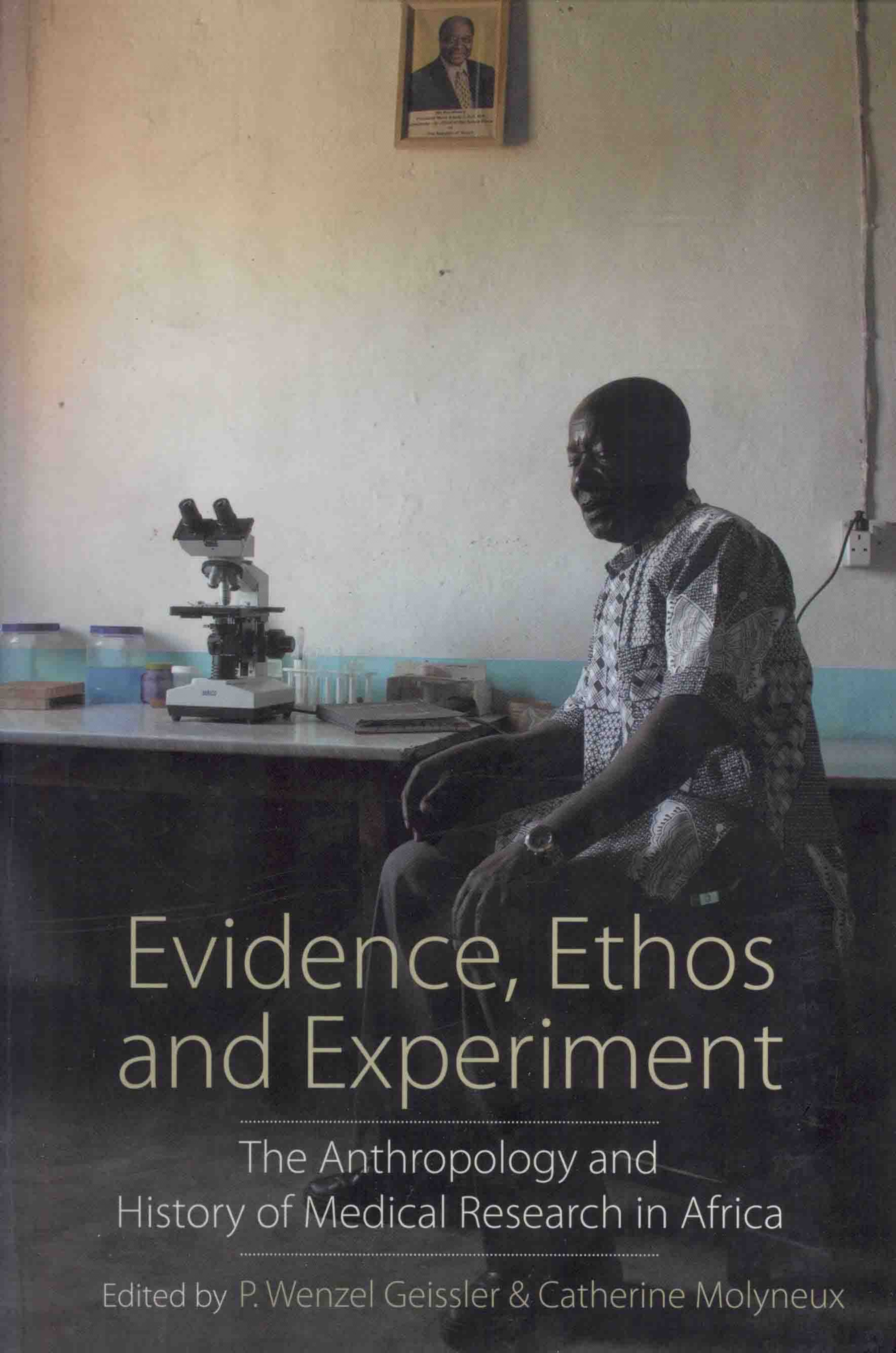

Evidence, Ethos and Experiment

The Anthropology and History of Medical Research in Africa

Edited by P. Wenzel Geissler & Catherine Molyneux

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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 assymetrical 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 Ombongi, 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.

The chapters below focus on contemporary medical research endeavours and, to a lesser extent, their postcolonial prehistory. They cover a range of African countries, and diverse types of medical research: clinical studies, drug development and randomised controlled trials, entomological surveys and vector control, ethnobotany and phytopharmacology, even medical anthropology. What they have in common is a commitment to understanding how medical research is shaped in the interactions — set within stark political and economic disparities — between global scientists and their institutions, national and transnational forms of government, and people who contribute time and effort, and often also bodily substance, to research projects, either as temporary employed staff, or as study subjects without direct, formal remuneration. The contributors ask why, and under which circumstances, scientific medical work takes on particular forms, and how the people and institutions involved determine what is right and wrong, and which direction to take. Underlying these inquiries is, for many of the authors, the question of how scientific investigations – as well as the public good that medical science makes possible – could be realised in a more democratic and equitable manner. Thus, their scholarly occupation with science in Africa is intertwined with reflections on the politics and ethics of medicine, in the 'overseas' situation of unequal scientific and technical capacity and great disparities in power and wealth.

The Ethos of Medical Science

This book could be said to be about the ethics of research, but it does not limit itself to the domain of discourse that recently has been cast as 'research ethics' or 'bioethics' in the regulatory sense of guidelines and principles of 'good clinical practice' (see e.g. CIOMS 2002), and which has given rise to some fruitful debate in public health and attendant social sciences. This literature blossomed in particular during the past decade, stimulated, among other sources, by the human rights discourse that evolved around HIV/AIDS, and, more specifically, by the debates provoked by the 1997 discussion among scientists and ethicists on appropriate 'standards of care' in African HIV research (see Angell 1997; Lurie and Wolf 1997). Simplifying a rich debate for the purpose of positioning this volume, we can discern a continuum across this literature, ranging from contributions that aim to produce better regulatory frameworks or to implement rules more systematically (e.g. Leach et al. 1999; Emanuel et al. 2004), to social research that enriches the debate through the use of sociological and anthropological method (e.g. Molyneux et al. 2004, 2005a,b; Fairhead et al. 2006; Parker et al. 2008).

The authors of the latter kind of texts often critique and qualify the terms set out in standard bioethics guidelines, or resituate research ethics in their political-economic context – thereby critiquing their inherent 'anti-political' effects (e.g. Benatar and Singer 2000). By contrast, the former – social science that remains within the delineations of the existing bioethics discourse – tends to reify these limitations of regulatory bioethics, excluding, at times explicitly, questions of political and economic inequality and interest from the purview of ethical 'worries' (see Emanuel et al. 2005). The contribution of this literature to critical debate about medical research and scientific knowledge, and thus to the creation of egalitarian and democratic science, is therefore limited by an implicit acceptance of the status quo. Setting themselves in particular apart from this normative version of the scholarly debate on medical research ethics, the anthropologist or historians below situate themselves outside the frames of existing normative 'bioethics', and many critique these frames or their epistemological and political premises (see e.g. Dilger, Heald, Strathern, White). In as far as they do directly refer to research ethics, they prise open the taken for granted closures of existing ethical discourses, in order to create the possibility of thinking up alternatives. In other words, the chapters collected in this volume wish to extend the critical and analytic end of the spectrum delineated above.[1]

While most contributors below acknowledge the importance of legal instruments to regulate medical research, the ethical impulse behind their chapters is different from that which drives bioethics guidlines in the sense embodied by 'Good Clinical Practice'.[2] For the sake of distinguishing it from 'ethics' in the restricted sense that is now often taken for granted in the context of medical research – emphasising the protection of individual rights at the expense of a wider societal project including the pursuit of justice – one could refer to this different concern as the 'ethos' of medical research, that is, the visions and projects that orientate and direct the discourses and practices of different actors and groups, in different places, situations and periods.[3]

Ethos in Time

Scientific ethos, or articulations of ethos in relation to medical science, is shaped by historical and political-economic circumstances, and revealed by close attention to how different actors, in different localities and times, produce scientific evidence in particular ways, how they express motivations and aims, take decisions, identify and solve problems, chose ways forward and evaluate past actions. Ethos can be articulated on diverse levels of scale – including, for example, commitment to thoroughness and pride in technical inventiveness, faith in progress and enlightenment, commitment to freedom, welfare, equality or democracy – and linked to different wider societal projects – such as the nation or a global commonwealth, the market or the welfare-state. In contrast to narrow definitions of 'ethics' in terms of guidelines and rules, the broader study of ethos emphasises the problem of direction over that of particular choice, the openness of intention and anticipation over the closure of a right or wrong action. Asking for the ethos of science is searching for the projects implied in it, the imagined futures and pasts, and thus it is as much about temporality as it is about morality (for the centrality of time for diverse articulations of ethos, see also Badiou 2002).

Articulations of ethos shift over time, and not infrequently the broad frames of one historically situated ethos serve as shared ground, upon which struggles about diverging interest can be carried out. A key example of this, which several of the chapters below attend to (e.g. Ombongi, Schumaker, Geissler), is the specifically modern, mid-twentieth century ethos which took modernisation, progress and development for granted, and which shaped science and drew upon it to expound visions of society and government. The outlines of this particular ethos may be particularly visible to us, today, for two reasons. It has been analysed, critiqued and deconstructed, most fruitfully by the Frankfurt School and later by the Foucauldian tradition, giving us a sense of distance from it; and yet, as we inhabit an increasingly uncomfortable and destructive sort of after-modernity, we cannot help but rediscover some of the attractiveness of the outdated hopes of our modern forebears (whom we now know have never been modern, leaving us with a task at hand).

Importantly, this modern ethos served also in the African medical context as a shared frame of reference for politically and economically radically opposed interests: colonial medical administrators could draw upon it to justify, for example, racial segregation, while anti-colonial freedom fighters could demand medical equality and redistribution of the fruits of progress. Claims and counter claims could thus be made with reference to this one overarching ethos. Choices could be contested, even fought over, within this frame, which did not provide simple moral answers. This potential inclusiveness, and ambivalence of ethos, which allows for diverging interests, conflict and dialectics, is an important difference to 'ethics' as conceived of in regulatory research ethics.

Ethos and Politics

In a similar way, a contemporary ethos based on individual freedom and rights and the value of life can be drawn upon to defend very different interests, for example those of the pharmaceutical industry claiming intellectual property rights, and those of treatment action campaigns demanding equal rights in HIV treatment; those of industry-sponsored 'patient advocacy' groups demanding high-cost drugs for unproven improvements of patients' lives, and those of 'right to die' activists, who oppose the dictate of life-extending medicinal technology (see Ong and Collier 2005). Thus, within the space of an overarching ethos different interests can be both disputed and brought together. Indeed, as most of the authors below will agree, contestation, consensus-making and contradictions are inevitable dimensions of the historical process, and must be named and articulated in the political engagement of science. At the same time, different articulations of ethos can coexist, compete and interrelate within one historical situation. For example, in the field of medical science and healthcare, individual rights provide for a very different ethos from that of older government public health; yet, both coexist around many of today's key health issues. If we, for example, want to engage with the ethical challenges that HIV research and intervention pose, we need to understand how these different kinds of ethos overlap, mix and conflict across this field; we must consider the different political and societal projects entailed by, respectively, emphasising individual rights to confidentiality and voluntariness, or the responsibility of government public health to minimise suffering and maximise citizen's welfare.

Commitments in the sense of ethos thus go beyond rule-set 'ethics principles'. The latter distinguish right and wrong, an inside and an outside, divided by a moral line. Such an apparently clear moral separation obscures the more ambiguous political and economic struggles that shape medical science, and the society that it exists in and brings about. Discussions about the 'ethos' of science include interest and conflict into the purview of ethical reflection rather than excluding them by the sanitising morality of principles. Ethical action can thus be anchored again from where it has been unmoored: if science is about truth and value – with all the term's moral-cum-economic ambiguity (see e.g. Kelly and Geissler 2011) – these are inseparable from power and resources. Whether science harbours the possibility of change – the improvement of knowledge, lives and societal order – depends crucially upon whether and how the linkages between ethics, epistemology and political economy are rendered visible, negotiated and contested. Struggles about ethos are thus linked to questions of truth as well as to matters of interest.

Trial Communities

Anthropologists are usually called to work on medical research with a clear remit: to study 'the community', that is what medical research protocols define as 'study populations' and 'participants' or 'volunteers'. Their task is, then, to describe certain characteristics of this group, such as 'preparedness' and 'response' to a clinical trial, or 'cultural' concepts and behaviours of significance to the trial or intervention. The aim of the anthropologists assembled in this volume, and their historian colleagues, is different. Their unit of analysis is, in diverse ways, not a particular, delimited group, but sections of a wider network that is constituted not through attachment to a place or 'culture', but by the work of collaborative medical research.[4]

When we met at the conference in Kilifi, Kenya, whence this book derives, we referred to this network of actors engaged in medical research – for some of us including non-human actants – as the 'trial community'. This definition of the subject has two implications: it opens the frame to include everyone concerned, and it shifts focus from the concerns arising from a particular social grouping to those arising from the relations between points, nodes and groups in the network. This allows discerning new collectives and solidarities – such as trial volunteers, data collectors and entry clerks and other workers in scientific production sites – and new connections, distinctions and separations, for example between Zambian and US American doctors, or between medical anthropologists and medical ethics. Finally, a focus on the production of associations destabilizes taken for granted boundaries – such as the line between 'community' and 'researcher', the difference between 'cultures', between scientific and traditional medicine and so on.[5]

Since we met in Kilifi in 2005 to study 'trial communities', which we then felt were an exciting, largely unexplored field, several important works have been published, which in diverse ways apply anthropological knowledge to overseas medical research, if not all of them in Africa, and which inspire many of the authors below in their ongoing work (e.g. Biehl 2005; Nguyen 2005; Petersen and Folayan 2005; Petryna 2006, 2009; Rajan 2006; Cooper 2008). The fact that these important books speak a somewhat different language from that of many of the authors below is not only due to the editor's tardiness (most chapters were written before these works became available to the authors) but also due to slightly different starting points. Most of these recent publications on clinical research aim to shift the location of anthropology to levels of scale that explode the notion of locality, as discussed previously, for example by Gupta and Ferguson (1997); they take a principal interest in what Ong and Collier described as 'global assemblages' (2005), working through the global construction, and transformation, of scientific production. The contributors to this volume come at similar issues and concerns from a slightly different angle, one perhaps grounded more in the empirical, ethnographic British-European tradition of social anthropology, starting out from concrete social realities – which not only, but also and importantly, consist of concrete, localised social engagements and experiences.

Moreover, these recently published works share an interest in the political economy of overseas research – which is what makes them so inspiring against the backdrop of less clearly political forms of medical anthropology and ethics. Partly therefore, they focus mostly on commercial, industry-driven transnational medical research or on the effects of private, capital interest in bioscience (e.g. Petryna 2005, 2009; Rajan 2006 Cooper 2008), and most of them take a particular interest in clinical trials – as the most advanced and industry-endorsed form of medical research – and less in the wider field of public health research. The papers in this volume do not pursue such a coherent agenda. In the open spirit of the Kilifi meeting, they are more diverse and eclectic, exploring different possibilities of making medical research and medical knowledge in Africa the centre of anthropological attention. Moreover, many of the authors below focus their interest mostly on medical research in the *public* domain, funded by government or bilateral arrangements and conducted by government or parastatal organisations. Although publicly funded and governed medical and public health research is of course increasingly affected by 'partnerships' with private enterprise and charity, and by reformulations of academic intellectual property rights in the wider neoliberal context, public scientific institutions and the research they conduct pose slightly different challenges from the (important) critique of commercial, openly profit-oriented research, and might also help us to discern diverse directions and intentionalities in the conduct of science today, as well as discover alternatives to the neoliberalisation of science that Cooper (2008) and others have successfully explored.

Critical Ethnographies

Underneath the diversity of geographical areas, scientific domains and historical periods, and different political viewpoints and disciplines, the papers assembled here share a commitment to ethnography in the sense of tracing relations and separations that shape social space. For most of us, ethnography implies both studying social relations across domains and levels of scale, and beyond locality, and understanding people's, including scientists, lives; both fascination with 'global assemblages' and attention to intimate social encounters and engagements. Both are needed to question formations and habits that have become commonsensical, to make visible structures and processes that are obscured or ignored, and to contribute to the critical analysis of science and society.

Most of the texts in this book could be said to be 'critical' studies of medical research and its ethos, in the sense not of 'anti-science' – all contributors are committed to scientific medical research and progress, and none has an issue with science as such – but of allowing us to see scientific research in a different way, and positioning science within relationships that at times are overlooked, at other times downplayed and ignored.

First, attention is fixed within the material realities, both of the research work and of the lives of people involved in research, including political and economic inequality and deprivation. Second, authors attend to the institutional relationships beyond the purview of research itself, within given localities such as between government healthcare system, pharmaceutical industry and medical research – and across levels of scale, between national government and transnational institutions and corporations. Analysing such networks means tracing visible as well as unseen connections, and exploring the aggregations and separations produced by social, spatial and epistemological categories. As such the critical study of medical research aims to prise apart the pre-existing and newly formed social relations – such as the 'community' that performs much work in contemporary understandings of research ethics – and to problematise separations such as that between researchers and research participants, which projects a problematic epistemological distinction onto social space and overlays, sometimes obscures, other social distinctions. Last but not least, contributors aim to reveal alternative solidarities, material similarities, overlapping interests and tensions attendant to these groupings – such as, relating to the previous example, the material similarities and overlapping interests among overseas research participants and some categories of technical re-