

News from here and there

Charlie Gard case raises questions about ethical treatment versus experimental medicine

The Lancet in an editorial in August 2017 and subsequently in its comments section discussed Charlie Gard's medical condition in the context of ethical versus experimental approaches to medicine. The case involved an 11-month-old boy admitted to Great Ormond Street Hospital (GOSH), London, diagnosed with a rare encephalomyopathic mitochondrial DNA depletion syndrome—a condition for which there is no proven treatment. The patient had repeated seizures, was ventilated in the intensive care unit and was declared as suffering from irreversible brain damage by the attending physicians. His parents, however, wanted to pursue an experimental nucleoside therapy in the USA and raised nearly 1.3 million pounds for the same via awareness campaigns, monetary donations and social media requests. A lack of consensus on the treatment plan for the baby led the case to be referred to the high court in London, then to the Supreme Court of UK and finally to the European Court of Human Rights, all of which ruled that it was in the infant's best interests to stop life support. The parents finally accepted the decision but raised questions on 'the critical time interval lost' where innovative treatment could perhaps have been of benefit. The infant passed away four days after the life support was withdrawn. The case was widely reported in the print, television and social media and both sides—the parents and the staff at GOSH attending to the case—were subjected to public vilification and abuse.

An extrapolation of this case forms the crux of the articles in *The Lancet*. The roles of parents as primary care-providers and medical personnel as experts on treatment have both been reviewed. This issue is especially relevant in the light of newer diseases that are being diagnosed with advances in medical diagnostics and which, at present, have no definitive therapy guidelines. Although the jury on the case recommended the establishment of an ethical framework to decide on access to experimental treatment for such cases in future, the consensus on approach to such ailments differs widely across nations. *The Lancet* recommended that best practice guidelines should be laid down for mediation between clinical teams and parents, along with a proposal for a framework to be used in case of experimental treatment. Appropriate and timely focus on palliative and hospice care, encouragement to clinicians offering alternative treatment and clear delineation of realistic proposed benefits, side-effects and potential complications of the said innovative medicine measures have also been suggested.

When contacted for a quote on the subject by this correspondent, Dr George Thomas (former Editor, *Indian Journal of Medical Ethics*, and Chief Orthopaedic Surgeon, St Isabel's Hospital, Chennai) said: 'The most remarkable aspect of the Charlie Gard case is the institutional mechanisms already in place to deal with the medical, ethical and financial implications of experimental treatment. Throughout the unfolding events, the medical team had support from institutional arrangements. Thus, the initial decision to offer an experimental treatment to the child was vetted by the hospital ethics committee. The later decision that the experimental treatment would not be useful in

the light of the child's deteriorating condition and that life support should be terminated, was also supported by the ethics committee. The parents' decision to continue to seek the experimental treatment with funds raised privately was taken to the courts, which decided not to permit it as the treatment was unlikely to succeed and would likely prolong suffering. It is this decision, where parents' autonomy came into conflict with the decision of the medical team and the courts that is the source of debate. The argument that individual autonomy should override all other considerations is difficult to accept, if one has sound institutions in place as the UK has. The emotional state of caregivers makes it difficult for them to make informed decisions. India should develop similar mechanisms for clinical decision-making. It would be a move towards a more caring, humane and rational society.'

MAHARRA HUSSAIN, *Dubai, United Arab Emirates*

Lack of oxygen cylinders in government hospital leads to death of 60 children

Over 60 children died in a week at the Gorakhpur Public Hospital, Uttar Pradesh, because of lack of oxygen cylinders.

Death has been a regular feature in this region because of encephalitis, which has claimed the lives of about 25 000 children in the past 40 years. However, the week of 7–13 August 2017 showed a sudden increase in the number of deaths. Many neonates who were not inflicted with encephalitis also died. Only a few cases had acute encephalitis syndrome (AES) while most infants were severely ill and required ventilatory support. Oxygen cylinders in adequate number were not available as per the requirements of the 950-bed hospital. During the hours of shortage, manual breathing bags were used by the staff assisted by family members.

The supplier of oxygen cylinders to Baba Raghav Das (BRD) Medical College, Gorakhpur allegedly stopped supply due to an unpaid bill of approximately ₹70 lakh. Despite letters to the authorities, only partial payments were made. However, the supplier denied the charges that the supply of cylinders was stopped.

These deaths highlight India's meagre health budget, acute shortage of trained staff and clinics, lack of well-managed intensive care units, poor infrastructure and primitive set-ups. The situation is worse in peripheral hospitals.

BRD Medical College and Hospital also attracts patients from Bihar and Nepal. It is the only tertiary care centre in a 300 km radius and hence the high patient load and increased number of fatalities. In the past two decades, the population of the state has increased by 25% and the government health facilities are not matched with current health requirements.

Dr Sridevi Seetharam (Consultant Pathologist and Ethicist, Mysore) told this correspondent: 'It has been a wild-goose chase to find those responsible, because it is still not clear what exactly caused the deaths ... how and why so many children died in such a short span of time and who are responsible. Unless we

know the distinct pattern of events that have led to the death of the children, i.e. the modus operandi of the “killer events”, it is difficult to pin down who is responsible. This is clearly a case that is crying for an analytical epidemiological investigation—a systematic and scientifically designed investigation to get to the root of the problem ... not merely to nail those who are responsible for these deaths, but also to know how, so that such events can be prevented from happening again.’

In a hospital, when a death certificate is issued, the doctor certifying the death comments on three aspects—the immediate cause, the antecedent cause and underlying cause of death. These important bits of information are invaluable in understanding how the death has occurred, besides informing

future health policy. Unfortunately, no such systematic investigation has been conducted and as time passes on, the trail grows colder. Nevertheless, there is enough evidence that the contributing causes for the deaths seem to be the poorly equipped and understaffed intensive care units, non-existent infection control protocols and overworked staff. Since the hospital is managed by the state government, it seems ridiculous, even unethical, for the government to investigate itself. It is a glaring case of conflict of interest. Can the government seriously be expected to come out with honest evidence and admission of its own culpability, if any?

JYOTI PRIYADARSHINI SHRIVASTAVA, *Gwalior, Madhya Pradesh*

IJME Ethics Award 2018

Award ceremony: December 05, 2018

Venue: St. John's National Academy of Health Sciences, Bengaluru

CALL FOR NOMINATIONS OR SELF NOMINATIONS

*THEME: Outstanding Contribution to Ethical Practices and
Improving Access to Healthcare for the Marginalised*

The first Bioethics Award will be conferred on December 5, 2018 at the 7th National Bioethics Conference, jointly organised with the International Association of Bioethics' 14th World Congress of Bioethics, from December 5 to 7, 2018, at St. John's National Academy of Health Sciences, Bengaluru. This award is supported by the Elsevier Foundation.

Eligibility Criteria (only for Indian healthcare providers)

1. The healthcare practitioner should be involved in the relevant ethics activity for at least the past five years.
2. Documentation of the activities carried out by the healthcare practitioner should be presented for assessment to the selection committee.
3. If required, the nominated healthcare practitioner should be available to interact with a member of the selection committee on telephone/Skype.
4. The nomination must be accompanied by at least two references from individuals explaining the contribution, and supporting the nomination, of the healthcare practitioner

Nomination or self-nomination must be done by means of the prescribed form (attached), accompanied by supporting documents and any other relevant material, and submitted by email at ijmeethicsawards2018@gmail.com.

Last date for sending nominations: August 15, 2018

IJME website: <http://ijme.in/>

Call for nomination: *Call for nominations: IJME Ethics Award 2018*

Twitter handle: @EthicsAwards2018