MORALITY, HOPE AND GRIEF

Anthropologies of AIDS in Africa

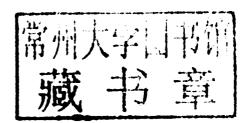


Edited by Hansjörg DILGER and Ute LUIG

Morality, Hope and Grief Anthropologies of AIDS

Anthropologies of AIDS in Africa

Edited by Hansjörg Dilger and Ute Luig





First published in 2010 by

Berghahn Books

www.berghahnbooks.com

©2010, 2013 Hansjörg Dilger and Ute Luig First paperback edition published in 2013

All rights reserved. Except for the quotation of short passages for the purposes of criticism and review, no part of this book may be reproduced in any form or by any means, electronic or mechanical, including photocopying, recording, or any information storage and retrieval system now known or to be invented, without written permission of the publisher.

Library of Congress Cataloging-in-Publication Data

Morality, hope and grief: anthropologies of aids in Africa / edited by Hansjørg Dilger and Ute Luig.

p. cm. -- (Epistemologies of healing)

Includes bibliographical references and index.

ISBN 978-1-84545-663-4 (hbk.)--ISBN 978-0-85745-796-7 (pbk.)

1. AIDS (Disease)--Social aspects--Africa. 2. Medical anthropology--Africa. I. Dilger, Hansjörg. II. Luig, Ute.

RA643.86.A35M675 2010 362.196'97920096--dc22

2010006676

British Library Cataloguing in Publication Data

A catalogue record for this book is available from the British Library

Printed in the United States on acid-free paper.

ISBN: 978-0-85745-796-7 (paperback) ISBN: 978-0-85745-829-2 (retail ebook)

Acknowledgements

This book assembles a collection of papers that were first presented at a symposium on AIDS and the Moral Order at Wulkow Castle near Berlin. On the occasion of this symposium, anthropologists and other social scientists discussed the social, moral and political-economic configurations that have shaped the course of the HIV/AIDS epidemic in sub-Saharan Africa and individual and collective experiences and actions in relation to the disease. Subsequent to the symposium, the papers were significantly revised in order to create a thematically coherent volume.

We would like to express our sincere gratitude to the contributors to this book who have taken up the challenge to revise their conference presentations based on an internal and external review process. We also thank the following panel discussants and chairs who made invaluable comments on the presentations at the symposium and whose comments formed a rich basis for broadening our own and our contributors' perspectives on HIV/AIDS: Paula Treichler, Peter Geschiere, Jamie Monson, Christine Obbo, Benedicte Ingstad, Stacy L. Pigg and Suzette Heald. Finally, we want to thank two anonymous reviewers for constructive comments on the final versions of the chapters.

We thank Duke University Press and Edinburgh University Press for granting permission to reprint shortened and slightly revised versions of the following texts: Jean Comaroff, 'Beyond Bare Life: AIDS, (Bio)Politics, and the Neoliberal Order' (first published in *Public Culture* 19(1) 2007: 197–219); Frederick Klaits, 'The Widow in Blue: Blood and the Morality of Remembering in Botswana's Time of Aids' (first published in *Africa* 75(1) 2005: 46–62). The article by Elizabeth Colson, 'The Social History of an Epidemic: HIV/AIDS in Gwembe Valley, 1980–2004', was first published in Philippe Denis and Charles Becker (eds), *The HIV/AIDS Epidemic in Sub-Saharan*

Acknowledgements

Africa in an Historical Perspective (online publication, 2006). Last but not least, we would like to thank the Volkswagen Foundation for generously funding and supporting the symposium in Berlin. Furthermore, financial support for the preparation of the index was provided by the Department of Political and Social Science, Freie Universität Berlin. A welcome address to the symposium was sent by the then minister for cooperation and economic development, Heidemarie Wieczorek-Zeul.

One note on the use of 'HIV', 'AIDS' or 'HIV/AIDS' in this book: These acronyms are often used interchangeably by the authors, less as referents to a biological entity but rather as social and political categories related to perception, experience and practice.

Hansjörg Dilger and Ute Luig, February 2009

Contents

List of Illustrations	vii
Acknowledgements	ix
Introduction. Morality, Hope and Grief: Towards an Ethnographic Perspective in HIV/AIDS Research Hansjörg Dilger	1
I. Giving Hope? Networks of Healing, Treatment and Care	
1. Beyond Bare Life: AIDS, (Bio)Politics, and the Neoliberal Order Jean Comaroff	21
2. Spiritual Insecurity and AIDS in South Africa Adam Ashforth	43
3. New Hopes and New Dilemmas: Disclosure and Recognition in the Time of Antiretroviral Treatment Hanne O. Mogensen	61
4. Health Workers Entangled: Confidentiality and Certification Susan R. Whyte, Michael A. Whyte, David Kyaddondo	80
5. 'My Relatives Are Running Away from Me!' Kinship and Care in the Wake of Structural Adjustment, Privatisation and HIV/AIDS in Tanzania Hansjörg Dilger	102



II. Moralities at Stake

6. The Social History of an Epidemic: HIV/AIDS in Gwembe Valley, Zambia, 1982–2004 Elizabeth Colson	127
7. Living beyond AIDS in Maasailand: Discourses of Contagion and Cultural Identity Aud Talle	148
8. Politics of Blame: Clashing Moralities and the AIDS Epidemic in Nso' (North-West Province, Cameroon) Ivo Quaranta	173
9. Gossip, Rumour and Scandal: The Circulation of AIDS Narratives in a Climate of Silence and Secrecy Graeme Reid	192
III. Experiences of Grief, Death and Pain	
10. 'We Are Tired of Mourning!' The Economy of Death and Bereavement in a Time of AIDS Liv Haram	219
11. Purity Is Danger: Ambiguities of Touch around Sickness and Death in Western Kenya P. Wenzel Geissler and Ruth J. Prince	240
12. Diseased and Dangerous: Images of Widows' Bodies in the Context of the HIV Epidemic in Northern Zambia Johanna A. Offe	270
13. Orphans' Ties – Belonging and Relatedness in Child-Headed Households in Malawi Angelika Wolf	292
14. The Widow in Blue: Blood and the Morality of Remembering in Botswana's Time of AIDS Frederick Klaits	312
Notes on Contributors	332
Index	337



firms. Source: Reuters, 18 April 2001.	35
Figure 5.1: Illustration in a booklet, instructions for 'good' and 'safe' care for people with HIV/AIDS. Source: Femina HIP Multimedia Initiative, Tanzania.	107
Figure 9.1: The SA Institute for Medical Research is investigating the possibility that AIDS is transmitted by insects or other animals How did you get AIDS? A poof-adder bit me Hey, what do you want to test here with that arse-o-meter! Source: Rapport,	
25 August 1985.	196



Morality, Hope and Grief: Towards an Ethnographic Perspective in HIV/AIDS Research

Hansjörg Dilger

AIDS as an Object of Anthropological Inquiry

Over the last couple of years, anthropological studies on HIV/AIDS in sub-Saharan Africa have taken an increasingly broad focus. While anthropological and social science publications during the first years of the epidemic tended to assume an applied and rather narrow approach to the disease by concentrating on risk behaviours, risk groups and prevention – increasingly also on care and support systems later more recent research has focused on the way HIV/AIDS as a social reality has become embedded in specific social and cultural contexts and how these contexts in turn are being modified, transformed and challenged by the presence of the disease. Thus, from an anthropological perspective, a 'thick description' of HIV/AIDS implies not only the examination of the political, economic and social forces that have prepared the ground for the spread of the epidemic in a given regional and historical setting (Farmer 1999; Schoepf 2001). It also involves the cultural, moral and political responses that various actors in a society have developed in relation to the disease and that give the epidemic its particular shape and meaning in a specific location and context (see also Heald 2003; Setel 1999).



A 'broad' approach to the study of HIV/AIDS raises immediate questions. If, for instance, we assume that HIV/AIDS has to be studied in relation to larger social, cultural and political-economic configurations, why then is it often discussed as a separate phenomenon and what is so exceptional about the disease? This question has no clear-cut answer. On the one hand, the chapters in this book emphasise that the study of AIDS is about the experiences and actions of individuals, families and communities that are struggling with the social, cultural and political transformations that have shaped their everyday lives in the context of globalisation processes and modernity. Thus, the anthropological study of AIDS is about the more general challenges of caring for and supporting the sick and the needy, the responsibilities of burying and remembering the dead, and the moral questions concerning social coherence and continuity in a society undergoing rapid political and economic transformations.

On the other hand, however, many of the chapters make it clear that there is something specific about HIV/AIDS that justifies the numerous studies that have evolved from the topic over the last two to three decades. The specific focus on the epidemic is due not only to the fact that international and national responses to HIV/AIDS have ascribed an 'exceptionalism status' to the disease for a long time: exceptional in relation to the high morbidity and mortality rates caused by the epidemic; the disproportionate funding allocated to the fight against HIV/AIDS (either 'not enough' or 'too much' compared with other diseases); and the social, economic and political impact that the disease has had on societies and communities in sub-Saharan Africa, which has led to the labeling of HIV/AIDS as a 'development problem' (World Bank/Africa Region 2000; Fredland 1998) and even as a 'security crisis' (Ostergaard 2002; Schönteich 1999).

This sense of exceptionalism is also reflected by the social realities and experiences that are associated with the HIV/AIDS epidemic in many African countries — with regard to the multiple prevention, care and treatment programs that have been established in wide parts of sub-Saharan Africa and also with regard to the strong societal stigma attached to the disease since it emerged as a social and cultural reality more than twenty-five years ago.

However, there is yet another aspect of HIV/AIDS that makes it a distinct experience in the life worlds of populations in the wider sub-Saharan African region: the suffering and dying of young to middle-aged men and women – as well as the children that survive them – who are most affected by the epidemic and who are at the centre of the social and moral orders of their families, communities and the larger state formations they inhabit. What makes AIDS so exceptional from this perspective is that the disease has the power to challenge the 'habitual' of everyday life and that it has become a

This book is a contribution to the larger corpus of AIDS studies that have increasingly emphasised the need to explore the social, cultural and political-economic dynamics that have been associated with the HIV/AIDS epidemic in sub-Saharan Africa over the last three decades and that have become the subject of moral tensions and struggles for a broad range of social units and actors in the region. In this regard, the book may be interesting for development workers who wish to learn more about the social and cultural contexts in which the communities and families - who have become the targets of transnationally funded interventions as well as 'grassroots' and 'community-based' programs' - experience and deal with the epidemic in their everyday life. On another level, however, this volume wants to open the study of AIDS for 'general anthropologists' and Africanists who are confronted with the consequences of the epidemic in their various research projects, but who have not taken up the challenge of integrating this issue in their analysis of the social, cultural and political-economic configurations in contemporary Africa.

disruptive and morally disturbing force in the productive and reproductive orders of kinship networks, community constellations and

society at large (see Schoepf 2001: 336).

By this, we as editors of this book do not mean that *all* anthropologists or Africanists should address the topic of AIDS in their research and writing. However, in a similar vein, as globalisation and/or modernity have become common (though not uncontested) topics in studies on societies and groups in contemporary Africa during the last fifteen to twenty years, we feel that more scholars should become aware of the ways in which the presence of the disease has affected local and household economies; gender and kinship relations; religious expression and organisation; conceptions of life, death and healing; and the organisation of social, cultural and political life in sub-Saharan Africa in general. In this regard, this volume wants to make a contribution to the 'normalisation' of the study of AIDS

Hansjörg Dilger

in anthropology and the wider humanities and thus contribute to reducing the sense of exceptionalism that has surrounded the epidemic in academic circles for many years (Heald 2003; Herdt 1987). In the following introduction, three aspects will be addressed that have become characteristic of the broader anthropological study of AIDS in Africa and that are also reflected in the chapters of this volume.²

Bridging the Local and the Global in AIDS Research

For almost two decades now, anthropologists have argued that the objects of ethnographic and anthropological inquiry can no longer be defined in relation to fixed localities and/or neatly defined social groups: globalisation processes, transnational power relations, migratory networks and the political economies of the emerging 'neoliberal world order' have had an impact on the way social relations and cultural politics are experienced and configured in populations worldwide (Gupta and Ferguson 1992; Ferguson 2006; Comaroff and Comaroff 1993, 2000).

In the context of HIV/AIDS, several authors have argued that the spread of the epidemic – as well as the way people have reacted to it – are intimately intertwined with political-economic processes and the dynamics of globalisation. Brooke Schoepf (1992, 2001) and Paul Farmer et al. (1993) have argued that the course of the HIV/AIDS epidemic in 'developing nations' – but also among socially disadvantaged groups in industrial nations – is determined by globally, nationally and locally produced structural forces such as class, ethnicity or gender. Paul Farmer has further grouped these analyses under the concept 'structural violence' and pointed out that entire groups and societies are exposed to increased risk of illness and suffering in the context of globally driven poverty, transnational power structures and a lack of access to health services and education (Farmer 1996, 1999).

The presence of international forces in relation to the epidemic has been most explicit in the context of HIV/AIDS in Africa, which according to Barnett and Whiteside (2002), has to be contextualised in the wider history of the continent (see also Iliffe 2006). Thus, according to these authors, the history of Africa has been shaped not



only by the destructive consequences of the slave trade, the systems of power and economic dependency that were established in the colonial era, or finally the wars of independence, military coups and Cold War interests that have affected living situations on the continent in the postcolonial era. More recently, societal, political and economic orders in Africa were also reconfigured by the structural adjustment programs launched by the International Monetary Fund and the World Bank that intensified the pressure on local gender and power relations and that created a 'risk environment' in which violence, sexual exploitation and now the HIV/AIDS epidemic have all been able to thrive (Barnett and Whiteside 2002: 124-56).

Some of the chapters in this book also emphasise the way in which the course of the HIV/AIDS epidemic in Africa has been entrenched in processes of globalisation and the power relations that have come to characterise the place of the African continent in an increasingly disparate world order. Jean Comaroff (in this volume) argues that the HIV/AIDS epidemic, coming 'at the time of a radical restructuring of the axes of a bi-polar world, of the liberal-democratic nationstate and the workings of capitalism itself, ... served as both a sign and a vector of a global order-in-formation – and with it, a new sense of the possibilities of the political'. By drawing on Agamben's theory of the Homo Sacer (1998), Comaroff points out that the HIV/AIDS epidemic - and the way international governments and agencies have failed to react to it for many years - made clear how strongly Africa has come to epitomise another otherness in the contemporary world order, 'less an axis of evil than of irrelevance'. In this context, people with HIV/AIDS in Africa can be seen as an embodiment of the homines sacri which are at once sacred and dispensable.

That Agamben's exclusive focus on the *homo sacer* – and the way human rights are enacted in a global world order in which the right to live is granted to some but not to others – may provide only a truncated perspective of globalisation processes in Africa and elsewhere, has been argued by Aihwa Ong. In Neoliberalism as Exception (2006: 14f.), she points out that Agamben's exclusive focus on human rights tends to preclude 'other visions of the good life [which] also provide normative guides and ethical claims for the performance of virtue within a given domain of living'; norms and claims, that is, that are promoted amongst others through the work of NGOs and community groups worldwide. In a similar vein, Comaroff (in this volume)

Hansjörg Dilger

argues that the multiple responses that nongovernmental organisations and community-based groups in sub-Saharan Africa have established in relation to the HIV/AIDS epidemic are reflective of the struggles that people on the continent have developed in their efforts to respond actively to the disease and to transcend the destiny of the 'passive AIDS victim'. As she puts it, '[t]he insistence on "positive" life – life imbued with ordinary, future-oriented expectations – is palpable in the forms of mobilisation that press for recognition of the disease. So too is the rejection of "bare death" (for a related argument, see Fassin 2007).

Some chapters in this book show that the analysis of the HIV/AIDS epidemic in sub-Saharan Africa has to take account of the wider political-economic forces that have shaped the course of the epidemic in the context of globalisation over the last few decades. At the same time, however, this volume demonstrates that while it is necessary to lay open how global inequalities have affected the course of the HIV/AIDS epidemic in Africa, it is equally important to focus on the 'local moral worlds' (Kleinman 1995) that determine the ways communities, families and individuals have responded to HIV/AIDS and that transcend and intersect the complex power structures that have been established by national and international actors over the last decades. They argue that we need to know more about the multiple struggles and responses of individuals, families and communities in relation to HIV/AIDS in order to grasp the way the disease is configured as a moral and cultural category and the way these processes produce and affect social, political and economic relationships on the micro- as well as the macro-level.

Adopting an Ethnographic Perspective in the Study of AIDS

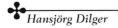
It has become commonplace in anthropology today to agree that 'culture' can no longer be understood as a system of beliefs that is held by all members of a group or society to the same extent or that *inevitably* guides these group members' decisions and actions in their everyday lives and in relation to fields as diverse as religion, kinship or the management of affliction and misfortune. In contrast to earlier approaches that ascribed a 'distinct culture' to neatly defined ethnic groups, contemporary anthropologists argue that culture should be



seen as only one possible system of reference through which people engage in historical processes and through which they make choices and decisions in relation to other systems of reference and identification (such as religion or science) that provide knowledge about the way human beings are situated in society and the world order at large (Abu-Lughod 1991; Gupta and Ferguson 1992).

Ethnography, with its holistic focus and its long-term approach for fieldwork, may play an important role in dismantling the various perspectives, practices and power relations that have come to shape the views, actions and experiences of a broad range of actors in global, national and local settings with regard to HIV/AIDS. A central argument of this book is that individual and collective experiences and actions in the context of HIV/AIDS are best described through the presentation of extended ethnographic case studies and the 'thick description' of a specific locality. As Mark Nichter has argued (2002), the management of illness involves more than the management of the physical disease through the definition of symptoms and/or the choosing of a certain therapy. Illness management is about the social relations that are negotiated in the context of a given illness and that shape the meanings, experiences and actions surrounding a specific illness. It is, furthermore, about the politicaleconomic conditions that determine the presence and distribution of a disease in a given locality, as well as the priorities and entitlement to resources people can claim in a community, household or family concerning the treatment of a disease.3 In a similar vein, the chapters in this volume emphasise that an 'ethnography of the particular' (see Abu-Lughod 1991) in the context of HIV/AIDS should pay close attention to the use of language and metaphors that have come to structure the social reality of HIV/AIDS in various African countries (Mogensen, Ashforth, Reid), the conflicts and tensions that have shaped people's actions and struggles for meaning and healing in the context of severe illness and death (Colson, Whyte et al., Dilger, Geissler and Prince) and the multiple efforts people undertake in negotiating belonging and the moral standing of individual community members following the deaths of a partner, relative or other community members (Offe, Haram, Wolf, Klaits).

However, while it can be argued that participant observation and the recording of extended case studies – often over many years, sometimes even over generations (Colson) - may establish a privileged



viewpoint for the study of AIDS, the ethnographic approach also bears problems. First, an ethnographic approach to the study of HIV/ AIDS - with its appeal to 'pause and look at the struggles' that have shaped the social reality of the epidemic in different settings and communities (Mogensen) – raises concerns about the ethical nature of long-term fieldwork: How ethical is it to engage in long-term research and academic debates when people are dving? While recent publications have discussed issues such as confidentiality, informed consent and also the aspect of mutuality in 'community-based AIDS research' (Baylies 2004), there is no rigid framework or blueprint that guides the anthropological study of HIV/AIDS for all researchers in the same way. Ultimately, it is upon the individual researchers themselves to find an acceptable way of dealing with the ethical dilemmas of doing research on a topic that is shaped so strongly by the continued presence of illness and death, either by collaborating with help organisations and agencies or by 'simply' accepting to be a 'witness' to the suffering in the communities one works with (see Farmer 1992a).

Second, as Paul Farmer (1996: 263) and Brooke Schoepf (2001) have argued, there is a danger of overemphasising the agency of individual actors by focusing too narrowly on the choices and negotiations that guide men's and women's actions in the context of HIV/AIDS. As Schoepf (347) has put it with regard to the situation of poor women:

[I]t is easy to exaggerate the agency of very poor women. ... The late twentieth century saw widespread use of mass rape as a weapon of war. ... That these are conditions of life and death for many millions must not be overlooked when arguing for attention to agency, negotiation, and choice. ... In the time of AIDS, many poor peoples' survival strategies have resulted in their destruction.

The contributors to this book do not want to question the existence of structural constraints and inequalities in the context of AIDS; nor do they negate the fact that individual and collective biographies and experiences are always embedded in 'large-scale processes such as labour migration, urbanization, industrialization, Christianization, and Western education that have disrupted and transformed local social structures and knowledge systems' in Africa during the last 100 to 150 years (Ashforth; see also Setel 1999). At the same



time, however, the authors in this volume emphasise the necessity of achieving a thorough understanding of the ways in which women, men and children in sub-Saharan Africa are struggling to come to grips with the existing structural constraints and how they negotiate relationships, meaning, hope and grief in the face of suffering and death.

A Battle of Ideas: Illness, Body, and Societal Transformation

A view of culture and society that highlights the way in which people draw on multiple – and often contradictory – systems of knowledge and value in managing their everyday lives has implications for the anthropological study of AIDS. What distinguishes the HIV/AIDS pandemic from other historical and contemporary diseases is the extraordinary variety of responses that the disease has produced in societies worldwide – on all levels of societal and political organisation (Iliffe 2006). As Shula Marks has suggested with reference to the medical historian Charles Rosenberg, '[l]ocal and national authorities, governments and NGOs, national and international agencies, political parties, patients and their advocates and above all the pharmaceutical industry have all had their own and often contradicting perceptions and agendas in addressing the challenges [the epidemic] has posed' (2002: 14). Thus, whilst a multi-level response to HIV/AIDS has often been called for in order to bring about a turn in the course of the epidemic (most explicitly in the case of international governments and African states that were criticised for not responding to the epidemic for too long), the involvement of different groups and sectors of society has led to often heated moral debates. As Justice Edwin Cameron has put it at the conference on AIDS in Context in South Africa in 2001, HIV/AIDS has 'from the onset involved as much a battle of ideas as a battle about bodies and organisms and cells' (Cameron 2001: 3).

The morally contested relationships between suffering, individual bodies and the larger society – and the way these relationships are perceived and discussed from a 'local' point of view – have long been the focus of anthropological discussion. According to authors like Victor Turner (1967), John Janzen (1978), and Susan Whyte (1997), illness and affliction in southeastern Africa have often been under-