

### Journal policies

Although journal editors have made promises to more rigorously detect and expose scientific fraud, there are still too many instances of this not being done effectively. The website, Retraction Watch (<http://retractionwatch.wordpress.com/>), has revealed the astonishing numbers of papers retracted from academic journals (over 200 a year at least), yet some journal editors refuse to publish the reasons for the retraction. This volume of retractions suggests that the peer reviewing process is significantly flawed, and that some journals are failing to ensure the highest standards in the papers they publish. So long as false claims and deceptive trial findings continue to get published in high impact journals, these dishonest activities will continue to corrupt both medicine and science.

### Education

Finally, there needs to be a consistent effort to prepare young scientists and doctors for the ethical hazards that lie ahead for them. It is only recently that modules on research ethics and research integrity have been introduced into medical and scientific courses, and they are still far from universally present. Unless the problems I have identified are to be allowed to increase exponentially, such educational initiatives should become mandatory worldwide. Then we might at least place some hope in the future generation acting more ethically than is now the case with many of their mentors.

### Conclusion

So, can virtue prevail? We have to believe that it will, for, otherwise we will witness the increasing corruption of medicine and science by practices which undermine their very *raison d'être*. In that doomsday scenario, all that will matter is commercial gain, and institutions which are fundamental to our civilisation and to our health and welfare will lose all credibility.

It is up to us never to let this happen.

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## Questions of ethics in public health policy

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Most discussions in public health policy revolve around the setting of priorities and issues of technological choice and programme design in achieving these prioritised outcomes. Priority setting and choice of strategy are political choices. They are negotiations between what the public perceives, what public health experts pronounce, and the perception of interest groups – or stakeholders, as they are more often referred to – of the impact of any particular choice. Here, I set out to examine the choices of priorities and strategies using an ethics lens.

I use the term “strategies” to be inclusive of choice of technology, programme design and systems designs. And when applying the ethics lens, one does so while being careful to note that questions of ethical values are historically and culturally determined and vary across contexts (but there is clearly a gradient) between what would be completely acceptable or unacceptable except to a small minority of fundamentalists at either end. So this discussion is situated in our context today, in early 21<sup>st</sup> century India – a rising economic and political power - which also remains one of the nations with a large burden of poverty and ill-health.

Questions of ethics in public health policy can be analysed from the relationship of the state to the individual and the community. One dimension of this relationship is the state as a coercive instrument. Classical neoliberal thought will see this role as predominantly negative and as an interference in market mechanisms – but inevitable and to some extent necessary – for safeguarding property and ensuring that contracts are adhered to, and so on. At the other end, socialist perspectives see the role of the state as a coercive instrument wielded by an economic elite to secure both its own interests and the consent and obedience of the majority.

The other dimension of this relationship is the state as accountable for the health of its citizens. This was so clearly articulated by the Alma Ata Declaration: “the attainment of the highest level of health is a most important worldwide social goal... Governments have a responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measure”. The accountable state matches with the rights perspective, though it is only in a socialist or social democratic persuasion that it would be seen as the purpose of governance. In the neoliberal state, where huge economic

inequity is not a problem, even seen as desirable, government legitimacy, so important for the protection of property rights, rests a lot on provisioning of healthcare.

Thus in every society that we have today, the dual identities of the state – as enforcer and as accountable, as coercive and as responsive – are the starting points from which we can examine the ethical dimensions of health policy.

To the coercive state, the central ethical question is: To what extent can the rights of the individual be abridged or trampled upon in the interests of the common good?

At one end of the gradient we would need public health laws for ensuring behaviours and practices that are essential for the common good. For example, few would argue that laws regarding food safety, quality of drinking water, hygiene in public spaces, or road safety unduly abridge the rights of individuals. Curbs on smoking would have been unthinkable a century ago, and only religious or family authorities could proscribe it, attaching a moral value to non-smoking. Today, the framework laws for the control of smoking are in place, increasing regulation of smoking is considered desirable, and its proscription from public spaces is completely acceptable.

But to what extent can immunisation be made mandatory? Does the family have the right to refuse to get its children immunised – for either religious reasons or because, in their understanding, they suspect that a particular vaccine is enforced for commercial interests and not for the common good at all? If a family were to refuse polio drops or measles vaccine, even if there is reason to apprehend an epidemic in that area, could we then forcibly immunise the child? Opinion would clearly be divided, with some arguing that there is an absolute right in the family to refuse; and others arguing that there is an absolute right with the state to enforce. Most advanced countries do routinely remove children from families and place them in foster homes if, in the opinion of the authority concerned, there is sufficient reason to apprehend danger to the child's interests. And the threshold for such a decision could vary widely between and even within cultures.

And what if a child gets vaccine-related paralysis? What is the accountability of the state? Here most would concede that the state has to pay compensation. But then in most countries, including ours, this compensation is far from routine and there is little outcry; because in public health terms this is only a one in a million, insignificant event. However, from an ethics lens, if one child has paid the price for a million others to be safe, then the government has to be accountable for the same.

One other major area where, in the name of public good, the government denies individual choice is the history and current practice of promoting the small family norm. Today, few would agree that compulsory sterilisation is justifiable, though quite often its rejection would be from a public health perspective and not an ethics perspective. Also, compulsory sterilisation does continue today in some category of patients in some cultures – like the mentally ill or HIV-positive woman – and clearly there is an ethical dilemma in such decisions. But the

larger, more widespread question concerns the incentives and disincentives in place to push small family norms. For example, a girl below the age of 19 who is pregnant is not eligible for a Janani Suraksha Yojana maternity entitlement, despite the fact that there is a much higher likelihood of death at delivery for both mother and child. This has been argued on legal and public health grounds; and on these grounds, this rule has been withdrawn in the high focus states for delivery at a public health facility. But it remains in force for all non-high focus states and for all home deliveries. Examining this decision from an ethics lens, we need to ask: What is this teenager's accountability? How morally defensible is the government decision on this? When we come to denying the third or higher order child this entitlement, the question is: What gives the government the right to impose its norms on the individual and family –including the unborn child? Where does this question lie on the moral gradient? Somewhere in the middle? Unfortunately, in my view, a large number of persons do feel that individual family rights may be abrogated on grounds of the common good.

But then add in another factor: unmet needs. If we are to establish that the third child is an unwanted child due to lack of availability of contraceptive services, we could argue that while the state need not pay compensation, on ethical grounds it would be indefensible to punish the family. Yet, though we know that attitudes to contraception and the small family norm have changed, and unmet need is the central problem, the government retains disincentive clauses especially for holding elected office in panchayats. We need to question the stated motives of the government. Is it purely as a form of control over the weaker sections, a way to abridge the rights that have had to be conceded under a different set of pressures? Re-examining the ethical dimension in such a changed context, we may conclude that what we see is clearly unacceptable.

We will then constantly have to worry about this dimension of the coercive state: the extent to which state actions are really about control and subjugation and not about public good at all. Public good then becomes just a context or justification for control. Further, this control need not be very effective; it just becomes a habit. There are theories of power that propose that the main form in which power acts is by establishing norms of behaviour, within which individuals, families and communities are forced to align and which therefore reduce their autonomy and decision making; that such norms become forms of thought control. For instance, the population question did play an ideological role as providing a popular answer to explaining and justifying poverty in such a way that it drew attention away from inequality and placed the burden on the people themselves.

One area where we are seeing an expanding role is in what we could term the "public health panopticon". There is a trend to build information technology-based systems that see everything and everyone at all times. Thus every healthcare provider and every healthcare user is sought to be brought under such comprehensive surveillance systems. The reality

is that all providers are subject to the act of filling in complex forms, and this data flows into huge, centralised databases, but the use of such information for local action is either left far behind – or is altogether missing. Another feature of the panopticon is that the “central watchtower” is usually vacant, and though the system is designed to be visible before a central eye, there is in fact no eye that is seeing. There is only the *possibility* of seeing. The mother and child tracking system for tracking every pregnant woman and child is an example. Potentially every mother and health provider, can be contacted from the central watchtower. In practice, very few are contacted and nothing much happens as a result. Local use of such a huge effort is marginal. All health management information systems have similar design features. One particular experiment even tried to put video surveillance within the sub-centre. Another uses GPS, a third uses biometric identification, and so on. The 12<sup>th</sup> Plan now proposes a system which would be linked to universal civil registration of births and deaths and which would then proceed to track every single health encounter.

The public health debate in which we have engaged is whether such an investment is useful, feasible, and cost-effective. But it is worth pondering on the ethical dimensions of such designs. What is the protection available to privacy or confidentiality? If a central eye has the mobile numbers of every pregnant woman and can ring her up to check, is this ethically desirable? What is the ethical cost of the public health gain? And to this calculus if we add the contention that it may not actually help improve health status or access to entitlements, then where do we place this question of the moral gradient?

Such questions have been posed about the Unique Identification (UID) project also. No doubt UID would enhance the power of the state to see any individual’s bank transactions or health records or education records and legal records and assets at will. But does it have any value for the individual? Does it make access to banking facilities or rations, or healthcare or education any easier? If it does, is it worth the loss of privacy? And if it does not, what is its merit?

Moving on to the accountable state, the main question is: to what extent is the government right to ensure healthcare an ethical obligation? Is it merely a political obligation, and one which may or may not be made into a legal obligation? Or, to put it negatively, to what extent is denial of healthcare – whether active or passive – an ethical issue as distinct from a legal or political issue? Here again, gradients on the judgment of right and wrong exist. Clearly courts have held that when food grains are surplus and rotting in godowns, the fact that a large part of the population especially children go hungry is legally indefensible and amounts to denying the right to life. Most would also argue that it is morally indefensible.

By this logic, every minimum basic provisioning for a life with dignity – food, water, clothing, shelter, education and healthcare – is an ethical imperative abridged only by the political and economic feasibility of making it available. And therefore with development and with growing political awareness, many political choices evolve into ethical choices

as well. To take an example, food supplementation in the Integrated Child Development Services (ICDS), like much of healthcare, was a distress-relieving measure to reach the most hungry who had inadequate access to food. But since 2002 and the Supreme Court ruling on this, and the consequent increase of *anganwadi* centres from 2 lakh to almost 14 lakh, this service is perceived as a right, and its denial as a legal and ethical issue.

This interface between politics and ethics and public health theory can be complex. Let us examine a decision like the introduction of user fees, and what we now acknowledge as its exclusionary character. In Uttar Pradesh, one of the poorest states in the country, till recently, not only were user fees charged, but 50% of the collections were given to the treasury as a government measure to earn revenue. The political decision was forced as an external funding conditionality. But in a neoliberal understanding of health systems development such collection of user fees was seen as desirable. We know now that it led to the exclusion of the poorest. Since this was an entirely predictable consequence of the introduction of user fees, should we not call this an ethical violation?

Or take the decision to limit government healthcare provisioning to only six or seven items based on a completely technocratic measurement – the dollar spent per DALYs saved – and leave the rest to the market, knowing very well the characteristics of the market in healthcare. There is one ethical principle that we are all responsible for: the predictable ethical consequences of our actions. Was not, therefore, the consequent exclusion and denial of care completely predictable? These are clearly questionable decisions – both as political and as public health choices – that failed to be examined within the ethical framework in which governments have an obligation to provide healthcare.

Another set of ethical questions arises from the viewpoint of public health practitioners and activists. No doubt we are responsible for the ethical consequences of our actions. But to what extent are we responsible for the consequences of our inaction? To the extent that is predictable, it should be considered unethical too. A glaring example is that of corruption, or rent seeking in any manner and form, which is no doubt morally indefensible – and often clearly criminal. The ethical dilemma is in looking the other way – while not oneself being involved. There are many areas, where there is a need to speak out against the denial of care, or against abrogation of the individual’s rights for a public good – especially when the so-called public good stands on questionable evidence or is serving vested interests more than the public good.

I do not attempt to answer all the questions I raise. The only point I make in this presentation is that there are major ethical challenges in the theory and practice of public health policy, and educational and training programmes must stimulate reflection on this dimension in their curricula. Meanwhile, there is much work to be done, in terms of establishing some fundamental principles of ethics in this domain of public health, so that it would guide decision makers and researchers in this area.