

# The Effects of Increasing Rates of AIDS-Related Illness and Death on Rural Families in Zomba District, Malawi

## A Longitudinal Study

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### Introduction

The primary purpose of the research conducted from January to December 2006 was to investigate the ways in which the AIDS epidemic was playing out in a Zomba District sample of households that had been studied since 1986. The single most important characteristic of this research is that we have information on the same households for twenty years, a span of time for a longitudinal study that we believe to be unique in current research in Malawi. After the initial research in 1986, additional full twelve-month rounds of research were conducted with the same sample in 1990 and 1997, with shorter visits to part of the sample between 1993–96. The data and analysis provided in this report concentrate on the households who were in both the original 1986 study and in the 2006 study.

The original sample of households was selected in 1986 through a combination of maps, village lists, and visits to villages to select households. The households were purposively sampled to include roughly equal proportions of tobacco growers, “large” maize growers, and “small” to “medium” maize growers. Since everyone grows maize, these last two categories translated into those with relatively large and those with relatively small land-holdings in the villages. The sample families follow matrilineal and matrilineal patterns of organization: descent and inheritance are traced through the mother’s line, and husbands move to their wives’ village on marriage. Land is inherited by female heirs and sons are expected to use their wives’ land.

The methods of the study combined ethnography with repeated questionnaire surveys, as in all previous years (1986, 1990, 1997). Research assistants lived full-time in the sample villages and the senior researchers spent part of each week in the villages. The research was designed and conducted on the basis of complementary and integrated methods of data collection in order to facilitate interpretation and analysis of the data. While survey methods produced quantitative data that were statistically assessed for significance, information gathered through ethnographic methods, based on residence and participation in village life, was essential to guide the appropriate interpretation of quantitative data. Conversely, an understanding of patterns of social relations in work, food consumption or marketing derived from the ethnographic analysis is based on necessarily non-random sets of individuals and families. Therefore, the research was designed to benefit from multiple methods of data collection and of analysis.

### Results

Results included that 50% of the sample households had had at least one death due (certainly to likely) to AIDS; and 29% were taking care of orphans during 2006. A central conclusion is that the matrilineal family continues to be the major, frequently sole, support to bereaved households. Without the mobilizing power of the matrilineal family, there would be far more homeless orphans, and far more acutely distressed individual persons and households. That the extended matrilineal family is able in most cases, so far, to absorb most of the very high costs, material and otherwise, of the epidemic should not be assumed to be “the” case for all of Malawi, still less for Africa. Many extended matrilineal families are already very stretched, and, in light of the increasing numbers of sick and dying people, without improvements in the services to help them increase their income level, their capacity to care for the increasing numbers of sick and of orphans, and to gain more equitable access to medical care, some may find it difficult to maintain their roles as primary caretakers.

The study supports those that have found considerable heterogeneity across households in terms of their ability to deal with the HIV epidemic, and a very low rate of household dissolution. The better-off households (with higher levels of resources and income) have, on average, been more able to absorb the effects of AIDS illness and deaths. About a quarter of adult deaths attributable to AIDS were of the principal couple—the key woman and husband. The immediate impact of such deaths is often acute, with reduced cultivation time and harvests, loss of other sources of income, and rising costs, financial and other, in caring for seriously sick people and in organizing funerals. However, in the large majority of cases, the households did not dissolve and were taken over either by a surviving wife who often remarried within a few years, or by adult daughters, sister’s daughters and a few sons. Any orphans were shared out among relatives and land was taken over by the female heirs. There were no cases of “land-grabbing.” While there was ambivalence and tension around deaths attributable to AIDS, the study found no evidence that “HIV widows” faced any more “stigma” or suspicion than any others.

Much of what the Zomba villagers do can be usefully seen as striving for normality. Rather than denying the abnormal circumstances of the rising toll of HIV-related illness and death, they might better be seen as trying to control those circumstances, making huge efforts to channel them

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into the normal and normative ways of their society. The ambivalence about naming the disease in relation to relatives, friends or others well-known to the speaker is better seen in terms of normalization than “denial.” Other efforts to normalize the stressful situation can be seen in the various interpretations given to illnesses and deaths associated with HIV infection. Some who avoid naming AIDS quietly accept the cause of the illness and death of a relative as due to the “new disease” (*matenda a tsopano*). Other posited causes include the malevolence of others, glossed as witchcraft, and the identification of a well-known sickness syndrome called *kanyera* that long predates the AIDS crisis. Fundamentally, most of the strain caused by AIDS illness and death, especially in the medium to longer term, is due to the preexisting and continuing levels of need and poverty at household and family levels and of acute shortages at institutional level. This conclusion points to the need to forge a stronger link between HIV policy responses and general social and economic policies, particularly to improve people’s access to food.

There is also evidence of change: while the level of voluntary testing is still extremely low, there have been increases in the availability of testing in the rural areas; some people are paying more attention to the known behavior of their spouses, friends, and neighbors and making changes in their own practices, such as young people not engaging in sex too early or too often, and adults holding each other to stricter standards than before.

No cases of orphans being put in orphanages arose in the sample and our findings on the importance of the extended family in taking care of orphans raise questions about the emphasis placed on orphanages in national and international efforts to date. The study suggests that a myopic focus on orphans as individuals may displace the efforts needed to provide aid to families who care for orphans. In spite of the vast amounts of funds pouring into Malawi for orphans, there are very few services actually reaching orphans and the families who care for them in the research site. The number of orphan care groups has proliferated over the past five years as a result of the availability of grants, but ‘on the ground’ delivery of real services to orphans and their families remains tiny. Even less help is received by families caring for people living with HIV.

There is also an over-reliance by donors and government on setting up community organizations to provide voluntary care and services to those affected by HIV-related illness and death. First, this ignores the fact that virtually all care and cooperative effort in villages are already (and always have been) “voluntary,” even though they have not been labeled such. Second, the large grants given to community groups to set up business enterprises intended to provide a “sustainable” source of funds for service delivery are inappropriate for most cases.



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### About RENEWAL

Facilitated by the International Food Policy Research Institute, RENEWAL is a regional “network-of-networks” in Sub-Saharan Africa. Currently active in five “hub” countries (Malawi, Uganda, Zambia, South Africa, and Kenya), RENEWAL comprises national networks of food and nutrition-relevant organizations (public, private, and nongovernmental) together with partners in AIDS and public health research. RENEWAL aims to enhance understanding of the worsening interactions between HIV, food security, and nutrition, and facilitate a comprehensive response to these interactions. RENEWAL is grateful for support, at present, from Irish Aid, the Swedish International Development Cooperation Agency (SIDA), the International Development Research Centre (IDRC, Canada), and the United States Agency for International Development (USAID).

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