

# The NBC and the bioethics movement in India

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It is well known that bioethics evolved in the West as a result of a series of scandals and a public outcry over the misuse of authority and control by the medical profession. By comparison, in India, the medical profession has not faced such public scrutiny or censure. Modern medicine, in particular, has been the product of the state in India. Unlike in the West, where the medical professional emerged largely as part of an entrepreneurial profession, which was only later brought into a nationalised service, in India, modern medicine was "built up" by both the colonial and the independent Indian state as the vehicle of modernity and welfare. The institutions of medical teaching and medical care were largely developed by the state as part of the project of development. Thus, its importance was considered self evident and its intentions, by default, unquestionable.

Thus, it is not surprising that the first real developments in bioethics should have taken place in the 1980s. The excesses of the family planning programme during the Emergency for the first time made the medical profession the frontline of the state's assault on human rights. In the mid 1980s, the mishandling of the Bhopal gas disaster was also a turning point. The state's reluctance to bring the guilty to justice demonstrated the extent to which big industry could control its actions. The 1980s was also the time when the fledgling private sector in healthcare made rapid advances and became a real employment option for the accomplished physician. The dissociation of the welfare state and the medical profession and the scepticism about the development project of the state itself was the background against which ethical issues in healthcare were raised by different players in different contexts.

Uniquely, in India, the field of medical ethics has a very mixed pedigree, drawing its followers from among medical professionals, health activists, health systems analysts and economists, various kinds of social scientists and consumer protection groups. In fact, if there is a singular absence, it is that of philosophers and academics. As a result, bioethics did not take root in our professional, basic sciences or humanities education, but instead was transmitted to the next generation in the field, at the bedside, during fieldwork, in campaigns and struggles of various kinds.

In India, those who consciously associated themselves with bioethics often found themselves outside the mainstream (and still do), were seen as mavericks, and were accused of being "anti-doctor". Western bioethicists, on the other hand, not only held high academic positions, but were often at the centre stage of state policy making, law-making and regulation. If anything, they faced the charge of being too much part of the "establishment".

The globalisation of the health industry, with India becoming a major supplier of health services, health personnel and health research resources, necessitated the "upgradation" of the Indian ethics regulatory framework to meet international standards in a hurry.

Consequently, India has gone from one end of the spectrum to the other, eagerly embracing the paraphernalia of the international research ethics regulation which includes the development of research ethics guidelines, research ethics committees and research bioethics training programmes.

However, this growth has come largely without the churning, debating and refining of ideas and concepts, application to practice and critiquing of that practice, the breaking and formation of public opinion, the coming together and parting ways of different groups, that is necessary for the organic growth of any discipline. Thus, the very doctors who avowedly do not know how to communicate with patients about simple treatment options are deemed qualified to obtain informed consent for complex randomised control trials, on the completion of some rudimentary training and certification. Even while we continue to bemoan the corruption and lack of accountability in every aspect of medical practice, we somehow expect institution-based research ethics committees to be independent and valiantly protect the interest of vulnerable research participants, simply because ethics review has been made mandatory and they have research ethics guidelines to which they can refer.

This is not to conclude that the latest turn in Indian bioethics is without any promise. Such contradictions are not unusual in India. We had medical schools before the vast majority of the population had become literate and our medical institutions can offer the most advanced and hi-tech medical care to the elite even while we seem unable to deliver basic immunisation services to all.

The focus on bioethics training, the availability of funding for those interested in a career in bioethics and the entry of institutions are all welcome developments. Unless and until bioethics becomes the primary preoccupation of a significant number of professionals, and this is backed up by suitable opportunities to undertake research, writing and training, we will never have

a bioethics discipline in India. There are limits to what can be achieved by individual professionals' part-time involvement, particularly when it is not linked to an institutional process or programme.

However, we must, at the same time, face squarely the contradictions of our situation and never lose sight of them. It is from these contradictions themselves that the most interesting debate and discussion can emerge.

It is against this background that the National Bioethics Conferences (NBCs) must be viewed. Organised under the banner of the *Indian Journal of Medical Ethics*, these conferences have created a space to discuss and debate the state of bioethics in India among a wide spectrum of people, not all of whom would even claim to belong to the bioethics community. The first conference was held in Mumbai in 2005, the second in Bangalore in 2007, and the most recent one in New Delhi in 2010. Each conference was attended by more than 350 delegates, with the Bangalore conference attracting nearly 600 delegates.

The NBCs have a participatory character with an organising committee comprising representatives of all collaborating organisations. Thus, the NBC requires co-ordination between 30-40 individuals representing their organisations to decide the programme, logistics, fundraising and overall management. At the same time, each collaborating organisation sponsors its delegates, mobilises funds, encourages individuals to submit abstracts and, often, organises workshops. The conference co-ordinators and secretariat are responsible for raising funds adequate to organise the main event, meet the costs of invited speakers and offer fellowships to some of the paper writers. This structure has been very useful in enlisting the commitment of institutions and enabling young faculty, researchers and students to attend the conference.

In every successive conference, we have seen an improvement in the quality of submissions, an increasing variety in the themes and subjects that are dealt with, and a wider range of contributors. Interestingly, even though the conference has been moving from city to city, and region to region, there is a core of about 100 participants who have attended at least two of the three conferences held so far. This includes a wide range of individuals - from bioethicists and ethics committee members to researchers and clinicians who could be considered as the core of the bioethics community in India. In the absence of a professional association of bioethicists, the NBC has taken the place of a biennial meet of such a potential collective.

The NBC has also increasingly become a platform for presenting bioethics research being conducted by different groups across India and even abroad. In a very heartening trend, the most recent NBC showcased presentations on a host of empirical studies exploring various aspects of ethics in research, medical practice and public health. Reflecting on the nature of the research, one can see that these are often building on the indigenous concerns of practising professionals in the healthcare field. At the same time, some of the research also speaks to a global audience which is predominantly concerned with ethics in international research. However, even this research and these researchers receive a quite different reception at the NBC where the audience extends much beyond the "bioethics" community.

As a result of this mixed profile of the NBC's participants, there can be vast differences in the discourse, tenor, preoccupations and politics of the participants, leading to heated debates and arguments. So far, these have been accommodated within the democratic character of the conference. The greatest tragedy for the NBC would be if such arguments cease to happen because "troublesome" factions have been driven out and a uniformity and perspective and ideology begin to prevail. Thus far, the broad-based organisational structure of the conference has prevented such a homogenisation. However, as the conference becomes larger and more expensive to organise, the demands of funding and human resources are increasing and pose a serious challenge to sustaining this kind of organisational structure.

Another area of challenge is increasing the publication of research in bioethics. While, as noted above, the quality of the papers presented at the conference has improved, the number of those eventually being published has been disappointing. This is partly a reflection of the fact that publications on ethics have much less academic value than publications in other professional disciplines. Thus, paper writers lose the momentum required, after the conference is over, to take their papers to the publication stage. Also impeding the development of such writing is the fact that institutions are not sensitised enough to regard bioethics as a legitimate specialisation and there are few opportunities for students and professionals to pursue research and writing in bioethics, while being encumbered by their other responsibilities. The lack of mentorship also contributes to this problem as paper writers often have no peers or faculty with the expertise to provide adequate review or support.

The NBC can only be a catalyst for more sustained bioethics activity at the local level. We continue to hope that the conference will spawn collaborations and ideas that take bioethics forward at the regional level. However, there has been very limited, sustained activity taken up collectively by individuals and organisations in a particular region. In specific institutions where the teaching of bioethics has been institutionalised, interest and involvement in bioethics are sustained. The local culture of the health sector in each region also plays a role in the stability of informal groups of interested individuals formed with the contacts and alliances built through the NBC. Typically, we have found that those groups which are also linked by other professional interests are more enduring. However, we have still not reached a stage where these collectives come together formally and organise themselves into an association or forum.

In brief, the NBC requires a serious input of commitment and resources from diverse sources which enable it to maintain its democratic character and pluralistic vision. Perhaps, the formation of a formal structure, such as a National Bioethics Association, is the best possible solution to meet these needs. The members of this association can provide the stable core of the conference body, even while new entrants are roped in. Thus, the NBCs must find a balance between fulfilling the academic needs of professional bioethicists and giving voice to the diverse struggles which reflect the state of ethics and values in our healthcare system.

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