

SOCIAL ACTION

A Quarterly Review of Social Trends

INTOLERANCE AND SHRINKING SPACE OF CIVIL SOCIETY

- ❑ Enhancing the Space for Civil Society (Editorial)
Sebasti L. Raj
- ❑ Research Ethics in Healthcare and the Role of Civil Society:
Learnings from Covid-19
Kathiresan Loganathan & Ratna Huiem
- ❑ Unveiling Digital Battlegrounds: Social Media and Intolerance
in Indian Civil Society
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Challenges for Civil Society in a Global World
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- ❑ The Role of Civil Society in the Advocacy for the Recognition of
Same-Sex Marriage amid Constriction of Democratic Spaces
Disha
- ❑ Reporting Protest through the Lens of Citizen Journalism:
An Exploration of User-Generated Content on YouTube
Shikha Rai & Sonali Srivastav

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Guest Editor: Sebasti L. Raj

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SOCIAL ACTION

Themes for forthcoming issues

Labour Codes: Challenges and Prospects

October-December 2024

(Last date to receive articles : 15 August 2024)

Women at Work: Paid and Unpaid

January-March 2025

(Last date to receive articles : 15 November 2024)

Religious Minorities in India

April-June 2025

(Last date to receive articles : 15 February 2025)

Caring for the Mother Earth

July-September 2025

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Enhancing the Space for Civil Society

Civil society plays an important role in promoting the effective functioning of democracy, as these organizations encourage the citizens to participate actively in the political process, beyond just voting. It provides platforms for people to voice their opinions, engage in public debate, and influence policymaking. It educates and mobilize the citizens, particularly the marginalized groups, to demand their rights and hold the authorities accountable.

Further, civil society functions as a watchdog, monitors government actions and policies, and ensures transparency and accountability in governance. It advocates for the public interest, lobbies for policy changes, and ensures that government actions reflect the needs and aspirations of the people. It plays a critical role in protecting human rights, advocating for social justice and safeguarding fundamental freedoms, bridging the divides within society by encouraging and promoting dialogue and understanding among different groups. It plays a key role in conflict prevention and resolution, peacebuilding, and promoting dialogue among different communities.

Often civil society comes into the picture where the government is unable or unwilling to act on issues related to social, economic, and environmental spheres and tries to find solutions. Civil society organizations (CSOs) also provide essential services -- education, healthcare, etc. – and thus complement the role of the state. Besides, civil society organizations focus on long-term and sustainable goals and solutions to issues and problems, thus promoting the overall development of the country or a particular group

Civil society functions as the voice of the voiceless, particularly the vulnerable, the marginalized people, the minorities, etc., and takes up their cause. Thus, civil society is indispensable in a democracy since it is engaged in promoting the welfare of the citizens, ensuring the accountability of the government, protecting and promoting the legitimate rights of individuals and groups, fostering social cohesion, and contributing to the overall growth and health of the democratic system. By working among ethnic, religious, and social divides, civil society promotes tolerance, understanding, and cooperation, thus strengthening the social fabric of the nation.

Civil society contributes to policymaking through research, data collection, and coming up with innovative solutions to social and economic challenges.

Since it experiments with new approaches at the grassroots level, it is in a position to develop models that can be adopted by the government for the overall development of the nation. Further, civil society organizations often work at the international level as well, particularly on issue and problems that have a global impact, such as the environment, epidemics, etc.

A genuinely democratic society calls for an ethos, where there is adequate space for open and inclusive public discourses and opportunities for participatory and collective approaches to social, economic, and political issues and concerns. In other words, in a democratic society, it is essential to give adequate space for civil society organizations to function freely, so that these organizations can make useful contributions for the growth of the nation. However, because of laws and regulations, such as increased bureaucratic hurdles and restrictions on foreign funding for NGOs, it has become difficult for civil society organizations to operate freely. Besides, they are facing different types of harassment under different legal pretexts.

The situation in India is similar to what is happening in many other developing countries. This goes directly against the interest of India, which is a pluralistic and democratic society, functioning under a democratic system of governance. Despite such hurdles and obstacles, many civil society organizations are functioning, and they advocate for human rights, freedom of expression, and inclusive governance. The articles published in this volume take up the role of civil society in handling or facing specific social, political, and economic issues and offer useful suggestions.

Kathiresan Loganathan & Ratna Huirem address the ethical dilemmas in biomedical/ healthcare research in the context of COVID-19 and look at additional dilemmas like the transparency of medical interventions, the role of the state during health emergencies and technological advancements, and equitable access. They also assert that good governance and the judicious usage of scarce resources are essential for ethical research and underline the need to promote the role of civil society as a partner in managing future health crises.

K.C. Libi and K.P. Vipin Chandra explore the consequences of social media usage on Indian civil society, particularly its role as a battleground for intolerance. It examines the multifaceted efforts undertaken by the civil society and governmental bodies to combat these issues. They are of the view that despite facing obstacles, the social media also presents opportunities for fostering communal cohesion and effective crisis management and underline the need to harness these benefits while

mitigating the risks, urgent measures are imperative.

Deepak Setia and Pradyuman S Khileri deal with the issue of shrinking space of CSOs along with analysing the range of mechanisms deployed by the state to curb their operations. A section of the paper also tries to understand and link how intolerance is among the many factors impacting CSOs. Lastly, the paper seeks to offer a perspective on how these atrocities can be addressed, while also highlighting the measure of international efforts and strategies.

Malsawmtluangi and Nagalaxmi M Raman investigate the relationship between civil society activism, intolerance, and border dynamics in Sikkim and the India-Bhutan-China axis. This study delves into the complexities of democratic engagement amidst geopolitical tensions through a case study. Using instances such as the Arunachal Pradesh anti-dam demonstrations and civil society reactions to the Bhutanese refugee crisis, it explains how civil society resilience opposes intolerance and campaigns for peace, environmental conservation, and human rights in the border regions. The research highlights the critical role of civil society in encouraging cross-border cooperation, resolving socio-economic inequities, and supporting inclusive governance in Sikkim and the India-Bhutan-China area.

M S Chandana Rajapantula explores the implications of the United Nations Security Council Resolution (UNSCR 1325) on Women, Peace, and Security, initially adopted in response to the impacts of the Yugoslav Wars. Taking case studies of how Resolution 1325 has been enacted through National Action Plans (NAPs) in Bosnia, Liberia, and Colombia, countries marked by protracted conflicts, this paper critically analyses the implementation of the resolution, which showed varied success in enhancing women's roles in peacebuilding. The research draws insights into the operational successes and challenges faced in these diverse geopolitical settings by reviewing policy documents and analysing NGO and government reports. The central research question for this paper is, "How can India benefit by enacting UNSCR 1325 through a NAP?" By juxtaposing how civil society organizations could play a role in implementing UNSCR 1325 in India, the paper derives the benefits for India, from increasing women's security personnel to reducing gender-based violence and promoting self-sufficiency of women in India.

Disha explores the pivotal role of civil society in advocating for same-sex marriage recognition in India amidst the constricting democratic spaces. Beginning with a historical overview, it examines the landscape

pre-2018, characterized by the draconian Section 377 of the Indian Penal Code and societal stigma. The paper reflects on the shrinking space for civil society in India, shaped by legal, political, and economic factors, while underscoring the resilience of CSOs in championing marginalized narratives. Looking forward, it emphasizes the ongoing battle for same-sex marriage recognition, highlighting the promise of a more inclusive future through the concerted efforts of civil society.

Shikha Rai & Sonali Srivastav assess the contribution of User-Generated Content in the form of videos on YouTube during the protests in Delhi in 2019. It is particularly important in today's context as the space for civil society to voice its opinions is shrinking. Shifting the fulcrum of coverage from anti- to pro-protests, the narrative of these YouTube videos was analysed extensively to highlight citizen journalism. The findings point out the emergence of opinion leaders in the form of social media influencers and a post-truth treatment of news. The results also hint at an increasing media plurality in political communication within the largest democracy in the world.

In conclusion, it is urgent and highly desirable that a democratic country like India, with its pluralistic culture, race, religion, language, food habits, etc., become a model for the increased role of civil society organizations. For this, it is essential to remove the existing restrictions and promulgate laws that will promote and ensure adequate space for the active involvement of civil society organizations in the task of peace-making, bridge building, policymaking, and establishing a harmonious and just social order. □

Dr. Sebast L. Raj SJ
Editor

Research Ethics in Healthcare and the Role of Civil Society: Learnings from Covid-19

Kathiresan Loganathan*
& Ratna Huirem**

Abstract

Research ethics in healthcare is very significant. Biomedical research, particularly those engaging with 'controlled' human trials must have sound research ethics. This review paper, therefore, addresses the ethical dilemmas in biomedical / healthcare research. It also looks at additional dilemmas like transparency of medical interventions, the role of the state during health emergencies and technological advancements and equitable access. The quest for the 'greater social good', must not compromise on ethics. COVID-19 propelled unprecedented reliance on technology and networking, which overlooked the poor. Informed consent too becomes dubious, when information itself is inaccessible. This paper asserts that good governance and the judicious usage of scarce resources are essential for ethical research. It also argues the case for promoting the role of civil society as a watchdog in the wake of state autocracy during the pandemic. Civil society's role as a partner in managing future health crisis is being advocated, as this will boost research ethics.

Keywords: Civil Society, Good Governance, Inequality, Research Ethics, Technology

Introduction

Issues in healthcare such as equitable access, transparency, racial disparities, confidentiality, and ethics are very pertinent. Scientists must not use ethics loosely or merely as a humanitarian approach. When the COVID-19 pandemic broke out, international ethical guidelines were established. Scarcities abounded for Personal Protective Equipment (PPEs), ventilators, respirators, reliable medications, beds, masks, and even sanitizers at the initial onset of the pandemic. Global digital networks contributed to the

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chaos, creating an uncontrolled ‘infodemic.’ Governments were questioned as to what should have been done or not done. In some instances, such was the distress that anyone who even pointed out that complacency at various levels led to the outbreak, was branded ‘whistle blowers.’

COVID-19 also induced a publication spree. Tripathy (2021) points out that the race to be first, prompted several researchers to publish incomplete or under-researched studies. This threatens the integrity of research by setting dangerous precedents for unreliability and potential harm. He, therefore, underscores the importance of ethics amongst researchers, editors, and reviewers. Maccaro et al. (2021) noted that several open-access articles without peer reviews were reporting as scientific studies, thus resulting in high retractions. They report that as of May 2021, 124 out of 264,530 papers on COVID-19 were retracted. Low-quality research points to inaccuracies, and poor ethics. Misleading reports can cause harm to people. A public, transparent, and well-coordinated set of national-level ethical guidelines is crucial for sound healthcare decisions and policy-making. Such ethical guidelines must be woven into the healthcare system and its social policies, which can enhance the quality and rigour of research and publications.

Equality, Safety Protocols, and State Intervention

If we look at healthcare in India, the private sector is predominant, where almost 75% of healthcare expenditure is out-of-pocket. This has adversely impacted several families and their economic well-being. COVID-19 hit people very hard. Social distancing was a near-impossible task for the poor who mostly lived cheek by jowl. Washing hands frequently, despite the lack of sufficient drinking water, was almost hollow propaganda for some. A vigilant ethics committee should prevent undue inducements to vulnerable individuals for clinical trials or while seeking treatment. Additionally, the welfare of the frontline health workers was also equally significant, especially, as there were multiple assault reports. Since social distancing was difficult for them owing to the nature of work, it was the state’s duty to ensure adequate provision of personal PPEs and other safety requirements. Psycho-social support is also warranted during such stressful situations, both for the patients as well as for the healthcare workers (Kasthuri, 2018). Mathur (2020) highlights that ethical preparedness for research during such sudden outbreaks involves five key parameters. They are: 1) building trust and communication; 2) protection and engagement; 3) collaboration and partnership; 4) quality ethics review, and 5) governance structure.

Civil society (CS), comprising both organized groups of individuals as well as organizations, can play a crucial role in terms of advocating patient rights, and the pursuit of ethical research. However, in many cases, all they could do was reinforce the government's efforts, or address the gaps in government support. In the same way, as individuals, all civil society organisations, felt compelled by an authoritarian state and strict regulations that had been notified in the interest of the "larger good", to work in tandem with the government. Thus, voicing any dissent about the dubiousness of research ethics became unimaginable. The state almost had unceasing power and control over research as well. Research ethics committees were in a dilemma over the balance between individual rights and community rights. Civil societies can play a huge role by not letting the personal rights of the marginalized be trampled. However, their 'shrinking space' became worrisome during the pandemic. There were pushbacks by the government on several non-governmental organisations, as the state adopted a more autocratic tone. There were also reports of journalists and the media being censored, on the pretext of curbing pandemic-related rumours. Sudden lockdowns increased the intensity of inequalities across the world (Lorch, et al., 2021). These are the spaces CS can inhabit in advocating for egalitarianism. A public health crisis like that of the COVID-19 pandemic cannot and must not be left solely in the hands of the government. Rather the state should look at partnering with CS actively. In fact, during the sub-crisis created by lockdowns in various places, it was civil societies that played a significant role in tempering the situation.

There is an immense need for equity and clarity in how governments inform citizens. Policies for COVID-19 must be contextualized to suit various communities and their traditional beliefs (Erwin et al., 2020). Care must be taken to ensure that the gaps between the rich and the poor are not worsened further (Thomas, 2020). COVID-19 has posed a host of ethical dilemmas to ethics committees in hospitals as well as to frontline healthcare workers. Despite the eventuality of material scarcities, and increased public paranoia, strikes were viewed as patient abandonment (Schuklenk, 2020). Referring to this, Gopichandran and Subramaniam (2020) evoke the reciprocity principle, based on which the state must provide for and protect the interests of the healthcare workers, who are risking their own lives.

Rakhmani and Sciortino (2023) report that research in the social sciences that present the problems of the marginalized, and the inequitable access to medical support systems in the COVID scenario had been stifled. They reiterate that health is universal and studies on healthcare must necessarily

be linked with social inclusion and exclusion. Hence, social scientists must have a place on ethical committees and research bodies that are committed towards healthcare. This will create space to promote the role of CS. The dominance of the medical sciences is questioned as social, psychological, and economic repercussions filled the COVID-19 aftermath. They also question the state's approach to the pandemic as a 'security and medical issue', while ignoring the socio-cultural aspects. Funding of research too becomes an issue. State policies need to adopt an inclusive, bottom-up approach to increase their efficacy and outreach.

Community Participation and Transparency in Research

Local communities and research participants must be included actively in the research. Kumar and Muthuswamy (2020), note that corroborating viewpoints between the community and the researchers will enhance community confidence and boost participation. Ethics committees should tighten their norms even more during pandemic times, when novel medical interventions could pose hazards. Rakhmani and Sciortino (2023) acknowledge the challenges faced by the state regarding rapidly implementing of containment measures and safety protocols, besides various economic concerns. However, they reiterate how research strategies or protocols could be expedited or stalled by the state, as it alone had the power to exercise discretion, given the nature and scale of the pandemic. National expert committees were formed, comprising bureaucrats, military personnel, and even social scientists. Yet, they note that critical scholarship was excluded. They also add that social scientists are usually perceived as anti-establishment, thus devaluing them further. Most social scientists organize themselves as CS activists or engage in academic activism. This was found wanting in the COVID-19 scenario.

To expedite ethics committee reviews and approvals, online meetings were the norm in most cases (Mathur, 2020). Many times, either due to lack of technology savviness or internet breakdowns, review processes were hampered or perhaps passed over. The ICMR COVID-19 ethical guidelines created provisions for such eventualities. Freedom was provided to locally constituted ethics committees to fast-track site-specific issues, instead of awaiting approval from the central ethics committee. The guidelines also created a provision for the replacement of Principal Investigators of COVID-19 research projects in case of any adverse eventuality on the person. However, travel restrictions and the fear of the virus, made it essential to have designated and localised places for research. Many times,

telephonic interactions were relied on instead of face-to-face. Stigma, fear, and general paranoia also posed different sets of challenges in accessing the requisite sample of human subjects (Kumar & Muthuswamy, 2020). These are also areas where CS can play a huge role.

Informed Consent

Informed consent, which is especially vital in biomedical research, was a major challenge during the pandemic. Nijhawan et al. (2013) highlight that in a vast and multi-cultural country like India such challenges prevail even during normal times. Language, religion, culture, superstitions, among others can be huge barriers. Kumar and Muthuswamy (2020) assert that COVID-19 patients would be either incapable of providing informed consent, or access may be limited owing to quarantine/isolation protocol. Electronic consent via digital options also posed challenges related to unfamiliarity and lack of privacy. Informed consent is a very vital aspect of ethics. When this is overlooked, whether in the procedure itself or in the reporting of the research, it reflects the limited role that CS plays. The implications of such research are an authoritarian and power-driven one, where the research subjects who are a part of society are bereft of a voice of their own.

Technology, Networking, and Information Sharing

It was evident that there was an immense need for worldwide networking to combat the pandemic, and as well as other future global emergencies. The interests of low and middle-income countries such as Africa, India, and Latin America were vital as their public health systems were already overstretched (Schuklenk, 2020). There has also been a huge boom in information, often referred to as an “infodemic”. However, even after several variants of the virus, information remains a mystery. The digital networks and a range of media also added to the chaos. Only the narrative changed, shifting from PPEs and hospital infrastructure to other concerns, to vaccine safety and scarcity, as the pandemic evolved. Stigma and discrimination against specific populations, such as Asians, abounded owing to uncontrolled information sharing. Owing to the several challenges of confidentiality, and digital inaccessibility, many technological applications became redundant too. The irrevocable significance and need for ethics in research are therefore underlined, despite all constraints of time and space (Maccaro et al., 2021).

Technology and Research Ethics

Reliance on artificial intelligence (AI) and data sharing peaked during COVID-19, when various contact tracing apps were used. Surveillance mechanisms such as facial recognition, often intrude on a person's privacy. Ethical dilemmas about naming an infected person publicly abounded. While the patient's privacy and confidentiality remained a major concern, such a confidentiality breach was deemed essential in the public health interest. It was argued that the common good prevailed over patient confidentiality rights, irrespective of the impact on the mental health of the patients (Vokinger et al., 2020). Technology as a measure against COVID-19, and the resultant concerns amongst those who do not have access to adequate internet services, or are not technologically literate is thus questionable.

Moss and Metcalf (2020) discuss the ethics of using advanced technology to detect hypoxia. Health professionals can visually detect hypoxia well by noting the paleness of complexion or blue lips. An additional technological test is an expensive intervention that adds to the triage process, increases the burden, and delays the initiation of critical care. Such investments were questionable when essential items like PPEs were scarce. Moreover, developing and adopting sophisticated technology, such as contact tracing apps, must ensure that financial, social, emotional, and medical resources are equipped to handle the resulting implications. If one cannot self-isolate, the app becomes redundant. These are indeed ethical dilemmas, which question equality of access to technology. There are indeed certain moral dilemmas associated with using AI and the accessing and sharing of information. There is a concern that states may continue using these tracking and surveillance mechanisms long after the pandemic is over. The fear is that these tracking tools should not go beyond public healthcare needs and creep into routine lives and breach the privacy of individuals.

Technology, Inequality and Covid-19

Societal risks are a necessary corollary of progress, technological advancements, and wealth. Increased wealth amongst the affluent and advanced nations increases vulnerabilities and risks among the less developed nations. The COVID-19 pandemic provided further evidence, as inequalities and inaccessibility to a technology-centric healthcare industry eluded the very poor (Moss & Metcalf, 2020).

The virus spread rapidly through jet planes and other means that are primarily accessible to the affluent. However, the repercussions were mostly felt by the weak and the uninsured poor. They neither had the purchasing power nor social safety nets. Social distancing and self-quarantining remained hollow concepts as their very livelihoods were at stake. Dependence on technology for safety remained mythical. For instance, in India, the '*Arogya Setu*' app was developed by the government for contact tracing. For the poor and vulnerable who must earn their livelihood outdoors, several factors impeded the usage of the app, namely, poor technological know-how, not owning an app-friendly device, and no internet facilities.

The affluent manage technology in ways that shift social risks on to the most vulnerable, thereby aggravating socio-economic inequities further. Moss and Metcalf (2020) argue that pandemic research cannot focus solely on microbiology. The impact of such rare yet life-changing events on society varies in scope and severity. The onus of 'staying safe' was primarily placed on the individual during the pandemic to stay indoors, irrespective of socio-economic contexts. Dependence on technology was tremendous for all kinds of safety protocols. Scarce resources were utilised to create socio-economic profiles, which were often used to police and hound them.

Technology in many cases has facilitated near-criminal practices in the guise of advancements. The very pertinent concern, therefore, especially in the context of COVID-19, is to reduce the technology-induced aggravation of social risks and harm. Machine applications for facial recognition, contact tracing, quarantine, triage, and other treatment and diagnostic procedures have been utilised during the pandemic to enhance medical performance and societal protection. However, such profiling has had certain undue fallouts on the socially and economically marginalized. Mitigation efforts are underway but limited in nature and scope (Moss & Metcalf, 2020).

The Covid-19 Knowledge Gap and Research Ethics

The pandemic presented multifaceted challenges where many evoked the greater good principle and argued for adopting exceptional ways. Stoeklé and Hervé (2020) favoured scientific knowledge and political concerns over-riding ethics, under severe constraints of time. Solbakk et al. (2021), counter this and underline human rights obligations, by citing instances of harmful consequences of earlier research. They also discuss pandemic surges in the past which may recur, due to more complex pathogens; and

disregard urgency as a premise for any ethics oversight. COVID-19 was characterised by uncertainty, risks, ignorance, and paranoia. Under such extremities, they question the ethics behind ‘controlled’ human infection studies.

The ‘Nuremberg Code 1947, was devised so that society can protect itself from such bizarre research undertaken by the Nazis, which became public during the War Crimes Trials. This Code laid down the prerequisites for research involving human subjects and emphasized voluntary consent. The Helsinki Declaration of 1964, which was revised in 1989, also reiterated the need for research ethics. Article 7 of the International Covenant on Civil and Political Rights, adopted by the UN General Assembly in 1966, emphasizes the need for free consent in case of medical or scientific experimentation. Thus, society looks to guard itself against the suppression of its rights and welfare in the process of scientific experimentation (Fokunang et al., 2013).

The Nuremberg code talks about making exceptions for high-risk research only in cases where physician-researchers are ready to conduct such experiments on themselves. The WHO also emphasizes the importance of obtaining clear and informed consent. During COVID-19, informed consent was ambiguous. In the event of adverse consequences, corrective options were yet unknown. Hence, taking up such high-risk studies without clear informed consent violates the existing global ethical guidelines. Moreover, study participants with COVID-19 were given remunerations, who were sourced from the economically vulnerable. They additionally belonged to racial and ethnic minorities, thus posing additional ethical dilemmas (Solbakk et al., 2021).

Solbakk et al. (2021) also question the term, “controlled human infection studies” as it gives the volunteers an impression that all things are under control. Contrastingly, even individuals who were fully vaccinated continued to test positive for the virus. Risks and uncertainties were rampant; hence ethical issues were a major concern. To illustrate their point, they cite a study at the Jewish Chronic Disease Hospital in Brooklyn, New York. It was conducted in the early 1960s by Dr. Chester M. Southam, where the research participants were injected with a suspension of foreign cancer cells. One was a group of cancer patients from a hospital, and the other was healthy individuals from an Ohio prison. In involving uninformed but healthy individuals, including prisoners, and not volunteering himself, he defiantly stated that he had no ‘hesitation’, but did not feel the need to participate since there were willing volunteers already.

The COVID-19 vaccine studies were questioned by ethicists and human rights activists. They were defended by the scientific community engaged in it based upon: a) scientific merit; b) high social value; c) exposure of a small number of individuals to risks in the larger social interests; d) one was anyway bound to be exposed; e) assurance of critical care and complete isolation; f) priorly induced immunity from the virus and; g) informed consent (Solbakk et al., 2021).

The “Priority of the Individual” Principle

The Declaration of Helsinki, 1964, brought this principle to the fore and highlighted the need for careful assessment and analysis of risks versus benefits. The interests of research subjects must always prevail over those of society and science. The World Medical Association, 2013, states it as general principle (para 8) that although the medical research is driven by the quest for new knowledge, individual rights and interests must never be overlooked. Article 3 of the UNESCO Universal Declaration on Bioethics and Human Rights, 2005, also lays this principle down. It amplifies that irrespective of the nature and scale of urgency or distress, the safety of research subjects must always be paramount and not be undermined by science or larger societal benefits. Studies on COVID-19 fell short of justifying this ethical principle (Solbakk et al., 2021).

Using crises as an excuse for lowering scientific standards and according to extreme urgency to the SARS-CoV-2 studies may be fatal, as quality, rigour, and ethics could be compromised. It would also shatter public faith in governments and science itself. Scarce resources, as well as human lives, would be lost. Rushed peer reviews to publish research findings have also affected the quality of research and several papers were retracted.

Peterson, et al. (2022) report that there were more than 125,000 articles published or released in the first year itself of the pandemic. Moreover, retractions were being done much quicker than the usual duration of 2 to 3 years, which is alarming. They searched the PubMed database for articles between November 01, 2019, and August 01, 2021, with the key term COVID-19. They also noted that similar investigative studies have reported disproportionately higher publications for COVID-19 as compared to other outbreaks and scientific topics like H1N1, Zika, Ebola etc.

Bramstedt (2020) asserts that there was thus a surge in journals publishing research articles about the pandemic, which hinted at ethical sidestepping. Moreover, with more open-access articles, clinicians could view them

easily. However, publishing faulty research results could be life-threatening. A robust peer-review process and complete transparency regarding conflict of interests, if any, must be ensured prior to publication. The pressure to deliver potentially reliable results at the earliest can be taxing and can affect research quality. Hence, mandatory research ethics and integrity training for all researchers to ensure quality and avoid misconduct is advocated.

Solbakk et al. (2021) emphasize that human subjects on whom emergent vaccines are tested may become unfortunate victims of an enhanced disease, or of life-threatening complications. This is indeed a very genuine ethical dilemma. Besides the probable benefits of such trial treatment procedures, the unknown risks involved must also be publicly declared. Scientific information during exigencies must always be shared publicly by the scientific body working on it to increase public faith and trust. Tripathy (2021) highlights that research publications should not be directed by the pharmaceutical industry, as their lobbying and influence can be very strong, particularly during such times of crisis. A vigilant community and ethical research practices can help prevent such undue influence.

Inequality during COVID Times and Civil Society

Emergency medicines and access to healthcare mostly eluded the poor. COVID-19 showed to the world in a stark way what inequality could bring forth. This is besides the questions regarding the ethics in COVID-19 vaccine research on human subjects involving the underprivileged. Sekalala and Rawson (2022) report that civil society also questioned ‘vaccine injustice’, and it pushed for the manufacture of vaccines in the less developed nations. They have also alerted how there is a dire need for having a World Health Organisation Pandemic Treaty with CS Organisations to promote equitable access to medical care and attention during future health disasters. They also discuss the need for systemic changes in international law and the entrenchment of human rights within it and advocate for poorer countries to manufacture their own vaccine for sustainability and ease of access in future health crises. Such issues fall within the larger domain of research ethics and only an active participation by CS as well as a receptive state will ensure it. More obligatory binding will have to be placed upon the states and the pharmaceutical industries. Thus, greater justice in global health can be brought about.

CS can be any organization or network of organizations working at the local, national, or international level. They can be engaged in a host of services in multiple fields such as health, law, medicine, etc., through policy

advocacy, structural changes in regulations, and coalitions. It has been reported that Uganda and Thailand have had great success with controlling the HIV/AIDS epidemic owing to high levels of CS engagement. Drawing from such successes, a lot can be achieved by them, provided they have the space to function.

‘Vaccine hoarding’ or ‘vaccine nationalism’ was another disturbing aspect that emerged during the pandemic. Thus, vaccine inequity was yet another ethical concern. It was reported that three in four people in high income countries had received at least one dose of the COVID-19 vaccine, compared to one in five people in low-income countries. CS organisations invoke human rights and the need for greater international cooperation at all stages of health care, starting with research, manufacture, distribution, and supply. Delays in vaccine technology transfer also further the vaccine inequities between the developed and low-income developing countries. The role of CS was very marginal during the pandemic as state supremacy nearly stifled their voices. There was a failure in ensuring an inclusive approach in terms of their participation. Vaccine inequity and injustice, beginning with the poor being roped in as research subjects, and then not getting timely access to it, can be curtailed to an extent by promoting CS’s role with a thrust on human rights via a new pandemic treaty.

The “herd immunity” factor that was sought to be achieved via rapid expansion of vaccination was inapplicable in the low-income countries. Their governments could not procure them in such large scales within a short period through trade; nor the capacity to self-produce. They also lack access to advanced infrastructure for both production and storage. These are pertinent equity issues, where civil society can intervene. They can play critical roles in promoting public-private partnerships at various stages of the vaccine production or procurement process as the government alone will not be best suited to deal with such unprecedented global health disasters, which may recur in the future too.

Conclusion

Advancements in technology have undoubtedly facilitated understanding of a host of diseases and enabled networking globally. The State has become monolithic in advocating and approving research in unprecedented times like that of the COVID-19 pandemic. Owing to the extraordinary nature and scale of the pandemic, ethics oversight may have abounded due to time constraints. The role of the State in promoting equitable access to treatment, and more importantly, ensuring that researchers uphold the

rights of the study subjects, is underlined during such times. Hence, good governance becomes the key to manoeuvring through such challenging situations. Technology must be designed and implemented to further the goal of equality. In an increasingly technology-driven world, the healthcare sector must be even more vigilant to ensure that the refrain of the “greater good” does not always trample over “individual rights.”

Engaging with civil society organisations, emphasizing upon the role and efforts of the social sciences, highlighting the behavioural and social aspects of biomedical science research, is indeed important rather than stifling them. The challenges that COVID-19 posed to the world was not just a health issue. It must be looked at from the holistic perspective of social and economic life. Inequalities have further worsened after the pandemic. State policies cannot ignore these, which sadly may be a reality, if fringe research reports are not brought into mainstream knowledge. Governments partnering with civil society which is closely linked with social sciences can prove highly beneficial in responding to, as well as planning and strategizing responses to future crises. □

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