

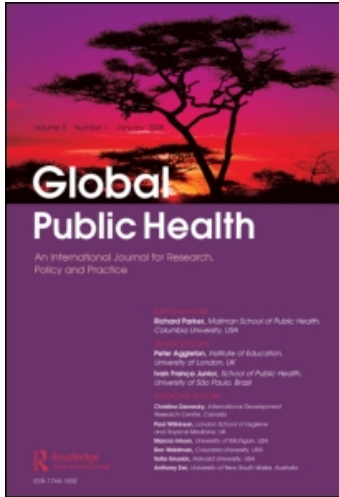
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Global Public Health

Publication details, including instructions for authors and subscription information:

<http://www.informaworld.com/smpp/title~content=t716100712>

Anthropology, knowledge-flows and global health

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First published on: 08 March 2010

To cite this Article Feierman, S. , Kleinman, A. , Stewart, K. , Farmer, P. and Das, V.(2010) 'Anthropology, knowledge-flows and global health', *Global Public Health*, 5: 2, 122 – 128, First published on: 08 March 2010 (iFirst)

To link to this Article: DOI: 10.1080/17441690903401338

URL: <http://dx.doi.org/10.1080/17441690903401338>

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Anthropology, knowledge-flows and global health

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(Received 2 March 2009; final version received 11 September 2009)

Global health programmes are damaged by blockages in the upward flow of information from localities and regional centres about realities of professional practice and about patients' lives and conditions of treatment. Power differentials between local actors and national or international decision-makers present further obstacles to effective action. Anthropological research and action, in its most effective current forms, make important contributions to these issues. This research often continues over the long term, intensively. It can be multi-sited, studying actors at local, national and international levels simultaneously. It studies the relative knowledge and power of impoverished patients and global decision-makers, all within a single frame. By doing so, anthropological research is capable of providing new and important insights on the diverse meanings of patient decision-making, informed consent, non-compliance, public health reporting, the building of political coalitions for health and many other issues.

Keywords: global health; anthropology; ethnography; public health; bioethics

Each step in the growth in capacity of global health institutions has made the need for local and regional knowledge more urgent. Even before the most recent period of rapid globalisation, knowledge-flows from localities to ministries of health were weak in the poorest countries, and the shift of authority over healthcare from national to global levels has weakened the influence of local knowledge even more. Brief social surveys and occasional focus groups in local sites are no substitute for regular reporting on practical knowledge and lived experience: about what it actually means to practice medicine with an unpredictable assortment of donated technologies; about how diverse groups within local communities experience the uneven benefits of globally provided technologies; about the meaning on the ground, in real people's lives, of rules on research ethics formulated at a distance of many thousands of miles; about the relative urgency of competing disease problems as experienced by the poor; and generally about the moral experience of illness, disease and medical practice in places that have little power to make their knowledge heard in decision-making centres.

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Anthropologists and others who study local experience intensively have the potential to play an important role in both mediating and studying flows of knowledge, and in translating knowledge into action. They are able to elucidate how medical interventions are experienced by those with little power. Intensive ongoing research at the local level often leads to conclusions and forms of understanding that diverge strikingly from what would be expected by global planners. One example is the issue of informed consent. In southern Uganda, the word for 'risk' turns out to have a broad fan of meanings without a straightforward equivalent to the meaning intended by international convention. Confucian ethics in China are largely ignored in NIH-sponsored research. In a malaria vaccine trial in the Gambia, the community from which research subjects were drawn defined the appropriateness of collaboration (which then led to consent or refusal) not on the basis of their understanding of the protocol or its formal definitions of risk, but rather on the quality of their personal relationships to the research team and the extent to which the team appeared to take seriously a broad range of local health problems. Because relationships were good, local people defined the study as a success, even though the vaccine itself failed.¹

It is not enough, if one wishes to understand these cases, to achieve a basic understanding of local cultural terms. Anthropologists no longer believe that culture is a reified object, easily described and mastered. Its analysis is a complex and open-ended process. In addition, two issues at the heart of the matter go far beyond cultural competence. What is needed first is an understanding of the pressing dilemmas – the harsh constraints on decision-making – faced by people who live and work far from the centres of policy-making power. What does it mean to be a member of an extended family where several relatives are living with AIDS, yet family resources are sufficient to pay for drugs for only one person? How do we understand the choices faced by nurses in Botswana, who must move HIV-positive patients into therapy quickly, but who are delayed by the wait for test results and lack adequate personnel to counsel their multitude of patients?² It is a matter of practical importance to think what it means to walk in their shoes.

The second matter needed that cannot simply be reduced to culture is attention to power relations. Within medical hierarchies, power operates not only at obvious moments of command, but also more subtly in the capacity of those with greater power to set priorities and to have their decisions carried out. Those with less power may find that their knowledge, while potentially important, is difficult to communicate to those above them or to translate into sustained action. When, for example, an auxiliary nurse midwife in India is compensated based on her ability to meet immunisation quotas, it becomes difficult for her to devote time to examining the babies she is immunising – to recognise, for example, that a baby might have a high fever or need oral rehydration solution. The immunisation campaign itself, as a whole, may be rational in its overall goals, but the health worker, with relative lack of power and as the recipient of specific instructions, finds it inappropriate or unfeasible to exercise personal discretion and judgement.³ Nor will her knowledge of local infant health conditions be translated to higher levels; such information rarely flows upwards. Similarly, where a developing country physician with few resources works in a world of vertical programmes (one for AIDS, another for malaria, yet another for childhood immunisations), that physician's own knowledge of medical conditions in the region can be devalued. There is little possibility for her knowledge to move up to decision-makers, given her own status

within the globally determined medical world, and given its division among disease-specific programmes.

Under these circumstances, researchers who study the local are most able to achieve a richly contextualised approach when they have the range of knowledge and experience to understand both power relations and the existential dilemmas of daily life. Current anthropological practice, in its strong forms, shows the possibility of achieving this, and has four significant strengths. First, ethnographers are well placed to build textured understandings of existential dilemmas, to reflect on the moral experience of their subjects and of themselves. They do this especially well when they live and work with the communities they study over long periods of time. The second and third strengths have to do with approaches to space and to power. The practice of multi-sited research – in village communities, among public health planners intervening in those villages, and at global agencies – makes it possible to study social systems that are local and global, simultaneously. Similarly, contemporary practice supports the study of institutions and groups of diverse power within a single frame of analysis: health planners and slum dwellers; pharmaceutical companies and villagers, all at once. Space and power intermingle in complex ways; actors at the local level often find ways to exercise globally derived power. Fourth and finally, research in communities, on multi-sited networks of influence, and on multiple levels of power can all be brought to bear in studying (and playing mediating roles within) the broad coalitions and social movements that sometimes emerge as powerful positive forces. The existence of these coalitions points the way towards a planning process with some reciprocity, one in which knowledge and influence do not always flow in a single direction (from the top down, or from global centres outwards), and the power of global actors to determine action at local levels is constrained.

Defining a frame of analysis that matches a field of social action makes it possible to simultaneously study public health interventions and the realities of patients' lives. This broader approach has the possibility of revealing crucial elements of disease-related social processes that would not otherwise be captured. For example, the ethnographic study of tuberculosis treatment in Delhi reveals the complex diversity of experiences underlying what is classified in health reports as 'patient non-compliance'. In fact, patient withdrawal from formal programmes is often a response to the failures of the programme itself, including the failure of first line therapy. Desperate families struggle in their lives with the consequences of this failure, which has a profound impact on family relations. The families, under stress, frequently turn to the resources of a large and complex medical marketplace where poorly trained practitioners (many of them legitimately licensed) offer hope and often a wide and inappropriate range of drugs. The search for help is characterised by elements of hopelessness and incoherence. The standard interpretations of non-compliance do not capture these social realities, which raise profound questions about the context-specific nature of patient response and also about the utility of protocols that are difficult to adapt to patients' experience.⁴

This example points to a further value of finely textured descriptions of human experience. Studies of 'the local processes (collective, interpersonal, subjective) that realise... values in ordinary living' (Kleinman 1999, p. 71) make it possible to move towards an acknowledgement of suffering, and of the fact that profound inequalities both reflect and further perpetuate structural violence. This has value in and of itself.

Additionally, there can be great practical value in bringing to light the realities within a heterogeneous medical–social field: such analysis can identify fundamental flaws in the basis on which social data are collected for public health purposes. We get important insights by studying the terms used by people in weak positions to define their own problems. For example, women’s health specialists working in regions along the eastern African coast, where infertility is a problem, are rightly concerned with the treatment of STI’s and with the dynamics of the relationship between the childless woman and her husband; they worry about the diversion of resources to traditional healers who, in their view, cannot cure infertility or STI’s. The act of traditional healing, meanwhile, often defines the problem in a different way: not as infertility but as childlessness among women who have seen their children die; not as a problem between husband and wife, but as one concerning the woman’s powerlessness within a broader range of relatives; and not as the result of pathogens, but of personal distress and the failure of the social network that is determinative of her welfare.⁵

Such analyses of the situation challenge assumptions about the individual autonomy of the patient that are at the heart of both bioethics and research about patient behaviour. Standard surveys elicit individual responses to a range of questions concerning patients’ responsiveness to the changes in the cost of treatment, choices among potential drug regimens, risk behaviours, household activities, transmission of public health information and much else. Meanwhile, well-grounded ethnographies across eastern and central Africa (and other places) demonstrate that many important health decisions are made by groups, based most often on extended family, but also on other bases such as neighbourhood or religious congregation (Chavunduka 1978, Janzen 1978, Feierman 2000, Dilger 2005). Collective decision-making goes naturally with forms of health care in which networks of ordinary people provide money, labour and other resources because publicly provided resources are inadequate (Foster 2007). A generation of social psychology studies has demonstrated that group decisions are not simply individual decisions writ large; asked the same question, individuals questioned separately will give one set of answers, while the same individuals aggregated into groups will give different ones. Despite this recognition, a great many health decisions are studied as though they are individual ones, as Western bioethics demands. On this basic issue, as on others, finely textured local studies are capable of providing insight on both key methodological questions and the moral experience of health and illness by those directly affected.

At a different level, ethnographies of health institutions and health workers identify systematic blockages in the flow of medical information as a result of inequalities in power and influence. Local health workers in resource-poor countries are poignantly aware of health problems that are not addressed by global priorities. Physicians, in particular, express needs for information that would have a direct impact on clinical practice, but these needs remain invisible. They are, once again, outside the line of vision, except to those who seriously study the social field of medicine at the local or regional level. Physicians want to know, for example, at what birth weight a newborn is viable, given local medical conditions; what is the prevalence of particular genetic hormonal disorders in the populations they treat; what are the outcomes of surgery for breast cancer when chemotherapy is not available; what are the best strategies for dealing with interruptions in drug supplies, when protocols call for continuous treatment (Feierman forthcoming)?

The same problem of blockage in the flow of information is revealed from the other side of the divide in ethnographic studies of enterprises that work in developing countries to provide clinical data about drugs to pharmaceutical companies. Contract research organisations have the task of creating data that can support claims of efficacy in industrial countries. They therefore try to seal off their data collection from the complex disease conditions and difficult medical dilemmas of the countries in which they are performing the research. They are specifically interested in collecting data that are *not* local, and so here, once again, the potential flow of useful medical information is blocked. Scholars know about this blockage only from fine-grained studies of the local social field of knowledge production, and how it is situated in its global context.

At stake here are not only issues of description and analysis, but also of social action, of work that supports the formation of coalitions of actors at all levels, so that the flow of information, with blockages released, becomes part of a political strategy for addressing health problems. Just such a coalition emerged to contest the blockage of pharmaceutical data in Brazil. Brazilian academic physicians questioned the manufacturer's recommended dosing for imiglucerase, an expensive drug used to correct the enzyme deficit in Gaucher's disease, a rare genetic disorder. The manufacturer, however, controlled all the patient data. The issue was resolved when the provincial government, the teaching hospital, activist patient groups, and primary care physicians formed a coalition to systematically collect local data, so as to be able to provide patients with adequate care with appropriate dosing. This is just the sort of coalition best understood through current ethnographic approaches: one that involves a social movement of patients; physicians at many levels; and government officials, all of them operating in a global business environment.⁶

The careful description and analysis of multiple fields of space, power, knowledge and moral experience reveal the power of coalitions that cross boundaries to challenge harmful blockages of information and influence. One remarkable example of this sort of boundary crossing can be found in the progression of Brazil's AIDS policy over the past several decades. Even early in the epidemic, popular social movements (of Afro-Brazilians, Christians, lesbians and gays, feminists and others) contested medical decisions and formed alliances with public health workers. These highly visible activities influenced Brazil's drug policy, and also contributed to the government's stated emphasis on alleviating poverty and structural vulnerability as key factors in its AIDS policy.⁷ A different kind of popular mobilisation occurred in Uganda, where numerous local-level groups emerged early in the epidemic and linked up with an engaged national medical community, a determined national president, global health donors and effective social networks based on kinship and community.

Anthropologists have long recognised that to understand the fate of those distant from the centres of power, one must account for both global and local action, intimate relationships and broad networks of power. The experiences of coalitions in Brazil and Uganda show that this strategy is more than just a descriptive one: successful health movements also take into account these multiple levels. Both effective study and effective action require attention to moral experience, social relationships and culture at every level of scale and, most of all, to the capacity for action of those who live and work under difficult conditions at the margins.

The challenge for global health is to build strategies that make local knowledge viable and salient in settings of policy and programme development, practice and evaluation. This will require an emphasis on interdisciplinarity, as well as greater openness to methods of knowledge production and projection that include qualitative approaches and also social science studies of global health as a particular institutional system affected by economic, political and cultural context. That context must be studied as much for being a barrier to as a facilitator of local–global communication about values and implementation.

Notes

1. Stewart (2007) made a detailed study of words used for risk and other central bioethical concepts, as they are currently used in the Luganda language, in Uganda. She undertook this focused and carefully specified study as a follow-up to her own ethical concerns that emerged during her extended research in Uganda for a Ph.D. dissertation. On Confucian ethics in China, see Kleinman and Nie (forthcoming). Research on consent in the Gambia is reported in Geissler *et al.* (2008). The research was based on extended interviews by the authors with fieldworkers about their lives and careers and their role in the malaria vaccine trials. The research is based, in addition, on questionnaires administered to 181 men from the vaccine trial villages, and 80 open-ended interviews with survey participants. Geissler has been engaged in extended field research in Africa since 1994.
2. For a rich account of the dilemmas faced by nurses and other health care workers in Botswana, based on ethnographic research from 2002 to 2004, see Carpenter (2008).
3. The ethnographic study of immunisation in India is reported on by Das (1999). The study is the product of a group Social Science and Immunization Project. Das has been doing ethnography in India for several decades.
4. The study of tuberculosis in Delhi is part of a larger longitudinal research project on poverty and urban health in India. A general description of this research, as it applies to pharmaceuticals, is given in Das and Das (2006). A more detailed analysis of responses to tuberculosis is in Das (2007).
5. This paragraph and the following one are based on a longitudinal ethnographic research project of Steven Feierman in Tanzania, since 1966. For a general account, see Feierman (2000).
6. The account of Gaucher's disease is given in an extended, multi-sited study of contract research organisations and their social context, based on ethnographic research over several years (Petryna 2009).
7. The account of AIDS policy and social mobilisation in Brazil is given by Richard Parker, based on ethnographic work since the 1980s. In addition, Parker spent a period from 1989 to 1990 as a staff member of the WHO's Global Programme on AIDS, a brief period in 1992 as Chief of the Prevention Unit for the Brazilian National AIDS Programme, and a number of years as Executive Director, then Secretary General, and then President of the Brazilian Interdisciplinary AIDS Association (ABIA). For an extended account, see Parker (2007). A brief account is given in Parker (2008).

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