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Ethics and morals in India's immunisation programme

The national project of paediatric vaccination has been interrogated from various ethical standpoints. However, as the authors of this study point out, most of those ethical deliberations have focused on ways to develop more appropriate and context-sensitive measures for interventions, and have critiqued the healthcare provider's utilitarian relationship with the client.

In this article, the authors present the findings of a qualitative study that mapped the ethical notions of care providers, and also the moral values that govern the outlook of parents. The study was conducted in select areas in Tamil Nadu and Kerala. Given the heightened awareness among parents about the process and consequence of immunisation, these two higher literacy states have had episodes of resistance to state-driven vaccination programmes. While the media has had a role to play in making vaccine-induced mishaps part of public knowledge, people were also seen to stay away from vaccination on the advice of their general practitioners and practitioners of alternative systems of medicine.

The authors noted in this study that among the authorities interviewed, there was a high moral tone attached to the process of immunisation. The intensity with which universal immunisation was vouched for was often seen to outweigh the necessity of taking proper consent from the parents. In fact, for several healthcare workers, consent was equivalent to a disruption of the process and needed to be done away with. The fact that the workers were severely chastised by their departmental seniors if vaccination targets were not met also played a part in making the immunisation drive more aggressive. When parental consent was taken, it was done so only to avoid any legal complications in the future, and not because of any ethical imperative on the part of the healthcare worker. Parents were seen to accept the overtly paternalistic roles of the caregivers. Some parents were seen to 'give in' to vaccinations because all others in their neighbourhood had done so, since nobody wanted to be a deviant. Caregivers were also seen to play up this aspect; hesitant parents were told that they owed this to their children and they would be blamed by the children later if they were not vaccinated.

The authors explore a critical area in the area of paediatric immunisation and methodically document how societal-parental moral views work alongside the ethical notions of caregivers to make an immunisation programme succeed or fail. Given India's thrust towards paediatric immunisation, this study offers valuable insights into the politics of ethics at work in this space.

Varghese J, Raman Kutty V, Ramanathan M. The interactions of ethical notions and moral values of immediate stakeholders of immunisation services in two Indian states: a qualitative study. *BMJ Open*. 2013;3:e001905.

Patient privacy and confidentiality in crowded hospital emergency rooms

Respecting the privacy of patients and ensuring confidentiality are regarded as essential obligations of healthcare institutions. However, almost no hospital has private or semi-private sections in its emergency departments. Consequently, patients who are admitted here stand the highest risk of having their privacy compromised. This article presents the results of a study designed to understand how patient privacy and overall patient satisfaction can be bettered in hospital emergency departments. As part of the intervention, the emergency department staff was oriented towards coping with the situation within the given resources.

The study was conducted in the emergency department of a hospital attached to an urban academic medical college in a country in South East Asia. It was crowded and chaotic, and many patients were treated in the hallway since beds were always full. The interview schedule attempted to understand patients' perspectives on physical privacy, informational privacy, decisional privacy and proprietary privacy.

After the interventions, there was a significant positive difference in the reporting of patients regarding their perception of privacy and confidentiality in the emergency department. The authors conclude by listing the factors that can work towards making the emergency department/room a patient-sensitive place: a well-planned re-organisation of the physical space of the emergency room, sharing of responsibility by the management towards ensuring these changes, bioethics training of staff, and ethics consultations.

The authors cite several other studies which have also shown how redesigning of physical spaces can increase the sense of privacy of patients. Small efforts like separating each bed with a curtain can also have a positive impact on the patient. Similarly, mandatory use of a low tone when discussing treatment options or informing the patient of the diagnosis/prognosis, avoiding taking a patient's history when other

patients are close by, not discussing medical cases in corridors, and not shouting instructions to nurses, were seen to add up to a significant positive difference. The authors end by asking institutions to emphasise patient-centred healthcare as a top priority and to invest in building an ethical environment and climate to improve the quality of care in emergency wards.

The scenario of crowded hospitals and mismanaged emergency rooms is overwhelmingly familiar in India. This study can throw light on how we could become more sensitive to patients' needs even while keeping in mind the limited resources available in an emergency room.

Lin YK, Lee WC, Kuo LC, Cheng YC, Lin CJ, Lin HL, Chen CW, Lin TY. Building an ethical environment improves patient privacy and satisfaction in the crowded emergency department: a quasi-experimental study. *BMC Med Ethics.* **2013 Feb 20. 14(1):8.**

The ethics of designing paediatric consent forms

As full, conscious and voluntary informed consent of a research participant is accorded utmost primacy, the 'consent' of a child is an even more sensitive and complex issue. In most cases, the parent is the authorised guardian to consent on the child's behalf; however, ethics should inform the design of a child's assent form, drafting withdrawal clauses and sharing the child's data with the parents.

In this study, 65 assent and consent forms exclusively for paediatric research were reviewed to find the gap areas and suggest best practices. Based on the findings, the authors suggest that in longitudinal and biobanking studies, researchers should re-contact children once they have matured and take their consent for the continuation of use of their data; other genres of studies could do with a 'broad consent' of the parents. Coding data rather than anonymising it is always better since it allows one to contact a participant at a later stage, if ever deemed necessary.

The authors note that conflict in withdrawing from a study is also a serious area of concern. The question is: who decides to withdraw? Consent forms should clearly state whether, when a participant withdraws, they would consider the decision of the mature child (even if it is opposed to what the parents want) as final; or whether only the decision of the parent (irrespective of what the child wants). Also, forms should make clear what happens if participants want to withdraw and not have their data used *after* the data has been anonymised.

It was found that, in several cases, the research team promised parents access to part or whole of the child's data and also the results of future routine tests. This posed an ethical problem. For instance a child might not want her parents to know the results of her pregnancy test or drug use. Researchers should think through such issues and, if needed, take the assent of mature children before sharing their data with their parents, and this should be clearly mentioned to the parents at the start of the study.

The study was designed to develop certain best practices in designing consent and assent forms. It also sought to orient researchers to think through these issues in a nuanced manner, and to not treat everybody under the age of 18 as incompetent and lacking in autonomy. The authors conclude with the appeal that best practices can improve consent forms and facilitate context-based approaches to ethical norms in paediatric research.

Dove ES, Avard D, Black L, et al. Emerging issues in paediatric health research consent forms in Canada: working towards best practices. *BMC Med Ethics.* **2013 Jan 30. 14(5).**

Effectiveness and ethics of physician incentives

There are managerial and ethical issues to tackle when it comes to physician incentives. While the former largely concern the effectiveness of the incentive system, ethical concerns primarily revolve around the issue of professional ethics and how incentives may unduly influence a physician while treating the patient, and lead to over- or under -provision of services.

The authors state that financial as well as non-financial incentives play a role in the healthcare system and the management should balance the incentives in such a way that maximum benefits accrue to patients, institutions and doctors. They refer to Max Weber's description of four types of incentives -- traditional, self interest, affective and shared purpose -- and suggest that these can be used to explain incentives in the healthcare system as well.

In the traditional approach. physicians may find it an incentive that they get to work in an organisation and be part of a group and its tradition. Financial incentives focus chiefly on self interest and should be used with caution as they have tremendous potential to introduce conflicts of interest and undermine trust in the physician-patient relationship. Affective incentives are useful in situations where physicians work as a community and where peer pressure can be effective in motivating them to perform better. The flip side of this approach is that too much peer pressure can have an adverse effect on physicians. The shared purpose approach is based on the goals of the healthcare organisation being in alignment with the physicians' sense of purpose. The success of this model depends on how incentives can be formulated in a framework where the hospitals' goals of good patient outcomes, better population health, and reduced costs are in tandem with the physicians' goals of patient welfare, autonomy and social justice.

The authors argue that the shared purpose model works better than the traditional, affective or self interest models. It promotes the sense of ethics, responsibility and moral agency among physicians, as they identify with the incentives system, rather than it being imposed on them. Even the shared

purpose approach needs to be integrated judiciously with the other approaches, depending on the history and culture of the organisation, and the context in which the incentive system is being implemented.

Biller-Andorno N, Lee TH. Ethical physician incentives- from carrots and sticks to shared purpose. *N Engl J Med.* 2013 Mar 14;368(11):981-3.

The open access debate

The production and distribution of scholarly work through peer reviewed journals is not a simple business. There are multiple stakeholders involved, ranging from the funding agencies donating money for the research, the universities and organisations that support the researchers and produce a conducive environment for research, the authors of articles, the publishing houses bringing out journals, and the libraries which purchase, organise and store these articles for research and teaching purposes. The widespread use of the Internet and digital publishing altered the stability of the system, and as a result, publishing houses started experimenting and developed a business model of digital rights management, restricting access to only those who could afford to pay for articles.

In this debate, Wolpert argues that restricted access undermines the very purpose of research. The limited access policy has not only affected readers but also the researchers or authors whose primary intention of publishing is to be widely read and quoted -- for their research findings to be disseminated. Both government agencies and charitable foundations want the research built on their investments to be widely accessible and not just limited to a few. This has led them to look out for alternate avenues of publications such as open access databases and open repositories of peer reviewed articles. Models of revenue generation such as payment of a publication fee by the authors, and research grants or institutions financially supporting the publishing of journals,

are also being tried out. The author refers to the Bethesda Statement on Open Access Publishing to note that the tradition of researchers publishing their work without expectation of financial gain, and the new technology of the World Wide Web and Internet will make open access a reality in the near future.

Presenting the opposing view, Haug looks at the downside of free and "rampant" open access publishing. The author discusses the "author pay" model in which authors pay to get their articles published in journals. She refers to unethical practices by publishing houses, fuelled by the pay-for-publishing model. For example, publishers may claim to have a peer review process without having one; they may not preserve the digital archives, and they may lower the standards of scientific publications while not adding to scientific knowledge. The author acknowledges that this system allows authors who are not able to publish in the highest ranking journals to publish their research. However, the author is disturbed by the fact that many such publishing houses which are nothing more than "online posting services" that have undermined the meaning of the terms "international", "scientific" and "peer reviewed" journal. The author cites the example of Elsevier that had published six "fake journals" sponsored by pharmaceutical companies which were made to look like journals. She reaffirms the significance of transparency in the publishing business so that readers are assured of the quality, significance and originality of the research they read.

Wolpert AJ. For the sake of inquiry and knowledge- the inevitability of open access. *N Engl J Med.* 2013 Feb 28;368(9):785-7. Haug C. The downside of open access publishing. *N Engl J Med.* 2013 Feb 28;368(9):791-3.

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