KWA WAZEE/REPSSI

KEEPING PARENTS LIVING WITH HIV ALIVE

AUTHOR

KURT MADOERIN PhD
P.O. BOX 56, MULEBA-KAGERA
TANZANIA
CELLPHONE 0754 99 98 76
EMAIL: kurt.madoerin@repssi.org
Executive Summary
The first case of HIV infection in Tanzania was identified in Kagera Province in 1983. Since then no other area of Tanzania has shown a faster spread of HIV. Infections are now as high as 30% of the population of the province. Thousands of children have lost one or both parents. Since 2006 antiretroviral therapy (ART) has been available and AIDS is no longer terminal but a life-long chronic disease. ART is a necessary but not the only condition that allows infected parents to care for themselves and for their children for a long time. People living with HIV and AIDS (PLWHA) continue to face challenges such as travel expenses to and from hospital to collect medication, enough nutritious food, care for their psychosocial wellbeing, the impact of ongoing stigma and resources to keep their children in school. Research shows that helping PLWHA meet these needs increases strict adherence to their treatment regime.

This paper looks at a pilot program developed between 2009 and 2014 by the small NGO, Kwa Wazee with support from the Regional Psychosocial Support Initiative (REPSSI) in the Muleba district of Kagera Province. This program attempts to keep infected parents alive and enable them to care for their children, by developing and preserving their human capital and helping them to rebuild livelihood resources. The cornerstone of the program is a monthly cash transfer of small amounts based on indicators such as CD4 counts, existing economic resources, general health status and number of minor children. Michele Adato underlines the importance of social cash transfer saying “Cash transfers have demonstrated a strong potential to reduce poverty and strengthen the human capital of children, and thus can form a central part of a social protection strategy for families affected by HIV and AIDS.” A microfinance program complements the cash transfers, allowing some participants to “graduate” from the cash transfer. PLWHA on ART who are healthy enough are helped to rebuild their economic base with access to micro-loans and support from entrepreneurial training.

Although social protection is increasingly recognized as “a key area for an integrated and comprehensive response to HIV and development” additional areas of intervention increase the impact of a social protection program. Kwa Wazee explores two areas of complementary activities:

- Rebuilding human and social capital through building of mutual support groups and training. In the time of ARV and the perspective of a prolonged life, building and rebuilding social capital is critical in order to reinforce the social security of the affected families and create a sustainable “foundation” for the future.

1 A study which started in 1991-94 followed up children who were not orphaned at this that time. In 2004, 23% of children who had not been orphaned had lost one or both parents before reaching the age of 15 years. (Beegle et al. “Orphanhood and the long run impact on children”, 2005)
2 WHO reported that 40% of the PLWHA in Africa South of the Sahara are dropping out of the ART-program mainly due to insufficient food, not having the fare to the hospital and the experience of stigmatization in the local community.
4 See the critical debate on “graduation” in “Pathways’ Perspectives” e.g. Stephen Kidd : “The Misuse of the Term ‘Graduation’ in Social Policy” (Pathways’ Perspectives, Issue No. 14, December 2013).
• Attention is also directed to the children of ailing parents who have taken over a huge burden in the care of their parents. They form a child-led organization with training, income generation projects and educational support.

Introduction
The introduction of ART “transforms the experience of HIV, shifting it from a once fatal disease, requiring intensive end of life care, to a chronic disease requiring a complete alteration of day-to-day illness management within families and self-care of patients” ⁶. Although this day-to-day illness management of the “fragile body” (de Klerck) constitutes an often heavy burden for the whole family it also offers the positive outlook to keep parents alive and to end the AIDS-driven orphan crisis which has created around 1.3 million orphans in Tanzania. The aim now is to keep 1.4 million ⁷ infected people productive and to help them rebuild a foundation for a modest but somehow sustainable livelihood. This is also reflected in the change of the paradigm for psychosocial care and support. We have moved from the “memory book”: to record the memory of the dying person for the children left behind to the “hero-book” which encourages and empowers the surviving family ⁸.

The small Kwa Wazee program based in Kagera Province has developed, since its start in 2009, a number of different interventions to add value to the benefit offered by the introduction of ART. The program is not a research project in the strict sense (it is more like a social laboratory exploring tools and methods) but it provides useful insights for those looking at broad social protection programs for families living with HIV and AIDS. The tools used by the Kwa Wazee program are:
• social cash transfers and microfinance in order to strengthen the economic recovery of the depleted households
• helping families living with HIV and AIDS to break through stigma, discrimination and isolation through forming mutual support groups
• protecting the human capital of the children of infected parents through educational support
• self-organization of children into child-led organizations,
• training of children in income generation and preparing them for their uncertain future.

In addition, a self-defense and lifeskills program for girls helps to reduce the sexual violence against them and avoid early pregnancies and infections with STD and HIV and AIDS.

The Kwa Wazee Program - research approach
Kwa Wazee began running a cash transfer program for older people (pensions and child benefits for grandchildren) in 2003 and since 2009 has added a cash transfer program for PLWHA. The Kwa Wazee programs are not research programs in a pure academic sense but are rather knowledge-oriented interventions that seek to “to influence thinking about issues in a general way” ⁹. Kwa Wazee puts much emphasis on a participatory approach combining “social investigation, education and action with the ultimate purpose of engendering broad community and social change“ (ibid).

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⁷ UNAIDS, United Republic of Tanzania: HIV and AIDS estimates (2013)
The pension program was evaluated in 2008 and 2013\textsuperscript{10}. The evaluations showed the positive impact of social transfers on the lives of older people and children. The PLWHA-program has been carefully documented in order to assure an ongoing learning process\textsuperscript{11}.

The scope of the intervention for and with PLWHA revolves turns around this question:

What interventions can add value to ART in that they keep PLWHA alive longer and in addition, make them more self-sufficient and personally effective? The long-term goal is to enable them to care for their children and in this way decrease the number of AIDS-caused orphans.

One area of intervention is cash transfer. Kwa Wazee operates cash transfer in a “drip-fed” way i.e. a continuous, expectable and steady flow of small amounts of resources that ensure families can sustain appropriate responses and improve their life. Harris\textsuperscript{12} describes this kind of approach to a “‘milk-van-low key, discreet, unobtrusive, nurturing, regular, reliable, long term – rather than a “fire brigade” – sudden, one off, invasive, crisis driven, hyped”.

Cash transfer is an important component (the Joint Learning Initiative on Children and HIV/AIDS calls cash transfer “the leading edge”) of a social protection agenda but it will not alone develop all that human beings are capable of. Other interventions are also needed. Research\textsuperscript{13} suggests that other interventions should include, the formation of mutual support groups and networks, formation of saving circles which support protective and productive activities and serve as a tool for risk management, reintegration into the communities through returning into the relationships of reciprocity with neighbors, friends and other family members and the starting of income generation projects.

The other area of intervention in the PLWHA-program focuses on the children living with parents with a chronic life-time illness. Most of the parents are women. As mentioned earlier, ART has introduced a significant alteration to most family activities because of the day-to-day illness management that needs to take place. Because of the prolonged need for care by the ailing parents the extended family cannot be relied on in fact as Seely\textsuperscript{14} points out the extended family becomes over time a “safety net with holes”. So most of the caring responsibility falls to the children of the PLWHA.

The parents in the PLWHA program described here are well aware of this. Early on in the intervention our participatory research with the parents showed that their children performed a number of household chores including cooking, washing clothes, fetching water, collecting firewood, shopping, cleaning, weeding and caring for the siblings. They also provided economic support by cutting and selling grass, doing casual work on farms, keeping animals, selling products and begging. In addition they


\textsuperscript{11} Kurt Madoerin: “Keeping parents alive” (Draft-paper, 2013)


\textsuperscript{13} A study group from Marburg University conducted research on this topic for the Kwa wazee Program: Jana Borchard et.al.: “Research Brief: Evaluation of Kwa Wazee’s Social Cash Transfer Plus Programme in Northern Tanzania based on Amartya Sen’s Capability Approach” (2012).

\textsuperscript{14} Quoted in Ruth Evans and Saul Becker: “Children caring for parents with HIV and AIDS” (2009).
provided health care which included reminding the parent to take the medication, collecting medication, accompanying the ailing parent to the hospital and stopping the ill parent from doing heavy work. They also gave personal care to their ill parents such as preparing juice and a special diet, preparing the bed, washing/bathing. Parents told us how their children also gave them emotional support such as giving hope to the sick parent, talking together and share secrets, helping to overcome the feeling of loneliness and singing nice songs to cheer them up\textsuperscript{15}.

In response to these findings about the heavy burden carried by the children of PLWHA we formed a child-led organization made up of more than 200 mutual support groups. These groups aim to build resilience in the children so they can cope with the present and with the future\textsuperscript{16}.

Personal protection has become a strong theme in this children’s program. The children experience a high incident of sexual violence because having ailing parents makes them vulnerable because of the general discrimination against PLWHA and because they are known to have to paternal protection. The action-oriented tool we have developed called “Self-defense for girls” allows them to acquire protective defense skills and to develop their self-confidence and a positive gender-identity. For the boys Kwa Wazee has developed a tool called “Peace is a Decision” which encourages them to adopt a non-violent ethic as boys and men.

Research findings
The ongoing, participatory research for action we have conducted throughout the life of the program has resulted in four key findings which we feel may benefit other programs. They are discussed in turn below.

1. Cash transfer
The table below indicates the number of beneficiaries accommodated in the program since 2008.

<table>
<thead>
<tr>
<th>Year</th>
<th>Women</th>
<th>Men</th>
<th>Children</th>
<th>Total</th>
<th>Amount TZS Single or emergency support</th>
<th>Amount</th>
<th>Total Cash Transfer TZS</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>87</td>
<td>27</td>
<td>13</td>
<td>127</td>
<td>30'452'250</td>
<td></td>
<td>30'452'250</td>
</tr>
<tr>
<td>2009</td>
<td>127</td>
<td>36</td>
<td>29</td>
<td>192</td>
<td>44'331'000</td>
<td></td>
<td>44'331'000</td>
</tr>
<tr>
<td>2010</td>
<td>141</td>
<td>35</td>
<td>37</td>
<td>213</td>
<td>50'462'900</td>
<td></td>
<td>50'462'900</td>
</tr>
<tr>
<td>2011</td>
<td>160</td>
<td>41</td>
<td>36</td>
<td>237</td>
<td>39'046'000</td>
<td>133</td>
<td>42'930'000</td>
</tr>
<tr>
<td>2012</td>
<td>192</td>
<td>56</td>
<td>65</td>
<td>313</td>
<td>47'935'000</td>
<td>160</td>
<td>52'819'000</td>
</tr>
<tr>
<td>2013</td>
<td>221</td>
<td>44</td>
<td>84</td>
<td>349</td>
<td>57'352'000</td>
<td>216</td>
<td>63'326'000</td>
</tr>
</tbody>
</table>

In 2010 Kwa Wazee requested 112 participants who joined the project in 2008/9 to identify their situation on a scale from 0 to 10 on different topics in 3 different time phases (before getting sick, before joining the project, December 2010). The table below summarizes their responses.

\textsuperscript{15} This data is in line with Evans/Becker ibid. and Glynis Clacherty/Rachel Bray: “Participatory child-led research with children who are carers: A report on four case studies undertaken in Angola, Nigeria, Uganda and Zimbabwe” (Save the Children, 2009).

\textsuperscript{16} The tool of “Child-led organization is described in Kurt Madoerin/REPSSI: “Mobilizing Children & Youth into their Own Child- & Youth-led Organization” (2008)
<table>
<thead>
<tr>
<th></th>
<th>Before getting sick</th>
<th>Before joining the project</th>
<th>December 2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working capacity</td>
<td>7.6</td>
<td>2.9</td>
<td>7.2</td>
</tr>
<tr>
<td>Food situation</td>
<td>5.2</td>
<td>3.5</td>
<td>4.3</td>
</tr>
<tr>
<td>Breeding animals</td>
<td>4</td>
<td>2.8</td>
<td>4.3</td>
</tr>
<tr>
<td>Savings</td>
<td>3.2</td>
<td>0</td>
<td>3.9</td>
</tr>
<tr>
<td>Social integration</td>
<td>7</td>
<td>3</td>
<td>8.3</td>
</tr>
</tbody>
</table>

The self-assessment of these over 100 participants indicates a clear improvement in the areas of working capacity and social integration and a slight improvement in the livelihood sector (animals, savings). The fact that the food situation weakened is explained by the fact that November and December are generally the most difficult months of the year because of the agricultural calendar. We requested one group to assess the food situation BEFORE November and December – they indicated that the food situation was 6.8 on the scale.

In different focus group discussions participants indicated the following:
- Health has improved and CD4 and weight has increased
- “We are less stressed – we get food for our family and the children”.
- The concerns about the school of the children have decreased.
- “We found new friends”.

2. Microfinance
Due to high demand and restricted funding for the cash transfer program Kwa Wazee started a microfinance program in 2011. It is worth pointing out that pure microfinance institutions would never lend money to PLWHA so we had to create an internal program of microfinance. By April 2014 we had 199 loan groups (or individuals) with a total of over 1,000 participants. Since 2011 loans amounting to €44,000 had been paid out. €30,000 had been repaid and the accumulated capital through shares stood at €3,200.

Kwa Wazee did an internal assessment in January 2013 among 107 beneficiaries who are both in the cash transfer program and in the loan program. 69% consider the loan program as a very important contribution to keep parents living with HIV and AIDS alive. The assessment showed that 92 of the 107 beneficiaries use the income from the loan program for small investments such as buying chickens and goats, buying land and constructing or repairing houses. 75 use it for food consumption and 57 for education and health expenditures.

3. Rebuilding social capital: The role of mutual support groups
The core idea of the concept of “social capital” is that if the amount of human interaction increases, people are more likely to help one another and even later become more politically involved and identify and defend their rights. Pierre Bourdieu, one of the fathers of the concept, stresses the value of a

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18 Note that these figures include indications of use for more than one category.
“durable network of more or less institutionalized relationships of mutual acquaintance and recognition”\textsuperscript{19}. The possession of membership in a group is regarded as an actual or potential resource.

AIDS affects not only the financial and human capital, but also the social capital. The participants in the program described unanimously how the number of social contacts and the social integration shrunk drastically after they had been tested positive.

In the context of ART and within the perspective of a prolonged life, building and rebuilding social capital is critical in order to reinforce the social security of the affected families and create a sustainable foundation for the future.

In a number of meetings the participants analyzed outcomes of being integrated in mutual support and loan group. This were some of the things they identified:

- Learning skills and knowledge from the group and integrating them into its own life.
- Getting and giving support
- Inclusion of the children: “Group members care for the children if the parents are not available”
- Increase in personal security

One unexpected outcome was the empowerment of the women. Most women in the groups agreed that the group was and is still extremely important and contributed much to empower the widows.

4. Children as young carers
One of the results of the availability of ART and the resulting prolonged life of adults with HIV is that children, who usually take over the main responsibility for the day-to-day care of the ailing parents need to be supported.

Kwa Wazee is centrally involved with the situation of these child carers. The main tool to build their resilience and capacities to cope with the future is the formation of the child and youth-led organization TATUTANO which includes children living with PLWHA (55%) and orphaned children living with grandparents (45%).

By April 2014 this Kwa Wazee program had 1 450 children and youth organized into 222 TATUTANO groups. These groups were involved in income generation projects such as agriculture, keeping of chickens and goats and commerce. There were 222 savings groups who each deposited between 200 and 300 Euros in their group accounts monthly. They had received training in agriculture, project planning, leadership and monitoring. In 2014 TZS 47 million allowed 784 Primary School and 360 Secondary School students to continue schooling. 1 550 girls had been trained in self-defense and are forming self-defense groups in their communities and 500 boys trained in the prevention of violence (“Peace is a decision”).

The children see this last project as particularly important. In an impact assessment with a sample of 82 TATUTANO participants who had received the girls self defense and lifeskills training almost all of them indicated a perceived increase in their personal security from 2.36 (on a scale of 10) before the training to 9.22 after the training. They gave the following reasons for the change: increased self-confidence,

knowing the techniques, change of their own behavior, solidarity among girls, better integration of boys and girls at home\textsuperscript{20}.

**Policy and program implications**

Tanzania’s Third National Multi-Sectoral Strategic Framework for HIV and AIDS observes in the Executive Summary that “comprehensive needs of PLHIV are often not being met” and requests that the “national response to HIV and AIDS ... [encompasses] ... other social and economic sector responses, including anti-poverty programmes”\textsuperscript{21}. The Joint Learning Initiative on Children and HIV/AIDS (JLICA) lamented that the responses from governments and their partners have fallen short\textsuperscript{22}. The report estimates that “families and communities continue to bear approximately 90% of the financial cost of responding to the impact of HIV and AIDS on children” which results in an increasing erosion of the coping capacities of families.

The Kwa Wazee program in Kagera is piloting a “community based care and support intervention response to HIV within their local context” \textsuperscript{23}. But as with many other HIV-sensitive social protection program the Kwa Wazee program has “been developed as [a] pilot and [is] small scale ... Scaling up social protection ... includes national ownership and working within existing social protection frameworks”\textsuperscript{24}.

The outcomes of the program in Kagera support the reinforcement and integration of complementary and comprehensive social protection elements into national HIV and AIDS policy. UNAIDS indicates that social protection programs can help to “mitigate the significant social and economic impacts of HIV on households and individuals” (ibid.) and refers to the main social determinants of the epidemic which are income inequalities, gender inequalities, and social exclusion.

The impacts of cash transfer to PLWHA respond not only to the “National Multi-Sectoral Strategic Framework for HIV and AIDS”, but also to the “National Strategy for Growth and Reduction of Poverty” (MKUKUTA), especially to cluster 1 (Growth and reduction of poverty) and cluster 2 (Improvement of quality of life and social wellbeing, including expanding social protection for vulnerable groups.) There is much evidence that PLWHA and their families form an extremely vulnerable group, not only in terms of economic wellbeing but also as a group which still is strongly exposed to stigma and discrimination – even by health care providers\textsuperscript{25}. A comprehensive social protection program can help to break through the isolation and even facilitate the integration of PLWHA into the reduction of the HIV-infection rate. For example, in the program described here some of the members of the PLWHA groups grew into the role of advisors in their villages, one of the members describes how, “People came to ask me for advice - if they should go for testing. They went: four have been positive, one had TB”.

\textsuperscript{20} Kwa Wazee: Impact assessment of Self Defense – the views of the participants (2011)


\textsuperscript{22} Joint Learning Initiative on Children and HIV/AIDS “Home Truths. Facing the Facts on Children, AIDS and Poverty”(2009)


\textsuperscript{24} UNAIDS: “HIV and Social Protection. Guidance Note”” (2011)

With regard to Cluster 1 (Growth and reduction of poverty) it is important to consider that cash transfer impacts not only the targeted family but the entire local economy. Barrientos/Sabates-Wheeler conclude from their study of the PROGRESA-program in Mexico “that cash transfer programmes are able to achieve much more than to raise welfare among direct beneficiaries” . Steven Kidds takes this even further by saying that if a country decides to invest in social security it will also boost its economy while strengthening the human capital and creating local demand.

Another advantage of cash transfer programs is that they are HIV-sensitive i.e. responsive to the particular needs of people and families living with HIV. Finally the cash-transfer has the potential to develop social capital and train new capacities if it is administered within the context of support groups as the Kwa Wazee program has been. A coordinated cooperation between national agencies, covering the financial commitment, and local NGO’s and CBO’s could constitute an interesting step towards keeping infected parents alive and develop the potential of ART to its maximum.

**Conclusion**

FANPRAN, discussing policy options for effective responses to the impact of HIV and AIDS in Southern Africa says “A big challenge is that the bulk of HIV and AIDS programs are focused on awareness campaigns, orphan care, and prevention of mother-to-child transmission. Few NGO’s have been involved in programs that seek to increase incomes and mitigate the impact of HIV and AIDS especially in rural areas”

The PLWHA-program of Kwa Wazee has developed and tested a small-scale program that responds to the social and economic impacts of the epidemic. The program contributes to the survival of adults living with HIV in order to enable them to fulfill their caring and educational role for their children. In conclusion, during our piloting of the program we have learned much. Our recommendations for adding value to ART are:

- Family care is the first line of protection for children. Measures of social protection – especially cash transfer – help to mitigate the economic and social impacts of HIV and AIDS in the family, help to reduce the burden of the children in an HIV-affected family and help to preserve the parents alive.

- A long-term funding of the family is critical (“drip-fed” – a continuous, expectable and steady flow of small amounts of resources that ensure families can sustain appropriate responses to keep parents alive and improve the life of children).

- Cash transfer is the leading edge of a broader social protection agenda, which includes rebuilding of social capital, development of capabilities and preservation of the human capital – including the human capital of the next generation (education).

- Considering the great importance of the children of PLWHA in the care of their ailing parents each program for PLWHA should include a program for and with their children.

- Children affected by HIV and AIDS – and especially girls – belong to the Most Vulnerable Children. Sexual assaults are frequent, which is not only a traumatic experience but represent also a danger for infection with the AIDS-virus. A combination of self-defense for girls and of gender-training for a non-violent boyhood of boys constitutes an efficient tool for the protection of the young carers.

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27 Stephen Kidd: “Social security and its contribution to economic growth”
Kwa Wazee supports the conclusion of Joanna White, that “the lion’s share of the donor funding ... has traditionally been channeled towards interventions on preventive and curative health and behavior change. Less attention has been paid to the social and economic impacts of the epidemic ... These impacts will persist long into the future, regardless of the success of any HIV prevention messages, increased access to antiretroviral drugs, and even the development of an effective HIV vaccine ...”

In order to keep the local livelihood and caring systems functional it is critical to develop complementary interventions to ART.

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