

## FROM OTHER JOURNALS

### **Research ethics in conflict zones**

The significance and challenges of adhering to the ethical principles of conducting research in a multicultural, multilingual and resource-starved setting have been described in this article. The author cites the example of research on malaria on the refugee population from Burma along the Burma- Thailand border. One practical challenge arises from the multiple languages that are spoken at the border with an influx of refugees from different regions. There is also a high level of illiteracy because people's access to education is negligible. Another question is how truly voluntary research participation can be when people have no access to other healthcare facilities, and when research is conducted among displaced people in times of concern and anxiety. The author points out that the process of community engagement loses its meaning in such a multicultural and multilingual context, as the community and its representatives are difficult to define. Research along border areas involves multiple international and regional stakeholders. Collaborations of these multiple stakeholders also pose a challenge to research as they have different priorities, objectives and perspectives about what constitutes ethical behaviour and what does not. The need for a practical and effective research model to address these ethical issues is discussed in the paper.

**Paker MJ. Moral and scientific boundaries: research ethics on the Thai-Burma border. *J Med Ethics*.2012;38:559-60.**

### **Participation in clinical trials: participant and client perspectives**

Two articles in the *Journal of Clinical Research and Bioethics* look at the challenges involved in recruiting potential participants for clinical trials. While one study aimed at obtaining information from potential participants, especially women, and was carried out among Nigerian women; the second study looked at the issue from the perspective of the investigators and was based in India.

The Nigerian study was undertaken on the premise that the existing gender stereotyping and lack of decision-making power discourage women from participating in biomedical research. The researchers found that in the study with 172 participants, less than 50% of the women were willing to participate in any form of clinical trial, and nearly 60% did not even understand the meaning of clinical trials. Gender inequalities and lack of autonomy; fear of side-effects and breach of confidentiality in the case of sensitive issues; cultural

and religious barriers and time constraints were the main reasons cited by the women for deciding not to participate in the trial. The women who participated in the study were of the opinion that improving women's educational status and level of awareness and empowering them would encourage more women to take independent decisions regarding participation in a clinical trial. The authors argue for efforts to address these needs so as to ensure greater participation of women in clinical trials. This will, in turn, result in evidence-based policies and practices that take into account the needs and priorities of women as well.

The second paper is based on a study exploring the perspectives of investigators regarding the barriers for subject recruitment in clinical trials. Negative media coverage about clinical trials and difficulty in finding eligible participants for trials on rare diseases were reported as two major barriers by the investigators. Unlike the women from the Nigerian study, the investigators perceived cultural restraints and educational status as minor barriers. The authors cite Jean Sullivan to elaborate on the different types of barriers and ways to overcome them. These two studies, albeit in two different settings, raise completely different concerns among potential participants and investigators regarding subject recruitment for a clinical trial. There is a need to understand the concerns and priorities of different stakeholders while taking initiatives to improve the conduct of clinical trials.

**Chukwunke FN, Ekwueme OC, Ezeonu PO, Onyire BN, Ifebunandu N. The challenges in enrolment and retention of African women in clinical trials: a pilot study in Nigeria. *J Clin Res Bioeth*. 2012;3:133. Ruckmani A, Vishaly S, ArunKumar R, Lakshmipathy Prabhu R, Priya A. Assessment of barriers in subject recruitment for clinical trials. *J Clin Res Bioeth*. 2012;3:125.**

### **For-profit industries and international humanitarian organisations**

The northern Nigerian state of Zamfara is the victim of mining and processing of lead-heavy gold ore and has been reported to suffer from one of the worst lead poisoning epidemics in history. It is in this context that the author has written about the role that the international humanitarian agencies could play in environmental emergencies caused by the mining or extracting industries, and about the potential risks in engaging with these industries. Many oil- and mineral-rich countries in the Sub-Saharan African region suffer from a "resource curse" or "paradox of plenty" in which the local inhabitants are

impoverished and suffer from a range of health side-effects of mining and other industrial processes. The health crisis calls for intervention by international humanitarian agencies who offer their technical, humanpower and other resources, as well as advocacy services, to improve the situation. However, there are global economic forces and huge for-profit organisations at play, especially in these industries and regions. The operation of the corporate social responsibility wing of many for-profit organisations and the outsourcing of health services to medical NGOs tend to privatise the health service provision in such areas. Conflicts of interest also arise from the investment interests of many philanthropic organisations. The author cites the example of the Bill and Melinda Gates Foundation which holds stocks in oil companies operating in impoverished areas. While companies might be able to make a distinction between their "for-profit" and philanthropic interests, the local population might view this as total indifference to their plight caused by the same industries. The author further explains three kinds of alliances between the industry and NGOs -- "broad alliances, conditional alliances and lack of engagement"-- of which the latter is preferred by many international humanitarian organisations to uphold their values and avoid conflicts of interest. Another option for humanitarian organisations faced with this challenge is to engage with and support public initiatives to improve living and health conditions in the area.

**Calain P. What is the relationship of medical humanitarian organisations with mining and other extractive industries?** *PLoS Med.* 2012 Aug;9(8):e1001302. doi:10.1371/journal.pmed.1001302

### **Maternal deaths and cash incentives for institutional deliveries**

The largest number of maternal deaths in the world occurs in India, and a majority of these are of women belonging to the *dalit* and tribal communities. It is presumed that institutional deliveries result in better maternal care and safe delivery; hence, since 2005, the country's policy has focused on cash incentives against in-facility deliveries. However, such policies, when implemented in a situation of poor quality of care, lack of accountability and discrimination, become highly unethical. This article investigates 27 maternal deaths in the district hospital of Barwani, Madhya Pradesh, which occurred in April-November 2010.

The investigation was done through verbal autopsies, review of case records, field visits, observations and interviews at the local health facilities and the district hospital. The findings show that of the 27 known deaths, 21 women belonged to the scheduled tribes. Cash incentives had increased the burden in health facilities without ensuring quality antenatal and post partum care, reflected in poor infrastructure, shortage of skilled manpower, and low motivation. Standard treatment protocols were not followed, and the women reported verbal and physical abuse and charging of user fees. Other major issues were poor governance and lack of accountability, including the complete lack of an effective referral system and grievance

redress mechanism.

The authors list a range of recommendations for better management of healthcare systems in the state and call for a policy shift from cash incentives to improved maternal services. The indicators for measuring maternal health should move beyond the number of institutional deliveries and include WHO process and quality care indicators, and the governance indicators in the health sector, particularly those relating to accountability, transparency and grievance redressal.

**Subhasri B, Sarojini N, Khanna R. An investigation of maternal deaths following public protests in a tribal district of Madhya Pradesh, Central India. *Reprod Health Matters.* 2012. 20(39):11-20.**

### **Role of litigation in promoting reproductive rights in India**

Factors that put women at risk of maternal death are rooted in widespread discrimination and inequality, with a resultant negative impact on reproductive healthcare, security and self determination. This paper examines the role of litigation in seeking redress for the death of Shanti Devi, a scheduled caste migrant from Bihar, and the power dynamics involved, from the family level to national and international institutions.

Shanti Devi approached a number of government hospitals for emergency obstetric care post her miscarriage. She failed to receive care from any of them. Following public interest litigation filed in the Delhi high court, she was taken back to the hospital on court orders. However, she did not receive any family counseling, contraceptive help or follow-up care, resulting in a subsequent pregnancy, and death the following year. Shanti Devi's obstetric history shows that she received absolutely no maternity services promised under the National Rural Health Mission in any of her six pregnancies. Even in the capital city of Delhi, she was refused free treatment because the family did not have documentation to prove their below poverty line status. During the hearing, the court made observations on important points regarding reproductive health programmes, such as the need to record and investigate every maternal death, and hold the government accountable when it fails to protect, respect and fulfil women's reproductive rights.

Shanti Devi's case was successful, since it brought compensation to the immediate family, ensured accountability and became a landmark instance of constitutional justice. However, the more challenging tasks of developing awareness, understanding and recognition for the reproductive rights of women, and wider institutional change can only be achieved by a sustained social struggle.

**Kaur J. The role of litigation in ensuring women's reproductive rights: an analysis of the Shanti Devi judgement in India. *Reprod Health Matters.* 2012 Jun;20(39):21-30.**

## **Doctors as entrepreneurs: the role of the Indian Medical Association**

The Indian Medical Association (IMA) is the biggest association of allopathic doctors in the country, and its opinion is often viewed as the opinion of the majority of doctors in India. However, time and again, the IMA has taken a stand against efforts to regulate medical practice in the country. The latest example of this policy was the call for a nationwide strike by doctors to oppose the implementation of the Clinical Establishments Act and the National Council for Human Resources in Health. The author points out that the practice of medicine in any setting contains elements of public service, education, scientific enquiry and commerce. State policy and the political as well as social environment play a significant part in limiting the role played by commerce in medical practice. Though public service was a major focus in the immediate post-independence era, with liberalisation and the growth of market forces, healthcare services in India have become excessively privatised. Doctors are influenced by the sense of professionalism, monetary benefits and increased opportunities offered by the private sector. The IMA unlike its American or British counterpart fails to involve itself in critical issues plaguing the health system of the country. Instead, the association has elected for itself a tainted leadership and continues to represent the commercial interests of the medical 'industry'. The author also notes the existence of a minority of medical professionals who associate themselves with community work and work to uphold ethics in healthcare. There is a need for professional associations to raise their voices and take proactive steps to ensure provision of quality health services to the majority that cannot afford private medical care, and not just restrict themselves to endorsements of healthcare and other commercial products and striking against regulations.

**Nagral S. Doctors in entrepreneurial gowns. *Econ Pol Wkly.* 2012 Sep 8;47(36):10-3.**

## **Health, ethics and climate change deliberations**

The 17<sup>th</sup> conference of the Parties to the United Nations Convention on Climate Change, concluding at Durban, resulted in a further extension of the period of voluntary commitment to the Kyoto protocol, legally binding nations to cutting down greenhouse gas emissions under the United Nations Framework Convention on Climate Change. While some consider the conference a failure because of this delay, others consider the fact that the United States, China and India have agreed to be part of a treaty to reduce climate change to be a major breakthrough. However, the health implications of climate change received scant attention during the meeting which was driven mainly by the environmental and economic repercussions of climate change, the remedial measures to be followed, and the negotiations between different foreign ministries. The author argues that health and health ethics must occupy a core position in climate change debates. The coal fire power plants which contribute substantially to climate change also result in mortality due to cardiopulmonary disease and cancer. Still, the power plants receive huge support from organisations like the World Bank and government agencies, in spite of the recognition of their damaging effects. The author argues that the ethical principles of beneficence, non maleficence, risk minimisation, reasonableness, relevance, accountability, transparency and risk benefit analysis should be endorsed by government and international agencies while financing industrial projects. He emphasises the role that should be played by health ministries and international health organisations like the World Health Organisation in the future climate change deliberations and meetings.

**Singh JA. Why human health and health ethics must be central to climate change deliberations. *PLoS Med.* 2012;9(6): e1001229.**

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