

CONFERENCE REPORT

Examining the significance of ethics during Covid-19: Overview of the proceedings of the 8th National Bioethics Conference, 2020

JAGRITI GANGOPADHYAY, J CHARLES DAVIS, SHRIDEVI KALKOTI, FARSEENA KHADDEEJATH, SRE RATHA

Introduction

The year 2020 will go down in history as the year of the Covid-19 pandemic, with the enormous challenges it posed to ordinary people and experts across disciplines, worldwide. Covid-19, which broke out in Wuhan in December 2019, soon spread rapidly in 2020 (1), till on March 11, the World Health Organization declared it a pandemic. According to the latest statistics, worldwide there have been a total of 173,331,478 cases of Covid-19 and 3,735,571 deaths (2).

Given these transmission and fatality rates, the pandemic has been compared to other major plagues such as the 14th century bubonic plague, which killed more than 25 million people in Europe; and the Spanish flu (1918-19), which infected 500 million people in less than a year and occurred in three waves (3). Both these epidemics saw the use of quarantine measures, personal protective equipment, and a host of potential remedies (4,5), with limited understanding of causative factors and no effective treatment available. Similar practices were implemented across the globe to fight Covid-19. Despite various strategies being adopted to handle the pandemic, India's public health system has been under scrutiny as India continues to report a large number of cases.

While countries across the world grappled with the pandemic, in India, the challenges were magnified owing to the weak public health infrastructure and large population. Soon, the country had the second highest number of active Covid-19 cases (6). This imposed immense pressure on the

health systems raising important ethical concerns. Discussion on the ethical concerns thrown up by the pandemic emerged as the need of the hour. Addressing this need, the Forum for Medical Ethics Society (FMES) and its two platforms, the *Indian Journal of Medical Ethics* and the Health, Ethics and Law Institute, together with the Center for Bioethics, Yenepoya (Deemed to be University), Mangalore, co-organised the 8th National Bioethics Conference (NBC) to identify, discuss, and debate some of the core ethical issues that have emerged during the pandemic.

The theme for the NBC was "Crisis within a crisis: Scientific, ethical and humanitarian challenges of Covid-19". The lockdown and physical distancing necessitated by the pandemic resulted in a virtual conference, spread over four Saturdays from November 28 to December 19, 2020. Unlike the earlier NBCs, which consisted of plenary talks, paper presentations, and workshops, the format of this NBC was modified to suit the virtual format. This comprised of four plenaries and eight webinars spread over the four Saturdays.

The Conference proceedings were woven around four themes: Access, Rights and Justice in a Public Health Emergency; Clinical Ethics and Healthcare in the Pandemic; Research Ethics in the Covid Pandemic; Healthcare Humanities. In addition, a pre-conference meeting covered important issues related to ethics and procedures in organ donation and transplantation. We hope the insights which emerged will contribute to the discourse on the ethical issues we confront during a continuing global public health emergency.

Covid-19, organ transplantation and donation: Insights from a pre-conference

The Network and Alliance of Transplant Coordinators (NATCO) and MOHAN Foundation organised the Annual Conference of Transplant Coordinators 2020, which was both an international conference and a pre-conference event of the 8th NBC. It comprised of key lectures on the World Brain Death Project (WBDBP) and its application in India; the impact of the Covid-19 pandemic on organ donation and transplantation; and women in transplantation.

Transplant coordinators spoke of their experiences related to organ allocation, and donation during the pandemic, their first donation, and techniques of supporting their patients

Authors: **Jagriti Gangopadhyay** (corresponding author - jagriti.g@manipal.edu), Manipal Centre for Humanities, Manipal Academy of Higher Education (MAHE), Karnataka, INDIA; **J Charles Davis** (j.davischarlesj@gmail.com), Albert Ludwigs University of Freiburg, GERMANY; St. John's Medical College and St. John's Research Institute, Bangalore, INDIA; **Shridevi Kalkoti** (shridevi.kalkoti@gmsil.com) Centre for Ethics, Yenepoya University, Mangalore, INDIA; **Farseena Khaddeejath** (farzeenapag@gmail.com) Centre for Ethics, Yenepoya University, Mangalore, INDIA; **Sre Ratha** (sre.ratha@gmail.com) Manipal Centre for Humanities, Manipal Academy of Higher Education Academy of Higher Education, (MAHE), Karnataka, INDIA.

To cite: Gangopadhyay J, Davis JC, Kalkoti S, Khaddeejath F, Ratha S. Examining the significance of "ethics" during Covid-19: Overview of the proceedings of the 8th National Bioethics Conference, 2020. *Indian J Med Ethics*. Published online on June 16, 2021. DOI: 10.20529/IJME.2021.047.

© Indian Journal of Medical Ethics 2021

undergoing transplantation. The first sessions covered the strategies adopted by the National Health Service Blood and Transplant (NHSBT), UK, for organ donation in ICUs and wards during Covid-19. The speakers highlighted issues such as:

- Novel barriers in communication encountered during the pandemic, loss of non-verbal feedback, and more verbal communication on the doctor's part. This made for shorter interactions which impeded communication.
- Protocols for transplantation during the pandemic. A serious challenge was the necessity to ensure preoperatively the recipient's access to drugs during the post-operative period, so patients would have the same stringent follow-up during the pandemic that they would have had otherwise.
- The consensus criteria developed in 2020 by the WBDP on diagnosing brain death/death by neurological criteria (BD/DNC) with the goal of harmonising practices across the world. The WBDP document recommends that BD/DNC be defined as "the complete and permanent loss of brain function as defined by an unresponsive coma with loss of capacity for consciousness, brainstem reflexes, and the ability to breathe independently". On the applicability of WBDP in India, the speakers indicated that the range of challenges faced included variable clinical practices, a lack of clarity regarding the concept of "potential donor", a weak legal system, and poor understanding of the law. In particular, the speakers emphasised that BD/DNC is an essential clinical assessment in all persons with devastating brain injuries who potentially meet the criteria for BD/ DNC, regardless of whether or not they are potential organ donors.

In the subsequent session, titled "Women in Transplantation", the speakers stressed the need to confront the challenges in the field of organ donation and transplantation, and strive to make a difference. This session especially highlighted issues associated with pregnancies post-kidney transplantation.

The final session dealt with the management of transplantation by the United States (US) during the pandemic. A comparison of the donation protocols in the US and India during Covid-19 was a learning experience for the delegates.

Public health ethics in the pandemic

The discussion on ethics in public health began with an exploration into how moral and ethical questions are conceptualised and contextualised. Speakers highlighted the significant role played by social identities, such as caste, class, and gender, in constructing ethical practice during a crisis like Covid-19. One of the speakers argued that public health and political issues are intrinsically linked. Therefore, any discussion of morality and ethics in public health must

include social and political identities, processes, and locations.

One of the key points of discussion was the pricing of medical essentials and supplies, such as PPE kits, masks, medicines, ventilators, and oxygen-equipped beds, during public health emergencies and how pricing caps did not include the private sector. These economic issues severely compromised the public healthcare system while privileging the private system, which is less accessible to the poor. This also exposed the vulnerability and ethical shortcomings of the Indian healthcare system in handling a pandemic. Other ethical issues discussed were: who the gatekeepers of the medical community are and the onus of the cost of protection of healthcare workers being on the patient.

The conference also highlighted the plight of villagers in India during the pandemic. A speaker narrated the problems faced by economically vulnerable villagers at healthcare facilities in South Rajasthan, where patients with non-Covid illnesses were denied treatment unless they tested positive for the virus. Moreover, certain diseases being rampant only in certain village clusters pin-pointed the inequality and injustice in the healthcare sector.

Speakers also discussed the various health issues, other than Covid-19, faced by different marginalised communities across India.

Marginalised communities and ethics

The Covid-19 pandemic resulted in a critical shortage of life-saving resources and restrictions on liberty. The pandemic brought almost the entire world to a standstill, and while everyone suffered either physically, spiritually, mentally or existentially, speakers focused on the already marginalised communities which were most affected. Their very right to life was threatened, besides their right to dignity, especially during the lockdowns imposed by the state during the pandemic.

The speakers highlighted specifically:

- The impact of the pandemic on sex workers, with their residential (red-light) areas being barricaded and termed as containment zones. They were further stigmatised as super spreaders of Covid-19 and segregated from the public. This adversely affected their general and reproductive health, medication for HIV, and their children's health. Owing to lack of proper documents, many migrant sex workers did not have bank accounts to receive the government's relief packages. Civil organisations and population networks, including Saheli Sangh, raised around US \$10 million to sustain and support thousands of sex workers in India.
- The transgender community was among the worst affected and most marginalised groups during the pandemic. Many incidents of killing and torture of

transpersons by their own family members were reported during the pandemic. Basic healthcare, anti-retroviral therapy (ART), gender affirmation services, and hormone therapies were denied to them. Several transpersons attempted suicide. Lack of access to psychiatric counselling was experienced, and the incidence of acute mental breakdown surged. The National Institute of Social Defence tried to provide a one-time payment of Rs. 1,500 to transpersons, but only 1% of them could receive the relief package. Mostly, transpersons helped each other.

- Tribal villages were severely impacted by the imposition of Covid-19 restrictions on movement, on information sharing, and by the withdrawal of transport facilities without sufficient warning. Moreover, the essential services and relief packages did not reach them. They were forced to sell their land and domestic animals at lower prices for survival. Forceful eviction of tribal communities from their traditional habitats had already disrupted their livelihood, and the pandemic increased their misery. Medical services were inaccessible during the pandemic. Only a handful of non-governmental organisations (NGOs) were able to help them. The returning migrant tribals were unjustly criminalised at state borders and were ill-treated at the Covid care centres.
- Women bore the brunt of the sharp increase in domestic, sexual, and physical abuse during the lockdown. Women from marginalised groups were further deprived of their human rights in the absence of legal aid and non-cooperation of the police. Several NGOs were shut down and women's helpline systems became non-functional. Medical care was inaccessible because hospitals were exclusively treating Covid-19 patients. Since all external support systems failed to address the concerns of women, domestic violence during the nationwide lockdown emerged as a major challenge for India.

Clinical ethics and healthcare in the pandemic

This session shed light on several issues that had emerged during the pandemic, in particular, on the various gaps in the healthcare system of India.

Frailties of our healthcare system

A special talk emphasised the frailties of the Indian healthcare system owing to meagre budgetary allocation, lack of preparedness, and resource diversion. Hierarchical vulnerability in the healthcare system was also elucidated through the experiences of nurses and auxiliary nurse midwives (ANMs) who faced heightened moral distress, lack of personal protection equipment, and burnout. Maintaining a distance from their patients created a sense of unease and discomfort among nurses. A general lack of sensitivity in our

medical system was stressed, particularly with regard to providing psychosocial care to patients, even before the Covid-19 crisis. The policies of the central/state governments and hospitals in preventing family members from interacting with patients or restricting their visits were criticised.

Triaging of ICU beds on prognosis

The speakers emphasised that although the intention was to provide quality care to patients based on expert advice, the lack of preparedness of the hospitals and the imbalance between demand and available resources resulted in challenges in triaging of ICU beds and accessing other essential services.

A silver lining was the adoption of a methodical action plan for limiting life-sustaining treatment during the Covid-19 crisis. With respect to palliative care, the Covid palliative and end of life care plan (COPE CP) was created. COPE CP helped patients who would not benefit from ICU care but needed end-of-life care. Separate palliative Covid High Dependency Units (HDU) were set up, which had oxygen supply and all requirements apart from ventilators for end-of-life care.

Inflated healthcare bills and profiteering: Caricature of healthcare service

Inflated costs to patients with the debatable justification being increased costs of healthcare workers' protection shed light on the commercialisation of the healthcare system. There is no denying that the safety of healthcare workers is of utmost importance, and it was emphasised that the rights of healthcare workers and of patients are not in conflict with each other as claimed. Indeed, the safety and protection of healthcare workers results in quality care of patients. In reality, the lack of PPE as well as denial of Covid-19 treatment for HCWs contradicted this claim.

Research ethics in the pandemic

The crisis of scientific and research integrity during the pandemic was another of the themes discussed. A speaker brought out how politics can negatively impact research and thereby influence evidence-based science. In particular, it was emphasised that despite the pandemic, randomised control trials should be conducted before making vaccines and drugs available to the public. Management of the disease should be based on scientific evidence rather than on media reports, which often publicise the use of non-tested therapies, jeopardising the lives of patients, scientific validity, and the future of medicine.

Scientific integrity in publication also emerged as a concern. Increased duplicate publications, poor quality research, the race to publish key papers on Covid-19, and the non-work pressure and priorities of editors and researchers leading to possible errors were highlighted.

Pandemic conditions brought new challenges before stakeholders of healthcare research. A central challenge

faced by Ethics Committees (EC) was to ensure the voluntariness of informed consent under the remote consent process adopted. The social restrictions of the pandemic posed a unique challenge to designing a simple, understandable and informative, informed consent document in the language of the participant without any room for ambiguity and misunderstanding or misinterpretation.

Despite these challenges, all the stakeholders learnt valuable lessons from Covid-19. For instance, amidst challenges, the ECs started posing more intelligent questions to the researchers regarding the design of the protocol, the informed consent process, ensuring a comprehensive and voluntary informed consent, contact tracing of vulnerable participants, data analysis and sharing, and use of data. The challenges stimulated the researchers to refine their skills, such as establishing trust and confidence without face-to-face interaction, while being sensitive to the increased vulnerability of participants. While the phone-based mode of interaction for research limits the ability to contact people without mobile phones, it nevertheless provides mobile-phone users with a platform to make their voices heard. In a way, the telephonic consent and data collection became a blessing in disguise as the researcher could get a real insight into the issues affecting vulnerable participants, which may not be freely expressed in a face-to-face session. Experience from the pandemic has provided insights into the wastage of service-based data, which could have been used for research, if obtained with prior consent. Concerns over prior consent becoming a compulsion in order to obtain health services were also raised.

Panellists referred to the grey areas in clinical trial approvals to highlight the crisis of oversight mechanisms in research. The amendments made to the Indian Council of Medical Research (ICMR) guidelines and to the regulatory processes to deal with the crisis arising from the pandemic, were discussed. Further, the confusion and wariness among the public and the scientific community about the terms and conditions based on which the regulatory bodies approve drugs/ vaccines for emergency-restricted use were highlighted.

Mental health, healthcare humanities and ethics

The final session began with a discussion on how mental health emerged as a major challenge during the pandemic. The speakers highlighted that though mental health infrastructure in rural India had improved significantly in the last 17 years, India continues to remain under-resourced with regard to mental healthcare professionals. As per the National Mental Health Survey (2015-2016) (7), 1 in 7 of the Indian population has mental healthcare needs, 197 million out of 1.3 billion suffer from dementia, substance abuse, and/or suicidal ideation. The pandemic has compounded mental health issues through the loss of loved ones or fear of dying alone in a Covid-19 ward. In addition to patients, healthcare

workers also faced anxiety and suffered mental trauma as they lost their colleagues and several of their patients.

The second session covered issues related to persons with disability, perspectives of medical students, and how to discuss the pandemic through poetry. One of the biggest challenges faced by people with disability during the lockdown was the non-availability of paid caregivers. Additionally, the speaker pointed out that there is very little data on people with disability across the world and there are no advisory groups for them in India or in the US.

The findings from a study conducted on medical students in two medical colleges of Karnataka were also presented. The study revealed that the pandemic had involved medical students directly and the outcome of this involvement was that the students became more self-assured about pursuing their profession permanently. Most students were confident of their career choice, a few were less confident, and a small number regretted their career choice.

Finally, this session ended with an illustration of how poetry was used to deconstruct the pandemic. Looking at the pandemic through the lens of poetry, healthcare workers expressed their experiences of anger, being over-burdened, burnout, and despite all the problems, responded with reflections, compassion, humanity, and empathy.

A panel discussion was held on the core ethical challenges faced by journalists while covering the pandemic. In particular, the discussion threw light on how journalists faced a moral dilemma while covering the plight of migrant labourers. Additionally, lack of reporting guidelines made it difficult for reporters to guard a patient's privacy while reporting on the healthcare system. The risk to their health faced by reporters covering the pandemic extensively, was also recognised.

The conference ended with a session exploring questions of equality, justice, and sustainability in a post-pandemic world. The speakers urged that, with the pandemic exposing severe inequalities across the globe, it was necessary to ensure that the vaccine drive should be inclusive and available to all people, irrespective of their caste, race, gender, and class status.

Concluding remarks

One core point that emerged across the deliberations was that the current pandemic was only the beginning and India, as well as the world, need to be prepared for more such pandemics. Hence, the 8th National Bioethics Conference, through its thematic discussions attempted to cover some of the key ethical concerns that have arisen during the current pandemic. The conference provided a forum for very engaging debates, and new insights emerged that could contribute to academic and policy discourse for the current as well as future pandemics.

Acknowledgements

We would like to thank Dr Sunita Sheel Bandewar, Dr Sumana Navin and Lt Col Cynthia Arunachalam for their insights on all the notes and drafts prepared by the Rapporteurs' Committee. We would also like to thank Ms Revathi Vyas, Mr Keni Philomin Raj Santhiah, Mr S Sebastian Velankanni and Ms Rhea Sakhardande for their contributions throughout the conference.

References

1. Pitlik SD. COVID-19 compared to other pandemic diseases. *Rambam Maimonides Med J*. 2020 July 23; 11(3):e0027. <https://doi.org/10.5041/RMMJ.10418>.
2. World Health Organization. Novel Coronavirus Disease. Situation Update Report-71. Geneva: WHO; 2021 Jun 9[cited 2021 Jun 15]. Available from: <https://cdn.who.int/media/docs/default-source/wrindia/situation-report/india-situation-report-71.pdf>
3. Robinson KR. Comparing the Spanish flu and COVID19 pandemics: Lessons to carry forward. *Nurs Forum*. 2021 Apr; 56(2):350-7. <https://doi.org/10.1111/nuf.12534>
4. Bassareo PP, Melis MR, Marras S, Calcaterra G. Learning from the past in the COVID-19 era: rediscovery of quarantine, previous pandemics, origin of hospitals and national healthcare systems, and ethics in medicine. *Postgrad Med J*. 2020 Oct
5. Franchini AF, Galimberti AF, Piga PM, Castaldi MA, Porro A. COVID 19 and Spanish flu pandemics: All it changes, nothing changes. *Acta Biomed*. 2020 May 11; 91(2), 245–50. <https://doi.org/10.23750/abm.v91i2.9625>.
6. Petersen HE. India becomes country with second highest number of Covid cases. *Guardian*. 2020 Sep 7[cited 2021 Feb 19]. Available from: <https://www.theguardian.com/world/2020/sep/07/india-becomes-country-with-second-highest-number-of-covid-cases>
7. Murthy RS. National Mental Health Survey of India 2015-2016. *Indian J Psychiatry*. 2017 Jan-Mar;59(1): 21–6. https://doi.org/10.4103/psychiatry.IndianJPsychiatry_102_1