

REPORTS

Ethical issues in death, dying and palliation: the *IJME* Sixth National Bioethics Conference

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Introduction

The *IJME* Sixth National Bioethics Conference (6th NBC), on the theme "Healing and dying with dignity: ethical issues in palliative care, end-of-life care and euthanasia," was held in Pune, Maharashtra from January 12–15, 2017. Palliative care (PC) and end-of-life care (EOLC) are closely related areas of concern, yet they have been neglected so far. There is an urgent need to discuss these issues in India due to the changing demographics, socioeconomic and work profiles of the population, people's living conditions and health status, and the contexts of the country's population. The lack of equitable and comprehensive PC compounds the matter. The extremely inequitable distribution of EOLC facilities across India is causing tremendous distress to a large number of patients and their families, leaving them reeling under the increasing impact of non-communicable diseases and cancers.

The theme of euthanasia was inspired partly by the debates surrounding the case of Aruna Shanbaug, who died recently, having spent nearly 42 years in a persistent vegetative state after she was sexually assaulted and strangled while on nursing duty at a government hospital in Mumbai. However, the debates on euthanasia remained divided and inconclusive. Euthanasia had been identified as a "gap in discussion" at the 5th National Bioethics Conference, 2014, as well.

The 6th NBC also aimed to inform policy on euthanasia, and consolidate processes for the reform of the legal and health systems in India. It was co-organised by the Forum for Medical Ethics Society (FMES), *Indian Journal of Medical Ethics (IJME)* and Mahila Sarvangeen Utkarsh Mandal (MASUM), along with 20 other collaborating organisations. The conference

comprised of six plenaries, 16 parallel tracks (during which about 60 papers were presented), 20 workshops and 16 poster presentations.

Participation

About 370 participants from nine countries and 15 states of India participated in the 6th NBC. The participants came from Pakistan, Sri Lanka, the United Kingdom, Canada, Singapore, the United States of America, Australia, Switzerland and India. They were from diverse backgrounds and included doctors, medical students, social scientists, academics, bioethicists, counsellors, economists, lawyers, philosophers, journalists, students, theologians, community workers, researchers, advocacy organisations, administrators and international organisations.

Pre-conference events

Two pre-conference workshops were organised, namely "Transitions of care in patients with advanced illnesses" and "Gender justice – towards a comprehensive response to an inter-sectoral dialogue on gender-based violence". The first workshop sought to establish a clear understanding of PC. It discussed the existing models of care in different states of the country. The dearth of skilled human resources – physicians, nurses and counsellors – for the provision of PC services, as well as budgetary constraints and lack of political will, were seen as being critical impediments to people's access to palliative services. The workshop also discussed the challenges of locating EOLC and palliative care within the framework of public healthcare. At the moment, these services are prioritised only in the overtly for-profit medical sector, which is largely geared towards curative services. The second workshop discussed recent reforms relating to gender-based violence, especially sexual violence, and deliberated on strategies to interconnect diverse constituencies. It drew upon the participants' experiences and insights with respect to addressing barriers to the response to survivors of gender-based violence.

Palliative care and end-of-life care

The discussions of the main conference on the ethics of PC and EOLC raised fundamental questions regarding the understanding of PC. It was clarified that PC must extend beyond the context of EOLC. The initiation of PC must follow soon after the diagnosis of a problem and should not be

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equated only with EOLC. The imperative of understanding PC especially in the context of people's social locations – including poverty, caste, disability (psychological, among others), gender identity and sexuality – challenged the popular notions of PC. The discussions emphasised the need to locate PC in the political economy of health and healthcare. The participants repeatedly stressed on the need to focus on the “whole” person, going beyond disease and focusing on the dimensions of social, psychological–spiritual care. The existing understanding of care is limited and the normative assumption is that curative care has to stop before PC can start, or that when PC starts, regular treatment regimens cease. This understanding needs to be broadened and a model of “convergence of care” must be developed.

Some of the conference workshops emphasised the need for those involved in PC to examine the perspectives of caregiver, acknowledge the gendered nature caregiving, and understand the health implications of this for the care-receiver. The participants felt that it was necessary to explore models of PC that go beyond institutions, such as community-based models. Strategies and opportunities that could help to set national standards on PC, and engagement with medical education in the sphere of developing curricula were discussed. The development of standards and protocols to include care of the marginalised was another area that was flagged.

The discussions stressed the ethical need to give equal importance to the quality of living as we do to the quality of dying. It was observed that “dying well” is often a *privilege* of the rich since good EOLC is actually an expensive service. At one of the workshops, it was stated that “the higher the GDP, the better the death index”, which provoked lively discussions. In another thread of the discussion, participants raised the question of whether PC is actually an alternative system that deals with the lived experiences of patients and the challenges of providing an index of subjective experiences (of pain). PC was also discussed as a “new model of care” as against individualistic and biomedical healthcare.

Some questions that triggered animated discussions were: how informed consent is sought from patients for EOLC; and what are, or should be, the situations in which patients' caregivers are approached for consent. The participants in a few workshops highlighted concerns regarding the autonomy and consent of people experiencing mental ill-health, and the assumption that they are not capable of giving consent. The Mental Health Act lays down that informed consent must be sought from the patient irrespective of his/her disabilities – that, disability does not necessarily mean disenfranchisement. The dignity and right of the patient are of primary importance; one cannot “pull the plug” merely because of the disability. Another question discussed was whether the physical and mental strain on the family members can be sufficient reason for one of them to end his/her life? In the case of lifelong conditions, PC should be able to support caregivers in terms of improving the quality of their lives. There is a need for guidelines on EOLC and also, on how to address the

dilemmas and complexities involved. The power of the family of a patient receiving EOLC has serious implications. For example, the family might disrespect the patient's decision. The access to EOLC might be limited to select people – something that is also determined by how marginalised the patient is. In some instances, the patients' “living wills” are respected by their families. Legal protection for the patient's wishes must be facilitated. In the workshops, drawing up guidelines and preparing other resources of knowledge for caregivers emerged as an important area for future action, especially given the need for a substantial increase in the number of skilled caregivers.

Communication with and counselling of patients and caregivers

Social determinants such as migration, urbanisation and other economic factors have led to changes in family structures, which have a strong influence on the modes of communication preferred. The vast variety and the dynamics of family relationships have specific implications for communication in the context of PC and EOLC. Sound communication skills are essential for increasing the clinician's ability to deal with difficult situations, as well as to influence patients' perceptions of pain and recovery.

Among the strategies discussed to enhance communication between providers and patients (especially cancer patients) and their relatives were role modelling, small-group training programmes and reinforcement of family members who are relatively more sensitive. One speaker stressed that truth-telling was a process and depended not only on the fact, but also on the context, and the state of preparedness of the recipient. The participants deliberated on models of communication pertaining to training in basic interview skills, the risk of suicide, management of burnout and empathy. Models of communication for handling angry patients, those with the attitude of “do not tell my parents”, delirious patients and bereavement were also discussed. In PC, situations in which the patient needs to be heard arise every day.

A good part of psychotherapy consists of attentive listening which resonates with what the patient might be experiencing. Any judgement is quickly picked up by the patient and usually impacts further communication. Moreover, any previous communication with the relatives or family should not be allowed to colour the communication with the patient. Body language or non-verbal communication, ie through touch and expressions, is as important, if not more, than verbal communication. Importantly, dignity begins with life, and not at death; treating people with dignity during their lives improves their chances of approaching death in a better way.

Dignity therapy was discussed in a session that emphasised the acceptance of the idea of death. The participants underscored the importance of talking about death rather than shunning the subject, and facilitating communication about dying. The need for counselling that is not limited to EOLC and must be provided throughout the process of PC was

emphasised. The disease, treatment and prognosis must be discussed with the person who is experiencing the problem before it is discussed with others. It was recommended that in case of any conflict between the family and the caregiver, another person or an ethics committee should be designated to mediate between the parties. For example, do doctors have the right to refuse to treat patients further if there is no long-term beneficence in treatment? Or can this decision be taken only by patients and/or their family or relatives?

Dilemmas and challenges facing the caregiver

Patients and their families seek out caregivers and it is with hope that they go to hospitals, especially at the tertiary level. They expect to receive the best care which would most likely reverse their health problem. Given this context, caregivers often find themselves in a dilemma since they might have to make unpleasant disclosures about the patient's health, which could destroy the latter's expectations. One of the challenges facing caregivers is the lack of skills and capacities to enable them to carry out a range of processes in the provision of PC and EOLC. In India, there is a huge gap between the number of caregivers required and the actual number available. The absence of protocols also creates challenges in the provision of PC and EOLC.

The challenges faced by caregivers in other contexts also came up for discussion. The example of frontline workers was used to discuss ethical issues. The targets set for them are perceived as so challenging that they are often driven to manipulate data, make informal referrals and register patients from outside. Such actions are justified on the ground that they ultimately contribute to the success of the programme, especially in a resource-poor setting. The challenges faced by caregivers are compounded by the larger ills of the health system – commercialisation, the paucity of human resources, finances and infrastructure, and other key factors. Here, what is meant by caregivers is healthcare providers at different levels of the health system and not caregivers within the families of patients. In the context of PC and EOLC, care giving can be an extremely long-term and hence, challenging responsibility.

Other significant ethical issues in the context of caregivers are disclosure and dealing with "medical errors". It is of critical importance to distinguish between medical errors, negligence and malpractice. It is equally important to own up to medical errors and understand that they are "systemic" rather than a flaw in the character of the caregiver. Documenting and addressing near misses are crucial for addressing errors. A system for reporting errors should have a low threshold, be applicable to all levels and involve analysis aimed at systemic improvement. A disclosure policy is necessary, and doctors' vulnerability needs to be countered by being viewed through the lens of medical hegemony, which tends to make doctors see themselves as unaccountable gods. The onus of the disclosure of an error invariably falls on the most junior or least powerful person in the hierarchy of the health system. Our institutions do not have a culture of accountability

and learning. Doctors justify errors and refuse to admit the consequences of these on their patients. An issue that created a stir among the participants was the increase in violence against doctors. One group said that the patients' families engaged in such behaviour to get their bills written off, while the other felt that commercial interests had eroded trust and that this, together with the absence of any meaningful redressal mechanisms, was a greater trigger for violent behaviour. Institutions must not avoid disclosure and have a special duty towards those they have harmed. A big challenge is to prevent the dehumanisation of caregivers through medical education, which also entails re-sensitising them.

End-of-life advanced directives, living will and last wishes

Another major area of discussion was the communication of a patient's last wishes and the ethical dilemmas related to this. Among the questions raised were whether all wishes should be respected, and whether "harmful" substances, such as alcohol and tobacco, should be provided if the patient so wishes. Although caregivers should not make judgements of right or wrong, how do they assess the risks versus the benefits? The gendered differences in the expression of the last wishes were also flagged for discussion.

Communication and the implementation of informed consent are perceived as very important, and poor communication is seen as having serious consequences in Canada. Instances of patients dying because they did not understand what the healthcare provider communicated, or because the healthcare provider did not understand what the patients were trying to say, were shared. The question of medically assisted dying being as important as questions about life was discussed. Another complex area was the "Do not resuscitate" (DNR) instruction. For example, many patients were suffering from depression when they opted for DNR, but therapy restored their will to live. It was felt that passive euthanasia and DNR had merely created confusion and hence, only voluntary active euthanasia or physician-assisted suicide was desirable. The conference strongly emphasised the need for clearer legislation, especially in the context of sensitive issues such as euthanasia.

Debating death

At a conference on EOLC, debates on death are inevitable. Death is the moment when life ceases – or so it is commonly believed. But is it? Or is death more a state of being once life has ended? Is it a moment or a phase or a process? The endeavour to define death has become increasingly complex over the past few decades, and we have had debates and discussions and passed legislation focusing on the definition of death – the moment of death.

In his keynote address, Professor Sundar Sarukkai pointed out that the complexity over "calling death" is the consequence of unprecedented advances in medical research and technology, especially those which made organ transplantation possible.

The demand for organs has shot up across the globe, and the technology and science for harvesting organs from cadavers have nearly perfected themselves. The need of the hour, he said, is to perfect the skills for retrieving organs during a medically produced limbo phase, when the body is both dead and not dead. In other words, it is dead enough for the removal of the person's organs, but not dead enough for the organs to have stopped being medically viable. In the light of these complex technologies, "death" has become more of a process, and the medical fraternity must negotiate three parallel definitions of death: neurological (ie brain death), circulatory and somatic death. Responding to this, Dr Sunil Shroff emphasised the need to categorically delink the project of organ harvesting and transplantation from research and definitions of death, especially brain death, implying an overt conflict of interest between the primary duties of the physician and the aspirations of transplant surgeons. In his keynote address, Shroff stressed the need to simplify the definition of death, saying that we should elaborate the definition instead of merely pluralising it.

In a polemical vein, Sarukkai flagged some questions for the audience to think over. One was whether we could see dying not as an end but as a beginning. In other words, he invoked a "theory of a body" to philosophically interrogate death. It is important to appreciate that the body is not produced just "naturally", but socially and culturally at the same time, and in death, what fundamentally collapses is the "unity" of the body. However, it is equally pertinent to ask which of the bodies dies. All notions of death depend on an *a priori* definition of the body: if we allow ourselves to imagine alternative theories of the body, we could actually have alternative theories of death. In the West, the question of the soul has permeated all discussions on death. That need not be what we, in our context, should examine when looking for alternative theories. Sarukkai stressed the need to invoke phenomenological accounts of the body. Science, he said, assumes matter to be the founding principle for its theorisations and production of knowledge; however, physics has moved much further ahead and engaged with alternative notions of materiality and reality that biology has not yet approached. Sarukkai feels that perhaps it is time to do so to be able to inaugurate a new understanding of and engagement with death.

The fragmented body

Advancements in medical technology bolstered the biomarket in India. The technologies in this sphere have made it possible to fragment the body, to perceive of it as a conglomeration of regenerative parts that can be put on sale or rented in the market. A presenter critiqued the neoliberal worldview of the state that fails to recognise the empirical realities on the ground, such as issues of caste, poverty, access and awareness. It was pointed out that discussions on bioethics have to include the economic, political and cultural contexts.

Another subject of discussion under this theme was surrogacy. Surrogates and intended parents are separated by a large gap

in income and differences in their degree of power. This has resulted in severe exploitation of the former. According to a study that was presented, surrogates suffered from higher levels of postpartum depression than biological mothers. The study showed that the stress of hiding the pregnancy from the larger family and neighbours took a toll on the mental health of the surrogate. The issue of payment, especially the amount of money, did not seem to be of the foremost importance to the surrogates when they were pregnant; the driving emotion was to be able to successfully carry the pregnancy to term. A rather interesting revelation was that the surrogates gave much more attention to the foetus – ie a remarkable degree of self-monitoring while following medical advice – than did biological mothers. Further, the educational qualifications of the surrogates were inversely related to the degree of emotional attachment they formed with the foetus. The discussions on surrogacy highlighted the point that the new surrogacy legislation in India overemphasises the moral validity of this procedure and ignores the issues of fairness and justice. New technology brings certain changes and the changes operate within the socioeconomic relationships; we grasp these technologies but fail to evaluate their impact.

Issues in organ donation

Organ donation – both cadaver and non-cadaver – is rife with ethical challenges. The participants actively debated which course of action should be followed when a patient is "dead enough to donate organs, but not dead enough to discontinue ventilation"; the ethical challenges of directed deceased donation; and dilemmas in organ allocation. One speaker pointed out the major ethical challenge involved in hurting the healthy, ie risking the health of individuals for the benefit of others, which is against the principle of non-maleficence. Ethical dilemmas arise when deciding the level and type of risk that is acceptable and ethically justifiable, and ensuring autonomous decisions. It was argued that factors such as the individual's character, the health system and the social welfare system should be considered during organ donations.

Another issue plaguing organ donation, especially in the Indian scenario, is the falsification of documents. Since Indian law allows a spouse to altruistically donate a kidney, people falsify marriage documents to show that the seller is married to the buyer of the organ. As illustrated by recent scandals, doctors, and even hospitals, are often party to this racket. The participants stressed the need for greater sensitisation of and vigilance among the medical fraternity, and emphasised that hospital ethics committees should be on their toes. They also highlighted the need to urgently revise the law so as to redefine the donor/seller as a victim and not a criminal. The dilemma related to using death as an "opportunity" to procure organs for transplants was vigorously debated. Transplant ethics is a dynamic field that is influenced by many factors, and while there is global consensus on some issues, there is none on some others. It was suggested that like Singapore, India could follow an opt-out system for organ donations.

Mental health

A welcome theme indeed – and one that spread across sessions – was that of mental health: the mental health of persons at the end of life and/or experiencing a terminal illness, that of their caregivers, and also, that of the medical providers and staff. One of the critical factors in this context is communication – that between the patient and the doctor, the doctor and the family, and the patient and the family. The importance of dialogic, lucid communication was repeatedly highlighted across several other presentations, discussions and plenaries. One workshop discussed the importance of programmes to train providers, staff and even family members in the modalities of good communication. Good communication skills are essential for increasing the clinician's ability to handle difficult situations, as well as to influence patients' perceptions of pain and recovery. It must be noted that in the Indian context, the family is more often than not intricately involved in communication on cancer. Studies have shown that good communication, the role of the family in providing physical and psychological support, and a balance between the patient's autonomy and the family's involvement are vital to the improvement of the patient's mental health.

It was also interesting to note the participants' reflections on how non-allopathic systems of treatment could have a greater potential to address issues of mental health, and might not require mental health concerns to be woven into it by conscientious practitioners. For instance, as pointed out at one of the workshops, homeopathy goes by the principle of individualisation or the treatment of the symptoms of the particular person; in doing so, it naturally considers the basic psychology of the person concerned. Homeopathy and psychology go hand in hand – homeopaths have to be very sensitive to what is happening in the mind of the individual and must actively listen to their patients. Human beings are bio-psychosocial and spiritual beings, and EOLC must make room to accommodate this. Further, if we are to be ethical and take into account all other systems of treatment besides modern allopathy, we would also need to question and deconstruct several of the concepts which we have been taught to treat as givens.

The branch of allopathic medicine that comes closest to integrating the body with the mind is psychiatry. However, in

India, even among the urban classes, psychiatry continues to be associated with stigma. The psychiatrist is demonised to some extent and the patient marginalised, which has an adverse effect on the treatment.

The discussions focused on the role of the physician in situations in which the demands of the patients, especially those with terminal diseases, clash with those of the family. Should the patient's mental satisfaction be given priority even if it goes against medical advice? The discussions on mental health also touched upon pain management, the sexuality of persons with physical disabilities, stopping treatment and the issue of confidentiality.

Finally...

Providing much food for thought and raising several questions to mull over, the 6th NBC ended on a positive note. However, notwithstanding the success of the conference, which generated many fruitful discussions and all the sessions of which drew capacity attendance, it is important to critically evaluate the gap areas so as to be better able to plug these gaps at the next conference. Unfortunately, there was not much discussion on alternative systems of medicine and healing *vis-à-vis* EOLC and PC. Another gap we identified was the lack of any discussion on PC and EOLC in the context of children, especially neonates. We hope these issues will be addressed in future conferences and other platforms.

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