

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.

(We gratefully acknowledge all the rapporteurs who volunteered for the 14th WCB and 7th NBC and worked hard to document the various sessions. The rapporteurs were- Agasthiya Singaravelu, Anuj Kumar Awasthi, Bevin Vinay Kumar VN, Bhawna Arora, Deepak Kumaraswamy, Dolly Joshi, Lavanya Rajendran, Gloria Benny, Hannah Elizabeth Hulshult, Kaneshka Palanisamy, Krishna Varshni Subramanian, Man Singh Jat, Mohammed Fahad Ahmed, Mounika Pellur, Nathalie Egalite, Neha Mohanty, Netravathi Srikanthacharya, Nishitha Aysha Ashraf, Noyana

Khatoniar, Pallavi Gahlaut, Pallavi Krishnamurthy, Pankaj Kumar Tiwari, Prafulla Shaligram, Priya Shreedhar, Rajeev B R, Ramya Jyothi Yellisetty, Senthilkumar Jayakumar, Shivabharathi P, Shrutika Murthy, Supriya Subramani, Uma Chaitanya Vipparthi and Victoria Henriques. Special thanks to Priya Shreedhar. Our sincere thanks to the rapporteur steering committee members, Dr Surekha Garimella, Gargi Mishra and Francis Masiye who along with others facilitated the process and worked on the final day presentation of the rapporteur committee.)

Notes

- ¹ (community) is inserted to convey the spirit of the point that was being made. It referred to the peer community.
- ² <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

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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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To cite: Vaz M, Timms O, Hegde R, Vaz M. The Parallel Arts Festival, 14th World Congress of Bioethics and 7th National Bioethics Conference, Bengaluru. *Indian J Med Ethics*. 2019 Oct-Dec;4(4) NS:325-8. DOI: 10.20529/IJME.2019.033.

Published online on June 27, 2019.

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synthesised across space, time and persons and allow for appreciation of ethics as a dynamic process.

A festival of the arts embedded within an ethics conference is not, however, without its challenges. It can be viewed as entertainment alone, rather than important to the ethics discourse, thereby leading to trivialisation of ethical issues. Careful curating and the presence of participating artists available to discuss the “language” of their disciplines and craft in relation to the ethical issues can help solve this problem.

Talking Hands was an outdoor installation of eighteen posters that used black and white photography and the imagery of hands to stimulate reflection. The objective was to include and amplify the presence and needs of people at the margins. The posters presented the voices of those with special needs, the stigmatised, and the vulnerable, among others. Each image carried a comment in the first person followed by a common question: “Do I matter?” Installations in public spaces have evolved from being largely commemorative to being expressions of social concern. They allow the viewer to interact with the installation in their own time and at a personal level. **Talking hands** was intended to evoke sensitivity through imagery and open-ended questions, appealing to a sense of social justice. The disadvantage of this particular installation in the context of the Congress was the absence of planning for any structured or comprehensive feedback or discussion around the installation.

The Dolls speak of an Unequal World was an exhibition by Francoise Bosteels, an iconic doll maker who is inspired by people's day to day life, their gripping struggles, pains and dreams and used intricately crafted “faceless” dolls to reflect life in all its complexities. Each doll had accompanying poems, stories or written reflections. The dolls speak of enduring tragedies on the one hand and of resourcefulness, resilience and the spirit of hope on the other. At one level, the dolls are a reflection of the issues of our times, but the intent of their creation is much more – they force people to confront harsh realities through what can be perceived as a purely artistic exhibit. It was not uncommon for people to enter the exhibition in a curious light-hearted frame of mind, only to leave, deeply moved, or disturbed. This is the power of carefully curated art exhibits – they can promote social change by providing “a space where we can give dignity to others while interrogating our own circumstances.” (3). The use of dolls for social change has resulted in various projects, some global, such as the “Dolls for Change” project which collects dolls from all over the world – the intent being to bring people together to discuss important issues – each doll becomes a voice, a voice for peace, climate change, clean water, human rights, and more (4).

Theatre has increasingly been used in medical education to engender student empathy, and to enhance ethics in education (5). Theatre may adopt conventional forms and the more experimental / participatory formats, such as theatre of the oppressed and forum theatre, among others. Theatre uses narrative and kinesthetics to communicate stories (2), through

both conventional and experimental/participatory formats. The Parallel Arts festival used the richness of both conventional theatre and experimental forms. Thus, **Monsters in the Dark** – a stage adaptation of Siddhartha Mukherjee's *The Emperor of All Maladies: A Biography of Cancer*, explored stories of cancer through the characters in the book. The development of the script was a collaborative effort with creative minds from the Bangalore Little Theatre taking the lead and doctors and researchers from St John's Research Institute and Mumbai's oncology centre, Tata Memorial Hospital, providing their perspectives. The “gaze” in the performance shifted from that of patient to researcher, doctor to regulator. In the process, ethical issues related to the doctor-patient relationship, the role of industry and the government as well as the ethics of research were exposed.

Unlike conventional theatre, newer forms of theatre have blurred lines between audience and performer (6). **Megha's Story** – enabled conversations around maternal mental health using the medium of Forum Theatre, a form of drama rooted in the Theatre of the Oppressed, which recognises the importance of providing a voice to disadvantaged groups in society. The audience were not mere passive spectators-they became “spect-actors” with the ability to change Megha's story. This story revolved around how a new mother struggles with feelings of guilt, anger, fear, and frustration alone-though surrounded by a loving family. Participatory theatre as a medium can have many goals; to empower, to question, to reflect, to be reflexive, to learn from experience, to create change in understanding, to challenge accepted ideas, to question and challenge power relations, to take power, to effect change, to explore metaphor through theatre, and to create vital communication between people (7). While all of these may not have been achieved within the limited time available, inroads were made into several of these areas, providing a unique introduction to participatory theatre for the uninitiated.

Performing Resilience: Illness, identity and narrative was another form of engagement with issues of stigmatisation, vulnerability and invisibilisation of illness, using narratives from illness, identity, culture and resilience. The aim of the performance was to build a larger narrative that breaks silences and speaks to structures and systems of healthcare and health systems. The engagement used elements of drama and patient artifacts to support the performance. There has been an increasing realisation that there is a need to convey otherwise “inaccessible” illness experiences to audiences that also challenge the distinction of the “objectivist” (objective, medical) and “subjectivist” (subjective, emotional) perspectives of the illness experience (8). Such pathographic performances promote empathic engagement in the audience through an exploration of suffering and shared sense of vulnerability (9).

The notion of frailty and vulnerability was also explored through the film - **The Poetics of Fragility** - A Transmedia Project developed in 2016 by Nicolás Grandi and Lata Mani. It is a “kaleidoscopic bilingual exploration of the texture, vitality and aesthetics of fragility. It interweaves stories of bodily frailty

with optical vignettes of nature's delicacy to reclaim fragility as intrinsic to existence, not something to be bemoaned or overcome". Its form - "video-contemplation," is an experimental conception that Grandi and Mani have developed to explore the audio-visual medium as a sensuous tool for social inquiry with a philosophical impulse. The stimulating discussion that took place post the screening, highlights the power of film to elicit ethical experience and provoke thought (10).

Less than 1% of India's 1.2 billion population has access to palliative care (11). It is estimated that in India around 1 million people are diagnosed with cancer every year, that about 80% of all cancers are diagnosed in the advanced stage and that <3% of cancer patients have access to adequate pain relief (12). While **Hippocratic – 18 Experiments in Gently Shaking the World** is a biographical film about Dr MR Rajagopal, the pioneer of palliative healthcare in India, the intent of the film was, in fact, to provide a platform for creating more conversations around palliative care, on the access to and availability of pain relief and to demand a healthcare system that treats the person and not just the disease. While there are multiple ethical issues in the provision of palliative care at the level of the individual patient and in the broader context of health policy and healthcare delivery (13), accentuated in resource poor conditions, the film speaks individually to each viewer and confronts them indirectly with powerful questions – how much do you care? And, how far will you extend yourself for the "other"? Throughout the film, the viewer is confronted with face to face encounters with people – this privileged proximity evoking Levinas' idea of extreme responsibility for the other (14).

In line with the theme of the Congress, the Arts Festival spotlighted the challenges of persons suffering from rare and orphan diseases, estimated by the World Health Organisation to be approximately 400 million people, worldwide (15). Often chronic, life threatening, and needing expensive treatments these diseases can mean a death sentence for patients in low- and middle-income countries. In India, there are in excess of 70 million people with about 7000 rare diseases, at a conservative estimate (16). The hidden ethical challenges of rare diseases were explored through a series of short films:

- *Living with spina bifida*- Shakti Krishnan;
- *Making a muscle* - Dystrophy Annihilation Research Trust;
- *The indomitable human spirit* - Maya Chandra Films;
- *Paper planes - dreams of a million children* - One Step at a Time;
- *Rooting for Roona-Trailer* - Curley Street Media.

The series was curated by Namitha Rao, an activist and spokesperson for rare diseases, who is living with thalassemia. The films highlighted the issues faced by patients with rare diseases and their families: lack of awareness among doctors leading to late diagnosis, high costs of treatment with limited government grants; and exclusion from insurance, absence of adequate research on rare diseases and cures, limited treatment facilities, the unmet need for inclusion and integration in society. The active discussion that followed the

screening called for a sensitisation of doctors and society to assist these unseen families, and a clear national policy for the treatment of rare diseases (17). Given the dismal government budgetary provision for health in this country, this will remain a challenge. Doctors may need to add their voices and efforts to those of patients and their families, currently the only hope for this sector.

As part of the Parallel Arts Programme a walking tour was organised around the **Maj Gen SL Bhatia Museum for the History of Medicine** on the St John's campus. Museums have traditionally been places of learning, particularly for history. There are compelling reasons why history can enhance ethical deliberations – the historical focus of "context" can help those involved in ethical deliberations to better understand time-place-choice" interactions. It helps shift the focus from novel, emerging technologies, to broader considerations of society-politics-governance which affect healthcare and the daily lives of patients (18). Multiple issues were discussed at various stations in the museum using striking narratives, including ethical issues in situations of war, lessons that can be learned from ancient medical history, social responsibility for health, and ethical issues in medical research.

The role of storytelling and the written word as a means to understand the human condition was explored in a session on **Reflective Narratives** by a literary panel comprising two well-known local authors, Kavery Nambisan, a surgeon and a widely published writer of fiction; and journalist author Gita Aravamudan who uses the genres of narrative fiction and non-fiction to create reflective stories. While Kavery spoke on why a doctor should write and how writing makes one a better doctor, Gita revealed that keen observation and eye-opening interactions are needed to develop the detailed narrative of real-life situations. As an exercise in developing the skill of the reflective narrative, students and faculty of St. John's Medical College under the guidance of the Health and Humanities division, wrote narratives on the reality of "Universal health care" through their personal encounters with patients, observations in the field and interactions with the health system. These reflective narratives were released as a booklet titled *Beyond cure: An Anthology of Reflections on Universal Health Care* (19).

The lecture demonstrations of two classical and one contemporary dance performance at the World Congress of Bioethics showed how conventional notions of the body, of women's role in society can be challenged and how the imagination of youth can overcome the impossible. Dr Anuradha Venkataraman, a professional Bharatanatyam dancer and Dr Vaibhavi Joshipura, a trained Kathak dancer and a Professor of Dentistry, both with more than a decade's experience in these classical dance forms of India, portrayed women's sexual rights in the context of a story from the *Mahabharata*, the classical Indian epic and the story of Sita (from the *Ramayana*, the other classical Indian epic), based on a Gujarati folk song that questions Rama's banishment of Sita while she is pregnant. The interaction with the audience

led to discussions of women's subjugation, patriarchy and suppression of the sexual rights of women, ethical issues that still plague our society. Interpretative dance -dramas such as these were seen as powerful means to challenge conventional notions and to provoke new thinking.

Perhaps, one serious lacuna of a parallel arts festival within an Ethics conference is the inability to engage in depth with any of the events. The limitations of time within a constrained programme result in only limited dialogue at the end of each event. This is unsatisfactory both for the performer / artist and for the audience, but appears to be a necessary compromise. It is also important that the parallel arts programme is not seen as an attempt to promote the simplistic dichotomisation of biomedical objectification and commodification and artistic humanisation, since that was not the intention.

Acknowledgements

Further details of the various programmes of the festival can be obtained by using the emails provided. *Talking Hands*; mariovaz@sjri.res.in, *The Dolls Speak of an Unequal World*; Francoise Bosteels- francoisebosteels@gmail.com, *Monsters in the Dark*; Bangalore Little Theatre -bangalorelittletheatre@gmail.com, *Megha's Story*; Radha Ramaswamy-radha@ccdc.in -www.ccdc.in, *Performing Resilience*; Azim Premji University - Benson Issac - benson.issac@apu.edu.in, Film - *Poetics of Fragility*; Lata Mani - maillatamani@yahoo.com, Film - *Hippocratic* - 18 *Experiments in Gently Shaking the World*; MR Rajagopal, Pallium India info@palliumindia.org, Films on Rare Diseases; Namitha A Kumar - International Institute for Art, Culture and Democracy - namitha@iiacd.org, History of Medicine- SL Bhatia Museum tours- https://m.facebook.com/medicinestory/; Literary Panel- Kavery Nambisan- kavery.nambisan@gmail.com, Gita Aravamudan- gita.aravamudan@gmail.com, Dance: Bharatanatyam- Anuradha Venkataraman, danseuse.anuradha@gmail.com, Kathak - Vaibhavi Joshipura - vnj1995@gmail.com.

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