

Final Report

**IDRC Doctoral Research Award
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**Is there any hope? Ugandan families managing in the context of
HIV/AIDS**

Dissertation Title (Preliminary):

Moving on with life: A case study of Ugandan families coping with the long-term impact of HIV/AIDS.

By

**Insaf Hag-Mousa, PhD Candidate
Department of Human Ecology
University of Alberta**

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Calendar of activities

Activities	Date Started	Location	Duration
1. Getting to know the place and settle down.	April, 2005	Kampala	9 weeks
2. Obtained approval from the Uganda National Council of Science and Technology (UNCST) to conduct the research.	June 2005	Kampala	6 Weeks (from date of submission to date of obtaining approval)
3. Pilot-tested and modified the interview guides, information sheet and consent form.	August 2005	Kampala	4 weeks
4. Contacted several local agencies to gain entrance to the population of	April 2005	Kampala	This ongoing process continued until April 2006.

interest to the study.			
5. Screened potential participants to be included in the study.	August 2005	Kampala	This ongoing process continued until April 2006.
6. Recruited and interviewed study participants.	September 2005	Kampala	This ongoing process continued until April 2006.
7. Collected other sources of data, mainly documents, from the field to provide context for the study.	August 2005	Kampala	This ongoing process continued until April 2006.
8. Conduced preliminary data analysis to determine data saturation.	November 2005	Kampala	This ongoing process continued until the end of March 2006
9. Conducted additional interviews with service providers in Kampala at different NGOs that were working	January 2006	Kampala	Continued until the beginning of April 2006

with people affected by HIV/AIDS.			
10. Transcribed all tape-recorded interviews.	October 2005	Kampala and Canada	Continued until June 2006
11. A summary report of the study was submitted to Uganda National Council of Science and Technology (UNCST).	April 2006	Kampala	
11. Gave a brief presentation on the study's preliminary findings at the Forum for People living with HIV/AIDS in Kampala.	April 2006	Kampala	One day

The study: Narrative Report

Methodology

The case study methodology was used to guide this research investigation. This methodology is especially useful when little is known about the research question of interest, when examining contemporary as opposed to historical events, and when “*how*” and “*what*” questions are being asked (Stake, 1995; Yin, 2003), as they were in this study. Questions of *how* HIV/AIDS-affected Ugandan families, particularly families headed by widows, were coping with the long-term impact of the disease were asked. Also, questions on *what* kinds of resources were available to the families and *how* those resources influenced families’ ability to cope were investigated.

The multiple case study approach was used in this research investigation. Yin (2003) and Stake (1995) argued that the findings from a multiple case study can be compelling, particularly when they reveal similar patterns across-cases when cross case analysis is conducted. Accordingly, multiple cases of Ugandan families affected by HIV/AIDS were included in the study. Detailed accounts of these families’ experience with the disease and how they coped with its aftermath, particularly after losing the husbands and fathers because of AIDS, were gathered. Special attention was given to investigating the issue of how resources affected the examined families’ ability to cope.

To conduct this case-study investigation, certain steps were followed as outlined by Stake (1995) and Patton (2002). First, the research question in the study was clearly defined to focus on investigating how HIV/AIDS-affected families in Uganda who were headed by widows who possessed certain resources, specifically education and employment, were coping with the long-term impact of this disease. Second, a definition

of what a 'case' was in this multiple case study was well established so that each case was represented by one affected family unit. Third, the criteria for the inclusion of families in the study were developed to help achieve the purpose of the study.

Sampling Strategy and Inclusion Criteria:

In accordance with case-study methodology guidelines, the selection of participants for this study followed a purposeful sampling strategy. Participants were included in the study because they possessed specific characteristics considered relevant to the study's purpose and, hence, provided detailed and rich descriptions with respect to the research questions. These criteria were

1. Women in the families had to be widows because they had lost their husbands/partners because of AIDS.
2. Widows had to be HIV-positive.
3. Widows had to have had completed at least Grade 12 (equal to the ordinary level, also known as the O level).
4. Widows had to be employed either in the formal or informal sector during the time of the study.
5. Finally, widows should have had more than one child to care for, either living in or not living in, in the same household.

Data Sources:

The study used multiple sources of data to answer its research question, including

1. A number of family cases, nine families, who were represented by the purposely selected family members who were included in the study.
2. Field notes taken during the data collection phase.

3. Field documents relevant to the research questions under investigation.

Data collection:

Prior to data collection, an interview guide was developed with a few questions designed to explore the different areas needed to answer the study's research questions. Probing questions were also included in the interview guide to further explore the issues under discussion. The interview guide was later pilot-tested while in the field to determine its language accuracy and to confirm that participants would correctly understand the questions. Necessary modifications and changes were made to the guide, which made it ready for use with the actual research participants.

After the researcher arrived in he Kampala, several visits were made to different key organizations known to be working in the area of HIV/AIDS in Uganda. The staff in one of these organizations was instrumental in identifying widows who possessed the study's inclusion criteria. A snow balling process recruited other widows and other family members for the study. All potential participants were approached and invited to participate in it. They were all given an information sheet describing the study in detail, and those who agreed to participate in the study had to sign a consent form. Twenty-three family members were interviewed in this study at a time and location of their convenience.

Data Analysis:

In the study, all interviews and field notes were transcribed into Word documents, and the transcripts were verified against the audio tapes. The word documents were coded to identify participants: widows, sons, daughters, sisters, brothers and friends. All participants' coded and formatted interviews and related field notes were later imported

into NVivo software. NVivo is known to be helpful in organizing, coding and categorizing large texts of interview data. After careful and repeated listening to the interview tapes and reading of the interview transcripts, a coding scheme was developed to guide the coding of the interviews' data and the field notes, and the data were later coded accordingly in NVivo.

When within-case analysis was conducted, the use of the case study methodology enhanced the researcher's understanding of how each studied family case was coping with the impact of HIV/AIDS, and also permitted the examining of similar coping patterns across family cases. This comparative element of the multiple case study methodology was especially important because it resulted in a clear understanding of how a specific type of family who was affected by the HIV epidemic had moved on after experiencing the loss of the family's husband and father. As well, looking across cases was important because doing so highlighted the range of coping strategies adopted by these families, and the range of resources that were available to the families, and how these resources were influencing the family coping.

Study Findings

After completing the data analysis, it became clear that the examined families had tried hard to cope with the devastating impact of HIV/AIDS on their family units. The interviewed widows "didn't want to wait for charity," as one widow mentioned, but they tried hard to provide for their families and to support their children.

The affected families implemented several strategies to cope with and manage their stressful situation. However, as some widows said, they "couldn't have done it alone." The affected families received support from other sources including members of

the extended families, friends, and community services. The presence of the so-called “resistance resources” seemed to have helped these families sustain themselves. Some of the examined families are now celebrating the success of the children who were enrolled in university during the time of the interviews. These children may have had a different future if their mothers had also died as a result of HIV/AIDS.

Data analysis revealed three major themes that ran across all nine cases, including

Theme 1: Impact of HIV/AIDS on examined families

The examined families experienced specific stressors related to living with and being affected by HIV/AIDS. All the widows and some of the children included in the study were HIV-positive. In some cases, the widows were not psychologically prepared to learn about their children’s HIV status and, therefore, did not take their children for testing.

The loss of the husband and father was another difficult situation that the families had to deal with. When their husbands died, the widows felt lonely and frightened about the new responsibility imposed on them as they became the heads of their families. Losing the husband’s income was a blow to the families’ financial security. The loss of the husband also contributed to some of the widows being in conflict with their in-laws, who were interested only in property-grabbing rather than helping the widows and their children.

The widows and their children all said that they had lacked certain resources, mainly financial resources, when the family income became inadequate after the husbands’ deaths. Paying school fees to keep children in school was the most difficult demand that families had to respond to. Sometimes, these families also lacked support

from others, either their extended family or the community. In most cases, the extended family members were also poor and had little to share with the widows and their children. The community, in some cases, did not support the families and discriminated against them because the husband was known to have died because of AIDS, and the community members thought the widow and her children were HIV-positive. In some cases, being HIV-positive led to loss of employment because the widows were stigmatized and discriminated against at their place of work. The result was a significant drop in family income and more stress and hardships for the families.

Theme 2: Family coping strategies

The examined families explicitly revealed the difficulties and hardships they had to cope with, and described in detail how they had experimented with and adopted different strategies in order to cope, including the following:

- ***Prioritizing:***

Surviving was the number-one priority for many widows. Therefore, they decided to invest in their health first before responding to any family demand. Before they had access to free ARVs, some of the widows had to buy these medications when they were very expensive. The widows knew they had to live so they could take care of their children. They wanted to live because they felt no one else would be able to provide proper care to their children.

The widows' second priority was to earn an income to satisfy their family needs. Some widows improved their education to advance their chances for employment. This strategy was successful in some cases. Widows who obtained a higher education were able to get good jobs that paid them a good salary. Another common strategy to raise

more money was to establish an income-generating activity (IGA). These IGAs included having a poultry farm, becoming a money lender, re-activating previous skills such as tailoring, building a structure for rent, and buying and selling commodities, mainly food. Most of the interviewed widows were also involved with NGOs working with people living with HIV. These widows became trainers and consultants in their communities and were paid every now and then when they worked on HIV/AIDS-related projects with local NGOs.

Moreover, income was needed mainly to pay for children's school fees. Widows learned how to negotiate with their children's school officials to pay school fees in installments. Paying school fees was an expense that could never be reduced, but other expenses related to food, clothing, and electricity at home could be cut to save money for paying school fees.

- *Using resources to cope*

The studied families talked about how different types of resources had influenced their ability to cope. Personal resources in the form of the widow's education and employment were seen as an asset to family coping. Widows who were educated stood a better chance of keeping their jobs and even getting better employment. These results increased their incomes and improved their ability to respond to their families' financial demands.

The studied families also discussed family resources. All the children supported their families. The children had grown up beyond their age and had learned to assume responsibilities such as helping their mothers with managing the IGA when on holiday from boarding schools. The children also did most of the housework whenever they were

home. The children provided emotional and psychological support to their mothers, cared for their mothers whenever they were sick, and obeyed their mothers in most cases.

Some families were able to receive extended family support. However, most of the families included in this study mentioned that their extended family members were poor and could not provide much help. Still, some extended family members tried to help with the little they had. Some came and stayed with the widows after the death of their husbands to provide moral and emotional support. They also came to stay with the widows during their illnesses, and some stayed with the widows in the hospital when they were sick and took care of their children while the widows were recovering. Some family members in the village would sometimes send the widows and the children some food from their gardens. In one case, a family member, a brother, moved in to live with the widow for few years to help her to establish an IGA and care for her children. However, all the widows included in this study indicated that after the death of their husbands, their in-laws had made life difficult for them. Most of the problems with in-laws were related to property entitlement, for the in-laws thought they should share property with the widows and their children. In one case, the in-laws even wanted to inherit the widow herself by re-marrying her to one of her late husband's brothers. Families who had a will written by the husband before his death were better off because they were legally protected from their in-laws' attempts to seize the family properties.

Community resources were also important for family coping. The availability of free access to ARVs was crucial to the widows, who were relieved to have this service and to be able to save treatment expenses in order to spend on other priority areas. NGOs working in the area of HIV/AIDS were also helpful to some of the widows, who were

able to get social and psychological support from these organizations. NGOs sometimes also provided financial support by contributing to the children's school fees, but this kind of support was always temporary and brief.

Friends were another important community resource that helped the affected families to cope. Friends nursed some of the widows when they were sick, provided some financial support whenever they could, and took care of the children when their mothers were sick in the hospital or away on a business trip. Friends also opened doors for employment to some widows and gave useful advice to help them and their families to cope.

- *Preparing for the future*

Family coping also involved preparing for the future. Most of the widows interviewed had a sense of urgency about accomplishing many things in a short period of time. This urgency stemmed from the widows' belief that they might die at any time because of HIV. The widows wanted their children to be self-sufficient so they would not have to beg in case their mothers died. Therefore, the widows were worried about their children's future and wanted to leave the children in an improved financial situation. The widows thought of leaving assets for the children such as building houses where the children could stay instead of having to move to someone else's home. The widows also wanted to leave other properties that their children could rent, so they would have money to finance their education and living expenses. Children's education was the main concern for the widows, who thought that if their children had a good education, they could be employed and thus be able to provide for themselves in the future.

Theme 3: Outcomes of family coping

According to the study's findings, the widows were able to cope to some extent with their HIV illness. This positive outcome was attributed to their free access to ARVs and medications for opportunistic infections, and to the widows' knowledge of positive living, which included proper nutrition when possible in order to benefit the most from the HIV treatments.

Some widows were able to obtain better-paying jobs than they had had previously. Those who did not have good jobs or were unemployed established IGAs that, in most cases, were successful. IGAs provided families with an income, which was used to meet their basic needs, although paying school fees continued to be difficult, particularly as the children grew older and their financial demands increased as they approached or entered university.

The widows also became a resource to others. Most not only were coping and caring for their children, but were also making contributions to their extended families and society. Some widows took care of not only their biological children, but of orphans as well. Widows also took care of some of their relatives. In some cases, the widows' parents depended on the widows for financial support. As well, the widows were continuing to be active participants in the fight against HIV/AIDS. Most of the widows who participated in this study worked as trainers and consultants in their communities to raise awareness about HIV prevention, testing and treatment.

Most of the children in the examined families were performing well in school, and some children were even excelling. Some of the children were either in university or about to be admitted to university. The children who excelled academically were able to secure government sponsorship, which paid for their tuition fees, and accommodation

and food at the university hostels. The presence of the mothers in these children's lives had kept the families together and provided the children with the opportunity to continue their education and, in most cases, to stay healthy. Therefore, supporting HIV/AIDS-affected families, particularly families headed by widows should be seen as a cost-effective intervention because the children in the examined families may have had a different future if they have had lost both parents because of HIV/AIDS.

Recommendations

Based on the findings from this study, the followings recommendations are made:

- For the widows, there is a need to
 1. Provide more employment opportunities and possibilities for upgrading of their skills when needed.
 2. Develop policies to support HIV-people in the workplace.
 3. Continue to provide free access to ARVs and medications for opportunistic infections.
 4. Offer affordable credit, microfinancing and bank loans, particularly for families experiencing extreme difficulties, such as HIV/AIDS-affected families headed by widows.
 5. Provide training on how to establish and run an IGA.
- For the children, there is a need to
 1. Formulate and implement policies to protect children in school, particularly orphans, from stigmatization and discrimination.
 2. Provide subsidies or financial support to pay for orphans' school fees, particularly for HIV- orphaned children.
- The community should

1. Be supportive and understating of the situation of those affected by HIV/AIDS.
2. Not stigmatize HIV/AIDS-affected individuals and their families.
3. Provide support to HIV-affected people at their place of work.