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Ethical Aspects of Healthcare Reforms in Malaysia

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Introduction: Novitiate's License

I propose in this paper to address selected bioethical issues in Malaysia. As a newcomer to the field of bioethics, I may perhaps be permitted a novice's naivete and license to liberally interpret the scope of *bioethics*, first in its conventional, narrower meaning, and then extending it to a less circumscribed notion of ethics in the social organisation of healthcare, and in medical and public health practice .

Biotechnology and Bioethics: The Narrower View

Advances in biotechnology, more specifically in reproductive technology, medical imaging, genetic and DNA technology, and most recently, cloning of mammalian tissue and organisms have brought to the fore pressing ethical issues in biomedical research and medical practice (*US National Bioethics Advisory Commission, 1997; Lewontin, 1997*).

Undoubtedly, these concerns will in time emerge in policy discourses in Asian countries including Malaysia and Singapore (*Abu Bakar (IKIM), 1998*), if indeed they are not already matters of grave concern. There is for instance apprehension that medical imaging (e.g. ultrasonography) and selective abortion may exacerbate the already unbalanced gender ratios and differential child survival in some populations (*Sen, 1986; Karkal, 1987; Murthi et al, 1995*).

Insofar as *biosafety* is inseparable from *bioethics*, the *National Advisory Committee on Genetic Manipulations (NACGM)*, which in 1996 published its *Guidelines for the Release of Genetically Modified Organisms (GMOs) into the Environment* (*Ministry of Science, Technology, and Environment, 1996*) was an early institutional expression of bioethical concern in Malaysia.

Some Bioethical Concerns in Malaysia

Currently, much of public and governmental concern in bioethics is centred on organ donation and transplant, when it is not directed at biotechnological applications in agriculture, industry and manufacturing. Religious authorities have been enlisted to argue the case for its ethical and moral probity (*IKIM, 1997*) and the first human heart transplant was successfully performed three months ago at the National Heart Institute (*Institut Jantung Negara*).

These efforts come on top of earlier and less-publicised attempts at an ethical balance between individual confidentiality and collective interest in HIV/AIDS screening and epidemic control (*Ministry of Health, 1997*). Sentinel surveillance of HIV seroprevalence among antenatal mothers, STD (sexually transmitted disease) patients, and TB patients, conducted in an unlinked anonymous manner, have for instance grappled with issues of *informed consent* and *notification of test results*, but the deliberations and policy decisions have been shrouded in official secrecy with little attempt at soliciting public inputs.

On the horizon however is a more wide-ranging issue which challenges us to consider a less circumscribed perhaps more mundane definition of the scope of *bioethics* in healthcare and medical practice. Going beyond even the bioethics of *tobacco promotion and marketing* (competing perhaps with *pharmaceuticals pricing* and *pesticide labelling* as the pre-eminent issues of public health ethics), is the prospect of *the market as decisive arbiter of healthcare access*.

The Ethics of Contemporary Healthcare Reforms: Need versus Demand

The worldwide push for *corporatisation* and *privatisation* of the public healthcare sector enters its second decade in Malaysia amidst a currency and financial turmoil which has seriously affected public sector spending for social services. This commitment to dismantle the public healthcare sector continues unabated even as all manner of policy initiatives are announced to stabilise the national economy in crisis (*Citizens' Health Initiative, 1998b*).

Still a public-private mix for the present, the healthcare sector in Malaysia has performed creditably since *Merdeka (independence from Britain in 1957)* in ensuring access for the vast majority of the population (*Heller, 1982*). 90% of Malaysian citizens live within an hour or 5 km. of a health centre. The World Health Organisation recognises Malaysian government healthcare as one of the most well-distributed health services in the Pacific region, indeed second only to Cuba worldwide. Preventive and promotive primary care have contributed to enviable vital statistics which are almost on a par with those of richer industrialised nations. The infant mortality rate for Peninsular Malaysia for instance is approaching that of the United States. Most remarkably, these achievements have been attained at quite modest cost, public sector health spending amounting to less than 2.5% of GDP.

This healthcare system is now on the threshhold of quite profound change. The chronic understaffing of the public healthcare sector is now confronted with investor-led interest in the longer-term growth prospects of a market-oriented private health services industry. This will accelerate the exodus of healthcare professionals from an already decimated public sector, and will engender major realignments and new constellations of emerging and colliding interests -- private hospital chains, pharmaceutical manufacture, wholesaling and retailing, hospital ancillary services, and insurance- and employer-initiated managed-care organisations among others (*Chan, 1996a; 1996b; 1997*).

In this rapidly evolving situation, a key question is the future of equitable, accessible healthcare of quality. The ethical issue that is at stake here, as elsewhere, is whether *demand*, as opposed to ***need*** should increasingly be the future basis for health policy and planning. In health policy circles, this is manifested as a struggle to defend the meaning of *efficiency* as understood by the mainstream of public sector health planning :

> [Need, or the] *capacity to benefit, rather than expressed demand (ability and willingness to pay),* [is] *the yardstick* [for efficiency] *against which the allocation of resources should be assessed. This means that the...patterns of morbidity and mortality* [and] *their causes* [and] *the effectiveness of health care technology...are factors which should be taken into account in assessing whether any particular configuration of health resources is socially efficient or not..... A situation in which...health resources is concentrated on a population which is willing to pay for them, but will have little or no measurable health benefits for them, is less economically efficient than a situation in which the same resources are devoted to people with conditions for which medical science has interventions which are effective, and which are at low cost. The choice between* ***need*** *and* ***demand*** *as allocative devices is a fundamental one : either the market determines the financing and consumption patterns for health care, or overall health status is pursued as the object of policy. In this respect WHO's* ***Health for All*** *commitment is a clear statement of concern with the health status of the population as a whole. The fact that the poor...tend to have greater health needs/capacities to benefit from modern health technology means that the direction of care to them should be a priority on economic efficiency grounds as well as on grounds of social justice.*
>
> *A.L. Creese, 1990*
> *World Health Organisation*

Bismarck's Legacy in Malaysia, with a Neoliberal Twist

In Malaysia, it is likely that a *national health insurance fund* will be established in parallel with the corporatisation of the public hospitals, if that comes to pass.

One scenario involves farming out the management of this health insurance fund to a profit-seeking enterprise (*New Straits Times, forthcoming*). This is of great concern to both healthcare professionals, and to patients and consumers (*Citizens' Health Initiative, 1998a*). In particular, they are worried that *cost containment* and *managed care* (perhaps even *self-medication?*) may become perverted as euphemisms for unwarranted compromises in quality of healthcare, if the US experience is anything to go by (*JAMA,* *Dec 3, 1997*). The worst scenario would have the patient-consumer caught between the imperatives of fee-for-service private healthcare providers on the one hand, and profit-oriented managed care on the other (*Chan, forthcoming*).

Perhaps of most interest to this symposium is the future possibility of discriminatory coverage of the at-risk population by using DNA screening for markers of disease risk. Whether it remains hubris or not (*Hubbard & Lewontin, 1996*), there would be much incentive for a managed-care organisation to fragment the client pool according to disease-risk profiles, in hopes of increasing their commercial gain through discriminatory premiums or even worse by excluding the allegedly high-risk sub-populations.

This may not be so far-fetched. Given our current fetish with high technology as *panacea*, in particular with information technology in medicine, one can imagine the *Multi Media Supercorridor (MSC)* being very receptive to detailed patient databases in healthcare management. Indeed, among the flagship applications identifed for the *MSC* are the *multipurpose electronic healthcard* and *telemedicine* (*Chee, unpubl.*). Patients' DNA profiles fit right in with this futuristic vision of millenial medicine.

Private Enterprise and the Social Character of Insurance: The Demise of Community

An insurance scheme is a profoundly social undertaking. Whether in the form of a publicly managed scheme, a co-op arrangement, or a commercially purchased policy, it is in essence a mechanism for pooling the risk of catastrophic events faced by individuals who band together in a collective enterprise.

It is necessarily a *group* undertaking because it is based on the recognition that the unfortunate, random individual, relying just on his or her resources, would be overwhelmed and unable to cope with the catastrophe. Cross-subsidy is therefore the heart and soul of insurance, the well subsidising the ill, with the important proviso that there is little prior indication as to who might suffer the catastrophic event. Such is the logic and rationale which drives the system.

The logic of private enterprise however is to maximise profit. In the field of insurance this means discrminating between risk categories, fragmenting the market into those considered at higher risk of illness, and those at lower risk.

This is why your insurance premiums increase when you cross the risk threshhold at age 40, and skyrockets when you enter your 60s and beyond. Family history of heritable illness, in time to be replaced by DNA screening, will attempt even finer discrimination between risk categories, notwithstanding the cautions of molecular geneticists, epidemiologists and ethicists most familiar with the limitations of the emerging technology (*Hudson et al., 1995; Li et al., 1992; Khoury et al., 1993; Nature, 7 December 1995; Hubbard & Lewontin, 1996*). Or more simply, just ask anyone with pre-exisitng chronic illness, or HIV seropositivity, who has attempted to enrol in an insurance scheme.

All this is understandable given the imperative of the commercial sector to turn a profit. *But what has happened here ?* An acknowledged and necessarily social undertaking is being subverted by a process of fragmentation and individualisation of risk whose logical end-point is its own antithesis : the sick to bear their own cost-burden of illness, the healthy to rejoice in their good fortune (or good genes ?).

Is this the kind of health care system we want ? Or the kind of society we feel comfortable living in ? What has happened to our Asian values and ethics, which put the priority of our collective welfare above that of individualist concerns ? Is insurance, a quintessentially social undertaking, compatible with the dictates of private enterprise ?

These are not alarmist fantasies. Other countries have taken heed of these disturbing tendencies. In Australia, there are legislative bans on risk rating, in favor of uniform community rating. Partial solutions will not work as evidenced by the experience of Blue Cross/Blue Shield, who saw their younger, healthier subscribers desert to the for-profits such as *Aetna* when they offered lower premiums to this low-risk group (*Bodenheimer et. al., 1974*). Blue Cross/Blue Shield was left carrying the baby, or more accurately, the elderly, who are intensive users of medical resources. To no one's surprise, the Blues eventually introduced their own risk rating just to remain viable.

A recent bill before the US Congress, cognizant of the implications of human genome research, specifically sought a ban on the use of DNA screening as a tool for risk rating in the insurance industry. Dr. Francis Collins, co-discoverer of the *cystic fibrosis* gene and current Director of the US National Center for Human Genome Research, urged the bill's sponsors, Senators Nancy Kassebaum and Edward Kennedy to explicitly disallow DNA screens (*Nature, 14 March 1996*). The subsequent compromise however limited it only to a ban on the use of genetic information in health insurance for workers who were in transition between jobs or employment status (*Nature, 8 August 1996*). The struggle for more comprehensive protection against genetic discrimination continues with Congresswoman Louise Slaughter's bill, currently in process. As drafted, this would prohibit health insurance plans from denying, refusing to renew, cancelling or changing the terms of a health insurance policy based on genetic information. Health plans would furthermore be barred from requiring genetic tests, and from disclosing genetic information to a third party (*Nature, 7 July 1997*).

In the meantime, the State of New Jersey had enacted the most sweeping protections against genetic discrimination among US state legislatures. Noteworthy among the anti-discrimination advocates were the biotechnology and pharmaceutical industry lobbies. Their principal objection to an earlier draft of the bill centred on a clause which declared *individual genomic information* to be *individual, private property*, with obvious implications for royalties and other benefits. Once this had been overcome, they willingly allied with the anti-insurance forces to push through the bill, fearing that patients would avoid DNA screening in the absence of explicit protections. As Paul Billings, an expert on genetic discrimination noted, "*We are recognizing how important an environment of non-discrimination is to maximise the benefits of this technology*", *and more to the point, sales*. George Annas, professor of law and public health at Boston University nonetheless found it "*bizarre that other people can own your genetic information, but you can't*" (*Nature, 21 November 1996*).

Privatisation An Asian Value?

The lack of clear policy statements by Malaysian (and Singaporean) authorities, on the joint implications of biomedical and informational technologies, adds to the mounting anxiety over the future accessibility of healthcare. This could be particularly worrisome in a Singaporean context which in the recent past has officially sanctioned *"positive"* and *"negative" eugenics* in its national population planning policies (see *Designer Genes, 1984; Chan, 1984*).

As a closing observation, it would not be inappropriate at a symposium on ethics and ethical values to note the irony of *Asian values* in cohabitation with *privatisation*. The demise of community that comes along with the privatisation of what are unavoidably communal support systems, the abdication of mandated communal responsibility, euphemistically labelled a "*re-invention of government*", is surely a very un-Asian abandonment of communal solidarity. That this should be most stark in Malaysia, arguably the most aggressively privatising of Third World countries (*Jomo, 1995*), while simultaneously the most vocal of Asian values protagonists, is an astonishing commentary on the state of public discourse in Malaysia.

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