

social is untenable.<sup>5</sup> Science is a social enterprise with social implications, and social processes have rationality—eg, in setting standards to evaluate success and guide practice.<sup>4</sup>

To move beyond hierarchies and dichotomies between science and society, and forge better relations, there needs to be opportunities for diverse groups to share their views so as to develop mutual understanding of differing roles, ideas, and values<sup>5,7,14</sup>—for instance, between journalists, scientists, business leaders, government policymakers, health-service providers, patients, and civil society organisations. Such communication opportunities would help scientists understand the perspectives of different groups and how better to communicate with them, and vice versa. Better communication would also facilitate building networks and “communities of practice”, which can be a powerful way of integrating diverse perspectives and resources to meet complex health challenges.<sup>1,14</sup> In conclusion, given the ever-changing nature of both science and society, health-research communication needs to be guided by theoretical and empirical advances and kept relevant and responsive through open and ongoing communication opportunities in research, education, policy, and programme processes.<sup>1,7-9</sup>

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## Research and clinical ethics after the tsunami: Sri Lanka

In late 2004, the *Journal of Traumatic Stress* published a special section about the ethics of disaster research, addressing ethical issues related to conducting research after disasters and terrorist attacks, and based on a meeting organised by The New York Academy of Medicine and the US National Institute of Mental Health.<sup>1</sup> Four areas of critical importance to development, evaluation, and conduct of research protocols after a disaster were identified: decisional capacity of potential participants, vulnerability of research participants, risks and benefits of research participation, and informed consent.<sup>2</sup> The participants at the meeting were mental health professionals, trauma researchers, public-health

officials, ethicists, representatives of institutional review boards, as well as family members and emergency personnel from the Oklahoma City and World Trade Center attacks. The attendees agreed that research after a disaster is important and can be done ethically. However, they felt that specific research proposals should be scrutinised by a single body to assess disaster-related research, as was the case after the Oklahoma City bombing, when a good deal of research was reviewed centrally and approved by a special process put in place with the approval of the state Governor.<sup>2</sup>

The attendees at the meeting recommended 12 points as guidance for research after a disaster (panel). These

include evaluation of research on the basis of level of risk, the novel nature of the research, and the uncertainty of the risk-benefit ratio for participants. Such evaluation might need additional procedural safeguards for participants because they are more vulnerable. The Belmont Report defined vulnerable populations as those groups that might “bear unequal burdens in research” because of their “ready availability in settings where research is conducted”, such as prisons, hospitals, institutions, and camps, and called for extra protection for these groups.<sup>3</sup> Delegates believed that information for potential participants about research should make clear whether there is therapeutic intent, and informed consent procedures should reduce the likelihood of participants mistaking research for clinical services.<sup>2</sup> These issues should be equally if not more important to developing countries because local ethical review processes might not be developed adequately.<sup>4</sup> In Sri Lanka, for example, biomedical ethics is still in its early stages of development.<sup>5</sup>

On Dec 26, 2004, a tsunami struck the rim countries of the Indian Ocean. This disaster was followed by a huge influx of foreign organisations and individuals offering humanitarian aid, including counselling to Sri Lankan survivors. However, in the rush to provide assistance, lack of familiarity of local customs can raise cultural concerns,<sup>6</sup> as shown by a number of unsubstantiated local press reports.<sup>7-9</sup> Furthermore, the notion of compulsory counselling for everyone affected is against the current recommendations by the Cochrane Collaboration and WHO.<sup>10,11</sup> Psychological debriefing as an early intervention after trauma is ineffective and it might be counter-productive by slowing down natural recovery.<sup>12</sup> Although definitive analysis of the tsunami’s psychological effect in Sri Lanka has yet to be published, the “trauma response” might be similar, irrespective of the cause of that trauma. Reaction to stress and adjustment disorders are clustered together in the International Classification of Diseases-10, not only on the grounds of symptomatology and course but also on the basis of an exceptionally stressful life event producing stress reaction or adjustment disorder.<sup>13</sup> Preliminary research in torture survivors suggests that most Sri Lankans need little support and encouragement to get back into their life after tremendous hardship.<sup>14,15</sup> Furthermore, social isolation and difficulty performing family roles are among some of the greatest concerns for survivors of trauma, compared with psychological symptoms such as flashbacks.<sup>14,15</sup> Most who sought

#### Panel: Guidance for postdisaster research<sup>2</sup>

- Competent research participant gives informed consent
- Capacity assessment tools should be used if needed
- Disaster-affected populations should not be necessarily considered vulnerable
- Specific research proposals should be scrutinised for novel nature of research and risk-benefit ratio
- Additional research is needed into risks and benefits in participation in disaster-related research
- Representative of community should be consulted about planning and implementation of research
- Informed consent procedure should clear therapeutic misconception
- Explanation about the research should be done in safe controlled environment
- Confidentiality and privacy of participants must be ensured
- Research staff should be trained and supported
- Participants should be informed about research findings
- Coordination by researchers should minimise redundant research and participants’ burden

mental health treatment wanted socioeconomic aid rather than relief from psychological symptoms.<sup>14,15</sup>

Other early findings imply that employment and short-term economic and housing aid help young people who have been exposed to war-related trauma to integrate their painful experiences into their lives and identities.<sup>16</sup> Initial research in a non-clinical sample of school-children in Sri Lanka suggested that Buddhist and Hindu children were less vulnerable to depression than Christian children, even though they reported more exposure to violent events such as bomb blasts.<sup>16,17</sup> There might be protective factors in the Buddhist and Hindu philosophies (eg, active acceptance of pain and suffering, an understanding that the future can provide relief through rebirth), which might be used to maximise recovery for survivors.<sup>16,18</sup>

The Forum for Research and Development organised a symposium in January, 2005, at the Sri Lanka Medical Association, on the ethics of trauma research.<sup>19</sup> A Sri Lankan national ethics committee, overseen by the Ministry of Health and dedicated to review tsunami-related research was proposed, but this has not yet been established.

When research is combined with humanitarian aid and at times clinical care (therapeutic misconception), there can be undue inducement for participation in this vulnerable population.<sup>2,20</sup> It might not be explicit to the tsunami survivors that what they are participating in is research. Issues get more complicated because researchers might rush to collect data, without adequate planning and under the disguise of “needs assessments”. Even

under normal circumstances, informed consent alone is not protective enough, because of the asymmetry in knowledge and authority between researchers and participants, particularly in the developing world.<sup>21</sup> Research can include clinical care but it should be made explicit to the participants because clinical care is something routine whereas research is not, particularly in the developing world. Otherwise survivors are at risk of exploitation for research disguised as clinical care.

Therefore, we appeal to journal editors to insist on proof of ethics approval from the country where the data were collected at the time of submission of a paper. Editors should also obtain an English translation of the information leaflet and informed consent form given to the participants to ensure that the participants knew it was research when they participated. We believe if policies or guidelines to that effect are made, it will be a deterrent to unethical data collection and exploitation of the disaster survivors. We also appeal to the international research community and ethicists to take this issue seriously because it has not been adequately addressed.

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## Deep brain stimulation for treatment of refractory depression

Deep brain stimulation is the stereotaxic placement of unilateral or bilateral electrodes connected to a permanently implanted neurostimulator. Although the mode of action is unknown, the hypothesis is that chronic high frequency (130–185 Hz) stimulation reduces neural transmission through inactivation of voltage-dependent ion channels.<sup>1</sup> Deep brain stimulation is widely used for severe tremor in Parkinson’s disease, an indication in which it is highly effective in reducing the severe motor complications (mainly tremor) associated with the disease, whereas

the overall process of degeneration cannot be slowed down, as shown in a recent study by R Hilker and colleagues.<sup>2</sup> Further clinical indications include essential tremor and primary dystonia. Use of the technique is also being investigated in treatment-resistant cluster headache (stimulation of the ipsilateral ventro-posterior hypothalamus),<sup>3</sup> treatment-refractory obsessive-compulsive disorder (stimulation of the anterior limb of the capsula interna), and treatment-refractory major depression (stimulation of a subgenual cingulate region and other regions; figure).<sup>4</sup>