, verified translations and

obtained clarification as needed. The principal and co-investigator also reviewed transcripts.

Data analysis

Analysis consisted of reading and rereading qualitative transcripts. We conducted a content analysis and identified salient themes and patterns of ideas related to study topics. Next, we identified codes for categorizing data. The iterative categorization of codes allowed a rich and in-depth focus on specific concepts. We coded transcripts using NVIVO 9 software (NVIVO 2010). We identified deviations from common themes and explanations for atypical responses, as well as anecdotes that provided insight into the broader study questions. We assessed corroborating and divergent views between study participants until we categorized all relevant concepts.

Results

Study respondents ranged from 33 to 65 years and were mostly female, which is expected given that 68% of transfer households are female headed (Table 1). Respondents received between US\$ 4.29 and US\$ 20 per month depending upon their household size. They had received the transfer for 7–20 months. Only two respondents received the minimum transfer for a one-person household (US\$ 4.29). The remaining 22 respondents received US\$ 10 or more per month.

All recipients reported that prior to the transfer, they lived in destitution, lacking food and basic necessities, were often sick, and had little support from friends or family members. For example, I am HIV positive, and so is my wife. Before the cash transfer we had problems because there was nobody who came here to help us. They feared that they could get HIV from us. They say we are already

Table I Demographics of interviewees

Gender	
Female	71%
Male	29%
Age	
Mean	42 years
Range	33-65 years
Household size	
Mean	4.7
Range	1-8
Monthly cash transfer MK (US \$)	
Mean (MK1988)	(\$14.20)
Range (MK600–2800)	(\$4.30-\$20)
Per capita average (MK420)	(\$3)

dead. They cannot share their things like plates, food, and clothes. They were not even greeting us. Before the cash transfer I often got sick; every week in bed with different types of disease [Male, 55]. Since I was very helpless, I would sometimes resort to begging from my mother, but eventually she got fed up and so it became difficult to get by. [Female, 36].

Respondents reported both physical and mental distress because of their circumstances: Before the transfer I used to have no money. I could not work for I was very weak because of this disease... I could not easily access food, soap or body oil. I reached a point of wanting to commit suicide. [Female, 36]. Before the cash transfer I was a very poor person and sicknesses and diseases often attacked me; I was bathing without soap, washing without soap, and even swelling because of lack of good food. [Female, 45]

The majority of respondents reported personal and household level impacts because of the cash transfer. Table 2 lists the different domains in which respondents reported experiencing improvements.

Many respondents reported improved healthcare and ability to access ARVs. They bought painkillers and used health services, rather than waiting and hoping that their sickness would spontaneously resolve. Since I have started to receive this cash transfer I am able to receive the ARV at hospital. I am able to buy medicine or use the money for transport to receive ARV tablets. [Female, 30] The frequency of falling sick has dropped now since receiving the transfers because I have something for food and painkillers. [Female, 55]. When I was listed in the scheme, I was very ill. For me to be alive is because of the cash transfer. My wife also got infected with HIV/AIDS. I make sure there is good food for us and make sure we take medicine (ARVs) as advised by doctors. [Male, 55]

 Table 2
 Reported Impacts of SCT on 24 respondents and their families

Personal impacts	
Improvements in personal health	41.7% (10/24)
Improved ability to obtain ARVs	37.5% (9/24)
Better personal nutrition and food security	70.8% (17/24)
Ability to purchase livestock and other basic necessities	62.5% (15/24)
Impacts on families	
Improved housing	54.2% (13/24)
Improved ability to meet education costs for children	75.0% (18/24)
Better household food security	66.7% (16/24)

ARV, anti-retroviral treatment; SCT, Social Cash Transfer Scheme.

The majority of respondents reported better nutrition, greater food diversity and improved food security among themselves and for family members. I am now able to buy relish, beef, eggs, fish, milk, sugar, salt and cooking oil. My life has really changed. [Female, 38]. We are now eating nutritious food like milk. I take breakfast every morning. I am better off than before; and we are gaining weight. Food is now available in the home. [Male, Age 55]. With the scheme, I bought chickens that lay eggs providing good diets. Thus my health is recovering. I usually take an egg in the morning and another at lunch. If there are more, I have one more in the evening. [Female, 43]. I bought fertilizer last season and my yield was one ox-cart that we have just finished. We never used to have food stocks this long. [Female, 37]

Respondents described how they were able to provide children with adequate food, which helped child education. These findings were confirmed in focus-group discussions with children (Miller et al. 2010d). They are going to school when their tummies are full unlike in the past when they went to school with empty stomachs. [Female, 42]. I can tell you that when one goes to school without food he/she cannot concentrate on lessons. I have a standard five child who was not performing well in the past but now he is topping the class; he has been number one the last two terms [Female, 36]

One respondent reported that nothing had changed in regard to nutrition and food security because he only received US \$4.29 per month: But nothing has changed on my health because the money is just too little [K600]. I am failing to buy nutritious foods because I am HIV/AIDS positive. [Male, 42]. The man reported buying maize, soap, and a chicken, and paying milling fees, but no other expenditures. Still he said that without the transfer, he would suffer and likely die.

Sixty-three per cent of respondents described how they used the transfer to improve crop production and purchase basic necessities and livestock. Last year I bought a bag of fertilizer which helped me to harvest more maize than usual. I rented land and I also bought goats. This year I have rented the same land and I have kept some money to buy three bags of fertilizer. [Female, 36]. I can now have my garden cultivated because the money I receive from the scheme enables me to pay for labour. [Female, 30]. The most important is maize. I bought salt, sugar, soap, a goat and eight chickens. [Male, 44]. I bought an old bicycle. This bicycle helps me when I am going to hospital, and my children use it when going to school. [Female, 49]

About half of the respondents reported using the transfer to improve their housing. A woman caring for her four children, and three orphans, reported using the transfer to solve her housing problems: *At first I made efforts to*

mould the bricks with help from my children. I hired the brick layer to do the work for me. I intend to leave the other houses for my children since there are many. [Female, 45]. The new house is leak proof. That took a plastic sheet, roof poles, thatching poles and grass for the roof. The children even have blankets now. [Female, 43].

Seventy-five per cent of respondents (82% of households with children) reported using the transfer on costs related to children's schooling. I have bought school uniforms for my two daughters. My daughters lacked school uniform and spare clothes, even laundry soap. They used to miss school very often but they now have those needs and miss no days. [Male, 42]. Sometime back, our children used to miss classes because of illness and they were chased because of lack of school uniforms. Now they are attending classes... On top of that, one child wrote her junior certificate and the other wrote his primary school certificate examinations because of the cash transfer. [Female, 47].

Most respondents reported improvements in the family's health because of better food choices and access to health services when needed. My children are in good bodily health because they are eating nutritious food, for example fish twice a month, with cash transfer money. [Female, 38]. Children are now able to go to hospital because of the cash transfer; we are able to pay the clinic bills now. [Male, 55].

Many respondents reported saving a portion of the transfer each month to buy larger items. I managed to buy a goat with this money. I had to save for 3 month-s.[Female, 34]. As of now I am [saving] for two bags of fertilizer to apply on my maize field. I had to save for 4 months. [Male, 54]

In contrast to the man living alone in the study, a woman receiving US\$ 4.29 per month reported that she was able to purchase food and other items. I and my HIV-positive friend keep the money for one another. We both receive this cash transfer. I do not keep my K600 but give it all to her just for her to keep it for me so that I do not waste. Then the following month I get my K600 as well as the one she kept for me and end up having K1200 that month, and I can put it to much better use. It really does work.

Respondents described community members' positive and negative attitudes towards them. In some cases, they reported that neighbours were jealous. More commonly, however, respondents reported that HIV and poverty-related stigma declined because of the transfer and they now felt as though they were more connected within their community: Before the scheme I could sometimes fail to collect my medicine because of lack of transport. I could not even borrow from anybody because they knew that I did not have any source of money. Now I am glad that I have easy access to health care because even if I don't have

money people are always willing to lend me some. [Female, 37]. The community members who are non-beneficiaries admire us beneficiaries. I can figure out by hearing what they say. It has drawn us out of bondage, fancy lacking even decent plates. Now we have livestock. [Female 41]

We asked recipients what would happen if the scheme ended. Several respondents described how they would begin income generating projects (IGAs), such as selling a portion of the harvest. None of the respondents were currently involved in IGAs. Without the transfer, respondents expected social exclusion, reduced access to ARVS, starvation, sickness, children losing access to school and even death. I would definitely die because I am living on the food I buy with the scheme's money. My children would not continue attending school. They would also starve because they would have nothing to eat. [Female, 38]. Since I get sick frequently, I need to be having good and plenty of food which I would not afford if the transfer ended. Then I would be very weak and unable to work even on my on small garden. Poverty would strike again. I would also find difficulties in going to...collect my ARVs...my condition would become worse. [Female, 36]. I would suffer a lot or even die because it will be difficult for me to get nutritious food. Access to ARVs would be a problem due to lack of transport. It would also be difficult to send my children to school due to lack of school necessities. [Female, 40]. I can't lie that I could stand on my own. I haven't invested in any livestock since most of my money is spent on medicine as I have been admitted four times at the district hospital this year alone. [Female, 351

Discussion

In this article, PLWHA describe the importance of transfers to their survival and livelihoods. Prior to the transfer, respondents experienced frequent illnesses and perpetual food insecurity. As transfer recipients, the majority of respondents reported positive impacts on health, food security and economic well-being. Respondents regained their health, improved household food security and crop production, and sent children to school. Many respondents also reported increased community inclusion. As PLWHA, they withstood stigma and discrimination, often receiving little or no help from communities. As cash recipients, they receive regular income and own valuable assets. They became 'worthy' of loans and began contributing to their communities (Miller 2011).

One respondent articulated the importance of the savings club that she initiated with another recipient which allowed her to maximize the small transfer and experience greater impacts than the male respondent who received

the same small transfer, but did not have a similar arrangement. However, owing to capacity constraints, the programme has no structured linkages or complimentary services, such as to savings clubs to help recipients maximize benefits. Additional services could further enhance the impact of the transfer, such as nutrition and HIV education, and psychosocial support to help PLWHA and their families improve health and well-being. Complimentary services could be delivered at monthly pay points when recipients are a captive audience.

One limitation of this study is that respondents were interviewed at one time point, rather than followed longitudinally and compared to a control group. However, the situation that respondents describe is consistent with quantitative and qualitative data from the larger study on cash transfer impacts (Miller *et al.* 2010a,b). While PLWHA are a subset of the larger evaluation sample, they are not that different from other vulnerable household heads who are elderly or have chronic illnesses or disabilities. Still, rather than providing exact impact estimates for PLWHA, this study compares the experiences of PLWHA prior to and once they became transfer recipients.

Despite promising findings, important programmatic concerns persist, such as the appropriate level to set the transfer. We found that in one-person households, the transfer may not be enough to cover transport, food and other costs. Conversely, households receiving US\$20 were able to purchase productive assets, livestock and more. While these are impressive impacts, households receiving the largest transfers (i.e. US\$20 per month) could still experience meaningful impacts with less money, which would enable additional households to receive the benefit and smaller households to receive a little more. Alternatively, more resources could be allotted to the scheme to ensure that all households that meet the eligibility criteria receive a minimum, but adequate transfer to meet programme goals. Further operations research and evaluation could help determine the minimum transfer that maximizes impacts across households (Miller 2010).

Another frequently debated programmatic question persists: Is it feasible for HIV-positive recipients to graduate from transfer schemes without reverting into poverty? Currently, the programme states that households should graduate after 2 years. However, 'graduation' has not occurred yet as this policy is debated. However, respondents repeatedly reported that they would suffer and even die without the transfer. The Malawi government may consider linking graduation to the achievement of benchmarks, such as asset accumulation, or other programme-related outcomes. Prior to graduation, recipients need assistance to plan for the loss of the transfer,

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including training on income generating activities, saving and investing, and linkages to other emerging government or NGO social programmes.

The Malawi Government plans to scale-up the SCT countrywide. However, capacity constraints at the district level persist (Miller *et al.* 2008). Moreover, the long-term sustainability of the scheme is still unclear and current funding commitments only extend through 2013. Nevertheless, this analysis presents evidence that the transfer scheme yielded important impacts for PLWHA and their families.

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