

INDIAN JOURNAL OF MEDICAL ETHICS

nbc

national bioethics conference

Indian Journal of Medical Ethics
Sixth National Bioethics Conference

THEME

**Healing and dying with dignity:
Ethical issues in palliative care, end-of-life care and euthanasia**



CONFERENCE HOSTS

Forum for Medical Ethics Society (FMES)

&

Mahila Sarvangeen Utkarsh Mandal (MASUM), Pune (www.masum-pune.org.in)

ASSOCIATE COLLABORATOR

The Interdisciplinary School of Health Sciences, Savitribai Phule Pune University, Pune, MH
(www.unipune.ac.in/snc/school_of_health_sciences/)

**CONFERENCE PROGRAMME,
INTRODUCTION AND ABSTRACTS**

YASHADA, Baner Road, Pune

Main Conference: Friday, January 13 to Sunday, January 15, 2017

Pre-conference: Thursday, January 12, 2017

Conference Organisers

1. Forum for Medical Ethics Society (FMES)

The Forum for Medical Ethics Society (FMES) was founded in 1989 and registered as a Trust and a Society in 1995. FMES seeks to highlight issues in medical ethics and bioethics, and generate discussion around them. FMES has published the *Indian Journal of Medical Ethics (IJME)* (www.ijme.in/) since 1993. IJME is the only indexed, peer-reviewed open access journal on bioethics and medical ethics published from India.

2. Mahila Sarvangeen Utkarsh Mandal (MASUM)

MASUM (<http://www.masum-india.org.in/>) founded in 1987 and based in Pune, is committed to women's rights within and outside the home. It works with a feminist perspective and a human rights approach, on the understanding that people can resolve their own problems collectively. MASUM focuses on advocacy for women's rights and physical and mental health, and on strengthening people's perspectives on democracy, equality, secularism and social justice.

Conference Organising Committee

1. **Hemalata Pisal**, Sr Associate, Mahila Sarvangeen Utkarsh Mandal (MASUM), Pune, MH, India; and Founding Trustee, Vidhayak Trust, Pune, MH, India
2. **Leni Chaudhuri**, Member, Managing Committee, Forum for Medical Ethics Society (FMES), Mumbai, India; Vice President, Narotam Sekhsaria Foundation, Mumbai; Founding Trustee, Vidhayak Trust, Pune, MH, India
3. **Ramesh Awasthi**, Co-convenor and Managing Trustee, Mahila Sarvangeen Utkarsh Mandal (MASUM), Pune, MH, India
4. **Sanjay Nagral**, Chairperson, Forum for Medical Ethics Society (FMES); and Member, Editorial Board, *Indian Journal of Medical Ethics (IJME)*, Mumbai, MH, India
5. **Sunita Sheel Bandewar**, Working Editor, *Indian Journal of Medical Ethics (IJME)*; Secretary, Forum for Medical Ethics Society (FMES), Mumbai, MH, India; Sr Associate, Tata Institute of Social Sciences (TISS), Mumbai, MH, India

National Advisory Committee

1. **Dr M R Rajagopal**, President, Pallium India, Arumana Hospital, and Director, WHO Collaborating Centre for Policy and Training on Access to Pain Relief, Thiruvananthapuram, Kerala, India
2. **Dr R K Mani**, CEO (Medical Services) and Chairman, Critical Care, Pulmonology & Sleep Medicine, Nayati Healthcare & Research Pvt Ltd, Gurgaon, Haryana, India
3. **Dr Soumya Swaminathan**, Director General, Indian Council of Medical Research; Secretary, Department of Health Research, New Delhi, India
4. **Dr Sundar Sarukkai**, Professor of Philosophy, National Institute of Advanced Studies, Bangalore, Former Founder-Director of the Manipal Centre for Philosophy and Humanities, Manipal University, Manipal, Karnataka, India
5. **Dr Thelma Narayan**, Director, School of Public Health, Equity and Action (SOPHEA), Secretary, Society for Community Health, Awareness, Research and Action (SOCHARA), Bengaluru, Karnataka, India
6. **Dr Vasantha Muthuswamy**, President, Forum for Ethics Review Committees, India (FERCI), Coimbatore, Tamil Nadu, India, and Former Senior Deputy Director General and Chief of the Division of Basic Medical Sciences, Traditional Medicine and Bioethics, Indian Council for Medical Research
7. **Vidyatai Bal**, Founder Member, Nari Samata Manch, Founder Member, *Milooni Saryajani* (a Marathi monthly magazine on women's issues), Pune, MH, India

Funding Organisations

1. **Cipla Foundation**, a charitable Trust registered in the year 2010 under the Bombay Public Trusts Act 1950; C/o Cipla Limited, Mumbai Central, Mumbai, MH, India.
2. **Indian Council of Medical Research**, V Ramlingaswami Bhavan, Ansari Nagar, New Delhi, India. [Ref No: No.7/686/16-Seminars (HRD)]
3. **Narotam Sekhsaria Foundation**, 1st Floor, Nirmal Building, Nariman Point, Mumbai, MH, India
4. **Wellcome Trust**, 215 Euston Street, London, NW1 2BE, UK [Ref No: 204126/Z/16/Z]

Conference Secretariat

FMES/IJME, C-5, Mantri Avenue – I, Panchavati, Pashan Rd, Pune,
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Web site: <http://ijme.in/nbc-20140321/index.php/NBC-6/index/pages/view/nbc6-home>

Collaborating Organisations

1. **Anveshi Research Centre for Women's Studies**, Hyderabad, Telangana, India www.anveshi.org.in/
2. **CanSupport**, New Delhi, India www.cansupport.org/
3. **Centre for Enquiry into Health and Allied Themes (CEHAT)**, Mumbai, MH, India www.cehat.org, www.gme-cehat.org and www.patientsrights.in
4. **Centre for Ethics**, Yenepoya University, Mangaluru, Karnataka, India <http://yenepoya.edu.in/colleges.php?id=41&org=center/>
5. **Centre for Health and Social Justice (CHSJ)**, New Delhi, India <http://www.chsj.org/>
6. **Cipla Palliative Care & Training Centre**, Pune, MH, India. <http://www.carebeyondcure.org/>
7. **The Department of Critical Care Medicine**, Bharati Vidyapeeth University Medical College, Pune, MH, India. <http://mcpune.bharativedyapeeth.edu/SiteData/pdf/Medical/CriticalCare.pdf>
8. **FIAMC Biomedical Ethics Center**, Mumbai, MH, India. www.fiamc.org
9. **HALO Medical Foundation (HMF)**, Osmanabad, MH, India. <http://www.halomedicalfoundation.org/>
10. **Jnana-Deepa Vidyapeeth (JDV)**, Pune, MH, India. www.jdv.edu.in/
11. **MOHAN (Multi Organ Harvesting Aid Network) Foundation**, Chennai, TN, India. www.mohanfoundation.org/
12. **Observer Research Foundation (ORF)**, Mumbai, MH, India. www.orfonline.org/
13. **Sama Women's Health**, New Delhi, India www.samawomenshealth.org
14. **Simpatico Palliative Connect**, Pune, MH, India. www.simpaticopalliative.org/
15. **Sri Chitra Tirunal Institute of Medical Sciences and Technology**, Thiruvananthapuram, Kerala, India <https://www.sctimst.ac.in/>
16. **St John's Medical College and Hospital**, Bengaluru, Karnataka, India. www.stjohns.in/
17. **University of Hyderabad and the Institutional Ethics Committee**, Hyderabad, Telangana, India www.uohyd.ac.in/
18. **Vidhayak Trust**, Pune, MH, India
19. **YR Gaitonde Medical, Educational and Research Foundation (YRGCARE)**, Chennai, TN, India www.yrgcare.org/
20. **Zonal Transplant Coordination Center (ZTCC)**, Pune, MH, India www.ztccpune.com

Media Team

1. **Sandhya Srinivasan**, Consulting Editor, *Indian Journal of Medical Ethics (IJME)*, Mumbai, MH, India.
2. **Lubna Duggal**, Treasurer, Forum for Medical Ethics Society (FMES), Mumbai, MH, India
3. **Sanyogita Dhamdhare**, Media Advocate, Pune, MH, India

Rapporteurs

1. **Aarshi Chandrasekhar**, Research Officer, Centre for Enquiry into Health and Allied Themes, Mumbai, MH, India
2. **Amruta Bavadekar**, Research Officer, Centre for Enquiry into Health and Allied Themes (CEHAT), Mumbai, MH, India
3. **Anant Bhan**, Researcher, Bioethics and Global Health, Delhi, India and Bhopal, MP, India; Adjunct Visiting Professor, Yenepoya University, Mangalore, Karnataka, India
4. **Deepa V**, Director, Sama Resource Group for Women and Health, New Delhi, India
5. **Mala Ramanathan**, Working Editor, *Indian Journal of Medical Ethics*, Mumbai, India; and Professor, Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram, Kerala, India
6. **Nehal Shah**, Senior Research Associate, Centre for Enquiry into Health and Allied Themes, Mumbai, MH, India
7. **Pragna Paramita Mondal**, UGC Senior Research Fellow, Women's Studies Research Centre, University of Calcutta, WB, India
8. **Rakhi Ghoshal**, Jt Secretary, Forum for Medical Ethics Society; Independent Consultant, Kolkata
9. **Sanjida Arora**, Sr Research Associate, Centre for Enquiry into Health and Allied Themes, Mumbai, MH, India
10. **Shyamala Nataraj**, Member, Forum for Medical Ethics Society, Mumbai, MH, India
11. **Suchitra Wagle**, Sr Research Associate, Centre for Enquiry into Health and Allied Themes, Mumbai, MH, India
12. **Sumitha T S**, MPH Scholar, Achutha Menon Centre for Health Science Studies (AMCHSS), Thiruvananthapuram, Kerala, India
13. **Sunita Simon Kurpad**, Member, Managing Committee, Forum For Medical Ethics Society; Professor, Department of Psychiatry, and Professor and Head, Department of Medical Ethics, St John's Medical College Hospital, Bengaluru, Karnataka, India
14. **Sunu Thomas**, PhD Scholar, Achutha Menon Centre for Health Science Studies, Thiruvananthapuram, Kerala, India
15. **Vijayaprasad Gopichandran**, Working Editor, *Indian Journal of Medical Ethics*; Asst Professor, Dept of Community Medicine, ESIC Medical College & PGIMS, Chennai, TN, India
16. **Teena Xavier, Akhila Vasan, Vijayakumar S**, Members of Karnataka Janaarogya Chaluvali, Bengaluru, Karnataka, India

INTRODUCTION: 6TH NATIONAL BIOETHICS CONFERENCE

Dr Sunita Sheel Bandewar, on behalf of the Conference Coordination Committee

National Bioethics Conferences: An overview

The *Indian Journal of Medical Ethics* (www.ijme.in) is a peer reviewed indexed journal (earlier known as *Medical Ethics* and *Issues in Medical Ethics*) which started publication in 1993 (www.ijme.in) as a forum for scientific exchange and debates on bioethics in India. IJME has now completed its 24th year as a pioneering platform for discussions in bioethics in India. As a leader in this field in low and middle income countries, it has been fostering a commitment to bioethics while contributing to scholarship in the field.

Most importantly, it has been facilitating opportunities for awareness building and sensitisation of institutions and individuals working in healthcare to the ethical dimensions of their work and the role they can play in improving the ethical and regulatory standards of health research, healthcare, and allied activities.

With the evolution of bioethics in India, the need emerged to share ideas and to build a platform for different stakeholders to come together and discuss ethical issues relating to the field of health and other areas that impact health, health systems and health research. There was a necessity to promote original thinking and exploration so as to develop analytical frameworks for ethical issues suitable for the specific contexts of India. It was in recognition of these needs that *IJME* decided to create the platform of the National Bioethics Conferences (NBC).

So far, *IJME* and other collaborating partners have organised five national bioethics conferences, the tradition having been initiated in 2005. NBC-1 on the theme '*Ethical challenges in health, global context, Indian realities*', was held at the YMCA International Centre, Mumbai from November 25 to 27, 2005, and was co-organised by 20 institutions. NBC-2, in 2007, was on the theme '*Moral and ethical imperatives of healthcare technologies: scientific, legal and socio-economic perspectives*' and was held at the National Institute for Mental Health and Neurosciences (NIMHANS) Convention Centre, Bangalore from December 6 to 8, 2007. 38 organisations participated in the second NBC. NBC-3, co-organised by 38 organisations from all over India, was on the theme of '*Governance of healthcare: ethics, equity and justice*'. It was held from November 18 to 20, 2010 at the All India Institute of Medical Sciences (AIIMS), New Delhi. NBC-4, co-organised by the Central University of Hyderabad, Hyderabad, Andhra Pradesh and the Council for Social Development - an affiliate of the Indian Council for Social Sciences - Hyderabad, Andhra Pradesh was held from December 6 to 8, 2012 with the theme '*Ethical and regulatory challenges in health research*'. NBC-5 was co-organised with St. John's National Academy of Health Sciences, (SJNAHS) Bengaluru, Karnataka and Society for Community Health Awareness, Research & Action (SOCHARA), Bengaluru, Karnataka from December 11 to 13, 2014. The theme for the fifth NBC was '*Integrity in medical care, public health and health care research*'.

Sixth National Bioethics Conference: significance and goal

The theme of the Sixth National Bioethics Conference is: '***Healing and dying with dignity: Ethical issues in palliative care, end-of-life care and euthanasia***'

Two closely related and neglected areas of concern are **palliative care** and **end-of-life care**. The extremely inequitable distribution, across the country of end-of-life care facilities leaves large numbers of patients and their families in tremendous distress. The need for palliation is essential, as non-communicable diseases and cancers become increasingly important. This is primarily due to the changing demographic, socioeconomic and work profiles of the population and its health status; changing living conditions and contexts; and the lack of availability of sufficient palliative care across the country, with certain exceptions, such as the areas served by Pallium India in Kerala.

The theme of **euthanasia** in NBC 6 is partly inspired by the debates around the story of Aruna Shanbaug, who died recently after spending nearly 42 years in a persistent vegetative state after she was sexual assaulted and strangled while on nursing duty in a government hospital in Mumbai. There is some progress in setting up systems to address sexual assault at the workplaces. However, debates on euthanasia remained divided and inconclusive.

The Sixth NBC will be an opportunity to discuss these three closely related themes in healthcare ethics which deserve much attention and clarity in order to honour the patients' right to healing and dying with dignity.

It is hoped that the Sixth NBC will be helpful in furthering policy decisions on euthanasia, and in developing processes for legal and health systems reform in India, building on the work done so far.

Goal

A central goal of the Sixth NBC is to bring together different key constituencies/stakeholders for sharing their diverse perspectives on the Conference theme – ***Healing and Dying with Dignity: Ethical issues in palliative care, end-of-life care and euthanasia*** - towards building better healthcare system; health policies and programmes; and legal environment which will not only provide accessible and quality treatment to those in need; but enable healing with dignity, and when such a situation arises, dying with dignity.

Specific objectives

- To bring together key constituencies – individuals and institutions – relating to the health care sector, bioethics, health policy, health laws, philosophy, social sciences, and religious studies to engage with ethical issues and challenges in providing quality palliative care to all those who need it;
- To enable dialogue between key constituencies and representatives of organisations which are engaged in debates on end-of-life care and euthanasia, towards locating common ground to help move forward with regard to formulating beneficial guidelines and policies;
- To offer a public platform for presenting emerging empirical research, theoretical and conceptual work from multi-disciplinary perspectives, in these three sub-fields which would help inform policies and programmes; and providing inputs for the necessary legal and policy reforms;
- To create a forum via workshops and symposia that will be organised at the Sixth NBC for skill-building and resource sharing in bioethics among different organisations and constituencies, especially on topics relating to the theme of the conference.

CONFERENCE PROGRAMME

PRE-CONFERENCE WORKSHOPS AND SATELLITE MEETINGS

THURSDAY, JAN 12, 2017, 9:00 am TO 5:30 pm

Venue: YASHADA, Pune, MH, India

1. **TRANSITION OF CARE IN PATIENTS WITH ADVANCED AND LIFE LIMITING CONDITIONS**** (Session details on page 13)

Co-hosts: Narotam Sekhsaria Foundation (NSF), Mumbai; Tata Memorial Centre, Mumbai; and the Sixth NBC Organisers - FMES-IJME and MASUM.

2. **PALLIATIVE CARE: A MATTER OF PUBLIC HEALTH CONCERN AND SOCIAL JUSTICE**

Co-hosts: Angus Dawson, Centre for Values, Ethics & the Law in Medicine, School of Public Health, The University of Sydney; Joint Editor-in-Chief: Public Health Ethics; AND

Lisa Schwartz, Department of Clinical Epidemiology & Biostatistics, Associate Member in the Department of Philosophy and member, Centre for Health Economics and Policy Analysis (CHEPA), McMaster University, Hamilton, Ontario, Canada

3. **GENDER JUSTICE: COMPREHENSIVE RESPONSE TO AND INTERSECTORAL DIALOGUE ON GENDER-BASED VIOLENCE**

Co-hosts: Lakshmi Lingam, Tata Institute of Social Sciences, Mumbai, India; the Sixth NBC Organisers - FMES-IJME and MASUM; and Centre for Health and Allied Themes (CEHAT), Mumbai, India

2.00 – 4.00 pm

[optional] Study Tour and Visit to the Cipla Palliative Care and Training Centre, Pune

and

[<http://www.ijme.in/nbc-20140321/index.php/NBC-6/index/pages/view/visit-to-cipla-palliative-care-and-training-centre>]

5:00 – 7:00 pm

MAIN CONFERENCE | FRIDAY, JAN 13 TO SUNDAY, JAN 15, 2017 | Venue: YASHADA, Pune, MH, India

DAY 1: FRIDAY, JANUARY 13, 2017

TIME	PLENARY AND PARALLEL SESSION DETAILS
8:00 am onwards	REGISTRATION
9:00–11:00 am	Day1 INAUGURAL AND FELICITATION
	<p>Opening: Connecting the dots amidst the Sound of Music (percussion by special kids)</p> <p>Welcome: Rakhi Ghoshal, Jt Secretary, FMES; Working Editor, IJME</p> <p>Introduction to FMES & NBC Platform: Lubna Duggal, Treasurer, FMES</p> <p>Introduction to IJME: Vijayaprasad Gopichandran, Working Editor, IJME; Assistant Professor, Department of Community Medicine, ESIC Medical College & PGIMS, Chennai, TN, India</p> <p>Introduction to MASUM: Hemlata Pisal, Sr Associate, MASUM, Pune, MH, India</p> <p>Announcement of the World Congress of Bioethics: Sanjay Nagral, Chair, FMES, Mumbai & Sarojini N, Executive Director, Sama Resource Group for Women and Health, New Delhi, India</p> <p>Felicitation and Inaugural Speeches</p> <p>Chairperson: Soumya Swaminathan, Director General, Indian Council of Medical Research, New Delhi, India</p> <p>Co-chairperson: Sanjay Nagral, Chair, Forum for Medical Ethics Society</p> <p>Guest of Honour: Sunil Pandya, Editor Emeritus, IJME</p> <p>Felicitation</p> <ol style="list-style-type: none"> Vidyatai Bal, Founding Member, Nari Samata Manch and Milooni Saryajani, Pune, MH, India Felicitation by Soumya Swaminathan, Director General, Indian Council of Medical Research, New Delhi, India Felicitation citation by Manisha Gupte, Founding Convenor, MASUM, Pune Syed Adibul Hasan Rizvi, Founder and Director, Sindh Institute of Urology and Transplantation, Karachi, Pakistan; Winner of the 1998 Magsaysay award. Felicitation by Amar Jesani, Editor-in-Chief, IJME and Felicitation citation by Sanjay Nagral, Chair, Forum for Medical Ethics Society, Mumbai Rajagopal M R, President, Pallium India; Director, Trivandrum Institute of Palliative Sciences; WHO Collaborating Centre for Policy and Training on Access to Pain Relief. Felicitation by Ramesh Awasthi, Founding Trustee, MASUM and Sunil Pandya, Editor Emeritus, IJME Felicitation citation by Leni Choudhuri, member, Managing Committee, Forum for Medical Ethics Society, Mumbai; and Vice President, Narotam Sekhsaria Foundation; and <p>Inaugural Address 1: Vidyatai Bal</p> <p>Inaugural Address 2: Syed Adibul Hasan Rizvi</p> <p>Inaugural Address 3: M R Rajagopal</p> <p>Opening the floor for Q&A</p>
11:00 – 11:30 am	DAY 1 TEA BREAK
11.30 am - 1.00 pm	DAY1 PARALLEL SESSIONS PAPER PRESENTATIONS AND WORKSHOPS: GROUPS P1 TO P6; & WS/S1 TO WS/S3

	<p>GROUP P1: PALLIATIVE CARE ETHICS - I: CONTEXT, POLITICS AND JUSTICE</p> <p>Chairpersons: Anita Jain, <i>BMJ</i>, Clinical Editor, <i>BMJ</i>, and independent physician and family medicine tutor, Mumbai, MH, India Nobhojit Roy, Member, Editorial Board, <i>IJME</i>, Mumbai, MH, India</p>
	P1(a): Alastair V Campbell: The end of life and injustice in healthcare
	P1(b): Sridevi Seetharam, Chaitra J, R S Rajan and Seetharam M R: Ethical dilemmas encountered by care-providers in a palliative care programme in urban Mysore
	P1(c): Afeeda K T: Embodied pain and politics of palliative care: A sociological study in Calicut district, Kerala, India
	P1 (d): Chaitra J, Pushpa Gaikwad, R S Rajan and Rekha Shanmukha: Ethical dilemmas encountered in the administration of an NGO-based palliative care programme in urban Mysore
	<p>GROUP P2: END-OF-LIFE COMMUNICATION AND ADVANCE DIRECTIVES</p> <p>Chairpersons : Ravindra Ghooi, Sr Consultant, Cipla Palliative Care and Training Centre, Pune, MH, India Sanjida Arora, Sr Research Officer, CEHAT, Mumbai, MH, India</p>
	P2 (a): Prerna Shetty, Ravi Vaswani and Vijaya Hegde: Knowledge and attitudes regarding advance directives among doctors working at a tertiary care hospital of Mangalore city: A pilot study
	P2 (b): Bilkis Vissandjée and Wendy E Short: End of life communication: An imperative in providing ethical care
	P2 (c): Gitanjali Borse-More: Last wishes and ethical dilemmas
	P2 (d): Malvinder Singh Sahi, Anupam Singh and Bables Mahawar: Futility of critical care in terminally ill cancer patients: a retrospective analysis of correlation between counseling and outcome in a tertiary level ICU.
	<p>GROUP P3: HEALTH SYSTEM AND PUBLIC HEALTH ETHICS - I: PREVENTION AND CONTROL OF DISEASES</p> <p>Chairpersons : Mala Ramanathan, Professor, Achutha Menon Centre for Health Science Studies (AMCHSS), Sree Chitra Tirunal Institute for Medical Sciences and Technology (SCTIMST), Thiruvananthapuram, Kerala, India Abhay Kudale, Asst Professor, School of Health Sciences, Savitribai Phule Pune University, Pune, MH, India</p>
	P3 (a): Solomon Salve and John Porter: Maintaining balance: Ethical dilemmas of frontline TB workers in implementing the DOTS strategy in India
	P3 (b): Pallavi Mishra: Less on prevention, more on cure: Exploring the ethical responsibility of public-private partnerships (PPPs) in malaria eradication
	P3 (c): Jagdish Patel and Siddarth David: Invisible numbers and unknown diseases: The absence of data on occupational health conditions in India
	P3 (d): Prabha Thangaraj and Sudha Ramlingam: Ethical issues to be considered in vaccination programmes: A review article
	<p>GROUP P4: ORGAN DONATION: ETHICS AND LAW</p> <p>Chairpersons : Arati Gokhale, Central Coordinator, Zonal Transplant Coordination Centre, Pune, MH, India; Peush Sahni, Editor-in-chief, <i>National Medical Journal of India</i>, New Delhi, India</p>
	P4 (a): Dominique E Martin: End-of-life care and deceased organ donation
	P4 (b): Sumana Navin, Sunil Shroff and Sujatha Suriyamoorthi: Ethics of organ allocation: Who should get the organ?
	P4 (c): Muneet Kaur Sahi: Financial incentives to donor families: ethical issues
	P4 (d): Nehal Shah: Kidney transplantation: Ethical issues in law and medical practice
	<p>GROUP P5: GENDER & ETHICS</p> <p>Chairpersons : Geeta K Vemuganti, Dean, School of Medical Sciences University of Hyderabad, Hyderabad, Telangana, India; Sarah Hodges, Associate Professor, History Department, University of Warwick, UK</p>
	P5 (a): Sadhana Khati and Anjali Pashankar: A Study of the physiological and psychological impact of sexual harassment on the victim with reference to the POSH ACT 2013
	P5 (b): Teena Xavier, Akhila Vasan, Vijaykumar S: Vulnerability, misogyny and medical practice: Fault lines of ethical violations
	P5 (c): Suaheha Siddiq Shekhani and Farhat Moazam: Why Pakistani female graduates do not practise medicine: Complex interplay of socio-cultural factors
	P5 (d): Sumitha T S: Consent/ assent and confidentiality issues in studies on institutionalised adolescents living in Integrated Child Protection Scheme homes in Kerala
	<p>GROUP P6: EDUCATION / TRAINING AND EMPIRICAL RESEARCH IN BIOETHICS</p> <p>Chairpersons : Shashikant Ahankari, President, Halo Foundation, Osmanabad, MH, India; Barun Mukhopadhyay, Professor, Biological Anthropology Unit, Indian Statistical Institute, Kolkata, WB, India</p>

	P6 (a): M Varalakshmi: Professional autonomy and moral resilience among health professionals: A descriptive cross-sectional study
	P6 (b): Vijayaprasad Gopichandran: Emotional intelligence for clinical care: A report of a fishbowl discussion among medical students in clinical training
	P6 (c): Shivakumar Iyer, Jignesh Shah, Prashant Jedge, and Members of the Expert ISCCM Committee: ISCCM online survey of end-of-life care practices
	P6 (d): Aditi Apte: Roles and responsibilities of members in ethics review committees: individual perspectives
	WS/S1: PALLIATIVE AND END-OF-LIFE CARE: CHALLENGES AND OPPORTUNITIES Facilitators: S Stephen Jayard, John Karuvelil, Nishant A Irudayadason and Charles Davies, (all from Jnana-Deepa Vidyapeeth, Pune, MH, India)
	WS/S2: LEGAL - ETHICAL ISSUES IN PALLIATIVE CARE, END OF LIFE CARE AND EUTHANASIA Facilitators: Veena Johari, Vivek Divan and Kajal Bhardwaj, (all from Health, Equity and Law Project)
	WS/S3: DISSEMINATION OF THE NATIONAL ETHICAL GUIDELINES FOR BIOMEDICAL AND HEALTH RESEARCH INVOLVING HUMAN PARTICIPANTS BY ICMR-WHO Facilitators: Roli Mathur, Indian Council of Medical Research Bioethics Units, National Centre for Disease Informatics and Research (NCDIR) Bengaluru, Karnataka, India : Nandini Kumar, Kasturba Medical College, Manipal ; and Madhur Gupta, WHO Country Office for India, New Delhi, India
1.00 - 2.00pm	DAY 1 LUNCH
1:30- 2:00 pm	DAY 1 POSTER DISPLAY & PRESENTATION [Posters will remain displayed until the end of Day 2]
	Poster 1: Ethical issues in disaster site mental health research: A case example by Avinash De Sousa
	Poster 2: Auto-euthanasia wishes in a geriatric couple : Ethical-clinical issues for the treating doctor by Avinash De Sousa
	Poster 3: Initiatives for promotion of research ethics by Manjiri Joshi and Ravindra Ghooi
	Poster 4: Affirmations - a mechanism for coping by Aruna Deshpande and Parikshit Patil
	Poster 5: "S/he is all I have" – ethical dilemmas in caregiver insistence for continuing care in incapacitated palliative care patients by Shridevi Warriar
	Poster 6: Nuances in informed consent in palliative care research – denial and collusion by Ravi Prasad Varma P
	Poster 7: Instilling empathy for the blind: Walk through the dark to understand those who live in the dark by Uma Kulkarni and Vina Vaswani
	Poster 8: Knowledge and attitudes related to medical ethics among medical students by Iswarya Santhana Krishnan and Bhuvaneshwari S
	Poster 9: Care for the dying – a spiritual dimension by Amarantha Donna Ropmay, Purnima Devi Laishram and Adorinia Nongrum
	Poster 10: Ethical issues in online psychotherapy: emerging ethical dilemmas for India by Avinash De Sousa
	Poster 11: Life after death : the dead shall teach the living by Aiswarya Sasi, Radhika Hegde, Stephen Dayal and Manjulika Vaz
	Poster 12: Role of dance as a treatment modality in health care by Sachitha Nandagopal
	Poster 13: Identifying ethical challenges in resolving male infertility: An examination of "One Part Woman" by Sunu C Thomas
	Poster 14: Dignity in darkness: The gender gripes! by Uma Kulkarni, Vina Vaswani and Ravi Vaswani
	Poster 15: Does the system care for its nurses who provide care to patients? by Pallavi Mishra, Joe Varghese and Solomon Salve
	Poster 16: Relevance of privacy for data collection in public health study: Field experiences, Gadag district, Karnataka, India by Bevin Vijay Kumar V N, presented Sunu C Thomas
2.00 - 3.30 pm	DAY 1 PARALLEL SESSIONS WORKSHOPS AND SYMPOSIA WS/S4 TO WS/S11
	WS/S4: ETHICAL CHALLENGES IN TEACHING MEDICINE –TEACHERS' NARRATIVES Facilitators: Sudharshini Subramaniam, Institute of Community Medicine, Madras Medical College, Chennai, TN, India; Priyadarshini Chidambaram, Department of Community Medicine, MS Ramaiah Medical College, Bengaluru, Karnataka, India ; and Vijayaprasad Gopichandran, Department of Community Medicine, ESIC Medical College & PGIMS, Chennai, TN, India
	WS/S5: SURROGACY IN INDIA – PAST, PRESENT AND THE PATH AHEAD Facilitators: Priya Satalkar, Institute for Biomedical Ethics (IBMB) University of Basel, Switzerland; Nishtha Lamba, Centre for Family Research, University of Cambridge, UK; and Avinash De Sousa, Desousa Foundation, Mumbai, MH, India

	<p>WS/S6: UNDERSTANDING MEDICAL ERROR - BEYOND THE BLAME GAME Facilitators: Aamir Jafarey, Centre for Biomedical Ethics and Culture(CBEC), SIUT, Karachi, Pakistan; and Nida Wahid Bashir, Patel Hospital, Karachi and CBEC, SIUT, Karachi, Pakistan</p>
	<p>WS/S7: ETHICS TRAINING MODULE FOR HEALTH PROFESSIONALS IN END-OF-LIFE SITUATIONS Facilitators: Olinda Timms, Christopher Vimalraj Hiruthya, Faculty of Medical Ethics, St John's Research Centre and St John's Medical College, Bengaluru, Karnataka, India; Shivkumar Iyer, Bharati Vidyapeeth Medical College, Deemed University, Pune, MH, India; Prachee Sathe, Critical Care Medicine, Ruby Hall Clinic, Pune, MH, India</p>
	<p>WS/S8: THE MARGINALISED IN PALLIATIVE CARE Facilitators: M R Rajagopal, Pallium India; Purnima Nagaraja, Arul Dhas, Bioethics, Christian Medical College, Vellore, TN, India; Sunita Sheel Bandewar, FMES, Mumbai, MH, India; R Srivatsan, Anveshi Research Centre for Women's Studies, Hyderabad, Telangana, India</p>
	<p>WS/S9: CAREGIVING - A CHOICE OR AN OBLIGATION Facilitators: Priyadarshini Kulkarni, Indian Association of Palliative Care; Pradeep Kulkarni, Madhura Bhatwadekar, all from Simpatico Palliative Connect, Pune, MH, India</p>
	<p>WS/S10: SKILLS OF PALLIATIVE CARE COUNSELING Facilitators: K N Chouhan, D S Homeopathic Medical College, Pune, MH, India; Megha Deuskar, Department of Psychology, Fergusson College, Pune, MH, India</p>
	<p>WS/S11: CHALLENGES OF INSTITUTIONAL ETHICS COMMITTEES AT THE UNIVERSITY OF HYDERABAD Facilitators: Geeta K Vemuganti, School of Medical Sciences, Varalakshmi Manchana, Justice T N C Rangarajan, Former Judge, High Courts of Madras and Andhra Pradesh; Prof P Mohanty, all from University of Hyderabad, Hyderabad, Telangana, India</p>
3.30 - 4.00 pm	DAY 1 TEA BREAK
4.00 - 5.30 pm	DAY 1 PLENARY I: PALLIATIVE AND END-OF-LIFE CARE: MATTERS OF JUSTICE AND EQUITY
	<p>Chairpersons: Anita Kar, Director, School of Health Sciences, University of Pune, Pune; Sarojini N B, Executive Director, Sama Resource Group for Women and Health, New Delhi</p> <p>Keynote address 1: Yogesh Jain, Founding Trustee, Jan Swasthya Sahayog, Bilaspur, Chhattisgarh, India [Issues of access to PC-EoLC in the land of lack of care and an unjust health care system]</p> <p>Keynote address 2: R K Mani, CEO (Medical Services) & Chairman, Critical Care, Pulmonology & Sleep, Medicine, Nayati Healthcare & Research Pvt. Ltd, New Delhi, India. [Critical Care Medicine perspective]</p> <p>Keynote address 3: Siby George, Indian Institute of Technology, Powai, Mumbai, MH, India [Being well at the anticipated end of life: A philosophical meditation]</p>
DAY 1: 5.45 – 7.15 pm IJME-FMES SESSION	
25th year of the Indian Journal of Medical Ethics: Looking back & looking ahead	
FMES-IJME entering into its Silver Jubilee Year in 2017 since its inception in 1993. Panel discussion with past five editors-in-chief of <i>IJME</i> - Sunil Pandya , Arun Bal , Samiran Nundy , George Thomas and Sanjay Pai – along with Amar Jesani , Current Editor in conversation with <i>FMES-IJME</i> readers, contributors, critics and the broader audience.	
DAY 2: SATURDAY, JANUARY 14, 2017	
9:30 – 11:00 am	DAY 2 PARALLEL SESSIONS PAPER PRESENTATIONS AND WORKSHOPS: GROUPS P7 TO P11; & WS/S12 TO WS/S13
	<p>GROUP P7: PALLIATIVE CARE ETHICS II: MENTAL HEALTH, SPECIAL NEEDS AND SITUATIONS Chairpersons: Reena Sharma, Head Palliative Care Field Services, CanSupport, New Delhi, India Priyadarshini Kulkarni, Chief and Medical Director, Simpatico Palliative Connect, Pune, MH, India</p>
	P7(a): K N Chouhan and Megha Deuskar: Homeopathy and psychotherapy: a useful aid in palliative care
	P7(b): Purnima Nagaraja: The new interface between palliative care and psychiatry
	P7(c): Sashikala Ramnath, Anne Panicker, and B S Ramakrishna Mudre (Presented by Sonia Jacob): Palliative care and ethical dilemmas in caring for children with special needs: An experience from a society dealing with providing rehabilitation services to persons with cerebral palsy and other developmental disabilities
	P7(d): Sujatha Suriyamoorthi, Sumana Navin, and Sunil Shroff: Ethical dilemmas in end of life care in handling potential brain dead donors in ICUs
	<p>GROUP P8: LEGAL ASPECTS OF SAVING-LIFE AND END-OF-LIFE CARE Chairpersons: T N C Rangarajan, Member, ERB, University of Hyderabad, Hyderabad, Telangana, India; and Former Judge, High Courts of Madras and Andhra Pradesh Stephen Jayard, Professor and Director, Centre for Applied Ethics, Jnana-Deepa Vidyapeeth, Pune, MH, India</p>
	P8(a): Smitha Nizar: The jurisprudence of euthanasia: The legitimacy of 'agency' in planning for death

	P8(b): Kriti Sharma: Court room battles on the right to euthanasia
	P8(c) : Christopher Vimalraj Hiruthya: Proposed legalisation of euthanasia in India: A bioethical reflection and response
	P8(d): Edward Premdas Pinto: The emergent ethics jurisprudence: A socio-political review of the jurisprudence of the prominent medico-legal cases and the application of ethical principles to critical life-saving care in India
	GROUP P9: HEALTH SYSTEM AND PUBLIC HEALTH ETHICS II: DRUGS AND SERVICES Chairpersons: Alastair Campbell, Visiting Professor in Medical Ethics and Emeritus Director, Centre for Biomedical Ethics, National University of Singapore, Singapore R Srivatsan, Anveshi Research Centre for Women's Studies, Hyderabad, Telangana, India
	P9(a): Adsa Fatima and Sarojini N: Access to medicines: Looking through ethics
	P9(b): Sarah Hodges: 'Wife of Spurious Drug Kingpin on the Run' and other episodes in the curious contemporary cultural history of fake medicine and India
	P9(c): Vijayakumar S and Akhila Vasan: Ethical and patient rights violations in government health insurance schemes in Karnataka
	P9(d): Arun Gadre, Nilangi Sardeshpande, and Abhay Shukla: Commercialisation of the private health care sector in India through the perspective of practising doctors
	GROUP P10: ASSISTED REPRODUCTION AND SURROGACY Chairpersons: Vina Vaswani, Director, Centre for Ethics, Yenepoya University, Mangalore, India Subrata Chattopadhyay, Head, Department of Physiology, College of Medicine & J N M Hospital, The West Bengal University of Health Sciences, Kalyani, Kolkata, West Bengal, India
	P10(a): Nishtha Lamba, Vasanti Jadva, Kaushal Kadam and Susan Golombok: A longitudinal study of psychological well-being of Indian surrogates
	P10(b): Pragna Paramita Mondal: From the 'why' to 'how?': Rethinking ethical positions in surrogacy
	P10(c): Priya Ranjan: Bioethics and the commercialisation of human bodies and tissues in India
	GROUP P11: ETHICS, INTEGRITY & PROFESSIONALISM Chairpersons: Deepesh Reddy, Public Health Consultant, Observer Research Foundation (ORF), Mumbai, MH, India Shamim Modi, Chair, Centre for Law and Society, the School of Law, Rights, and Constitutional Governance, Tata Institute of Social Sciences, Mumbai, MH, India
	P11(a): Sanjai S and Vijayaprasad Gopichandran: Selfless giving in medicine: A study of altruism among medical students
	P11(b): Savitha D, Manjulika Vaz and Mario Vaz: "Thinking Ethics": A novel programme of integrating ethics into the Physiology curriculum in South India
	P11(c): Abeer Salim Habib and Nida Wahid Bashir: Medical error reporting system: An initiative
	P11(d): Priya Satalkar and David M Shaw: Writing their own rules? Researcher perspectives on authorship guidelines
	WS/S12: GUIDELINES FOR DOCTORS ON SEXUAL BOUNDARIES, AND NEXT STEPS Facilitators: Sunita Simon Kurpad, FMES and Department of Medical Ethics, St. John's Medical College, Bengaluru, Karnataka, India; Ajit Bhide, Department of Psychiatry, St. Martha's Hospital, Bengaluru, Karnataka, India
	WS/S13: SUPPORTING PATIENTS AND CAREGIVERS TOWARDS THE END OF LIFE: A WORKSHOP BASED ON THE BOOK 'BEING MORTAL' Facilitators: Anita Jain, <i>BMJ</i> , Mumbai, MH, India
11:00 – 11:30 am	DAY 2 TEA BREAK
11:30 – 1:00 pm	DAY 2 PLENARY II BODIES IN LAW, HUMANITIES AND MEDICAL SCIENCES: WHO DECLARES ME DEAD & WHY?
	Chairpersons: Nandini Kumar, Former Deputy Director General Sr. Grade (ICMR), Dr. TMA Pai Endowment Chair, Manipal University, Adjunct Prof., Kasturba Medical College, Manipal, Karnataka, India Sandhya Srinivasan, Consulting Editor, <i>IJME</i> , Mumbai, MH, India Keynote address 1: S V Joga Rao, Visiting Faculty, National Law School of India University, Bengaluru, India [The notion of body in law in relation to death and euthanasia] Keynote address 2: Sundar Sarukkai, Professor of Philosophy, National Institute of Advanced Studies, Bengaluru; Founding Director, Centre for Philosophy and Humanities, Manipal University, Bangalore, Karnataka, India [Death and the problem of the body] Keynote address 3: Sunil Shroff, Director, MOHAN Foundation, Chennai, TN, India [Brain death and the need for Uniform Declaration of Death in India]
1.00 - 2.00 pm	DAY 2 LUNCH

2.00 - 3.30 pm	DAY 2 PARALLEL SESSIONS WORKSHOPS & SYMPOSIA: WS/S14 TO WS/S18
	<u>WS/S14: ADVANCED CANCER CARE: ETHICS OF COMMUNICATION PREFERENCES OF PATIENTS, THEIR CARERS, CLINICIANS AND SOCIETY</u> Facilitators: Barun Mukhopadhyay , Biological Anthropology Unit, Indian Statistical Institute, Kolkata; Soumitra S Datta , Department of Palliative Care and Psycho-oncology, Tata Medical Centre, Kolkata, WB, India; Subrata Chattopadhyay , Department of Physiology, College of Medicine & J N M Hospital, The West Bengal University of Health Sciences, Kalyani, Kolkata, WB, India; Krishnangshu Roy , Institute of Health and Family Welfare, Government of West Bengal, Salt Lake City, Kolkata, WB, India
	<u>WS/S15: INTEGRATING SEX AND GENDER IN HEALTH: AN ATTEMPT TO ADDRESS EQUITY WHEN DEALING WITH SENSITIVE ISSUES SUCH AS END OF LIFE CARE</u> Facilitators: Bilkis Vissandjée , Faculty of Nursing and School of Public Health, Université de Montréal, Montréal, QC, Canada; and Wendy E Short , Faculty of Nursing and School of Public Health, Université de Montréal, Montréal, QC, Canada
	<u>WS/S16: ORGAN DONATION AND TRANSPLANTATION IN INDIA: ETHICAL CHALLENGES AND SOLUTIONS</u> Facilitators: Sunil Shroff , Multi Organ Harvesting Aid Network (MOHAN) Foundation; Sumana Navin , MOHAN Foundation; Dominique E Martin , School of Medicine, Faculty of Health, Deakin University; J Amalorpavanathan , Vascular Surgeon, and Member Secy, Transplant Authority of Tamilnadu, Chennai, TN, India; Farhat Moazam , Chairperson, CBEC, SIUT, Karachi, Pakistan; Lalitha Raghuram , MOHAN Foundation, Chennai, TN, India
	<u>WS/S17: STRATEGIES IN PALLIATIVE CARE</u> Facilitators: M R Rajagopal , Pallium India; Thiruvananthapuram, Kerala, India; Mary Ann Muckaden , Tata Memorial Centre, Mumbai, MH, India; Anita Kar , Integrated School of Health Sciences, Savitribai Phule Pune University, Pune, MH, India
	<u>WS/S18: DEFINING 'FUTILITY AND INAPPROPRIATE INTERVENTIONS' AND RESOLVING ETHICAL CONFLICTS THAT ARISE IN DELIVERING 'APPROPRIATE EOLC' IN ICUs</u> Facilitators: Shivkumar Iyer , Critical Care Medicine, Bharati Vidyapeeth, Pune, MH, India; Jignesh Shah , Bharati Vidyapeeth, Pune, MH, India; Raj Mani , Nayati Super Speciality Hospital, Mathura and Nayati group of hospitals, New Delhi, India
3.30 - 4.00 pm	DAY 2 TEA BREAK
4.00 - 5.30 pm	DAY 2 PLENARY III COMMUNITY ENGAGEMENT IN PALLIATIVE & END-OF-LIFE CARE
	Chairpersons: Murlidhar P Tambe , Professor and Head, Department of Preventive and Social Medicine, B J Medical College & Sassoon Hospital, Pune, MH, India Ramesh Awasthi , Founding Convenor, MASUM, Pune, MH, India Keynote address 1: Soumitra S Datta , Consultant Psychiatrist, Department of Palliative Care & Psycho-oncology, Tata Medical Centre, Kolkata, WB, India; Visiting Researcher, Institute of Psychiatry, Kings College London, London, UK [Social Interface of Medicine: In health, disease and end of life] Keynote address 2: Suresh Kumar , Director, WHO Centre for Community Based Palliative Care, Calicut, Kerala, India; [Community Participation in Palliative Care and End of Life Care - Challenges and Opportunities] Keynote address 3: Harmala Gupta , Director, CanSupport, New Delhi, India [Healing & dying with dignity: People's perspectives]
5:45 -7:15 pm	DAY 2 CULTURAL EVENING [PERFORMANCE BY HRSHIKESH PAWAR AND HIS CO-ARTISTES] <i>Walking Tall, Dancing Taller</i> In India life is considered to be celebration hence songs, dance & literature are written for all occasions. While one has numerous complaints about life, the key to happiness lies within one's core; to discover one's strength and move, live and inspire. We start with a traditional recital and move ahead into a Contemporary Dance vocabulary. The performance captures some soul searching moments of these dancers whilst celebrating the human spirit. SO stand up, Walk tall and Dance taller!
DAY 3: SUNDAY, JANUARY 15, 2017	
9:30 - 11:00 am	DAY 3 PARALLEL SESSIONS PAPER PRESENTATIONS AND WORKSHOPS: GROUP P12 TO P16; & WS/S19
	<u>GROUP P12: PALLIATIVE CARE ETHICS - III: SPIRITUAL, RELIGIOUS & SOCIAL ASPECTS</u> Chairpersons: Stephen Fernandes , Executive Director, FIAMC, Mumbai, MH, India Sanjay Pai , Working Editor, <i>IJME</i> , Mumbai, MH, India
	P12(a): Arul Dhas: Spiritual suffering of a palliative care patient
	P12(b): Swami Dayapurnananda: The science of medicine and the art of dying: reflections from the Indian legacy

	P12(c): Sudha Ramalingam: Social, cultural and spiritual attributes of a dignified death- End of life practices in rural south India
	P12(d): Priya Satalkar: "I want to be my own author!" Debate on "completed life" and right to euthanasia in the Netherlands
	GROUP P13: HEALTH SYSTEM AND PUBLIC HEALTH ETHICS - III: PUBLIC HEALTHCARE, BIOBANK & TISSUE DONATION Chairpersons: Lisa Schwartz, Professor, Department of Clinical Epidemiology & Biostatistics, An Associate, Department of Philosophy and Member, Centre for Health Economics and Policy Analysis, McMaster University Faculty of Health Sciences, Canada Dominique E Martin, Senior Lecturer in Health Ethics and Professionalism School of Medicine, Faculty of Health, Deakin University, Australia
	P13(a): Rakhi Ghoshal: Contingent-caregivers and acrimonious care: caregiving in a public hospital maternity ward
	P13(b): Joe Varghese, Solomon Salve, and Pallavi Mishra: Nursing leadership thrives in dignified contexts: Lessons from West Bengal government initiatives in strengthening nursing cadre
	P13(c): Subhashini and Sudha Ramlingam: Ethical issues in sperm donation : A review
	P13(d): Aamir M Jafarey, Sualeha Siddiq Shekhani and Bushra Shirazi: Biobanking in Pakistan: Unchartered waters
	GROUP P14: REPRODUCTIVE HEALTH: AUTONOMY AND JUSTICE Chairpersons: Bilkis Vissandjée, Professor, Faculty of Nursing and School of Public Health, Université de Montréal, Montréal, QC, Canada Neha Madhiwalla, Research Scientist, Ramalingaswami Centre on Equity and Social Determinants of Health, Bangalore, Karnataka, India
	P14(a): Hemlata Pisal, Shubhada Deshmukh, Kajal Jain, and colleagues: Insights into women's access to reproductive health care services in Vidarbha region of Maharashtra, India, with reference to National Rural Health Mission
	P14(b): Kajal Jain, Hemlata Pisal, Ramesh Awasthi, and colleagues: Community-based health intervention for reproductive health care needs: MASUM's experience
	P14(c): Bhavna Dhingra, Brian S Carter and Angela D Knackstedt: Ethical and socio-cultural issues related to adolescents capacity to provide consent for treatment
	P14(d): Wendy Short and Bilkis Vissandjée: Stigma experienced by Women Living with HIV in India: The contribution of the Biopsychosocial Complex Model
	GROUP P15: ETHICS IN CLINICAL CARE Co-chairpersons: G D Ravindran, Professor and Head Medicine and Ethics, St John's Medical College and Hospital, Bengaluru, Karnataka, India Farhat Moazam, Professor and Chairperson, Centre for Biomedical Ethics and Culture (CBEC), SIUT, Karachi, Pakistan
	P15(a): Swarupa Bhagwat, Jayashree Sharma, and Santosh Salagre: Transfusions in Jehovah's Witnesses: Changing ethical paradigm?
	P15(b): Jyotismitha Sarma: The quest for cure for disability: Understanding the ethical issues involved
	P15(c): Rhyddhi Chakraborty: Hodgkin's Lymphoma and the underlying ethical pitfalls
	GROUP P16: ETHICS: APPROACHES AND PERSPECTIVES Chairpersons: Sisira Siribaddana, Founder Professor & Chair, Department of Medicine, Faculty of Medicine & Allied Sciences, Rajarata University of Sri Lanka, Saliyapura. Vijayprasad Gopichandran, Working editor, <i>IJME</i> ; Assistant Professor, Department of Community Medicine, ESIC Medical College & PGIMS, Chennai, TN, India
	P16(a): Angus Dawson: Climate change, justice and collective responsibility
	P16(b): Subrata Chattopadhyay: On decolonising western bioethics: Toward a bioethics sensitive and responsive to moral aspirations and needs of Indian people
	P16(c): Radhika Jadhav: The concept of health in <i>Ayurveda</i> : Implications for the discourse in contemporary bioethics
	P16(d): Deepesh Reddy Vendoti: Religious perspectives on end-of-life-care issues
	WS/S19: IMPACT OF NEW REGULATIONS ON THE FUNCTIONING OF ETHICS COMMITTEES: CONSTRAINING OR FACILITATING? Facilitators: S Swarnalakshmi, Y R Gaitonde Center for AIDS Research and Education/, Chennai, TN, India; Anant Bhan, Bioethics and Global Health, Delhi/Bhopal, Yenepoya University, Mangalore, Karnataka, India; Prabha Desikan, Department of Microbiology, Bhopal Memorial Hospital and Research Centre, Karond, Bhopal, MP, India
11:00 – 11:30 am	DAY 3 TEA BREAK
11.30 - 12.15 pm	DAY 3 PANEL CONVERSATION HEALING AND DYING WITH DIGNITY: MAKING IT POSSIBLE

	<p>Anchors: Manisha Gupte, Founding Trustee, MASUM; and Sunita Sheel Bandewar, FMES-IJME</p> <ul style="list-style-type: none"> • Roop Gursahani, Consultant Neurologist & Epileptologist, P.D.Hinduja National Hospital, Mumbai, MH, India • Lakshmi Lingam, Professor, Tata Institute of Social Sciences, Mumbai, MH, India • Veena Johari, Courtyard Attorneys, Mumbai, MH, India • Sadhana Tayade, State in-charge, MH, Non-Communicable Diseases, Mumbai, MH, India • Mary Ann Muckaden, Head, Dept of Palliative Care, Tata Memorial Centre, Mumbai, MH, India
12:15-1:00 pm	DAY 3 VALEDICTORY
	<p>Chairpersons: Thelma Narayan, Director, School of Public Health, Equity and Action (SOPHEA); Secretary, Society for Community Health, Awareness, Research and Action, (SOCHARA), Bengaluru, Karnataka, India Amar Jesani, Editor-in-chief, IJME, Mumbai, MH, India</p> <p>Summing up: Anant Bhan, Member, FMES and Researcher, Bioethics & Global Health, Bhopal; Deepa V, Member, Editorial Board, IJME and Director, Sama Resource Group for Women and Health, Delhi, India; Rakhi Ghoshal, Jt Secretary, FMES; Shyamala Nataraj, Member, MC, FMES; and Sunita Simon Kurpad, Member, MC, FMES, Professor of Psychiatry and Head Department of Medical Ethics, St. John's Medical College, Bengaluru, Karnataka, India</p> <p>Valedictory address: Mohan Agashe, Professor, Department of Psychiatry, B J Medical College and Sasson Hospital, Pune, MH, India; Founding Director, Maharashtra Institute of Mental Health, Pune, MH, India; Former Director, Film and Television Institute of India, Pune, MH, India</p> <p>Vote of thanks: Hemalata Pisal, Sunita Sheel Bandewar, and Leni Chaudhuri, Conference Organising Committee Members</p>
1.00 - 2.00 pm	DAY 3 LUNCH AND CONFERENCE CLOSURE
2.00 – 4.00 pm	DAY 3 [optional] Study Tour and Visit to the Cipla Palliative Care and Training Centre, Pune, MH, India

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PRE-CONFERENCE WORKSHOP THURSDAY, 12TH JANUARY 2017 TRANSITION OF CARE IN PATIENTS WITH ADVANCED AND LIFE LIMITING CONDITIONS; 9.00 AM TO 5.30 PM	
TIME	SESSION DETAILS
	Palliative care services in India are marred by several challenges. Lack of trained human resources, non-implementation of government's palliative care policies, limited availability of opioids, overtly curative nature of health care with minimal scope to address psychosocial needs of life-limiting conditions are some of the impediments for care. This workshop attempts to provide a holistic overview on transition of care with special focus on advanced care planning, medical interventions, ethical framework of care and legal dimensions in delivering palliative care services.
10.00 - 10.45 am	<p>Transition points in patients with advanced illness</p> <p>Speaker: Dr Mary Ann Muckaden, Head, Palliative Care Department and Professor of Oncology, Tata Memorial Hospital, Mumbai, MH, India</p>
10.45 - 11.30 am	<p>Decision making in advanced illnesses</p> <p>Speaker: Dr Shivakumar Iyer, Professor, Department of Critical Care, Bharati Vidyapeeth University Medical College, Pune, MH, India</p>
11.30 - 11.45 am	TEA BREAK
11.45 - 12.30 pm	<p>Advanced care planning and discussing goals of care</p> <p>Speaker: Dr Roop Gursahani, Consultant Neurologist and Epileptologist, P D Hinduja National Hospital, Mumbai, MH, India</p>
12.30 - 1.30 pm	LUNCH BREAK
01.30 - 2.15 pm	<p>Advanced medical communications in life limiting illnesses</p> <p>Speaker: Dr Nagesh Simha, Medical Director, Karunashraya, Bengaluru, Karnataka, India</p>
2.15 - 3.00 pm	<p>Ethical framework in palliative care</p> <p>Speaker: Dr M R Rajagopal, Founder chairperson, Pallium India, Trivandrum Institute of Palliative Care Sciences, Trivandrum, Kerala, India</p>
3.00 - 3.30 pm	TEA BREAK
3.30 - 4.15 pm	<p>Legal aspects of palliative care</p> <p>Speaker: Dr R K Mani, Group CEO and Chairman, Critical Care and Pulmonology, Nayati Super Speciality Hospital, Mathura, UP, India and Nayati Group of Hospitals</p>

ABSTRACTS

DAY 1 | FRIDAY, JANUARY, 2017 | 11:30 am – 1:00 pm

PARALLEL PAPER PRESENTATIONS

GROUPS P1 TO P6 & WS/S1 TO WS/S3

GROUP P1: PALLIATIVE CARE ETHICS - I: CONTEXT, POLITICS AND JUSTICE

P1(a): The end of life and injustice in healthcare

Alastair V Campbell

In this paper, I argue that discussion of ethics at the end of life must not be divorced from the wider question of injustice in healthcare *throughout* life. To give a clear focus to this claim, I shall be looking at a survey that was carried out by the *Economist* Research Unit for the Lien Foundation, Singapore, which sought to develop a 'quality of death index'. This interesting document lists a number of criteria across several categories (such as availability, quality and affordability of palliative care) and then ranks 80 countries on its index. Not surprisingly, wealthy countries as a whole do much better than poorer countries. (The UK comes out on the top and Iraq on the bottom of the scale; India, Pakistan and Bangladesh are all very near the bottom.) This has led me to wonder if the obsession with euthanasia and physician assisted suicide, which dominates much bioethics discussion about the end of life in the West, is not merely an indulgence of the rich, and a distraction from facing up to the massive injustices in international healthcare provision. I shall tease out this idea by looking in more detail at the assumptions and findings of the Death Index survey, and then showing that the core issue is related to social and economic realities, which deprive millions of people of the capability for health from the beginning to the end of their lives.

P1(b): Ethical dilemmas encountered by care-providers in a palliative care programme in urban Mysore

Sridevi Seetharam, Chaitra J, R S Rajan, Seeetharam MR

Background and Purpose: Palliative care in India is mostly community supported and home-based, driven by NGOs, charities or trusts. Since the dictum of Palliative care is affordable care and qualified professional care is expensive, programs are compelled to use semi-trained care givers with limited awareness in relevant medical, ethical and legal aspects. They regularly encounter disconcerting moral

situations that reflect the deep vulnerabilities of patients and their care-givers. Lack of access to formal ethics consultation or training also leave them ill-equipped to address ethical dilemmas.

This study seeks to explore and understand the ethical dilemmas encountered by care-providers in a palliative care programme in urban Mysore.

Description of research method: Qualitative case study research was conducted with IRB approval. Case studies identified by programme staff were explored through in-depth interviews to understand and frame the ethical dilemmas. The moral justification underlying their approach to the dilemma are explored and compared with contemporary ethical norms.

Results of research: The spectrum of ethical dilemmas identified include truth telling, conflicting medical opinions, allocation of limited resources, competing needs for empathy and respecting patient's wishes.

Discussion: Approaches that were in alignment and those deviating from contemporary ethical norms are discussed. Awareness, training and access to professional ethics consultations may support and increase the capacities of care-givers, protect the dignity of the patients as well as inform future policy.

P1(c) : Embodied pain and politics of palliative care: A sociological study in Calicut district, Kerala, India

Afeeda KT

Studies in medical sociology have critically engaged with the biomedical articulation of pain in our society. Theorists like Foucault (1973) analysed the historical development of biomedicine and shows with great precision the contingencies of the discipline and the institutional settings in which such knowledge is produced. Palliative care is an initiative within biomedicine which claims a deviation in its approach. It offers a holistic approach in biomedicine by adding non-medical factors like emotions, spirituality, economic and social. Palliative care proposes a new model of 'care' against individualistic biomedical care. In Kerala, palliative care is an emerging medical system with wider community participation. This study critically looks at the departing juncture of palliative care from biomedicine at both conceptual and practice level. This is a sociological enquiry to see whether Palliative Care is an alternative medical system in dealing with lived experience of pain and conceptualising the idea of care.

Detailed fieldwork was conducted with palliative care in Calicut district, Kerala. It explores the practice of 'holistic care'

at three delivery centres of care; clinical, in-patients and home care. Using embodiment as a theoretical framework the study problematises the perception and treatment of experience of pain from various networks of palliative care like doctors, nurses and community volunteers. The study finds a gap in the practice of palliative care in understanding the lived experience of pain where factors like language, caste, age, class etc matter and see how palliative care slips into larger politics of the care industry in the medical field.

P1 (d): Ethical dilemmas encountered in the administration of an NGO-based palliative care programme in urban Mysore

Chaitra J, Pushpa Gaikwad, R S Rajan, and Rekha Shanmukha

Most of palliative care in developed countries is provided through hospices or palliative care homes and supported by the government. In India, community-supported and home-based care is more common. It is mainly funded through NGOs, charities or trusts. In Mysore district, an estimated 20,000 people need palliative care. There is no state-sponsored palliative care program in Karnataka. Most of the terminally ill patients face an abysmally poor quality of life due to lack of access to palliative care. Five years ago, the Swami Vivekananda Youth Movement, an NGO involved in development, set up a free, home-based palliative care program. The program is implemented by a small team consisting of two nurses, two social workers and volunteer doctors. It is funded through pooled donations in cash and kind.

The program faced many ethical administrative dilemmas like setting priorities among the huge number of patients in need, delivering quality care with limited technical capacities of the team, balancing program needs with donor conditions etc. Free programs are conventionally directed at the desperately poor. But patients in middle and upper income group also request care. The paper elaborates on these dilemmas.

Palliative care programs in India are grappling with basic issues like sparse funding, limited technical skills and challenges in fair allocation of resources. Decisions are often arbitrary, emotionally driven, at spur of the moment, rather than based on any objective, principle-based analytical process. Increased awareness and training of the administrative personnel and governance bodies of NGOs would help in guiding the programs towards proper decisions. Principles drawn from public health ethics may strengthen the approach.

GROUP P2: END-OF-LIFE COMMUNICATION AND ADVANCE DIRECTIVES

P2 (a): Knowledge and attitudes regarding advance directives among doctors working at a tertiary care

hospital of Mangalore city: a pilot study

Prerna Shetty, Ravi Vaswani and Vijaya Hegde

Advance directives are written, legal instructions regarding the patients' preferences for medical care, if the patient is unable to make decisions for herself. Since, advance directives are relatively new in the Indian context, in spite of the Medical Treatment of Terminally Ill Patients (Protection of Patients and Medical Practitioners) Bill being introduced as a draft in the Parliament, and being found unsatisfactory, this study attempted to assess the knowledge and attitudes regarding Advance Directives among doctors working at a Tertiary Care Hospital of Mangalore City.

Institutional ethical clearance was obtained before the start of the questionnaire based cross sectional study. After obtaining informed consent, a close ended questionnaire was distributed to the doctors working in A. J. Hospital, Mangalore based on convenience sampling. Those doctors, who were willing to give consent, were included in the study.

56.7% of the study subjects agreed that patients must initiate discussions about life sustaining treatments. 46.7% strongly agreed that an advance directive limits the role of the primary care provider. 40% agreed that advance directives are appropriate only for the elderly while 53.3% agreed that patients would lose hope if advance directives were discussed during the time of illness. 50% agreed that the hospital was the ideal setting for the initial discussion of advance directives.

Advance directives honour the autonomy of an individual even when she is unable to consciously make decisions for herself. The study revealed that there is inadequate knowledge about advanced directives, and doctors thought that they are difficult to execute. Doctors also seemed reluctant to broach the issue of death and end-of-life planning. However, the ethical dilemma persists: does an individual have the right to die?

P2 (b): End of life communication: An imperative in providing ethical care

Bilkis Vissandjée and Wendy E Short

In Canada, an increasing number of women and men are realising their wish to die in the familiar surroundings of their own homes. As a result, provision of high quality, person-centred end of life care is likely to be an important part of the primary health care nurse's role. However, care at the end of life may present a number of legal and ethical challenges within primary care nursing practice, must be resolved in communication with patient, family and concerned healthcare professionals. In Canada, due to significant rates of immigration, the proportion of women and men who are unable to adequately speak the local dominant language while interacting with provided care services has increased tremendously over the past seventy years. In a clinical context, language is a primary medium for providing quality care and for ensuring the establishment of a trusting relationship; as also that consent for specific procedures is adequately

obtained, and that patient dignity is respected. Effective communication is therefore central to the provision of compassionate, high-quality nursing care, and resolving issues of communication challenges is key to achieving justice for women and men at the end of life.

Given that language is a special vehicle for attending to ethical norms in nursing, such as informed consent or respect for women and men's dignity, this presentation aims: **1.** To discuss the opportunity for an ethical nursing practice to consider unique challenges inherent in end of life care, and **2.** To highlight the challenges in providing end of life care with a conscious and sensitive approach to clear, respectful and effective communication

P2 (c): Last wishes and ethical dilemmas

Geetanjali Borse-More

Patients and their relatives often express last wishes, which though easy to fulfil, present ethical dilemmas. Some of the wishes are culturally driven, while others may be fanciful. Attempts to fulfil these wishes, is a part of palliative care, but these often conflict with end-of-life care. A number of patients or their relatives express last wishes of dying patients. The medical staff and others responsible for the care of the patient often differ in fulfilling these. More relevant is the discord that is more common among relatives about what should be done in that crucial period.

We describe a group of patients whose last wishes ranged from a sip of water to having a favourite food. Some of these are considered harmless and fulfilled; sometimes they go contrary to end of life practices and are denied. In either situation there is dissatisfaction among relatives and often discord among staff, which could be avoided. Palliative ethics demands precedence for the patients and their wishes. Medical and other staff must understand this and educate the relatives accordingly, well before the time comes. A consensus must be reached regarding what actions are to be taken and what are to be avoided. The primary care giver must be given the authority to take decisions, if necessary, without fear of blame. Last wishes are more important than extending life by minutes, unless the wish is likely to cause more agony. A guideline for ethics in palliative care may help in establishing a standard practice towards last wishes.

P2 (d): Futility of critical care in terminally ill cancer patients: A retrospective analysis of correlation between counseling and outcome in a tertiary level ICU

Malvinder Singh Sahi, Anupam Singh, and Bablesh Mahawar

Critically ill patients of progressive cancer being admitted to the ICU of a tertiary cancer hospital and their attendant families undergo severe physical torment and stress, be

it financial, psychosocial or related to quality of life. Our Intensivists and primary care oncologists conscientiously try to convince attendants about the futility of aggressive forms of treatment in selected cases, which are clearly or apparently beyond redemption. This retrospective study of 100 such cases of progressive disease requiring only palliative/ end of life care will analyze the factors and features of these cases where attendants were convinced, as a result of the counseling, about need for limiting aggressive care. The study will also calculate the percentage of cases having a fatal outcome and attempt to discover the effectiveness of counseling utilizing Confidence Intervals. Families of patients with poor financial status, lack of insurance cover and where early effective counseling was performed readily agreed to limit aggressive therapy to their patients. Discussions based on results lead to issues of development of guidelines and advisories for physicians to initiate talks and counseling early in the course of disease so that ethical principles of beneficence, judicious use of precious critical care resources and patient autonomy are satisfied.

GROUP P3: HEALTH SYSTEM AND PUBLIC HEALTH ETHICS - I: PREVENTION AND CONTROL OF DISEASES

P3 (a): Maintaining balance: Ethical dilemmas of frontline TB workers in implementing the DOTS strategy in India

Solomon Salve and John Porter

The Revised National Tuberculosis Control Programme (RNTCP) in India depends on Frontline TB workers (FTWs) for implementing the Directly Observed Treatment Short-Course (DOTS) policy for the control and treatment of tuberculosis. They are an important link between the public and the private health system, and the patients. This paper explores ethical dilemmas FTWs face in their daily practices while implementing DOTS at a sub-district level.

The data was collected between November 2010 and December 2011 in a district of a southern Indian State, employing participant observation, informal interactions and in-depth interviews with 24 FTWs working with TB Units.

The FTWs often worked in resource-limited settings and, at the same time, were under pressure to achieve programme targets. They used informal ways to achieve targets -data manipulation, registering patients outside TB units, and seeking informal referrals from private practitioners. Although on one hand these strategies were seen as a mechanism for 'maintaining balance' in reporting and recording that would save them from being reprimanded by those higher ups, on the other hand they felt regret about their manipulative actions. As a result, FTWs seemed to be working with an ethical dilemma.

From a top-down perspective, the practices of FTWs can be viewed as a violation of policy guidelines, however, from a bottom-up perspective their actions demonstrates their ability to cope with pressure and to make the DOTS strategy work.

Nonetheless provision of adequate resources will lessen their pressures and reduce the ethical dilemmas they face.

P3 (b): Less on prevention, more on cure: Exploring the ethical responsibility of public-private partnerships (PPPs) in malaria eradication

Pallavi Mishra

In the last few decades Public Private Partnerships (PPPs) were begun to be seen as a viable option to control and eradicate malaria from the endemic regions of Low and Middle income Countries (LMICs) in Africa lacking minimum public health infrastructure. Drawing from the operationalization of Global Fund to Fight AIDA, Tuberculosis and Malaria (GFATM) and Medicines from Malaria Venture (MMV) this paper tries to understand the ethical responsibilities of these PPPs in eradicating malaria from the endemic regions of Africa.

This exploratory study relies majorly on literature review and a few Key Informant Interviews (KIs) of the officials of GFATM, MMV and global malaria policy makers from the World Health Organization.

GFATM and MMV are two of the big and resourceful PPPs working for malaria control in the endemic regions. GFATM is an issue based partnership, whereas MMV is a product development partnership. In the last twenty years these partnerships are making efforts to provide treatment to malaria patients in the region; however malaria eradication still seems a faraway dream. Essentially both these partnerships have been focusing more on curative care and less on the prevention at local level. Their efforts are more towards expanding the drug market by making drugs available at cheaper costs, but there is no focus on prevention of malaria. The stipulated goals and resources used by these PPPs make them liable to be ethically responsible while drawing up their malaria control strategies. Until these PPPs take the ethical responsibility of adopting measures like strengthening local infrastructure and preventable vaccines malaria can never be eradicated.

P3 (c): Invisible numbers and unknown diseases: The absence of data on occupational health conditions in India

Jagdish Patel and Siddarth David

Rapid industrialization in India has employed millions of people, however, the largely unorganized nature of labour, frail socio-economic conditions of the workers and limited access to healthcare makes occupational health and safety a critical public health issue. Moreover, the absence of clear policies, poorly enforced regulations and lack of systematic reporting of occupational diseases severely limits the process of evidence-building and developing solutions to address this issue in India.

This study critically examines existing legislations, available reports by different agencies like the Ministry of Labour

and Employment, the Directorate of Industrial Safety and Health, National Human Rights Commission on occupational health and information sought through from filing of petitions under the RTI (Right to Information) Act by different activists to understand the issues in collecting data, gaps in the current laws and inadequacies in information on occupational diseases. It would also use 4 case studies based on the empirical work done by the authors from the heavily industrialized state of Gujarat to elucidate how this impedes the process of identifying, treating and compensating occupational diseases in India.

These are in clear violation of the International Code of Ethics for Occupational Health Professionals, of which India is a member, on key principles such as protecting the life of the worker, discharging duties impartially, acquiring competence and maintaining independence. Most importantly it highlights how the ethical obligation to have good quality data for data driven decision making in occupational health is grossly ignored in the Indian context where policy makers aspire to make the country a global manufacturing powerhouse.

The study emphasises the need to expand the scope of existing laws and regulations to improve data-capturing mechanisms and better respond to occupational health in India. It advocates the formulation of strong guidelines based on the principles of ethics to ensure workers' health and safety.

P3 (d): Ethical issues to be considered in vaccination programmes: A review article

Prabha Thangaraj and Sudha Ramlingam

One of the greatest public health achievements is vaccination. Implementing vaccination programmes often precipitates vigorous discussions on ethical issues, especially among parents and guardians of infants and children targeted to receive the vaccines. Vaccines have features distinct from that of a drug. They are mainly used for prevention against disease and that too on healthy individuals, mostly children and infants. The key ethical debates related to vaccine regulation, development, and use generally revolve around: (1) mandates, (2) research and testing, (3) informed consent, and (4) access disparities.

Data sources used to select article were - MEDLINE, PubMed and Google scholars. Studies related to ethical issues in vaccination published after 2006 were found using the key words- vaccines, vaccination, immunization, ethics, ethical issues, consent and vaccine, research and vaccine, mandate and vaccine access. Only those articles freely available were selected. The search resulted in 22 published articles. Based on the review of these articles the issues that emerged for discussion were the following. While making certain vaccines mandatory, the autonomy of the individual is at stake. Obtaining informed consent for research purpose and administration of vaccines is essential. Ethical issues in obtaining consent during emergency period. Vaccine trial among children should be done only if that disease is

prevalent in that locality. When vaccine supply is limited, priority is given to children and health care workers.

Epidemiological analysis is essential before making vaccine mandatory. Study design for testing vaccine has to be carefully chosen. Informed consent should be explained in detail to the parents or care givers.

GROUP P4: ORGAN DONATION: ETHICS AND LAW

P4 (a): End-of-life care and deceased organ donation

Dominique E Martin

Despite the value of deceased organ donation, and the severity of unmet demand for organ transplantation, many donation opportunities are missed during the provision of end-of-life care to potential donors. Several factors facilitate donation opportunities; in particular, the attitudes and beliefs of physicians involved in end-of-life care. Physicians may experience ethical dilemmas that discourage efforts to facilitate donation opportunities, such as concerns about potential conflicts of interest in end-of-life decision-making and allocation of intensive care resources. End-of-life care and ethical dilemmas at the end-of-life are often regarded as highly individualised concerns, and physicians may struggle to integrate consideration of the societal dimensions of end-of-life decision-making in practice and in policy-making, particularly where conflicts are perceived between the interests of dying patients and of those in need of organs for transplantation.

Ethical dilemmas: I argue that physicians have a prima facie professional obligation to routinely consider and facilitate opportunities for deceased donation during end-of-life care. I discuss concerns about conflicts of interest and allocation of healthcare resources, and identify circumstances in which these concerns may justly override obligations to facilitate donation.

Results of ethical inquiry: Where deceased donation programmes are integrated into systems of end-of-life care, and decision-making at the level of clinical practice and policy, many of the dilemmas currently experienced by physicians may be eliminated or reduced.

Discussion: Although the interests of individual patients in end-of-life care remain paramount, physicians involved in end-of-life care must recognise the interests of individuals and their families as socially embedded.

P4 (b): Ethics of organ allocation: Who should get the organ?

Sumana Navin, Sunil Shroff and Sujatha Suriyamoorthi

WHO Guiding Principle 9 (Distributive justice and equity) relating to organ donation and transplantation states that donated organs should be made available to patients based

on medical need and not financial or other considerations. Families of deceased who are potential organ donors often ask “who will get the organ?” while patients on a waitlist for a deceased organ transplant are anxious about the criteria for listing and prioritization. There are different priorities and categories. For instance, certain transplant waitlist registries award extra points to paediatric patients who are given priority during organ allocation. In case of liver transplants for alcoholics, most hospitals insist on an abstinence period of at least six months and a psychiatric evaluation before listing a patient. Some families of deceased donors agree to donate only if an organ is given to a relative; others make a request unconditionally. The ethical dilemmas that arise here are as follows: (a) Should paediatric transplants get priority over adult transplants?, (b) Should a non-alcoholic get priority over an alcoholic for a liver transplant?, (c) What should be the approach in conditional or directed donation?

In deceased organ donation there needs to be ‘ethical justice’ in transplanting to the ‘best’ recipient since it is an altruistic act by the donor’s family. The ethical principles in allocation encompass utility (patient/graft survival, quality of life, age), justice (medical urgency, waitlist time, geographical fairness), and respect for persons (right to refuse an organ, allocation by directed donation, and transparency of processes and allocation rules).

P4 (c): Financial incentives to donor families: Ethical issues

Muneet Kaur Sahi

The concept that financial incentives be offered as a potential solution to the ongoing organ donor shortage has been previously considered and debated among experts in the fields of transplantation, ethics, law & economics. The background for the proposal remains the ever-growing need for increased organ acquisition and the undeniable fact that the current system, despite 20 years of experience based on altruistic donation, has yet to meet this need. A financial incentive for deceased organ donation could be accomplished by direct payment for organs, waiving of the donor’s hospitalization costs, reimbursement for funeral expenses, and various proposals to support the donor’s family members, including preference in jobs, free lifelong railway passes and support for children’s education. The Transplant law in most countries disallows incentives for organ donation except in Iran, but even with their legal payment system many ethical problems persist with the Iranian model.

Arguments in favor of financial incentives for organ donation are founded in the hope that such a system would increase the supply of organs and thereby secure the basic ethical concern of saving lives that may otherwise be lost due to the lack of this resource. Compelling arguments against financial incentives for organ donation have also been made, practical questions as to the source and amount of compensation, when during the process it would be offered, and how the system would be

administered are raised first. Instituting financial incentives to encourage organ donation is a contentious and controversial issue because any form of compensation inevitably commodifies the act of donation. Pilot studies, public surveys and polls need to be carried out and until supportive data becomes available that is universally accepted as accurate and representative, the feasibility & effect of financial incentives for organ donation remain questionable.

P4 (d): Kidney transplantation: Ethical issues in law and medical practice

Nehal Shah

The Transplant of Human Organs Act 1994 was passed to prevent commercial dealings in organ donation. Under the Act, for living kidney donations, only near relatives may donate or unrelated individuals can donate for altruistic reasons without any commercial transaction. Yet recently, the police intervened in a case of an illegal kidney transplant between an unrelated recipient and donor shown as husband and wife respectively at Powai's Dr L H Hiranandani Hospital on 14th July 2016. This case is part of larger kidney racket flourishing despite the law. Statistics show high demand for kidney transplants and poor supply of organ donations. Even among organ donations occurring, those from deceased donors form a paltry number compared to living donors. Such situations become a perfect breeding ground for a racket where middle agents help rich kidney recipients find poor donors as kidney sellers. To prevent such illegal transplants from occurring, the law defines the role of a hospital and the medical profession in verifying the true relationship, protecting the interests of donors and informing them about risks involved. The medical profession has opposed the provisions of the law in same vein as they have all other regulations. Based on legal interventions made available to the kidney donor in Hiranandani case, we examine larger issues with the law, its implementation and the role of all stakeholders involved. It raises questions on the culpability of various people involved in such cases. It raises ethical discussions on responsibilities of doctors and the stand of medical fraternity in the matter.

GROUP P5: GENDER & ETHICS

P5 (a): A study of the physiological and psychological impact of sexual harassment on victims with reference to the POSH Act 2013

Sadhana Khati and Anjali Pashankar

Background and Purpose: The presentation will give a landscape review of sexual harassment in India with specific reference to the landmark case of Bhavari Devi, and the consequent Vishakha guidelines, Convention on Elimination of Discrimination Against Women (CEDAW) and the Constitution

of India. The purpose of this presentation is to highlight and present the granular reality of the Sexual Harassment of Women at Workplace (Prevention, Prohibition and Redressal) Act, 2013 ("Prevention of Workplace Sexual Harassment Act" –POSH 2013) in terms of acceptance, awareness, implementation and impact of the law among various corporates in India as well as government enterprises.

Description of research method or ethical issues / dilemmas: The methodology being used is case study approach. The ethical issues referred will be breach of constitutional rights of women under section 14, 15, and 21 as well as corporate governance.

Results of research or outcome of ethical inquiry: Lack of comprehensive awareness of sexual harassment among women and men employees due to compliance-oriented attitude of corporates, less to no prevention activities and paternalistic social norms have made sexual harassment or similar behaviors acceptable and intuitive in men. Corporates tend to look at sexual harassment as a personal matter not related to workplace, while others view it as just another law for women and a headache to deal with. This has a negative impact on the hiring of women at workplace which in turn affects the mental and physical state of women's health due to the pressure to earn and survive.

P5 (b): Vulnerability, misogyny and medical practice: Fault lines of ethical violations

Teena Xavier, Akhila Vasan, and Vijaykumar S

Exploitation and objectification of women's bodies by the medical fraternity has reached epic proportions with increasing commercialization of health care and continued vulnerability of poor Dalit women. KJC activists undertook a fact-finding exercise after they observed rising number of hysterectomies in their area of work in Kalaburagi district. This paper draws data from the fact-finding exercise of the Karnataka Janaarogya Chaluvali (KJC) where 707 women who had undergone hysterectomy were line listed, a subset of 82 women interviewed and 69 medical records reviewed by an independent panel of experts.

KJC's fact-finding exercise found that 98% of the hysterectomies were conducted by private doctors who had misled women (half of whom were less than 35 years of age) to undergo hysterectomies by providing grossly unscientific information to create fear of 'cancer'. More than two-thirds of the hysterectomies were assessed to be 'unwarranted'. 83% women reported continued health problems and three women (<25 years of age) had died following hysterectomy.

In addition to flouting standards of good clinical practice, the private doctors were also guilty of several other gross ethical violations and medical misconduct such as withholding information and failure to make necessary referrals, performing appendectomy along with hysterectomy without consent, trivialising women's problems, victim-blaming and violating women's dignity and bodily integrity.

A patriarchal, commercialised medical profession has reduced women to their constituent parts, either pathologising or trivialising their health issues to suit its "business" interests. The medical profession is fuelling and unabashedly 'cashing' in on the misogynist culture that views women's bodies and biological processes as polluting.

P5 (c): Why Pakistani female graduates do not practise medicine: Complex interplay of socio-cultural factors

Sualeha Siddiq Shekhani and Farhat Moazam

In 1995, Pakistan introduced an open merit system for medical college admissions replacing a policy limiting female admissions to 30%. As a consequence, currently 70% to 80% of students admitted to medical colleges are women, of whom a majority does not practise following graduation. Considering this to be a major reason for physician shortages in the country, in 2014 the Pakistan Medical and Dental Council (PMDC) recommended restricting female admissions to 50%, a recommendation currently stayed by a ruling of the Lahore High Court. The aim of our qualitative study was to explore with students the paradox of increasing numbers of women entering medical colleges yet failing to practise medicine, and whether they believe the PMDC recommendation would resolve the problem.

Twenty in-depth interviews and two focus group discussions were conducted with final year medical students from four medical colleges in Karachi. Our findings reveal that while parents encourage higher education for their daughters, favoring medicine over all other fields, this is largely perceived as "a safety net" in case of problems following marriage, rather than a step to a career in medicine. Moreover, norms of early, arranged marriages lead to uncertainties for women in planning careers due to the strong influence of husbands and in-laws. However many female students also perceive their role as mothers to be empowering and give precedence to home over careers. Males are accepted as "bread winners" while earnings by females are considered "optional." Dissenters complained of lack of appropriate social and state assistance to address hurdles for women who wish to combine a career with family life. Respondents also highlighted a lack of PMDC focus on the reasons behind large numbers of male graduates going abroad.

P5 (d): Consent/ assent and confidentiality issues in studies on institutionalised adolescents living in Integrated Child Protection Scheme homes in Kerala

Sumitha TS

The Integrated Child Protection Scheme (ICPS, 2009) aims to reduce the vulnerabilities of and rehabilitate children at risk. A cross-sectional study of children in ICPS homes in Kerala was attempted and this raised several ethical dilemmas. The study

aimed to measure the individual and social-environmental level protective factors for mental health of institutionalized adolescents. Subjects included inmates in the age group 12-18 years who are living in ICPS homes in Kerala.

The study raised consent/assent process and confidentiality issues as data could only be collected in the presence of the superintendent or an official authorized by the superintendent in the concerned home. Overall clearance for the study was given from the Director, Social Justice Department, while consent was to be obtained from the official who was present during the study and then each child was requested to give assent/dissent. In some of the homes, the temporary staffs were made to issue the consent. As the norm for such children is that they should not disclose their identification details, the embarrassment was high among them when requested to give their assent or dissent. As the law itself has imposed several restrictions, it was quite difficult to implement the study. The implication to ethics is whether it is ethical for mainstream research to sideline such difficult studies, given the practical difficulties in conduct of such studies.

GROUP P6: EDUCATION / TRAINING AND EMPIRICAL RESEARCH IN BIOETHICS

P6 (a): Professional autonomy and moral resilience among health professionals: a descriptive cross-sectional study

M Varalakshmi

Background and Purpose: Caring for patients and their families in their vulnerable moments is a great challenge to healthcare providers. Moral distress occurs when healthcare professionals cannot carry out what they believe to be ethically appropriate for patient care. Imbalance between authority and responsibility, frustrating patterns in healthcare teams and the inability to make ethical decisions for patient care are more commonly associated ethical dimensions for practice resulting in moral distress.

Description of research method: Registered Nurses (RN) (n=65) and physicians (n=25) between the ages of 22-58 years, with a minimum of two years of work experience, working in a government urban area hospital, who were willing to participate were included in the study. After securing informed consent, data was collected on demographic information and on moral distress and job satisfaction.

Results of research or outcome of ethical inquiry: The mean scores were found to be 90.86 in nurses and it was 60.85 in physicians. 68% of the nurses and 52% of the physicians were not satisfied with the quality of patient care provided. Among them 69% of RN expressed powerlessness in decision making, while 8% of the physicians agreed on the powerlessness experienced in patient care decision making. 58% of the nurses

were dissatisfied with the type of decision-making in patient care; whereas 58% of the physicians were fully satisfied with patient care decisions implemented.

Discussion (relate to bioethics principles and theories) and implications for bioethics: Considering the relationship between moral distress at work and job attrition, a significant relationship is found between increased moral distress and poor job satisfaction. A study by (Zuzelo, P. R. (2007)⁷ discusses the strategies for resolving moral distress, which in turn lead to a lower employee turnover, greater organisational commitment, and better job performance. This in turn translates into an atmosphere of positivity and consistency with professional and ethical mandates and improved resilience in health professionals.

P6 (b): Emotional intelligence for clinical care: A report of a fishbowl discussion among medical students in clinical training

Vijayaprasad Gopichandran

Background: Emotional Intelligence is the capacity of a person to be aware of, control and express one's emotions and to handle interpersonal relationships by appropriately responding to other people's emotions. Teaching emotional skills and empathy in medical school has always remained an enigma.

Purpose: To facilitate a fishbowl discussion on the role of emotions in clinical care and understand the perceptions of medical students about emotions.

Methods: A fish bowl discussion was organised among students studying in the sixth semester of the MBBS course in a college in Chennai. A total of 86 students participated in the discussion comprising of 50 women and 36 men. The entire discussion was recorded and transcribed verbatim for documentation purposes. Thematic analysis of the transcript was performed by the facilitator.

Results: The students perceived that being emotionally intelligent encourages empathy, trust, comfort, satisfaction, support and patience. Some students also perceived that expressing their emotions to patients communicated incompetence, can breach the patient's privacy, lead to loss of objectivity in decision making, impair efficiency of performance and can lead to paternalistic attitudes. Another theme that emerged was the inevitability of emotions in clinical care.

Discussions: There is a wide variety in the viewpoints of students about the role of emotions in clinical care, which cognitive reflection exercises like fishbowl technique can bring out effectively. Sensitising students to the importance of emotions in medicine should happen very early in their training. Emotional competence will improve quality of clinical care and hence is an ethical responsibility.

P6(c): ISCCM online survey of End-of-Life Care practices

*Shivakumar Iyer, Jignesh Shah, Prashant Jedge and members of the Expert ISCCM Committee**

Background: Patients and care providers in India face a range of ethical dilemmas in end-of -life care (EOLC) in ICUs often resulting in poor patient care. Despite the ISCCM and IAPC guidelines on EOLC there is surprisingly little data on the attitudes of intensivists to EOLC. The recent draft bill titled 'Terminally Ill Patients (Protection of Patients and Medical Practitioners) Bill' by the government of India would help to offer a legal framework that safeguards interests and rights of patients as well as those of healthcare providers. Against this background, we present the findings of an online survey on EOLC practices in India amongst intensivists. We aimed to understand them with reference to do-not-resuscitate, withholding/withdrawing therapy, discharge against medical advice (DAMA), using living wills/advance directives and the use of "slow code".

Methods: We defined the terms related to EOLC by reviewing the literature and developed a survey questionnaire through an online consultative Delphi process amongst members of an expert committee of the ISCCM. The questionnaire was pre-tested and then circulated by a link sent on email to potential participants from the ISCCM database.

Results: 6333 emails were sent to all ISCCM members and we received 630 responses. 438 responses were complete. Respondents were predominantly male, Hindu and from an urban background. The type of hospital respondents were working in was predominantly private hospitals with a lesser number of public or trust hospitals. Most units had a director, full time intensivist, 1:2 nurse to patient ratio and some form of accreditation or teaching training programme for critical care. (NABH, JCI, National Board, MCI, ISCCM).

The most common EOLC practice was withholding/withdrawing therapy followed by DNR. LAMA/DAMA was also a common practice. Living wills or advance directives were noted in relatively fewer respondents. Slow code was practised by 34% of respondents. Most respondents felt that EOLC practices could be implemented with consent and documentation in a transparent manner with or without an ethics committee. About 10% felt it could not be done as there was no relevant law. Commonest causes for EOLC decisions were terminal chronic organ failure and sepsis with multi system failure. Many respondents reported that inability to afford treatment influenced EOLC decisions. Lack of a relevant law and the fear of law were the commonest reasons cited for not practising EOLC. Most respondents reported a need for change in the MCI code of ethics with regard to EOLC. Most felt that even after brain death family consent is required before withdrawing life support. Most respondents also agreed that WH/WD in critical care was different from euthanasia or stopping support for brain dead patients and that it should not be called passive euthanasia.

Discussion: There was awareness and broad agreement amongst respondents about the ISCCM guidelines but the practice of LAMA/DAMA and the slow code and the fear of law suggest that a change in the code of medical ethics and creation of a law will help improve ethics in EOLC practices in India. Financial issues play an important role in deciding futility and initiating End of Life Care in ICU's

*Members of the expert committee

Dr. Raj Mani, Dr. Jigi Divatia, Dr. Sheila Myatra, Dr. Subhash Todi, Dr. Dhruva Chaudhry, Dr. N. Ramakrishnan, Dr. Rajesh Chawla, Dr. Sriram Sampath, Dr. Ram Rajagopalan, Dr. Farhad Kapadia, Dr. Dilip Karnad, Dr. Atul Kulkarni

P6 (d): Roles and responsibilities of members of ethics review committees: Individual perspectives

Aditi Apte

Background and Purpose: Scientific and non-scientific members of ethics committees make a distinct contribution to the ethical review of research proposals in order to protect the rights and safety of participants. This survey was conducted to assess the views and perceptions of members of ethics committees (EC) regarding the role and responsibility of each member and the extent to which they were being fulfilled.

Description of research methods: A validated questionnaire was administered to members of ethics committees in the city of Pune through an internet survey. The questionnaire had three parts - information regarding the member; perceptions regarding roles and responsibilities, and the extent to which the member believes these are being fulfilled. Responses were analysed using standard statistical methods.

Results of research: The responses were mailed without revealing the identity of the individual participant. Results showed that most members understood their roles and responsibilities on the EC, but left a lot to be desired in fulfilling them. They suggested methods for improving the contributions of members and these will be discussed.

Discussion: We have come a long way on the road to ethical conduct of research, but we still have a lot to achieve. The proper selection of members, adequate training and commitment to their work will ensure a higher level of ethical oversight.

WS/S1: Palliative and end-of-life care: challenges and opportunities

Facilitators: S Stephen Jayard, John Karuvelil, SJ, Nishant A Irudayadossan, and Charles Davies, (All from Jnana-Deepa Vidyapeeth, Pune, MH, India)

Palliative and end-of-life care aims at providing relief from pain and suffering for patients, helping them to face death with dignity and serenity. It provides a supporting system to the family of the patients to deal with a stressful situation. As modern technologies make the prolonging of one's life

possible, several questions arise: How long should we allow the patient to live, especially in a vegetative state? If medical treatments are unaffordable, are the families morally bound to spend on patients with hope of recovery?, is it justifiable to invest scarce resources in trying to save such patients? What is the fundamental value of human life? The whole process of caring for the patients and the families is to be seen in a wider context. Death is to be befriended rather than seen as an enemy.

Discussion on the well-being of the sick, the suffering and the dying becomes more crucial in the present times, of the 'use-and-throw' culture, as they are generally seen as burdensome to families and society.

In order to bring a deeper awareness about the value and dignity of human lives, from conception till cremation, this workshop seeks to approach the theme from moral, religious and spiritual perspectives, with a special focus on Hindu, Christian and Jewish religious traditions.

Format of the workshop: Four speakers below will speak for 15 minutes each on the stated themes, to be followed by 30 minutes of discussion: (1) Charles Davies: Perspectives of Bio-Medical Ethics; (2) John Karuvelil, SJ: Hindu and Christian Traditions; (3) Nishant A Irudayadossan: Perspectives of Jewish Moral Philosophy; (4) S Stephen Jayard: Perspectives of Spirituality.

WS/S2: Legal and ethical issues in palliative care, end-of-life care and euthanasia

Facilitators: Veena Johari, Vivek Divan and Kajal Bhardwaj, Health, Equity and Law Project

With advancement of medical science, although life may be prolonged, this does not ensure that the quality of life will improve. There has been much debate on the right to life as being inclusive of the right to die. Earlier judgments of the Supreme Court in India did not recognize the right to die as part of the right to life. However, in 2011, the court gave assent to passive euthanasia.

Other countries like the Netherlands, Belgium, Switzerland, etc. have legalized euthanasia to some extent. This workshop shall highlight the Indian Supreme Court's position, and provide an overview of the extent to which end-of-life care and how the processes followed in that context are laid out in other jurisdictions.

End-of-life care raises a gamut of legal and ethical issues, which will be raised and discussed in the workshop. For instance, effective and humane end-of-life care sometimes requires key pain-reducing drugs to be prescribed for patients. However, the law can pose a barrier in obtaining such drugs, as more often than not these are considered banned narcotic and psychotropic substances, thereby preventing their availability for end-of-life-care. How should legal frameworks address these contradictions?

Other questions will include: should the right to die with

dignity be recognised as a fundamental right under the Indian Constitution? Should there be a law on end-of-life care, euthanasia? What legal ethical issues – both substantive and procedural – need to be addressed in such a law? (The latter questions will be informed by two draft laws presently being discussed by stakeholders.)

Format of the workshop: The workshop will be interactive, providing basic knowledge on the law, constitutional rights and principles, law relating to Euthanasia in India and abroad, law as a barrier / facilitator for end of life care, palliative care and for euthanasia. Presentations will be around Constitutional rights and duties, legal and ethical issues relating to end of life care, palliative care and euthanasia. Law relating to euthanasia, end-of-life care in India and in other countries, availability of drugs, healthcare provisions, etc., and whether there should be a law relating to the issue shall be discussed in detail.

Three short presentations of 15 min. each, leaving about 45 min. for discussion and debate.

WS/S3: Dissemination Of The National Ethical Guidelines For Biomedical And Health Research Involving Human Participants by ICMR-WHO

Facilitators: **Roli Mathur**, Scientist-E and Head, ICMR Bioethics Unit, National Centre for Disease Informatics and Research (NCDIR), Indian Council of Medical Research, Bengaluru, Karnataka, India; **Nandini Kumar**, Former Deputy Director General Sr. Grade (ICMR), Dr. TMA Pai Endowment Chair, Manipal University, Adjunct Prof., Kasturba Medical College, Manipal; and **Madhur Gupta**, Technical Officer-Pharmaceuticals, WHO Country Office for India, New Delhi, India.

ICMR has been on the forefront in setting the standards for

ethics in biomedical and health research in order to safeguard the rights, welfare, safety and well being of human participants in research. With the recent developments in science, technology and medicine, there are emerging ethical concerns; and since it has been a decade since the last guidelines were released, the need to update the document was widely realised. After a series of meetings and deliberations, a draft was prepared by members of the 12 subcommittees; further deliberated upon; and finalised by an expert advisory group at ICMR. The finalised draft was made ready for public consultation and posted on the ICMR website for a period of 10 weeks, to invite comments from all interested stake holders. A large number of comments were received. Every comment was deliberated upon and efforts were made to incorporate the useful suggestions. The document was also harmonised with the recent amendments in the Rules for the Drugs and Cosmetics Acts. The revised draft guidelines now has 13 sections and a number of newer topics have been added. The revised document has received appreciation from a large number of experts.

To further improve the process of consultation, ICMR in collaboration with WHO-Country Office for India had organised a consultation meeting- Regional Consultation in Bangalore on Oct 4, 2016. Thereafter the guidelines were reviewed and approved at the National Consultation Meeting on Dec 14, 2016. In order to initiate the process of dissemination, a session is being planned at the National Bioethics Conference, 2017, with support from WHO-Country Office for India. It is expected that the revised guidelines would be received well, adapted, used and would fulfill the needs and requirements of the research community in line with the ethos of our culture and thereby support the ethical conduct of research in India.

DAY 1& 2 | FRIDAY& SATURDAY, JANUARY 13 & 14, 2016 |

1:30 pm to 2:00 pm

POSTER PRESENTATIONS

Poster 1: Ethical issues in disaster site mental health research: A case example

Avinash De Sousa

Disaster mental health services have not been fully developed in India. The present poster illustrates a real ethical scenario as experienced by the author when he tried to initiate mental health research in a disaster site in India. Post the Uttarakhand floods, the author sent a team of doctors (psychiatrists) to help out in the disaster rebuilding and healthcare activities in the area. It was also decided that a research study be conducted while the doctors were positioned there. The institutional ethics committee approved the proposal from an ethical point of view but mentioned that it cannot give full ethical clearance as a local ethical committee would be in a better position to do so. No ethics committee is present at disaster sites for research clearances and the ethics committees from local medical colleges in Uttarakhand shunned us away saying that we were from another city and not locally based. The author in this poster reviews the various ethical dilemmas experienced in the disaster mental health setting in India and illustrates the practical problems faced by sincere researchers at the ground level.

Poster 2: Auto-euthanasia wishes in a geriatric couple: Ethical and clinical issues for the treating doctor

Avinash De Sousa

This poster provides the ethical and clinical elaboration of auto-euthanasia in elderly couples, a previously unexplored phenomenon in the Indian perspective. A couple undergoing treatment for geriatric depression with a psychiatrist, strongly wish to die together at a self-directed moment, despite not suffering from a life-threatening disease but having moderate depression. The couple is living by themselves and all the children are abroad. The poster elaborates their mindset, experiences and considerations prior to such a decision. The couple was counselled using an existential-cognitive behavioural and philosophical perspective. Auto-euthanasia with self-determination and a wish to die is presented here in the light of geriatric mental health issues and the growing emptiness seen in old age due to aging and loss of physical mobility and the empty nest syndrome with no children or grand-children around. The decision to end life is largely based

on the anticipatory fear of further deterioration and no help being available and being bedridden leading to painful and sad death as well as how one would live without the other depending on whose death occurs first. The couple's need for auto-euthanasia was an obstacle that had to be overcome and their concerns differed from the concerns voiced by the treating psychiatrist. The role of depression in leading to their need for auto-euthanasia is also questioned. This poster elucidates the clinical, ethical and practical implications for geriatric mental health professionals and family medicine doctors when working with such cases and the relationship between depression, auto-euthanasia and the psychology of aging is traced.

Poster 3: Initiatives for promotion of research ethics

Manjiri Joshi and Ravindra Ghooi

Background and Purpose: Ethics committees are responsible for ensuring that biomedical research on human subjects is done ethically. This requires an initial review and approval of the research project and continued oversight till the end of the project and even beyond it.

Description of research: All over India there are around 1100 ethics committees of which 59 are in Pune. Forty three committees are institutional and 16 are independent. One of the hurdles of ethical review is the competency of the committees. Ethics is a subject that finds no place in medical and scientific curricula. Unlike the US where a definite level of competence is required of EC members, there is no such requirement from either ICMR or the Drugs Controller General of India.

Results of research: A number of EC members of the city met in 2013 to establish an organisation which would have training of ECs as one of its main functions. This group 'Ethical Research Initiatives' is registered as a non-profit organisation with the registrar of societies.

Discussion: The organisation helps in setting up, registration and re-registration, training, audit of ECs and providing advice to individual ECs when faced with problems. Going by the Pune experience we suggest the setting up of similar organisations elsewhere.

Poster 4: Affirmations: A mechanism for coping

Aruna Deshpande and Parikshit Patil

Background and Purpose: Stress, sickness and death is inseparable from life, and a person who can cope with these

has a better quality of life compared to one who cannot. Helping patients cope with disease and the associated problems is an important part of palliation that our centre specializes in.

Description of Research Method: A variety of techniques are used for coping, and patients are encouraged to pick up one that suits them best. Different patients pick different techniques or develop one that they think is new. We collated the experiences of five patients who used this method.

Results of Research: Five patients used affirmations, two chose and followed them, and two used them to counsel their fellow sufferers, while one maintained a diary, which he circulated in the ward. The last patient was an introvert who spent most time in reading, but later became social, wrote prolifically and even published his thought in the local newspaper.

Discussion: Affirmations become instruments of empowerment, and patients benefit from them. These patients experience an improvement in the quality of life, and have satisfaction at the end of life. Becoming mentors gives patients a sense of control which they enjoy. Affirmations also help patients cope with the disease, an important step in ethical palliative care.

Poster 5: "S/he is all I have": Ethical dilemmas in caregiver insistence for continuing care in incapacitated palliative care patients

Sreedevi Warriar and Raviprasad Varma P

Background and Purpose: Many patients reach palliative care settings in conditions where they are unable to communicate their wishes on further medical treatment. Several ethical dilemmas arise when caregivers become the primary decision makers for such patients.

Description of ethical issues / dilemmas: This case study reflects on two situations in palliative care practice where the spouse of the patient has insisted on continuing medical treatment and keeping the patient alive as long as possible.

Outcome of ethical inquiry: This case study looks at situations faced by the palliative care team while caring for Mr X, 62 years, a stroke survivor with coronary artery disease and on tracheostomy, Ryles tube feeding and urinary catheter; and Mrs Y, 63 years, with motor neuron disease. There is no way to comprehend what Mr X or Mrs Y would want as far as further medical treatment is concerned. Mr X's son has had to quit his job and his daughter has stopped studies because of the family's situation.

Discussion: Several issues arise in relation to the autonomy of the patients, questionable beneficence of continuing aggressive medical treatment with increased risk of infections, in a situation of increasing financial liabilities, particularly in the family of Mr X. These exist in a social context where situations like widowhood can be problematic

Poster 6: Nuances in informed consent in palliative care research: Denial and collusion

Ravi Prasad Varma P

Background and Purpose: While recruiting persons receiving palliative care for research, the requirement of informed consent can bring up certain ethical challenges that may be very common in such settings.

Description of ethical issues / dilemmas: Provision of information in the current research paradigm is envisaged as "complete information" at one go with clearing of all doubts. However, there may be collusion in concealing diagnosis or prognosis between the treating physician and the care giver. Prevalence of collusion can be as high as 40% among patients reaching palliative care services. Denial is also a common state among such patients.

Results of ethical inquiry: Autonomy and self ownership of one's medical information is a contentious issue in clinical care of life limiting conditions – many patients do not know their diagnosis or prognosis. Giving information on a proposed study to such a patient may inadvertently break any collusion on the patient's disease and prognosis that exists between the caregiver and formal care provider and may trigger reactions like anxiety or anger.

Alternatively, patients in palliative care settings may prefer a staggered delivery of information as they take time to cope with the realities they face and the choices they need to make.

Discussion and implications for bioethics: These problems are a reflection of ethical issues in patient care – such as autonomy, self-ownership and non-domination. They could also arise in the informed consent process and may do some harm to the patient and jeopardise further care. While recruiting palliative care patients, researchers should consider these characteristic nuances and work closely with trained palliative care providers to ensure smooth conduct of the informed consent process.

Poster 7: Instilling empathy for the blind: Understanding those who live in the dark

Uma Kulkarni and Vina Vaswani

Background and purpose: Caring is as vital as cure for the blind and a substantial component of care is derived from "empathy". Studies show a sad prevalence of depression, suicidal tendencies and separations among the blind. A slice of empathy could transform relationships into "caring" ones.

Purpose: This study was conducted assuming that "experiencing blindness" by sighted people, albeit, temporarily may induce or strengthen "empathy" towards the blind.

Methodology: An interventional study was conducted after ethical committee clearance on twenty normal sighted young participants using the following steps: (a) Pre-intervention questionnaire to assess the awareness of the needs of the blind and their attitude towards the blind., (b) Simulation of blindness: Eight day-to-day tasks were performed by them after being 'blinded' by wearing plastered goggles., (c) Post-

intervention questionnaire to assess the change in attitude to the blind and their needs.

Results: Simulated blindness made a favorable impact on the participants: their sensitivity towards the needs of the blind increased, their attitude improved and they were more willing to help and care for the blind in future.

Discussion: This method of "simulation of blindness" in inducing "empathy" may be an effective tool in clinics for sensitising the care-takers of the blind, thereby extending 'beneficence' to the blind and preventing 'maleficence' in the form of physical and psychological harm. This may also help in ensuring that the blind are able to be more independent through greater respect for their 'autonomy' and 'justice' by ensuring adequate opportunities to lead a normal life.

Poster 8: Knowledge and attitudes related to medical ethics among medical students

Iswarya S and Bhuvaneshwari S

Background: There has been growing public awareness regarding the ethical conduct of medical practitioners, and complaints against physicians appear to be escalating.

Objective: To determine knowledge and attitude to medical ethics among final year undergraduate medical students

Methodology: After obtaining permission from the institutional ethics committee, (IHEC), the purpose of the study and nature of information to be furnished was explained to final MBBS students. Willingness to participate in the study was obtained from participants using written consent forms. Data was collected using a self administered questionnaire. They were asked if they agreed or disagreed with certain statements concerning ethical conduct, autonomy, paternalism, confidentiality, informing patients about wrongdoing and informed consent. The respondents were asked to grade their responses on a 5 point Likert scale.

Results: Out of 140 final year students 135 students participated in the study. The majority (87%) of students felt patient wishes must always be adhered to. In contrast 65% of students felt doctors must do what is best, irrespective of patient's opinion. Around 65% of students felt even clinically confirmed cases should also undergo laboratory investigations as a routine. The fact that many respondents had neutral opinions to some questions may indicate their lack of awareness or knowledge in that area and their inability to decide.

Conclusion: This study findings indicate a gap exist in knowledge about practical aspects of health care among students. Hence there should be sufficient training classes, workshops, conferences to stress the importance of ethical practice.

Poster 9: Care for the dying: A spiritual dimension

Amarantha Donna Ropmay, Purnima Devi Laishram and Adorinia Nongrum

Medical care for the dying has, for the most part, focused on alleviating physical suffering and easing distressing symptoms. Although this is widely accepted as standard treatment, there is evidence to show that the right dose of spirituality makes the process of dying less agonizing for the concerned patient. A holistic approach with an added spiritual dimension paves the way to a peaceful and dignified death. It imparts meaning and purpose to life, prepares the individual to let go and encourages him to run the final race without fear. Spirituality has been described as connectedness with a Higher Power expressed in our relationship with others around us. Thus, while caring for the terminally ill, the carer's physical presence and practical assistance go a long way in restoring a patient's integrity and sense of self-worth. Just 'being there' for the sick and perishing is enough to comfort them in the twilight moments of their lives. An unwavering faith in the Divine facilitates a smooth transition from a fleeting world of pain and misery to an eternal world of joy and rest.

On the other side of the coin, not all patients may respond positively to this kind of approach. In fact, some could even turn hostile or present a different belief system altogether. Thus, health workers cannot impose their faith on somebody who is unyielding. Such situations may pose possible limitations to adding a spiritual dimension to 'care for the dying.'

Poster 10: Ethical issues in online psychotherapy: Emerging ethical dilemmas for India

Avinash De Sousa

Advances in information and communication technology have facilitated the development of online psychotherapy in India. This form of psychotherapy connects people who do not have access to mental health care to better and viable mental health care services. At the same time there are various ethical, legal and regulatory issues yet unanswered and unresolved in online psychotherapy. The present poster highlights the major ethical issues surrounding the use of online therapy conducted via e-mail, chat or interactive video. Case examples of the ethical dilemmas are posited and practical solutions suggested for the same. There is a skewed opinion on psychologists in India considering expanding their practice to include online psychotherapy and there is also a scarcity of literature available on the subject. This poster uses case scenarios based on the author's experience and seeks to dissect the major ethical issues in this area particularly in India and shall also make the same applicable from the developing world perspective.

Some of the ethical and legal issues that will be underlined are as follows: there are no laws that govern online psychotherapy and there are no guidelines that determine how online psychotherapy must be conducted and used. Issues like confidentiality and whether online psychotherapy is legally

accepted are issues that abound us with new ethical dilemmas posited by the modern digital age.

Poster 11: Life after death: The dead shall teach the living

Aiswarya Sasi, Radhika Hegde, Stephen Dayal and Manjulika Vaz

Body donation for anatomy is not widespread in India. It brings to the fore a person's beliefs of death and afterlife. There are relatively few published studies, especially in the Indian context, about the motivations and expectations of people who donate their bodies, their religious beliefs and attitudes towards death. We explore this in an inter-disciplinary qualitative study.

In-depth interviews using a semi structured guide were conducted with 12 donors and their next of kin who have registered with the body donation program in St. John's Medical College between June-November 2016. Religious philosophies and cultural norms around death and afterlife that could influence body donations in India were collected through oral narratives with key community persons, purposefully sampled. Sample size is driven by data saturation.

The respondents were from different religious and community backgrounds. Qualitative data analysis using open coding shows that a trigger that gets people to make this decision is the death of a close family member, usually a parent or a spouse and the overwhelming feeling of the futility of the rituals and practices around death. Many of the respondents were couples in the 65+ age category who have made a joint decision after much deliberation. The motivation of wanting to do something useful and meaningful with their bodies after death is a common theme. None, among those interviewed, were looking for anything in return, all preferred anonymity, not be told of the details of how their bodies would be used but would hope to have better trained, empathetic doctors. This fits into the Indian philosophical concept of '*daan*', as an ethical framework of giving, which is to give without expectation of return but for a higher purpose. Is there a link between the virtue of giving and a person's coming to terms with the end of his/her life, a preparation towards death?

Poster 12: Role of dance as a treatment modality in health care

Sachitha Nandagopal

Background & Purpose There is a paradigm shift in the objective of health care that now focuses on wellness. Exploration of supplements to regular therapy has become imminent. Healthcare professionals are now looking to treat bodily ailments more holistically through strengthening of the mind. Supplementary treatment modalities are coming to the fore, dance being one of them. We can construe that Dance can be used as a medium to improve mental conditions of patients

with different ailments thereby increasing the chances of the recouping process.

Objectives: Dance plays a significant role in adding therapeutic value to primary care. This presentation is aimed at impressing the advantages of incorporating art form into medical education.

Methodology: Three persons with different disease conditions underwent a structured, modular dance-training program with me & showed significant improvement based on their feedback.

Content of dance therapy: Knowing the ailment of a person the therapist works out suitable steps and movements to heal the specific ailment.

Ethical issues: Medical profession can fulfil ethical obligations to society by giving informed choices on holistic healing processes. Autonomy means the patient's right to self determination. In other words, he should be able to determine for himself the form of treatment. This will only happen if the patient receives full information on all modalities of treatment. A dance teacher has no obligation to a professional code of conduct, but needs to be circumspect with regard to patient privacy and data confidentiality.

Discussions & Conclusions: If healthcare provider is sensitized to the possibilities of healing through fine arts and dance we can hope for a future where healthcare becomes truly holistic and integrated. It will also result in more research and therefore more evidence-based practice. The risks of using this form of healing as supplementary to the routine care versus the possible benefit seem to be in favour of bringing this into mainstream consciousness.

Poster 13: Identifying ethical challenges in resolving male infertility: An examination of 'One Part Woman'

Sunu C Thomas

Background: Motherhood is as important to the gender identity of a woman, as fathering a child is to the gender identity of a man. However, the procreative body function of men is always associated with sexuality, unlike with women. Therefore, the failure in this function for men threatens their gender identity.

Method: I use the grounded theory approach to analyse Perumal Murugan's text "One Part Woman" to identify the ethical dilemmas involved in dealing with male infertility within the community. The emerging conceptualization of male infertility will be validated using published studies on infertility.

Outcome of ethical inquiry: The inability to produce a child challenges the virility of a man. The book identifies the moral conflicts experienced by a man when he learns that he is the infertile one within the couple. This challenge to "manhood" can be resolved if his wife chooses to spend a night with a stranger to get pregnant; thereby masking the stigma of infertility for the man.

Discussion: A decision to resolve infertility of a couple could involve immediate family and the community as well. The issue of male infertility is resolved by the consent of the woman to allow her body to be impregnated. The resolution to male infertility can challenge female bodily integrity and the coercion to resolve infertility can be from the partner and the collective family. Such a choice has the potential to harm the child that is born. Therefore, resolution to male infertility challenges the bodily integrity of the female and pose potential harm to the child born and the benefit of not being stigmatised accrues to the man.

Poster 14: Dignity in darkness: The gender gripes!

Uma Kulkarni, Vina Vaswani and Ravi Vaswani

Blindness amounts to devastation. It breeds dependence, low self esteem, and poor quality of life. While old age intensifies it, gender bias worsens it. Our study explores the impact of gender on the old and blind.

A qualitative study was done to explore the influence of gender on the life of the old and blind after ethics committee clearance. The methodology used is 'in-depth interviews' of sixteen old, blind men and women delving into the impact of their gender on their dignity, dependence, nature of care received and the quality of life. The analysis is aided by the WEFT software. Analysis of the transcripts of the interviews led to 'codes' (caring, care giver, gendered care, dependence, self-esteem, etc.). The codes were correlated and developed into themes (gender issues, care issues, dignity) and finally the theory is evolved from the transcripts of the interview of the participants as in a grounded theory.

Results clearly indicate that blind old women feel less cared for. Men rely on the women for help, but women do not. Socio-economic-cultural factors influence the self-esteem of women. Perceived neglect is evident among women. However, women adapt to blindness better than men and complain less.

The presentation discusses the following ethical queries. What determines the dignity of old blind men as opposed to women? Is care ethics a domain of women and not men? Do the ethical principles wane with age for the women in dark? The authors explore the ethical principles in relation to gender determined dignity of the old blind individuals.

Poster 15: Does the system care for its nurses who provide care to patients?

Pallavi Mishra, Joe Varghese and Solomon Salve

In rural areas mostly nurses are the first contact persons to respond to the health related requirements of the vulnerable population, however, nurses themselves face several challenges pertaining to their professional identity. Drawing on a case of formation of the Nursing Directorate (ND) in the state of Odisha, this paper tries to understand the role of ND in providing leadership position to nurses.

This exploratory study draws on 43 in-depth interviews of nurses and other stakeholders and observations at the sub-centre and block CHC in two districts of Odisha- Ganjam and Kandhamal. A case study approach has been used to get deeper insights about the link between the health system responses to the needs of nurses.

Odisha is the first state in India to establish a ND in 2013, to streamline nursing governance. It was decided that for the initial five years doctors will administer the directorate. ND was mandated to develop leadership skills of nurses in these years so that leadership positions at ND could be handed over to them after five years. Nurses lamented that doctors heading the ND have remained unaware of the nursing issues in the state and thus no visible efforts were made by the ND to develop leadership capacity of nurses. Nurses also have limited promotional avenues in the state, which deters the possibility of them getting the leadership positions in the ND in near future. Nurses can help in building trust and relationship between the system and the patient and do justice to their duties only when the health system is just and provides a conducive environment for them to work. Therefore, even after the establishment of ND, the professional identity of nurses as the leaders of care giving profession has not been developed.

Poster 16: Relevance of privacy for data collection in public health study: Field experiences Gadag district, Karnataka, India

Bevin Vijay Kumar V N; presented by Sunu C Thomas

Introduction: Privacy during data collection is an important concept particularly while dealing with stigmatising or sensitive issues.

Methods: We propose to examine the relevance of privacy for data collection and data validity on non sensitive topics particularly among marginalised groups. The study describes experiences during a field exercise in data collection, using a mixed-methods approach to examine healthcare access for childhood illness for Banjaras and non Banjaras in Gadag, Karnataka.

Results: In the non-Banjara section of the village, one woman was reluctant to be part of the study when approached in a group. Subsequently, when interviewed in her home, she narrated her experiences of not being able to access healthcare for her child. She explained that her reluctance to participate was because she did not wish to reveal her inability to provide health care for her child publicly. On another occasion in a section where only the Banjaras reside, another woman was able to narrate her personal experiences of being stigmatised in the health center for wearing her traditional clothing. This she could narrate at home because there were people who wore similar attire in her neighborhood.

Conclusion: Research on sensitive topics such as child health and illness among marginalised groups should ensure privacy during data collection. Lack of privacy can result in responses that deviate from real experiences. This can affect data quality and validity of estimates obtained from them.

DAY 1 | FRIDAY, JANUARY 13, 2016**2:00 pm to 3:30 pm****PARALLEL SESSIONS****WORKSHOPS AND SYMPOSIA WS/S4 TO WS/S11****WS/S4: Ethical challenges in teaching medicine: teachers' narratives**

Facilitators: **Sudharshini Subramaniam**, Assistant Professor, Institute of Community Medicine, Madras Medical College, Chennai; **Priyadarshini Chidambaram**, Assistant Professor, Department of Community Medicine, MS Ramaiah Medical College, Bengaluru; and **Vijayaprasad Gopichandran**, Assistant Professor, Department of Community Medicine, ESIC Medical College & PGIMSR, Chennai, TN, India. (All members of a non-profit, public health academic, advocacy and action group, NODAL Point)

Background: Medical education in India is going through a major flux in recent times triggered by the 92nd Parliamentary standing committee report on the functioning of the Medical Council of India, move to scrap the Medical Council of India, Supreme Court verdict upholding the National Eligibility cum Entrance Tests for admission to undergraduate and postgraduate courses. One prominent observation made by the 92nd Parliamentary standing committee on medical education and services in the country was the declining quality of medical education. Medical teachers face several important ethical challenges.

Purpose: This seminar intends to highlight the ethical issues faced by medical teachers in the process of teaching.

Methods: Three medical teachers, SS, PC and VG from three different medical colleges, one run by the state government, one by a private trust and third one by the Employees State Insurance Corporation will speak in this seminar. They will narrate their experiences and highlight the ethical challenges that they face under the following themes:

Ethical challenges in the curriculum: (a) shift of focus from primary care to speciality care, (b) drop of postgraduate entrance coaching centres and tuitions, (c) focus on exam passing and pass rates than competencies, (d) No focus on soft skills, humanities, ethics

Ethical challenges in pedagogy: (a) large number of students in a batch, (b) focus on cognitive skill and less focus on psychomotor skills, (c) Reliance on lectures and PowerPoints with poor focus on innovative pedagogy

Ethical challenges in evaluation: (a) Exams as a formality rather than evaluation of competency, (b) Malpractices in examinations, (c) Archaic evaluation methods that do not assess skills

Each presentation will be for a time limit of 15 minutes. There will be discussions for about 30 minutes following all the presentations. The last 15 minutes will include a summary of the presentations and discussions.

Expected outputs of the symposium: The main proceedings of the presentations and the discussion points will be summarized as a policy brief.

WS/S5: Surrogacy in India: past, present and the path ahead

Facilitator: **Priya Satalkar**, post-doctoral fellow, Institute for Biomedical Ethics (IBMB), University of Basel, Switzerland; **Nishtha Lamba**, doctoral student, Centre for Family Research, University of Cambridge, UK; and **Avinash De Sousa**, Founder Trustee and Consultant Psychiatrist, Desousa Foundation, Mumbai, MH, India

Surrogacy is exceedingly complex in its ethical, socio-cultural, biological and psychological implications. However, often the community's sentiments and policy decisions do not move beyond an ethical argument. Be it developed countries like France, the United Kingdom or Italy or developing nations like India, Nepal or Thailand, governments have reiterated that surrogacy is exploitative and commercial transactions in it should be banned. At this workshop, we shall address various ethical issues that surround surrogacy especially in the Indian context. We will discuss key concepts like exploitation, risks and harms, reproductive justice; and provide insights into surrogacy from socio-cultural-ethical perspectives while engaging the audience in an active discussion.

In the light of recent changes in surrogacy laws in India, we will explore and compare commercial and altruistic surrogacy contracts drawn from across the globe. Finally, we will turn the focus on psychological aspects including harms and benefits for various actors involved in surrogacy contracts with a focus on the notion of family, disclosure to the future child, the desire to have a biological link with the offspring and adoption as an alternative form of family formation. Surrogacy being an extremely challenging phenomenon requires in-depth discussion. The goal of this workshop is to stimulate discussion on changes in the Indian surrogacy model from commercial to altruistic, to anticipate its impact, and propose ways to implement the new legislation and monitor its impact.

Format for the workshop

Priya Satalkar (5+10 mins): Surrogacy – setting the stage (The participant will be divided into groups to answer following questions: 1. Who are the stakeholders in surrogacy debate?

And how different are they in their vulnerability?; 2. hat are the ethical or moral differences from selling a kidney and renting a uterus?)

Nishtha Lamba (10+20 mins): Commercial versus Altruistic surrogacy – the ethical debate in India and the way forward (After introducing three different surrogacy models, the participants will be divided into groups to answer following questions: 1.What are the strengths and weaknesses of India’s revised ART/ surrogacy bill?, 2. Who is being included and who is being excluded?, 3.What do we need to do to ensure implementation of the new bill and monitoring)

Avinash De Sousa (15+15 mins): Sociocultural implications of surrogacy (The participants will be invited to debate impact of new regulation on our understanding of family, desire for having biological link with the offspring and alternative of adoption.)

Participants together with the speakers (5 mins): Wrap up

WS/S6: Understanding medical error: beyond the blame game

Facilitators: Aamir Jafarey, Professor, Centre for Biomedical Ethics and Culture(CBEC), Sindh Institute of Urology and Transplantation (SIUT), Karachi, Pakistan; and **Nida Wahid Bashir**, Consultant General Surgeon, Patel Hospital, Karachi; and Associate faculty of CBEC, SIUT, Karachi, Pakistan

Medical error is reported to be the third leading cause of death in the USA and it tops the US list of accidental deaths. Various measures are taken under the umbrella of patient safety to address this issue internationally. But it is interesting to note that awareness and understanding of healthcare worker in this area is addressed very seldom in our part of the world.

Medical error carries the burden of shame, anxiety, fear of loss of reputation, loss of patient – healthcare worker’s trust relationship, increased cost of healthcare and litigation. Its identification and reporting requires personal courage and an organisational culture that is conducive. It entails the imperatives of truth telling, professionalism, justice and an ethical organisational conduct.

Recognising this need, and the ethical imperatives pertaining to medical error reporting, we have designed a workshop which attempts to impart basic understanding of the subject including the definition and differentiation of error, negligence and malpractice and explores possible tools to deal with it.

This workshop identifies the local perspective through interaction and attempts to bring out the ethical concerns through real life examples shared by the participants.

This will be an interactive workshop which will begin with brain storming on the topic followed by presentation on basic definitions, differentiating between error, negligence and malpractice and a Power point presentation and discussion on the ethical imperative pertaining to error reporting and disclosure. This will be followed by a movie “To err is human” and small group discussion on events shown in the movie. The

Workshop will end with the presentation on suggested tools to deal with error and possible outcomes.

WS/S7: Ethics training module for health professionals in end-of-life situations

Facilitators: Olinda Timms , **Christopher Vimalraj Hiruthya**, Faculty of Medical Ethics, St John’s Research Centre and St John’s Medical College, Bangalore, Karnataka, India; **Shivkumar Iyer**, Professor Critical Care Medicine, Bharati Vidyapeeth Medical College, Deemed University, Pune, MH, India; **Prachee Sathe**, Director, Critical Care Medicine, Ruby Hall Clinic, Pune, MH, India

End of life situations are fraught with clinical challenges that can test the mettle and spirit of even competent health professionals. The complexity of the medical condition itself, the uncertainty of therapeutic response, the limitation of time and possible futility of certain interventions, are aspects of end-of-life care that accompany decision making in this area.

For the most part, the expertise and training of the health professional will be directed at relieving suffering and extending life. Some aspects of decision-making in these situations may be problematic, unclear or counter-intuitive, requiring a deeper understanding of ethical issues and related legal implications of medical decisions on patient’s rights and autonomy.

Given the patient load and limitations of resources in the Indian setting, the emphasis is generally on clinical competence and expediency rather than on medical ethics, which has hitherto not been a part of undergraduate training. So handling of ethical dilemmas tends to be ‘learned on the job’, for the most part.

Would it be useful to create an end-of-life-ethics training module for health professionals? This awareness building exercise and reflection can prepare doctors and the health care team to empathize with, anticipate and deal with dilemmas they may encounter in end-of-life care, and even have a positive impact on patient outcomes..

Until medical ethics becomes a part of the UG curriculum and the emphasis on ethical conduct pervades practice, an ethics-training intervention could fill the gap in this area of medical training.

This 90-minute workshop will provide an opportunity for stakeholders to evaluate the need and relevance of such an Ethics-training intervention in end-of-life care situations in hospitals in India with the following format: (a) Welcome and brief introduction of the topic by the Moderator., (b) Panelists sharing and discussion: Panelists will speak on consent issues in end of life situations; breaking of bad news; and ethical issues in futile care situations. This will be followed by questions from the audience., (c) Break out session: Audience will be divided into groups, and will discuss (i) an ethics training module based on specific areas or needs expressed in the Panel discussion; (ii) Possible challenges to implementation of training., and (d) Sharing of the outline and design of curriculum developed by individual groups

Expected outcome: Initiating debate on the need for ethics training for health professionals working in end-of-life situations, identifying gaps in such training which may be filled by a training module, and possible framing of curriculum and design of such a module.

WS/S8: The marginalised in palliative care

Facilitators: **M R Rajagopal**, Chairperson, Pallium India; **Purnima Nagaraja**, Consultant Psychiatrist; **Arul Dhas**, Senior Lecturer, Bioethics, Christian Medical College, Vellore, TN, India; **Sunita Sheel Bandewar**, Secretary, FMES, Mumbai, MH, India; **R Srivatsan**, Anveshi Research Centre for Women's Studies, Hyderabad, Telangana, India

Today, disease-focused curative care is the main line of 'attack' against illnesses faced by individuals. Such care is mechanical, focused on correcting biochemical/physiological pathologies in human bodies without any consideration given to the physical and psychological needs of the person who is suffering. It is our contention that disease focused biomedical care is both inadequate and in a profound sense unethical: inadequate because it does not consider the psycho-socio-spiritual needs of the patient; unethical because the absence of the recognition of the psycho-socio-spiritual dimension amputates the patient's body from her person and experience of suffering.

This of course does not obviate efforts to alleviate avoidable pain and other symptoms using drugs or interventions aimed at improving quality of life.

Palliative care encompasses not only caring for a person's disease, but needs to address the patient's physical as well as psycho-socio-spiritual needs, covering the provision of succor, emotional comfort and a sense of purpose to those who are in situations of mental desperation as they confront implacable pathologies.

Current palliative care service focuses so much on cancer in many parts of India, that the suffering of those with psychiatric disorders and chronic mental illness, women, the very old, and the poor in general can be said to be marginalised. It is estimated that less than one percent of the needy have access to palliative care. But the palliative care service that reaches that one percent of the population automatically becomes something like a role model for the rest of the country, for future care delivery systems for the Governments and for legislators.

Purpose: The purpose of the workshop is to discuss and learn the issues of the marginalised in palliative care. A working group had created a national standards tool for palliative care in 2006. Discussion on the above marginalised groups could provide pointers for a possible revision of the existing national standards tool which in turn could lead to relief from unnecessary health-related suffering in India.

Method and format: Each speaker gives an illustrative case history and presents the relevant problems, possible solutions and minimum standards in training of professionals:

Rajagopal M R (7 mins): Introduction of the theme; Purnima Nagaraja (7 mins + 5 mins for audience participation): Those with chronic mental illness, especially women; Arul Dhas (7 mins + 5 mins for audience participation): Those with spiritual suffering; Sunita Sheel (7 mins + 5 mins for audience participation): Women; Rajagopal M R: Those at the extremes of age

Srivatsan R (7 mins + 5 mins for audience participation): The poor and their suffering

Discussion on minimum standards of training in the above domains (15 mins); Conclusion and buffer time (8 mins)

WS/S9: Caregiving: a choice or an obligation

Facilitators: **Priyadarshini Kulkarni**, Medical Director, Simpatico Palliative Connect, National Secretary of Indian Association of Palliative Care; **Pradeep Kulkarni**, Consultant at Simpatico Palliative Connect; **Madhura Bhatwadekar**, Director – psychosocial support, Simpatico Palliative Connect, Pune, MH, India

When someone is living with life limiting illness, family caregivers become the backbone for all the support they require. Most caregivers willingly take this responsibility. Situations like informing patients about their life limiting illness, deciding on treatment options and dealing with dying patients with aggravating symptoms at home, can be major sources of suffering. Continued stress over long periods also exposes them to health risks and could be overwhelming. Improving interpersonal communication patterns may help caregivers in making ethical decisions while respecting the patient's autonomy.

When death approaches and after death, caregivers may go through different phases of grief. Expressions of grief are personal and should be the choice of individual; but mourning rituals may help caregivers to come to terms with the loss. It is a societal obligation to respect the griever's way of mourning.

Though difficult, care-giving is an opportunity to create positive memories. It can improve relationships and heal the past. If care-givers are trained, the process will be more satisfying and help them move on with their lives.

Structure: Priyadarshini Kulkarni (25 mins): Meaningful conversations as a tool to resolve ethical dilemmas (4 case studies highlighting need for discussion amongst family members for ethical decision making); Pradeep Kulkarni (25 mins): Ethical issues – caring for caregivers videos related to caregiver stress, discussion followed by case discussions); Madhura Bhatwadekar (25 mins): Ethical framework for caregivers to move on in life (Presentation on grief and bereavement, and interaction with audience); Discussion and Q/A (15 mins).

WS/S10: Micro-skills of palliative care counseling

Facilitators: **K N Chouhan**, Reader, D.S. Homeopathic Medical College, Pune, MH, India; **Megha Deuskar**, Assistant Professor, Department of Psychology, Fergusson College, Pune, MH, India

While a large number of people in the world today are playing the role of care givers to terminally ill patients or people who are nearing the end of life, many of them are not equipped with adequate skills for communicating effectively with such patients. Medical practitioners, social workers or even family members who are involved in care giving inadvertently disturb the patient psychologically, despite their good intentions and goodwill for them. Knowledge of simple skills such as non-judgmental listening, appreciative enquiry, empathic life story gathering, opening issues surrounding death and dying and validation can go a long way in alleviating the distress faced by a dying or suffering patient. The workshop aims at imparting these important micro-skills to participants. Ethical issues such as offering choice of treatment to the patient and aggravation of symptoms as a result of catharsis of buried emotions will be discussed.

Format of the workshop

1. The meaning of the word "dignity" will be brought out through an opening talk, a small role play and a one- line sharing round. (15 minutes)
2. A 5-minute video clip from the movie "One flew over the Cuckoo's Nest" will be shown, followed by a short discussion. (15 minutes)
3. The concept of active, empathic but non- judgmental and non-advisory listening will be introduced especially keeping in mind the needs of terminally ill patients. This session will also include discussion on the importance of allowing patients to talk about existential issues, especially death openly. (30 minutes)
4. There will be a role play of talking and active listening, validation and empathy, following which participants will split up in pairs and practice active listening. (15 minutes)
5. There will be a discussion about ethical issues, such as the risk associated with the catharsis of painful emotions for an already fragile client and the effect of such catharsis on the survivors. (15 minutes)

WS/S11: Challenges of institutional ethics committees at the university of hyderabad

Facilitators: **Geeta K Vemuganti**, Dean, School of Medical Sciences, University of Hyderabad, Telangana, India; **Varalakshmi Manchana**, Sr Faculty, University of Hyderabad;

Justice T N C Rangarajan, member, ERB, University of Hyderabad and Former Judge, High Courts of Madara and Andhra Pradesh; Prof P Mohanty, University of Hyderabad

As per the mandate of ICMR Ethical Guidelines for Biomedical Research on Human Participants, all proposals on biomedical research in University of Hyderabad (UoH), involving human participants, are routed and cleared by Institutional Ethics Committee to safeguard the welfare and the rights of the participants. The IEC is entrusted not only with the initial review of the proposed research protocols prior to initiation of the projects but also has a continuing responsibility of regular monitoring of the approved programs to foresee the compliance of the ethics during the period of the project. In a diverse university like University of Hyderabad there are interesting and challenging issues that are observed by IEC which we intend to share in this workshop. Below is the format for the workshop.

Understanding the needs of the University of Hyderabad and the growing needs of IEC is the critical first step in helping Institutions build infrastructures that support the protection of research participants and improve the scientific quality of health research and also train the investigators in the procedures involved.

In a Central University with academic and research programs ranging from behavioural studies to participating in clinical studies submitted by PG/Research students to senior faculty, many interesting issues and challenges are observed by the committee members. The understanding of ethical principles, obtaining informed consent from participants and obtaining institutional permissions is highly variable. Additional issues that need to be addressed related to funding agencies, permissions and memorandum of understanding between participating institutions, intellectual property rights and patents etc.

The objective of this workshop is to discuss the challenges experienced and work for the solutions in order to build the capacity of IECs at the Higher education Institutions like University of Hyderabad.

Speakers and Topics:Varalakshmi Manchana: Issues of Informed Consent & Institutional Permissions; Justice Rangarajan: Challenges of studies on vulnerable populations; P Mohanty: Community based Research related to Social Sciences and Public Health; Geeta K Vemuganti: Preclinical studies and Biomedical Research

DAY 2 | SATURDAY, JANUARY 14, 2016**9:30 am to 11:00 am****PAPER PRESENTATIONS AND WORKSHOPS****GROUPS P7 TO P11 & WS/S12 TO WS/S13****GROUP P7: PALLIATIVE CARE ETHICS II: MENTAL HEALTH, SPECIAL NEEDS AND SITUATIONS****P7(a): Homeopathy and psychotherapy: A useful aid in palliative care***KN Chouhan and Megha Deuskar*

Dr. Hahnemann, the Father of Homeopathy, promoted holistic care of patients as early as the 17th century, when the mental health system was not even established. The recognition that the mind and body are inseparable makes homeopathy, as a branch of modern medicine, closely interconnected with psychotherapy. Integral to the homeopathic approach to care is the idea that human nature is basically creative and that the organism has implicit self-healing capacities. The present paper offers some ways in which homeopathy and psychotherapy can be used in combination, for palliative care. Two detailed case studies have been described, one of cancer and the other of chronic renal failure to substantiate these methods. Homeopathic remedies such as Arsenicum Album, Conium Maculatum, Kreosotum and Phosphorus which were used in these apparently incurable conditions offered substantial relief in pain without adverse side effects. These medicines can and do complement the counselling process that encourages patients to accept all of their emotions rather than denying them. Engaging with those emotions and expressing them frees up the energy which has been blocked due to habitual responses and long-term trauma. Even in end-of-life care several psychologically incomplete gestalts can be facilitated to reach closure, helping patients to feel an overall sense of well-being. However, while these alternative approaches hold great promise in palliative and end of life care, there are certain legal as well as human ethical dilemmas that clinicians face. The present paper highlights ethical issues such as denying a known therapy like allopathy, running the risk of aggravation of symptoms due to catharsis of painful emotions and the risk associated with an initial aggravation of symptoms which is the hallmark of a perfect homeopathic medicine. The merit of these approaches lies in the fact that they are gentle and thus help preserve the dignity of the dying patient.

P7(b): The new interface between palliative care and psychiatry*Purnima Nagaraja*

From the earliest stages of the modern hospice movement, there was an acknowledgement of the depth of psychological distress that many dying patients experience.

During the early years of its development, palliative care seldom involved psychiatrists. More recently, significant progress has been made in expanding the interface between psychiatry and palliative medicine. While palliative care has matured as a field – with consolidation of content expertise, formalisation of an accredited medical subspecialty, and expansion of services in both hospice care and palliative care consultation – the past decade has also seen significant growth in the development of palliative care psychiatry as a sub-field bridging these two disciplines. Increasingly, psychiatrists have brought their skills and knowledge to the care of seriously ill patients.

The discipline brings expertise in understanding the psychosocial dimensions of human experience to the care of terminal patients and support of their families. The goals of this presentation are: (a) to briefly sketch an overview of palliative care in India and summarise the evidence for its benefits; (b) to describe the roles for psychiatry within palliative care; (c) to review recent advances in the research and practice of palliative care psychiatry; and (d) to consider the formulation of a protocol for psychiatric intervention in palliative hospice and end life care and to explore dimensions of Hospice and Palliative Psychiatric care in severe mental illness and treatment resistant mental illness.

P7(c) : Palliative care and ethical dilemmas in caring for children with special needs: An experience from a society dealing with providing rehabilitation services to persons with cerebral palsy & other developmental disabilities*Sashikala Ramnath, Anne Panicker, and B S Ramakrishna Mudre**Presenter: Sonia Jacob*

Background and Purpose: Care of persons affected by Cerebral Palsy (CP) is life-long, complex and multi-disciplinary. Initially, care involves training in motor skills, activities of daily living, special education and speech therapy for communication. Later, the learning curve flattens out and there is not much to offer further, in terms of training. There is no cure for CP but it is not a terminal illness and it is a moral imperative to maintain

the dignity and quality of life in an affordable manner.

This paper presents arguments to demonstrate that long term care for a non-terminal condition like cerebral palsy is equivalent to Palliative care, with a similarity in the ethical dilemmas.

Description of ethical issues: Case studies drawn from the experience of an NGO based in Mysore City are presented.

Outcome of ethical inquiry: A variety of ethical dilemmas were encountered in selecting children into their program, designing training and therapies. The complexity of dilemmas increased when the autonomy of the patient was compromised, and when the physical capacities of primary care-givers diminished due to ageing.

Discussion: Despite a consultative approach amongst all stakeholders, decisions are not easy. The process of managing these dilemmas is discussed in an ethical framework.

P7(d): Ethical dilemmas in end of life care in handling potential brain dead donors in ICUs

Sujatha Suriyamoorthi, Sumana Navin, and Sunil Shroff

Deciding about organ donation of a loved one who has just been declared dead is an extremely difficult decision to make. During this period of extreme grief, the families are requested to make a decision about organ donation which is a difficult process and can be time consuming. The end of life care (ELC) of the potential multi organ donors can depend on the decision of the family members.

There are multiple ethical dilemmas here. In some situations the patient is dead enough to donate organs but not dead enough to be taken off from the ventilator; family agrees for organ donation, but due to clinical conditions the organs are not used for transplantation. Does the family need to wait until cardiac arrest occurs or can the ventilator be switched off and the body handed over to the relatives? Further, who decides the care plan when family says "No" to organ donation, but wants to continue the care until cardiac arrest occurs? Will the family's decision be respected? Often families require more time to make a decision about organ donation. Will a busy government hospital continue the same care irrespective of the family's decision? Will continued care be in conflict with another patient waiting for a ventilator? How does one address the issue of rationalising the ICU resource? ICUs in India are constantly challenged and the ethical dilemmas in this situation can be complex and require better clarity.

GROUP P8: LEGAL ASPECTS OF SAVING LIFE AND END-OF-LIFE CARE

P8(a): The jurisprudence of euthanasia: The legitimacy of 'agency' in planning for death

Smitha Nizar

This paper is framed in the background of legalization of Passive euthanasia in India. The purpose of this research paper is to bring out the imperceptible ethical conflicts hovering around euthanasia. The paper uses qualitative methodology, restricted to the analysis of relevant case laws.

Taking euthanasia as a viable medical option to plan for death would create intolerance towards any undesired life on account of 'suffering'. It is violation of the Hippocratic Oath. Euthanasia represents a sophisticated manner of denial of medical responsibility, which is in violation of medical ethics. *Aruna Shanbaug* has brought out a new jurisprudence of legalised passive euthanasia in India. The Court ruled that pending legislation, euthanasia is permissible on case by case basis. A close examination of the judgment depicts that the court took a narrow view of an unrest issue that has ramifications across the medical, ethical and social dimensions of the society.

Euthanasia either in active or passive procedure entails umpteen unsettled medical, ethical and social implications to the inherent value of human life. Euthanasia implicitly leads to cost-benefit analysis and "quality of life" judgments to measure the value of human life. Consequently, it raises the question, does euthanasia contradict the medical ethics to preserve each human life and the views of a just society. A just society always affirms basic freedoms to its members and each individual gets their due. However, during the course of planning for death of an individual, both the decision maker and the medical professionals are at ethical stake about the right to take decision of death for another individual. This paper seeks to examine whether the line of medical ethics is endangered in legalization of euthanasia.

P8(b): Court room battles on the right to euthanasia

Kriti Sharma

Across the world courtrooms have grappled with the raging legal and bioethical questions surrounding euthanasia—whether active or passive euthanasia be made permissible; if so,, under what conditions; what are the guidelines for those assisting the act as legal surrogates? Through this paper, the author looks at the legal controversies around the issues of euthanasia, voluntary suicide and attempted suicide within the Indian jurisdiction.

The specific contexts in which legal debates on euthanasia have emerged in India require special attention. , Can we allow the law and the state to take overt control over our

bodies? Do voluntary 'non-violent' suicide practices, such as *santhara* and *prayopavesa*, in India require an understanding of the right to die with dignity, are they different from the one present in law borrowed from Judeo-Christian pro-life claims? Lastly, when criminalised what violence emerges out of penalisation of 'attempt to suicide' for legal category of persons including those with 'mental illness'?

The author attempts to extract these dilemmas and questions from the case law, in the context of seeking settled legal principles in the rapidly changing social realities. In particular, it calls into question the role of the State as the final arbitrator, pointing to the ultimate irony that the guardian of right to life in euthanasia cases does not feel culpability in its own arbitrary and discriminatory act of taking away the right to life through the death penalty.

P8(c): Proposed legalisation of euthanasia in India: A bioethical reflection and response

Christopher Vimalraj Hiruthya

Passive euthanasia in India was already legalised by the Supreme Court, since the Aruna Shanbaug (a PVS patient for 42 years) case in 2011. However, the Supreme Court of India has referred the question to a Constitutional Bench. This presentation would uncover what could be an ethical response to legalisation of euthanasia in India?

The methodology of this presentation will involve an overview of the current bioethical literature on both sides of the debate on euthanasia. In addition, the sources for the philosophical foundations (including writings from legislatures, courts, parliamentary committees, ethicists, lawyers, philosophers, and a myriad of others on euthanasia and assisted suicide) for important strands of the debate will be identified and critically analysed. The research will also delve into Hinduism, Islam and Christianity to understand their influence on contemporary Indian culture. The presentation offers various definitions of personhood, including the physicalist, cognitive, Hinduistic, Islamic and Judeo-Christian. The 'life and death' perspectives of these religious traditions on contemporary Indian culture are indispensable to understanding the dilemma. The study will use medical literature to understand terminal illness, pain and suffering of patients and the usefulness of palliative care.

The paper adopts a multi-disciplinary approach to palliative care, including the psychiatric, psychosocial, existential and spiritual. The haphazard provision of palliative care, the paucity of opioids, rampant poverty and corruption in India, are all uncovered through a review of peer reviewed journals. These findings are evaluated taking into consideration the dignity of the human person, in the light of 'Ordinary and Extraordinary means of care', and assesses its relevance to artificial hydration and nutrition for PVS patients in India. The socio-economic contexts are discussed to fortify arguments against legalization of euthanasia in India. An urgent proposal is made for the establishment of extensive palliative care facilities in lieu of legalising euthanasia.

P8(d): The emergent ethics jurisprudence: A socio-political review of the jurisprudence of the prominent medico-legal cases and the application of ethical principles to critical life-saving care in India

Edward Premdas Pinto

Saving life is deemed to be the noble purpose of medical profession. However, when encountered with deaths, indignity and violations in seeking critical care, citizens have accessed courts for justice. This paper seeks to understand the moral and ethical principles that intersect the healthcare jurisprudence in such litigations. This paper is part of a primary multi-disciplinary doctoral research with a mixed method design. A triangulation of data from (a) the document review of 10 judgments of Supreme Court and High Courts on emergency medical care and medical negligence selected through keyword search in legal data bases (b) 45 in-depth and expert interviews conducted with respondents - judges, advocates, public health experts and petitioners, form the primary evidence for analysis. The respondents were selected based on qualitative research design. The analysis is guided by political economy and moral-ethical perspectives of right to healthcare. The analysis points to ethical principles of right to life and dignity forming the foundation of the jurisprudence laid down in these judgements. 'Preservation of life' and 'duty of care' are established as the absolute, non-negotiable and paramount constitutional obligations of the medical profession and of the State. Conversely, not providing adequate and emergency care in institutions such as police stations, prisons, railways, public and private medical establishments is declared as a violation of the fundamental right to life. The ethics *jurisprudence* is constrained by the commercial-profiteering ethos that has marked the policy context of healthcare in India. However, it provides a strong foundation to accentuate the *dignity of care* for citizens and towards shaping the health care system to meet, among others, the critical, chronic and emergency needs.

GROUP P9: HEALTH SYSTEM AND PUBLIC HEALTH ETHICS II: DRUGS AND SERVICES

P9(a): Access to medicines: Looking through ethics

Adsa Fatima and Sarojini N

Accessibility and affordability of medicines are critical components of the public health response to people's health rights. The drug development processes to advance available treatments and explore newer innovations include clinical trials involving bio-medical research on human beings. A widely accepted ethical justification for biomedical research involving human beings as 'subjects' is that it holds purpose of benefitting people's health, which invariably then narrows down to the question of ethics towards the people participating in these trials. Sama's previous work on understanding perspectives of participants enrolling in

clinical trials had brought out the aspect that participants experiencing benefits from the drug in trial get concerned about its access and affordability post the trial completion. Often the drug tested in a country is not necessarily marketed there and in cases where it is marketed, its price can be prohibitively high making it unaffordable and inaccessible to people in that country. However, if drugs tested and approved in India do not meet the disease burden need here, then these trials merely serve as the mechanism for testing the drugs on Indian patients only to be useful in other countries.

Sama undertook a study on accessibility and affordability of medicines that underwent clinical trials in India between 2005 and 2010, by compiling data from clinical trial registries. The proposed presentation shall raise the ethical points for discussion from this study concerning various aspects of the trials and accessibility issue. Data maintenance of clinical trials on registries open to public domain, use of placebo controlled trials, trial designs, profile of the participants, disease focus by sponsors are some of the points to mention. The presentation aims to critically raise such aspects and engage with them towards developing a nuanced understanding from the perspective of ethics.

P9(b): 'Wife of spurious drug kingpin on the run' and other episodes in the curious contemporary cultural history of fake medicine and India

Sarah Hodges

Background and purpose: Fake drugs pose an awkward object of study. Whilst some accounts estimate that India produces a staggering 75% of the world's counterfeit drugs, the same reports announce that the trade in fake drugs is nearly impossible to spot, quantify or prevent. This paper looks at a 2010 'spurious drugs' media episode in Tamil Nadu, India, which has over 500 registered drug manufacturers and over 40,000 retail and wholesale drug merchants. We may know that fake drugs are a problem, but it is far harder to pin down what kind of problem, and to whom, fake drugs present. What's at stake in the fake?

Description of research method or ethical issues / dilemmas: Using the tools of cultural history--close readings of everyday popular ephemera-- this presentation suggests a series of preliminary answers to these larger questions.

Outcome of ethical inquiry: A close reading of this 'spurious drugs' episode evidences a substantial misalignment between a 'global health' framework for assessing the risks that India's fake drugs trade presents to the world at large, and the evidence of risk in episodes of spurious drugs scandals within India.

Discussion: I end by suggesting that attentiveness to the longer history of racial politics that fuels the project of global health helps to make sense of how these misaligned relations both enable and perpetuate such misrecognitions.

P9(c): Ethical and patient rights violations in government health insurance schemes in Karnataka

Vijayakumar S and Akhila Vasan

Karnataka has relentlessly pursued health insurance schemes as a strategy by empanelling private hospitals to provide treatment for a select few conditions. While there is substantial evidence of moral hazard of fraud, cost escalation, cherry picking and lack of reduction in out of pocket expenditure associated with health insurance, there was an urgent need to understand people's experiences of trying to access care under the schemes and its consequences. Data for this paper is drawn from a film research project that used a combination of participant observation, FGDs and interviews to gather data and focuses on design and implementation of the Vajpayee Arogyasri scheme (VAS) and the experiences of patients who tried to access critical care under it.

Patient experiences revealed widespread ethical and patient rights violations and discriminatory practices against the 'poor scheme' patients that reinforced casteist segregation and crass double standards. The 'free' scheme was accessible only to patients who could mobilize time, money and family support. Critically ill 'scheme' patients were denied admission and pain relief medication, they had no access to a second opinion, their medical records or care for post-intervention complications. Grievance redressal mechanism was absent and deaths under the scheme were neither accounted nor audited. Conflict of interest in the design, composition and functioning of the Suvarna Arogya Suraksha Trust (SAST) that administered VAS resulted in decisions being skewed in favor of the empanelled private hospitals that created formidable barriers for patients, threatening their safety and survival.

Health insurance schemes raise fundamental ethical questions about how the government that is supposed to protect citizens against violations is itself turning a violator by pushing undemocratic structures, and promoting profit -making private entities that directly threaten patient safety and survival as schemes for social justice and equality.

P9(d): Commercialisation of the private health care sector in India through the perspective of practicing doctor

Arun Gadre, Nilangi Sardeshpande, and Abhay Shukla

On the commonplace experience that not everything is right in ethics as observed by the private healthcare sector in India, this study was undertaken to find out what doctors have to say about the prevalent unethical practices in private healthcare sector.

It was a purposive study. The author personally interviewed 78 doctors across India, mostly from the private healthcare sector. The author began with those doctors who he knew would speak freely and the number increased with further references to potential interviewees from among the doctors interviewed. In the beginning, the author was unsure whether private

doctors in the privately run hospitals would talk openly. But surprisingly doctors talked with candor and force.

The number of unindicated procedures and operations is quite high. There are targets for angioplasty, MRI, CT scans and lab tests. Even those who are not really patients are induced to get routine investigations done and are converted into patients to undergo procedures; by pointing to some insignificant finding.

Stark commercialisation of the private healthcare sector aided by the near absence of regulation has taken a fatal toll on medical ethics in the private healthcare sector in India. The corporate sector, pharmaceutical industries, and private medical colleges are important drivers of unethical practices. Even the basic ethics in medical practice, ie; following evidence based guidelines are not being followed by a large section. Patients suffer huge economic losses from risks involved. The doctor-patient relationship is now adversarial. Ethical doctors suffer. Violence against doctors is on the rise. There is a most urgent need to establish ethics in the private healthcare sector in India.

GROUP P10: ASSISTED REPRODUCTION AND SURROGACY

P10(a): A longitudinal study of psychological well-being of Indian surrogates

Nishtha Lamba, Vasanti Jadva, Kaushal Kadam and Susan Golombok

Background & Purpose: Commodification of women's bodies in vulnerable poverty-stricken populations and lack of alternative choices for surrogates in India have raised many ethical concerns regarding their psychological well-being. Other concerns arise from a low support network for surrogates and the social stigma surrounding surrogacy.

Research Methods: A longitudinal and cross-sectional study was conducted comparing Indian surrogate to a matched group of expectant Indian mothers over two time points: (a) during 4-9th month of pregnancy (Phase 1: 50 surrogates, 70 expectant mothers, N = 120) and (b)

4-6 months after delivery (Phase 2: 45 surrogates, 49 expectant mothers, N = 94).

Semi-structured interview and questionnaire (Anxiety, Depression and Stress Scale,

ADSS, Bhatnagar et al., 2011) was administered in Hindi.

Results: Surrogates psychological well-being did not significantly deteriorate or improve post-delivery. No significant group differences were found in levels of anxiety, depression

or stress during pregnancy or after delivery. A non-significant trend indicated higher

depression levels in surrogates post-delivery ($F(1, 87) = 3.34, p = 0.07$). Upon further

exploration, it was found that lower support network ($\beta = -0.41, p = 0.00$), hiding surrogacy ($\beta = -.30, p = 0.04$), and facing criticism ($\beta = .33, p = 0.02$) were predictive of higher incidence of depression in surrogates post-delivery.

Discussion & Implications: Change in law in surrogacy in India does not erase concerns regarding psychological well-being of a surrogate. Preventative intervention offering timely counseling services and social support networks to surrogates (and their families) before, during and post pregnancy needs to be established.

P10(b): From the 'why' to the 'how'? Rethinking ethical positions in surrogacy

Pragna Paramita Mondal

Background and Purpose: A focus on the recent legislation on surrogacy in India suggests that there is an increasing tendency to overemphasize the moral validity of this sort of technological intervention within the pro-nationalist envisioning of the Indian society, as opposed to the more potent queries on its connection to issues of fairness and justice. Also the latter formulations, I argue, have either been perceived in terms of the intrinsic value of maternity or as a sanction of the principle of 'permissible harm' that such a human reproduction-based technology could possibly survive on. The purpose of this paper is to work through these layers of notional contestations and to understand how policy resolutions and debates on surrogacy could relate to the *procedural* (how) rather than the *ontological* (why) aspects and thereby redefine the idea of 'efficiency' in biomedical practices.

Description of research method or ethical issues/dilemmas: The discussion is based on the evidences and findings of a field research conducted among surrogacy clinics in West Bengal that included ethnographic narratives and conversations with the principal stakeholders. The ethical issues that would be addressed within the scope of this paper are the role of *preference* in reproductive decision making, *consent*, *anonymity*, and *agency*.

Results of research or outcome of ethical inquiry: The deniability of the transactional aspect of surrogate motherhood would by no means dilute the ethical constraints that surround it. In fact, it is not the marketability of surrogacy which needs to be challenged but the regulation and rationing of priorities within that market that have to be effectively achieved.

Discussion and implications for bioethics: It would be an imperative to analyze whether altruism in surrogacy could be defined as a morally superior category to commercialism; or if procedural clarity with respect to contractification and the distribution of the rights/outcomes among the surrogate, the child and the parents could enhance the ethical quality of the exchange.

P10(c): Bioethics and the commercialisation of human bodies and tissues in India

Priya Ranjan

New advancements in life sciences and biomedicine are increasingly bringing the vitality and regenerative capacity of human bodies, tissues, and cells into the explicit calculation of the global market. With the emergence of neoliberalism as the dominant policy framework to in the 1970s, life sciences and biomedicine emerged as one of the most favoured investment sectors.. The functioning of neoliberal economies coalesces with new developments in life sciences and biomedicine, where the deployment of 'promissory futures' for present financial gains has gained traction.

Over the past one decade, India has witnessed the rapid expansion of Assisted Reproductive Technologies (ARTs) industry, commercial surrogacy, and clinical trials, primarily based on the mobilisation of the bodies and tissues of poor women and other marginalized sections. The inclusion of the vitality and the regenerative capacity of our bodies, into the logic of the market has thrown up fundamental bioethical challenges. Some questions this paper seeks to address are— how does the emphasis on bioethics seek to protect the rights of vulnerable populations; is the bioethics discourse geared towards legitimising the commercialisation of human bodies and tissues; is bioethics internal to the growth strategies of the global biomedical industry?

This paper will examine the economic and political calculations underlying the demand for a universal bioethical standard, and the promotion of 'free choice' and 'informed consent' as the cornerstones of this framework. It will probe the correlations between production based on universal bioethical standard, the free movement of goods and services, and guilt-free consumption of biomedical products and services. Finally, this research paper shall investigate the contradictions between standardised and universalised bioethical framework and the specific moralities shaped by local social relations.

GROUP P11: ETHICS, INTEGRITY & PROFESSIONALISM

P11(a): Selfless giving in medicine: a study of altruism among medical students

Sanjai S and Vijayaprasad Gopichandran

Introduction:In India, as the medical profession is rapidly evolving into a trade, there is a need to understand whether altruism really drives the professional motivation of medical students. This study focuses on whether medical students in the 1st-3rd years in a medical college in Chennai have an altruistic orientation, and what factors influence their altruism.

Research Method:Using a cross sectional analytical study design, a sample of 224 students from years 1– 3 was tested. A questionnaire based on the Altruistic Personality Scale, and socio-demographic variables influencing altruism was

administered to the students after obtaining informed consent and analysed using SPSS software version 21.

Results:The attitudes of the students were largely grouped into four categories on factor analysis namely, (i) simple acts of altruism, (ii) recognised acts of charity, (iii) altruistic activities that put the self at risk, (iv) humanitarian acts. K means cluster analysis using the factor scores showed that the students can be grouped into three clusters namely, (i) those who engage in simple acts of altruism (43.3%), (ii) those who engage in simple acts as well as risky acts of altruism (30.8%) and (iii) those who do not engage in altruism other than humanitarian acts (25.9%). It was further seen that younger students, males, those whose parents donated to charity, those whose friends engaged in organising charitable activities, and those who had role models in college who were charitable, performed more simple acts of altruism.

Conclusion:A significant proportion of medical students who were surveyed had altruistic tendencies and these were influenced by their parents and role models in college. These tendencies can be nurtured at home and by an enabling environment in medical schools.

P11(b): “Thinking Ethics”: A novel programme of integrating ethics into the Physiology curriculum in South India

Savitha D, Manjulika Vaz and Mario Vaz

Background: While stand-alone ethics courses have been introduced into the medical curriculum, an added integration of ethics into core subjects allows for continuous exposure. Integrating ethics into preclinical subjects is important as there has been some suggestion of a dehumanizing curriculum leading to a disconnect with the ethical competencies of a doctor.

Methods: First year medical students (n=60) underwent 11 sessions of a 'thinking ethics' programme during the physiology course. Triggers derived from the regular teaching sessions were included in the theory and practical classes such as the ethical use of residual samples, informed consent, stigma, affordability of care, and animal ethics. The sessions were open-ended, student-centred, with a neutral observer to evaluate each session. During the entire programme, the student's perceptions were recorded through a semi-structured questionnaire and focus group discussions.

Results: The students found the programme highly thought provoking, fully integrated and relevant, seldom interfering with the physiology teaching. Further, they emphasised that the programme was unique, created sensitisation and awareness, and prepared them to be 'ethical doctors'. The observers felt that the programme was required for the preclinical year, was apt in its content, delivery and student involvement.

Conclusions: This exercise demonstrated the feasibility of a student-centred integrated ethics programme in the Physiology course. The students identified the need for

discussions on ethical issues embedded in curricular subjects from the very beginning of the medical course. They strongly suggested that the programme should be both horizontally and vertically integrated into medical education.

P11(c): Medical error reporting system: An initiative

Abeer Salim Habib and Nida Wahid Bashir

Background and purpose: Systemic failure accounts for 90% of in-hospital preventable deaths¹. Most hospitals use sentinel event reporting with an inherent tendency for stigmatization and blame. There is a dearth of available regional literature on medical error reporting systems. A potential solution is an error reporting mechanism focused on highlighting systemic deficits. Patel Hospital introduced its medical error policy providing anonymous reporting in 2014, aiming to sensitise hospital staff about the significance of medical error reporting, identify areas responsible for error occurrence and contribute to system improvement.

Description: The medical error policy was disseminated through awareness sessions focused on the significance of anonymous reporting. A medical error analysis committee was established. Reporting forms (English / Urdu) with drop-boxes were placed. In collaboration with concerned departments, root cause and preventive measures were identified and suggestions were forwarded to the administration. Six-monthly and one year follow up was planned to assess implementation.

Results: A total of 547 forms were received of which 357 were medical errors. The rest were either incidents or not errors. Significant measures for system improvement included a newborn gender documentation policy, SOP for oxygen delivery system, implementation of surgical site marking policy and WHO checklist, printed patient identification labels, digitising diet and medication systems, online theatre booking and blood bank systems.

Discussion: Adherence to error reporting addresses ethical imperatives such as truth-telling, patient advocacy, professionalism, beneficence and moral virtues like courage temperance and justice. Anonymity focuses on a system-based approach. Development of such a system promotes organisational ethics. By implementing this initiative, we are addressing these ethical imperatives around medical errors.

P11(d): Writing their own rules? Researcher perspectives on authorship guidelines

Priya Satalkar and David M Shaw

Authorship and publications in high impact factor journals are critical in the career success of researchers. Several international guidelines define assignment of authorship, but the value and meaning of a particular position in the author list varies between disciplines. The disproportionate importance of number of high impact factor publications, relative authorship position and the 'publish or perish' paradigm can push

researchers to compromise research integrity. In this paper, we describe and discuss researchers' comments on authorship and related issues when shown a specific vignette.

Our exploratory qualitative research study with medical researchers in Switzerland aims to understand their experiences of and perspective on research integrity (PRISM: Perspectives on Research Integrity in Science and Medicine). At the end of in-depth interview, we present all respondents with three vignettes addressing three different issues critical to research integrity, one of which is on authorship assignment. We will analyse researchers' perspectives on this particular vignette in comparison to key international authorship guidelines and their own personal experience with authorship attribution. We have already conducted 24 interviews and will continue recruitment until theoretical saturation is reached.

Preliminary results of our study indicate that the practice of authorship assignment is defined more by the established norm and culture within the research organization than by the authorship guidelines specified by journals. There was a clear difference between responses from junior and senior researchers faced with the same vignettes.

Our study suggests that considerable tension exists between authorship guidelines and the practices of both junior and senior researchers. Whether a researcher is perceived as deserving of authorship on a given paper is affected by many complex interactions, and conflict of interest in authorship attribution is a significant factor. A move to a more transparent research environment might reduce some of these tensions.

WS/S12: Guidelines For doctors on sexual boundaries, and next steps

Facilitators: **Sunita Simon Kurpad**, Member, MC FMES, Professor of Psychiatry, and Head Department of Medical Ethics, St. John's Medical College, Bengaluru, Karnataka, India; **Ajit Bhide**, Senior Consultant and Head, Department of Psychiatry, St. Martha's Hospital, Bengaluru, Karnataka, India

While the two thousand year old Hippocratic Oath specifies that doctors should not get into sexual relationships with patients, the Medical Council of India states that doctors should not engage in 'immoral conduct'. The Bangalore Declaration Group and the Indian Psychiatric Society (IPS), have recently drafted guidelines for doctors on sexual boundaries in the doctor-patient relationship in India.

Non-consensual sexual activity is obviously a crime, but doctors agree that even 'consensual' sexual activity in a 'power imbalanced' relationship like that of between doctor and patient, is not truly consensual, invariably harming both in the long run.

It is important that all doctors- indeed all health professionals are aware of the issues involved, as no professional group is immune from the potential to abuse.

Sexual abuse is an unfortunate reality in all groups in society, particularly difficult to talk about truthfully and safely in traditionally respected (and 'power imbalanced') groups like

doctors, teachers, armed forces and religious leaders. The occurrence of false allegations, unfortunately, compounds the problem. It is hoped that this workshop will encourage other groups in India too, to begin to safely address the problem of sexual abuse in our society.

Format of Workshop: 1. Sunita Simon: Brief presentation of background and need for guidelines; 2. Ajit Bhide: Guidelines for doctors on sexual boundaries; 3. Sunita Simon: Next steps. 4. Sunita Simon and Ajit Bhide: Facilitated discussions seeking audience participant discussions facilitated by Sunita and Ajit Bhide); 5. Sharing resource materials: papers, free link to sensitization video and a website with some FAQs

WS/S 13: Supporting patients and caregivers towards the end of life: a workshop based on the book '*Being Mortal*'

Facilitators: Anita Jain, Clinical Editor, *BMJ*, and independent physician and family medicine tutor

Target audience: Medical students, doctors, nurses, and health professionals who engage with patients

Aims: The workshop aims to reflect on aging and our interaction with patients and families faced with difficult decisions at the end of life.

Key themes: In this workshop, key themes from Atul Gawande's book '*Being Mortal*' will be shared as below: (a) The Independent Self – autonomy, good & difficult deaths; (b) Aging – frailty, patterns of decline, issues of dependence; (c) Dependence – physical and emotional changes of age, assisted living, care homes; (d) Letting go – terminal care, what does it mean to 'let go'; (e) Hard conversations – discussions towards the end of life; (f) Courage – difficult decisions, spirituality & mortality

Format: Through a series of individual exercises and group discussions, participants will be encouraged to reflect on mortality and issues that patients and families grapple with, and develop a sensitive approach in their clinical practice.

The BMJ has been leading a campaign on partnering with patients. Palliative care forms a key area where we have patients and caregivers share how health professionals and health systems could have supported them in making end-of-life care decisions and in dying with dignity.

Encouraged reading: *Being mortal* by Atul Gawande; *When breath becomes air* by Paul Kalanithi; *Inside the O'Briens* – Lisa Genova; Palliative care is not just for those who are dying. *BMJ* 2016 Jun 15;353:i2846; Townsend JD. Before I kick the bucket I want to say thank you. *BMJ*. 2015 Oct 14;351:h4706.

DAY 2 | SATURDAY, JANUARY 14, 2016**2:00 PM TO 3:30 PM****PAPER PRESENTATIONS AND WORKSHOPS****WORKSHOPS & SYMPOSIA: WS/S14 TO WS/S18****WS/S 14: Advanced cancer care: ethics of communication preferences of patients, their carers, clinicians and society**

Facilitators: **Barun Mukhopadhyay**, Senior Faculty, Biological Anthropology Unit, Indian Statistical Institute, Kolkata; **Soumitra S Datta**; Senior Consultant Psychiatrist, Department of Palliative Care and Psycho-oncology, Tata Medical Centre, Kolkata; **Subrata Chattopadhyay**; Head, Department of Physiology, College of Medicine & J.N.M. Hospital, The West Bengal University of Health Sciences, Kalyani; **Krishnangshu Roy**; Director, Institute of Health and Family Welfare, Government of West Bengal, Salt Lake City, Kolkata

India has a million new cancer patients every year and many of them are in advanced stages of the disease. Patients are mostly supported financially, physically and emotionally by their families in advanced stages of the disease. In the era of globalization, a changing pattern of relationship between the care providers (doctors) and care receivers (patients) is discernible. Globally, it appears that medical care is moving away from a paternalistic model of care to a more open dialogue between the receiver of care and the providers of health services. Against this backdrop, the proposed symposium will discuss the ethical aspects of doctor-patient communication in India, considering several dimensions including the role of individual vis-à-vis family in clinical communication. The symposium will provide insights into the theoretical aspects of doctor-patient communication as well as empirical insights on the matter using appropriate case studies that demonstrate ethical dilemmas of the health care providers and their resolutions. An inter-disciplinary focus on the choice of speakers will be followed. By the end of the symposium, we expect the participants to have an understanding about the nuances of ethical dimensions of doctor-patient communication in India.

Format: 1. Barun Mukhopadhyay: A sociological perspective of 'individual' and 'family' in India – Theoretical issues and changing empirical scenarios; 2. Soumitra S Datta: Qualitative exploration of communication preferences of patients with cancer and their families; 3. Subrata Chattopadhyay: Autonomy: east meeting west; 4. Krishnangshu: Communication skills training - Need of the hour for all clinicians

WS/S 15: Integrating sex and gender in health: an attempt to address equity when dealing with sensitive issues such as end of life care

Facilitators: **Bilkis Vissandjée**, Professor, Faculty of Nursing and School of Public Health, Université de Montréal, Montréal, QC, Canada; and **Wendy E Short**, Faculty of Nursing and School of Public Health, Université de Montréal, Montréal, QC, Canada; Faculty of Humanities and Social Sciences, St. Lucia, University of Queensland, Queensland, Australia

Where social constructions of sex and gender result in social vulnerability, access to health care is often inequitable with differential outcomes. With respect to providing sustained quality end-of-life care, the gendered perspectives of medical and other carers exacerbate the vulnerability of the ill.

This 90-minute workshop will provide insights for both younger and senior researchers seeking to integrate sex and gender awareness and deliver from a social justice perspective. The workshop will begin with two focused presentations providing theoretical grounding for this approach. (40 minutes in total); participant groups will then discuss case studies from published literature pertaining to this section; the groups will report on their discussion; a final wrap up will be provided by the Workshop team.

Objectives: To explore the concepts of sex and gender as key determinants in health research and consider the challenges of achieving health care access equity in this context; highlight the impact of gender ideologies of healthcare professionals on quality of healthcare and patient agency; seek sensitive responses from healthcare providers to patients at end of life.

Finally, the workshop will involve gathering insights from the assembly regarding: innovative means of delivering accessible projects to women that are cognisant of their life pressures; identifying intersections of social inequity which prevent women accessing health care; creative ways of ensuring that the women recipients are involved from conception to implementation in future projects.

A list of suggested readings, including case studies, will be provided closer to date. Case study summary sheets will be provided to discussion groups during the workshop. (a) End of Life Issues, Chapter 3. *The Canadian BioEthics Companion. An online textbook for Canadian ethicists and health care workers.* <http://canadianbioethicscompanion.ca/the-canadian-bioethics-companion/chapter-3-end-of-life-issues/>; (b) Pega F, Veale J. The case for the World Health Organization's Commission on Social Determinants of Health to address gender identity. *American Journal of Public Health.* 2015;105(3):E58-62., (c) Johnson J, Sharman Z, Vissandjée B, Stewart DE (2014) Does a Change in Health

Research Funding Policy Related to the Integration of Sex and Gender Have an Impact? *PLoS ONE* 9(6).DOI:10.1371/journal.pone.0099900, <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0099900> ; (d)Johnson JL, Greaves L, Repta R. Better science with sex and gender: a primer for health research. *International journal for equity in health*. 2009; doi: 10.1186/1475-9276-8-14.

WS/S 16: Organ donation and transplantation in india: ethical challenges and solutions

Facilitators: **Sunil Shroff**, Managing Trustee, Multi Organ Harvesting Aid Network (MOHAN) Foundation; **Sumana Navin**, Course Director, MOHAN Foundation; **Dominique Martin**, Sr Lecturer, Faculty of Health, Deakin University; **J. Amalorpavanathan**, Member Secy, Transplant Authority of Tamilnadu, Chennai; **Farhat Moazam**, Chairperson, CBEC, SIUT, Karachi, Pakistan; **Lalitha Raghuram**, Country Director, MOHAN Foundation

Organ donation and transplantation in India is fraught with ethical challenges and dilemmas. Living donation was synonymous with organ commerce till the law makers stepped in to regulate it. In spite of this, scandals repeatedly surface and the recent incidents in private hospitals in Delhi and Mumbai have thrown up more questions than answers. Given that the requirement for organs is not going to go down anytime soon, living donation is something that one has to live with. This means that the ethical concerns surrounding living donation need to be addressed. Deceased organ donation and transplantation needs to be examined just as carefully, if not more, since altruism is the cornerstone here. The ethics with regard to the needs of the families of deceased donors, transparency in organ allocation, directed donation, uniform definition of death, validity of the pledge form, information about recipients need to be clarified.

Objectives: 1. To gain understanding of the international perspective on Transplantation ethics; 2. To get an overview of the recurring scandals in living donation in India; 3. To gain insight into the various ethical challenges in deceased organ donation in India

Expected audience: Doctors, transplant coordinators and medical social workers

Outcomes: 1. Measures to adopt international standards of Transplantation ethics, 2. Suggestions to strengthen protocols related to living donation, 3. Practice of objective ethics to meet the ethical challenges in deceased organ donation.

WS/S17: Strategies in palliative care

Facilitators: **M R Rajagopal**, Chairman, Pallium India; Thiruvananthapuram, Kerala, India; **Mary Ann Muckaden**, Professor of Palliative Medicine, Tata Memorial Centre, Mumbai, MH, India; **Anita Kar**, Director, Integrated School of Health Sciences, Savitribai Phule Pune University (SPPU), Pune, MH, India

The workshop will be conducted to involve the participants in three main areas of palliative care, namely Difficult Conversations, Networking and Communitizing of palliative care. Discussing diagnosis, prognosis and many aspects of care with the patient and family requires skill and empathy and is collectively called 'difficult conversations'. While in most diseases there is some difficulty in communicating with the patient, in cancer the level of difficulty is significantly higher. There is need for a lot of understanding, empathy and skill to do so. Dr. Rajagopal is a recognized master at this. He will discuss the basics of difficult conversation and take the participants through the task with role plays and other interactive means. The second session will cover networking in palliative care. Palliative care in specialized centres has now achieved acceptable levels, but beyond these centres, the people are not familiar with even the concepts. There is a need to build networks that include specialized centres that have palliative care experts, local medical practitioners, social workers and volunteers. The session will include a group discussion. The last session will be on communitizing palliative care. There is an urgent need to involve the entire community in palliative care. A patient living in the community should be aided to live in the community even towards the end of life, and for this the entire community must help. This session too will involve a group discussion. In fact the group discussion for session 2 and 3 will be grouped together and at the end the groups will present a brief report on their deliberations. The workshop will end with summarizing the role of palliative care as a means of improving the quality of life of patients and their families when affected with this debilitating disease.

WS/S18: Defining 'futility' and 'inappropriate interventions' and resolving ethical conflicts that arise in delivering 'appropriate eolc' in ICUs

Facilitators: **Shivkumar Iyer**, Lead, ICU Unit, Bharati Vidyapeeth, Pune, MH, India; **Jignesh Shah**, Faculty, Bharati Vidyapeeth, Pune, MH, India; **Raj Mani**, Group CEO and chairman critical care and pulmonology, Nayati Super Speciality Hospital, Mathura and Nayati group of hospitals

Background: Ethical challenges are extremely common in End of life Care (EOLC) for both health care professionals and patients and their families. The Indian Society of Critical Care Medicine (ISCCM) and the Indian Association of Palliative Care (IAPC) have time and again published ethical position statements and guidelines on this subject. The practice of appropriate EOLC however is lagging behind because of lack of awareness among the health care professionals and patients and families. The ethical conflicts that arise are complex and multifactorial in origin. Financial difficulties too play an important role.

Purpose: This workshop/symposium aims to help participants define futility and inappropriate interventions, to identify ethical challenges in EOLC and deliver appropriate EOLC using a case based approach. The ethical aspects of futility and the common ethical dilemmas health care professionals and families face will be highlighted.

Methods: Case scenarios will cover common EOLC situations in ICU and will be presented in modules covering the stepwise approach outlined in the ISCCM/IAPC guidelines "Integrated Care Plan for the Dying" with special emphasis on identifying and resolving the ethical conflicts that arise during EOLC.

The ethical issues that will be discussed include: (a) Speaking to the family without involving the patient even when he/she is competent.; (b) Diffusion of responsibility among the treating team especially the clinicians leading to difficulties for family in identifying the "captain of the ship"; (c) Identifying the appropriate surrogates.; (d) Exploring the definition and concept of futility and inappropriate or disproportionate therapy.; (e) Lack of agreement in treating team and surrogates regarding futility and treatments goals.; (f) Ethical conflict between patient/family autonomy and best interest of

patient (beneficence/non maleficence) as judged by treating team.; (g) Role of 2nd opinion and clinical ethics committee in resolving such conflicts before resort to courts or judicial help.

The discussion will be structured around case scenarios like advanced metastatic cancer, chronic neurological illness, chronic respiratory failure, elderly frail patient and sepsis with worsening organ system failure.

Structure of the workshop: (a) Introductory remarks-10 mins.; (b) 3 Case presentations (7 - 10 min each)-Total 30 mins., (c) Expert opinion and audience participation (5 - 10 min per case)-30 mins., (d) Summing up-10 min

Expected output:The presentations and discussion will be summarised as a policy brief for future use by health care.

DAY 3 | SUNDAY, JANUARY 15, 2017

9:30 AM – 11:00 AM

PAPER PRESENTATIONS AND WORKSHOPS

GROUP P12 TO P16 & WS/S19

GROUP P12: PALLIATIVE CARE ETHICS - III: SPIRITUAL, RELIGIOUS & SOCIAL ASPECTS

P12(a): Spiritual suffering of a palliative care patient

Arul Dhas

Palliative care patients go through different kinds of suffering. One dimension which is often ignored or sidelined is the spiritual dimension. Spiritual care is an integral part of holistic care. Some people ignore this because of lack of knowledge, lack of resources or lack of sensitivity. Even in the centres where spirituality is understood as important, when there is a resource crunch, the first area which is affected or compromised is spiritual care.

Those who are going through palliative care go through questions connected to faith, end of life, meaning, God, belonging, relationship, etc which pertain to the area of spirituality. Some of the difficult feelings like guilt, bitterness due to various life experiences come to the surface when people go through pain and suffering.

When death seems to be imminent, some ultimate questions come to mind. What is the meaning of life? What happens when I die? What will happen to my loved ones? Will my loved ones continue to remember me? Have I fulfilled all that is meant to be completed? It is not possible that the caregiver knows the answers for these questions. However, the caregiver could learn to be comfortable with listening to these questions. Rather than running away, being with the person in suffering is a great service one could provide to the sufferer.

'Doing good' is the fundamental ethical responsibility of a caregiver. When we realise that addressing the spiritual pain of the patient is our ethical responsibility, training, sensitivity, and execution of the spiritual care becomes an obligation to healthcare providers and institutions.

There is a plurality of understanding with regard to these types of deeper questions in life. The caregiver could learn the skill of accommodating different viewpoints. In addition, he/she could learn the skill of instilling hope and meaning in the midst of plurality. Some of the basic counselling skills will help in this area. Therefore the administrators of palliative care units could pay attention to these areas which might help equip the caregiver better. Rather than ignoring or not recognising the spiritual suffering of the person, we will be able to better

address the spiritual needs of the person in the palliative care unit with empathy and sensitivity.

P12(b): The science of medicine and the art of dying: Reflections from the Indian legacy

Swami Dayapurnananda

Death is the most inevitable truth that life presents before us. The medical science aims at alleviating the pain accompanied with the end stage of life but has mostly failed in relieving the mental suffering, agony and primarily the inherent fear associated with the act of dying. Present medical world is more equipped in the fight against dying but has undermined the necessity and acceptance of letting go. This study aims at searching some death-related issues from the various instances presented in Indian Philosophy and discusses the opportunities provided to overcome the obstacles leading to a more meaningful and dignified way of facing death.

Indian culture revolves around the concept of DHARMA which is usually wrongly translated as the English word religion with a much narrower meaning. Sanskrit root Dhri, from which the word is made means that which sustains, meaning dharma actually is a source of sustenance to walk the inroads of life, and not mentioning the dogmas or belief often associated with it. The Sanatana Dharma of the Indian continent, or the eternal religion, again commonly coined as Hinduism with a narrower meaning, extolls the ethical implications of dying in its ancient Vedic literature till its modern exponents as Ramana Maharshi and others.

Srimad Bhagavad Gita mentions about the thought process while dying and the Upanishads describe the end stage of life with their ethical significance. Indian heritage assumes the dying process as a phase of transition towards a greater reality rather than an end in itself. One may question about the truth of this peculiar claim of Indian mind, but the ethical implications of such an issue cannot be denied. Patanjali Yoga Sutra, Yogavasistha Ramayana, Tripura Rahasya and other texts help and guide a grieving mind and care-provider both to ensure a better and fruitful acceptance of death by creating greater empathy.

P12(c): Social, cultural and spiritual attributes of a dignified death: End-of-life practices in rural south India

Sudha Ramalingam and Subhashini G

End of life care practices is a sensitive topic in our socio cultural ethos. Many terminally ill patients are taken home

to die a “peaceful” and “dignified” death surrounded by their loved ones. There are sporadic reports which look into end of life practices in some parts of rural Tamilnadu. However, there is a dearth in literature on these practices and the several determinants which lead to these practices.

A focus group discussion (FGD) was carried out among 15 residents who were long term residents of the area with/without prior experience in taking care of the terminally ill in a rural area in Tamilnadu. This was followed by an in-depth interview (IDI) of 8 women from 3 different neighboring villages to get a better understanding of the differences in the practices within the community. The discussion and the interviews were recorded with the consent of the participants and were transcribed.

The major finding that emerged from the FGD was that various practices (e.g. multiple oil baths, *Thalaikoothal*, feeding tender coconut water, etc.) are being followed in the rural community to facilitate peaceful death. Content analysis revealed major themes such as moral, spiritual, socio-cultural and economic factors which contribute to such practices and the differences in the beliefs between the communities. While the legal nuances of euthanasia are being debated in India, it is evident that similar practices are already closely intertwined in the culture and are socially acceptable as “dignified deaths,” which calls for the discussion on the ethical dilemmas behind it.

P12(d): “I want to be my own author!” Debate on “completed life” and right to euthanasia in the Netherlands

Priya Satalkar

Background and Purpose: ‘UitVrijeWil’, a citizen’s initiative in the Netherlands is advocating the right to euthanasia for elderly Dutch citizens who feel that their life is complete. The purpose of this paper is to explore the reasons, decision making process and expectations of individuals who endorsed this initiative and to understand its implication on ethical debate on euthanasia, the right to die and self-determination.

Description of Research Method or Ethical Issues / Dilemmas: This qualitative exploratory study involved a thematic analysis of 11 in-depth interviews with Dutch citizens who had endorsed the initiative.

Results of Research or Outcome of Ethical Enquiry: Individual autonomy and self-determination shaped respondents’ decision to support the Initiative. They argued that the current euthanasia law is physician-centred and restrictive in its interpretation of unbearable suffering. Long struggles of their close family members with death influenced their views about dignified death. Through the Initiative, they challenged the power of medicine over death and tried to regain control of the moment and the process of dying.

Discussion and Implications for Bioethics: The goal of the Initiative to draw public attention and to challenge “medicalisation” of dying and death was achieved to a large extent. But the definitions and concepts of ‘completed life’ and

‘life fatigue’ are ambiguous. “Completed life” exudes a positive sense whereas “life fatigue” or “being tired of life” has a negative one. It could be interpreted as a person’s lack of desire to go on living and hence the preference for a peaceful death with minimal suffering. The Initiative raises a number of ethical and social questions on the limits of self-determination and urges us to re-examine the growing power of medicine on life and death.

GROUP P13: HEALTH SYSTEM AND PUBLIC HEALTH ETHICS - III: PUBLIC HEALTHCARE, BIOBANK AND TISSUE DONATION

P13(a): Contingent-caregivers and acrimonious care: Caregiving in a public hospital maternity ward

Rakhi Ghoshal

While the literature on caregiving largely works within the contexts of chronic and terminal illness which requires medium to long-term care giving, this paper examines situations when caregiving happens across much shorter durations. It focuses on caregiving in maternity wards where intrapartum and postpartum women are cared-for typically between two and five days. Based on an analysis of 12 qualitative, in-depth, semi-structured interviews and 7 free-flowing narratives conducted as part of my doctoral research, the paper analyses, what it calls, ‘contingent care’ in a West Bengal public hospital maternity ward.

Though nurses are traditionally involved with patient care, in this maternity ward, care was typically provided by the ward-ayahs (*mashis*). *Mashis* are a complex category of providers who are neither employed nor acknowledged by the institution, with no unions, decision-making power or pay. And yet, they remain a fundamental part of the institution’s care-economy. How does this dynamic shape a politics of care, especially when the carer herself is rendered vulnerable by the institution it represents?

Patients were systematically compelled (ironically, by the institution which did not however acknowledge *mashis*) to hire a *mashi* every 12-hours against rates that were non-negotiable, creating an informal system where the illegitimate caregiver routinely and compulsively sold care. Such circumstances also complexly informed women’s experiences of institutional birth.

This form of contingent-care is informed not by empathy but acrimony: in this context care becomes a political act, invested more by an economic than affective imperative and, to-care-for is the obverse of the carer’s struggle to survive, i.e. to care for her own self. Did the patients then unknowingly become caretakers to their caregivers? How much was the institution responsible for consolidating this convoluted structure of contingent-care? These are some of the questions that animate the paper.

P13(b): Nursing leadership thrives in dignified contexts: Lessons from West Bengal government initiatives in strengthening nursing cadre

Joe Varghese, Solomon Salve, Pallavi Mishra

Background: The educational background of nurses, and their roles and responsibilities, give them a professional identity distinct from other health workers. However, their professional dignity in India remains challenged for varied reasons ranging from doctor dominance to cultural factors. This paper explores the West Bengal (WB) initiatives in strengthening nursing leadership, and shows how professional identity and dignity of nurses has a close relationship with strengthening their performance

Methods: This exploratory study was conducted in WB during 2015-2016. In-depth interviews were conducted with nurses, medical professionals, and programme managers. The data was thematically analysed using the framework approach for applied policy analysis.

Results: We present here cases of three different nursing cadres in West Bengal. The recently created Nurse Practitioner Midwives identified their role as different from that of a gynecologist, saw themselves equipped with greater 'independence, accountability and responsibility.' Nurses specifically trained for critical care units worked hand in hand with the Medical Officers. Nurses felt empowered as they shared a larger role in decision making in critical care. In the public health domain, District Public Health Nursing Officers are placed at the district level as key functionaries responsible for all national health programmes. Their strong administrative position brings respect and authority to deal with nursing issues.

Conclusion: Investing nurses in the health system with authority and dignity would benefit the health system in the long run.

P13(c): Ethical issues in sperm donation: A review

Subhashini and Sudha Ramlingam

Scientific developments in assisted reproductive technologies (ART) have evolved so rapidly that human reproduction has gone through a revolution. Advancements in ART introduced social, political and ethical controversies in all aspects. Hence it becomes imperative not only to celebrate the medical achievements of ART but also to discuss the ethical values and dilemmas in relation to sperm donation in assisted reproductive technologies.

Articles were searched using search engines like Medline, PubMed, Google Scholar. Keywords used for search were: "Ethics" AND "sperm donation"; "Ethical issues" OR "social issues" AND "sperm donation"; "Issues" AND "sperm donation". Totally 280 articles were retrieved, after quality assessment of the content and relevance to the topic, 36 articles and 16 reports / guidelines were included for review, and the ethical

issues in sperm donation were reviewed under the following headings: (a) Anonymity of the donor Vs Anonymity of the recipient parents (Right of the donor to be anonymous Vs Right of parents to seek information); (b) donor anonymity to the concerned Offspring (Right of the child to know Vs Right of parent's privacy); and (c) Ethics involved in selective human reproduction: That is prospective parents to choose the sex of their child, to avoid the birth of a child with a disability, or even to choose deliberately to create a disabled child Ethics related to religion and culture in sperm donation

Thorough and considerate review makes it clear that sperm donation though a scientific breakthrough should be guided by thoughtful, progressive and ethically binding regulations.

P13(d): Biobanking in Pakistan: Uncharted waters

Aamir M Jafarey, Sualeha Siddiq Shekhani and Bushra Shirazi

The concept of biobanking is fast emerging as an important tool for biomedical research. There are already several well established biobanks operating, many with close collaborations that often take the shape of centres in the East providing biosamples to the biobanks in the more developed West.

This paper uses a two pronged strategy to look at the various perceptions and ethical concerns that are perceived to be connected to biobanking in Pakistan. Using mixed method quantitative and qualitative methodology, the authors conducted a pilot survey among one hundred medical and one hundred non-medical students at two premier educational institutions in Karachi, Pakistan, gauging their perceptions related to biobanking. The themes emerging from the survey were then compared and contrasted with perceptions of 40 scientists, bioethicists and administrators who converged for a two-day workshop in Pakistan on ethical issues of biobanking.

There was practically a unanimous lack of clarity regarding what exactly constitutes a biobank. Majority of the participants of the workshop and survey believed that informed consent was necessary for storage of biomaterials, although participants were unsure on how this could be achieved for specimens stored indefinitely for use in future research. Few participants expressed confusion regarding whether anonymization of the sample was possible. Although majority of the participants of the survey found it acceptable to transfer biospecimen across borders, possibility of misuse was discussed. Ethical concerns with respect to re-consent for participation, privacy of individuals and ownership of biospecimen material were raised, similar to those written up in international literature. Both the pilot study and workshop also revealed cultural insights important for informing biobank governance policies for the future, particularly within the context of Pakistan.

GROUP P14: REPRODUCTIVE HEALTH: AUTONOMY AND JUSTICE

P14(a): Insights into women's access to reproductive health care services in Vidarbha region of Maharashtra, India, with reference to National Rural Health Mission

Hemalata Pisal, Shubhada Deshmukh, Kajal Jain, Manish Rajankar, Madhuri Khadase, Koustubh Pandhripande, Keshav Gurmule, Yogini Dolake, Hemlata, Arati Bais and Ramesh Awasthi

Background: The National Rural Health Mission (NRHM, now National Health Mission – NHM) launched in 2005 in India was a significant development, with the stated goal “to improve the availability of and access to quality health care by people, especially for those residing in rural areas, the poor, women and children.” However, the ground realities have been uneven, even in 2015, and don't necessarily align with the commitments made in NHM. For example, a number of non-government organisations from Vidarbha region, Maharashtra, partners in an initiative by Mahila Sarvangeen Utkarsh Mandal (MASUM), have noticed deficits in the quality of rural public health care facilities (PHCFs), especially in reproductive health care in their own geographical areas.

Through a deliberative and consultative process, the partner organisations decided to engage with the public health care facilities in their areas. They adopted the evidence based approach to advocacy towards making PHCFs gender just and accountable, focusing on improving the quality of reproductive health care services.

Method: Nine partner NGOs of this initiative collected data during 2015-16 from 30 rural hospitals (RH) from across about 50% of blocks from six of the 11 districts in the Vidarbha region. The data items included health care services, such as infrastructural facilities, type of health care services provided - minor surgeries and specialised services, human resources and availability of medicines.

Results: Overall RHs were well-equipped (about 80%) with various infrastructural facilities including functional operation theatres (93%). However, specialty services even to provide maternal health care were seriously deficient (No gynecologist at 60% of RHs; no anaesthetist at 72% of RHs). Furthermore, a large percentage of RHs lacked service such as caesarian section facilities (86% of RHs), abortion (75% of RHs), and hysterectomy (93% RHs). No RH offered pap smear screening. Non-availability of reproductive and maternal health services in RHs forces women to be dependent on the private health care system which is at a high cost. Women's approaching private health care services is also due to the inaccessibility of the next referral point, ie, district hospitals (DHs). For example, only about 27% of RHs were located within the reasonable distance of 25 km from DHs.

Discussion: These findings demonstrate that the deficit in the

public health care system in rural areas is worrisome. It also demonstrates that NRHM goals set in 2005, despite being praiseworthy and gender-just, have not been met over these past ten years in this region. The partners are using these data to engage with elected peoples' representatives and state administrators at various levels, such as, members of legislative assembly, and Director of Health Services. The advocacy efforts are ongoing.

P14(b): Community-based health intervention for reproductive health care needs: MASUM's experience

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Background: In the context of Sustainable Development Goals (SDGs) it is mentioned that significant strides have been made in relation to indicators such as life expectancy and containment of some of the common killers associated with maternal mortality. However, the SDG policy document also notes that only half of the women in developing countries have received the health care they need. Globally speaking, expanding women-friendly public health services remains central to the developmental agenda. In countries like India, wide ranging constraints adversely impact realisation of this agenda. Programs like National Health Mission (NHM) are praiseworthy initiatives and yet women's access to reproductive health services continues to be unsatisfactory.

Against this background, non-governmental organisations working with a focus on health tend to develop interventions and programs to respond to health care needs of women in their intervention areas. This paper reports on women's reproductive health needs, and a community-based health intervention by Mahila Sarvangeen Utkarsh Mandal (MASUM) from a rights-based perspective.

Method: The intervention primarily includes perspective building and skill training of selected women as community based health workers over one year, involving 3-4 days residential contact sessions every month. It is complemented by ongoing training and inputs for the health workers. The perspective building is aimed at helping them appreciate women and health within patriarchy and social structures.

This paper analyses information from women's health screening – general health, reproductive health, including visual inspection with acetic acid (VIAA), first line of treatment and/or appropriate referral to public health facilities- intervention organised in 38 villages of Purandar block, Pune, over the years 2010-2015. Generally, screening is organised twice a year. So far, 205 screening events have been organised. Each of these events involves closer engagement with communities, awareness building about the need for screening and its role in prevention, and overall health education. Of more than 6000 women who participated in these screening events, about 2878 women consented to undergo internal examination with speculum, and to VIAA administration.

Results: A significant number of women (65%) were diagnosed with reproductive health morbidities; the majority (66%) being in the reproductive age. Sixty three percent were diagnosed with primary level morbidities and were offered treatment at the community level. Timely referral of 37% women to public hospitals reduced their burden of disease and suffering.

Discussion: MASUM's experience with the aforesaid approach to women's health care needs intervention has been encouraging. The approach of MASUM to training health workers has been extensively elaborate, which is both its strength and weakness (as in this form it might not be scaled up). A variant of this approach was adopted in the public health system in two blocks of Satara district, Maharashtra, with a focus on cervical cancer pre-screening. This included training of ANMs /LHVs to conduct early screening of gynaecological morbidities and cervical cancers at primary health centres, timely referrals, treatment and follow up in public health care facilities.

The approach needs to be tested in various different contexts in other parts of Maharashtra. The learning from these could inform incorporation of this strategy into the government's primary health care programme. It would help in getting one step closer to a gender-just public health care system.

P14(c): Ethical and socio-cultural issues related to adolescents capacity to provide consent for treatment

Bhavna Dhingra, Brian S Carter and Angela D Knackstedt

Parents are supposed to act with the best interest of the child at the core of their decisions. This paternalistic attitude may be at conflict with the needs of adolescent at times and this raises certain ethical issues and dilemmas. A 16 year old boy previously treated as ALL at 11 years of age presented with a second relapse. The parents wanted to go ahead with therapy while the adolescent did not want any treatment as he neither wanted to undergo any further suffering nor did he wish his family to suffer because of him. His wishes were overruled and he was made to undergo treatment and succumbed to his illness in a few days.

Can the *lack of 'assent'* from the adolescent be prioritized by healthcare team to stop treatment over the wishes/consent of parents? Due to apparent reasons, his autonomy and decision were not respected and overruled by those of his parents. By refusing treatment he is not only desirous of limiting his own painful exposure, he tried to limit his family's fiscal and psychological burden. If health care was accessible and affordable and the adolescent did not have to worry about financial implications, would it have influenced his decision?

Is it ethical to overrule/disrespect an adolescent's wish to not undergo painful treatment for his/her condition simply because his parents want him to receive treatment? How do we understand autonomy and increasing capacity to decision making of the adolescent versus their best interest as decided by the parents? What is the role of healthcare personnel and

how do they influence this decision? How do societal issues of inequitable resource distribution and accessibility/affordability of health care services influence this decision?

P14(d): Stigma experienced by Women Living with HIV in India: The contribution of the Biopsychosocial Complex Model

Wendy E Short and Bilkis Vissandjée

Access to effective antiretroviral drug treatment has made HIV infection a survivable chronic illness, allowing long-term health management to focus on maintaining quality of life and infection containment. Given the effectiveness and availability of treatment, a purely biomedical perspective might predict an improvement in the quality of life of the 2.1 million Indian people living with HIV. However, not only has stigma survived the advent of antiretroviral drug treatment in India, but it remains pervasive, impacting life patterns and disrupting biomedical interventions. Based on the analysis of current published medico-ethnographic literature, this paper argues that a more complex biopsychosocial lens as proposed by Engel would help in the understanding of the experience of living with HIV infection in India.

Due to cultural beliefs and unequal power relations, women living with HIV in India are particularly engulfed by stigma. By apprehending the common experiences of married, monogamous women living with HIV that are all characterised by stigma, it is possible to identify the interrelated threads of hegemony which reduce their quality of life, limit implementation of biomedical redress, and increase the likelihood of terminal illness and infection transmission. Practically, adopting a coordinated biopsychosocial approach offers the potential to engineer intervention programmes identifying, prioritising and addressing the interrelated needs of the almost one million HIV positive Indian women. The imperative to further develop, test and implement such an approach originates in appreciating the dehumanising impacts of stigma and a desire to reduce the greatest barriers to women accessing treatment, quality of life and survival.

GROUP P15: ETHICS IN CLINICAL CARE

P15(a): Transfusions in Jehovah's Witnesses: Changing ethical paradigm?

Swarupa Bhagwat, Jayashree Sharma, and Santosh Salagre

The members of the religious sect "Jehovah's Witnesses" (JWs) do not accept blood transfusions even if their life is threatened, thus presenting bioethical dilemmas. We present two such cases and also review the changed JW policy and advances in medical sciences in relation to these ethical issues.

A 67 year JW male was referred for an emergency abdominal surgery but refused to accept blood transfusion. A competent

adult JW patient's religious freedom, autonomy and the right to refuse a treatment were in conflict with the bioethical principles of beneficence and non-maleficence on the part of the physician in a life-saving situation. The patient was explained in a non-threatening environment about the risks and benefits of accepting and refusing transfusions. The patient consented to accept transfusions as a life-saving treatment if the confidentiality was assured. Another JW patient posted for a planned orthopedic surgery with low haemoglobin was given the option to wait and choose haematinics, and intraoperative cell salvage, if required. Changes in the policy and mindset of the JW Society and increased awareness about informed consent have resulted in a wider scope for patient's autonomy in deciding about blood transfusions. Members can avoid religious punishment if their confidentiality is protected. Recent policy changes for acceptable blood products and advances in bloodless surgical techniques have reduced the chances of ethical dilemmas especially in non-emergency situations.

The physician needs to ensure competence and voluntariness of JW patient before his refusal of transfusion. There are growing numbers of dissidents questioning the rigidity of this practice. Assurance of medical confidentiality is important. There are acceptable blood products and transfusion alternatives available. Thus, it has become essential to treat members independently of the sect's official policy by exploring personal convictions and preferences.

P15(b): Quest for cure for disability: Understanding the ethical issues involved

Jyotismitha Sarma

The medical model explains physical, sensory or cognitive disabilities in terms of medical etiology and focuses primarily on cure and overcoming the disability. This model has been criticized by the proponents of the social model which locates the problem of disability within the society for systematically oppressing and discriminating against persons with disabilities and the negative attitudes that they have to encounter throughout their lives. In the Indian context, where access to healthcare is limited by a number of intersecting factors, the medical model of disability still holds great relevance for persons with disabilities and doctors alike.

This paper has emerged out of the author's ongoing research on the lived experiences of women ageing with different locomotor disabilities acquired in childhood in the Kamrup (Metropolitan) district of Assam. The research uses the life history method to understand the lives of 22 women with different locomotor disabilities. These women were contacted with the help of four organizations that are working in the disability sector in both the rural and urban areas of the district. During the interviews with the women, several of them recounted their experiences of accessing the healthcare system where often they underwent medical/surgical interventions without being informed about the long

term consequences on their bodies. This paper questions the ethicality of such interventions given the profound influence of these on the bodies and minds of the women, due to which they are often very hesitant about accessing the healthcare system later in their lives. These experiences are often compounded by the stigma and internalized oppression that these women bear throughout their lives.

P15(c): Hodgkin's Lymphoma and the underlying ethical pitfalls

Rhyddhi Chakraborty

Hodgkin's lymphoma is a rare form of curable cancer that can occur at any age. Its all-age incidence rates are low in India but are associated with poor socioeconomic conditions. Against this backdrop, this study examines the ethical issues involved in Hodgkin's lymphoma. The clear and explicit consideration of these ethical issues would help to guide in formulating just policy prescriptions for prevention of disease. Using India as a case study and by conceptual analysis of the existing literature as the method, this study finds that serious ethical challenges arise during the detection, diagnosis, and treatment of Hodgkin's Lymphoma, which, when ignored, *contribute to health inequity*. However, there is no existing systematic ethical analysis of these issues and the disease is yet to be recognised as a global health concern. Using the prevalence and incidence of the disease in India and specifically using the bioethical principle of justice, this study seeks to help expand the ethical perspectives in the literature on cancer studies as well as in health ethics.

GROUP P16: ETHICS: APPROACHES AND PERSPECTIVES

P16(a): Climate change, justice and collective responsibility

Angus Dawson

The issue of climate change is surprisingly little discussed in bioethics. This paper begins by exploring the reasons for this, and suggests that we have good independent reasons for having a broader view of both bioethics as a concept and the relevant values. I argue that the dominant values in much of bioethics, including much public health ethics, are actually a poor starting place to guide how to think about the relevant difficult ethical issues related to climate change. I begin to outline an alternative that draws upon the idea of environmental justice, an approach that seeks to move beyond the dominant model of current political philosophy that sees the central issue of the distribution of various goods. I explore the idea of responsibility in the context of climate change and argue for a focus on a more collective idea of responsibility. Examples are drawn from the Indian context.

P16(b): On decolonising western bioethics: Toward a bioethics sensitive and responsive to moral aspirations and needs of Indian people

Subrata Chattopadhyay

That bioethics is 'Western' is no new discovery. As the 'US-born-Western-bioethics-headquartered-in-Paris' reaches the Indian soil, a myriad of important conceptual, analytic and methodological issues arise that defy easy answers. Cases in point are numerous; a few may be offered as illustrations. How does ethics, a branch of Western philosophy, relate to the concept and lived experience of *Dharma*, the doctrine of *Karma* or Eastern philosophical systems and worldviews? How does the individual-centered, rights-based, mainstream Western secular bioethics resonate with the ethos of traditional Indian cultures and societies? Such questions are hardly acknowledged, let alone addressed, in bioethics discourse.

There are no segregated, airtight compartments of science, philosophy, religion, spirituality, and ethics, in the Indian worldview, as Knowledge is considered whole and Truth is One. Further, meaning of Truth (*Satyam*) includes its auspicious nature (*Shivam*) and aesthetic appeal (*Sundaram*) in India. Part of the problem that Western bioethics poses for India is that this discipline is focused on 'rights' (*Adhikar*) with no concomitant emphasis on 'duty' (*Kartavya*) which is of utmost importance in ethos of Indian life. Translated as *Niti* in Sanskrit and other Indian languages, 'ethics' is intertwined with the concept, meaning and lived experience of *Dharma* which – incorrectly translated as 'religion' – appears to be broader than and inclusive of 'ethics' in Indian sub-continent. An individual is embedded in the web of relationships in India. This makes the "interests and welfare of the individual" having "priority over the sole interest" of society as absurd and an assault on the notions of duty toward others, matrix of interpersonal relationships and collective good. Practitioners of biomedical ethics in India need to comprehend the importance of these issues which, if unaddressed, would create a moral vacuum in the Indian psyche and run the risk of making bioethics as a vehicle of Western moral imperialism.

P16(c): The concept of health in Ayurveda: Implications for the discourse in contemporary bioethics

Radhika Jadhav

Ayurveda, the ancient Indian Science of Health and Medicine, has several insights to offer on crucial problems that contemporary Medicine and Medical Ethics encounters. One such significant topic is the concept of Health. The purpose of this paper is to reveal the different aspects of the notion of Health and to bring out the underlying normative considerations. This research is purely textual, based on Caraka Samhita, one of the primary treatises of *ayurveda*. Research shows that the *ayurveda* concept of Health has a broader perspective encompassing the ethical dimension of individual health and its contribution towards in bringing about happy and good life.

The Science of *Ayurveda* in general and Caraka in particular, equate health with happiness. The holistic approach of *Ayurveda* towards longevity, happiness and leading a good life is an outcome of their holistic understanding of the concept of health that covers several dimensions including the physical, psychological, spiritual, social and ethical. Amongst these, it is the ethical dimension that forms the basis of a healthy and good life. An individual is accountable towards maintaining his own health and during times of ill-health, as a result of this accountability, should seek help from a medical professional in order to restore it as soon as possible. Ethical considerations have been so embedded in the *Ayurvedic* concept of health, that human action forms an integral part in the process of maintenance and restoration of health which are the two primary objectives of *Ayurveda*. Such a profound, normative and philosophical concept of Health plays an important role and is fundamental to the discipline of Bioethics, in its broader account.

P16(d): Religious perspectives on end-of-life-care issues

Deepesh Reddy Vendoti

Background and Purpose: In our society, faith and religion understandably occupy the core support structure for people passing through difficult phases and having to take critical decisions on end of life care scenarios. However the religious factors influencing the decision making in such scenarios are not well documented. Hence the need exists for the medical fraternity and policy makers to consider this perspective while delivering their services with greater sensitivity and responsibility.

Description of research method or ethical issues / dilemmas: This is a qualitative study gathering opinions of religious leaders through a group discussion of representatives from various faiths/religions and includes personal interviews with religious leaders of various faiths.

Results of research or outcome of ethical inquiry: Results would comprise a summary of the opinions gathered from these discussions focusing on the following aspects: (a) Specific aspects of end of life care issues, where we can draw the relevant inferences from preachings, books, practices etc.; and (b) Opportunities through the religious channels to strengthen the clinical care and alleviate the suffering of people facing end of life care issues.

Discussion: As faith and religion play an important role in Indian society, it is very important to understand the intricacies in the decision making around end of life care through the lens of religion. This might give valuable insights to both the medical fraternity and policy makers to be sensitive to the patients' beliefs while also giving an opportunity to dispel misconceptions if any.

WS/S19: Impact of new regulations on the functioning of ethics committees: constraining or facilitating?

Facilitators: **S Swarnalakshmi**, IRB Manager, Y. R. Gaitonde Center for AIDS Research and Education/ Member Secretary, YRG CARE Institutional Review Board, Chennai; **Anant Bhan**, Researcher, Bioethics and Global Health, Delhi/Bhopal. Adjunct Visiting Professor, Yenepoya University, Mangalore; **Prabha Desikan**, Prof and Head, Department of Microbiology, Bhopal Memorial Hospital and Research Centre, Karond, Bhopal

The workshop is planned to be part of a continuation of the series of workshops organized at previous NBCs by the same set of facilitators and will be supported and promoted by 'IEC-Exchange', India's first e-forum for ethics committees.

Research stakeholders depend on Ethics Committees (ECs) to oversee ethical aspects of research: this involves not only granting initial approval and providing ongoing monitoring of study conduct, but also ensuring that the highest ethical standards are maintained during the review and conduct of the project. The ECs' approval serves not just to meet regulatory requirements, but also to ensure the dynamic and continuing responsibility of promoting ethical conduct of research. ECs might differ in their functioning, however their key goal remains to protect the safety and welfare of study participants.

The purpose of this workshop is to discuss the recent regulatory updates in India and its impact on the functioning of ECs, given the constraints and challenges these function under. The workshop will discuss updates in Standard Operating Procedures to fulfill the new regulatory requirements, and deliberates of how to address challenges and identify solutions and best practices.

It is essential to address the problems faced by ethics committees in view of the structural constraints within which ECs operate when they attempt to strike a balance between the regulatory requirements and the practicalities in following the same. These include limited training in bioethics, inadequate administrative and financial support, insufficient

time for review due to heavy workload, space constraints, ambiguity regarding their roles and responsibilities, and limited scope for self evaluation and assessment.

We propose to have a maximum number of 30 participants. The target audience of the workshop would be EC members, especially chairs/administrators/member secretaries - this would enable the audience to seek clarifications in meeting the regulatory requirements in their institutions. The key learning objectives would be: (a) To enable EC members to understand what are the latest updates in the regulatory scenario for the ethics committees; and (b) To help EC members understand how to balance regulations within their institutional setting.

Format of the Workshop: The workshop will have presentations, case studies and open discussions as follows: (1) Introduction of workshop, facilitators, key learning objectives of the workshop - 5 minutes.; (2) S. Swarnalakshmi (20 min presentation+ 5 minute clarifications) Presentation on 'Recent Regulatory Developments in India': Facilitator - (handouts will be provided); (c) Prabha Desikan and S Swarnalakshmi (40 minutes): Presentation of case study(ies) on how ECs have responded to recent updates: (a) Informed Consent and Audio Visual Recording (b) Serious Adverse Events and Compensation, followed by plenary discussion—current regulations, best practices and issues related to context - Facilitators -; (3) Anant Bhan (15 mins): Facilitators to conclude session and outline the key criteria identified through the workshop to be used for preparing Indian ethics committees to update their SOPs in the new regulatory scenario.; (4) Wrap-up and workshop evaluation (5 min)

Feedback from participants will be obtained through a feedback form as well as interaction with them.

Expected outcome: It is hoped that this workshop will help prepare ECs to update their functioning, in view of the recent regulatory developments. This will be collated for dissemination through an article/workshop report which would include a set of recommendations for the purpose of efficient EC functioning.

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Abstract Review Process

Abstracts were invited for oral paper presentations, poster presentations and workshops /symposia. The submitted abstracts were anonymised and then distributed among a panel of reviewers. Each submission received has been reviewed by a sub-Scientific Committee comprising of three experts. The reviews were compiled and shared with the sub-committees. The final decision was arrived at taking these ratings into account and through a consultative process involving members of the Conference Organising Committee, Sixth NBC. In some cases where there were conflicting recommendations, a senior core team member of *IJME* was invited to act as the moderator to help arrive at final decisions.