

## CONFERENCE REPORTS

# Bringing solidarity, justice and equity to the centre of the bioethics discourse: Overview of proceedings of the joint 14th World Congress of Bioethics and the 7th National Bioethics Conference, 2018

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### Introduction

Forum for Medical Ethics Society (FMES), Mumbai; St. John's National Academy of Health Sciences (SJNAHS), Bengaluru; Society for Community Health Awareness Research and Action (SOCHARA), Bengaluru and SAMA Resource Group for Women and Health, New Delhi co-hosted the joint 14th World Congress of Bioethics (WCB) and the 7th National Bioethics Conference (NBC) in Bengaluru. The theme of the Congress was, "Health for all in an unequal world: Obligations of Global Bioethics" (1). The conference was held at an opportune time when we also commemorate 70 years of the Declaration of Human Rights of 1948 and 40 years of the Alma Ata Declaration of 1978. Both declarations affirmed Health as a fundamental Human Right. We have discussed earlier the significance of the congress theme in the year 2018 (1).

The WCB platform was established by the International Association of Bioethics (IAB), an international network established about three decades ago in the early 1990s, with the purposes, among others, of exchanging information among those working in bioethics in different parts of the world; organising and promoting international conferences in bioethics; and upholding the value of free, open and reasoned discussion of issues in bioethics. Over time, the IAB has also been able to encourage its members from the larger peer community of bioethicists to develop networks of scholars in specific areas of bioethics. These networks promote dialogue and action. Membership in IAB Networks is open to researchers interested in themes or issues addressed by specific groups. So far about eight such Networks have been established. (<http://www.bioethics-international.org/networks/>). The

platform of the WCB aims to be truly international, linking all those working in bioethics and related fields, facilitating mutual contact, and encouraging the discussion of cross-cultural aspects in bioethics. Past Congresses have been held in Edinburgh (2016), Mexico City (2014), Rotterdam (2012), Singapore (2010), Croatia (2008), China (2006), Australia (2004), Brazil (2002), the United Kingdom (2000), Japan (1998), the United States (1996), Argentina (1994), and Amsterdam (1992).

The NBC platform was established by FMES and its journal, the *Indian Journal of Medical Ethics* in 2005. Founded in 1993 by a group of medical practitioners disillusioned with unethical medical practices, it evolved into a wider umbrella group for individuals from diverse backgrounds interested in bioethics. FMES publishes *Indian Journal of Medical Ethics* (IJME), the only indexed and peer reviewed leading journal on bioethics in India and South Asia. In 2005, it established a platform, the National Bioethics Conference (NBC), for reflection, debate and the coming together of people interested in the improvement of the healthcare system. Since then NBCs are organised every two years. So far, six such NBCs have been organised, each attracting between 350 and 700 participants. They are co-hosted by various entities – academic institutes, and non-government organisations, with FMES, in different cities of India. Although called the National Bioethics Conference, it does attract participants from the South Asia region, and from the Global North.

The co-hosts were responsible for all activities relating to successful conclusion of the congress which included conceptualising the congress and its thematic strands; fund raising; setting up processes for review of submissions received; bursary application screening and the process for awarding bursaries. The IAB board members and other IAB colleagues provided guidance to the congress co-hosts from time-to-time, drawing upon their own experiences from past congresses.

The WCB was hosted for the first time in South Asia and India is now among the few Southern countries that have hosted the congress. Around 655 delegates from 74 countries across the globe participated in the conference. Participants included 372 women, 278 men and 5 from non-binary or undisclosed genders. 6 participants were from South America, 19 from Africa, 22 from Australia, 35 from Asia Pacific countries, 58

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from North America, 109 from Europe and 406 from South Asia. There were a total of 417 participants from LMICs. 315 participants were involved in various capacities such as plenary speakers, oral presenters, panelists at the Rapid Round Tables or workshops, poster presenters and chairpersons of sessions and the rest were participants. Healthcare professionals, researchers, academicians, students and activists from the fields of medicine, public health, administration and management, life sciences, humanities including law, media and philosophy, and social sciences made up the participants.

The Congress was organised on a spectacular scale. The Main Congress was preceded by the 12th Feminist Approaches to Bioethics (FAB) Congress spread over two days, which deliberated upon feminist responses to global challenges in health and healthcare. There were eight Pre-Congress workshops/symposia on diverse topics: organ donation and transplantation; framing case reports for bioethics journals; paediatric bioethics; bio-markets, ethics, gender and political economy; developing a public health ethics curriculum; public engagement in controlled human infection model (CHIM) studies; and healthcare directives of the Catholic Church in India.

In addition to five plenaries on the congress theme, including an "Editors' panel" as part of the closing plenary, 32 parallel tracks for oral presentations (112 presenters), eight parallel tracks for rapid round presentations (32 presenters), 48 in-congress workshops/symposia, and 96 poster presentations spread across three days enriched the deliberations. A Parallel Arts Festival on Bioethics was one of the unique features of the congress. It explored the Congress theme through a range of art forms which could speak to the uninitiated about the meaning of bioethics, alongside academic sessions. It was also intended to promote plurality through cross cultural perspectives (2).

This year, FMES and the *Indian Journal of Medical Ethics (IJME)* have instituted an award to recognise and honour individuals for their contributions to healthcare ethics and bioethics in India; and to focus on role models in the healthcare professions who have upheld the highest ethical practices despite all odds. The first *IJME* Ethics Award was conferred at the Congress on Dr Aquinas Edassery of the Swasthya Swaraj Trust, Odisha, for her self-less and dedicated efforts to provide healthcare to underprivileged and under-served people in Karnataka, as well as in tribal areas of the Thuamul Rampur block, Odisha, India.

Rich tributes were paid to Dr Amit Sengupta, an untiring proponent of "Health for All", who was to speak at the opening plenary, but unfortunately met with an untimely demise. His work will continue to inspire the "Health for All" movement in India and worldwide.

In this report we present insights drawn from the congress proceedings theme: "Health for all in an unequal world: Obligations of Global Bioethics". The deliberations suggest that globally the ground realities in terms of access to healthcare remain concerning. Many speakers highlighted the socio-

political determinants of health foregrounding adverse implications of power asymmetries in various contexts of health and health seeking. The deliberations delved deep to critically look into the factors at meso and macro levels which explain sustained disparities in health.

## **I. Inequities in social determinants of health, health status and access to healthcare**

*"Are we a country (community)" of onlookers?"*

One of the plenary speakers at the conference asked this question to draw attention to the apathy with which extreme inequities in the status of health and access to healthcare are being tolerated globally and in India. The conference highlighted inequities, which especially put the most underserved populations at a great disadvantage. Speakers also reminded the audience not to lose sight of the fact that a person's right to health is simply an extension of their right to a secure and dignified life; and access to healthcare is but one socio-political determinant of health. The bio-ethics community needs to focus also on the range of determinants of health which is unequally distributed among communities and which also, influences access to care. The problem is acute not only in the context of low- and middle- income countries; but also in pockets of high income countries, where a wide range of inequities are linked to poverty, religion, geography, gender, caste, ethnicity, specific vulnerabilities and situations of conflicts and natural disasters; in a context shaped by a neo-liberal economy-based development model, patriarchal dominance, rigid gender binaries, hierarchical and hetero-normative societal organisation, and exclusionary rather than inclusive policies and programmes by the state add layers of obstacles to achieving the goal of "Health for All". Dysfunctional public health systems, unaccountable private health services and consequent impoverishment form another important context to these inequities. For example, it was reported that, over 60 million people in India are pushed below the poverty line annually due to out-of-pocket expenditure on healthcare, and areas that suffer from more ailments and vulnerabilities have fewer hospital and healthcare services available.

### **Marginalised ethnicities**

The exploitation of tribal and indigenous communities in multiple countries was an important point of discussion during workshops and presentations. Very often, indigenous tribal communities are poorly placed in terms of their socio-political-economic location, nutrition, access to education, means of livelihood, transportation, water, housing, healthcare and parameters of health status as recounted from India and Australia. Historically, in India, the tribal communities, also known as *Adivasis*, are known for their diverse sources of food such as: meat from hunting; fruits, nuts, honey; fishing and hill-side farming carried out in the spirit of synergistic living with nature rather than erosion of the natural environment. However, tribal communities are now prevented from freely accessing forests for gathering and farming and hunting wild animals, are unable to stop wild animals from destroying their

crops and are often driven out of forests. Thus, this community has become the prime prey to starvation and malnutrition, as a result of policies and programmes which have failed to appreciate the socio-cultural and environmental context of tribal communities.

The lack of infrastructure in general, and public health services in particular, in tribal areas reflects the absence of political commitment and a failure of the state's obligations to serve its most vulnerable populations. Examples of poor access to menstrual hygiene, health education, health facilities and infrastructure, transportation of the sick and the dead, forcing families to make their own arrangements, impoverishment and high levels of emotional stress on account of inaccessible healthcare were recounted. Women from primitive and very primitive tribal groups (PVTGs) in central India were till recently, banned from voluntary use of temporary and permanent sterilisation, because the state saw them as protected tribes whose populations were dwindling, rather than as autonomous persons free to decide for themselves, thus adding to their morbidities and vulnerability. Speakers expressed concerns about the slow pace of change to help tribal communities to be on par with others, while also questioning development programmes which ignore these particular contexts of their lives.

Presentations from Australia, Africa and India also focused on reducing the hegemonic and alienating power of modern knowledge systems and engaging with tribal and indigenous communities' ethnic knowledge and cultures to learn their understanding of healthcare, barriers to care, healing traditions and new approaches to bioethics which may contribute to alternative perspectives on responding to complex bio-ethical dilemmas; and also to further enrich debates. Examples included using the concept of '*Ubuntu*' or collective personhood and collective responsibility from Africa in informed consent procedures; and the use of Australian indigenous ethical knowledge to resolve complex issues of human and environment health.

### **Caste as a socio-political determinant**

Caste is the traditional hierarchical kinship-economic system, rigidly organising communities into groups on the basis of birth rather than the person's achievements or choice and is unique to India and some other parts of South Asia. Caste endogamy and enforced caste-based occupations running in families ensure that the caste system continues and is reproduced with each generation (3). Some groups who were forced to follow "polluting" occupations such as cleaning human waste, skinning dead animals, leather tanning and such others did not find a place in the caste system and were "outcastes" or "untouchables" (3). A respectful term to refer to these groups is *Dalits*, which literally means "highly subordinated". *Dalit* communities, the most marginalised (out) caste groups, especially in India, are among those who face high levels of discrimination and deprivation as became clear in the deliberations. Researchers described how healthcare staff too practice caste-based discrimination.

For lack of opportunities in other dignified occupations some *Dalit* communities are forced to engage in manual scavenging, the practice of manually cleaning human excreta from pit latrines which have very limited access to water and includes cleaning of open drains and sewage systems. A representative from the community spoke vividly about their travails. Neglected by successive governments, even the most celebrated '*Swachh Bharat* [Clean India]' public mission has paid little attention to the plight of this community, instead worsening it. Neglect has directly led to poor access to healthcare, safety equipment and compensation for work-related deaths, increased and disproportionate morbidities, increased susceptibility to alcohol and substance abuse and early and untimely deaths. In the absence of policies responsive to these unacceptable ground realities, the communities themselves have organised and use community mobilisation and systematic advocacy embedded in a multi-sectoral and social determinants approach towards claiming their rights.

### **Malnutrition and access to water**

India has one of the highest rates of malnutrition globally. Tracing the stories behind more than 60 hunger deaths reported in the media, a plenary speaker from the Right to Food campaign showed that the most vulnerable members of food insecure families had succumbed to death. Most of these deaths happened among the *Dalits*, tribal or indigenous communities, and minorities. Many had a history of denial of food-grains from the public distribution system and of employment under the Rural Employment Guarantee Act (MNREGA); some were single women dependent on others while others were landless labourers. In several cases, denial of services was linked to failure of the recently introduced *Aadhar* system, a unique identification number to be issued to all residents of India. *Aadhar* uses biometric data to "authenticate" beneficiaries and "enable" access to social security schemes, but cases of failures abound.

The speaker explained that, very often, the problem of food security in India is posed in medico-technical terms as though malnutrition were a disease and not the result of hunger. Underlying reasons for malnutrition include communities losing control over common and natural resources, being displaced from their lands due to forced land acquisition for public as well as private projects, and also being deprived of free social services, and by supplementary feeding programmes being privatised. Instead of food security, there is a recommendation for food fortification. Big private corporations are invited to introduce fortified, ready-to-use foods, such as the "plumpy" nut for Severe Acute Malnutrition (SAM), instead of locally sourced, freshly-cooked food served by local women's collectives, as has been practised in some states. This not only devalues local solutions to the problems, but it also increases dependence on markets. The speaker emphasised that safety nets such as supplementary feeding programmes, free public distribution supplies and employment support are not doles, but the hard-won rights

of people, based on constitutional entitlements. There is also a need to systematically address the agrarian crisis and rural distress, and to secure rural and urban livelihoods, the loss of which form the backdrop to these starvation deaths.

A number of countries across the world face water stress, an important determinant of health. Nearly 50% of India's states are currently suffering from inequitable distribution and mismanagement of water resources leading to drought, agrarian crisis and rural distress. Very often discussion on water is limited to potable safe drinking water and water for cooking, cleaning and bathing. Some barely have access to essential water while for others, water for domestic use includes luxury bathing facilities and swimming pools, with absolutely no accountability for this disparity. To ensure equitable access to water, regulations are needed on water for luxuries, and a definition of "basic minimum" for drinking, cooking and cleaning is required. Concerns over privatisation of water (of both resource and service provision) underscore the fact that water governance is not merely a techno-managerial responsibility of the state. Access to water must be re-politicised and wholly integrated with discussions of justice, equity and environmental ethics.

While one plenary was dedicated to the theme of "Rethinking Bioethics in the context of Health for All" which covered malnutrition, water as a determinant, and environmental justice, we wonder why there were hardly any presentations on these topics in the parallel sessions. While environmental justice will be taken up again, later in this report, the lack of adequate emphasis on these issues should concern us as a global peer community of bioethicists and allied fields looking into health justice. The goal of "Health for All" is impossible to achieve without a strong emphasis on these crucial determinants.

### ***Gender and sexual orientation as determinants***

Gender further complicates and adds to the intersectional nature of discrimination and this was extensively discussed at the conference. We highlight here the salient points. A major violation of women's rights is seen in the reproductive and sexual health and rights arena, ranging from women being disrespected, humiliated and abused in the labour rooms robbing them of comfort, dignity and autonomy, lack of life-saving maternal health services leading to unnecessary deaths and morbidities, lack of access to contraception and safe abortion services, to criminalising underage sexual activity leading to deprivation of reproductive health services to adolescents.

Gender based violence (GBV), the gap in education of health care providers in understanding GBV and caring for the survivors, and consequent absence of or insensitive services to women were narrated by multiple speakers. This gap need to be bridged. Female genital cutting (FGC) was also discussed as a form of GBV. Speakers gave a nuanced account of how conflicts and natural disasters further compound women's vulnerability to GBV and poor access to health services, such

as happened in Sri Lanka during the civil war (1984-2008) and Tsunami (2004).

The heightened risk for pregnant women of infections such as Zika and Ebola, was also discussed, along with the added concerns of their access to healthcare because of their exclusion from clinical trials for vaccines and newer drugs. The effect of gender has also been neglected in diagnosis, treatment and research in diseases especially affecting women and trans-people, tuberculosis (TB) being an example. Another aspect of gendered inequity in healthcare is that faced by care-providers, mostly young women in families or domestic workers, burdened with supporting a sick member's care, with little or no support from the public systems, as presented in the context of rural China, India and Singapore. The high burden of work and poor support as well as poor compensation also plagues women community health workers, as seen in the case of ASHAs (Accredited Social Health Activists) in India. A gender equity lens, an integral aspect of social equity, should be used in order to achieve equity in determinants of health, health care and health status.

Gay and trans-people in several southern countries face criminalisation of same-sex behaviour. Recently, in India, Section 377 of the Indian Penal Code, one such criminal provision, was read down, and this has been widely welcomed. However, speakers recounted the many transgressions suffered by the community, among which is discrimination within the health system ranging from dis-interest and disapproval at every level, to sexual harassment and violence against them which deprives the community of health care with dignity. The medical profession, parliamentarians, and society as a whole must work to set these wrongs right, move toward inclusivity, and increase support for rights of LGBTQIA (Lesbians, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual).

### ***Living with disability***

Individuals with disabilities confront challenges in societies which are organised for and by ableists, which then become further compounded for other marginalised persons, and especially for women. As explained in a plenary talk, a woman living with a disability, mental illness or intellectual disability is not seen either as person enough or as woman enough; she is not person enough to have the rights and facilities which others take for granted; and not woman enough to have sexual desires, desire to marry and have a child. There is no attempt made to provide information and access to reproductive and sexual education or healthcare to them. Informed consent for procedures such as abortions or hysterectomies is often not sought from women with intellectual disabilities. While providing hysterectomies frees providers and families from hardships associated with menstrual management or prevents repercussions of sexual assault such as unwanted pregnancies, such assaults themselves may continue.

Persons with disability are also much more likely to face violence due to their dependency and suffer injuries more often due to accessibility issues. Despite this, they are generally

invisible to policy makers. 80% of the world's people living with disability are in the low and middle-income countries and often lack infrastructure and accessibility, including within the context of health care. A study regarding experiences of children living with disability in an urban slum in India discussed the lack of understanding of their situation by health workers, lack of outreach interventions, exclusion from social services such as supplementary feeding programs and absence of health status data. All persons living with disability or mental illness need to be accorded full personhood and efforts need to be made so that they are meaningfully able to access their rights. An important recommendation is to make better data available at all levels including through general surveys so that people living with disabilities become visible to policy makers; better infrastructure and facilities for accessibility; and more investment in building capabilities of the differently abled. A critique provided by disability rights, scholars and activists of what they call exclusionary medical genetics, which attempts to weed out people with 'bad' genes (eg physical or mental disabilities) was also shared.

### ***Neglect of mental healthcare***

Neglect of mental healthcare in the discipline of public health has long been recognised as needing urgent corrections. A speaker from Pakistan noted that young people under the age of 30 years face high levels of mental health problems, with suicides being highest among young men and self-harm being highest among women. The context of suicides in Pakistan includes a high level of stigma as both religion proscribes it and law constitutes it as a crime. Such conceptualisation may well hamper youth from acknowledging the problem, hinder services for prevention and prevent free exchange of information. In an intervention study of pregnant women in India facing gender-based violence (GBV), 29% were found to have suicidal ideation. Psycho-social counselling was found to improve the coping and safety behaviour of the women. Another speaker from the US brought to attention similarly concerning findings, sharing that suicide is also the second most common cause of death among youth studying in colleges and universities, and nurses and nursing students are especially vulnerable. In this context, the finding that moral distress may often precede suicides and mental health problems has provided a new thought and direction to understand mental health. Also discussed were new digital technology-based solutions that now exist to address mental health problems such as mental health apps, therapy chat bots, social media based programs and video games. However their usefulness and ethical concerns need to be studied and debated. Bioethicists can lead the way in steering societies to think of suicidal behaviour as an illness, neither a sin nor a crime; work to eliminate stigma linked to suicides; and use new theoretical understanding in preventive mental healthcare as well as early detection of mental health problems.

### ***Old and emerging infections***

The conference discussed new epidemics such as Zika in Mexico and Ebola in West Africa affecting the poor and most

vulnerable people in the community. More than 4000 pregnant women had already contracted Zika by early 2017. On the other hand, old infections such as TB are being increasingly recognised, sometimes in a highly drug resistant form, and in the context of HIV infections. Central India continues to see infections such as Leprosy which was once thought to be on the brink of complete elimination, and attendant problems of unmet care needs and stigma. The poor and marginalised, indigenous people, pregnant women and children from Asian and African countries continue to be most vulnerable to vector-borne diseases such as Dengue discussed in the context of Pakistan and Indonesia; Malaria and Zika in Africa which are potentially life threatening. Speakers from multiple countries spoke about the ethical challenges posed by new research to combat vector borne diseases such as genetically engineered mosquitos to prevent transmission of malaria and Zika, Controlled Human Infection Model (CHIM) trials such as those for Malaria, in Kenya; and trials for new vaccines including obligations incurred at the end of such trials as discussed in the context of Ghana and Tanzania.

### ***Access to medicines***

Delegates spoke about concerns of access to medicines which seriously hampers the idea of "Health for All", ranging from stock outs of drugs in public health facilities, increasing costs of drugs, unethical drug promotional practices and aggressive marketing, giving rise to conflict of interest for doctors, profiteering, unethical patenting, evergreening of pharmaceutical patents, and the lack of medical research in drugs for health problems of low income countries. For example, a speaker from Costa Rica discussed the injustice caused due to non-availability of snake anti-venom in health facilities of low-income countries where a large number of poor, rural people die of snake bite, enough to constitute a 'public health emergency'. Newer medicines for multi-drug resistant (MDR) TB, too, are accessible to very few in low income countries. A drug for MDR TB, Bedaquiline, was made available in India through a conditional access programme on the basis of waiver of phase III clinical trials. The case raises ethical dilemmas in balancing access to newer drugs with ensuring patient safety, including compensating for deaths. The conditional access nature of the programme itself severely restricts access to the drugs.

Thailand and India were at the fore-front in providing generic drugs which helped in controlling AIDS deaths; and China provided active pharmaceutical ingredients for the same. However, the on-going Regional Comprehensive Economic Partnership (RCEP) negotiations, appear to be giving multinational pharmaceuticals control over the generic industry in the Asia Pacific region by way of changes to the patents regime. These are some of the ways in which access to essential drugs continues to be undermined. On a more positive note, it was found that pre-grant opposition to patent applications filed by pharmaceuticals, a platform available and being used in India curbs frivolous claims to patents and reduces unnecessary work-load on the patent offices.

## Wars, conflicts and humanitarian situations as public health emergencies

Speakers referred to contexts of wars such as those in Syria and Palestine, and low level continued conflicts in South Asia, to underline that wars and persecution have displaced nearly 65 million people, making them the most serious threat to public health in terms of deaths and disability, surpassing many major diseases put together. In addition to conflicts destroying the familial, social and cultural fabric, causing displacement, triggering trauma and devastating the environment, war expenditures deprive citizens of resources that could otherwise have been used for healthcare, social services and development. Mass migrations as a result of conflicts creates large refugee populations living in sub-human conditions and creates challenges to the provision of decent living and health care. Doctors in Germany were conflicted when asked to restrict care provision to post-conflict refugees seeking asylum to 15 months from arrival as opposed to their practice of providing healthcare without distinction among patients. The irony was that refugees are classified as “vulnerable” populations which, by definition, would indicate need for more, not less, health care. Similarly, Sri Lanka faced two periods of humanitarian crisis as mentioned before. Both crises displaced thousands of people, separated families, and tore apart public health infrastructure, severely curtailing all health services. Bioethicists can strongly root for war and conflicts to be recognised as serious public health emergencies and work towards their prevention. A delegate from the UK brought out the need to use the concept of vulnerability to understand structural injustice in the context of conflicts, and guide humanitarian actors to decide on priorities, without exacerbating existing inequalities.

### Promising strategies

A number of promising strategies to increase access to healthcare were discussed along with their pit-falls, especially strategies bringing services physically closer to communities (example from China and India), strengthening public services (example from China), cost containment strategies (example from Switzerland) and instituting insurance mechanisms (examples from Nigeria, South Africa and India). Speakers also strongly recommended furthering access to healthcare by curbing the commercialisation of medical education; ensuring comprehensive cost regulation of all essential medicines, implants and consumables; opposing service delivery targets of any kind being imposed on doctors; eliminating all forms of commissions, kickbacks and unethical inducements to promote the hospital business, to name a few. There was a growing consensus for the need to strive towards Universal Access to Health Care which is a moral imperative for our times.

## II. Environment and sustainable development

*“Are we doing right? Are we doing enough?”*

The contexts which underpin our human vulnerability today are excessive urbanisation, deforestation, climate change and forced migration. As pointed out by one speaker, the human

species is increasing in population, whereas that of every other species is declining.

Among the human species, the indigenous communities, who lived in an intimate and synergistic relationship with the environment have been forced into historical processes of colonisation, modernisation, assimilation and homogenisation with a complete disregard for their lives, contexts and subsistence economies as discussed by speakers from India and Canada. Such development processes have led to conflict, marginalisation and loss of identities, cultures and livelihoods for them, together with irreparable loss to the environment through a capital and market driven development model. As put forward by a speaker from Australia, rethinking ethical responsibilities ought to be grounded in the idea that human health is profoundly influenced by environmental and animal health, and the health of the planet itself.

Global inequalities are at the heart of global warming, climate change and the resulting impact as discussed in one of the plenaries devoted to environmental justice and moral responsibility. The richest 10% of world citizens are responsible for 49% of carbon emissions while the poorer 50% of the world population contributes only 10% to the carbon footprint. The poorest 10% contribute even less, that is 1% to the carbon footprint. However, again the poorest communities are disproportionately impacted by climate change and the resulting “natural” disasters such as heat waves, storms and floods, forest fires leading to decline in food production, conflicts over fresh water, emerging infectious diseases, environmental migration, over-harvesting of fish stocks and extinction of species. The speakers reminded us that the bioethics community is well-situated to recognise our responsibility in this global system, beyond the duty to advocate for financial aid, compensation and legal remedies.

A perspective of responsibility informed by structural injustice compels us to identify which of our living processes produce and reproduce unjust economic and social structures, and to find ways to redress them. As one speaker put it, one may contribute to this by simply being a citizen of a high-income Western country as demonstrated by high contribution to the carbon foot-print. Fortunately, individuals can begin to reduce their ecological footprint by reducing air pollution, eating less meat, reducing air travel, bicycling and walking more, and designing cities for this. This can also lead to improvements in health, highlighting the importance of a healthy environment in ensuring that all human beings fulfil their potential.

An insatiable desire for wealth, justified under the guise of bettering individual lives, has nonetheless wrought environmental degradation, widened disparities and weakened community relationships. There is an urgent need to examine the risks attached to the current scale and pace of human activities including lifestyles and returning to themes of interdependency, responsiveness, and reflexivity. Localisation – human lifestyles centred on local activities rather than on large-scale commercial activities—emerged from Japan as a core idea in the practice of sustainability movements. Localisation

aligns with the promotion of health, improved quality of life and respect for human rights; contributes to reducing ecological footprints and deepening community bonds.

Meanwhile, re-evaluation of the risks of human activities should be extended to the catastrophic effects of war and violence as discussed earlier. The threat of nuclear weapons stands out as especially worthy of abolitionist efforts by ethicists, healthcare providers, scientists, public health activists and civil society organisations. 'Physicians For The Prevention Of Nuclear War' and 'Indian Doctors For Peace And Development' made a forceful argument for an ethical obligation to organise for a "nuclear weapons free" world as well as to build public opinion towards this.

As mentioned before, for the discourse on "Health for all" to be meaningful we need to integrate it with environmental ethics which centre stages and revives the thinking that human kind is only a small part of the environment and nature; and that our health is closely intertwined with the overall health of the planet. Towards this goal, more needs to be done by the global peer community of bioethicists and the discipline of bioethics which was originally conceived to capture this close relationship between us and nature as we pointed out in the conference editorial (1).

Finally, speakers also emphasised that the worth of the environment needs to be recognised for its intrinsic value, in contrast to its mere instrumental value in an anthropocentric society.

### III. Antipolitics in health: Obligations to respond to systemic and structural inequities

*"Speaking of ethics in an unethical world"*

The discussions throughout the conference underlined the reality that "Health for all" depends on factors much beyond access to healthcare. Taking an expanded understanding of social determinants of health which includes cognisance of inequities and discrimination, global factors influencing health and health of the planet as a whole, including wars and conflicts and human-made and natural disasters, the deliberations at the conference foregrounded that the largest impact on health is when there is action at the level of these social determinants. Talks, presentations, and discussions also underscored that the region, country, physical, policy and political environment, and social group that a person is born into is a bigger marker of life-span and health than is genetics.

Yet a consistent criticism that was made at the conference was whether we provide adequate attention to these wide ranging macro and global level factors either in the context of "Health for all" or more specifically as the a core responsibility of the bio-ethics community.

One of the key questions central to the congress proceedings was: whether the development model that is being promoted over the past few decades is appropriate to ensure "Health for all" given its propensity for increasing inequities across

the globe and between sections of people. For example, one speaker discussed the findings of the Oxfam International Report of 2017, which shows that 82% of all the new wealth created globally in the year 2016 - 2017 went to the richest 1% of the global population while the poorest 3.7 billion people which constitute half of the world population got nothing. While the wealth of billionaires has grown at the rate of 13% since 2010, the income of ordinary workers grew at a mere 2% per annum, indicating serious intra-country inequality as well. The average gender pay gap globally is 23% and women are among the poorest people and dependent on the most insecure and precarious occupations<sup>2</sup>.

Not only do systemic and systematic inequities exist, but the discussion brought out a clear gradient in quality of life, health indicators and access to social determinants of health from the richest and most privileged section of society to the poorest and most marginalised. It was also posited that often global influences from richer countries determine the health, medical and research priorities in less privileged countries which indicates a continuing neo-colonial situation, a concern for the sovereignty of countries to decide on matters of health. In spite of this, the development model which has led to this situation continues to skew the distribution of wealth, while global and national politics promote neo-liberal policies, undermine social security mechanisms and promote unregulated private enterprise including in the sphere of public goods.

### **Politics and anti-politics of health**

The WHO Commission on Social Determinants of Health, referred to during the presentations, states that the unfair distribution of global health is a result of, *"a toxic combination of poor social policies and programmes, unfair economic arrangements, and bad politics"*. Any change in this situation will require tackling the inequitable distribution of power, money and resources within society/countries and between countries/regions across the globe.

One of the speakers pointed out that the lack of attention to this "politics" of health or "anti-politics", is the biggest concern and hindrance to achieving "Health for all". Anti-politics is the deliberate exclusion of politics from health; which also excludes the discussion on social determinants of health; leaving health in the domain of technical medical fixes and de-politicised strategies; relegating bioethics to the confines of safeguarding individual rights and autonomy in a narrowly defined framework. He presented the analysis of the WHO commission which incisively critiqued technology-based approaches to address entrenched health inequities within and across countries. The commission, which argued for global political solutions, identified five dysfunctions of the global governance systems, which are- democratic deficit, weak accountability mechanisms, entrenched power disparities in institutions, inadequate policy space for health and missing or nascent international institutions to protect and promote health. While the speaker welcomed the accurate identification of the problem, he also noted that the recommendations seemed to fall far short of the requirements for change in the

situation. The speaker posed an important question: whether "anti-politics" was here to stay.

### **From being reformist to transformists: Shifting the paradigm**

A radical reassessment of conventional approaches to health would entail a shift from tinkering with the system or a reformist agenda to transforming the landscape which fosters global inequities and power imbalances, a fundamental determinant of ill-health and injustice. Speakers indicated that such a transformation would entail an entirely new and revolutionary outlook towards "Health for all", notably a "one health" approach. Here not only would one person's health be connected to every other person's but also to the health of the planet as a whole. The values which would drive this transformation would be communitarianism, solidarity, justice, social care, compassion and meaningful participation of people. As one speaker put it "caring and sharing" is the way ahead.

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### **Notes**

- <sup>1</sup> (community) is inserted to convey the spirit of the point that was being made. It referred to the peer community.
- <sup>2</sup> <https://www.oxfam.org/en/tags/inequality>

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## **The Parallel Arts Festival at the 14th World Congress of Bioethics and the 7th National Bioethics Conference, Bengaluru**

**MANJULIKA VAZ, OLINDA TIMMS, RADHIKA HEGDE, MARIO VAZ**

The theme of the 14th World Congress of Bioethics (WCB) was "Health for All in an Unequal World; Obligations of Global Bioethics". The Parallel Arts Festival was embedded within the programme of the Congress and curated to reflect its theme.

There are compelling reasons to engage with the arts in order to deepen and enrich academic insights, particularly in a field

like bioethics. Film, theatre, literature, poetry, art and dance are not only powerful means of communicating complex ethical issues but also allow for the reflection of personal experiences and an enabling of vivid recall, because "ethics is a fluid discipline, not something a person learns once and then never revisits" (1). The Parallel Arts Festival explored the Congress theme through a variety of art forms; alongside academic sessions, helping to connect with a larger audience not necessarily grounded in ethics, rather than having a closed discourse with the already "converted".

The festival of arts also promotes plurality; providing cross cultural viewpoints that can challenge traditional understanding, and artistic rendering has the power to unveil truths and present the heart of dilemmas beyond words. Thus, it has been suggested that understanding or knowing "may come in a flash (epiphanically) through engagement with the arts, while this may occur panoramically, through engagement with synoptic disciplines such as history, philosophy and religious studies." (2). These methods also allow issues to be

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