AIDS AND RURAL LIVELIHOODS

DYNAMICS AND DIVERSITY IN SUB-SAHARAN AFRICA

Edited by

ANKE NIEHOF, GABRIEL RUGALEMA AND STUART GILLESPIE

AIDS and Rural Livelihoods

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Dynamics and Diversity in Sub-Saharan Africa

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Anke Niehof, Gabriel Rugalema
and Stuart Gillespie

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Preface and acknowledgements

HIV is unique among the major epidemics in that it has now been around for about 30 years. When the epidemic first broke out, it was expected that, sooner or later, a medical solution would be found, conveniently consigning AIDS to history. Thirty years later and despite major advances in science and medicine, the disease is still with us. Indeed, we have noted in the first chapter of this book that *'while there have been significant medical advances in understanding and responding to the virus and the disease, the wider set of social and economic drivers of HIV epidemics and the multiple, downstream impacts of AIDS on societies and economies are less well known.'* While the observation is valid, at the same time, we acknowledge that there is a growing body of literature based on recent research addressing these issues. Various perspectives have been presented in literature and they have helped shed some light on how the epidemic has driven, and continues to drive, social, cultural and economic changes. Learning lessons from this multitude of research findings, however, is complicated by the different designs underlying the studies; they can be cross-sectional (mostly) or longitudinal, focused at micro-level mechanisms or macro-level trends, and so on. Researchers also make different choices in handling the ethical and methodological problems that inevitably arise when collecting empirical data on AIDS impacts in situations where the disease is still surrounded by secrecy and stigma. The pervasive role of local and context-specific factors in influencing prevalence and shaping impacts further reduces the comparability of research findings. For this reason the quotation above speaks of HIV epidemic*s*, in the plural, for we argue in this book that there is no one single HIV epidemic. What is referred to as 'the HIV epidemic' is in fact a constellation of epidemics of varying intensity distributed across space and time. Sometimes these epidemics coalesce, sometimes they don't. In this book, we have used the concept of diversity to underline not only the epidemiological diversity of HIV but also the differences one sees when examining how different communities and households have responded to the morbidity and mortality effects of these epidemics.

As we continue to learn more about the impacts of AIDS, notions of 'conventional wisdom' are constantly redefined. Scenarios that emerged in the early years of the epidemic had predicted catastrophe, particularly in East and Southern Africa. Hunger would intensify, thousands of households would dissolve, those that would survive would be headed by children orphaned by the epidemic, according to this narrative. Looking back in time, it is obvious that the worst-case scenarios did not come to pass. Indeed, despite its tenacity, AIDS has exacerbated livelihood problems including poverty, but it has not entirely overwhelmed the social fabric of society. To help understand these effects, we emphasize the need to understand the dynamics through which, over time, society grapples with the impacts of epidemics.

The overarching message we try to convey through this book is therefore that unless we understand the differences and the dynamics that characterize the epidemic at local level, it will remain very difficult to draw firm conclusions on its longer term and wider ramifications. Chapters presented in this book illustrate the various dimensions of diversity and dynamics of HIV and AIDS in various rural settings in Africa. In putting together this volume, we try to show how an epidemic moulds or is moulded by the social context in which it occurs. This line of thinking has benefitted from our comparatively long experience in AIDS research. At Wageningen University, Anke Niehof coordinates the AWLAE (*African Women Leaders in Agriculture and Environment*) Project, in which 19 women scholars from 11 African countries undertook PhD research (2004–2008) on topics relating to AIDS and women's roles in food and livelihood systems in sub-Saharan Africa. Findings were published in a special issue of the *Wageningen Journal of Life Sciences*, NJAS (2008, issue 56/3), in the AWLAE Series of Wageningen Academic Publishers, as well as in PhD theses and international journals. Five AWLAE scholars contributed to this book. Gabriel Rugalema's monograph on AIDS and the crisis of rural livelihoods in Tanzania (1999) was the first of its kind. Since then he has widely published on the subject and has been initiating and supervising research on AIDS and rural livelihoods and agriculture in his work at the Gender, Equity and Rural Employment Division of FAO in Rome. In 1989, while working with FAO, Stuart Gillespie published the first paper on the potential impacts of AIDS on African farming systems. Ten years later, after joining the International Food Policy Research Institute (IFPRI) in Washington DC, he co-founded RENEWAL – the Regional Network on AIDS, Livelihoods and Food Security to promote a networking approach to fusing locally relevant research on HIV and hunger with capacity strengthening and policy communications in eastern and southern Africa.

Publishing a book is a long process. There is always a great number of people behind the project. Some may have clear-cut roles and responsibilities, some may not. However, it takes the effort of all those actors to bring the project to fruition. Indeed, behind this project there are numerous actors without whom the book could not have been written: the anonymous respondents and participants in research projects, many of whom have been given a loud and clear voice by the researchers documenting their plight. They allow us to gain insight into how HIV and AIDS affect people's lives, making it possible to look beneath the surface of the figures and statistics that portray the magnitude of the AIDS problem. Having said this, there are a number of more specific acknowledgements that ought to be made. We would like to acknowledge the funding of The Netherlands Government of the AWLAE Project that yielded such valuable research. We are grateful to the NJAS board for allowing Rose Fagbemissi and Lisa Price to use their article in the special issue for a contribution to this book. We also acknowledge generous funding from Irish Aid and the Swedish International Development Cooperation Agency (SIDA) to RENEWAL that supported the involvement of Stuart Gillespie and E. Wairimu Mwangi, along with three studies reported here (Twine and Hunter, Swaans et al, and Mwangi). Finally, we would like to express our particular gratitude to E. Wairimu Mwangi for her invaluable assistance in the editing process, in addition to writing her own contributions to this volume.

The editors
March 2010

Chapter 1

AIDS in Africa: dynamics and diversity of impacts and response

Stuart Gillespie, Anke Niehof and Gabriel Rugalema

Introduction

In the three decades that have passed since the first cases were reported, AIDS has become one of the most highly studied diseases in history. While there have been significant medical advances in understanding and responding to the virus and the disease, the wider set of social and economic drivers of HIV epidemics and the multiple, downstream impacts of AIDS[1] on societies and economies are less well known.

In 2000, HIV was placed firmly on the global development agenda by UN Security Council Resolution 1308, which stated: *'the spread of HIV can have a uniquely devastating impact on all sectors and levels of society'*. A year later, in July 2001, the UN convened the General Assembly Special Session on HIV/AIDS – the first time such a session has been devoted to a single disease. It has only been during this last decade that we have started to unravel the complexities of epidemics – what drives them, what happens as a result of them, and how people respond in the face of their impacts. AIDS epidemics – and there are many – are long-wave events, and their effects will be felt for decades to come, especially in southern Africa where prevalence is highest. Despite the recent slow decline in the rate of new HIV infections, the number of people living with HIV in Africa slightly increased in 2008, partly due to increased longevity stemming from improved access to treatment.

The purpose of this book is to present an account of how, despite the decline in incidence, AIDS epidemics continue to impact rural agricultural-based livelihoods in

[1] In this book, when we are discussing infection, we refer to the virus (HIV); when discussing the disease, the broader epidemic, or its impacts, we refer to AIDS.

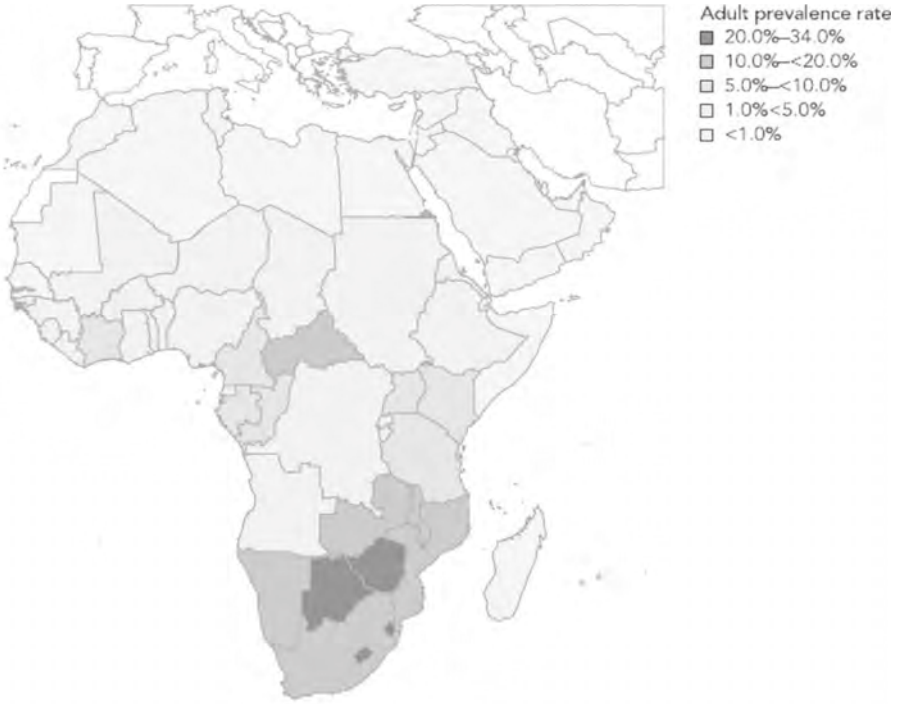

Figure 1.1 *Map of adult HIV prevalence in Africa*

Source: UNAIDS, 2006

Africa and how households and communities respond. Unlike many past analyses, our intention is to bring a number of perspectives into the analysis of impact and responses. First, the critical importance of time has hitherto been neglected, yet historical and recent evidence show that interaction between disease and human society is mediated through time (DeSalle, 1999; Sherman, 2007). We have to recognize that the effects of AIDS are not static, nor is the process through which households and communities respond to impacts. This perspective offers one important advantage: it provides incentive and space for analysing both the impact and responses longitudinally, thus helping to decipher their trajectories through time. Second, the multi-level nature of vulnerability and impact has often been referred to but has remained on the analytical margin. Multi-level here refers both to geographical dispersal of AIDS epidemics across space and time and the various levels of society (micro, meso and macro) at which complex forms of response to AIDS interplay.

This book focuses on Africa for one obvious reason. Since the beginning of the epidemic, sub-Saharan Africa remains the region most affected in the world and is home to two-thirds (67 per cent) of all people living with HIV worldwide. In 2008, 72 per cent of all AIDS deaths occurred in this region. The epidemic is estimated to have orphaned more than 14 million African children. Nine countries in southern Africa – where AIDS is 'hyperendemic' – continue to bear a disproportionate share of the global

AIDS burden – each of them has an adult HIV prevalence greater than 10 per cent and together they represent around one-third of all HIV cases and AIDS deaths globally (see Figure 1.1). With an adult HIV prevalence of 26 per cent in 2007, Swaziland has the most severe level of infection in the world, while South Africa continues to be home to the world's largest population of people living with HIV – 5.7 million in 2007.

By the end of 2008, 44 per cent of adults and children in the region in need of antiretroviral therapy had access to treatment (a huge increase from 2003 when the regional treatment coverage was only 2 per cent). As a result of treatment scale-up, people are living longer in many countries. In Kenya, for example, AIDS-related deaths have fallen by 29 per cent since 2002.

Women and girls continue to be disproportionally affected by HIV in sub-Saharan Africa. Throughout the region, women account for 60 per cent of all HIV infections. Young women between the ages of 15 and 19 are particularly vulnerable to HIV. In Kenya, for example, young women are three times more likely to become infected than their male counterparts.

Outside southern Africa, the epidemic appears to be under control: Uganda has shown how high levels of political commitment and community-led responses can stabilize HIV prevalence. In other locations in eastern Africa, such as Tanzania, infection rates peaked at a lower level than those currently seen in southern Africa. HIV prevalence in West and Central Africa is much lower than in southern Africa, although two countries have significant epidemics (Côte d'Ivoire at 3.9 per cent HIV prevalence and Ghana at 1.9 per cent).

We will shortly turn to discuss the complexity of the causes and consequences of Africa's AIDS epidemics, but first it is important to provide a quick historical perspective of their evolution.

Three decades on – a brief history

1981–1996: Understanding a new disease

The AIDS epidemic was recognized in 1981, initially among gay men in New York and San Francisco (USCDC, 1981). It was officially named Acquired Immune Deficiency Syndrome (AIDS) in July 1982, and in 1983 the human immunodeficiency virus (HIV) was identified as the cause. The number of cases rose rapidly across the USA and was quickly identified in Europe, Australia, New Zealand and Latin America. The main groups at risk in developed countries were gay men, haemophiliacs, blood transfusion recipients, and intravenous drug users. In central Africa, however, health workers were beginning to observe new illnesses such as Kaposi's sarcoma (a cancer) in Zambia; cryptococcosis (an unusual fungal infection) in Kinshasa; and there were reports of 'slim disease' and unexpectedly high rates of death in Lake Victoria fishing villages in Uganda (Bayley, 1984; Hooper, 1999; Iliffe, 2006). These illnesses were occurring in heterosexual adults. By 1982, cases were being seen in the partners and infants of those infected (Shilts, 1988; Iliffe, 2006).

Early responses were biomedical in nature as public health specialists, epidemiologists and scientists struggled to identify what caused AIDS and how it spread between people. This was followed by a focus on how to prevent the spread of HIV by reducing high-risk behaviours (Chin, 2006). At this time there was no treatment available for AIDS and

initial hopes of a vaccine faded fast. The World Health Organisation (WHO) led the international response to HIV from the mid-1980s, and national AIDS programmes began to be developed (Mann and Tarantola, 1996).

A handful of academics began to explore the wider implications of AIDS during this time; in 1989, the first paper investigating the potential impact of AIDS on food security in Africa was published, following work commissioned by the FAO (Gillespie, 1989). Yet, denial, underestimation and over-simplification remained rife at all levels in these first 15 years.

1996–2010: The antiretroviral revolution, and new perspectives

By 1996 – the mid-point of the history of AIDS – major changes were underway, as academics and politicians began to take on board the multisectoral, developmental dimensions of the burgeoning AIDS crisis in sub-Saharan Africa. UNAIDS began operations in Geneva in 1996 signalling a realization that AIDS was more than a health issue, requiring better coordination between many UN agencies. At the XIth International AIDS Conference in Vancouver, the arrival of new drugs in developed countries to treat AIDS was announced, and mortality among those being treated plummeted.

In 2000, at the XIIIth International AIDS Conference in Durban, South Africa, Nelson Mandela closed the conference with a call for drugs to be made accessible to all. Since then, the response to AIDS has been dominated by new initiatives for making treatment accessible, especially in developing countries. The price of drugs has fallen dramatically with the manufacture of generic drugs (Graaff, 2007). In 2001, United Nation's Secretary General, Kofi Annan, called for spending on AIDS to be increased tenfold in developing countries, and the Global Fund for AIDS, TB and Malaria was established. The same year, US President George W. Bush announced the Presidential Emergency Plan for AIDS Relief (PEPFAR), targeting 15 developing countries. In 2003, the WHO and UNAIDS proclaimed the '3 by 5' plan, to treat 3 million people in developing countries by the end of 2005.

Over the decade from 1996 to 2006, more financial resources than ever before were made available for the response to AIDS, with emphasis increasingly on making treatment available in the developing world. In 1996 there was about $300 million for HIV/AIDS in low and middle income countries; by 2006 this increased to $8.3 billion. This massive response in recent years – largely a result of treatment becoming available and affordable – led to a remedicalization of AIDS discourse and practice.

New perspectives

Yet the mid-1990s also saw an emergence of a new parallel interest on the part of a broader group of scholars and programme officers in the individual, social and economic environments that underpinned vulnerability to HIV infection.

The role of biological susceptibility linked with chronic malnutrition and ill-health – largely ignored by public health authorities in the early years – was investigated. Detailed social research began to reveal the complex factors that affect behaviour and which extend far beyond the influence of individuals. Academics and programme officers learned how social justice, poverty and inequity conditioned the uneven spread of the virus within and between communities and societies.

The notion of 'risk' – in relation to certain individuals who adopted certain behaviours – became better balanced with a broader focus on *structural drivers* of the epidemic and on social and economic 'risk environments'. The notion of AIDS as a development issue, not purely a health problem, opened the door for many new researchers and development professionals.

Meanwhile, as the impacts of AIDS mounted, a greater focus was also applied to the downstream issues. More questions were being raised about the interaction of AIDS with food and nutrition security. Could AIDS precipitate food insecurity – or even famine? This again brought in the focus on another form of vulnerability – to *impacts* of the disease, not to infection by the virus – and to its converse: resilience.

Biomedical approaches continue to be the basis for the core HIV strategies, but the biomedical hegemony in the scientific study of HIV and AIDS has made way for more contextual approaches and more holistic and interdisciplinary explanatory frameworks (Schoepf, 2001). More attention is now being given to the wider socio-economic, cultural and political ramifications of vulnerability, culminating in widespread recognition that to fully and sustainably address AIDS epidemics, we need to go beyond biomedical and narrowly defined behavioural change solutions.

This realization is reflected in the recent shift away from the 'AIDS exceptionalism' espoused by UNAIDS in the early years of the last decade – to a broader 'AIDS plus' agenda. Climate change, food price hikes, environmental degradation and the emergence of new zoonotic diseases have added to pre-existing livelihood threats, such as poverty. Stillwaggon (2006) places AIDS in a socio-epidemiological framework in which it is one of a cluster of factors that both reflect the conditions of poverty and can lead to further impoverishment. AIDS is but one of several 'multiple stressors' – hugely important, but not the only one threat, and – moreover – one that does not work in isolation. This synergy of factors impacting on rural livelihoods poses several methodological challenges in disentangling the particular effects of AIDS from other poverty-related effects; we will discuss these challenges in the final chapter.

To understand people's responses to the reality of having to live with AIDS in their communities and families, to help them mitigate the impacts of AIDS and curb the spread of HIV infection, one has to pay attention to their perceptions of its causes and the meanings they attach to it. Such emic pictures can be elicited by qualitative anthropological research. AIDS is the kind of affliction of which Susan Sontag (1978, p.58) once said: 'Any important disease whose causality is murky and for which treatment is ineffectual tends to be awash in significance.' AIDS then becomes a metaphor for evil and adversity as is, for example, apparent from its association with declining soil fertility (Misiko, 2008), pests in crops (Githinji, 2008) or witchcraft (Nombo, this volume). The fear that HIV inspires as a condition that is hidden until the infection develops into AIDS, is expressed by the following statement documented in research among the Azande: 'Witches, like HIV positive people, may look like everybody else, but are secretly killing those around them' (Allan, 2007, p359).

AIDS epidemics are thus complex, diverse and dynamic – in terms of what drives them, their effects and the way people perceive them and respond to them. In the face of such complexity and context-specificity we need to continue to develop and refine the evidence base. Only in this way can appropriate, comprehensive, multisectoral responses be developed and sustained. This book is one contribution to this growing evidence base, and to the developing policy discourse on AIDS and livelihoods.

Diversity

HIV is diverse in terms of the factors and conditions that determine its spread, its impacts and the types of responses that people make to these impacts. Early fears the virus would spread rapidly outside Africa have not materialized. Even within sub-Saharan Africa, there are several epidemics with widely differing national prevalences – ranging from less than 1 per cent in some western African countries to 26 per cent in the case of Swaziland. The hardest-hit countries, where AIDS is considered to be 'hyperendemic', are all in southern Africa.

A good survey of the diversity of AIDS epidemics in Africa is offered by John Illife in his seminal work entitled, 'A history of the African AIDS epidemic' (2006). There is no point in repeating that discussion in detail here, but we agree with Iliffe's analysis on the epidemic drive from its epicentre in central Africa to eastern and southern Africa. The critical drive was and remains the movement of people. Thus, locations closer to highways, rapidly expanding trading posts, and some parts of urban centres have been and continue to be hardest hit by AIDS simply due to their geography – places where people and goods converge. It follows that there is no single national or regional epidemic. A national epidemic is often comprised of small subepidemics of varying intensity. A good example is offered by the 2003–2004 Tanzania HIV/AIDS Indicator Survey conducted by MEASURE DHS. The data clearly indicate that HIV prevalence among adults at the time ranged from less than 2 per cent in remote regions with little degree of human mobility and migration to over 10 per cent in some parts of the capital, Dar-es-Salaam, and the southern highland region (characterized by high mobility, migration and trade within Tanzania and to Zambia and Malawi and beyond). Yet, had that study been conducted in the early 1990s, the highest HIV prevalence would have been found in the northwestern region. This tells us that epidemics are not only diverse, they are also dynamic. Areas with high HIV prevalence 20 years ago may not have high prevalence today. The twin aspects of diversity and change are given a sharp focus in this book because they shed light on the diverse and dynamic community and household responses to the onslaught of the epidemic.

Dynamics

AIDS has been described as a 'long wave event' (Barnett and Whiteside, 2002). It takes years for an epidemic to spread through the society and generations for the full impact to be felt.

During the evolution of AIDS epidemics, it's useful to distinguish three sequential phases of vulnerability – upstream (relating to risk of an individual becoming exposed to, and infected with, HIV), midstream (individual risk of developing opportunistic infections after HIV infection) and downstream (risk of serious impacts in households or communities living with HIV) (Gillespie 2008; Edstrom and Samuels 2007). These are depicted in the 'HIV timeline' in Figure 1.2, along with the three core HIV strategies of prevention, care and treatment, and mitigation.

We can view this timeline through the lens of individuals, households and/or communities. Each of these phases of vulnerability have particular drivers and consequences. It is also important to recognize the potentially *cyclical* nature of this