



MEDICAL HUMANITIES

BETWEEN MACROETHICS AND MICROREALITIES

Three papers presented at the decennial
meeting of the Association of Social
Anthropologists of the Commonwealth
University of Manchester, July 2003

EDITED BY DR BOB SIMPSON
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Between Macroethics and microrealities:

What might an anthropology of bioethics look like?

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Introduction

The Wellcome Trust decided to sponsor a panel at the Decennial Meeting of the Association of Social Anthropologists (ASA) in order to draw attention to the funding opportunities available through our programmes in Biomedical Ethics. In particular, the ASA meeting was an early opportunity to highlight a new funding initiative (launched in autumn 2002) to provide support for research on the 'Ethics of biomedical research in developing countries'.

This initiative adopts a broad definition of ethics, and seeks to stimulate contributions from a range of disciplines, including anthropology. It also adopts a broad definition of research; applications will be considered for studies of any part of the research process, from decisions about what biomedical research is undertaken, how the research is conducted, what happens after the research is over, through to its implications for policy and practice.

The papers examine biomedicine and biomedical research on three continents – Africa, Asia, and Latin America – and highlight a range of questions around the ethical conduct of research, and the interaction between local and global approaches to issues in biomedical ethics. We hope that anthropologists will find them stimulating, and will go on to formulate their own grant proposals in this field.

The articles in this paper present the authors' own views and opinions. They do not represent a statement of Wellcome Trust policy.

The ASA panel was organised by Dr Bob Simpson of the University of Durham, whose research has been supported by the Wellcome Trust, and Martin Sexton (Policy Officer in the Biomedical Ethics Department of the Trust). We are very grateful to Professor David Parkin for chairing the panel at ASA2003 and providing a preface to these papers. We are also grateful to Dr Jeanette Edwards, Professor Peter Wade, Professor Penny Harvey and the organisers of ASA2003 for including the panel in the ASA2003 conference programme.

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Preface

The papers in this short collection were first delivered at the Association of Social Anthropologists Decennial Conference held in Manchester in 2003. The theme of this conference was 'Anthropology and Science' and the workshop, convened by Bob Simpson (University of Durham) and Martin Sexton (Wellcome Trust), set out to explore anthropological perspectives on the rapidly burgeoning field of biomedical ethics. The question of ethical relativism as against universalism recurs in all three contributions, which variously draw on fieldwork in Sri Lanka, South Africa and Mexico. This analytical distinction is sometimes partially caulked onto that between micro- and macroethics, or local and global moralities, and is in all cases the source of dilemmas. Thus, Simpson speaks of "an emergent field which captures the interweaving of a transnational logic of virtue with a multiplicity of local beliefs, practices and contexts" (p. 8). He later turns description into process in rephrasing the distinction as having to shift from the macroethics of biomedicine to the microrealities of local circumstances (pp 16–17). Preston-Whyte and Bodasingh talk of "the tension between a relativist stance that recognises the importance of local context and the universalist orientation of much human rights discourse" (p. 26), and go on in some detail to illustrate this tension. Should people included in externally funded biomedical research trials be given the best possible treatment available in the world, or should the local, and therefore inferior, system of care be permitted for, say, the control group, whose treatment in effect amounts to that of being given a placebo? Finkler explicitly argues for what she calls "a relativist approach to bioethics...which recognises that medical ethics needs to be appropriately contextualised for specific societal settings" (p. 46). But she also wants to take account of "a universalist stance" that observes the effects of globalisation in impoverishing local people and the healthcare available to them, and so proposes that we develop a metabioethics that seeks to allocate overall resources equitably throughout a population. Each author, not surprisingly, takes as their starting point local-level understandings of morality with regard to the appropriate medical treatment and also, by implication, the effects on local ideas of personhood, gender, age and status of the macrorealities of biomedicine and biomedical research.

The distinction between relativism and universalism is, of course, really only heuristic. We might think of biomedicine as based on universalist presuppositions. Once introduced, however temporarily, to local practices and ideas, including those of healing, the boundaries between them are likely to become fuzzy and commonly crossed. More boldly, we might claim that relativism is really only of use as a methodological starting point. It focuses initially on local circumstances as the primary reality for the people to be studied and makes no prior presumption of external effect, however much this then is brought to bear. It would be going against the tenets of anthropological methodology to have a universalist starting point. We do not, or should not, define and apply assumptions and theories of globalisation. Universalism is really a project in prospect, namely the search for generalisations arising from comparing different local situations. Methodologically, then, relativism and universalism are neither contrastive assumptions nor epistemological counterparts to each other. Rather, relativism guards against assuming different situations are alike. Similarities have to be discovered case by case. Relativism thus clears the ground for inductive comparison leading to generalisation and thence to something approaching, though invariably falling short of, universal claims.

However, as the three contributions here argue, biomedical researchers and practitioners do commonly assume that their science can be applied to all situations more or less universally. This is why each contributor wants to see bioethics as inevitably transformed once it is applied to the societies in which they work, and not as preserving some kind of unalterable essence. Finkler shows how a range of institutions and concepts in Mexican society shape the relationship of physician to patients. The strength of the family militates against much emphasis on patient autonomy, or indeed patient privacy and confidentiality. The patient is indeed consulted, but in the context of the whole family who, with the patient, express their wishes about a

particular treatment course. Trust, or *confianza*, prevails over an affectively neutral adherence to rules, for “Mexican bioethics requires a case-by-case approach” (Finkler p. 45). The Aristotelian insistence on virtuous behaviour and respect for the patient is thus preserved within a more general compliance with the expectations of a kinship network.

For Simpson the local transformation of biomedical ethical issues began the other way around. He was first interested in kinship and how the new reproductive and genetic technologies might affect local ideas of personhood, relationships and identity in Sri Lanka. But he saw how local doctors and other professionals had to fit these new technologies into their existing moral and social frameworks. Is it even possible to say that a macro-biomedical ethics exists only at the abstract level of international committee and textual injunction, to be applied and thence transformed by local interpretations? It is worth noting here Simpson’s development of the idea of a Sri Lankan biomedicine, not just of biomedicine being applied to Sri Lanka (p. 10), even though he also acknowledges the distinctive epistemological and ontological properties of that professional tradition in its globally established guise. Sri Lankan biomedicine is regarded by its practitioners as replicating that of their British forebears. At first, Sri Lankan biomedicine, in its insistence on reproducing British-introduced ethical procedures, would seem to be quite the opposite of that described by Finkler for Mexico, where family and kinship values have re-shaped much bioethics. But even in Sri Lanka there are some recent indications of a slight turn to integrating medical teaching more fully with indigenous (Ayurvedic) medicine, much resisted by some doctors, and even of a more relaxed attitude among some to the traditional healers (*vedarala*), for whom medical ethics was traditionally integral to their role of providing compassion as well as medicine.

Preston-Whyte and Bodasingh uncover, so to speak, some possible consequences of biomedical research for research participants and their communities, among whom the focus is human immunodeficiency virus (HIV)-positive patients. *Prima facie* such research would be deemed beneficial, so satisfying one of the principles of bioethics, namely beneficence. But, as they show, the considerable stigma attached to people with HIV and acquired immune deficiency syndrome (AIDS) means that they are fearful of being seen as participants in research trials, and yet, either through hope of cure for themselves or their unborn children, or as a result of poverty and the need to participate in a trial in exchange for a monetary incentive, they agree to do so. Do researchers always take sufficiently into account these problems of stigma and visibility? Are the rules and ethics of procedure governing biomedical research flexible enough to lessen the sense of harm suffered by participants under these conditions?

The issue of the four principles of bioethics is fundamental to any discussion on the subject, not because they are necessarily comprehensive but because they are the guidelines which ethical research committees of the participants and researchers take into account in deciding whether research should be carried out. They are beneficence, nonmaleficence, justice and autonomy. As the example just cited indicates, good intentions cannot always prevent harm being committed. A notion of just research would give equal treatment to all participants, and yet the very notion of a control group in the research precludes this, while the use of a local standard of care will by definition usually imply a much lower standard than would be acceptable in, say, the country of the researchers or their sponsors. Perhaps the most difficult concept, discussed fully by each contributor, is that of autonomy; it presupposes the values of Western individualism and the idea that, by his or her own volition, a prospective participant should alone decide whether to be recruited to the project, having understood the purposes and consequences of the research before giving consent. It is of course embedded in the discourse on universal human rights, which are in fact the rights ascribed to persons moulded by the major industrial capitalist democracies. For anthropologists it is probably the biggest source of ethical dilemmas, for our very notions of personhood are drawn from different ethnographic experience and vary among themselves as well as differing in some respects from that deriving from the European Enlightenment. Such differences affect local ideas on the acceptability of, for example, cloning, with some Sri Lankan Buddhists having no problem with this

form of possible human reproduction (Simpson p. 15). After all, individuals are reborn from earlier lives and are not the result of *ab initio* fertilisation of sperm and egg. Continuity through cloning and as *karma* seem paradigmatically similar. In the South African and Mexican cases, individual autonomy is much tempered by an expectation that most biomedical decisions involve families and kin, with the exception in both societies of HIV-positive and AIDS victims for whom, as mentioned, the stigma isolates them cruelly and yet does not confer on them the alternative of a dignified autonomy.

Finally, the famous problem surrounding the status of informed consent turns in part on assumptions made by the creators of the forms that it is an opportunity for individuals to make perfectly clear their understanding of the research and their readiness or otherwise to participate. As Preston-Whyte and Bodasingh explain, informed consent is the heir to the Hippocratic oath and is “the bedrock of Western medical research and practice” (p. 29). In fact, it is doubtful if even in parts of the so-called developed world, all members of society fully understand what biomedical research participation involves. They are at least surrounded by popular media that are quick to report on apparent abuses. Elsewhere, lack of exposure to the nature of research trials makes understanding difficult, with consent itself sometimes made by persons acting in customary proxy (husbands for wives, elders for younger persons, political and religious leaders for subjects, etc.). Participants may feel they have to be part of the research trial as a result of pressure or out of fear of not being seen to participate. Fully informed consent is almost everywhere a chimera, which does not lessen its status as an ideal to be approximated as much as possible through much effort and imagination.

Mention is made by one of the contributors of a consent form consisting of six pages. There are reports of such forms being even longer. It is perhaps part of the globally spreading audit culture that shifts the intention of such forms as increasingly being to protect the researcher more than to elicit justly and informatively the permission of the participant. The culture of litigation has already reached Europe from the USA and it is surely only a matter of time before it surrounds biomedical research trials in Africa and Asia. At one level, this might satisfy the demand for a bioethics with teeth, which serves people who might otherwise be vulnerable to exploitation. At another level, it is bound to affect the sense of beneficence that is supposed to characterise the relationship not only of doctor and patient but also researcher and participant. Litigation of this kind arises in conditions of commercial opportunity and so is not unconnected to the apparently global increase in privatised medicine. It is surely an aspect of the way “the free market has come to shape the form and content of contemporary medical practice” (Simpson p. 16), a development described extensively by Finkler for Mexico, where privatised and different types of state healthcare exacerbate existing divisions between the employed and unemployed, urban and rural, solvent and poor. As all the contributors indicate, moralities are socially constructed. With socioeconomic and political change, then, we may expect radical alterations to the Hippocratic-based ethics of care in biomedicine. We may also assume that there will be corresponding change in the field of biomedical research ethics. Indeed, it is a paradox of all ethical systems that they lay down rules of proper behaviour and procedure to be unswervingly followed as if cast in stone, and yet are themselves transformed by the circumstances of their production and operation.

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What might an anthropology of contemporary biomedical ethics look like?

Some reflections on the development of bioethics in Sri Lanka

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The question posed in the title of this paper is a somewhat presumptuous one. To ask what an anthropology of contemporary biomedical ethics might look like is rather to imply that there isn't one already. This, of course, is not the case. Numerous anthropologists have been drawn into research and commentary on the rapidly burgeoning field that considers the relationship between Western biomedical knowledge and human value systems (for example see Kleinman 1995; Callahan 1999; Das 1999). However, this relationship seems to have been a rather uneasy one (Marshall 1992; Muller 1994). Anthropology's general orientation to the developing world, in contrast with the predominant focus of biomedical ethics on Euro-American societies, has meant that points of overlap have hitherto been relatively few. At a conceptual level, one might also draw attention to the significance attached by anthropologists to the question of relativism in making sense of cultural diversity. In mainstream biomedical ethics, questions of relativism are prioritised rather differently; culture is a relevant variable but its significance is secondary to the quest for commensurability in over-arching concepts such as rights, justice and equality. Consequently, how relativism is theorised within anthropology and what its implications are for understanding human circumstance has often resulted in anthropologists landing askew the evolving field of biomedical ethics (Macklin 1998). It would seem that anthropologists' compulsion to draw attention to what is morally relevant in people's lives is apt to be mistaken for an assertion of the absoluteness of moral relativism (Benatar and Singer 2000: 825).

These differences in orientation are important to explore as they touch on perennial themes in the debate over how cultural pluralism might be reconciled with attempts to construct universals of one kind or another. However, recent developments in the velocity and spread of biomedical knowledge require us to think rather differently about how the discipline of anthropology might inform the burgeoning field of expert discourse known as biomedical ethics. As Rabinow has argued, the current forms taken by the expansion of capitalism result in a rapidly changing relationship between consumption, markets and monetary value and what might be thought of as belonging to those realms. The conjunction of changed economic conditions, new scientific knowledge and the strategies of political actors create new fields in which morality, humanism, justice and, ultimately, the meaning of *anthropos* itself is problematised and re-constituted (Rabinow 2002; see also Palsson and Rabinow 1999). To conceive of such fields, let alone research them, requires anthropologists to think afresh about how their 'fields' are situated in relation to global processes. But, to imagine 'a world transfigured by transnationality' (Ong 1999:10) does not just draw attention to local problems of cultural reproduction and identity formation – it must also highlight the economic and epistemological hegemonies within which these processes are framed and which continue to fabricate illusions of consistency and homogeneity. Biomedical ethics is itself a part of this oscillation between the local and the global, the general and the particular and, as such, plays its part in defining new arenas for the exercise of transnational virtue (Rabinow 2002:143).

In the course of this paper, I elaborate on the relationship, actual and emergent, between anthropology and biomedical ethics. The desire to embark on this exercise is prompted by a piece of research in which I am currently engaged that deals with the reception of new reproductive and genetic technologies in Sri Lanka. This research did not arise out of an interest in biomedical ethics as such, nor even medical anthropology, but a longstanding interest in kinship and a curiosity about how these technologies might impact upon ideas of personhood, relationship and identity in the Sri Lankan context.

However, it soon became apparent that before embarking on that exercise there were some important preliminary tasks to be completed. Foremost of these was the need to capture ethnographically something of the intellectual activity set in train among local doctors, clinicians, lawyers, scientists and administrators as they set about mapping new technologies onto local ethical, legal and social structures. As in other settings where the new technologies have been debated and contested, new areas of expertise and intersecting interests emerge as questions of public policy, human rights, philosophy, law, insurance and ethics collide (cf. Konrad 2002). Paying attention to this activity in the Sri Lankan context highlights what happens when the assumptions about ethics, humanism and the individual that underpin the use of the new technologies in the West are transferred into contexts where these assumptions are at the very least in contention with other versions of morality, virtue and personhood.

An attempt at ethnographic capture of this site of intellectual exchange, as articulated and instantiated in debates, media reporting and formal structures such as working parties, ethics committees and special advisory groups, thus brings into focus the particular tensions, anxieties and concerns that manifest as the revolution in genetic and reproductive technologies touches this corner of the developing world and begins to be shaped by the distinctive history, cultures and polity of contemporary Sri Lanka. My main contention here is that paying close anthropological attention to these institutional and intellectual connectors and mediators reveals an active response to the globalising and universalising tendencies of Western biomedical ethics. Indeed, there are negotiations, conflicts and novel forms of accommodation, not just in response to technological change but to the more general ethical packaging in which these and other biomedical developments seem to come ready wrapped. Before exploring this assertion in more detail however, it is necessary to step back and consider what is meant by macroethics in this context or, more specifically a biomedical ethics that is now an international currency when it comes to thinking about the morality and values underpinning clinical treatment and biomedical research.

Biomedical ethics as transnational virtue?

The origins of biomedical ethics, as distinct from the much older tradition of medical ethics, are to be found in North America during the 1960s, when a peculiarly hybrid field, fashioned mainly out of philosophy, theology and medical law, began to emerge (Jonsen 1998). The discipline developed, in part, out of recognition that the traditional relationship between ethics and medicine was inadequate to cope with the issues raised by the burgeoning possibilities for medical intervention. Doctors were no longer just humble servants in the face of malfunctioning nature but potentially its masters, capable of a range of interventions that appeared to extend beyond what was hitherto thought to be naturally ordained. Developments in genetics, pharmacology, organ transplantation, prenatal testing and the technology of life support, to name but a few, all served to muddy the distinction between doing good and doing harm. Medical practice was moving beyond a comfortable world of paternalistic beneficence in which medical ethics was broadly about professional standards and into a much more complex field, where the 'good physician' of Hippocratic fame would have to operate in the face of growing incursions from technology, business, research and the market. To assist in making decisions about how to proceed in this changing landscape, doctors and medical researchers were assisted by a growing body of specialists engaged in the production of a meta-commentary on biomedical practice that soon came to acquire all the paraphernalia of an academic discipline: canonical texts, journals, professional organisations, centres of excellence and training courses.

To a considerable extent, the task of connecting 'biological knowledge' with 'human values' fell to moral philosophy and with this came a particular conception of the kinds of persons that lay at the heart of the biomedical ethics project. In philosophical terms, the tradition was dominated by the empiricist and pragmatic Anglo-American tradition of moral philosophy and with this came a focus on rights, principles and a particularly North American version of liberal indi-

vidualism. As Fox has stated: "the conceptual framework of bioethics has accorded paramount status to the value complex of individualism, under-scoring the principles of individual rights, autonomy, self-determination, and their legal expression in the jurisprudential notion of privacy" (Fox 1990:201–217). With the development of biomedical ethics, the aspirations of the American body politic were transposed onto the destinies of physical bodies. The development of this perspective reached a kind of florescence in the approach referred to as 'principlism'. Using the four cardinal points of justice, beneficence, nonmaleficence and autonomy, it was believed that bioethicists could systematically navigate their way through the kinds of problems that progress in biomedicine were increasingly throwing up (Beauchamp and Childress 1989). What emerged from this approach might best be characterised as a restrained utilitarianism: attempts to serve the public good at the expense of the individual would have to be carefully justified – human beings must be treated as ends, not means. Within this paradigm, autonomy began to take a primary position when it came to questions of how to proceed in decisions about medical treatment or research, and with this, issues such as informed consent, the nature of proxy consent, truth-telling, confidentiality and privacy emerged as central preoccupations of biomedical ethics. It was as if the broader quest to link biological knowledge with human values had shrunk so that it extended little beyond the encounter between a doctor and a patient. As Muller put it: "rationalistic thinking and deductive utilitarian orientation to problem solving provide an illusion of objectivity and logic. Informed by the legacy of Cartesian duality, the analytical style of bioethics contributes to a distancing of moral discourse from the complicated settings and interactions within which moral dilemmas are culturally constructed, negotiated and lived" (Muller 1994:52). Characterised in this way, the very wrinkles and creases that anthropology struggles to describe and theorise are rendered flat, featureless and peripheral.

Rendering local conceptions of morality, social networks and culture as featureless while at the same time foregrounding ethics is troubling enough when conducted against the backdrop of Euro-American cultural pluralism (Hoffmaster 1992:1421–1432; Clouser and Gert 1994). When exported beyond Europe and North America these concerns are considerably amplified, leading bioethicists themselves to speculate on the disjunction between Western models and their application in Asian, African and South American contexts (for example see Osuntokun 1992; Pellegrino 1992). Indeed, the tendency of biomedical ethics to focus rather narrowly on principles systematically applied to individual cases produced calls for the internationalisation of biomedical ethics (Crigger *et al.* 1988; Gillon 1994; Veatch 1989). This demand is in recognition that foundational concepts such as informed consent, privacy and patient autonomy may be construed rather differently when transposed into developing world settings. Indeed, the elaboration of these concerns may prove to be of little consequence in contexts where balancing costs, benefits and equality of access to healthcare generate altogether different sets of ethical priorities for doctors and clinicians (Engelhardt and Tristram 1998). Garrafa and do Prado, speaking from a Brazilian perspective, have sought to push this debate further by calling for a 'hard' bioethics, presumably in contrast to a soft bioethics, which they see as currently being diffused from northern countries (Garrafa and do Prado 2002). Their 'bioethics of intervention' seeks to prioritise policies that produce the greatest good for the greatest number, even though this may adversely affect individual situations; in this approach, autonomy and individualism are clearly subordinated to a broader quest for justice, equality of access to healthcare and the pursuit of collective benefits.

Voices from the South have also been heard in the context of research ethics in which a mismatch between First World ethics and Third World problems raises issues of abuse and exploitation. For example, in a scathing critique, Marcia Angell has labelled the work of Western researchers in the developing world a form of 'ethical imperialism' (Angell 1997; see also Lurie and Wolf 1997; Anonymous 1997). Her focus was the use of a placebo control group in a clinical trial of short-course zidovudine given to HIV-infected pregnant women to prevent mother-to-child HIV infection (see Preston-Whyte and Bodasingh, this volume). Angell raised questions about the use of placebos when what should have been provided for the control group was a reasonable 'standard of care'. Failure to provide the 'best proven treatment'

as the yardstick to evaluate the new treatment was seen as a hypocritical evasion of the ethical standards that would be expected to prevail in the developed world. However, such allegations produced responses that pointed out the impracticality of expecting Western standards to prevail when placed in the broader context of developing world socioeconomic conditions (Levine 1999). One important response came from people in the countries where the trials took place, who pointed out that ethical clearance had in fact been sought and approved in the host countries. Edward K Mbidde, Chairman of the AIDS research committee of the Uganda Cancer Institute, for example, suggested that it was somewhat 'imperialist' of Angell and others to think that they knew what was best by seeking to override decisions made by local ethics committees (Mbidde cited in Macklin 2001:25; see also Benatar and Singer 2000).

The fact that this particular trump card was played in the face of a debate that raged across conferences, journal editorials and refereed articles is illuminating because it raises a crucial but often overlooked issue in the biomedical ethics debate. In a nutshell, at the point where North meets South, there is not a chasm, devoid of structure, agency and creativity, waiting to be filled by the virtuous deliberations of Western biomedical ethicists, but responses that emerge out of local insight and experience and, as such, ones that are worthy of careful investigation. These responses are not merely bureaucratic but suggest a complex two-way traffic in which the totalising instruments of biomedical ethics put out by organisations such as the World Health Organisation (WHO), World Medical Association (WMA) and the Council for International Organisations of Medical Science (CIOMS) are passed down and guidelines, laws, regulations and institutional structures which carry a local inflection are passed up. As Macklin has pointed out, it is easy for all to agree on the abstract injunctions, with which internationally agreed guidelines are peppered, such as 'research participants should not be exploited', but quite another to work out just what this means when these are rendered into the vernacular of specific sociocultural contexts (Macklin 2001:26). To consider what such injunctions mean in local contexts is to raise perplexing questions of relativism, context and power. Considering these questions enters a familiar terrain for anthropologists but one which is much more discomfiting to many philosophically informed biomedical ethicists. Thus, the idea that local ethical review bodies may produce verdicts that are inconsistent with those that would be produced in Western contexts has prompted the suggestion that the experience and competence of local ethical review boards may be lacking when it comes to dealing with issues thrown up by research on human subjects or the introduction of new technologies. Such an assessment fails to recognise that local bodies may arrive at different outcomes than their Western counterparts, yet do so using competences that are more closely linked with local cultural values. However, this is not to say that just because decisions are made locally that they are good or right decisions. Rather, it is to highlight a powerful trend within biomedicine that sees the parochialisation of ethics as something that must be resisted lest the process become infected with custom and thereby lost in the quagmire of relativism and cultural absolutism. To adopt this perspective is to render local responses at best peripheral and, at worst, inconsequential. Yet, biomedical ethics is fundamentally about disputes over what constitutes the most moral or virtuous way to proceed in the face of difficult choices and, furthermore, trying to persuade others to approve or disapprove of one justification over another. It is thus a rhetorical and deliberative pursuit that is deeply rooted in cultural and historical circumstance. Treating it like an abstract and absolute science that can be easily downloaded into a variety of cultural settings, on the other hand, is likely to obscure and distort the way that local responses to biomedical ethics are being formulated in the developing world. Paying attention to what is to be found in the spaces between macroethics and microrealities is therefore crucial when it comes to imagining what a contemporary anthropology of bioethics might look like: an emergent field that captures the interweaving of a transnational logic of virtue with a multiplicity of local beliefs, practices and contexts.

Useful parallels may be drawn here between biomedical ethics and human rights discourse. As Wilson suggests, in recent decades human rights has become “one of the most globalised political values of our time” (Wilson 1997:1). In years to come we may see biomedical ethics running a close second; a transnational logic that aspires to universalism and consistency of application that can be found in the spaces between and above nation states. Like human rights it also claims to champion the causes of disempowered, marginalised and impoverished groups of people who find themselves caught in structures that discriminate, oppress and abuse. A global biomedical ethics thus undoubtedly carries many warm themes: protecting the vulnerable, challenging paternalism and exploitation, re-dressing global inequalities in health-care, and improving standards of treatment in the developing world. However, it also carries cool themes. Critiques begin to crystallise around global biomedical ethics as a civilising phenomenon: a strategy to further liberal and market-led notions of individualism and freedom as a common baseline for humanity. As with other transactions in virtue, a binary opposition is put in place that renders the other morally inferior while at the same time ensuring that the West retains a position of moral superiority (cf. Bhaba 1994; Said 1978; Todorov 1987).

New forms of inclusion also bring with them new forms of exclusion. For example, in a somewhat different take on the debate about Euro-centrism and moral inferiorisation, Appadurai has drawn attention to an emerging epistemological exclusion that operates around the production and validation of knowledge and particularly as this relates to the medical sciences (Appadurai 2001:2). The rapid movement of people, capital, information and resources around the globe creates a growing inability of many nations to participate in the mapping out of new forms of knowledge. The result is a systematic exclusion from the creation and use of expert discourses and increasing marginalisation when it comes to setting new agendas for technological innovation and scientific research. The main targets for this critique to date have been agreements around patenting, copyright and ownership. Instigated by the leading industrial countries, trade sanctions have become closely linked to infringements of intellectual property rights through the World Trade Organisation’s General Agreement on Trades and Tariffs in 1994. Eventually consolidated through the Trade Related Aspects of Intellectual Property Rights Including Counterfeit Goods (TRIPS), such agreements make it possible to appropriate things that previously could never have been imagined as property: seeds, bacteria, Ayurvedic treatments, traditional agricultural practices, artistic designs and so on. The drift towards epistemological exclusion accelerates considerably once we move into high-tech fields such as genomics, where blood, cell lines, genes, genetic tests, portions of DNA and even databases begin to fall into the realm of property and ownership.

However, the globalisation of virtue that accompanies such developments does not proceed unchecked and does not necessarily equate with a homogenous and standardised Westernisation. There is indigenous resistance to the imposition of ‘foreign moral paradigms’ (Tan Alore and Lumitao 2001:6) and there are also strategies to identify and combat epistemological exclusion. Much work goes on at the interface between global forms and local settings. The work I have in mind in the biomedical context is carried out in hospitals, universities, professional associations and government committees. It takes the form of debates, discussions and arguments, which may be formalised in published guidelines and protocols or remain backstage as part of the complex power games that are integral to professional life everywhere. This work is not easily visible from the dominant perspectives of biomedical ethics, which is rarely tuned to pick up local social, cultural and political inflections. The contribution of medical anthropology to the debate about biomedical ethics may not have helped in recognising the significance of this work either. The standard approach of medical anthropologists has tended to focus efforts on bringing into discussion the cultural underpinnings that sustain particular ethical constructs in matters of health and illness – ‘the X believe such and such and this is how it deviates from the standard Western biomedical model’. More sophisticated versions of this formulation engage with the evident reality of medical pluralism – ‘the X believe such and such and this is how it articulates with the standard Western biomedical model’.

However, in both these approaches the biomedical model, along with the ethics that inform and underpin its practice, are assumed to have been spread in a uniform and consistent manner and rarely has the biomedical model itself come under scrutiny in the developing world (see Finkler 1999 and this volume for a notable exception). The standard medical anthropological approach thus tends to reinforce the invisibility of the institutional structures that mediate between the ebbs and flows of biomedical knowledge and indigenous belief systems. I would suggest that to focus on the work that goes on among elites and professionals not only opens up an important methodological avenue into the field of comparative biomedical ethics but also creates alternative possibilities for anthropology to contribute to a richer theoretical understanding of how this discourse plays out in developing countries. For the remainder of this paper I turn to an elaboration of these ideas in relation to the specific context of Sri Lankan biomedicine. The term 'biomedicine' is used in what follows in preference to 'Western' or 'allopathic' for reasons similar to those put forward by Kleinman (1995:25), namely it captures the notion of a distinct institutional, professional tradition that is globally established and which has its own particular epistemological and ontological imperatives.

Biomedical ethics in Sri Lanka

The 'Democratic Socialist Republic' of Sri Lanka is an island of some 19 million people. The main ethnic groups are Sinhalese (74 per cent), Tamils (19 per cent) and Moors (7 per cent), with smaller groups such as Malays and Burghers accounting for less than 1 per cent. In terms of religious affiliation the main groupings are Buddhist (69.3 per cent), Hindu (15.5 per cent), Moslem (7.6 per cent), and Roman Catholic (6.9 per cent). The largest communities within Sri Lankan society at present are Sinhala Buddhists (approximately 69 per cent of the population) and Tamil Hindus (approximately 15 per cent). In relation to other countries in the South Asian region, Sri Lanka has a favourable per capita GDP (US\$829) and a very high rate of literacy (estimated to be over 90 per cent). Since independence from British colonial rule in 1948, Sri Lanka has been able to develop and maintain a free national health service with reasonable access across the island. Details such as these provide a necessary backdrop to a discussion of how bioethics is received in contemporary Sri Lanka, but before examining this broader picture it is necessary to look a little more closely at the history of biomedicine in Sri Lanka.

The tradition of biomedicine is very firmly established in Sri Lanka. The Civil Medical Department of the British colonial administration was first established as a department separate from the one dealing with the occupying military forces in 1858. Although aimed specifically at the control of smallpox, the creation of a department to address the health needs of the local population, as distinct from the needs of the colonisers, marked an important step on the road to a national health service (Uragoda 1987:81). The Colombo Medical School, opened in 1870, is the second oldest in Asia and has a distinguished tradition of providing biomedical education to the local population. It is a source of considerable pride to Sri Lankans that from a very early stage there were few foreign doctors in the medical service, which was essentially 'Ceylonese' in its composition and outlook (Uragoda 1987:131). Yet, even today the medical profession preserves a strong sense of identity modelled upon the structures that took root during the British colonial period. The existence of colleges for practitioners of the main medical specialisations, local medical journals, a national medical association and the form of professional examinations all served to replicate traditions consonant with the former colonisers, ensuring that the medical profession constitutes what one former colonial administrator referred to as 'a little bit of England' (see also Pieris 2001:123–136). The Anglicisation of medicine was, and continues to be, reinforced by the use of English medium in medical (and other professional) education. In the post-independence period, attempts to encourage the use of *Swabasha* or 'own language' has had little impact on medical teaching. Pieris (2001) reports only three publications carrying biomedicine into local languages. These were an English–Sinhala dictionary of medical terms by Wijerama, a textbook of forensic medicine by Nandadasa Kodagoda (1971) and an English–Tamil glossary of physiology terms by

Sinnetamby (1974). This is in marked contrast to the numerous texts covering indigenous medical systems. The language issue thus remains a source of tension, as the majority of the population receive primary and secondary education in their mother tongue (Sinhala or Tamil) but then have to take their medical degrees in English. Unlike the English-speaking middle classes, the majority of the population find this transition into English higher education a serious obstacle. An entrenched professional elitism within the medical community is thus consolidated by social elitism. Furthermore, the spread of biomedicine has had the effect of marginalising indigenous systems of medicine. Until recently, doctors appear to have been locked into a rather narrow, Cartesian view of illness, responding to traditional healers and their clients with scepticism and derision. This attitude is in contrast to Ayurvedic practitioners who regularly incorporate biomedicine into their practice (Waxler 1984). However, the ease with which this synthesis takes place has created concerns within the medical profession about the growing number of 'quack' doctors, many of whom are Ayurvedic physicians who have resorted to dispensing allopathic drugs as part of their treatment repertoire (Liyanage 2002). As Pieris notes, in the nineteenth century, discussions regarding the development of a medical school identified one of its aims as being to "send out well-educated young men to open up the dispensaries of the Island and to diffuse a knowledge of European medicine among the poorer classes of the community and (thereby) in time supersede the ignorant *vedarala*" (cited in Pieris 2001:17). Such attitudes became well established and continue to manifest among some contemporary practitioners of biomedicine. For much of its history, then, the medical profession has not only been highly Westernised, English-speaking and of high status but one that was cut off from the beliefs and values about health and illness held by the majority of the population.

In recent times, other factors have come to shape the culture of biomedical practice in Sri Lanka. One of the most important of these has been an inexorable shift towards deregulation and an open-market economy. Following the election in 1977 of a right-wing government with an agenda for fundamental market reform and economic liberalisation, the private sector has come to play an increasingly important role in healthcare, raising concerns that it might even displace the State as the key provider of health services. In 1978, for example, doctors were for the first time allowed to do private practise in addition to their government responsibilities, a development that spurred a spectacular growth in private provision, particularly in tertiary care. More recently, the import of equipment to private medical institutions has been greatly accelerated by the granting of duty-free concessions. The result of these and other developments has been an overall trend towards high-quality private medicine. In contrast, the public sector, which to date has provided free healthcare at the point of need, has fallen further behind the private sector in some fields. For example, whereas maternal and child care continues to retain a high standard of public provision (Seneviratne and Rajapakse 2000), in many other fields the State is rapidly becoming a residual provider, catering for the large numbers of people who are unable to afford private care. The government sector has been further undermined, particularly in primary care provision, as pressures from the World Bank and other international financial institutions force cuts in welfare expenditure (Jayasinghe 2002:6–7).

Under these circumstances, the consolidation and expansion of biomedicine continues to proceed apace. However, for many doctors and their patients the acceleration in scope and complexity of medical treatments brings with it a certain ambivalence. Versatility in biomedicine is undoubtedly a source of power, kudos and a firm link with global systems that betoken modernity and development. The embrace is often a resentful one. There is a deep concern that doctors, who were once "gods amidst men" (*Daily News, Readers' Mail*, 1 March 2003) have now fallen prey to the market and become selfish money grubbers who have turned their backs on compassion and social responsibility. This trend is further evidenced by the growing numbers of medical negligence cases in recent years. In the very recent past the idea of prosecuting such cases would have been simply unheard of. Likewise, uncritical acceptance and imitation of everything that emerges from the West is no longer acceptable. The record of foreign governments and multinationals, particularly where pharmaceuticals are concerned, has prompt-

ed a more sober evaluation of the costs and benefits of what is on offer and a good deal of self-critical examination of the medical profession in the post-independence period (see for example Dharmasiri 1997 for a particularly caustic critique).

In response to these concerns there have been numerous attempts to carve out an identity for biomedical practitioners that encapsulates both high scholarly and professional standards in medical practice but also asserts the integrity and legitimacy of local needs and values. One of the most important examples of this line of thinking is to be found in the work of Senake Bibile, who in an attempt to resist 'drug colonialism', established the State Pharmaceutical Corporation and developed a national formulary (Weerasuriya 1995). An important feature of such endeavours has been the attempt to link current practices with traditions and values that are indigenous, and pre-colonial. However, this strategy is not without its critics and the assertion of a more nationalistically attuned medicine divides as well as unifies. For example, there are some doctors who would like to see medical teaching integrate more fully with indigenous medicine and thereby connect up more actively with systems that inform the thinking and feeling of the majority of the population. Others however, draw a very firm line between the two and fervently argue for the preservation of a kind of medical apartheid in which medical teaching and practice is free from the irrational, unregulated and unscientific practices which supposedly characterise indigenous healing systems.

Implicit in the emergence of a more critical evaluation of the benefits of medical science has been a parallel debate about the appropriateness of Western biomedical ethics and from where a more appropriate ethics might be derived. To date the development of medical ethics in Sri Lanka has been strongly influenced by the Western Hippocratic tradition and subsequently incorporated values and orientations found in canonical documents such as the Nuremberg Code and the Helsinki Declaration (Babapulle 1992). However, as Arseculeratne (1999) has pointed out, this creates a serious paradox. Doctors versed in Western medical ethics practice on a population that is predominantly Asian in ethos and outlook, and the doctors, to a large extent, are ignorant of indigenous traditions of healing and medical ethics; as he put it in a lecture given in November 2002, they remain "Asian in blood and English in morals, intellect and attitude".

This sense of mismatch between the values that inform the Western tradition and the reality of local circumstance has led to growing disenchantment. The question that some doctors are now beginning to pose is that it is not so much 'what have we gained by engagement with Western medicine and the ethics that come with it?' but 'what have we lost?' As in the West, there is a fear that the ever-accelerating transformation and extension of new technologies and treatments takes place long before appropriate structures of accountability and regulation are in place. The image is a familiar one: society and its democratic institutions are somehow left behind, struggling to get a hand on the tail of runaway medical and scientific progress. However, in the developing world the problem has additional dimensions. The development of biomedical ethics in the West is premised on certain assumptions about affluence, stability and the toleration of pluralism. However, it is unlikely that biomedical ethics will spread rapidly and evenly in circumstances where there are not only different ethical traditions to contend with but also poverty and crises over the management of pluralism itself are the experience of the majority. Similarly, the unevenness of spread or penetrance of biomedical ethics discourse is also affected by the extent to which it is given a local inflection. If biomedical ethics discourse and practice remains with the elites of the medical world, who restrict their practice to a wealthy, Westernised clientele, then there is little call for modification; the continuities between London and Colombo when it comes to what is available for paying customers should not be underestimated. However, the further these techniques are carried beneath this affluent veneer and into the harsh realities of Third-World living, then the more trenchant are the calls for a biomedical ethics that is both relevant and appropriate. Debates emerge about how local perspectives might be meaningfully incorporated into rapidly diffusing models of hegemonic and transnational virtue. Indeed, in the same way that people have asked whether there are systems and

philosophies that are quintessentially Asian in relation to notions such as values (Bauer and Bell 1998), capitalism (Dirlík 1996), counselling and psychotherapy (Laungani 1999), this question has also been posed: is there a culturally distinct Asian bioethic? (De Castro 1999). The essence of such an ethic is summarised by Pellegrino as being “less dialectical, logical or linguistic in character, less analytical, more synthetic, or more sensitive to family or community consensus than to individual autonomy, more virtue-based than principle-based” (Pellegrino 1992). In other words, the tendency to medicalise society at every turn is countered by local voices that plead for the socialisation of medicine. In Sri Lanka, as in many other developing world contexts, there is a push among some intellectuals, doctors and medical scientists to move away from an ethics that relies on rules, analysis and intellection towards one that is more experiential and oriented to practical results. In Sri Lanka, it is argued that this kind of ethics lies closer to the epistemological orientations of Asian religious and philosophical traditions in general and Theravada Buddhism in particular (Premasiri 1996, cited in Arseculeratne 1999).

The idea of a culturally appropriate biomedical ethics thus necessarily involves attempts to reach back into traditions that were previously denigrated and subordinated. Thus, for example, at the World Organisation of National Colleges and Academies of Family Medicine (WONCA) conference held in Colombo in 2002, a session dealing with ‘human rights, heritage and values in family practice’ concluded with a slide showing an ancient saying: ‘*rajakam naetnam vedakam*’, which was translated as ‘if you cannot be a king be a doctor’. Linking doctors with the glorious beneficence of the ancient kings was clearly an attempt to remind doctors of the nobility and honour that is attached to their profession. However, for an audience of Western-trained family doctors, it is significant that the ‘doctor’ referred to in the quotation was never an allopathic doctor but a practitioner of the older tradition of Ayurvedic medicine. The Ayurvedic physician or *vedarala* is for many Sinhalese a venerated figure, highly respected for their commitment to healing and the epitome of compassion, kindness and generosity (Nichter and Nordstrom 1989). For the *vedarala*, medical ethics was never something that was separate and that needed to be acquired as a kind of veneer upon technical mastery, but was wholly integral to his practice. Yet, at a time when the idealised image of the *vedarala* is often used by a critical public as the means to highlight the shortcomings of biomedical doctors, it is interesting to note that doctors themselves seek to align their values and attitudes with those of this more ancient tradition. Similarly references by doctors to canonical texts such as the Bhagavadgita (2500 BCE), the Ayurvedic treatises of Susruta and Charaka (c.800 BCE) and the chronicles of medieval Sinhalese history such as the Mahawamsa (461–479 CE) in the contexts of medical ethics serve to link their own practice to an Eastern tradition while at the same time pointing out that these traditions are of far greater antiquity than those that underpin biomedical ethics in the West.

In contemporary Sri Lanka, linking current medical practice with values, attitudes and orientations that connect with traditions that are authentic and legitimate in that they are to be found beneath the heavy overlay of science, medicine and ethics brought by the colonisers is an entirely laudable aspiration. However, in practise this is rather less straightforward given the highly conflicted notions of just what constitutes authenticity and legitimacy in post- and neo-colonial settings; the management of pluralism, even in the field of ethics is a fraught activity. Thus, when in the evolving discourse of biomedical ethics there is talk about cultural differences that need to be respected and treated with sensitivity, one is inclined to ask which culture and which differences? Assumptions made, for example in documents such as the Nuffield Council on Bioethics (2002), that there is a unitary and global system of biomedical ethics that encounters cultural units that, while different on the outside are, in a quaintly functionalist sort of way, uniform and consistent on the inside, is deeply problematic. At a time when biomedical ethics appears to have begun to take on board the significance of international cultural differences, it is appropriate to draw attention to the importance of intra-national cultural differences also. For the majority of Sri Lankans, who are Sinhalese and Buddhist, the logical place to begin to build a locally informed response to Western biomedical ethics is out of Buddhism’s own tradition of virtue-based, consequentialist ethical analysis.

However, there are other traditions – Hindu, Christian and Moslem – and other positions – secular, humanist and rationalist – that render ‘culture’ far from homogenous and harmonious but complex, conflicted and contested.

Biomedical ethics in a hot climate

Sri Lanka is a country currently experiencing the relief of a tentative peace process. The possibility of living without daily anxieties about individual and collective security comes after 20 years of brutal and traumatic civil war. Throughout this period the government of Sri Lanka was pitted against a ruthless and determined campaign by the Liberation Tigers of Tamil Elam (LTTE), who wished to secure a separate state in the north of the island. In the late 1980s the country also experienced violent convulsions as educated but disenchanting rural, Sinhala, youth began a Marxist-led insurrection, which resulted in widespread civil disorder. Estimates vary but as many as 100 000 people may have been killed during these bouts of ethnic and civil strife in Sri Lanka over the last two decades. As a result of these two cataclysms, civil society, human rights and democracy itself have all been weakened. In a climate of violence and fear, the bureaucratic and institutional spaces that make public life possible have lost the confidence of many and the operation of power and authority has become capricious and unpredictable in its consequences. A widespread response to this weakening of confidence in civil society has been a tendency to retreat into zones of trust and security built out of the primordial networks provided by kinship, religious affiliation and caste. These networks have always been of great significance in Sri Lankan society but under circumstances of extreme social disruption they have become even more critical in the management of day-to-day life. Reliance on such networks, it would appear, is often the most logical way to render the workings of power and authority relatively predictable and amenable to control. This process has been reinforced by the extraordinary growth of local and international non-governmental organisations that have created what Wickremasinghe has perceptively characterised and analysed as ‘new circles of power’ (2001) operating between the sovereignty of the State and the individual, and seemingly beyond the reach of either. However, the parochialisation of representation that this process entails is often at odds with attempts to create an inclusive, participative and openly democratic civil society. Touching as it does on issues of rights, duties and what is moral and virtuous in medical practice and research, the task of institutionalising biomedical ethics is no less implicated in the ambivalence that underpins the project of creating a strong civil society in postcolonial, postwar Sri Lanka.

Thus, on the face of it, the institutionalisation of ethics might appear to be a very modernist aspiration in that it attempts to establish collectively agreed and widely shared codes, guidelines, and protocols indicating how to proceed when confronted with difficult choices in the face of human suffering and distress. However, the development of biomedical ethics in this and other developing world contexts is also a postmodern phenomenon in that it is implicated in the management of pluralism, hybridity, fragmentation and other tendencies inimical to the totalising discourse of Enlightenment thinking. In practice, the institutionalisation of ethics must engage with the internal disputes and conflicts that are generated in attempts to build and sustain the nation-state. Furthermore, this engagement betokens a kind of resistance to the bureaucratic and rationalising forces that emanate from the West and which threaten to level and homogenise the very differences that fuel those disputes and conflicts. Between these two positions, which I have broadly characterised as the modernist and the postmodernist, many medical professionals find themselves caught, committed to both the global rationality of medical science and the particularities of local traditions and identities.

This paradox was in evidence in discussions with doctors and clinicians about the task of regulating the new reproductive and genetic technologies, both fields in which there is currently little or no local regulatory framework (Simpson 2001). The ease with which these technologies are transferred, coupled with their potential to generate complex ethical, legal and social

questions has raised concerns that little is being done by the medical profession to oversee the proliferation of reproductive options that these technologies offer. Discussions with doctors regarding the prospects and strategies for regulation of the new technologies identified four major concerns.

First is what might be thought of as the problem of representation. The emergence of a transnational biomedical ethics is built upon a broadly secular and rationalistic aspiration in which ethical review is constituted as an extension of democratic representation. For example, WHO's 'Operational Guidelines for Ethics Committees that Review Biomedical Research' suggests that ethics committees should be "multi-disciplinary and multi-sectoral in composition, including relevant scientific expertise, a balanced age and gender distribution, and laypersons representing the interests and concerns of the community" (WHO 2000). That there should be community representation in the regulation of the new technologies is readily acknowledged by those with whom I spoke. However, 'community', in this context, often equates with representation by the major religions. While carrying local practice beyond Western models of medical humanism and into the realms of an Asian bioethic is a desirable objective, suspicions and concerns were voiced about the involvement of representatives of religious groups in the operation of ethical review. In particular, there was anxiety that such involvement could bring the divisive and destructive assertion of religious fundamentalisms into play. The trick would appear to be how to construct an ethical framework that is secular enough to allow rational dialogue to proceed, but religious enough to give the impression of inclusive representation. As the religion of the majority community, Buddhism occupies a special position in this regard. On the one hand, Buddhism provides an important focal point for resistance to globalisation and the hegemonic forces of Western capitalism (Wickremasinghe 2001:150). As such, Buddhism is enlisted by some as part of a populist, anti-development, anti-Western-science discourse that seeks to challenge the preoccupation that doctors have with progress. However, in the context of technological development, there is also a countervailing tendency that threatens to bring conflict between Buddhism and other religions. The nature of Buddhism means that the membrane that separates science from religion is altogether more permeable than with other religions. Absence of divinity, rejection of creationism, belief in rebirth and a highly rationalistic analysis of phenomenal existence tend to identify Buddhism with science in a way that is not shared with other religions. Within Christianity and Islam, for example, core tenets are more often than not threatened and undermined by scientific advance. Indeed, the radical insistence on materialism as the grounds for knowledge brings Buddhism into a powerful alignment with biomedicine for many medical practitioners who happen to be Buddhist. The place of Buddhist representation in the institutionalisation of ethics is thus doubly problematic: for some there are concerns that it could provide an unhelpful brake on progress, but for others the worry is that it might propel acceptance of new developments in ways that people from other religious communities find troubling and offensive. For example, although reproductive cloning is outlawed in many parts of the world, surveys regarding the attitudes of doctors and medical students to these techniques suggest a surprisingly high level of acceptance with 40 per cent of doctors and 25 per cent of students prepared to countenance such techniques (Simpson *et al.* unpublished:19). Furthermore, Buddhist understandings of the process of embryogenesis entail different notions of how individuality comes into being from those held within theistic traditions. For some Buddhists, the fact that individuality arises from the process of rebirth and not from the material circumstances of fertilisation means that cloning is, in theory, unproblematic.

A second theme concerns the relationship between the processes of ethical regulation and the larger field of political relations within which it is located. As suggested earlier, authority and power in Sri Lanka do not operate in the abstract but through definite social conduits of relationship and shared personal and professional history. As many of my informants pointed out, they work in a 'small world'. Concerns about 'cronyism' and undue political interference in the conduct of decision-making are common and a certain despondency that honest attempts to

realise procedures that are fair, transparent and robust are all too often confounded as decisions made or guidelines agreed meet with limited compliance outside of this or that committee. Indeed, the problem of how to give regulation and review 'teeth' was a recurrent theme in the discussions. Influence over the private sector was a particular source of anxiety in this regard, with some doctors expressing extreme pessimism that, as long as the private sector was so much in the ascendant, any meaningful regulation of the new technologies was possible at all. The third issue raised in discussion was that of how to incorporate the voice of the public in the regulation of the new technologies. As indicated previously, the medical profession has enjoyed a position of considerable status and power in Sri Lankan society – a rather different notion of untouchability than the one usually invoked in the Asian context. Consequently, there is not a tradition of ordinary people questioning the actions of medical professionals or indeed having any sort of rights in their dealings with them. In ethics, as in other areas of medical practice, there is a deeply ingrained assumption of top-down, paternalistic beneficence among professionals and their public. However, there has in recent times been a growing cynicism about the extent to which these assumptions translate into sound practice and particularly given the way that the free market has come to shape the form and content of contemporary medical practice. This is particularly so when the interventions in question impact upon the process of reproduction itself and the social and genetic relationships that are thereby created. Yet, the structures through which a bottom-up, participative articulation of what is culturally and practically appropriate are widely acknowledged as being weak and only now are beginning to develop through workshops and efforts at capacity building in the field of bioethics.

Finally, doctors themselves are uneasy in negotiating this area of their practice. Making doctors in Sri Lanka entails induction into rigid professional hierarchies and the inculcation of authority, confidence and a kind of medical omniscience. However, the attention now being drawn to biomedical ethics, as opposed to an earlier and more gentlemanly medical ethics, means a step into unfamiliar terrain. At the outset, it is necessary to acknowledge that, in any move to socialise medicine, answers are not clear and authoritative, and there is ignorance and limited capacity within the medical profession when it comes to dealing with such issues. Likewise, uneasiness is created by the prospect that other disciplines have important things to contribute when addressing complex ethical questions. But, most of all, it is necessary to recognise that patients and research participants have a voice that needs to be heard, acknowledged and acted upon.

Conclusion

In this paper I have covered a lot of ground and perhaps it is a little too much ground skated over too thinly. However, the move from macroethics to microrealities necessarily entails 'shifting contexts' (Strathern 1995) and the attempt to bring into focus new fields. The field to emerge from this enquiry is an anthropology of biomedical ethics that pays careful attention to the structures: bureaucratic, institutional and intellectual that mediate between transnational biomedical ethics and the complexities of local circumstance. Neither biomedical ethics nor medical anthropology have been effective in bringing this crucial tier into focus in their attempts to shift between the 'global' and the 'local'. The primary focus on the North–South divide that features in most biomedical ethics discourse as applied to the developing world obscures the fact that in many developing countries the North is already culturally and historically embedded in the South and in microcosm replicates many of the concerns about inequality, hegemony, exclusion and imperialism that characterise the broader North–South opposition. In short, globalisation has been with us for a long time and 'orientalist' constructions that assume a homogenous alterity in this, as in other fields, obscure a far more complex and interesting reality. Although operating from the other end as it were, medical anthropology has tended to be preoccupied with the distinctiveness of traditional systems of healing and to date has not yet fully realised its potential to contribute to an anthropology of biomedical ethics.

In the light of these observations, we should perhaps turn our attention not so much to what lies ‘between microrealities and macroethics’, but in a radical shifting of contexts think about what lies between microethics and macrorealities. In other words, the ethics of the Western tradition are probably alien to the experience of the majority of the world’s population and we would do well to focus ethnographic attention upon the ways that very particular and often parochial versions of biomedical ethics are shaped by relations, practices and processes that transcend locality. Indeed, without this focus it will be difficult to advance our attempts to understand the emerging relation between biomedicine, society and economy in particular localities beyond abstract characterisations such as Foucault’s ‘bio-politics’ (1979) or Rabinow’s ‘biosociality’ (1996). In other words, looking at these dynamics through the lens of detailed ethnographic fieldwork is essential if we are to effect a more productive engagement between anthropology and bioethics.

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HIV/AIDS research in South Africa: A new tyranny?

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The purpose of this paper is to argue that biomedical research, even though guided and controlled by codes of medical ethics may, in practice, open research participants and their communities to various kinds of harm. That this is the case would be unacceptable to most social scientists but, more to the point, it is unacceptable in terms of the codes of ethics of the researchers carrying out the research. Conflicts of this sort often present social scientists working in multidisciplinary research teams in the HIV/AIDS field with a dilemma: should they withdraw from the research or should they argue with their medical colleagues for changes to the research design? Unfortunately, this dilemma often presents itself as a Hobson's choice, that is, little or no choice at all.

Some of the reasons for this situation relate to the power dynamics of working in what are often large multidisciplinary teams. While espousing the notion of inter- and multidisciplinary, the collaborations are nonetheless driven by biomedical interests and perspectives. Other reasons can be found in the conflicting and apparently intractable loyalties to different ethical priorities. For example, those demanding the protection of the individual research participant are often in conflict with longer-term priorities such as the 'greater good' of human society achieved through the universal application of scientific knowledge in the medical field. This is an old debate, but for social scientists it is one that appears in new guises. In the health arena, new research contexts arise as well as new challenges, such as the need to consider appropriate healthcare and access to care for research participants. Many of the issues raised by these debates are closely linked to an increasingly vocal discourse around human rights, in which the universal versus the local context is once again a dominant refrain. In this we echo strictures made from within the medical arena by Beyrer and Kass that, in certain social and political contexts, research that at first sight seems to be low in risk may become high in risk (2002:246).

The perspective we adopt to explore the issue of ethical behaviour and harm is an anthropological one deriving largely, but not entirely, from recent ethnographic work in South Africa in the field of HIV/AIDS. We do not attempt to offer answers to the dilemmas we identify, and, following Christakis, take the view that "ethical systems do not exist in order to eliminate ethical discourse ... they provide a framework for such discourse" (Christakis 1992:108). Thus, despite an increasing awareness of the potential harm to research subjects, as evidenced in current reformulations of major codes of medical ethics, the social context in which some medically oriented research and follow-up care is occurring remains beyond their scope. Our purpose here is to highlight from an anthropological perspective some areas of concern.

Paradigms and power

At the time of writing, the South African National Department of Health estimated that the national HIV prevalence rate is 26.5 per cent. In some areas such as KwaZulu Natal, where much of the research reported here was undertaken, the rate is as high as 36.5 per cent (Department of Health 2002). Although the government position has recently shifted to a more positive advocacy of retrovirals, at the time of research responses to the provision of antiretroviral (ARV) treatment within the national health system ranged from being cautious to downright hostile.¹ The moral and ethical pressures faced by anthropologists in crisis situations such as this can be intense. How is the professional training and insight of the anthropologist to be utilised in the face of such a catastrophe? In answering this question the relationship with biomedical researchers is

¹ This position has changed. On 20 November 2003, in a Cabinet Press Statement issued by Government Communications, it was announced that the roll-out of ARVs was to occur as expeditiously as possible.

crucial yet problematic. Much of the difficulty here stems from an unequal power relationship between medical and social science in which biomedical collaborators all too easily assume their ascendancy. This leads to the assumption that biomedical professionals will take the lead in designing and signing off protocols for multidisciplinary and community-based HIV/AIDS research. Social scientists might be consulted as an afterthought. The reason for this is in part that the medical ethical review boards, to which most proposals for AIDS research are automatically directed (even if they go also to the social science equivalents in some universities), are populated by medical scientists and it is they who are effectively the gate-keepers when it comes to conferring ethical clearance to undertake research. Their gate-keeping does not only cover hospital or clinical settings, but also extends to the wider community. We believe that in operating in this setting, their touch may be less sure than when operating in a clinical setting.

With only a limited knowledge of qualitative research methods, the members of medical ethics committees often find proposals, based on participant-observation and open-ended ethnographic interviewing, alien and 'non-scientific'. Similarly, coming from a narrowly quantitative background, research results that are thin on numbers and thick on description are seldom taken seriously. Methodological misunderstandings also lead to inquiries about the existence of 'control groups' and individually signed consent forms of the kind required for drug trials carried out in clinics and hospitals. In considering proposals which impinge on social issues and seek to adopt methodologies not familiar in traditional medical circles, medical ethics committees and review boards appear unaware that individually signed consent forms may not always guarantee that participation in research is truly voluntary. Anthropologists and sociologists, in particular, have long been only too aware of the possibilities of subtle forms of coercion and in their own ethical guidelines draw attention to such situations (Beals 1969; Berreman 1973a; Berreman 1973b; Horowitz 1973; Jones 1971; Preston-Whyte 1989; van den Berghe 1969). Undoubtedly, the narrow view of methodology is changing in some circles. For example, there has been much healthy debate on such issues as evidenced in the guidelines drawn up by the United States National Bioethics Advisory Commission in 2001 (see www.bioethics.gov). Nonetheless, in our experience decision making by medical review boards invariably takes for granted that the considerations raised by medical codes of ethical practice are adequate to ensure participant protection. Furthermore, they assume that in the highly visible catastrophe characterised by a medical condition, their principles are not only necessary but *sufficient* protection against 'harm', as it is usually understood in the medically sacrosanct injunction to 'do no harm'. The instances that we will cite call these assumptions into question.

The view from the North

A second set of problems, at least in the African context, relate to standards of care. As a number of the protagonists in the debates we will review have already pointed out, many of the criteria determining ethical clearance for research to proceed were developed in First-World situations where standards of care are considerably higher than can be currently achieved in developing countries. Similarly, and we believe critically for the argument developed here, these criteria were derived largely from experience in one-on-one clinical settings and, with the exception of Voluntary Testing and Counselling, focus almost exclusively on the nature of the treatment and medical advice offered. Despite the much-discussed changes to the CIOMS Guidelines, what stands at present does not fully take into account the difficulties experienced outside the clinic or hospital in adhering to the prescribed regimen. While many medical colleagues now acknowledge that dealing with HIV/AIDS requires a 'sociological' as well as a medical approach, in practice this is limited to advice on how to promote 'behaviour change', either in terms of adopting protective behaviour or achieving higher levels of adherence to medication regimens. It is still rare for social scientists to be sought as equal partners in designing programmes that might move out of the clinic and into the wider community. Where such moves do take place, it is usually the medical messages that predominate in importance and the role of social science is to ensure these are adhered to – at the cost, possibly, of local conventions, traditions and ideas.

As it has developed in the West, the clinical model is first and foremost a matter of individual consultation and treatment, often via medication and a change in lifestyle. What is not taken into account is that 'patients' are part of families and communities and may be constrained in following prescribed treatment regimens. This is not because of any lack of ability to change personal behaviour or an inability to conform to the discipline needed to adhere to a complex drug regimen, but because of the social context in which adherence must be played out. Let us give some concrete examples.

In South Africa, as elsewhere in the world, high levels of stigma surround those struck down by, or thought to have contracted, HIV and AIDS. Among the many complex reasons for not adhering to treatment regimes and also for not consulting centres of Western medical care, is the fear of being identified by family, friends and neighbours as HIV-positive. This is particularly the case in small rural or overcrowded peri-urban squatter communities, where nurses and other healthcare workers are often neighbours or members of the same community or church congregation. Agreeing to an HIV test exacerbates the fear of identification and this increases if a positive diagnosis is returned and treatment advised. True, ARV medication is not generally available as yet in South Africa, but, in the case of pregnant women, nevirapine has now been available for some time. However, women provided with pills to take following the onset of labour were often afraid to take these home for fear that they would be found by members of the family and, particularly, by a spouse or mother-in-law. Although a single dose is currently given in a hospital or clinic at the time of birth, a greater dilemma still awaits an HIV-positive mother. Even a single dose of nevirapine to mother and baby may help to prevent the transmission of HIV in breast milk, although this can be lessened by exclusive breastfeeding for about six months before moving to alternative forms of feeding. In the face of the increasing promotion of alternatives to breast milk, paediatricians and healthcare workers in Africa have dedicated many years of work to promoting breastfeeding as the best form of infant feeding in poverty-stricken areas, and as a protection against general infant infections and particularly those associated with bottle feeding in areas without running water or power for boiling the little water that is available. Before HIV, breastfeeding, with early and substantial supplementation of gruel and solids, had become once again the chosen course of infant feeding for the majority of black women. In one fell swoop HIV has changed this. The new mother must now decide whether to breastfeed or not, and if so, for how long. Either way, not breastfeeding or doing so for a limited time only, immediately identifies her as HIV infected (Preston-Whyte 1999:151). Even more obvious indicators of HIV status are the many pills that constitute ARV treatment for those who are either fortunate enough to be able to afford them or to be on drug trials. For many new mothers, the choice is clear and the chance of survival for their baby makes them brave. But, the tongues of their neighbours still wag, and for some, admitting their status brings isolation, or they fear that it will do so in future.

We are glad to say that the notion of 'social context', once foreign in many medical circles, is gaining ground (for example see Singer and Benatar 2000; 2001). However, in South Africa, 'social context' still occurs more often in debates around what is and what is not permissible in terms of treatment in drug trials, rather than as indicating an enlarged view of what affects behaviour outside the clinic or consulting room (Benatar and Singer 2000:824).

HIV in South Africa: Echoes of tyranny?

There are multiple levels at which social context may be critical to adherence or compliance with treatment and care. Given the high degrees of stigma and denial surrounding HIV/AIDS, it is not surprising to learn that relations with family, partners, peers and local leaders all influence behaviour in relation to the HIV/AIDS epidemic. Furthermore, the national political context in which these relations are embedded is also significant as is evident in repeated claims that campaigns to persuade men to use condoms were hampered by the longstanding and

implacable denial by top South African political leadership of a causal link between the transmission of HIV and AIDS and sexual behaviour. Similarly, the prioritising by senior government medical personnel of 'adequate' nutrition and 'healthy lifestyles' over the use of ARVs has tended, perhaps intentionally, to create confusion in respect to the efficacy of these drugs. This stance has not only affected care and treatment, but the publication and subsequent impact of research findings. Recently, important reports indicating the magnitude of the epidemic, including one on AIDS mortality, were withheld by state bodies – until their contents were effectively common property following numerous 'leaks' to the press (www.mrc.ac.za/bod/AIDSindicators2002.pdf).

In a country such as South Africa, fears of tyranny, or what could be seen as its precursors, lie close to the consciousness of many citizens. Such fears may well also dissuade some from particular avenues of research. This kind of insidious, self-imposed censorship lay behind much of the apparent compliance with the demands of the Apartheid State's segregation policies. Although we are not suggesting that anything of that magnitude is involved in the approach to HIV/AIDS, the similarity of the general patterns gives food for thought. In humanitarian terms one might draw attention to the barriers to ARV treatment, for so long imposed by the current South African State (in the form of the National Department of Health) and particularly the drawn-out stonewalling of attempts to access the massive resources of the Global Fund for HIV treatment and the development of large-scale programmes – some with a research intervention component – to deal with the epidemic. Although attempts have been made to offer an explanation, if not a justification, of the South African government's position on HIV/AIDS and ARVs (see Posel 2003), this was tyranny indeed. In fact, the HIV/AIDS epidemic can be seen as imposing 'a new tyranny' at a number of levels. First, this can be in the biomedical sense in that ever-increasing numbers of individuals and their families are infected and affected; second, in terms of the stigma which is attached to both the infected and those most closely associated with them; third, and most important in terms of the theme of this paper, as a direct result of the government's prevarication over both the issue of the 'cause of AIDS' and of their failure to provide timely treatment for those requiring antiviral therapy. As we will argue in the conclusions to this paper, researchers may within the highly stigmatised and emotionally draining context of the current epidemic, add a further level to this tyranny by not being sensitive to the impact of their observations.

The only response to make a noticeable dent in the State's position has been the human rights-based activities of the Treatment Action Campaign (TAC at www.tac.org.za). Indeed, both the State and researchers would do well not to underestimate the power of social movements such as TAC. In this case they were able to initiate change, contribute in a very practical manner to advance care issues and reduce stigma by incorporating HIV-positive people into their fight against the epidemic. In all this, TAC, rather than researchers from the academy, has led the way in securing the essentials of HIV/AIDS care in South Africa. Along with the Trade Union movement, TAC draws on the resources provided by a long history of opposition to government by activist groups in the country. Indeed, anti-Apartheid political rhetoric has infused and strengthened much of the current discourse of the 'fight' or 'struggle' against AIDS. This rhetoric, reinvented to fit the current crisis, brings hope of freedom from the certainty of death and may serve to lessen some of the more virulent forms of stigma against HIV-positive people. On numerous grounds then, the TAC campaign is in the forefront of the fight against the tyranny of HIV/AIDS. For some, if not all researchers, espousal of its cause is seen as enjoined by personal, as well as professional, responsibility to their research participants.



At another level, anthropologists also need to consider their position in this struggle. At the height of Apartheid, the newly formed Association for Anthropology in Southern Africa drew up the first ethical guidelines for the professional conduct of anthropological research in the country. The seriousness of the political situation at that time led many members of the Association to call for a clear rejection of Apartheid to be included in the guidelines. After considerable debate, the following clause was included under the heading ‘Responsibilities to the wider society’:

Anthropologists have responsibilities towards other members of the public and the wider society... In this connection they should ... be opposed to the system of Apartheid and accept a commitment to widening the understanding and practice of democracy, non-racialism and non-sexism. (AASA Ethical Guidelines:2)

A link was thus made between professional responsibilities and what was considered by some to be a purely personal political stance. This action led to a breakdown in the delicate *rap-prochement* between members of the Association who were opposed to government policy and their more conservative colleagues.

In most other respects the Guidelines followed those of the Association of Social Anthropologists of the UK and Commonwealth (ASA)² and the American Anthropological Association (AAA),³ with which many South African anthropologists had close ties. The particular clause condemning Apartheid was time and context specific, but, with the dismantling of overt and politically structured racism, might be re-drafted to cover such political situations as the current government’s handling of the AIDS epidemic in the country.

Ethics and human rights

It is clear that one strand of the argument advanced here is situated within the increasingly persuasive and sophisticated human rights discourse which informs global healthcare and health research. The discourse, like that of the TAC, is in essence an activist one operating with a clear political agenda and mandate. Currently an important issue on the human rights agenda is the extension of adequate and ‘equal’ healthcare across the globe. This is based on the tenets of the Universal Declaration of Human Rights, to which representatives of many countries, but by no means all local cultural and religious groups, were signatories. Although not always recognised as such, definitions and the lineaments of what are taken to be universal ‘human rights’ are essentially Western constructs and their spread a matter of globalisation in a world shrunk by increasingly easy access to the technology of mass communication and, in particular, the internet. The result is a virtual hegemony of the opinions and messages of the most powerful and rich countries in that world. Human rights are, at base, Western rights and have their roots in a very particular history and philosophical tradition. Other societies and tra-

2 <http://les1.man.ac.uk/asa>; <http://les1.man.ac.uk/asa/Ethics/ethics.htm>

3 www.aaanet.org

ditions, as anthropologists well know, often had and still have somewhat different views of human rights, of who is 'human' and, indeed, who within that category has the right to 'rights', and to what sort of rights. It is when cultural particularities such as the privileging of men and boys over women and girls come into conflict with contemporary, and mostly Western, aspirations for universal gender equality, that problems arise. These conflicts are easily exacerbated in situations of limited opportunity for the exercise of other universal rights such as those to education and, in the context discussed here, access to treatment. Where such constraints have been accelerated by global inequalities resulting from colonial exploitation, the controversy and advocacy on behalf of those excluded from benefits, is likely to be intense. The case reviewed below indicates this very clearly.

It may appear that we have wandered from the topic of ethics. However, in reading the current literature on ethics, healthcare and HIV, both in the medical and social sciences, a clear convergence is discernible between the issues of human rights and ethical practice (Beyrer and Kass 2002). Issues of wellbeing and access to the best available treatment for disease are now major concerns in this burgeoning literature. This discussion moves the ethical debate beyond the context of individual, community and state (though these remain important) to the inequalities in global health. This inequality is particularly acute in terms of the affordability of treatment for the AIDS-infected and as such the discussion has also encompassed wider frames: the censure of drug companies, the question of the ethical responsibility of the State, and more recently ethical responsibilities of the North in relation to the South (Sachs 2001). This latter debate has translated into a call for funding for the provision of drugs to be channelled from the richest nations in the North to the poorest in the South. It is pointed out that the North has benefited for generations from an exploitation of Southern mineral and human resources, and the majority of those now infected live in the poverty-stricken countries of the South. However, we live in a world of complex interdependencies, not only of North and South, but of all nations. Current concerns regarding global insecurities arising from epidemics, such as HIV (and more recently severe acute respiratory syndrome [SARS]), that cannot easily be contained within national boundaries present common threats and challenges (Altman 2002). At this point arguments about ethics and human rights shade into the more fundamental expediency of survival at the level of human society.

However, it appears from even a cursory reading of the major medical journals that medical scientists themselves are not at one when it comes to the way that ethics and human rights should be brought together in practice. To illustrate this point we will review one such controversy in the AIDS arena. The debate we focus on developed around the 'standard of care' to be adopted for participants in research on the effects of ARV therapy to protect against transmission of HIV from HIV-positive mothers to their babies at birth. The controversy provides a useful illustration of the tension between a relativist stance that recognises the importance of local context and the universalist orientation of much human rights discourse. With hindsight, it is clear that had a stringent human rights stance been preserved, some of the most important current practices in preventing peri-natal transmission would not have been developed (Specter 2003).

The ARV research also raised other important ethical issues. How 'informed' was the informed consent given by the women who participated in the trials? How much did participants understand about the treatment and its implications? Did the participants understand that they had a right to refuse to join research programmes? Finally, in a situation where no protection is available outside the research programme, was there an undue incentive or pressure present for them to participate? Were they, in fact, 'free' to refuse?

Local standards of care and the place of placebo arms in ARV trials to reduce perinatal transmission of HIV

Although debates about standards of care have erupted in many poor countries, a landmark case occurred in South Africa in the mid-1990s. At the heart of this case were ethical principles brought into conflict with one another when local context was set against the backdrop of an unequal distribution of wealth and access to healthcare across the globe. The controversy raised the issue, not so much of protecting human rights in the usual sense of preventing active infringements, but rather ‘doing harm’ to research participants by not providing them with the best treatment option available in other parts of the world. This was despite the fact that at the time such treatment was not available locally and seemed unlikely to become available in the foreseeable future. Although a number of such trials were being conducted in different parts of the world and elsewhere in Africa, the eye of the storm came to centre on South African drug trials.

The study design used in South Africa (the so-called Petra study [Saba 1999]) involved the recruitment of HIV-positive pregnant women and their assignment to different groups in which they would either be given experimental doses of a drug regimen thought to lessen the likelihood of transmission of the HIV virus from mother to child at delivery or a placebo. Since drugs that would reduce peri-natal HIV transmission were generally unavailable at the time in South Africa, the women in the placebo arm of the trial were receiving what was effectively the ‘standard of care’ in the local situation. However, earlier trials (of the so-called ACTG 076 regimen) carried out in other countries had indicated that this particular drug regimen would lessen the transmission by about two-thirds, and HIV-positive pregnant women in the North and, particularly, in the USA were already being given these drugs. The women and their babies in the African placebo group were disadvantaged, relative to them, in that they had no chance of taking drugs that might reduce the transmission of HIV at birth.

The ‘universalist’ position

The situation came to the notice of a number of internationally based medical scholars and ethicists who interpreted it as a clear violation of the ethical principle that people included in such trials should be given the best or the equivalent of the best possible treatment available – by implication, they argued, *anywhere in the world*. The principle, from which they took their cue, was stated as follows in the version of the Declaration of Helsinki current at that time:

... in any medical study, every patient – including those of a control group should – be assured of the best proven diagnostic and therapeutic method.

[Declaration of Helsinki 1996]

In a similar vein, the guidelines of the World Health Organisation endorsed Council for International Organisations of Medical Sciences (CIOMS) on international biomedical research involving human subjects in developing countries indicated that:

The ethical standards applied should be no less exacting than they would be in the case of research carried in [the sponsoring] country.

[CIOMS 1993]

In this case, the sponsoring country was the USA.

The issue of the country actually sponsoring and, by implication, paying for the research, should be noted, though it is unlikely that similar objections to locally funded research would not be raised by international ethics review boards to which most high-cost and high-profile research will be submitted at some point. In most cases, such trials have international as well as local research partners and the former must clear their work through the ethics review boards of their own institution. Given the cost of many ARV studies in the First World, let alone in developing countries, it is unlikely that they could, in any case, be financed completely from within developing countries.

The 'universalist' position had been argued cogently by Angell (1988) but was quickly taken up by Lurie and Wolfe:

Residents of impoverished, postcolonial countries, the majority of whom are people of color, must be protected from potential exploitation in research. Otherwise, the abominable state of health care in these countries can be used to justify studies that could never pass ethical muster in the sponsoring country.

[Lurie and Wolfe 1997:856].

It was not only in the developing world that such placebo-based trials were underway. Upon investigation, Lurie and Wolfe identified 18 randomised control trials of interventions to prevent peri-natal HIV transmission that were either in process or planned when ACTG 076 was reported. Though most were in developing countries, two were USA-based. The latter were suspended or women were given access to ARV drugs. Calls were made to do the same in developing countries, including South Africa. A major controversy followed, much of which focused on the South African researchers involved, many of whom were among the most respected research paediatricians in the country. They put the case for local standards by arguing as follows:

1. Since ARVs were not available in South Africa, women in the placebo arm of the Petra study were receiving the local standard of care.
2. The local context of care for the majority of pregnant women in South Africa and particularly for poor black women – by far the numerical majority – was completely different to that in developed countries in that most only presented for antenatal care very late. ACTG 076 demanded early administration of the trial drugs, certainly well before most women in both urban and rural areas usually came to an ante-natal clinic. Many presented, in addition, with severe deficiencies in micronutrients and with genital diseases. These factors could account for the higher rates of vertical transmission in Africa than those reported in the USA – 15–30 per cent as opposed to 30–35 per cent in South Africa – and could well have damaging results if ignored (Coovadia and Rollins, 1999).
3. Complicating the situation immeasurably was the fact that the use of ARVs before and after delivery increases the likelihood of HIV being transmitted to the baby in breast milk. In the North, women on ARV treatment are advised not to breastfeed their babies, but to adopt substitute infant feeding. In Africa, poor women are advised to breastfeed in order to maximise the protection this offers the baby against infection and the diseases that plague infants in resource-poor settings with limited access to running and boiled water. Indeed, in keeping with a longstanding WHO mission to promote breastfeeding in developing countries, the same paediatricians who were running the trials had been among leaders in promoting breastfeeding for many years.
4. There was a further twist to the controversy. The use of a placebo arm in drug trials was not the only method of testing available, even though it was rated as the most scientifically acceptable and, before the debate, was considered ethically acceptable. In cases where drugs are available but more efficacious ones are to be tested, equivalency studies are sometimes undertaken. These provide subjects in a control arm of the study with the existing drug. The differences in efficacy are then measured against this base. There was, however, concern over the length of time such research designs would require to bear fruit since they demanded large numbers of subjects. It was argued that the time needed for this strategy was just what was not available in resource-poor settings of developing countries with high levels of HIV transmission. In any case, the value of equivalency versus placebo studies has been questioned by Varmus and Satcher (1997), leaving the issue more open than Lurie and Wolfe had suggested.

5. Another element entered into and fuelled the controversy. The South African researchers felt strongly that their professional integrity had been impugned. Furthermore, the attempt to impose universal standards on their studies smacked of unwarranted interference by Northern researchers and ethicists who did not understand the nuances of the local situation. Their position is well summed up in Coovadia and Rollins (1999) and was soon echoed by Singer and Benatar (2001), who each called for foreign researchers to take local context into account before undertaking research.

Clearly this case speaks to the immediate issue of depriving the women enrolled in the South African study of access to the universally available standard of care. It also speaks to another strongly held view in the South: objection to intellectual 'domination' of the South by the North. Indeed, South African researchers turned the accusation that they were exploiting local women of colour on Lurie and Wolfe themselves by arguing that, in attempting to impose inappropriate universal ethical standards in the absence of any understanding of the local context of care, they and their lobby were akin to postcolonial intellectual imperialists.

In summary, the difference of opinion between the international scholars and the local researchers rested on what constituted the best possible care – was it that available in the country where the trial was being carried out or that available anywhere in the world? Was the referent to be local or universal? The African trials that took as their standard that which was locally available – even if this was no treatment – were branded as unethical and the situation was likened to the use of placebos in the infamous case of the Tuskegee Syphilis trials conducted on prisoners during the 1950s (Brandt 1985). Despite the knowledge and availability of treatment, many subjects in that study were denied the latest available treatment for their condition. This, of course, led to early attempts to develop Codes of Ethics for medical research. Being linked with the notorious Tuskegee trials was a slur on the integrity of South African researchers who, in retaliation, accused their detractors of being arrogant and uninformed of local conditions as well as practicing a kind of Western intellectual imperialism.

The controversy simmered until it was found to be possible to provide ARVs in much smaller doses and for these to be administered at the time of delivery without danger to the mother. However, the transmission of HIV in breast milk still remains a threat to the infant unless the mother adopts a substitute feeding method after taking ARV treatment.

Informed consent: Is it possible or necessary in the context of HIV in South Africa?

'Informed consent' on the part of the research subject or patient forms the bedrock of Western medical research and practice. It is given voice in the Hippocratic oath and is enshrined in virtually all codes of medical ethics and ethical guidelines. A useful description of the concept is given as follows: "Informed consent implies that the researcher and participant have entered into a voluntary agreement without any element of coercion and that the participant is fully knowledgeable of the implications of participation. Four principles underpin ethical norms in biomedical research. Autonomy, beneficence, nonmaleficence, and justice are principles based on the 1975 Declaration of Helsinki and the 1947 Nuremberg Code. They aim to ensure that the participant understands the research sufficiently to make an enlightened decision, that the participant endures no harm, that the research contributes to the general welfare and health, and that recruitment respects the concept of fairness." (Abdool Karim *et al.* 1998:637).

Freely given consent is also the basis of good research practice in anthropology and permeates the ethical guidelines of the professional Associations of Anthropologists in the UK and the Commonwealth, as well as of the USA. The relevant provision of the Anthropological Association of South Africa (AASA) Ethical Guidelines is as follows:

Anthropologists should endeavour to protect the physical, social and psychological well-being of those whom they study and to safeguard their rights, interests, sensitivities and privacy. If a conflict of interests arises, *the rights of the participants come first*.

[1987:2 (author's emphasis)]

Consideration for the rights and, indeed, the feelings and possible reactions of research participants is, perhaps, the most important aspect of anthropological methods that are often premised on long and close association between fieldworker and those met 'in the field'. The relationships developed are usually long-term and, with time, increasingly informal and often emotionally rewarding on both sides. The translation of key research participants into 'friends' is often noted by anthropologists when writing about their experiences in the field (see for instance Lee 1979). It is hardly surprising, therefore, that anthropologists feel very strongly the obligation to protect their research participants from all kinds of harm, both physical and emotional.

In terms of medical ethics, what is referred to as informed consent is usually taken to imply that research subjects are fully informed of the purposes of the research, its methodology and of any potential dangers related to taking part in the study. They are also informed that participation is voluntary and they may withdraw at any time during the study. This process is usually followed by the signing of a formal consent form previously scrutinised and accepted by the appropriate ethical review board.

During press coverage of the 'standard of care' debate, doubt was expressed as to whether the women recruited to the Petra study had fully understood the implications of what they were agreeing to, and, in particular, that they would not be given the same care as women in the 'developed' world. Similarly, questions were raised as to their appreciation of the fact that, although some might reap the benefits of the treatment being offered to women in the treatment arm of the study, they would not know if this applied to them or not. Subsequently, at least one participant was quoted as saying that she had not understood the concept of a placebo arm, nor, indeed, much of the background to the study. Nonetheless, she had given her consent to participation. This could hardly be construed as 'informed' consent. Another woman reported that she had agreed because it seemed the only way to get treatment that might save her baby from infection. Was this not undue pressure?

Similar questions have been asked of other studies, many of which are not related to HIV, and a large literature exists on the question of inducements (Christakis *et al.* 1991; Christakis 1988, 1992; Barry 1988; Ekunwe 1984; Ijsselmuiden 1995; Richter 1999). The main issue here is whether research subjects are persuaded to participate in biomedical research by the benefits they expect to gain and which override other considerations. Questions are also asked about the ethics of enrolling people who cannot read and write and are unused to the protocols of Western medicine, especially in relation to medical research. Are they in any position to give true 'informed' consent? Even where the consent form is read and explained carefully to recruits, doubts have been raised concerning the level of understanding and hence the extent to which consent is 'informed' and freely given. Nonetheless, ethics review boards and committees usually pass such proposals after assuring themselves that the recognised procedures will be gone through, and a copy of the consent form (translated into the local language if appropriate) is lodged with the committee before the research begins.

Under ideal circumstances, consent forms are administered by experienced researchers who spend as much time as is necessary explaining the issues and any possible dangers that may be involved in the research. This is particularly important when potential participants cannot read the consent form with ease. However, at worst, obtaining consent may be a perfunctory and purposefully misleading exercise that plays down the dangers inherent in the research. To avoid or limit such cases, strict policing has been proposed, but this would be time-consuming and is now considered hardly practical in many circles.

A disconcerting possibility, not touched on as yet, is that the potential participants may be simply too polite to refuse to take part in such studies. This is not unknown in cultures where politeness is highly valued. Such issues arise particularly in circumstances where respect for medical professionals (be they traditional or Western) is high (Christakis 1992) and where the medical profession is regarded as a major benefactor. It seems unlikely that researchers, even if they consider these possibilities, would go to the extreme of aborting the proposed research on these grounds. Indeed, would it be right for them to take this step, particularly in light of the possible benefit that might accrue to the participants and society at large?

A far more insidious possibility is that recruits are afraid not to participate. Such coercion may not be recognised by researchers (Christakis 1988) or even discounted altogether. Once again, the experience of HIV care in South Africa and its related research throws up a telling example. This time, the case in question concerns research undertaken in a large KwaZulu Natal hospital where rates of HIV were mounting daily (Abdool Karim *et al.* 1998).

This innovative study was situated within the context of a programme for voluntary counselling and testing of women presenting for care at the hospital who were deemed at risk of being HIV-positive. Before deciding whether or not to be tested, women were routinely counselled by trained and experienced nursing staff, who carefully explained the mechanics of HIV transmission and offered testing, but at the same time made it clear to the best of their ability that the choice about taking a test rested with the individual woman concerned. The research itself consisted of exploring whether two samples of women who had attended the hospital and were counselled had (1) understood the information offered to them about HIV transmission and the implications of testing, and (2) had felt that they had been 'truly' free to refuse the test. An unexpected finding of the research was that a high proportion of the women who were approached to join the research chose to be tested but had felt under pressure to acquiesce.

The uptake of testing between the two groups that were investigated was excellent (86 per cent and 93 per cent, respectively) and the results on the issue of understanding equally positive (Abdool Karim *et al.* 1998:638–639). However, on the question of their having felt entirely free to refuse to be tested, the results were disturbing. In each group, 84 per cent and 93 per cent of the women believed that testing was compulsory. In terms of the research, the situation was just as serious, with 88 per cent and 93 per cent of the women admitting to having felt compelled to participate. In addition, 28 per cent had "perceived the research to be integral with the service at the hospital and agreed to the HIV test because they thought that refusal would compromise their care" (Abdool Karim *et al.* 1998:640).

In commenting on their findings, the authors suggest that a 'subtle coercive element' may, to some extent, have stemmed from the study being carried out in a hospital environment, where health professionals are regarded highly. Furthermore, they warn of a reported perception on the part of the research subjects that 'the hospital' would not have allowed them to quit the study even though they had been assured that they had this freedom. The authors point out that patients who are poor in South Africa have few alternatives open to them in terms of healthcare and that this also may have influenced their willingness to participate in the research.

The same, of course, applies to their willingness to be tested as part of the routine offering made to those presenting at the hospital. On both scores the findings give cause for reflection among healthcare professionals and researchers. The results highlight a very real possibility that participation, which those in control believe is considered voluntary, is not perceived as such by participants and this is despite careful counselling and briefing prior to signing the consent form.

Who gives consent?

Like their medical colleagues, anthropologists and other social scientists take the view that voluntary consent is the cornerstone of professional conduct. For the latter this view emerges out of long-term, ethnographic work 'in the field' engaged directly with their research 'subjects' or 'participants' in discussions. Controversy arises, however, on a number of scores. Exactly how is individual permission to be obtained for research? Under what conditions, if any, is it advisable to obtain formal permission for the research, from someone who stands in a position of guardianship or authority in relation to the prospective research participant? Situations have been reported, for instance, in which women believe they cannot participate in research without the permission of senior men in the family or lineage. Similarly, political leaders might also be expected to act as gate-keepers to community access. These are situations well known to anthropologists working in isolated small communities. In current HIV/AIDS research the issue of proxy consent is particularly pertinent as research with children is fast developing as one of the main areas of concern. AIDS orphans have been identified as an important category for research and intervention. Where these children are approached as research participants, is it the child's guardian who gives the necessary consent (as is currently the legal position in most countries) or should the children themselves be consulted and allowed the right to refuse to be the objects of research? Alternatively, if parents refuse to grant permission, should or could the children overrule this and agree to participate?

Questions also arise in many research situations concerning the feasibility of obtaining individually signed consent forms where whole communities are the object of ethnographic methods and long-term participant observation. Using such approaches, even casual encounters may be critical in formulating conclusions. The subtleties of these distinctions are often lost on medically dominated review boards that have little experience of humanistic research processes or techniques.

The important issue in these contexts may be not so much consent *per se*, as whether it needs to be 'written' – that is, formalised by a 'consent form' of the kinds used in medical research. Many would argue that in long-term research it is continued participation by research participants that indicates 'consent' rather than the existence in the filing cabinet of some university office of a document signed at the outset of the long journey of mutual discovery that characterises most anthropological inquiry. Where communities or sections of communities continue to tolerate and even welcome the researcher, the issue would appear to be answered in the affirmative. However, it is often argued that more formal consent is required when long, extended in-depth interviews are to take place. Certainly the research participant should be fully informed not only of the expected time commitment, but also of the implications of the publication genre of this type of research data, particularly if there is a possibility that it may be in any way harmful or unwelcome. Another thorny issue is whether in long-term research the consent of each new person encountered needs to be solicited, particularly if the bona fides of the researcher is guaranteed by the more longstanding research participants or by those who speak for them.

The answers to these questions lie in a careful engagement with the local context of the research. Fortunately, as already noted, these complexities have recently been recognised by one of the foremost bioethics forums in the USA (www.bioethics.gov). Not all local medical review boards have, however, caught up with this advance. It is important that, not only ethnographers, but their medical colleagues take cognisance of the general tenor of this document (see especially Commentary on Guidelines 4 [Process, Language, Documentation of Consent, Waiver of Consent Requirements, Cultural Considerations] and Commentary on Guideline 8). These statements allow for alternative cultural traditions and authority structures to those operative in the West to inform 'informed consent', and for written consent to be waived in some instances.

It must be stressed, however, that where relaxation of these processes is deemed acceptable, it must not be taken as licence to exploit potential research subjects or to waive the demonstration of common courtesies expected of a visitor entering a community that is new to him or her. Nor should it overrule individual agreement (be it verbal or written) by the research participant. To a large extent, in ethnographic research, this is (as suggested earlier) indicated by the willingness of research participants to continue to interact with the researcher living in their midst. Were this to be taken seriously in long-term medical research, it is possible that subjects would feel less pressurised to participate and thus remain research participants in the study.

The implications of the above discussion are clear. It is important not only for researchers to be sensitive to the wide range of subtle pressures that may be brought to bear on research participants, but that new contexts of research may present new challenges which it is the duty of researchers to consider. Above all, it is critical that ethical guidelines are not merely taken for granted but ongoing research is actively and regularly interrogated against them. This interrogation should inform both the stage of proposal writing, but even more so, the operationalisation of research, for it is in the later phases that unexpected ethical dilemmas may present themselves. It is useful, particularly in HIV/AIDS research, to schedule regular, reflective sessions on the topic of ethics and the responsibilities of fieldworkers towards research participants. This is, in fact, mandated by a number of ethics review boards in the form of annual reports upon which continued ethical clearance is promised. However, a further responsibility faces senior researchers: they need to ensure that more junior research colleagues, fieldworkers and students are included in ethical debates and that ethical issues are incorporated fully in all graduate curricula. This last point is underscored in the Code of Ethics of the American Anthropological Association:

Teachers/mentors should impress upon students/trainees the ethical challenges involved in every phase of anthropological work; encourage them to reflect upon this and other codes; encourage dialogue with colleagues on ethical issues; and discourage participation in ethically questionable projects.

[AAA 1971 IV.3]

These words, while directed at anthropological colleagues, might well act as a broader injunction to all who work in multi- and interdisciplinary teams where the focus is now moving to address community-level issues. The debates around these issues seem particularly pertinent to work in the HIV/AIDS field.

Concluding remarks: Research ethics and the vulnerability of the HIV infected and affected

In concluding this paper we would like to stress the very real vulnerability of the poor and HIV infected. Despite working with the best of intentions, researchers often fall back on a position of power – backed by large research grants – in the recruitment of research subjects. These researchers may be outsiders to the country concerned, but they may also be from inside the country. As we have demonstrated, undue pressure is often experienced by potential participants for a variety of reasons ranging from the payment of ‘incentives’ that poor people are hard pressed to refuse, to more subtle pressures such as those described by Abdool Karim *et al.* (1998) and which are encapsulated in the words of the woman in the Petra study who claimed to have agreed to participate in the study as the ‘only hope’ for her unborn child to escape infection through peri-natal HIV transmission.

In the case of HIV, yet another disturbing element is increasingly present. Not only is the severity of the epidemic a spur for research, but the very size and easy accessibility of the HIV-infected and affected communities in South Africa makes it a magnet for researchers. In some cases, large research grants have been made available specifically for research in Africa (or other developing countries). While at one level the sentiments behind such funding decisions

are to be applauded, at another they fuel the race by researchers to benefit from this munificence. In South Africa, poverty-stricken communities have for long been asking prospective researchers the question 'how will we benefit?' In a similar vein, those infected and affected by HIV – virtually all in the black community – are asking the same question, particularly in the face of the widespread inaccessibility of ARVs, not to mention the lack of social welfare provisions to bolster individuals and families affected by the disease.

In light of the earlier discussion, it is hardly surprising that two requests are increasingly put to HIV researchers: 'How can we get the cure?' and 'Please respect our privacy and sorrow'. The first question is as taxing for researchers as it is for care-givers and is likely to remain so even when ARV treatment becomes more generally available. The reason for this is that the infrastructure of care is weak and few care-givers are conversant enough with the drugs to administer and monitor ARV care. As a result, any national 'roll-out' will not be able to cover anything more than a fraction of the population for some time to come. Support for campaigns for ARVs to be made generally available, such as that by TAC, was thus deemed critical by many. TAC's support for the authorities in the nationwide process of roll-out to the far corners of rural areas has been incorporated in TAC's national agenda. Exactly what such 'support' might be and what it would involve in concrete terms is a matter of individual conscience and, as important, individual skill. There is nothing more problematic than well-meaning but ill-informed offers of assistance to busy campaigners and activists. Researchers thus need to be sensitive to their own limitations, but equally to the power that they could wield with the pen and open advocacy from a platform of the knowledge they command by virtue of the excellence of their research. This may, of course, involve mastering alien forms of dissemination, such as those called for in providing the ammunition for advocacy in a form of documents that are palatable and accessible to decision-makers.

On the question of 'respecting privacy and sorrow', a response is more directly within the control of researchers. It could involve limiting demands that the infected and their families answer apparently endless questions, and particularly that they fill in massive and successive questionnaires. Such demands diminish ever further the waning strength of AIDS patients as well as the emotional reserves of the people who love and care for them. Perhaps worse in the current context of stigma, is an insensitivity to the fact that visits and attention by researchers is often seen as a sign to family and neighbours that a person is HIV infected. This may well not be the case and the visit is merely one indicated by the methodological process of random selection. Nonetheless, undue attention by researchers and research teams can lead neighbours to draw erroneous conclusions. Even if the stigma is decreasing, the perception remains among both infected and affected that it is strong, and the fear of what might happen following disclosure is enough to prevent those who are diagnosed as HIV positive from telling even their family members. Similarly, family members are afraid to admit to having an HIV-infected relative and try, by all means, but often to no avail, to hide this fact from their neighbours. These are fraught situations and a thoughtless word or slip of the tongue may jeopardise the fragile equilibrium of those affected by the epidemic. 'Loose talk' by researchers or even innocent questions to neighbours for directions to particular homes may have drastic repercussions in terms of local gossip. Although these are oft-repeated warnings to researchers, the elementary caution they argue for is sometimes breached or ignored.

Finally, we should note that what are effectively breaches of confidence are sometimes justified on the grounds of the need for research, particularly when it may lead to medical advances and the long-term benefit of the community as a whole. Still the dilemma of the researcher's individual responsibility to research participants remains. Anthropologists have, as we have seen, long enshrined the priority of this responsibility over all other considerations. In the context of HIV/AIDS, it seems to the authors that this is as critical as it ever was in situations such as war or under totalitarian regimes where the danger was the physical one of death or incarceration. For many, HIV/AIDS has much the same effect.

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Bioethical practices in developing countries: The case of Mexico

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Anthropological health research in economically developing nations has customarily centred on traditional healing beliefs and practices and their meanings. With some exceptions,¹ much less attention has been given to the ways in which biomedicine is practised in these societies and few studies have been concerned with the ethics of medical activities cross-culturally (Marshall and Koenig 1996; Wertz 1998). Wertz's impressive work used survey rather than traditional anthropological techniques, including in-depth interviews and observation.

The aim of this article is to explore how bioethics is perceived and practised by physicians in a developing country such as Mexico. My focus is on medical ethical practices in a clinical setting, rather than on the ethics of clinical research, although I hasten to add that treatment and research are frequently combined and that problem requires separate treatment. The question that arises now is whether bioethical approaches developed in the USA are applicable and readily transferable to other cultures, such as Mexico.

The field of bioethics has usually addressed classical issues of abortion, organ transplantation, end-of-life matters, including euthanasia, problems associated with the new reproductive technologies (Crigger 1998) and, more recently, the new genetics (Finkler 2003). Its four pillars are: beneficence, nonmaleficence, autonomy and justice that ought to inform medical practice and research universally. Despite the numerous critiques of these principles, they continue to dominate bioethical discourse in the USA. Even in Mexico the four principles form the basis of bioethics as is evidenced, for example, in a recent Mexican publication prepared by ethicists for legislators charged with drafting bioethical laws for the medical profession (Garcia Colorado and Lopez Brito 2003). Thus, we must examine how these bioethical principles are played out in day-to-day practice when they are transplanted to Mexico.

I begin with a short overview of the development of bioethics in the USA and its cultural, religious and political underpinnings. I will then move briefly to biomedical practice in Mexico in general and specifically to bioethical conceptualisations based on field research. As we will see, while the four principles are the official basis of Mexican bioethics, Mexican physicians conceive of bioethics in a variety of ways, reflecting Mexican cultural comprehensions and economic realities. While Mexican physicians do not refer to the four principles, their understanding of bioethics conflicts in part with the principle of autonomy, including confidentiality, and privacy, but emphasises the principle of justice that also intersects with the principle of beneficence and malfeasances. In the conclusion, I will consider whether bioethical principles can be universalised or whether there can only be a localised bioethics. To address this question is to call attention to the tension between relativism and universalism, a fundamental theoretical concern in anthropology. Related to this point, I will briefly consider whether a bioethics can exist at all when it is assumed that human nature is shaped by self-interest.

where is footnote 1 here?

Development of bioethics in the USA

Whereas preoccupation with ethics in Western thought goes back to Aristotle and medical ethics has its roots in Hippocratic medicine (Thomasma 2000), contemporary concern with bioethics is a relatively new phenomenon, having emerged in response to changes in medical professional practices and the doctor–patient relationship (Jonsen 1993; Rothman 1991) that have taken place in the USA in the mid-twentieth century. Traditional medical ethics, rooted in Aristotelian conceptualisations of virtue, was based on notions of trust and respect for human dignity, life and compassion. These values may have been appropriate until the early part of the twentieth century, when personalistic and communal ties prevailed in medical practice in the USA, but when medical practice moved from community and home to hospitals, patients began to lose trust in physicians managing their illness (Rothman 1991). The expansion of medical technology and specialisations tended to diminish the role of clinical medicine, decrease the personal relationship with physicians and hospitals tended to be regarded as foreign institutions. Moreover, transplantations and new procedures in neonatal care raised questions about informed consent and definitions of life, death and personhood; about human experimentation and allocation of economic resources (Fox 1990; Rothman 1991). With limited means, concern with the just distribution of medical care began to be expressed in notions of cost containment. As American society became more fragmented following the growth of new social movements in the late 1960s and 1970s, distrust of authority and medical authority ensued, as did the notion of the meaning of medical ethics. People began to wonder whether the doctor was indeed working in the best interest of the patient, leading to an increased frequency of malpractice litigation beginning in the 1970s (Henderson 1994; Rothman 1991).

The four principles developed by Beauchamp and Childress in the 1960s (Gillon 1994) have many roots, including Greek medicine, American liberalism, Kantian philosophy as well as in Hobbesian notions that for humans to act morally they must have rules to live by (Jennings 1998). They reflect an American cultural emphasis on individualism (Tocqueville 1980), as well as on Christian, specifically Calvinist, theology (Jonsen 1991; Wolpe 1998), having initially been taken up by theologians (Wolpe 1998). The Hippocratic School laid down the principles of *beneficence* and *nonmalficence*, which physicians can fulfil by leading virtuous lives, casting back on Aristotelian ideas regarding virtue as right action at the right time and place as the essence of ethics.

Today, the Kantian philosophy relating to human *autonomy* and reason has become the overarching bioethical principle (Wolpe 1998) thereby supplanting the principle of beneficence (Henderson 1994). It asserts that the physician must treat the patient with respect as a rational being. The respect for autonomy assumes that humans can make rational choices and have the responsibility to do so – unsurprising, since in modern Anglo-American society the individual has no options but to make choices (Strathern 1992). The principle of autonomy calls for full disclosure, truthfulness, confidentiality and informed consent. Informed consent requires a freedom of choice associated with personal responsibility and voluntary action and privacy. Privacy has been elevated in American culture to a sacred state, separating the person from the rest, presumably allowing the individual to grow and reflect (Laurie 2002).

It must be stressed that the principle of autonomy tends to remove physicians' responsibilities for their patients' treatment decisions, and, arguably for this reason they easily accepted it, especially since people began to lose trust in the doctors. It also tends to remove responsibility from the State to regulate and monitor medical procedures and practices on the grounds that the individual, not the physician, chooses the treatment. But it is often overlooked that patient autonomy is as good as the information the individual possesses, and this may vary by social class and ethnic background. Related to this point, the emphasis given to the principle of autonomy suggests that bioethics deals with micro issues concerning individual patients rather than

macro issues, for example poverty in developing nations that must be addressed from an ethical perspective (Rothman 1991), a point to which I will return to in the conclusion.

The principle of *justice* comprises more than one principle (Beauchamp 1994) and there is little agreement on its meaning (Gillon 1994). Following Rawls' (1971) theory that the foundations of justice rest in fairness, I take it to mean that national and local institutions and physicians will make no distinctions between people respecting their rights to the fair distribution of scarce resources and that each person will benefit equally from a society's healthcare system.

Critique of bioethical principles

The critics of bioethics argue for a contextualised ethics. They include social scientists, as can be seen in the work of Simpson, and Preston-Whyte and Bodasingh in this volume (also Kleinman 1995), as well as ethicists and philosophers who normally may take a universalist stance (Devries and Subedi 1998; Elliot 1999; Hoffmaster 1992).

Generally speaking, anthropologists recognise that the content of any moral system is socially constructed, emerging out of human lived experience rather than out of rationally produced doctrines. Not surprisingly, then, anthropologists have been the most vociferous critics of bioethics. But, philosophers and historians, too (Hoffmaster 1992; Rothman 1991; Elliot 1999) have questioned the universalistic nature of bioethics. Hoffmaster proposes a quotidian ethics (Hoffmaster 1998). Elliot (1999), a philosopher, suggests correctly that ethics does not stand apart from the society in which it is embedded. He argues correctly that moral concepts are bound up in the society's daily way of life. He states, "Ethical concepts are tied to a society's customs, manners, traditions, institutions – all of the concepts that structure and inform the ways that a member of the society deals with the world" (p. 147).

More specifically, the applicability of each of the four principles has been questioned. Wertz (1998) has demonstrated that the concept of autonomy is even difficult to translate in other cultures. Moreover, scholars (Florida 1994; Kasenene 1994) have argued that these principles are not relevant cross-culturally as, for example, the Buddhist tradition of justice that refers to hierarchical, rather than egalitarian, social arrangements (Florida 1994). In Africa, beneficence applies to the entire community rather than the individual, and autonomy is a foreign concept, as it is in most societies that are rooted in a tradition of familism (Kasenene 1994). In fact, the principle of autonomy has been the most problematic, even in societies such as Britain. For example, risk need not be disclosed if it may create unnecessary anxiety (Henderson 1994).

Additionally, while arguably most would agree that malfeasance may be a universal principle, notwithstanding the iatrogenic effects of medical technology and prescription medicines, can beneficence be similarly applied? Do physicians have a right to impose treatment on religious groups, such as Jehovah's Witnesses who refuse treatment when blood transfusions are required?

Biomedicine and bioethics in Mexico

Bioethics is molded by Mexican culture, despite the powerful influences of American biomedicine (Finkler 2001). The materials I present here on physicians' approaches to bioethics were collected in Mexico City in 2003, in the largest general hospital in Latin America, where I had previously carried out a two-year study of biomedical practice. During my recent field stay, I questioned 29 (19 men and 10 women) physicians of different specialities, ages and stages in their medical careers about their definition of bioethics and whether they had experienced any ethical dilemmas in their practice.

Healthcare delivery in Mexico

By way of background, biomedicine is the predominant professional healthcare delivery system in Mexico and in large measure it is controlled by the State. The mixed economy of Mexico that combines state-managed and private economic enterprises is reflected in biomedical

healthcare delivery. Biomedical healthcare is provided by state institutions and by private physicians. Additionally, there are alternative healing systems, including professional and folk. The former includes homeopathy and acupuncture; the latter includes spiritualist healing, *curanderas*, and a variety of other traditional healing modes (Finkler 1994).

The Mexican Social Security laws guarantee healthcare to all employed workers. Furthermore, the State has taken charge of its population's health through its three major public institutions. These state institutions each operate networks of extensive, independently administered primary, secondary, and tertiary hospitals and clinics. The National Institute of Social Services (IMSS) was established for workers in 1943. With the expansion of the Mexican bureaucracy, the Institute for Social Security for State Workers (ISSSTE) was founded in 1960 (Cleaves 1987). Subsequently, other government enterprises, including the National Oil Co. (PEMEX), the Railroad Workers, the Electrical Workers, and the Society of Marines, launched health services for their employees (Lopez Acuna 1980). All these institutions are financed jointly by the federal government, employers and employees. People who lose their jobs forfeit medical benefits provided by these institutions.

The government healthcare programmes cover about half of Mexico's population. The remaining population of unemployed workers, peasants, self-employed merchants, and shopkeepers has access to health services provided by the Health Ministry (Secretaria de Salud), which manages a network of hospitals and healthcare centres in rural and urban areas. These institutions furnish primary, secondary or tertiary services, one of which is the general hospital. Healthcare provided by the Department of Health is open to all citizens, including foreigners. Only token fees are charged. Unlike the IMSS/ISSSTE systems, the Health Ministry institutions fail to provide free medication. The General Hospital maintains a pharmacy that sells medications at very low cost, but its supplies are usually inadequate and, therefore, patients seeking treatment there, unlike those from other state institutions, must purchase drugs and other medical accoutrements from private pharmacies and medical supply houses. While the General Hospital enjoys a national reputation for providing excellent healthcare, by and large the Health Ministry's facilities are considered inferior to those operated by the IMSS and ISSSTE systems. Additionally, physicians employed by the latter are also paid higher salaries than those working for the Health Ministry.

The Mexican government allocates a small part of its national budget to healthcare relative to the rest of Latin American nations (Alvarez 1987; Horn 1983; Lopez Acuna 1980; Peña-Mohr 1987). Medical expenditures hover around 2 per cent of the Gross National Product, with 70 per cent of the budget earmarked for curative rather than preventive medicine. Most importantly, about half of the national health budget is earmarked for the Social Security Service as compared with only about one-tenth of that for the Health Ministry.

The relatively poor funding allocated to the Health Ministry establishments is reflected in the impoverished conditions under which physicians carry out their activities in the General Hospital. Not only are quarters congested and poorly lit, but physicians need to share basic medical tools. Not surprisingly, the unequal budget allocations within the public medical sector reflect the Mexican government's commitment to the development of capitalist industrialised institutions, many of which are multinational corporations. By guaranteeing free healthcare to the working population, the Government subsidises the industrial-capitalistic model of development with its provision of healthcare to the employed through the Social Security System (IMSS) at many times the level given to the Health Ministry that services the population of unemployed. Thus, the Mexican state safeguards a healthy labour force for the capitalist industrialised sector of society by providing healthcare to factory workers and the state bureaucracy. However, the Health Ministry's facilities furnish a last resort for the urban unemployed, the petty merchants and street vendors, unemployed women with children, and the

rural poor, after private physicians' treatment has failed. In short, unequal governmental support of medical institutions in the public sector results in subsidising the globalisation process in Mexico by removing the responsibility of the health of its workers from the private industrial sector and in turn by providing free healthcare delivery for the working class. Significantly, in recent years the economic crises in Mexico have led middle- and upper-class Mexicans to seek treatment and technological management in the public sector, including the General Hospital, where well-dressed people can be seen mingling with the majority of poor people.

Mexican medical tradition goes back to the Preconquest and Colonial periods, when Hippocratic medicine prevailed. Biomedicine was introduced to Mexico from Europe in the nineteenth century and from the USA in the twentieth century, and Mexican physicians are taught the biomedical model developed in the USA (Finkler 2001). However, biomedical practice, and especially etiological explanations, becomes transformed and reinterpreted in a Mexican way, notwithstanding physicians' medical training. For example, to explain a patient's disease, physicians often combine biomedical with traditional folk understandings, such as emotional upsets that include anger, nerves and fright. Clinical judgements, too, are shaped by a physician's personal experience, and moral values (Finkler 2001, 2003).

Not surprisingly then, bioethics, which has become an important issue in Mexican biomedicine in the past ten years and is now a required subject at the National School of Medicine (UNAM), is shaped by Mexican sensibilities, even though ethics and research committees established within the past seven years follow the four principles developed in the USA. While Mexican medical institutions formally accept this model, in day-to-day practice physicians follow chiefly personal and cultural interpretations of medical ethics.

All physicians in the current study were asked to define medical ethics. The most common response was that bioethical behaviour is situational. The prevailing theme emerging out of all the interviews was that physicians do not follow any specific guiding ethical principles. While each physician defines and establishes his or her own ethical criteria that reflect held moral values depending on his or her religion, social position, and economic status, a patient's condition is also considered. In the words of one physician, mirroring the views of most, "It is not what is done but who does it. If the doctor is ethical the patient will be treated ethically." Moreover, patients with different diseases raise dissimilar ethical problems, especially if a patient suffers from a chronic or acute disorder. For example, one physician explained that an individual with a chronic disease impacts the entire family both emotionally and economically, thus he must direct his treatment to both the person and the family; whereas in cases of acute disorders, the physician must treat mainly the disease rather than the patient and his or her family.

Reminiscent of Aristotelian virtues, most physicians indicated that medical ethics entails good character, professional comportment and, most importantly, respect for the patient. Some also included medical competence and giving a patient confidence as part of ethical medical practice. Interestingly, a few of the residents incorporated in their definition the need for educating patients about their condition and describing the risks and advantages of a proposed treatment. For one doctor who claimed to be absolutely certain of his diagnoses at all times, there existed but one ethical rule: to tell the patient the unrelenting truth. Most other physicians were less authoritarian about applying a universal rule of truth, recognising, along with the Hippocratics, that the decision to tell or not tell a patient the truth about a bad prognosis depends on the patient and the family.

The major ethical topics recognised by most all physicians revolved around abortion, transplantation, and active and passive euthanasia. With the exception of passive euthanasia, the classical bioethical issues are not the physicians' immediate daily ethical concerns, although they certainly must confront them. While the physicians do not speak in terms of distributive justice or beneficence, their ethical preoccupation, as they perceive it, revolves around these

issues and those which they discuss in terms of how to provide their patients the best possible care, given the meager resources available to them. The overwhelming majority of physicians identified the lack of economic resources as the overarching ethical dilemma they face. To quote the Head of Haematology, "central to a patient's prognosis is money and not what we do for him. Since both our patients and the hospital possess very meager resources their prognosis is poor from the start." Among the most common ethical quandaries associated with economic scarcity reported by the physicians is their inability to prescribe the most effective medicines on the market because they are the most costly. For some this dilemma is compounded by the problem of whether to let patients choose between expensive and cheap medications or whether to simply prescribe the cheapest medicine to avoid creating false aspirations for them. In fact, some residents noted that they frequently gave their own money to patients to purchase medications. What is more, since patients need to pay for various medical procedures, including operations, and often they may have to purchase parts for the medical apparatus that will be used in such treatments, many physicians take the cost of these procedures into consideration before prescribing them.

Other ethical dilemmas voiced by individual physicians include, in one case, a physician whose department must accept the overflow of patients from other specialities when neither she nor her colleagues consider themselves competent to treat persons with disease outside her speciality. Another physician indicated that his major conflict is between treating his patients or competing for resources in order to keep his research position. A third physician noted that he was conflicted ethically because of his involvement in various randomised, double-blind studies that impede him from providing the proper treatment to patients in the study and that he must watch them suffer.

While physicians must confront the consequences of poverty daily, paradoxically the absence of resources also leads to perpetuating the inequalities. For example, in infrequent cases of transplants, implants, kidney dialysis or other complex and costly procedures, patients are selected on the basis of where they live and their economic possibilities to maintain themselves and thrive. These criteria take into account whether the patient has a permanent place to live, and whether he or she will be well-cared for by a family in good standing to assure that the patient will get the best possible postoperative care. Scarce resources cannot be wasted on patients who will not thrive. Ironically, in these instances, equal access to healthcare is but a luxury only developed nations can afford.

Related to this point, some physicians must confront the problem of passive euthanasia, especially in cases of elderly patients. In Mexico, people have a right to decide whether or not to have sustaining life supports by leaving a living will. However, these wills are not legally binding, and the doctors may decide in cases of passive euthanasia, without necessarily informing the family. The physicians who raised the issue of passive euthanasia did so within the context of scarce economic resources rather than in relation to the patient's quality of life, and they usually did not sanction the practice, even though they claimed that others did.

The extreme effects of the hospital's scarce resources are mitigated by the commanding presence of the family as the basic unit of Mexican society. All doctors count on an alliance; some even refer to it as a marriage, between themselves and the family, to assist them in attending to the patient by mobilising the family to support a proposed treatment plan. If they must discharge a patient prematurely, they know they can rely on the family to care for him. On the other hand, the family can also insist on a procedure against the doctor's will and, in recent years, the spectre of legal procedures tends to put pressure on physicians to carry out procedures against their better judgement. In fact, there is now a growing fear of patients' rights to sue that did not exist even ten years ago. Interestingly, one doctor attributed this nascent trend, as well as demands for technological assessments, to the influence of American television programmes depicting the miracles of modern medicine.

The position of the family as the basic unit of a Mexican existence calls into question the universality of the principle of autonomy. Autonomy is associated with confidentiality and privacy, but these are not regarded as ethical concerns. Bauman (1998) suggests that privacy is a modern way of life, emerging out of an individual's isolation and leading to an absence of responsibility for the other. Given the immersion of the individual in the family unit in Mexican daily life, neither patients nor physicians are concerned about privacy and confidentiality, excepting in cases of AIDS, which are usually feared less on moral grounds than on grounds of contagion. Kin are always present during a medical consultation and are usually informed about the patient's health state and treatment requirement. For example, the patient is accompanied by any number of people to the hospital and, depending on the available space in the consulting room, all family members will be present during the doctor visit. Interestingly, during my previous research I found that even when strangers were present at the time of the medical consultation, patients reported that they regarded the presence of others as a sign of interest in them.

Most physicians indicated that they respect their patients' decisions but that they respond variously to their choices. In much the same way as the Hippocratics used rhetoric to convince patients to follow doctors' orders and to gain their trust (Bartz 2000), doctors in Mexico believe in rational persuasion: if they explain the reasons for a treatment procedure and the patient signs an informed consent form, he or she will unproblematically comprehend the explanations. If the patient refuses the proposed treatment, the patient will be asked to sign him or herself out of the hospital. At present, physicians respect a patient's autonomy to refuse treatment more out of moral than legal considerations, but they also consider that they must have the patient's cooperation to facilitate their work.

The refusal of treatment has become an especially acute problem with the increasing population of Jehovah's Witnesses in Mexico in recent years. They have presented ethical conundrums for a number of physicians because they refuse to permit blood transfusions. With the exception of one doctor who claimed to have found a way of treating such patients' problems without using transfusions, in all other cases requiring a transfusion the Jehovah's Witnesses were requested to sign themselves out of the hospital.

It has been observed that the consent form, symbolising a person's autonomy, has been substituted both for the relationship of trust between doctor and patient and for beneficence. Indeed, within the past seven years hospital patients have been routinely asked to sign a six-page consent form in all cases of invasive and complex procedures and research protocols. However, physicians recognise that in the majority of cases, the patient and family do not understand the meaning of the form or what they are signing, a not uncommon occurrence the world over (Churchill et al 1998).²

Conclusion

Bioethics is changing Mexican biomedical practice, beginning especially within the past seven to ten years, when it was first discussed and taught at the university. But, in a postmodern world where there is no one authority, where it is believed that self-interest is inherent to human nature and, where market forces dominate human experience (Bauman 1998), can we have a bioethics of any kind? Can we expect physicians and the medical establishment to accept an ethic that transcends self-interest and market forces? Rather than attempt to answer this question, I can only but pose it here because the answer would require a complex analysis of contemporary society, although I hasten to add that this fundamental assumption is, arguably, not held universally, including in Mexico.³ However, I will note that it is remarkable that bioethics, despite the modern assumptions about human nature, has become a major preoccupation of the medical establishment worldwide, perhaps because it may be recognised that ethical behaviour serves mutual interests by facilitating ministering to patients, especially since medicine may be losing its authority. The contemporary concern with bioethics the world over

may also suggest that perhaps our assumptions about human nature are faulty. Possibly, human nature is propelled by moral impulses as much as, or more than, by self-interest.

However, conditions of economic scarcity impede the practice of medical ethics. Whereas in the USA the matter of how to spend health dollars for universal healthcare, for older or younger people, is a source of conflict, in Mexico, as in most developing nations, the dollars are simply not available to be spent.

There are numerous causes for Mexico's present economic condition, but the globalisation processes especially have exacerbated the extant economic disparities within the country. Notwithstanding the economic situation, the Mexican government has decided to underfinance the healthcare system, in general, and the Health Ministry, in particular. Physicians ministering to thousands of poor people at the General Hospital must negotiate their meager resources among themselves, among the different specialities and with their patients and their families. Given this situation, it is not surprising that there are no hard and fast ethical rules physicians follow; instead they improvise ethical stances in response to the situation they encounter in daily practice.⁴ Improvisations of this type may in the long run be to the advantage of Mexican medical practice. Significantly, Dewey and Tufts (1908) argue against fixed rules of morality that they suggest may reflect class and authoritarian interests. These philosophers correctly stress that moral principles are but tools and guides for an analysis of specific situations that are usually highly complex and, because moral acts have consequences, that they must be carefully deliberated on within each given situation.

The four bioethical rules trade in generalities and yet they are now becoming the ethical currency the world over. As the inheritors of Hippocratic ethics, all the physicians I studied attempt to fulfil the principle of beneficence, even though such attempts cause them great frustration – a frustration largely intensified by the flourishing of technological medicine imported from developed nations; this contributes to the unjust distribution of access to healthcare. One might even ask whether state investment in medical technology is warranted given the absence of competent personnel to manage it and, most importantly, given the overwhelming need to control infectious disease such as parasitosis and tuberculosis brought about by abysmal public health conditions. The economic resources invested in complex technologies would better serve the population at large if the water and sewage systems were cleaned up comparable to the public health conditions in developed nations.

Medical technology provides the hospital with an aura of competence and modernisation, and it stands at the intersection between decision made on the macro level and the day-to-day medical practice on the micro level. Whereas physicians in Mexico overwhelmingly practise clinical medicine, or what they identify as 'French' medicine, they use modern medical technology to confirm their clinical judgements. When their clinical data contradict the results of technological analyses, they usually rely on the clinical data.

Curiously, however, older physicians observed that prior to the introduction of modern technological medicine, all patients had the same access to care. With the advent of modern technology, not only its use has become a health management strategy, but it also has led to ethical dilemmas because, according to many of the physicians, in cases of life-threatening conditions, a disparity was created between those who could and could not afford its use. The older physicians recognise that 30 years ago there was more of a level playing field – a time when patients' treatment was dependent solely on clinical management of disease. While some physicians regard the use of superfluous technology as unethical, others, especially the younger ones, tend to order more technological examinations than the older doctors, even though they, too, depend on clinical judgements and may not even obtain the test results.

Benevolence and justice merge in Mexico, although some physicians acknowledge the possibility of malfeasance that could be caused by the iatrogenic effects of various medical procedures. Generally speaking, however, whereas the principle of distributive justice is usually considered within the context of macro-level governmental policies, it intersects in Mexico with physicians' day-to-day practice. This intersection comes into bold relief when physicians select patients in the best economic circumstances to provide life-saving treatments.

Ideally Mexican physicians desire to follow the Aristotelian rule to behave virtuously toward patients, coupled with the Kantian notion of respect for them. While in many cases physicians attempt to convince patients by using rational explanations to demonstrate the advantages of a particular treatment course, in the final analysis, they seem to acquiesce to the wishes of the patient and family, be it out of respect or out of current uneasiness about potential legal complaints.

Whereas it can be said that patients' autonomy is accepted with regard to treatment options, confidentiality and privacy are not part of Mexican cultural baggage. Given the important role the family plays in Mexican daily life, neither patients nor physicians are concerned about privacy and confidentiality.

Trust, or *confianza*, is a recurring theme in Mexican culture and defines all close social relations. Hippocratic physicians sought trust and established an alliance between doctor, patient and family (Bartz 2000) much as it is practised by Mexican physicians today. In contemporary times this trust is being supplanted by routinised procedure of informed consent, which in Mexico is flawed because patients do not understand what they are signing. In the USA, informed consent may substitute for trust but when it fails the legal system may kick in. In Mexico, the legal system is very frail and may not protect patients from some unscrupulous physicians and researchers who may feel that they need no longer work to gain the trust of the patient because he or she has signed an informed consent form.

Considering the present economic circumstances in Mexico, what would a Mexican bioethics look like? Currently, Mexican bioethics draws on culturally constructed conceptualisations developed in the USA. However in practice, Mexican bioethics emerges out of the conditions of Mexican existence and out of the cultural comprehensions that were influenced in part by classical Greek and Colonial sensibilities. While I believe that my Mexican colleagues must develop a specific Mexican bioethics, I propose in broad strokes that Mexican bioethics must be contextualised on the level of the patient and his affliction, be it chronic or acute; on the level of the family and its resources; on the level of the institution, whether it is private or public; and tailored to the specific population being treated. A Mexican bioethics requires a case-by-case approach rather than the creation of a set of rules that, in all likelihood, would not be followed, and that may not be appropriate to the present socioeconomic and legal conditions. A Mexican bioethics must therefore capitalise on physicians' moral sensibilities, as human beings, and sense of responsibility to the patient. We can call it benevolence, or, arguably, paternalism. However, it must not be overlooked that benevolence may turn into malfeasance, especially when medical technology may be used incompetently, resulting in iatrogenic effects and heroic measures, as some Mexican physicians recognise.

Within the context of the doctor-patient interaction, I have found in my previous study (Finkler and Correa 1996: 199-207) that the single most important factor influencing patients' recovery is patients' participation in their treatment - when the physician educates them about the disease and they readily ask questions during the medical consultation. It is not enough for the doctor to depend on simple rational explanations when the patient may be least capable of exercising his autonomy to rationally decide on a proposed treatment. For this reason, it is necessary to rely on family judgements that ought to be incorporated into medical assessments. By relying on patients' autonomous decisions, the physician relinquishes his responsibility to the patient. What I call the 'patient participation approach' requires the recognition, following

Levinas, that human beings have a responsibility for and to the other and, thus, that doctors have a responsibility to patients not simply to recognise their autonomy, but to acknowledge that the patient may require compassion, empathy, and intelligible explanations. Perhaps with this approach, the legalism that Mexican physicians currently fear may not materialise.

If medical ethics must be contextualised appropriately for specific societal settings, is there a need for a universalised bioethics? In short, do we need a metabioethics? Consider, however, that the ongoing globalisation process, which in the Mexican case has furthered its impoverishment, and the widespread use of advanced medical technologies imposes similar ethical quandaries external to a specific society's daily existence and creates new predicaments in all developing nations. For this reason, we must also develop a metabioethics that provides a universal guide for the allocation of resources for a population's medical needs. A metabioethics is necessary based on the principle of distributive justice, which holds that every member of society has the right to an equitable share of healthcare resources.

A metabioethics is urgently needed for all developing nations with a skewed resource distributive system. Several points made earlier therefore merit repeating. In Mexico, while the hospitals' means are poor, investment in modern medical technology has diminished equal access to care. Thus, one might question whether state investment in medical technology, in the absence of competent personnel to manage it, is fair and just given the overwhelming needs of the Mexican population to control infectious and parasitic diseases brought about by appalling public health conditions. These conditions predominate in all developing nations. We must question the ethics of national and local medical institutions' decisions to invest in complex medical machinery rather than in daily needs that would make available more and improved medications to the average hospital patient, and that would facilitate a physician's daily practice.

The metabioethics would apply to developing nations where epidemiological profiles, medical needs and experiences differ from those of developed societies. A metabioethics applied to developing nations would attend to distributive justice and to malfeasance of superfluous medical technologies that drain the budgets of the state by guiding governmental medical investments. It would address the economic inequities of a nation that reverberate on the daily actions of every physician. Whereas the ethics of clinical medical care on a day-to-day level must be left to individual medical institutions, the international establishments that oversee universal human rights need to attend to the ways in which healthcare resources are appropriated on a *macro level* and to recognise that all human beings have a right to equal access to healthcare.

This study is based on interviews with physicians in one type of government hospital. We need similar studies comparing private and better-equipped public medical institutions to learn how bioethics is played out in different venues under different economic conditions within the same society and cross-culturally in a globalised economy.

1 For references to such studies see Finkler (2000).

2 In my earlier studies of patients' responses to medical treatment, it was reported that procedures were performed on them without their consent. See for example the case of Nomi in Finkler (2001), who had her diseased kidney removed without her permission. In fact, she reported that she would never have given permission had she known that her kidney would be removed.

3 Moreover, since physicians work for the State, they do not benefit personally by promoting any one particular procedure.

4 Of course, direct observations are needed to confirm the data I gathered by interview. However, the results of the interviews were sufficiently consistent that I believe they reflect actual medical practice.

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Selected resources

Declarations, guidelines and reports

Declaration of Helsinki, World Medical Association:

www.wma.net/e

Council for International Organizations of Medical Sciences:

www.cioms.net

Nuffield Council on Bioethics:

www.nuffieldbioethics.org

US National Bioethics Advisory Commission:

www.georgetown.edu/research/nrcbl/nbac

European Group on Ethics:

http://europa.eu.int/comm/european_group_ethics/index_en.htm

Selected websites

Global Forum on Bioethics in Research:

1999–2002:

www.fic.nih.gov/programs/bioethics/globalfrm.html

2004:

www.inserm.fr/Geneweb/GlobalForum.nsf/Accueil?readForm&Lang=FR

John E. Fogarty International Centre:

www.fic.nih.gov/index.html

Scidev.net:

www.scidev.net

NIH Bioethics pages:

www.nih.gov/sigs/bioethics

University of Toronto Global Bioethics Resources:

www.utoronto.ca/jcb/Global/global_bioethics.htm

Wellcome Trust overseas units and centres

Kenya:

KEMRI – Wellcome Trust Collaborative Research Programme:

www.kemri-wellcome.org/index.htm

Thailand:

Wellcome Trust – Mahidol University Oxford Tropical Medicine Research Programme:

www.tm.mahidol.ac.th/wellcome/index.html

Vietnam:

University of Oxford – Wellcome Trust Clinical Research Unit, Hospital for Tropical Diseases,
Ho Chi Minh City

www.jr2.ox.ac.uk/ndm/Tropical_Medicine/pages/viet_nam_unit.htm

Malawi:

The Malawi–Liverpool–WellcomeTrust Clinical Research Programme
College of Medicine, University of Malawi

www.liv.ac.uk/lstm/Well_Trop/locations/mlw_prog.html

South Africa:

The Africa Centre for Health and Population Studies, KwaZulu-Natal

www.africacentre.org.za/index.ASP