

Book Reviews



The Ethics and Politics of Human Experimentation. By Paul M. McNeill.
Cambridge: Cambridge University Press, 1993. xiv + 315pp. Hardcover A\$49.95

McNeill has appropriate, but unusual, qualifications for writing on this subject. He is a graduate in law and psychology, with a PhD. in the history and philosophy of science, but teaches community and public health in the University of New South Wales, Sydney. His is a radical approach, on the side of people and subjects, without being overbearingly moralistic or ideological.

He confines himself largely to medical research and to human experimentation, so this review is not forced into the much more controversial area of the interrelations between ethical review committees and social science research. His central argument is that both researchers and their institutions have a vested interest in research going ahead. Furthermore, they are represented on ethics committees, and, even when they are not, they have the status and power to influence because of their knowledge and expertise.

McNeill's thesis is that the only way of protecting the subjects of experimentation is to have them represented on committees, perhaps by such bodies as consumer health groups or civil rights bodies. Even representatives of this type should not draw predominantly on their own beliefs or ideologies, but should attempt to contact the population pool from which the subjects will be drawn in order to explain to them the issues and to canvass their reactions. The theory is clear. The practice will undoubtedly be extremely difficult without weighting the argument and the evidence too far one way or the other. Indeed, the very argument will either have to be drawn from the influential scientists with their vested interests or will be a reaction – and perhaps a suspicious or unfair one – against those views.

Perhaps the weakest part of the book is Chapter 1 with its record of wartime atrocities and postwar atomic and nuclear experimentation. These are events on quite a different scale and essentially in the real political field in contrast to the sense in which McNeill employs political to mean the interests of institutions and programs. The issues he deals with in the rest of the book are on a smaller scale and hence are more subtle and more difficult.

I used the book for guidance on an important issue of medical ethics that will inevitably come to the fore, and found it of little help. Soon, the first experimental HIV/AIDS vaccines will become available. It will be possible to test them only on human beings. There is a tremendous need for safe vaccines to come into mass use in places like Uganda, where parts of the south-west and the capital, Kampala, exhibit levels of adult infection approaching 40 per cent of the population. No satisfactory vaccine may come into use unless the first vaccines can be tested, and until they are tested millions may be condemned to death in East and southern Africa. Yet, who will guarantee that the first experimental vaccines will not infect some of the recipients with HIV or will give complete protection from sexually-transmitted HIV? The researchers intend to cover themselves morally against the latter eventuality by warning all the subjects to take no sexual risks. But, if the advice is given so forcibly that everyone heeds it, the protective value of the vaccine will never be tested. A successful test presumably rests on the assumption that some people will not heed the advice, perhaps because it was not sufficiently convincing. The moral dilemma does not end here. The subjects in an HIV-vaccine test will almost

certainly be volunteers, yet, in Uganda and other parts of sub-Saharan Africa, some of these subjects will have volunteered precisely because they intend to continue a high-risk life-style if science can offer any hope that they will have some protection. They will take any warnings to arise out of the researchers' desire to protect themselves emotionally, ethically and legally – as indeed will be the case – and accordingly will discount it. The easy solution is to keep postponing the tests, but this will almost certainly result in far more deaths than it saves. These are issues with which McNeill will probably find himself deeply involved, and I look forward to his writings on the subject.

John C. Caldwell
Health Transition Centre
National Centre for Epidemiology and Population Health
The Australian National University

Pregnancy, Birthing and Family Planning in Kenya: Changing Patterns of Behaviour. A Health Survey Utilization Study in Kisii District. By Alanagh Raikes. Copenhagen: Centre for Development Research. CDR Research Report No. 15, 1990. 1–192 pp. Paperback. DKK64,00 (postage and bank charges included).

A considerable amount of research has been conducted during the past 25 years on maternal and child health (MCH) and family planning (FP) in developing countries. Important gaps in information continue to exist, however. There is, for instance, less knowledge of various aspects of MCH than of FP programs. There are fewer studies specifically focusing on what is happening at the local level (villages, districts) than at the national level. And there are also fewer in-depth studies aiming at acquiring a picture of the overall situation than studies solely relying on quantitative data using cross-sectional sample surveys. The relevance of Raikes's study is, therefore, its promise to fill us in on some of the abovementioned gaps in knowledge.

The study specifically deals with the use of antenatal, maternity and family-planning services in the Kisii District in Kenya, with equal emphasis on all three services. Another feature of the study is the use of different methods of data collection. In addition to information derived from a cross-sectional survey conducted among 723 mothers in 1985–1986, in-depth interviews were held with mothers in 20 households; personnel of 31 health centres were interviewed and nine traditional birth attendants were visited. So what have we learned from this study or, more importantly, what can policy-makers in Kisii, in other districts of Kenya, in Nairobi and in international agencies learn from this study?

Two of the findings are that 90 per cent of mothers visit antenatal services at least once during pregnancy and that 41 per cent of all deliveries take place in hospitals or health centres. Various reasons are discussed for why some women do not make antenatal visits and why some decide to deliver at home. These reasons are classified as predisposing, enabling and health-service factors. Existing beliefs and practices relating to pregnancy and childbirth are extensively discussed as a group of predisposing factors. Age of the mother, parity and socioeconomic status are examples of enabling factors. Among the health service factors mentioned are the characteristics of hospitals and clinics and the views of hospital and clinic staff on the operation and problems of antenatal and maternity services.

A similar approach is used with respect to family planning (FP) and the use of FP services. Noteworthy in the category of predisposing factors is the description and discussion of the role of traditional customs and methods of spacing births, in particular breastfeeding, abstinence from sexual relations and polygamy. The impact of demographic and socioeconomic characteristics on FP

acceptance is described in a section dealing with enabling factors. Especially relevant in the category of health service factors is the analysis of features of government-operated FP clinics compared with those of a private organization.

A major conclusion with respect to maternity services is that the existing services are very inadequate in terms of both facilities and staffing. They would be much more intensively used if there were more of them and if they were of better quality. With respect to the use of FP services it is concluded that FP is not a top priority for women in Kisii. Mention is made again of the contrast in services provided by the government (integrated with MCH) and a private organization (not integrated with MCH). This leads to the conclusion that there certainly is an important role to be played by non-governmental agencies and that '...for a while integrated MCH/FP [may] not [be] the most viable way to expand the [FP] service' (p. 139).

The study by Raikes is complementary to the existing studies undertaken so far. It is important that equal attention is paid to MCH and FP, because it happens too often that studies that claim to deal with both MCH and FP, in practice give much more attention to FP. Another noteworthy feature of the study is the use of a variety of sources of information. Especially useful is the description of beliefs and behaviour relating to pregnancy, childbirth and family planning as well as the results of in-depth interviews with staff of clinics, health centres and hospitals. It is to some extent disappointing that less than maximum use was made of the opportunities which were available. The study deals with a number of topics relevant for MCH and FP, but the analysis is not always thorough enough and the evidence in favour of several conclusions too sparse and not convincing enough. For instance, the results of the cross-sectional survey are somewhat meagre. More topics could and should have been included, for instance, on perceptions of women and mothers on 'high risk' pregnancies needing delivery in hospital and on their views on the quality of services provided by hospitals and clinics. It is also a pity that the study did not make optimal use of already existing information dealing with Kisii District as well as of results of epidemiological and other studies on MCH and FP which have already been conducted in Kenya and other East African countries. In spite of these limitations the report by Raikes is a welcome addition to the already existing literature.

Jeroen van Ginneken
Netherlands Interdisciplinary Demographic Institute
The Hague

AIDS: The Making of a Chronic Disease. By Elizabeth Fee and Daniel M. Fox, eds. Berkeley: University of California Press, 1992. vi+430 pp. Cloth US\$45.00, paperback US\$15.00.

Almost from its very beginnings, AIDS has demanded attention from historians. In 1988, medical historians and policy makers were treated to the publication of *AIDS: The Burdens of History*, edited by Elizabeth Fee, from the School of Public Health at Johns Hopkins University, and Daniel M. Fox, who is now President of the Milbank Memorial Fund and Professor of Social Sciences in Medicine at the State University of New York, Stony Brook. The volume set a new standard for contemporary history, with a collection of essays that were as theoretically bold as they were immediately relevant. Now, the same two editors have gathered another set of treatments of AIDS. Like their earlier effort, this new volume will reward scholars and students who come to it from a wide range of approaches. The contributions to this new volume reflect a set of major changes in the definitions of AIDS, most notably a shift from conceptualizing AIDS as an acute infectious disease towards seeing AIDS as a chronic disease.

These essays demand understanding on multiple levels. The collection is an exploration of the different ways that the natural sciences on the one hand, and the humanities and the social sciences on the other hand, give various degrees of insight into the phenomenon that we now think of as AIDS. And what is AIDS? Perhaps the book's central theme is the contingent nature of that definition. Part of its strength is that at the end (or even not far from the beginning) the reader has been disabused of the naive notion that 'AIDS' or related terms have any meaning outside of a specific social, economic, and historical context. At another level, these essays try, more or less effectively, to articulate the relevance of history to contemporary health policy. At yet another level, these essays say a great deal about the phenomenon that is killing people around the world. Relativism will go only so far. Physicians, public health providers and policy makers must finally decide to act, no matter how aware they are of the arbitrary nature of the definitions that they decide to use. However, given the rapidly changing nature of the empirical evidence, this is a book that will be most valuable for its conceptual insights.

Some of the sixteen contributions have been published previously, although many of them have been somewhat revised for this volume. The editors' cogent introduction emphasizes how the ways historians think about a given issue are different from the ways that scholars in the other social sciences think; and it emphasizes the relevance of an historical approach for understanding health policy. Throughout the book, written by members of the 'Greater Historical Profession' (p. 12), historical themes are very much in evidence.

The first section of the book considers efforts to represent the virus that is defined as causing AIDS. Stephen S. Morse looks with a virologist's eye at the evolutionary nature of the HIV virus, stresses the inseparable nature of pathogens and their hosts, and speculates about other viruses that may follow. Gerald M. Oppenheimer examines how groups of people, such as those working at the Centers for Disease Control in the United States, and ways of thinking, such as an epidemiological approach, tended to define the disease in certain ways and not in others. In the second section of the book there is a great deal about how legal and public policy matters helped create the response to AIDS. Harvey M. Sapolsky and Stephen L. Boswell give a fascinating account of how the two major groups that provide blood and plasma reacted, differently, to changing ideas about the infection. David J. Rothman and Harold Edgar compare the different ways that drugs for cancer and drugs for AIDS have been evaluated. Because AIDS was initially defined as an acute infection, the FDA chose to insist on randomized, placebo-controlled trials. Had AIDS been treated as a chronic cellular illness instead, drug trials might have more resembled those typically used to test cancer treatments. There, randomized, placebo-controlled trials are not considered ideal, either in principle or in fact.

A third section of the book examines the response of affected populations, such as the gay community and intravenous drug users. It includes a powerful set of photographs of women with AIDS by Ann Meredith, together with comments by the women about their lives. The book's fourth and final section includes excellent international perspectives on the disease. Two essays examine the response of communities in the United Kingdom and Japan, illustrating the difference made by different cultural contexts. Randall M. Packard and Paul Epstein compare AIDS research in Africa with research in Africa on venereal disease and tuberculosis. They point out that a fixation on African sexuality shaped Western attitudes towards AIDS. They also claim that needle use and malnutrition have not received adequate attention from AIDS researchers. Finally, Paula A. Treicher deconstructs both 'eyewitness' and statistical accounts of AIDS as carried out from the developing world.

Taken as a whole, this volume presents a complex, multifaceted analysis of what we now call 'AIDS'. It will be useful for those who study the disease, as well as for those who teach medicine, history, and policy.

Joel D. Howell
 University of Michigan
 Departments of Internal Medicine and History
 Ann Arbor

Constructing Questions for Interviews and Questionnaires: Theory and Practice in Social Science. By William Foddy. Melbourne: Cambridge University Press. xii+228. Hardcover A\$75.00.

Foddy has concentrated on the task of understanding the nature of verbal data, with the ultimate aim of increasing the validity of the questions used in social research. Although Foddy describes his text as a practical book, a number of the early chapters are devoted to defining the issues and to providing a theoretical framework within which to consider the methodological assumptions underlying the use of verbal data.

Foddy describes a model in which the respondent is an active participant in the communication process, rather than a passive agent, as has been the case with much previous survey research. Subsequent chapters deal with the factors affecting responses to questions and the subjects ability to respond. Issues addressed include contextual influences and the limitations of memory.

The final chapters of the book concentrate more on 'how to do it' and it is to these chapters that most readers will first turn. For example, Foddy's more practical chapters discuss the use of filters, reducing question threat, the use of open versus closed questions, the measurement of attitudes and how to check that questions work as intended.

This book does not deal with issues such as sample selection, questionnaire layout, or how to conduct interviews or analyse data. It deals with the more fundamental problem of how to formulate questions. Anyone who has attempted this task knows how difficult it can be. Foddy's book is excellent. It should be read by everyone involved in social science survey research.

David Crawford
 National Centre for Epidemiology and Population Health
 The Australian National University

Paths to Asian Medical Knowledge. By Charles Leslie and Allan Young, eds. Berkeley: University of California Press, 1992. ix + 296pp. Cloth US\$40.00, paperback US\$15.00.

Paths to Asian Medical Knowledge is the result of a conference entitled 'Permanence and Change in Asian Medical Systems' held in 1985 and funded by Wenner-Gren. It provides a sequel to the first volume on Asian medical systems published in 1976 under the editorship of Charles Leslie, which came out of the 1971 conference. While the former volume emphasized 'the history and ethnology of Islamic, Indian, and Chinese humoralism' (1992:7), the essays in this volume, as the title indicates, concern 'the sources and modalities of medical knowledge' (1992:14).

The volume comprises twelve substantive chapters divided according to geographic or cultural area into three main sections: Chinese and other East Asian traditions, with five chapters; Ayurveda and other traditions of South Asia, also with five chapters, and the Islamic-Humoral Traditions, consisting of two chapters. The collection is preceded by a general introduction by Charles Leslie and Allan

Young (pp. 1–18), and there are also short but useful introductions to each of the three sections. The general introduction surveys the major theoretical issues in the literature on Asian medicine and in this context also provides a useful overview of the major published sources on Asian medicine from the 1970s to the present.

The offerings in the first section, 'Chinese Medicine, Cosmopolitan Medicine, and Other Traditions in East Asia' are diverse. Kuriyama, in 'Between Mind and Eye: Japanese Anatomy in the Eighteenth Century' provides a careful study of eighteenth century Japanese responses to Dutch anatomical engravings, drawing on ideas about the nature of visual perception. Farquhar's study, 'Time and Text: Approaching Chinese Medical Practice through Analysis of a Published Case', importantly gives us access to 'the temporal and practical forms of medical life' (p.63) through an account of the nature and uses of published cases in Chinese medicine. A contribution to the understanding of the foundations of current Chinese practices of traditional medicine in Taiwan is provided by Seaman who compares folk categories of thought in medicine, agriculture, and geomancy. Unschuld's 'Epistemological Issues and Changing Legitimation: Traditional Chinese Medicine in the Twentieth Century' provides an interesting and important discussion of the essentially Western ideological sources for the legitimacy and dynamism of traditional Chinese medicine over the last 80 to 90 years, while comparing it to developments in Western medicine. Finally, Lock, in 'The Fragile Japanese Family: Narratives about Individualism and the Postmodern State' presents a wide-ranging account of the 'remaking of a cultural identity in postwar Japan' (p.99) as it affects the nuclear family and particularly the mother in the family. She shows how points of tension in contemporary society have become subject to medicalization and makes use of this to provide a provocative critique of the concept of medicalization as well as other forms of explanation which may be used to legitimate a particular political or moral order.

Section 2 of the volume cover Ayurveda and other traditions of South Asia and is also diverse in terms of the topics which are addressed. Trawick's valuable essay 'Death and Nurturance in Indian Systems of Healing' takes up four different systems of healing in India, analysing them as both systems of thought and practice as they are manifest in contemporary Tamil Nadu. She shows how symbolic interrelationships between these differing systems act to generate an overall pattern or set of healing traditions which may actually contribute to the process of healing. Obeyesekere's 'Science, Experimentation, and Clinical Practice in Ayurveda' deals with the scientific character of Ayurveda through the observation of and interviews with specific practitioners, for 'there are no professional scientists of Ayurveda, that is, those whose main role is the generation of scientific knowledge through research'. Rather, 'their science emerges out of their medical practice' (Obeyesekere, p.162). The confrontation between Ayurveda and biomedicine in the context of the historical development of Ayurveda as a professional system of thought and practice is the subject of Leslie's interesting study, 'Interpretations of Illness: Syncretism in Modern Ayurveda'. Leslie shows how and why Ayurvedic scholars cling to the concepts underlying Ayurveda as well as work to reconcile it with biomedical knowledge. Zimmermann's 'Gentle Purge: The Flower Power of Ayurveda', details how both in South Asia and in the export of Ayurvedic therapies to the West, the 'modern emphasis on gentle elements in Ayurveda changes the tradition significantly' (p.210). These alterations to classical doctrine are used 'to reveal the significance of catharsis—both purification and purgation—in historic Ayurveda' (p.210). Lastly, syncretic forms of explanation and understanding used by the Tuluva peoples in Karnataka State when they are faced with a new, tick-borne epidemic disease is the subject of Nichter's contribution, 'Of Ticks, Kings, Spirits, and the Promise of Vaccines'. These are examined in reference to the ecological, political and sociocultural context in the region.

The remaining two chapters in the volume make up a section entitled 'Islamic Humoral Traditions'. The first, by Good and Good, 'The Comparative Study of Greco-Islamic Medicine: The Integration of Medical Knowledge into Local Symbolic Contexts', provides an important template for the comparative consideration of the humoral traditions of the Islamic world. It commences with the problem of how the humoral medical tradition grounded in classical cosmology can be 'suited to map the life world of extraordinarily diverse Muslim societies' (p.258), and outlines a number of means through which humoral medicine may become symbolically integrated in diverse cultures, as well as the implications of this integration at both biological and sociocultural levels. Lastly, Laderman's chapter, 'A Welcoming Soil: Islamic Humoralism on the Malay Peninsula', provides a study of the integration of Islamic humoral ideas among the cultures of the Malay peninsula by comparing humoral medicine to accounts of indigenous systems of thought drawn from ethnographic sources on aboriginal peoples.

The book provides a useful source for the exploration of key epistemological issues in the study of thought and practice with Asian medical systems and in comparative medicine generally. It also offers the reader a range of interesting substantive accounts of and perspectives on Ayurvedic, Chinese, and Islamic traditions drawn from various regions and historical periods.

M.L. Lyon
Department of Archaeology and Anthropology
Faculty of Arts
The Australian National University