

Santé et droits humains : volume 2, apprendre par l'exemple, des études de cas comme outils d'apprentissage

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When Jonathan Mann and his team launched the first post-graduate course on health and human rights offered in an academic setting, at the Harvard School of Public Health 15 years ago, many wondered if there was a real place for such a subject in higher education.¹ Was “health and human rights” a science, a discipline, a method, an advocacy line or an ill-defined assembly of concepts that would probably turn students away in favour of “harder” public health matters such as epidemiology and statistics? A student in one of Mann’s classes argued that, indeed, public health “attached much more importance to *P*-values than to values” and that, in many respects, a health and human rights course was opening a new thread of reflection on the value of public health policies and action. Since that time, courses on the subject have flourished. In 2006, an (incomplete but growing) inventory of courses on health and human rights in academic and other settings listed 57 such courses in 24 institutions.^{2,3} This count does not include regular or ad hoc courses now offered in developing countries, whether these are targeted at students, public health practitioners or members of civil society. No doubt, the offers of education and training opportunities in health and human rights have fast expanded and so has the demand.

The second volume of *Santé et droits humains* by Véronique Zesiger et al. brings one more piece to the set of educational materials available from

multiple sources, mostly although not exclusively in the English language. Intended primarily for health practitioners and written by a solid group of co-authors, this 215 page book, published in French, incorporates a succinct introduction laying out essential concepts, principles and mechanisms relevant to the congruence – some would say the synergy – between public health and human rights. Ten case studies follow, each constructed around clearly set learning objectives, including questions to be addressed, highlights of the public health issue and references to specific human rights relevant to the case study, sources of pertinent information and bibliography. In all, the book delivers what its title promises: “Learning through examples – case studies as tools for apprenticeship”. Its publication in French makes it a valuable tool for education and training in Francophone countries, including the 10 African countries for which the course material was originally designed under a sponsorship by the *Direction du Développement et de la Coopération Suisse*. Francophone African countries have suffered for many decades from availability of translated materials that are commonly first published in English and seldom translated into other languages. This book helps bridge this persisting language gap.

The case studies focus on major public health issues such as maternal mortality, female genital mutilation, access to medicine and prison health. They constitute a useful tool for classroom education as well as self-learning. As Internet access expands in low- and medium-income countries, the material presented could serve to structure a distance-learning facility (a field in which one of the co-authors specializes) with interactivity between learners and their mentors. This transition would give the authors an opportunity to further improve the printed publication, in particular its formatting and layout, which are rather poor, the occasional disharmony in the depth of the case

studies, and the amount and type of reference information.

More substantively, the book could have been more succinct when listing human rights concerned by each case study. It could also have been more explicit on the practical application of these rights by providing specific reference to their core contents and monitoring indicators, information of practical value to both public health practitioners and human rights defenders. Also lacking emphasis are two concepts central to the practical application of analytical and action-oriented frameworks for health and human rights. The first is the principle of progressive realization applicable to certain rights, a concept that is so relevant to resource-constrained settings. The other is the principle of legitimate derogations on rights, which would have, among few other ambiguities encountered in the book, helped query the appropriateness of compulsory immunization as an example of the potentially nefarious impact of public health policy on human rights. But these are not insurmountable shortcomings. Beyond the rhetoric of health and human rights, evaluating the effectiveness of the series of case studies against their learning objectives will give the true measure of their success. ■

review by Daniel Tarantola^a

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The collectors of lost souls: turning kuru scientists into whitemen

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Kuru, later known to be an incurable degenerative neurological disorder transmitted by prions, was first noted in the Fore people of Papua New Guinea by Australian administrators and a few anthropologists exploring the area in the 1950s. The young, adventurous American doctor, Daniel Carleton Gajdusek (1923–2008), first came to Papua New Guinea in 1957, planning to make only a short stop there on his way from Australia to the United States of America (USA). Gajdusek had learned to love the excitement offered by epidemiological investigations in challenging circumstances in Afghanistan, the Islamic Republic of Iran and Turkey. Rapidly enchanted by the Fore and the tropical environment, Gajdusek became fascinated by the bizarre epidemic, which particularly afflicted women and children. The study of kuru became a life-long passion of the brilliant, flamboyant and troubled doctor. His scientific passion culminated in the award of the Nobel Prize in 1976, although his deep entanglement with the Fore people led to accusations and a subsequent conviction of child molestation in 1996.

The story of kuru and of prions has been told many times from the scientific perspective. The human side of the story, encompassing a remarkable cast of Fore people, colonial officials and researchers, is equally intriguing. Gajdusek, and later Stanley Prusiner, attracted most of the attention while the Fore people provided the exotic background. Especially after the bovine spongiform encephalopathy

(known as mad-cow disease) crisis, the Fore people became increasingly sidelined and their story was all too often reduced to the phenomenon of ritual cannibalism.

In his book, Warwick Anderson, a medical doctor and science historian, recounts the complexity of the story by portraying *how* scientists learned about kuru, not *what* they found out or who got it right. Anderson offers an absorbing account of kuru that is partly a biography of Gajdusek, and partly a historical and anthropological story of an encounter between the two worlds of modern biomedicine and a Melanesian culture.

Gajdusek was enmeshed in two fragile and complex systems of gift exchange. The concept of “the gift” has long been an entry point into the anthropological study of Melanesian cultures. Unlike commodities, gifts establish a relationship between the exchanging subjects and do not primarily satisfy desires. But gift economies are not restricted to pre-modern societies. Anderson thus draws parallels between the gift economy of the Fore and the practices of biomedicine in the 1950s and 1960s. To build his scientific reputation, Gajdusek had to enter into exchange relationships with his colleagues in Australia and the USA. To achieve this aim, he also had to participate in the gift economy of the Fore. For the Fore, each person is a microcosm of relations that have been activated through individual agents. Gifts produce such relations and as a result “make” persons. Gajdusek was allowed to receive the brains that made his research possible (and also increased his repudiation) because he gained the trust of many Fore people through gift exchange and, as a consequence, became a true person in their view. However, as soon as the Fore body parts passed from one exchange regime to the other (the modern scientific community), they became alienated and were no longer considered

parts of persons. Gajdusek could never disentangle himself from the reciprocal relationship with the Fore and for him the specimen always reminded him of the person from whom they came – people for whom he often cared in the last agonizing days of their lives.

This emphasis on the gift economy may seem arcane but it has wide-ranging consequences. First, it demonstrates how the commodification of biological items – genes, cells or tissues – has altered the way science is done since the 1960s. The relationship between scientists is no longer exclusively based on reciprocal trust. The biological materials that earlier were exchanged to form and foster relationships have now become commodities. Second, the gift economy of the Fore challenges fundamental assumptions of bioethics. Unlike in classic Eurocentric social theory, there are no stable, autonomous individuals in Melanesian social practice. In this context, “informed consent” becomes a somewhat unsuitable principle for the framing and resolution of bioethical questions. People build trust through gift exchange. In Gajdusek’s case, this trust then served as the basis for the passage of body parts to him and the global scientific enterprise.

Anderson’s book is a valuable and sometimes provocative contribution to the study of science and medicine in colonial and post-colonial contexts. He shows how the relationships between scientific researchers and their “tribal” research subjects have changed in the past 50 years. Modern bioethics has constructed welcome limits to research activities in this regard, but these limits are often defined purely from the perspective of the western world. Anderson gives an eloquent voice to other concepts and shows that truly global bioethics still face many challenges. ■

review by Thomas P Weber^a

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