

Evidence, Ethos and Experiment

The Anthropology and History
of Medical Research in Africa

Edited by
P. Wenzel Geissler and Catherine Molyneux



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Contents

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List of Figures

viii

Introduction

Studying Trial Communities: Anthropological and Historical Inquiries into Ethos, Politics and Economy of Medical Research in Africa

1

P. Wenzel Geissler

Engagements

1. Writing Knowledge and Acknowledgement: Possibilities in Medical Research

29

Susan Reynolds Whyte

2. Can One Rely on Knowledge?

57

Marilyn Strathern

3. Being 'with Medical Research Council': Infant Care and the Social Meanings of Cohort Membership in Gambia's Plural Therapeutic Landscapes

77

Melissa Leach and James Fairhead

4. Contextualizing Ethics: Or, the Morality of Knowledge Production in Ethnographic Fieldwork on 'the Unspeakable'

99

Hansjörg Dilger

5. Testing a New Drug for Leprosy: Clofazimine and Its Precursors in Ireland and Nigeria, 1944–1966

125

John Manton

6. Elucidating Ethics in Practice: Focus on Accountability <i>George Ulrich</i>	145
Evidence	
7. When Physicians Meet: Local Medical Knowledge and Global Public Goods <i>Steven Feierman</i>	171
8. The Plausibility Design, Quasi-experiments, and Real-world Research: A Case Study of Antimalarial Combination Treatment in Tanzania <i>S. Patrick Kachur</i>	197
9. Remember Bambali: Evidence, Ethics and the Co-production of Truth <i>Ann Kelly</i>	229
10. Foetuses, Facts and Frictions: Insights from Ultrasound Research in Tanzania <i>Babette Müller-Rockstroh</i>	245
11. Healers and Scientists: The Epistemological Politics of Research about Medicinal Plants in Tanzania or 'Moving Away from Traditional Medicine' <i>Stacey A. Langwick</i>	263
12. Parasite Lost: Remembering Modern Times with Kenyan Government Medical Scientists <i>P. Wenzel Geissler</i>	297
13. Is the Sharia of the Doctors Killing the People? A Local Debate on Ethics and the Control of HIV/AIDS in a Rural Area in Kenya <i>Suzette Heald</i>	333

Politics	
14. The Historical Interface between the State and Medical Science in Africa: Kenya's Case <i>Kenneth S. Ombongi</i>	353
15. The Intimate Rules of the French Coopération: Morality, Race and the Postcolonial Division of Scientific Work at the Pasteur Institute of Cameroon <i>Guillaume Lachenal</i>	373
16. The Mosquito Taken at the Beerhall: Malaria Research and Control on Zambia's Copperbelt <i>Lyn Schumaker</i>	403
17. Trial Communities: HIV and Therapeutic Citizenship in West Africa <i>Vinh-Kim Nguyen</i>	429
18. Differences in Medicine, Differences in Ethics: Or, When is It Research and When is It Kidnapping or is That Even the Right Question? <i>Luise White</i>	445
Notes on Contributors	463
Index	473

List of Figures

1.1	Questionnaires from Dr Frank's Project (author's photograph).	31	12.4	Mobile Laboratory, 1950s (from 'DDT vs. Malaria') (photographer unknown).	308
1.2	The Author Writing This Paper in the Project Office at Makerere University (photograph by Michael White).	38	12.5	Portrait with 'The Mosquitoes of South Sudan' (author's photograph).	311
1.3	Collecting Knowledge, Acknowledging the Other (author's photograph).	48	12.6	Portrait of 'Yellow Fever Inspector', 1941 (photographer unknown).	312
8.1	Map of IMPACT Tz Study Districts in Southern Tanzania.	204	12.7	Portrait with 1982 Uniform and 1970s Land Rover (author's photograph).	313
8.2	A Strategic Framework for Considering Interventions to Optimise Antimalarial Combination Treatment in Tanzania (adapted from Marsh, Kachur and Mehra, 2002).	205	12.8	Plate with Mixed Photographs of DVBD Colleagues, 1960s and 1970s (photographer unknown).	314
8.3	Participatory Methods Were Used to Conduct Formative Research to Develop Information, Education, and Communication Materials in Support of ACT Implementation in Rufiji District.	214	12.9	Urban Housing in Shauri Moyo Estate, Kisumu Where DVBD Staff Lived With Their Families in the 1960s (author's photograph).	315
8.4	Colour-Coded Dispensing Envelopes Were Developed for Deployment of ACT.	215	12.10	Younger DVBD Staff Members, Mid 1970s (photographer unknown).	320
12.1	The Staff of DVBD Kisumu, Around 1962 (photographer unknown).	302	12.11	Organigram of the Entire DVBD Displayed at the Director's Office, DVBD HQ, Nairobi (author's photograph).	320
12.2	Technologists Bench Training in a DVBD Laboratory, 1960s (photographer unknown).	303	12.12	Group Picture of DVBD Staff Families on the Occasion of the 1963 Christmas Party (photographer unknown).	321
12.3	Officer's Tent with Kisumu Head of DVBD, 1960s (photographer unknown).	306	12.13	Portrait of Mr O. 2005 and 1945 (author's photograph).	324
			15.1	Cameroonisation as Technical Emancipation. A Laboratory at the Centre de Recherches Médicales du Cameroun (Future Pasteur Institute) in 1957.	376
			15.2	Professor Etoundi, Head of the Centre Pasteur/IMPM, Interviewed for the National Daily <i>Cameroon Tribune</i> (28 December 1978).	380

15.3	'We Were Wearing the Coat of a Mechanic'. A Laboratory Technician in a Dark-Green Coloured Coat, c1986.	391
15.4	Unskilled Staff Wearing Dark Blue Uniforms at the Centre Pasteur du Cameroun, c1986.	392
16.1	Garden City – Roan Mine. (no date given) (Plate 31, in Malcolm Watson, <i>African Highway</i> ; with permission from John R. Murray).	413
16.2	European House, 1935. (Plate 32, in Malcolm Watson, <i>African Highway</i> ; with permission from John R. Murray).	415
17.1	Slogans at a 'Community Meal' of Positive Women in Ouagadougou (author's photograph).	435

Introduction

Studying Trial Communities: Anthropological and Historical Inquiries into Ethos, Politics and Economy of Medical Research in Africa

P. Wenzel Geissler

Overseas Medical Research

This book is about medical research carried out in Africa, by African institutions and their collaborators from Europe and the USA. It is thus about what used to be called 'overseas' medical research, a term which – unlike more recent terms such as 'transnational' or 'collaborative' – recalls its imperial origins as well as the asymmetrical topography of power and resources it still involves. Overseas research is shaped by its geographical and political-economic frames, as well as by colonial history and by the process of nation building, and decay, that marked the postcolonial era (or, as Om-bongi, below, distinguishes, the 'postcolonial' and the 'post-postcolonial'). This is why the authors of this volume, participants of the conference 'Studying Trial Communities', held in 2005 at the Kenyan Medical Research Institute (KEMRI) Centre for Geographical Medicine in Kilifi, Kenya, include historians among the majority of anthropologists, and why many of the anthropologists here draw upon historiography or historical sources for the purpose of their ethnography. Medical research in Africa is an area intensely shaped by history, and the fact that it often is oblivious to its own origins and genesis makes it particularly important that we combine ethnographic and historical-archaeological investigations.

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Chapter 4

Contextualizing Ethics: Or, the Morality of Knowledge Production in Ethnographic Fieldwork on 'the Unspeakable'

Hansjörg Dilger

There is a saying in Uganda: If a snake comes into your house do not waste time asking where the snake comes from, but kill it first and ask questions afterwards. (Noerine Kaleeba et al. 1991)

Why are anthropologists doing fieldwork on HIV/AIDS in Africa? Why are they engaging in long-term research and academic debates when people are dying?

In this chapter, I discuss some of the multiple challenges surrounding anthropological fieldwork on HIV/AIDS in eastern Africa with regard to its ethical and methodological implications. I argue that at a time when the boundaries between applied and basic anthropology have become less rigid,¹ questions about the ethicality of ethnographic fieldwork on HIV/AIDS-related issues should focus less on *why* such research is being done and more on how it can be carried out in ethically, and therefore methodologically, informed ways.

By drawing on fieldwork that I conducted in rural and urban Tanzania between 1999 and 2003, I will show that the planning and conducting of this research was shaped, on the one hand, by the precariousness of doing fieldwork in a context where the physical and material survival of many of my informants had to be secured on a daily basis; and where access to adequate healthcare – including confidential HIV testing and life-prolonging therapies for HIV/AIDS – was not available to the majority of the studied community (cf. Farmer 1992; Baylies 2004). In this regard, my research agenda which explored the meanings and practices surrounding

HIV/AIDS-induced illnesses and deaths inevitably triggered questions about global inequalities and the anthropologist's 'right to be there and observe' (Schramm 2005: 172).² From the outset of my research, it was clear that my research approach would not allow for substantial improvement of my informants' health or living conditions. In this sense, the nature of my fieldwork could critically be described as 'bourgeois luxury' – or, as Paul Farmer (1992: 315) has more constructively termed it, as a 'witnessing' of the way in which HIV-infected people live with the disease and how they die from it. In a yet more hopeful formulation, however, such fieldwork represents the view that a careful analysis of the practices and ideas that have evolved around HIV/AIDS may contribute to more differentiated knowledge about the social and cultural contexts in which the epidemic thrives, and thus to creating the basis for locally adapted strategies of prevention, care and treatment (cf. Heald 2003).³

On the other hand, my fieldwork on HIV/AIDS in Tanzania raised issues with regard to questions of confidentiality and informed consent and, more specifically, the politics of speaking about a stigmatised disease loaded with biomedical meanings. As my research evolved, I became aware that in order to establish effective communication about HIV/AIDS on the 'local' level, I had to learn to 'speak properly' – that is, in a socially and morally accepted way – about HIV/AIDS-related illnesses and deaths. Thus, while local discourse on HIV/AIDS in wide parts of eastern and southern Africa is structured essentially by concepts and practices of public health and international development, it is equally configured by silences, rumours, metaphors and 'narratives of illness' (Mogensen 1997) that have come to shape meanings and actions related to the epidemic in all those settings where the language of global development and biomedicine has not been pervasively established.

In the following, I will draw on the various research sites in which I did fieldwork in Tanzania – kinship and village networks, Pentecostal churches, non-governmental organisations – and argue that the ethical and methodological challenges of HIV/AIDS research in eastern Africa are shaped, on the one hand, by social relationships and power hierarchies that in turn shape different modalities of speaking and non-speaking about the stigmatised disease. On the other hand, the social and moral constellations in research sites – of which the participant-observing anthropologist is likely to become an integral part – have a deep impact on shifting interpretations of illness and healing, and consequently on the way in which the ethical topoi of confidentiality and informed consent have to be dealt with by the

researcher and his or her informants. In conclusion, I argue that the insights that can be drawn from my fieldwork in Tanzania shed light on some issues that characterise the moral and social embeddedness of ethnographic research in more general terms. These insights may therefore become relevant for the work of research commissions and ethics' committees, which are increasingly confronted with research proposals that are crossing disciplinary as well as geographical and cultural boundaries.

Before I introduce the social and moral context, which is the starting point for my further reflections on the ethics of HIV/AIDS research – as well as on the modalities of knowledge production in ethnographic fieldwork in more general terms – I will start with a description of the way I became involved in my various research sites in Tanzania through the process of applying for and obtaining an ethical clearance.

Starting Fieldwork in Tanzania⁴

In 1999, I submitted my application for research clearance to the Commission for Science and Technology in Tanzania (COSTECH). The proposal represented a streamlined version of my outline for Ph.D. research and carried the long-winded title 'How people living with HIV/AIDS and their families are coping with the disease in rural and urban Tanzania'. As may be easily recognisable, this rather dry and formalistic heading was primarily a reflection of the way I expected the reviewers at COSTECH to react to a proposal for anthropological AIDS research that in their view might be too far removed from the fields of applied research and/or public health. After all, my proposal, which incorporated issues such as family and kinship relations, support and care within NGOs and churches, 'traditional' healing and the ritual cleansing of widows, was firmly situated in the tradition of basic social-anthropological research. I did not receive a response from COSTECH for several months. However, upon my arrival in Dar es Salaam I was informed that my application had been transferred to the National Institute for Medical Research (NIMR), which was to issue an ethical clearance before the actual research clearance could be processed.⁵

COSTECH's decision did not come as a surprise to me at that time. Indeed, the fact that the discussion of the ethical implications of my enterprise had been neither a standardised requirement of COSTECH nor of the German Research Foundation (DFG), which had provided the grant for the project I was involved in had taken me aback, considering the intense scholarly debates surrounding the ethics of social science and anthropological

research which have dominated discussions in Anglo-Saxon countries over the last decades (e.g. Barnes 1977, Caplan 2003, Fluehr-Lobban 2003).⁶ It was therefore only after I had finished my fieldwork in Tanzania – and after I had experienced how some of the methodological and ethical core assumptions of my revised proposal had proven untenable during the research process – that I started to wonder why the ethical clearance had been issued by the National Institute for Medical Research (and not COSTECH); and whether the ethical guidelines that direct the work of health researchers are appropriate to direct the work of anthropologists, too.

In retrospect, COSTECH's decision became more comprehensible to me when I realised that the processing of my research clearance through the NIMR was probably the only viable solution for COSTECH at that time. Due to the fact that my research involved interviews with 'People infected with HIV' and 'People sick with AIDS', it would have been difficult to figure out – both for the scientific officers at COSTECH and for myself – how this research could actually be carried out without being based on the same ethical assumptions guiding the work of health researchers. After all, it had initially been health researchers, development experts and AIDS activists who had developed ethical codes for the 'personal, professional, institutional and governmental response' to the HIV/AIDS epidemic (African Networks on Ethics, Law and HIV 1994). Health researchers were also the ones who proposed ethical guidelines for doing research with people with HIV/AIDS, especially regarding obtaining informed consent in the context of clinical trials, testing and treatment (cf. Wolf and Lo 2001; Bhutta 2002).

Would it have been ethically and methodologically acceptable for COSTECH, I wondered in hindsight, *not* to evaluate my proposal on guidelines that were derived essentially from health research and that were, at the same time, rooted in the human rights discourse on HIV/AIDS? Would it have been ethically sound for *me* not to base my research proposal on these guidelines – despite the fact that I pursued a social-constructivist argument that perceived health-related behaviours as the outcome of social, cultural, economic and political processes? Would it have been possible to *completely* ignore the larger context of HIV/AIDS research in Africa, which is so heavily dominated by biomedically driven research and by the interests of (international) development organisations and funding agencies which are aimed at rapidly applicable research results?

The answers that I found to these questions changed considerably over the course of my research and also over the time I analysed and processed my field data. In the following, I will show that the endeavours of finding

answers to some of these issues – and, above all, the ethical, epistemological and methodological challenges that are implied in these answers – have to be taken back to the various social, economic and moral constellations in which I carried out fieldwork in Tanzania. I will argue that the theoretical and methodological basis of social-anthropological research on HIV/AIDS can hardly be grounded on a universally valid model of disease, health and ethics, but that the epistemologies of illness and disease, and the methodological and ethical implications that derive from them, vary with the research setting and the way in which anthropologists are involved in shifting research sites. In the next section, I turn first to the setting of NGOs and the practices of health citizenship which have shaped modalities of speaking about HIV/AIDS – as well as perceptions of ethically sound social science research on HIV/AIDS – in the context of neoliberal health policies and structural adjustment in Tanzania.

'We Would Be Dying Like Chicken': Notions and Practices of Health Citizenship in Dar es Salaam

Starting in the early to mid-1980s, African healthcare sectors became subject to far-reaching reforms resulting primarily from the introduction of structural adjustment policies imposed by the World Bank and the International Monetary Fund (IMF) in reaction to the growing economic and political crises of African states. In wide parts of sub-Saharan Africa, these reforms caused severe cuts in governmental expenditures for social services and have led to growing privatization and transnationalization of the health field, which became ever more reliant on the funding mechanisms of international donors.

The privatization and transnationalization of the health field have become most visible in the context of HIV/AIDS – whose emergence and growth conspicuously parallels, and whose course reflects on, the structural reforms in Africa's wider healthcare sectors. In Tanzania, public health responses have been shaped largely by the growing NGO industry which has based its activities on notions of human rights, self-responsibility and empowerment and in recent years has aimed at the involvement of 'affected communities' into its manifold activities. Vinh-Kim Nguyen (2005: 126) has subsumed the various practices and ideas that have emerged in the fields of care, treatment and AIDS activism over the last 10 years under the concept of therapeutic citizenship – a transnationalized form of citizenship

which makes claims on the global economic and social order based on a shared therapeutic predicament (i.e. being infected with HIV). According to Nguyen (2005: 125f.) the social and cultural practices that have evolved in the context of HIV/AIDS have been organized around a complex set of confessional technologies and processes of self-fashioning which are closely interwoven with internationally acclaimed forms of HIV/AIDS activism and essentially draw their legitimacy from the economic, political and biological inequalities existing in a globalizing world.

In Tanzania, the privatization of the healthcare sector and the concurring introduction of public-private partnerships in the country's healthcare system have also led to shifting understandings of rights and citizenship. While colonial and post-independent understandings of law in the country regarded the existence of legal frameworks predominantly as 'constitutive of state power, not as a limitation upon it' (Harrington 1998: 151), the transition to a multi-party system and the growing influence of the international development community from the mid-1990s onwards have defined law as a code for which the state can be made liable; thus opening a space for the perception that health is a right individuals are entitled to (ibid.). In Tanzanian society, such shifting perspectives have not resulted, however, in an open challenging of the state in relation to its alleged responsibility for people with HIV/AIDS – as for instance in South Africa where the demonstrations and activities of the Treatment Action Campaign have become symbolic for practices of health citizenship in the post-apartheid state (Robins 2004). In Dar es Salaam, it was almost exclusively on the safe ground of the NGOs that members of the HIV/AIDS support groups expressed their critique of governmental authorities which, according to them, have failed to take care of their HIV-positive and AIDS-sick citizens. As can be seen in the following statement, this critique was directed primarily at the state level, without taking account of the wider political and economic processes that from the mid-1980s onwards have forced the Tanzanian government to reduce its expenditures for social welfare and which have led to an increasing dependence of the country's healthcare sector on external funding (Harrington 1998: 149). Zephania (male, 37), a support-group member knowingly living with HIV since 1994, said:⁷

Hansjörg: Has the government changed its stance on HIV/AIDS?

Zephania: Yes, this is what they claim, but I haven't seen that they have truly changed their attitudes. ... So far they haven't done anything. ... These people from the government do not come and talk

with us – the ones who are affected by the disease. They only wait for the reports of those who are not affected. ...

I have been to the Muhimbili,⁸ I live in the quarters [of Dar es Salaam], I know the real extent of the problem. ... This question of AIDS is still far removed from them, they haven't helped us with anything. If it wasn't for these NGOs – if it was only for the government – we would be dying like chicken (tungekufa kama kuku). (Emphases added)

By the year 1999, four of the internationally funded AIDS NGOs in Dar es Salaam had established numerous services for people with HIV/AIDS which all focused on notions of human rights and empowerment. The underlying idea of their approach being the assumption that people with HIV/AIDS – equipped with the appropriate (biomedical) information and backed up by a range of social, economic and political measures – would be able to make their own choices and decisions, thus leading a self-determined life.

In addition to the provision of basic medical and counselling services, the NGOs in Dar es Salaam offered legal and economic support programmes, home-based care services for AIDS patients and also support groups for people with HIV/AIDS. These support groups comprised around 20 to 40 men and women each – the majority of them between 25 and 40 years old and with a primary or secondary school education background – who came together for group meetings on a monthly basis. Many NGO clients were members of two or more groups, which meant they could have up to four meetings per month and got to know each other fairly well. Some of the men and women I talked to had previously been interviewed by other researchers or by the media,⁹ and at times they played an active part in requesting an interview or asking questions about my research.

All of the interviewees in the NGOs – including the NGO workers and directors – were comfortable with the way I addressed the ethical implications of my research. Following NIMR's request, I had prepared a short research statement in Kiswahili (*karatazi ya maelezo*) that I read to my prospective research participants, asking them for their oral consent to participate in my research project.¹⁰ Beneath the main research question and a short description of the overall research objectives, the statement guaranteed the interviewees the right to ask questions about my research and to withdraw from the interview process at any time. Furthermore, it contained a paragraph that ensured the confidentiality of any information and names revealed during the interviews.

This latter point of confidentiality was – due to the strong stigma attached to HIV/AIDS in Tanzania – of crucial importance for most of the men and women I interviewed. It was less important, however, for the members and leaders of the NGO SHDEPHA+ (Service Health and Development for People living with HIV/AIDS) who were all HIV-positive: according to them, HIV/AIDS had become a ‘normal disease’ (*ugonjwa wa kawaida*), and one of the ways they educated the public on AIDS was to talk ‘openly’ (*wazi*) about their HIV-infection at public events such as World AIDS Day and also in the media. For them, HIV was the acknowledged cause of their illness and the attitudes they developed towards their infection were shaped by notions of health citizenship, and more specifically by practices of ‘Living PositHIVely’ (Dilger 2001).

However, even those support-group members of other NGOs who were afraid that their HIV-infection might become known to their families or neighbours, seemed to have no general problem with participating in a research project dealing with ‘AIDS’ (*ukimwi*). While many people with HIV/AIDS were stigmatized and discriminated against in Tanzania at that time, the premises of the NGOs offered a zone of confidentiality and protection to their clients and provided – in varying degrees – the basis for a ‘positive’ attitude towards living with their illness.¹¹ A consequence of this general acceptance of the biomedical nature of their illness was that when the NGO clients discussed ‘witchcraft’ (*uchawi*) or ‘traditional healing’ (*matibabu ya kienyeji*) in relation to HIV/AIDS – individually or in the context of the support groups – they found these issues either irrelevant or started mocking the work of traditional healers who were often designated as ‘quacks’ or ‘liars’ (*waongo*).¹²

‘God Can Do the Impossible’: HIV/AIDS and the Neo-Pentecostal Gospel of Health and Prosperity

The second setting of my research was the Full Gospel Bible Fellowship Church (FGBFC) in Dar es Salaam. I learned about this neo-Pentecostal church through two HIV-positive women in the NGO support groups who claimed that the bishop of the church, Zachary Kakobe, was healing people with HIV/AIDS. The FGBFC was founded by Kakobe in 1989 and grew rapidly during the following years. By 2000, the church claimed more than 120,000 members nation-wide and had established more than 500 regional and local sub-branches throughout the country. In Dar es Salaam alone,

the congregation comprised roughly 30,000 members, who in 2003 could no longer gather in the church’s main building which held around 10,000 people during Sunday Services.

One of the church’s main attractions were the healing prayers carried out collectively for all kinds of affliction during the Sunday services and in individual healing sessions during the week (Dilger 2005: 227–81, 2007). Additionally, between March and April 1999 the church offered healing prayers specifically for AIDS which drew around 300–400 people per week and plenty of media attention resulting in pictures of these events in the local newspapers (e.g. *Daily Mail*, 27 March 1999). The overwhelming interest of the public in the AIDS healings was however, also the reason that the AIDS prayers were abandoned soon after they had started. While the church members I talked to remained vague about the reasons why the AIDS healings had been discontinued, they indicated that the church leaders had underestimated the pressure that was put on HIV-infected people as a result of their exposure to public interest: Church members repeatedly told me that a person whose HIV-infection became known in his or her social and familial environment was likely to commit suicide (*kujiua*), since it was unbearable to live with the disgrace of this ‘shameful disease’ (*ugonjwa wa aibu*).

The view of HIV/AIDS as a disease of sinners also shaped the atmosphere that prevailed in my interviews with church members at the home of Pastor Mbwambo, one of the church pastors. For the purpose of the interviews, the pastor had offered me a room of at his home which had earlier served as a garage. Smelling of petrol and furnished sparsely with two metal chairs, the room did not provide the ideal atmosphere for the rather intimate conversations I was aiming for. However, for the men and women I talked to, it was more important that the door to this room could be shut and that the other church members – who were waiting in the neighbouring living room for their individual healing sessions – could not overhear what we were talking about.

Due to the strong stigma associated with HIV/AIDS in the FGBFC, presenting the research statement that I had used for the NGOs and that branded my fieldwork as ‘research on HIV/AIDS’ was impossible. Pastor Mbwambo therefore introduced me to the church members by stressing that I was interested in spiritual healing of *all* kinds of illnesses and afflictions, and by asking them to reply openly (*wazi*) to any questions (*maswali yoyote*) I might have for them. A consequence of this rather vague introduction was that over the following months I could never be certain if my

interviewees were HIV-positive or not, and – if yes – whether they knew about their infection and also wanted to confide in me what they knew. In very few cases did my interviewees actually open up during the interviews and reveal to me that they had tested HIV-positive at a local hospital. In others, I could only suspect that they might be infected with HIV from the way in which they talked about symptoms and diseases they experienced which had often become commonly accepted metaphors for HIV/AIDS illness in Tanzania (as, for instance, 'tuberculosis', 'herpes zoster', 'ulcers' or 'wounds in the stomach'). The most important mode of talking about all kinds of affliction in the church was, however by referring to malevolent spirits (*pepo*) and witches (*wachawi*) which were said to have entered or attacked the bodies of church members and to have diverted them from their state of being saved (*uokovu*). According to the FGBFC followers, satanic forces had taken possession of the world and were responsible for all kinds of suffering (including HIV/AIDS) plaguing the lives of men and women throughout the world. It was only through the firm belief in God and the power of the Holy Spirit that these evil forces could be exorcised from individual bodies and church followers could lead a healthy and prosperous life.

Rumours, Silences and Uncertainty: The Morality of Kinship Relations in Rural Tanzania

The uncertainty about the factuality of the HIV status of my interviewees was also a central issue in my third research setting, the rural area located on the eastern shores of Lake Victoria. This region had been characterised by growing poverty and the increased outward migration of the young generation since the mid-1980s. I was familiar with the rural setting from an earlier stay in 1995–1996 when I did research on the moral discourse on AIDS and the way the epidemic had affected young people's sexuality (cf. Dilger 1999, 2003). When I returned to the villages in 1999, however, it turned out to be rather difficult to approach people on the very sensitive issue of HIV/AIDS illness, despite the close relationships that I had established with some families and individuals during my previous stays.

Shortly after my return to Mara, I presented my research plans to the director and the administrative leaders of one of the local hospitals. Without hesitation, they agreed to assist me generously with 'any requirements' I

might have during my research and introduced me to one of the two hospital HIV/AIDS counsellors, asking him to put me into contact with some of his HIV-positive patients for the purpose of interviews. To the obvious irritation of the director (and of myself), however – and despite the explicit relation of dependency that shaped the hierarchy between the director and the counsellor – the latter explicitly expressed his unwillingness to collaborate on this issue and declined to put me into contact with patients he had counselled or was about to counsel.¹³

The second counsellor I approached turned out to be more supportive than his colleague. Through his facilitation I was able to participate in three post-test counselling sessions in which the result of an HIV test was disclosed to the hospital patient or, in one case, to his mother. In another instance, the counsellor introduced me by letter to a young couple who had tested HIV positive at the hospital and who happened to be the counsellor's relatives. Despite these engaged efforts, however – and despite the fact that oral consent to my participation in the counselling sessions was obtained through the presentation of my research statement – interviews with the hospital patients turned out to be problematic. On the one hand, this was due to the fact that the counsellor himself insisted on being present at all of the interviews carried out in the hospital, resulting in the course of the interviews being blocked at exactly those points which I had hoped to discuss in my research (especially with regard to kinship dynamics, witchcraft or the breaking of taboos). On the other hand, even in the one case where I paid a home-visit to the young HIV-positive couple together with my research assistant we did not have the opportunity for a more elaborate conversation. After arriving at the residence of the young HIV-positive wife, we presented her husband with the letter from the counsellor in which he asked for their 'collaboration' (*ushirikiano*). However, instead of talking 'openly' (*wazi*) with us about 'their problem' (*shida yao*) the couple seemed visibly worried that the cause of their illness had been revealed and they were obviously disinclined to consent to an interview.

Acknowledging the inappropriateness of approaching my interviewees through the hospital – and feeling deeply concerned about the situation I had induced for the young couple – I decided to follow the advice of my research assistant, a 40-year-old man from the area who, from the beginning of our research, had guessed that it might be difficult to approach HIV-positive men and women in rural Mara in the very straightforward manner I had intended. Over the following months we approached people who were, supposedly, infected with HIV or sick with AIDS through the kinship

network of my research assistant, as well as through friends and other acquaintances from the rural area. This was a rather precarious enterprise as I depended on rumours and gossip that were circulating in the villages about HIV tests that had been carried out in the hospitals, as well as on information that was provided by distant relatives of HIV-infected men and women who were often more open about these issues than close family members. Following this system of snowballing and guessing, I could never be certain if the men and women of my research were 'really' infected with HIV or if it was only a rumour that had no 'factual' – i.e. biomedically confirmed basis. I often became more certain only if the person I had talked to became sick and displayed visible symptoms that could be said to be HIV/AIDS-related. In other cases, it became easier for families to talk about the cause of their relative's illness after he or she had passed away and had been buried.

Once the contact with HIV-infected persons and their families had been established, I remained vague in the ensuing conversations about the actual focus of my research by introducing the topic of my project not in relation to 'HIV/AIDS', but with regard to 'chronic and deadly diseases' (*magonjwa sugu*) and the situation of family care for bedridden relatives in rural areas. Having presented the objectives of my research in these very general terms, I left it up to my conversation partners how they chose to talk about their own or their family member's illness. The consequence of this was that our conversations often addressed very different versions and interpretations of the same illness, relating its etiology to biomedical diseases such as tuberculosis and herpes zoster – sometimes also HIV/AIDS – as well as to witchcraft or the breaking of taboos, which in rural Mara is known to result in an illness called *chira*.¹⁴

I often felt somewhat uncomfortable with regard to the ethicality of my proceedings. However, at the same time I understood that it would have been equally critical to ask my conversation partners directly about a possible case of HIV/AIDS illness on the respective compound (about which, in most cases, I was not even certain). To confront HIV-positive men and women in rural Mara with the 'biomedical reality' of their illness would have been tantamount to accusing them of being immoral persons who had led a sinful life. It was therefore only after I had learned to adapt to the social and moral codes which constituted a respectful and non-offensive conversation on 'HIV/AIDS' that my conversation partners and I could discuss the core issues of my research project in a meaningful manner.

From Epistemology to Methodology to Ethics: The Politics of Doing Research on 'the Unspeakable'

According to the Ethical Code of the American Anthropological Association (AAA) ethical guidelines of anthropological research are strongly dependent on the values, codes and norms which prevail in a specific research site and can therefore not easily be transferred from one research setting to another. While, according to the AAA, 'anthropological researchers should obtain in advance the informed consent of persons being studied ... [it] is understood that the degree and breadth of informed consent required will depend on the nature of the project and may be affected by requirements of other codes, laws, and ethics of the country or community in which the research is pursued. ... [It] is understood that the informed consent process is dynamic and continuous ... It is the *quality* of the consent, not the *format*, that is relevant' (American Anthropological Association 1998, emphases added).

In the case I have presented on the previous pages, the research statement that I had developed in agreement with the National Institute for Medical Research in Tanzania in order to obtain the oral informed consent of my interviewees had been an important instrument for my research in the NGOs of Dar es Salaam, as well as in the hospital context of rural Mara. However, the shift to other research sites required the adaptation and switching to different social and moral constellations, expectations and values which constituted ethically acceptable and non-offensive behaviours as well as modes of speaking and doing research about AIDS in these other social contexts.

The obvious differences that existed between the NGOs, the FGBFC, and the kinship networks in Mara were now, I would argue, closely related to the respective epistemologies that shape notions of illness and healing – and the concurring ethical perceptions – in these individual settings. In the NGOs, people shared a model of HIV/AIDS as it is promoted by medical researchers and by international organizations, which are the main donors of programmes on prevention, care and treatment. In the FGBFC and in rural Mara, on the other hand, epistemologies of illness and healing were shaped not solely by biomedical views of disease, but at the same time by notions of demonic possession, witchcraft and the breaking of taboos. Each of these latter epistemologies provided its own particular interpreta-

tion of disease and affliction, thereby opening up moral debates and conflicts which attributed the cause of a particular illness to the moral failures of individuals, as well as to the growing deterioration of kinship networks and society at large.

As HIV/AIDS is a disease that requires, at least from a 'local' perspective, more than the technical and medical solutions offered by governmental and non-governmental health programmes (cf. Heald 2003), anthropologists have to be sensitive not only towards the different epistemologies that govern practices and ideas around illness and healing in a specific research setting; they should also pay heightened attention to the methodological and ethical challenges that are implied in these epistemological truths, as well as to the modalities of speaking and non-speaking about AIDS they are producing. Finally, shifting epistemologies of disease and illness have varying implications for the relationships between the anthropologist and the study participants, the anthropologist's emotional and moral involvement in the research, and the 'production of knowledge' in ethnographic fieldwork in more general terms. Let me illustrate these aspects with further material from my research in rural Mara.

Different Epistemologies, Shifting Moral and Methodological Agendas

In Mara, the shift from one epistemology to the other challenged, on the one hand, the empirical foundations of my research. Most of the data I collected in the villages with regard to specific cases of HIV/AIDS illness were based on rumours, gossip and speculation. As mentioned above, it was often only after a person became ill or died that I could gain more certainty about the biomedical basis of my previous classifications in which I had identified my interviewees and their family members as 'HIV-positive', as 'ill with AIDS', or as the 'relative of a person infected with HIV'. However, while in many cases doubts remained about the 'factual' foundations of the collected data, I want to follow Luise White (2000), who defined stories, ideas and meanings that are produced, negotiated and perpetuated in rumours as social and therefore 'real' and powerful facts. In rural Mara rumours about suspected HIV infections did not only play an essential role in the ways people with HIV/AIDS experienced and dealt with their own illness – whether it was 'really' AIDS-related or not; rumours about HIV/AIDS also determined to a large degree the way in which social and

familial relationships for the care and support for sick relatives were constituted and the way in which social and moral obligations and priorities were (re)formulated in the course of illness, death and burials (cf. Dilger 2005, 2008).

On the other hand, my adaptation to locally accepted modes of speaking about illness as well as my growing involvement in the social and moral relationships of the area challenged the methodological and ethical implications of my research on several levels. First, the strong reliance on participant observation and on less formalized conversations in the village context required a flexible use of field methods and of speaking about disease: Many of the men and women I talked to were in an advanced stadium of their illness – others were grieving for their relatives who had recently passed away – in neither case, however, would it have been possible to tape-record our conversations or to make notes about them at the time we talked. Similarly, it would have been unethical to confront the affected person and his or her family with the biomedical diagnosis 'AIDS'. Any urge one might have felt to address the 'real' nature of a disease or to talk about a sick person's approaching death gave way to the desire to give hope and reduce anxiety and fear. In many instances it was not even acceptable to talk at all as we were all overwhelmed by the situation and the helplessness we felt at being exposed to the grief and suffering of those who were about to die or had already died.

On another level, reflecting on the ethical assumptions of HIV/AIDS research demands a careful reflection on how the researcher is able to protect him- or herself throughout the course of fieldwork. The immediate encounter with suffering and death in an environment in which the participant observer is gradually becoming a part requires emotional stability and the ability to keep 'social distance', which is normally expected from trained health workers, medical professionals or psychologists but not from social anthropologists. At times, confrontation with the suffering and death of others has a creeping effect not only on one's emotional state but also on one's physical condition. As Vera Kalitzkus has remarked with regard to her fieldwork on organ transplantation in Germany, an anthropologist doing research on death and suffering will at times find him- or herself struggling, in the literal sense of the word, 'to keep the illness and death of others away from his or her own body' (Kalitzkus 2003: 38ff., my translation).

Finally, the decision to become part of the various epistemological fields from which HIV/AIDS is negotiated and acted upon implies an ethical decision by the researcher with regard to his or her own capacity to act. The

more one becomes involved in the 'culture of silence' on HIV/AIDS – and the more one becomes engaged in the logic of speaking about other kinds of illnesses and disease etiologies – the more difficult it becomes to know for certain what is ethically sound behaviour and what not. Thus, once the anthropologist has gained a deeper insight into the everyday life of people in a research setting, he or she will inevitably notice that HIV-positive men and women – sometimes without their own knowledge, sometimes obviously on purpose – are infecting others with the disease. In some cases, the researcher will feel a strong impulse to address these issues openly and to prevent the person in question from infecting others. In 2000, for example, there was the case of a young man in rural Mara who had tested HIV-positive in the hospital and who, according to people in the village, had been informed by a doctor about his diagnosis. However, while people critically watched how this man continued to sleep with young girls – and allegedly infected some of them with HIV – they did not dare to confront him directly. When I asked people in the community what they could do about these events, I did not obtain a clear answer – except for the often heard statement that 'the only possibility to stop this man is to beat him up or to kill him'. What could a non-applied researcher do in this situation? Would it have been ethically appropriate to initiate a public controversy about this issue, considering that this step might have resulted in an outburst of violence? Would it have been advisable to consult the village authorities about this case, hoping that legal action might be taken against the man in question? (Which, by the way, I did, thereby learning that the local authorities were as helpless about this issue as I myself or the other people I had talked to as they claimed to have 'no legal evidence' for action as test results from the hospital were confidential.)

In less obvious cases deciding on ethically sound behaviours is equally difficult and triggers a slew of ethical and moral dilemmas. In principle these dilemmas are quite similar to the dilemmas also experienced by counsellors at the local hospitals in Mara – thereby rendering their sometimes unorthodox methods of counselling as described above more understandable. One of the counsellors asked me if, for instance, the widow of a man who has died of AIDS was to be cleansed by a relative of her late husband through sexual intercourse in order to avoid *chira* – what should he do and what were his responsibilities in this situation? Should he inform the man who was about to cleanse the widow about his late relative's illness – thereby preventing not only the infection of this man and his wife, but possibly also of other members of his family (e.g. the couple's unborn children)? Could

he do this on the basis that HIV tests in the hospitals are often being carried out without the explicit consent of the patient or of his or her relatives? Should the counsellor hazard the risk that the widow – possibly together with her children – would be abandoned by her late husband's patrilineage, thus contributing to the further weakening and disintegration of kinship networks in Mara and possibly driving the widow into 'prostitution'?

To conclude, the different modes of speaking and non-speaking about HIV/AIDS in Mara – which are organised around complex moral dilemmas as well as around different epistemologies of illness and disease – are adding further layers to the politics and ethics of the unspeakable as sketched in the previous sections. As an anthropologist in Mara, I was confronted with at least three conflicting strategies shaping the discourse and silence on HIV/AIDS illnesses and that were employed in situated – and sometimes convergent – ways by families and individuals. These discourses, silences and moralities formed an entangled web of meanings and codes that in its intertwinement with social relationships and economic realities shaped a 'culture of silence' around AIDS (cf. Meursing 1997; Dilger 2005: 282–330) and was essentially organised around the three following (mutually contradicting) axes:

First, many people – not only those who worked in a health organization or were otherwise connected to an 'institution of modernity' – felt the urgent need and/or moral responsibility to control the spread of the disease by establishing pervasive biomedical knowledge about HIV and a corresponding practice of 'openness' and 'disclosure' among the population. While this practice should ideally be the result of a voluntary process that is, among others, enhanced and promoted by AIDS NGOs, some of my interviewees felt that it should, if necessary, be enforced by the Tanzanian state. This opinion was expressed most vividly by a male nurse in Mara who told me: 'It would be good if the government tested everybody of whom they know that his or her relatives are HIV-infected. These people should then be made known to the public so that everybody knows about them. All tests should be made under the supervision of the government and the government should then announce the names of all sick people'.

The second strategy is shaped by people's desire to control the ruptures which families and communities ascribe to an increase in deaths and illnesses among young men and women as well as to the wider social and moral implications of rural-urban migration and related processes that are understood to lead to the disintegration of social relationships in the context of modernity. The idioms of illness that correspond to this strategy –

and that challenge an over-simplified view of public health, according to which the HIV/AIDS epidemic has resulted in an all-embracing silence on cases of illness – are the idioms of witchcraft as well as possession through satanic forces or the breach of social and cultural norms (*chira*). All of these idioms refer cases of illness to the wider social, cultural and spiritual contexts of the affected individual and his or her families, thereby emphasizing the 'how' and the 'why' of disease as inseparable aspects of individual and collective experiences of illness and affliction (Heald 2003: 229f.).

Finally, an outspoken silence around cases of HIV is triggered by sensations of danger and pain that are connected to the thoughtless and non-voluntary revealing of the 'true cause' of another person's illness. Not only may an enforced disclosure raise anxieties in the affected person about his or her approaching death. It may also have serious consequences for the reputability and the social and economic standing of the affected individual and his or her family because of stigmatization and the threatened exclusion of the affected persons from kinship and community life. Finally, 'forced disclosure' may have an adverse impact on community life as it is feared to set in motion a cycle of mutual accusations that in the long run may endanger social relationships in unpredictable ways.

Conclusion: Knowledge, Power and the Moral Embeddedness of HIV/AIDS Research

Early on in the debate on HIV/AIDS and anthropology, Paul Farmer (1992) has argued that anthropological fieldwork on HIV/AIDS implies, on the one hand, problems and dilemmas that are associated with ethnographic fieldwork in general. According to Farmer, HIV/AIDS research poses not only the question of how conflicting interests within specific research sites – represented by governments, funding agencies, NGOs, and research communities – shape the agendas of fieldwork and consequently the research outcomes. Ethical considerations in AIDS research also touch upon the relationships between anthropologists and their informants and the way in which the often unequal distribution of power in the field affects access to research data and confidential information, as well as the representation of study subjects in research reports and publications. Finally, ethnographic AIDS research addresses the way in which the source of funding affects the epistemological presuppositions and the methodologies of fieldwork (Farmer 1992).

On the other hand, HIV/AIDS research also confronts anthropology with more specific ethical and methodological challenges. The dramatically high HIV infection rates in many African countries – and the fact that HIV-infected and AIDS-sick people in resource-poor settings have long had a low prospect of getting access to antiretroviral treatment – raise urgent questions about the applicability of research results and the ways in which informants and their communities can profit from the research in a timely manner. Certainly, the issue of applicability speaks again to more general debates on ethics and anthropology which have centred on the question for whom ethnographic knowledge is being produced: the community, the state, the funding agency or simply for the sake of 'science'? However, while the overall relevance and accountability of ethnographic research have moved to the centre stage of debates on anthropology and ethics since the 1970s (Hymes 1972; Scheper-Hughes 1995; Caplan 2003: 5ff.), I would maintain that there is a qualitative difference between HIV/AIDS and other topics that are not immediately connected to questions of how research results can not only improve the living conditions of communities under study but actually 'save the informants' lives'.

Finally, research on a stigmatised topic like HIV/AIDS is affected by the multiple challenges and dilemmas that result from the way in which confidentiality and access to knowledge about the HIV-positive status of individual persons is embedded in power relations that are constituted far beyond doctor–patient relationships or the local research sites. In many parts of southern and eastern Africa, people living with HIV are reluctant to disclose their illness to third parties; others do not know about their HIV-positive status, either because of the lack of access to counselling and testing services or because the information is withheld from them by the personnel of health institutions (cf. Harrington 1998: 160f.). As the confidentiality of an HIV-positive diagnosis is protected by medical laws in many African countries, the knowledge acquired by an anthropologist regarding individuals' HIV-infection involves critical questions not only with regard to the way in which he or she obtained this information but also to whom he or she imparts this knowledge (e.g. within the research team) and for what purpose.¹⁵

In this chapter, I have argued that the various ethical implications of anthropological AIDS research – in Africa as well as in other parts of the world – cannot be dealt with as static and unchangeable entities but, have to be subject to continuous reflection and reconsideration throughout the process of doing research. In the same vein as it is impossible to offer a

blueprint for ethically sound research in contexts of poverty and threatening violence (cf. Scheper-Hughes 1995), ethically sound codes and behaviours on confidentiality and informed consent in AIDS research can not simply be retrieved from textbooks, formalized guidelines or pre-interviews with key informants, but are gaining shape only through dialogical processes and the growing social and moral involvement of the anthropologist in his or her research setting. As a consequence, ethical codes in anthropology can not be defined with reference to the standardized procedures of health research – nor, as many AIDS activists might prefer to have it, to a universalistic discourse on human rights. While human rights values may often converge with the personal values of an anthropologist and his or her research subjects, at other times they are ‘lifted out of any particular context and raised to the level of the categorical imperative’ (Caplan 2003: 16), thereby representing a clear discontinuity with local moral worlds and becoming ethically questionable for anthropological research.

I have argued that the multiple ethical dilemmas of HIV/AIDS research as described above are further complicated by shifting epistemologies of illness and healing which in turn shape different modes of speaking and non-speaking about HIV/AIDS in shifting research settings. These epistemologies open up a slew of moral and ethical dilemmas with regard to HIV/AIDS research and have a deep impact on how the ethical *topoi* of confidentiality, informed consent, applicability of research results etc., have to be dealt with by the non-applied working anthropologist and by his or her informants. In conclusion, I want to maintain that all of these questions are tied into the more encompassing issue of knowledge production in anthropology as opposed to knowledge production in the natural and to a large extent, also in the social sciences.¹⁶ Knowledge production in anthropology is a reflexive process that – while mostly starting out with a clearly defined research question – may lead to less predictable outcomes throughout the course of fieldwork, the analysis of field data and the writing-up of research results. Social and cultural anthropology are not based on the collection of discrete samples or of objectively quantifiable and reproducible knowledge – nor do they rest on the assumption of a morally and socially neutral researcher. As has been shown most vividly by Clifford and Marcus (1986), the subjectivity of the anthropologist and the necessity for critical reflection on the researcher’s own position in the whole course of the anthropological enterprise, challenge the ethnographic authority of the researcher and hint to the importance of making transparent the social interactions which lead to the production of knowledge in the

course of fieldwork, data analysis and writing. For all these reasons it may seem even more necessary to reflect on some of the dilemmas addressed in this text before the research process starts. However, it is difficult (and almost impossible) to tackle *all* of them in a research proposal or in an application for research clearance to be evaluated predominantly by medical and health researchers whose writing and research is based on theoretical, epistemological and methodological assumptions that often significantly differ from those of anthropologists and/or the communities under study.

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Notes

1. See the discussion in *Current Anthropology*, 1995, 36(3). According to Antweiler (1998), ‘applied’ research does not necessarily imply the immediate translation of research results into a policy-making context. ‘Engaged anthropology’ can refer to a wide diversity of contributions to non-academic audiences through which anthropological insights are made available for public discussion.
2. Schramm’s work dealt with the ‘homecoming’ of African-Americans to Ghana and essentially involved questions about the political legitimacy of a white, European researcher doing fieldwork on this topic. However, the ethical dilemmas I experienced in encounters with death and suffering in Tanzania were similar to Schramm’s experience in that they substantially challenged the ‘mere presence’ of the anthropologist.
3. During my fieldwork in Tanzania, NGO experts and representatives of international organizations repeatedly expressed astonishment about the long-term approach of ethnographic fieldwork ‘when people were actually dying’. However, one may justifiably also ask: Have the numerous HIV/AIDS interventions that have been developed and implemented over the last 10–20 years had a significant impact on preventing all the infections and deaths that have not occurred? Is it not

highly relevant for the development of effective interventions to have more detailed knowledge about the social, political and economic processes that shape people's ability and/or willingness to adapt their behaviours to the messages of local, national and international AIDS campaigns? (cf. Campbell 2003).

4. My research in Tanzania was carried out during several stays between 1995 and 2006 (altogether 22 months). In 1995/96, the fieldwork focussed on young people's moral perceptions of HIV/AIDS, as well as on intergenerational and gender relations within the context of modernity (see Dilger 1999, 2003). Between 1999 and 2003 – the period which is also the focus of this chapter – I studied relationships of care and support in extended kinship networks in the Mara region, as well as through observations at NGOs and in a Pentecostal church in Dar es Salaam (Dilger 2005, 2007, 2008). In 2006, I returned to Tanzania for a brief visit focusing on the introduction of antiretroviral treatment and the growing presence of Neo-Pentecostalism in the country.
5. Tanzania's National Institute for Medical Research (NIMR) was established by an Act of Parliament in 1979 and became operational in 1980. According to the NIMR website 'the institute is responsible for carrying out, controlling, coordinating, registration, monitoring, evaluation and promoting of health research in Tanzania'. Among the research priorities of the NIMR are Malaria, HIV/AIDS and Sexually Transmitted Infections (STI). The NIMR is affiliated with the Commission for Science and Technology (COSTECH), which is the umbrella organization for research, science and technology in the country and which was established in 1986 as a successor to the Tanzania National Scientific Research Council (UTAFITI).
6. The teaching and research position I have held at the University of Florida between 2005 and 2007 has made me even more aware of the different prevailing national standards regarding the politics and ethics of ethnographic fieldwork. At public US Universities all research proposals involving human subjects must be submitted to an internal Institutional Review Board (IRB) which confirms the ethical soundness of the project and particularly of the Informed Consent Process.
7. According to Harrington (1998: 149), the national budget allocation for healthcare in Tanzania fell from 9.4 per cent in the 1970s to 5 per cent in 1990/1991. In the early 1990s, 80 per cent of capital expenditure for the healthcare sector was coming from external sources.
8. Tanzania's largest government hospital.
9. See, for instance, the work of Janet Bujra and Scholastica Mokake on WAMATA (2000). One client of WAMATA was featured in an interview in *The Express* under the somewhat sensationalistic headline 'Full-blown confessions of an HIV victim' (*The Express*, Dar es Salaam: 26 November – 2 December 1998).
10. Initially, the NIMR had requested the preparation of an Informed Consent Form. However, since it would have been paradoxical to ask prospective research participants, for whom confidentiality was one of the most pressing issues when considering an interview with me, to sign a written consent form, I made an agree-

ment with the NIMR that a 'research statement' and oral consent would be the more appropriate instruments for my purposes.

11. How fragile this basis often was became obvious when NGO workers visited clients in their homes. Thus, one of the NGOs had to park the car which was used for visits in the context of home-based care and on which the name of the NGO was written, at a distance from the respective client's house so that his neighbours would not become suspicious of the reason for the visit and the nature of the client's illness.
12. A more respected form of 'traditional' medicine in the NGO context was Traditional Chinese Medicine. At the time of my research TCM was being offered through the Society for Women and AIDS in Tanzania (SWAA-T), whose director, a medical doctor, was involved in a research project on Chinese medicine. According to Elisabeth Hsu (2002), the popularity of Chinese Medicine among patients in Dar es Salaam is due to the 'rapid effects', as well as to the 'scientific' and 'modern' appearance TCM pills and treatment are said to have.
13. It might be argued that the unwillingness of the counsellor to support my research project was based on ethical concerns about revealing the HIV-positive status of his patients to third persons. However, as I found out later, the counsellor was probably more concerned that I might gain insight into his somewhat unusual and problematic methods of counselling. While HIV-positive patients in Tanzania do have the right to be told about their diagnosis according to the national law (Mashalla 1997; Harrington 1998: 161), many counsellors do not disclose this information to all of their patients, but instead disclose it to their family members – and in some cases, not at all. For the *Guiding Principle on Medical Ethics and Human Rights* that has been established by the Medical Association of Tanzania and which provides legal protection for individual citizens with regard to access to medical test results as well as against the breach of confidentiality by doctors, see Harrington (1998: 161).
14. The illness *chira* is said to result from the breach of norms and prescriptions concerning the regulation of sexuality and involving strict rules on how, between whom and in which periods of time sexual intercourse is allowed or even prescribed, and in which cases the neglect of these regulations may cause illness (cf. Parkin 1978: 151; Dilger 2005, 2008; Prince and Geissler 2010).
15. According to Baylies (2004), confidentiality is particularly problematic to maintain in a context where alone the participation in a study on 'HIV/AIDS' may lead to the stigmatization of informants as well as of researchers and their assistants. Moreover, the disclosure of personal information, for example in a focus-group discussion may lead, upon completion of the interview, to the participants' enhanced reflection on their own HIV-status or that of others, which implies that the mid- and long-term effects of the research cannot always be controlled.
16. The opposition between health and social science research, on the one hand, and anthropological research, on the other, lies not so much in the fact that health researchers or social scientists would not take into account the different perspectives

characterizing shifting research contexts. Marilyn Strathern (this volume) has argued intriguingly that health researchers are very aware of these contexts and perspectives. The opposition consists, however, in the way the researcher becomes ethically and morally involved in the values, practice and norms prevailing in the community under study.

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Chapter 5

Testing a New Drug for Leprosy: Clofazimine and Its Precursors in Ireland and Nigeria, 1944–1966¹

John Manton

In the increasingly laboratory-centred context of mid-twentieth century pharmaceutical research, the persistent difficulties in subjecting leprosy to laboratory investigation presented a paradox, thrusting conceptions of the field, field ethos and field research conditions centre-stage in assessing the efficacy of chemotherapy in leprosy. Until 1948, with the ratification of Dapsone at the International Leprosy Congress in Havana, there was no universally recognized effective drug therapy for leprosy, and continued problems in supervising the administration of Dapsone in the following years ran alongside an increasingly active search for alternative drugs. One group of compounds with evident potential for the treatment of leprosy was developed at the laboratories of the Medical Research Council of Ireland (MRCI) on the grounds of Trinity College, Dublin (TCD), through the 1940s and 1950s, leading to the synthesis of B.663, the compound later known as clofazimine.² This compound, subjected to clinical trials in Nigeria in the early 1960s, is still an effective component of the multidrug regimen used to treat leprosy today.

The development of clofazimine, and the demonstration of its efficacy in treating leprosy, brought together chemists, biologists, clinicians and medical researchers from locations and institutions in Africa, North America and Europe over a period of over ten years, building on a complementary set of earlier networks in Irish science and medicine, and articulating a new ethos of field practice and international collaboration in leprosy research. This chapter describes the personal and institutional networks, the scientific knowledge and practice, and the medical problems which brought the MRCI research laboratory, originally conceived in order