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## **THEME - HEALING AND DYING WITH DIGNITY**

**Stigma and disease as seen by patients and healthcare staff**

**Workplace safety for women**

**When corruption becomes the norm**

**Book review: An uncertain glory**

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## Who decides when you die?

If one were ill with a painful incurable disease, would one want to choose a quick death, or prefer to carry on existing? Or leave the decision to family members or doctors, to fate or the courts? Is any sort of moral or physical support available for family members of the terminally ill? These and other complex questions are discussed in our theme section, guest-edited by Sunita Bandewar, with a view to opening them up to greater debate in the wider context of emotional, social, legal, and religious perspectives. This subject was centre-staged recently with the death of Aruna Shanbaug, the nurse whose life was so brutally misshapen into a vegetative existence for over 40 years. A commentator examines the closely linked issue of women's lack of safety at work, especially that of nurses exposed by the very public nature of their work to abuse.

A research study focuses on the important question of stigma related to certain diseases, and another on that of patients' rights as seen by patients themselves. A commentator lays bare the corruption prevalent in our healthcare system. We also have a critical response to the central government's declared plan to create another healthcare council. Finally, editors of several leading biomedical journals have come together on behalf of the Indian Association of Medical Journal Editors, for a joint editorial critically examining the attempt of the Medical Council of India to regulate academic publication for the purposes of promotion. *IJME* was one of the first journals to criticise this step in its October issue. All this, plus thoughtful reviews and letters, as we wish our readers a rewarding and happy 2016.

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The Journal is owned and published by the Forum for Medical Ethics Society, a not-for-profit, voluntary organisation. The FMES was born out of an effort by a group of concerned doctors to focus attention on the need for ethical norms and practices in health care.

Contributions to the journal, in the form of original papers, research findings, experiences in the field, case studies, debates, news and views on medical ethics, are welcome. All submissions must be in English and are subject to editorial review.

**Contributors are requested to refer to the detailed guidelines for submission available on the journal website, [www.ijme.in](http://www.ijme.in)**

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*Cover credit: Original painting entitled Euthanasia, courtesy of the artist, Saravanan Perumal*

## EDITORIAL

# The revised guidelines of the Medical Council of India for academic promotions: need for a rethink

RAKESH AGGARWAL, NITHYA GOGTAY, RAJEEV KUMAR, PEUSH SAHNI, FOR THE INDIAN ASSOCIATION OF MEDICAL JOURNAL EDITORS\*

Measuring academic achievements is never an easy task. This is particularly so when individuals are assessed for promotions in several fields with differing job descriptions. Assessment by peers is time-consuming and may be prone to bias; thus, objective criteria are required to minimise these concerns.

The Medical Council of India (MCI) has laid down guidelines for appointments and promotions of teachers in medical institutions in India. Among the criteria used for promotions, publication of research is an essential requirement. Though the need for this requirement has been debated, it is believed that the quality of teaching improves when medical teachers are involved in research. Many countries have made it mandatory for their medical faculty to do research; some other countries incentivise the conduct and publication of research. Reports have also lamented that the physician–scientist might become an endangered species(1,2). Thus, linking publications with promotions might benefit both the individual and society. The flipside is that the time spent on research might take teachers away from teaching or clinical duties, particularly in under-staffed specialty departments. Further, the quality of research is likely to be poor when the resources and training in research are lacking(3). Poor quality may even discredit research as a professional activity. Insistence on a certain amount of published research to maintain teaching credentials may lead to the phenomenon of ‘publish or perish’(4). Finally, it is important to consider that biomedical research may, at times, be relevant to non-biomedical journals and criteria for awarding credit to such publications should also be devised.

The MCI requires that the medical faculty engages in research. One measure to achieve this goal is the mandatory “thesis” for postgraduate (Masters; MD/MS/DNB) and post-doctoral (DM/MCh/DNB) courses. Each student, regardless of specialty, is required to undertake a research study with a faculty member as the guide and often one-to-a-few faculty members from the same or related subjects as co-guides. Apart from providing training in doing research, the thesis is expected to inculcate an appreciation for research methodology and critical analysis. This experience is relevant to students who will become full-time researchers, and is also beneficial to medical practitioners who may never conduct further research but should be able to discern the merits of newer management options for their patients.

The MCI’s initial guidelines for promotion to the position of Associate Professor and Professor required publication of at least two research papers by the candidates(5). In September 2015, the MCI issued a “clarification” on what constitutes “research publications” for promotion of teaching faculty of medical colleges/institutions in India (Box 1)(6). This “clarification” raises the following issues.

### E-journals

The new guidelines stipulate that publications in e-journals will not be considered for promotion. This guideline is probably in response to the proliferation of predatory journals, almost exclusively among e-journals, over the past five years. It is worrying that the largest number of authors and publishers seem to be from India(7). Predatory publishing is perhaps a manifestation of the “publish or perish” phenomenon with authors willing to pay for a publication(7).

While the MCI’s corrective measure is laudable, the definition of “e-journals” is variable(8). We assume that the MCI implies e-journals are those that do not have a print version. This guideline would exclude many high-quality journals that are published only in the electronic format, eg the PLoS group of journals, the Biomed Central (BMC) journals, *British Journal of Clinical Pharmacology*, and *New Zealand Medical Journal*. It might also exclude journals that publish papers in a longer e-version and a shorter print version (*BMJ*). Many believe that “paper journals” of niche specialties (with limited circulation) may soon cease to

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appear. Publishing is rapidly shifting to the electronic format and an explosive growth in e-journals is envisaged. Thus, the embargo on all e-journals seems unfair. The main objective of this guideline appears to be to limit predatory publishing and to ensure quality. This can be achieved by insisting on other criteria such as indexing, because reputed indexes are unlikely to include predatory journals.

## Indexing

Indexation or inclusion in select databases is an imperfect surrogate for quality. A more direct measure would probably be an assessment of each individual journal by peers. Till such an evaluation is available, we agree with the MCI's requirement that the journal of publication be listed in a recognised database. However, we suggest that the list of databases provided in the MCI's order needs a re-look. For example, Index Copernicus was last updated in 2014(9). Some journals listed on this index, and their publishers appear on Beall's list of potentially predatory journals(10). In fact, Beall's blog says "Index Copernicus has no value"(11). Although the MCI's order lists Medline and Index Medicus separately, these are actually one database. Similarly, PubMed is not a database but a search engine that searches various databases including Medline and PubMed Central. More important is the omission of Science Citation Index, an important database currently published by Thomson Reuters and of IndMed, a database of Indian medical journals, curated by the Indian Council of Medical Research. We suggest the following list of acceptable databases: Medline, PubMedCentral, Science Citation Index, Embase/Excerpta Medica, Scopus and IndMed.

## Article types

The MCI guideline states that only "Original research articles" and "Original research papers" will be eligible for consideration. The objective here appears to be to include papers with original data and to exclude case-reports and reviews or opinions. However, this guideline is not precise because different journals classify original research variously under these two and some other sections, such as brief communications, short reports, etc. Further, this clause discredits meta-analyses and systematic reviews that involve scientific interpretation of original data. Instead of prescribing specific article-type labels, the MCI could suggest that the paper should report "original research data or its interpretation in a meta-analysis or systematic review"(12). The guidelines' implication that case reports, reviews and opinion pieces should not carry any value remains debatable since these are an important part of scientific dialogue.

## National versus international journals

The distinction between "national" and "international" journals is unclear. The inclusion of words such as "India" or "Indian" in the title does not necessarily make a journal of lesser quality. Similarly, the presence of words such as "international", "global" or "world" in a journal's name does not confer it with a higher quality. National journals are in fact more likely to publish research that is relevant to the local population. Again, this discrimination by the MCI appears to be a surrogate marker for quality. Since indexing has already been included as a criterion, the terms "national" and "international" have little value. We also suggest that the criterion of society journals be removed as indexation covers the quality requirements. The quality of a number of non-society journals (for example *The Lancet*) is widely recognised.

## Place in authorship sequence

Finally, the MCI guideline of limiting credit to only the first two authors of a paper is too restrictive. This guideline seems to be an attempt to weed out the malpractice of gift authorship. Again, the MCI's aim is laudable but the implementation can result in greater harm. The first name in a paper is generally associated with the person who did the maximum work, with the last name being that of the supervising senior(13). The MCI guideline suggests that other names except the first two on the byline are those of "guests".

The research scenario has moved towards collaborative and multidisciplinary projects conducted by large teams. To publish a paper in a high-quality journal, a researcher needs to look at a research problem from diverse aspects (eg clinical, laboratory, genetics, and immunology). Hence, good papers often have multiple authors with equal contribution, and all of them deserve equal credit.

The MCI guideline may not only deny credit to all those who have contributed, it may even encourage the practice of denying first authorship, and credit, to junior researchers whose contribution is often the maximum. Experience of many medical editors shows that it is not uncommon to find the senior-most author as the first author (even in case reports) due to the premium placed on this position(14). Therefore, we suggest that this guideline should be removed, and all the authors of a paper should receive credit for it.

We appreciate the MCI's intention to give research its due recognition in academic institutions as well as for streamlining the process of promotion of teachers. Our suggestions to amend the existing guidelines, summarised in Box 2, can help remove ambiguities in the new MCI guidelines. These could also serve as the starting point of a wider consultation on the evaluation of research performance of medical teachers in India.

**Box 1: Guidelines for counting research publications for promotion of teaching faculty of medical colleges/institutions in India as laid down in an order by Medical Council of India in September 2015**

- a. **Index agencies:** Scopus, PubMed, Medline, Embase/ Excerpta Medica, Index Medicus and Index Copernicus
  - b. **Types of articles to be considered:** Original research articles and original research papers.
  - c. **Criteria for National/International journal:** Published by a National/International – specialty journal/journal of a national/international society provided it included in one of the indexes mentioned above.
  - d. **Authorship:** First author, second author
  - e. **E-journals:** E-journals not included
- The above would also be applicable for 'accepted for publication' papers/articles.

**Box 2: Our suggestions**

- a) **Acceptable databases:** Medline, PubMed Central, Science Citation Index, Embase/Excerpta Medica, Scopus and IndMed
- b) **Types of articles to be considered:** Articles reporting original research data or their interpretation in a meta-analysis or systematic review
- c) **Authorship:** All authors

**Note:** This editorial is being published simultaneously in the *Indian Heart Journal, Indian Journal of Anaesthesia, Indian Journal of Gastroenterology, Indian Journal of Medical Ethics, Indian Journal of Medical Microbiology, Indian Journal of Occupational and Environmental Medicine, Indian Journal of Pathology and Microbiology, Indian Journal of Pharmacology, Indian Journal of Physiology and Pharmacology, Indian Journal of Urology, Indian Pediatrics, International Journal of Health Research & Medicolegal Practice, Journal of Anaesthesiology Clinical Pharmacology, Journal of Ayurveda and Integrative Medicine, Journal of Clinical and Scientific Research, Journal of Conservative Dentistry, Journal of Family Medicine and Primary Care, Journal of Indian Academy of Forensic Medicine, Journal of Mahatma Gandhi Institute of Medical Sciences, Journal of Postgraduate Medicine, National Journal of Integrated Research in Medicine, and The National Medical Journal of India.* It may also be published in forthcoming issues of other journals. Note: This editorial is being published simultaneously in the *Indian Heart Journal, Indian Journal of Anaesthesia, Indian Journal of Gastroenterology, Indian Journal of Medical Ethics, Indian Journal of Medical Microbiology, Indian Journal of Occupational and Environmental Medicine, Indian Journal of Pathology and Microbiology, Indian Journal of Pharmacology, Indian Journal of Physiology and Pharmacology, Indian Journal of Urology, Indian Pediatrics, International Journal of Health Research & Medicolegal Practice, Journal of Anaesthesiology Clinical Pharmacology, Journal of Ayurveda and Integrative Medicine, Journal of Clinical and Scientific Research, Journal of Conservative Dentistry, Journal of Family Medicine and Primary Care, Journal of Indian Academy of Forensic Medicine, Journal of Mahatma Gandhi Institute of Medical Sciences, Journal of Postgraduate Medicine, National Journal of Integrated Research in Medicine, and The National Medical Journal of India.* It may also be published in forthcoming issues of other journals.

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## THEME EDITORIAL

# Healing and dying with dignity: Where does India stand?

**SUNITA V S BANDEWAR, SANJAY NAGRAL**

The articles in this special issue have emerged from work towards the sixth National Bioethics Conference entitled "Healing and dying with dignity: Ethical issues in palliative care, end-of-life care and euthanasia". These contributions from physicians and social scientists touch upon three closely linked concepts, and raise complex ethical issues that must be faced by patients and their families, as well as by healthcare providers.

Palliative care is a neglected issue in the Indian healthcare system, with few exceptions. The peer community – individuals, patients and their families, medical professionals, and lawyers – is sharply polarised in the discourse on the ethics of assisted dying or euthanasia in the Indian setting. The diversity of sociocultural contexts, philosophical traditions, and religious and faith systems adds to the complexity of this debate. Individual patients, their families and medical professionals must deal with either poorly equipped public healthcare or exorbitantly priced private healthcare largely driven by profit motives. Both these systems ignore people's palliative care needs. Patients facing end-of-life situations, as well as their providers, are ensnared in a web of ignorance, apathy and helplessness. Clinicians and institutions in such situations often prevaricate under the pretense that there is inadequate "legal" clarity. This leads to prolongation of futile treatment and hospitalisation with the attendant agony and financial burden, undermining the trust of patients and their families in the medical profession.

This issue presents five papers which together offer insights into the complexities of the subject from ethical, legal and medical perspectives against the backdrop of the Indian healthcare system and the entrenched inequities in peoples' access to healthcare.

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The authors of these essays have been part of the processes involved in shaping key policies, programmes and laws on these issues.

Jaywant (1) shares her experiences of interacting with patients during their last days in a private multi-specialty hospital setting. Her account and reflections point to how inadequate human and economic resources constrain the families caring for the terminally ill. The disabilities brought on by illness can force the dying into a position of complete dependence. Their quality of life can be so poor that they might actually prefer to leave this mortal world rather than linger on in a sub-human life, and the family might feel the same way. The helplessness of caregivers, who are generally family members, stems from extreme economic adversity as well as the insensitivity of the healthcare system. Jaywant's compelling narratives are an indictment of healthcare providers who prescribe futile procedures instead of helping families understand that treatment options are exhausted. This is because the legal environment in India has encouraged defensive healthcare practice, but also because of the culture of silence around death. The author underscores the fact that the needs of caregivers and family members feature nowhere in the discussion. She concludes by suggesting simple measures to partially address the appalling condition of palliative and end-of-life care. Will they be sufficient, helpful and implementable? This may be an area for empirical investigation.

Against this backdrop, Rajagopal (2) helps identify the systemic constraints which obstruct access to palliative care. He attributes this to a restrictive legal framework for the medical use of narcotics drugs and psychotropic substances, the paucity of healthcare professionals adequately trained in modern pain management science, and to the fact that "...palliative care is practically unknown in most parts of the country". (2: p 25) Major changes in recent times should improve the situation: morphine is included in the list of essential medicines by the World Health Organisation; the 'right to pain alleviation' is backed by various UN conventions to which India is a signatory; progressive amendments have been made to India's Narcotics, Drugs and Psychotropic Substances Act; and palliative care has been recognised as a medical specialty by the Medical Council of India (MCI). However, Rajagopal argues, more is needed for these changes to have an impact. He points out that palliative care is low cost, and suggests that "... a society which does not provide palliative care to the needy, does not have a moral right to consider euthanasia". (2: p 26) He underscores the role that healthcare professionals must play as advocates of palliative care, and spells out what they must demand from the MCI to ensure people's access to quality palliative care.

Gursahani and Mani (3) centre-stage the notion of dignity and individual autonomy in the context of end-of-life care, arguing that this falls within the very ambit of the Constitution of India. They highlight the fact that all except a small percentage of "sudden deaths" are predictable, giving individuals the opportunity to determine how they should be treated – or not treated – in their last days. However, conversations around death are considered taboo in India, despite the naturalisation of the notion of death in Indian philosophical traditions and various faith systems. Concepts and tools such as advance care planning, "do not resuscitate" orders and "living wills", which have largely been effective in the western world, have remained unexplored in the Indian context. Moreover, there is no legal guidance for healthcare providers regarding withdrawal of care except for persons declared brain dead, and in a persistent vegetative state -- the latter an outcome of public interest litigation motivated by the case of Aruna Shanbaug. They note the Supreme Court of India's recent order revoking the Rajasthan High court judgement making *Santhara*, or voluntary dying, illegal. Indeed, it is difficult to comprehend the contradictions in the judiciary's approach to individuals' right to make healthcare decisions for quality of life during their last days.

Gursahani and Mani argue for the enactment of a sound law in India that "...would enable the good doctor to give morally and ethically sound end-of-life and palliative care without fear of litigation." (3: p 34)

Shukla (4) brings out the ethical conundrums inherent in the notion of "passive euthanasia" which was made legal in India in 2011 in response to the case of Aruna Shanbaug. The author problematises the distinction made by the Supreme Court between active and passive euthanasia. She also notes the failure of the Supreme Court to adequately distinguish between active euthanasia which is viewed as killing and therefore immoral, and passive euthanasia, which is defined as withholding an intervention or withdrawing life support. The moral relevance of the patient's suffering has been neglected in the legal discourse on euthanasia in India. There is a need to look into the practical implications of legalising passive euthanasia. Her work demonstrates the obvious disengagement of the legal discourse on euthanasia from that of ethics.

The last paper (5) is another strong plea for legislative reform in India, locating the Indian scenario in the global context. Kishore, too, notes the restrictions in current laws that permit passive euthanasia and only after approval of the High Court. This precautionary approach is based on the risk that the law can be misused, given the vast vulnerable population in India. However, he stresses the need for better legislation, with safeguards to prevent abuse. The law is essential to honour individuals' right to self-determination and freedom from suffering, and the sanctity of life. Kishore traces discussions on the right to end one's life back to western philosophical traditions, commenting briefly on the core values in arguments for assisted dying, ranging from love and compassion to human dignity, rationality and equity.

The risks of misuse can be reduced if the law draws upon the experiences of other countries with similar legislation. Kishore's insights into the law in the Netherlands and in the state of Oregon in the USA, and his analysis of judicial decisions from around

the world on requests for assisted dying, offer a global perspective on the matter of legislating assisted dying. He touches upon the safeguards that have been enacted to prevent abuse of these laws, which can inform Indian legislative strategies. His list of questions on legislative reforms reminds us to be mindful of specific contexts. The judiciary can offer only temporary solutions; it cannot be a substitute for comprehensive and fine-tuned legislative strategies, he emphasises. In our assessment this fact has been vindicated by the current realities in India.

It may appear premature to focus on a discourse on end-of-life care in a country where the right to life and decent healthcare is still severely compromised. However with the rapid and widespread advance of market medicine and the availability of technology, the growing needs of palliation as well as withdrawal of care come up daily in the real world of clinical medicine. Moreover, the evolution of deceased donation has unfortunately been inextricably linked to the development of an end-of-life care philosophy in intensive care. The linking of organ donation with brain stem death in the Transplantation of Human Organs Act of 1994 has led to a bizarre situation: when families of brain dead patients give consent for organ donation, the organs are removed after which life support systems are withdrawn, but if the family does not consent to donation and asks for the ventilator to be disconnected, the request is turned down (6).

Collectively, these contributions point to the need for systematic empirical research that will inform policies, programmes, and legislative reforms on palliative care, end-of-life care and euthanasia. These enquiries should not only cover medico-legal aspects but also delve into sociocultural and religious perspectives, and the economic dimensions of the matter.

While empirical evidence and experiential knowledge from across the world are critical, they are not sufficient to formulate laws and policies sensitive to the Indian context. For example, it is evident that ignorance and misconceptions about palliative care as a concept and an obligation of the healthcare system are ubiquitous not only amongst the general public but also amongst healthcare professionals. The lack of availability of such care even at otherwise well-equipped hospitals, including cancer specialty centres, reflects the disengagement of healthcare practitioners from advances in medical science that could afford a better quality of life to the terminally ill. We must reflect on why medical and nursing education, healthcare professionals and the system as a whole is so apathetic towards human suffering. This apathy is at odds with the foundational principle, namely compassion, of medical and healthcare ethics. Similarly, the notion of dignity features prominently in discussions on this subject, as is evident in the contributions to this special issue. However, little is known as to what it may mean to people and how it should be translated into healthcare settings in the Indian context.

The situation calls for informed, systematic and sustained public engagement to democratise the processes involved in shaping policies, programmes and laws. When the debate is dominated by medical and legal perspectives, it often ignores the sociocultural, economic and religious backgrounds of the terminally ill and their families as well as those of healthcare professionals. These are critical elements in the ethics discourse. There is also a need to develop conceptual clarity regarding euthanasia, assisted dying and other related terms which are often used interchangeably and without precision. The ethics movement is best positioned to connect these dots.

We have a long way to go before we can have in place a legal framework for end-of-life care and euthanasia or assisted dying that is informed by the Constitution of India and international conventions. We also need wider engagement to ensure that such laws will be effective in a healthcare system dominated by an unregulated private healthcare sector and a resource-constrained public healthcare system, and despite India's poor track record of implementation of laws, vigilance and audit, to prevent their abuse.

We hope this collection of papers will set the stage for further discussions that can influence the agenda for research, advocacy and practice, leading to patient-centred legal reforms towards healing and dying with dignity.

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## ARTICLES

# Perceptions of stigma among medical and nursing students and tuberculosis and diabetes patients at a teaching hospital in southern India

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## Abstract

*Stigma has a significant impact on the diagnosis of a variety of illnesses, patients' compliance with treatment and their recovery from these diseases. However, the Indian medical and nursing curriculum has given relatively little attention to recognising and addressing the issue of stigma. This study compared the perception of stigma with respect to tuberculosis (TB) and diabetes mellitus (DM) among medical and nursing students to that among patients with these diseases. The Explanatory Model Interview Catalogue (EMIC) questionnaire was used for all patients and student groups. Focus group discussions were held with only the students to understand their concept of stigma and the challenges they face while addressing stigma, and to explore their role in addressing stigma. The data showed that patients with TB prefer not to disclose their illness, while DM is not perceived of as stigmatising by patients. As a group, medical and nursing students attached excessive stigma to patients with both DM and TB, and this may mean that medical professionals subconsciously do harm through their interactions with patients and the attitudes they project to society. The perceptions of stigma were linked to the patient's socioeconomic background, apart from the medical condition itself. The students recognised that they lacked the skills to understand and address stigma. We recommend that the subject of stigma be integrated into the curriculum of medical and nursing students.*

## Introduction

Stigmatising attitudes to disease on the part of health professionals, as well as inappropriate attitudes leading to stigma and gaps in addressing it, have medical and ethical implications. A range of illnesses are widely stigmatised, and stigma has been extensively studied in the cases of leprosy, epilepsy, tuberculosis (TB) and human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS),

apart from mental illnesses (1). The impact of stigma on the diagnosis of illnesses, treatment-seeking, compliance with treatment and extent of follow-up, among other things, has also been well documented. Health-related stigma is defined as a social process or related personal experience characterised by exclusion, rejection, blame or devaluation as a result of an enduring feature of identity conferred by a health problem or health-related condition (2). Stigma can be enacted, endorsed or accepted by one side (the stigmatiser), and be internalised or anticipated by the other (the stigmatised) (3). The issue of stigma has received relatively little attention in the medical and nursing curriculum. However, a growing body of evidence, especially in the areas of HIV and mental health, suggests that health professionals may actually contribute to stigma. A study of stigmatising attitudes across disease groups among medical students in the UK showed that the attitudes of the most experienced medical students were worse than those of the others (4). Studies of interventions involving medical students have shown a change in perceptions and a greater awareness of the stigma attached to mental illnesses, in particular (5).

Stigma can also be seen as part of a wider problem in the health practitioner-patient relationship – the problem of “bias”. This is very often unconscious and like a “blind spot”, and could go beyond the illness and include socio-economic-cultural factors as well (6). The ethical consequences of this on the judgment of the health practitioner, his/her attitude towards the person and the family, and the inevitable reinforcement of such biases among a wider community have not been explored in the Indian context.

TB is an infectious disease that causes millions to suffer from ill health each year and is ranked as the second leading cause of death among infectious diseases, after HIV (7). Of the total number of TB cases worldwide, 2–2.5 million are from India alone (8). Data from India show that there is widespread stigma attached to TB among patients of the disease, and a high percentage of them hide their disease from friends and neighbours. This is more the case among the middle and upper-middle classes than the lower-middle and lower classes (9). At the community level, the important health consequences of non-disclosure of the disease for fear of ostracism and discrimination are delayed diagnosis and treatment. This increases the period of infectiousness and promotes the spread of the disease (10,11). It has also been found that the attitudes and behaviour of health professionals

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towards those suffering from TB may lead to even greater stigmatisation of TB patients (12).

While most work on illness-related stigma is on communicable or externally visible diseases, it has been recognised that people with non-communicable diseases, such as cancer, diabetes mellitus (DM), cardiovascular disease and chronic respiratory disease, also face stigma. India, where more than 62 million people are currently diagnosed with DM (13) and DM is said to be growing in epidemic proportions, has been called the "diabetes capital of the world". The International Diabetes Federation, in its "Call to action", suggests that millions of people with diabetes face stigma and discrimination. It notes that this promotes a culture of secrecy which can create barriers to services, employment and even marriage, and which may stop patients of diabetes from playing an active role in society. Therefore, an appeal has been made for the reduction of diabetes-related stigma so as to enable these patients to claim their rights and responsibilities (14). There is little literature on stigma and diabetes, though there is a wider sociological and psychological understanding of the impact of all chronic illnesses that affect lifestyle, of which diabetes is one.

The objective of this study was to compare perceptions of stigma with respect to a conventionally stigmatising disease (TB) and a relatively non-stigmatising disease (DM) among medical and nursing students with perceptions of stigma among patients of these two illnesses. Apart from discussions of stigma in relation to HIV and during psychiatric postings, there does not appear to be any formal coverage of stigma in the medical and nursing curriculum.

## Methodology

### *Study design*

This was a cross-sectional study using mixed methods, covering medical and nursing students across several years of the curriculum in a tertiary care Christian medical and nursing college in southern India, as well as patients with TB and DM from the same medical college hospital.

The participants' perceptions of stigma were assessed using the Explanatory Model Interview Catalogue (EMIC) questionnaire, along with a brief sociodemographic questionnaire with some questions on clinical history. The EMIC was chosen because of its simplicity of use, its adaptability to different cultural settings, the fact that it has been used previously in India, as well as the fact that it has been used for different health conditions, including TB (1). It has been used both for self-perception of stigma and community perception of stigma (15). The EMIC has 15 items and a scoring of 0–3 (No, Uncertain, Possibly, Yes) for each item. The scores on each single question were added up to get a composite score. This composite score indicates the perceived stigma. The higher the score, the higher the level of perceived stigma. Some of the qualitative explanations given by TB and DM patients regarding their responses on the EMIC scale were also recorded.

Focus group discussions (FGDs) were held to gain an insight into the understanding of stigma among medical and nursing students, challenges to the perception of stigma, and the consequences of stigma in relation to health and illness. The domains of the EMIC were used to design the qualitative guide for in-depth information on the potential doctors' and nurses' broader understanding of stigma in a health setting, their experiences and observations of stigma, challenges to the perception of stigma, consequences of stigma and ways to address it.

### *Study setting and participants*

Three batches of undergraduate medical students (first year, mid-course and final year) and two undergraduate nursing student batches (first year and final year) were covered. The students were from various states in India. English was the medium of instruction and all FGDs were conducted in English.

All patients with TB were either sputum-positive or their disease was confirmed by a physician. Patients with comorbidities such as DM, cancer, psychiatric illnesses and HIV were excluded. Those with extra-pulmonary TB were not included. Patients who had been cured and were being followed up were included. The patients with DM were enrolled from the outpatient department of endocrinology, the nutritional and lifestyle disorders clinic and from among those admitted as inpatients in the same hospital. All were confirmed patients with DM and those with TB, cancer, psychiatric illnesses and HIV were excluded. To evaluate differences in the perception of stigma between medical/nursing students and patients, going by their composite scores of perceived stigma using the EMIC scale, a minimum sample size of 31 in each of the groups was found to be necessary (at an alpha value of 0.05 and 80% power). We oversampled in both groups to allow for any additional analyses, dropouts and incomplete questionnaires.

### *Data collection and analysis*

All EMIC questionnaires were administered between July and November 2013. Between October 2013 and February 2014, the first author conducted eight FGDs among four groups of medical and four groups of nursing students. The FGDs were conducted till data saturation was reached, ie till no new data seemed to be emerging. Each group consisted of an average of eight participants. Written informed consent was taken from all those who were willing to participate in the study.

The EMIC questionnaires and FGDs were assigned IDs to maintain anonymity. Data entry and analysis was done using SPSS version 21. The responses to each item of the EMIC scale were compared for each disease condition, ie TB and DM, across all the medical and nursing students and the respective group of patients using percentages and the Chi square test. The responses "Yes" and "Probably" were clubbed together to denote acceptance of the statement, while "No" and "Uncertain" were clubbed together to denote non-acceptance of the statement. Analysis was performed of grouped statements

under the domains of disclosure (statements 1 and 2), self-esteem (statements 3 and 4), community behaviour (statements 5, 6, 7, 8 and 9), family life (statements 10, 11A, 11B, 12), work life (statements 13 and 14) and medical condition (statement 15). The independent t-test and one-way ANOVA were used to compare values across two groups or multiple groups, respectively. The null hypothesis was rejected at  $p < 0.05$ .

The FGDs were audio-recorded and transcribed by an external consultant. The transcripts were then reviewed by the interviewer, who listened to the audio recording while reading through the transcripts to check for accuracy. Next, the transcripts were analysed thematically by two researchers simultaneously, using NVivo 9.2 qualitative data analysis software.

### Ethics statement

The study protocol was granted ethical approval from the institutional review board of the St John's Medical College, Bangalore, India (IEC Study Ref. No: 70/2013). The purpose and procedure of the study were verbally explained to participants. All participants signed an informed consent form. In the case of illiterate participants, the signature of a witness was obtained. No monetary compensation was provided to the participants.

### Results

#### Sociodemographic characteristics of participants

Table 1 provides the sociodemographic characteristics of the participants. The patients with DM were older, more educated and more likely to be married than the patients with TB. A very small number in both categories of students (medical and nursing) had a personal history of either TB or DM. However, 65 of the 111 medical students (58.5%) and 38 of the 79 nursing students (48.1%) had a family history of DM, while 3.6% of medical students and 12.6% of nursing students had a family history of TB.

#### Perceptions of stigma related to TB and DM across study groups

The overall perception of stigma among those with TB was eight times higher than that among those with DM (composite

score  $9.0 \pm 7.1$  for TB and  $1.2 \pm 2.4$  for DM). The perception of stigma related to TB was two-and-a-half times higher among the medical and nursing students than among the patients themselves with TB. Similarly, the perception of stigma was seven times higher than that of the patients themselves with DM. There was no significant difference between the perceptions of medical and nursing students both in the case of TB and DM (Table 2).

The medical and nursing students' perceptions of stigma with respect to TB were of a significantly higher level in the case of most of the individual statements of the EMIC questionnaire, as compared to the perceptions of the patients with TB. The exceptions were for statement 1, which relates to a patient's preference to disclose that he/she has TB, and statement 14, which refers to staying away from work and social groups. In the case of these two statements, the responses were relatively similar.

In the case of DM, there was a significantly high level of stigma attached to the disease by the medical and nursing students. The areas concerned were disclosure of the illness (statement 1), lowered self-respect among people with DM (statement 3), the children of persons with DM facing social problems in the community (statement 10), the disease acting as a barrier to marriage for the person with DM or a family member and a troubled marital life (statements 12, 11A and B), and a perception of greater medical problems (statement 15).

The patients of TB had a lower perception of stigma than did the students because, as they said, "TB is treatable," and "People will forget they had it after some time." DM was seen as a common disease and was associated with affluence. According to one person, "Everyone believes that now diabetes is okay. It's a trend, like a symbol, moving up the ladder." Another said, "Every other person has it." There was some lack of understanding about the sequelae of diabetes, such as diabetic foot and chronic kidney disease, with the patients not fully aware that these are related to diabetes. The student community seemed to have a highly medicalised view of both illnesses.

*... he got TB because of lower immunity, so while he is suffering from this disease there are chances of getting other diseases also. (Nursing, Year 1)*

*People with diabetes are essentially normal on the outside. They may have complications later on, which they wouldn't really think about that much but per se, they are able to function pretty normally, except for an odd injection or tablet. (Medical, Year 4)*

The analysis of subgroups of students showed that first-year medical and nursing students associated TB and DM with greater stigma than did their peers in later years. There was a significant difference between the responses of students in different years with regard to the impact of TB on the patients' marriage. The number of first-year medical students who believed that patients with TB would have marital problems

**Table 1: Description of subjects across the study groups**

|  | Students |         | Patient groups |         |
|--|----------|---------|----------------|---------|
|  | Medical  | Nursing | TB             | DM      |
| N <sup>a</sup>                         | 111      | 79      | 51             | 50      |
| Age (years) (mean, SD)                 | 22±3     | 19±2    | 36±13          | 51±10   |
| Gender distribution (M/F)              | 47/64    | 0/79    | 30/21          | 32/18   |
| Year of study (first/mid/final)        | 40/39/32 | 39/0/40 | ---            | ---     |
| Personal history of TB/DM              | 3/3      | 2/1     |                |         |
| Family history of TB/DM                | 4/65     | 10/38   | --             | --      |
| Duration of illness (years) (mean, SD) | --       | --      | 0.5±0.5        | 7.5±6.4 |
| Educational status (≤ middle school)   |          |         | 23 (45)        | 15 (30) |
| Marital status * (married)             |          |         | 32 (64)        | 47 (96) |

<sup>a</sup> Total intake of medical students is 60 per year and of nursing students is 100 per year.

\* Widowed N = 1 in each group, Numbers indicate the mean and ± indicates standard deviation

**Table 2: Distribution of responses for each item of the EMIC scale for TB and DM across the study groups**

| Statements   | Medical students                   |                                     | Nursing students                  |                                    | Patients                     |                                  |
|--|------------------------------------|-------------------------------------|-----------------------------------|------------------------------------|------------------------------|----------------------------------|
|  | TB                                 | DM                                  | TB                                | DM                                 | TB                           | DM                               |
| 1. If possible, would you prefer to keep people from learning about your TB/ DM?   | 80/110<br>(72.7)                   | 50/109<br>(45.9)                    | 47/79<br>(59.5)                   | 34/76<br>(44.7)                    | 36/51<br>(70.6)              | 4/50<br>(8.0) <sup>a</sup>       |
| 2. Have you discussed this problem with the person you consider the closest to you, the one whom you usually feel you can talk to the most easily? | 7/111<br>(6.3)                     | 5/110<br>(4.5)                      | 8/77<br>(10.4)                    | 1/76<br>(1.3)                      | 2/51<br>(3.9)                | 1/50<br>(2.0)                    |
| 3. Do you think less of yourself because of this problem? Has it reduced your pride or self-respect?   | 61/111<br>(55.0)                   | 34/110<br>(30.9)                    | 44/78<br>(56.4)                   | 15/77<br>(19.5)                    | 12/51<br>(23.5) <sup>a</sup> | 4/50<br>(8.0) <sup>a</sup>       |
| 4. Have you ever been made to feel ashamed or embarrassed because of this problem?   | 65/111<br>(58.6)                   | 25/110<br>(22.7)                    | 52/76<br>(68.4)                   | 16/76<br>(21.1)                    | 7/51<br>(13.7) <sup>a</sup>  | 0/50<br>(0) <sup>a</sup>         |
| 5. Do your neighbours, colleagues or others in your community have less respect for you because of this problem?                                   | 45/111<br>(40.5)                   | 8/110<br>(7.3)                      | 45/78<br>(57.7)                   | 9/76<br>(11.8)                     | 10/51<br>(19.6) <sup>a</sup> | 1/50<br>(2.0)                    |
| 6. Do you think that contact with you might have any bad effects on others around you even after you have been treated?                            | 33/110<br>(30.0)                   | 5/110<br>(4.5)                      | 19/78<br>(24.4)                   | 7/77<br>(9.1)                      | 5/51<br>(9.8) <sup>a</sup>   | 0/50<br>(0)                      |
| 7. Do you feel others have avoided you because of this problem?  | 77/111<br>(69.4)                   | 6/111<br>(5.4)                      | 55/79<br>(69.6)                   | 7/79<br>(8.9)                      | 3/51<br>(5.9) <sup>a</sup>   | 0/50<br>(0)                      |
| 8. Would some people refuse to visit your home because of this condition even after you have been treated?   | 60/111<br>(54.1)                   | 5/109<br>(4.6)                      | 40/78<br>(51.3)                   | 5/77<br>(6.5)                      | 4/51<br>(7.8) <sup>a</sup>   | 1/50<br>(2.0)                    |
| 9. If they knew about it, would your neighbours, colleagues or others in your community think less of your family because of this problem?         | 35/111<br>(31.5)                   | 11/110<br>(10.0)                    | 30/79<br>(38.0)                   | 8/77<br>(10.4)                     | 5/51<br>(9.8) <sup>a</sup>   | 0/49<br>(0)                      |
| 10. Do you feel that your problem might cause social problems for your children in the community?  | 63/111<br>(56.8)                   | 17/109<br>(15.6)                    | 46/78<br>(59.0)                   | 14/76<br>(18.4)                    | 10/50<br>(20.0) <sup>a</sup> | 0/50<br>(0) <sup>a</sup>         |
| 11A. Do you feel that this disease has caused problems for you in getting married? (Unmarried only)  | 67/108<br>(62.0)                   | 45/108<br>(41.7)                    | 44/78<br>(56.4)                   | 41/77<br>(53.2)                    | 3/16<br>(18.8) <sup>a</sup>  | 0/2<br>(0)                       |
| 11B. Do you feel that this disease has caused problems in your marriage? (Married only)  | 52/106<br>(49.1)                   | 30/104<br>(28.8)                    | 24/62<br>(38.7)                   | 17/60<br>(28.3)                    | 2/34<br>(5.9) <sup>a</sup>   | 1/48<br>(2.1) <sup>a</sup>       |
| 12. Do you feel that this disease makes it difficult for someone else in your family to marry?   | 31/111<br>(27.9)                   | 20/110<br>(18.2)                    | 27/76<br>(35.5)                   | 17/76<br>(22.4)                    | 3/51<br>(5.9) <sup>a</sup>   | 1/49<br>(2.0) <sup>a</sup>       |
| 13. Have you been asked to stay away from work or social groups?   | 65/110<br>(59.1)                   | 8/110<br>(7.3)                      | 47/76<br>(61.8)                   | 2/77<br>(2.6)                      | 4/51<br>(7.8) <sup>a</sup>   | 1/50<br>(2.0)                    |
| 14. Have you decided on your own to stay away from work or social groups?  | 65/110<br>(59.1)                   | 13/110<br>(11.8)                    | 51/78<br>(65.4)                   | 10/77<br>(13.0)                    | 25/51<br>(49.0)              | 2/50<br>(4.0)                    |
| 15. Because you have TB/DM, do people think you also have other health problems?   | 75/111<br>(69.4)                   | 82/110<br>(74.5)                    | 51/77<br>(66.2)                   | 53/77<br>(68.8)                    | 4/51<br>(7.8) <sup>a</sup>   | 0/50<br>(0) <sup>a</sup>         |
| COMPOSITE SCORES   | N=103<br>21.3 <sup>a</sup><br>±6.6 | N=110<br>8.3 <sup>a,b</sup><br>±5.6 | N=54<br>20.4 <sup>a</sup><br>±8.1 | N=57<br>8.1 <sup>a,b</sup><br>±6.7 | N= 48<br>9.0<br>±7.1         | N=47<br>1.2 <sup>b</sup><br>±2.4 |

The numbers indicate Yes + Possibly responses out of the number who responded to that statement, with the percentages indicated in parentheses. The composite scores indicate mean,  $\pm$ SD, <sup>a</sup> = significant difference from corresponding patient group (TB, DM), and <sup>b</sup> = significant difference between diseases within the subgroups (medical students, nursing students, patient groups).

was twice that of the final-year students who held such a view. First-year nursing students had a three times greater perception than did their senior counterparts that patients with DM would have marital problems.

In the FGDs, junior nursing students explained that family and traditional beliefs influenced the way they thought. First-year students in both the medical and nursing courses were less clear about the aetiology of the diseases than their seniors. The possibility that the students' perceptions of the stigma faced by these patients were influenced by what they thought were socially appropriate responses cannot be ruled out.

There were no significant differences in the perception of stigma across most items in the EMIC scale between male and female medical students. The exceptions were that there was a sense of shame in the case of TB (statement 4,  $p < 0.05$ ), a perception that the patient's children would face trouble from the community (statement 10,  $p < 0.05$ ), and the perception that

if there was a patient with TB in the household, his/her family members would face problems getting married (statement 12,  $p < 0.05$ ). In the context of these issues, it was the female medical students who overestimated the stigma. In the case of DM, male medical students had a significantly higher perception than female students that those with the disease would receive less respect from the community members (statement 5,  $p < 0.05$ ).

#### *Comparison of perceptions of stigma across six domains across the study groups*

Across all domains, there was a significantly lower perception of stigma among the patients with DM than those with TB. The medical and nursing students had a significantly higher perception of stigma than the patients with TB and DM across all domains, except disclosure (domain 1) in the case of TB and the impact of the illness on work life (domain 5) in the case of DM. There was no difference between the perceptions of

**Table 3: Composite scores under various domains for the diseases across study groups**

|                                 | Medical students               |                                  | Nursing students              |                                 | Patients        |                               |
|---------------------------------|--------------------------------|----------------------------------|-------------------------------|---------------------------------|-----------------|-------------------------------|
|                                 | TB                             | DM                               | TB                            | DM                              | TB              | DM                            |
| Domain 1<br>Disclosure          | N=110<br>2.2±6.6               | N=109<br>1.5 <sup>a,b</sup> ±1.3 | N=77<br>1.9±1.4               | N=75<br>1.3 <sup>a,b</sup> ±1.4 | N=51<br>2.1±1.4 | N=50<br>0.3 <sup>b</sup> ±1.0 |
| Domain 2<br>Self-esteem         | N=111<br>3.1 <sup>a</sup> ±1.7 | N=110<br>1.7 <sup>a,b</sup> ±1.9 | N=75<br>3.3 <sup>a</sup> ±1.8 | N=76<br>1.3 <sup>a,b</sup> ±1.7 | N=51<br>1.2±1.7 | N=50<br>0.3 <sup>b</sup> ±0.7 |
| Domain 3<br>Community behaviour | N=110<br>6.1 <sup>a</sup> ±3.1 | N=109<br>1.1 <sup>a,b</sup> ±2.2 | N=77<br>6.8 <sup>a</sup> ±3.6 | N=76<br>1.5 <sup>a,b</sup> ±2.6 | N=51<br>2.3±3.2 | N=49<br>0.1 <sup>b</sup> ±0.6 |
| Domain 4<br>Family life         | N=106<br>4.2 <sup>a</sup> ±2.2 | N=103<br>2.0 <sup>a,b</sup> ±1.9 | N=63<br>3.8 <sup>a</sup> ±2.5 | N=59<br>2.1 <sup>a,b</sup> ±2.2 | N=48<br>1.3±2.0 | N=49<br>0.2 <sup>b</sup> ±0.5 |
| Domain 5<br>Work life           | N=109<br>3.4 <sup>a</sup> ±1.5 | N=110<br>0.6 <sup>b</sup> ±1.2   | N=76<br>3.3 <sup>a</sup> ±1.9 | N=77<br>0.5 <sup>b</sup> ±1.1   | N=51<br>1.7±1.9 | N=50<br>0.2 <sup>b</sup> ±0.8 |
| Domain 6<br>Medical condition   | N=111<br>1.9 <sup>a</sup> ±1.0 | N=110<br>2.0 <sup>a</sup> ±1.0   | N=77<br>1.8 <sup>a</sup> ±1.0 | N=77<br>1.8 <sup>a</sup> ±1.2   | N=51<br>0.3±0.8 | N=50<br>0.1 <sup>b</sup> ±0.3 |

Data indicate mean ±SD; analysis – one-way Anova; <sup>a</sup> = significant difference from corresponding patient group (TB, DM); <sup>b</sup> = significant difference between diseases within subgroups (medical students, nursing students, patient groups).

medical and nursing students across all domains; both groups overestimated the perceptions of stigma to a similar level in the case of the two illnesses.

*What does “stigma” mean to medical and nursing students? (A qualitative exploration)*

i. **Meaning of “stigma”**– The words associated with stigma were isolation, rejection, taboo and victimisation. Stigma was associated with circumstances beyond disease. While explaining the word, a fourth-year nursing student said, “They (people) don’t go near widows and they won’t let small children or pregnant women go near a widow – that is stigma. It is isolation” A third-year medical student made the following comparison: “In India, premarital sex would be taboo.”

There was only one group – the first-year nursing students – which was not familiar with the word “stigma” in the psychosocial context, and described its botanical meaning (“part of a flower”). Some were also of the view that stigma could be a “false belief” or an “unnecessary fear”. When the group was not familiar with the word “stigma”, the FGD was conducted using the word “rejection” or “discrimination” which emerged from their discussion.

ii. **Origins of stigma** – The themes arising from the discussions on the origins of stigma included those that influenced the participants’ own perceptions as well as those that influenced the community’s perceptions. The primary origin of stigma, according to most students, was ignorance or lack of knowledge and the fear arising out of this. Fear emerged as a critical factor, particularly among the nursing students.

*There was this patient with a congenital bone deformity and he wanted to use the toilet in our hospital, but the lady who works in the hospital didn’t let him because she thought it would spread infection. She wanted him to go down to the floor below... (Medicine, Year 3)*

*Even though they are educated, they still fear the things they are not sure about. They say, ‘Let me be on the safer side.’ Because of a little bit of fear and a little*

*bit of selfishness also, he will not go near that patient or he will try to keep him away and that is where stigma originates... (Nursing, Year 4)*

Stereotypes of stigma appear to originate from deep-seated cultural beliefs and traditions, from societal norms, passed on and perpetuated through family dictates, and from media projections. The medical or nursing students were not immune to these influences.

*People will stay away from HIV patients and treat them as outcasts. This has developed over the years. .. There are so many other ways in which you can get HIV, but anyone who is HIV-positive is automatically labelled immoral. (Medicine, Year 1)*

*It’s because our ancestors said it’s not proper, it’s become a stigma. It started and it kept on going the same way. Later, when we started understanding stuff clearly, we realised we don’t need stigma but the behaviour continues. (Nursing, Year 4)*

*...The media has a big role to play in this. Even in the movies they portray things that are not real or true; they don’t realise that this causes stigma as well. (Nursing, Year 3)*

iii. **Perceptions of stigma reflected in health professionals’ action** – The healthcare professionals’ perceptions of stigma appear to be influenced by their observations and experiences and fall into two categories. The first of the stigmas is that related to people’s socioeconomic and cultural circumstances, which can be called “social stigma”. This type of stigma takes into account factors such as rural background, literacy levels, housing conditions and so on. The following are a few relevant quotes from the nursing and medical students.

The following are a few relevant quotes from the nursing and medical students.

- *We consider the people who come from villages as illiterate or unaware of things, so we tend to stigmatise that group.*
- *If a person speaks a different language, “doctors tend to get frustrated and treat the patient differently and are more rude.*

**Table 4: Examples of social and disease-related stigma as perceived by students**

|                                 | Social phenomena   | Disease-related phenomena  |
|---------------------------------|--|--|
| Enacted by society              | <ul style="list-style-type: none"> <li>• Rejection due to food habits / culture / religion</li> <li>• Rejection due to financial status and ethnicity</li> <li>• Humiliation due to physical appearance</li> <li>• Stigma against women working</li> </ul>   | <ul style="list-style-type: none"> <li>• Fear of living in same house on patient’s discharge from hospital</li> <li>• Keeping a distance and keeping away</li> <li>• Rejection due to association with bad luck</li> <li>• Dismissal from job</li> </ul>   |
| Enacted by health professionals | <ul style="list-style-type: none"> <li>• People who come from villages are considered illiterate or unaware of things, so that group is stigmatised</li> <li>• If a person speaks a different language, “doctors tend to get frustrated and they treat the patient differently and are more rude”.</li> <li>• It is believed that people mainly in the slums and illiterate people have diseases like TB and are avoided by others.</li> </ul> | <ul style="list-style-type: none"> <li>• Reduced treatment for fear of disease transmission</li> <li>• Keeping a distance</li> <li>• Avoiding meeting and communicating with patient</li> <li>• Using mask and gloves only for certain cases</li> <li>• Fear about managing illness, eg mental illness</li> <li>• Asking for unnecessary tests – HIV tests for all patients</li> </ul> |

- *Mainly those in the slums and illiterate people have TB and all, and are avoided by the people.*

The second category of stigmatising behaviour shown by the health professionals was “medical stigma,” ie stigma related to disease and associated fears of acquiring the disease or managing the disease. The following include two quotes from the nursing and medical students.

*When dealing with HIV patients, we use double gloves. We wear our mask, which we would really not do with any other patient.”*

*We have a fear of managing, for example, mental illness, so we try to avoid meeting and communicating with the patient.”*

*Asking for unnecessary tests – HIV tests for all patients.*

Table 4 gives more examples of social and medical stigma as perceived by the medical and nursing students.

- iv. **Challenges to the perception and management of stigma** – The students were aware of the need to perceive of the stigma that patients may be experiencing and that addressing the stigma would help in treating them. According to the students, being or feeling stigmatised could be indicated by the body language of the patient, his/her relationships with his/her family members and friends, the patient giving up working, etc. The students acknowledged that the perception and management of stigma were a challenge as they were not equipped to address stigma.

- *We need to ask questions about family life, social behaviour and work-related issues, which we are not comfortable or trained to do.*
- *Addressing stigma needs rapport-building time. In a busy, crowded OPD, it is difficult.*
- *We tend to focus on the doctor’s role and not function as a people’s person.*
- *Because of stigma, we can miss the diagnosis completely.*

- v. **How to address stigma** – The medical and nursing students suggested the following measures to help address stigma.

- a. Health professionals need to be more empathetic.

- *Put yourself in the shoes of the other person.”*
- *We should think of the patient as our family member.*
- *Build a rapport with the patient even if it takes time.*

The students rightly felt that it was difficult to teach this and were of the view that it would be easier to imbibe it through good role models.

- b. There is a need to avoid re-labelling diseases and one should, instead, address the more deep-seated issues related to disease. Re-labelling a disease, eg leprosy as Hansen disease or HIV as retroviral or “flower case”, does not eliminate stigma.
- c. There is a need to address issues surrounding the patient, eg family issues, misconceptions of the disease at the community level. This was especially identified by nursing students.
- *They (the community) will not listen to anyone at their own educational level, but if someone of a higher educational level comes and talks to them, they will definitely listen...we are someone great for them.” “We will try to make them (the family) understand ... we will tell the father/mother/ brother/sister ... ‘You take prophylaxis... It will not spread.’ (Nursing, Year 4)*
- d. A good knowledge of the disease is a must to remove fear and prejudice and to learn about and follow universal precautions.

**Discussion**

The study shows that TB is still stigmatised, as at the level of the patients, their preference is not to disclose their illness. However, the fact that TB is treatable and curable emerges as a major reason for which treatment is sought and the level of stigma has decreased. DM, contrary to a few studies in the West, is not perceived as stigmatising by persons with DM, as assessed using the EMIC scale in this study.

As a group, medical and nursing students had an excessive perception of stigma both with respect to patients with TB and DM. The qualitative data suggested that students stigmatise patients on the basis of social factors, such as a lack of formal

education, low economic status and rural background. A few other reasons for their high perceptions of stigma were an unreasonable fear of the transmission of disease, their having witnessed their seniors' use of gloves and masks, and their having seen their seniors make repeated requests for tests for only certain diseases. These factors could lead to conflict and guilt about focusing excessively on self-protection, and could lead to confusion about which is the right or wrong response. The students acknowledged that patients' socioeconomic and cultural standing influenced their perceptions. They said that social stigma created a burden for patients insofar as their work and family life were concerned. This coincides with the hidden burden of stigma in relation to illness (16). Within each student group, first-year students associated the conditions with a greater degree of stigma than did their senior peers. This could be due to their limited knowledge of the conditions and their treatment, or their inability to change the situation. Alternatively, their responses could have been driven by the urge to be socially correct. Medical students felt a stronger inability to address the social burden associated with disease than the nursing students. This is possibly because the nursing course covers more of the social sciences and also includes more outreach activities. The FGDs seemed to reveal the existence of unconscious biases among the students and also, a heightened feeling that they would be unable to respond to sources of stigma, whether in the community, within themselves or among their peers. The relatively high perception of stigma among the students could influence their behaviours towards their patients, and this has several ethical implications. Another factor to be noted is that responses to the patient are not always overt and may exist at the level of thoughts and perceptions, which influences the behaviour of healthcare personnel. In the USA, while racial issues appear to be central to the prejudices harboured by doctors, ethnographic studies have shown that responses to social inequality and physical appearance do exist at the unconscious level and are masked due to training or conditioning (17).

An ethical construct of stigma is presented in Figure 1. The emphasis on responding to the ethical consequences of stigma is derived from the work of the French-Jewish philosopher, Emmanuel Levinas (18). The need for this response is centred around the virtue of "radical responsibility for the other". This model would be useful to construct teaching methodologies to address the lacunae in the understanding of stigma among medical and nursing students, as seen in this study. It brings to the fore the principles of medical practice, viz to do good (beneficence), to do no harm (malfeasance), and to address the individual (clinical role) as well as community role (societal role). This model questions the ethics of a passive acceptance of something that appears beyond one's control but has significant potential for harm. This is important in the context of the current study since the students recognised the connect between stigma and disease, but felt powerless to do anything about it. The model calls for an understanding of stigma beyond biomedicine and within a sociocultural system. The construct also takes elements from the sociological model

of Erving Goffman (19), in which stigmatisation is a social process resulting from interpersonal interactions. However, a key point to note is the health professional's role in either alleviating or exacerbating the felt stigma through his/her interactions with the patient or patient's family.

When an illness is socially stigmatised and stigma is enacted against patients by people in high positions (eg doctors), the stigma has a greater chance of becoming internalised. As a consequence of this, a process of self deprecation and "self stigma" occurs even without an external stigmatizing behavioural trigger. (20,21).

By overestimating the stigma attached to the two diseases, there is a possibility that health professionals actually do harm (malfeasance), both in their interactions with patients and the attitudes they project to society. Health practitioners are extremely influential and held in high regard in society, so their attitude has a snowball effect on the community, which wishes to emulate them.

In this schema, the stigma enacted by the health professional against the patient could be covert (in the form of thoughts, perceptions and indirect behaviour), or overt (in the form of avoidance, insults and rejection). When stigma becomes internalised, the consequences of self-stigma are often a loss of self-esteem and a loss of autonomy (22). These may result in a decrease in the disclosure of illness, a delay in diagnosis or the initiation of treatment, reduced adherence to treatment, a fall in the quality of life and a worsening of the prognosis of the disease. Apart from the impact on the individual patient, there is a risk to the person's family and the larger community in the case of a communicable disease. If health professionals inadvertently ally themselves with the family or community in a manner that is discriminatory towards the patient, they will only perpetuate the stigmatising effect (20).

Addressing issues of stigma goes beyond the formal line of biomedical "duty". One must spend time to explain the illness to the patient and educate him/her on it, be alert to a possible "Nocebo" effect (23), ie the effect that negative news can have on one's health, and address observed prejudices and stigmatising behaviour among the patient's peers, colleagues and caregivers. Disclosure of the illness to the patient's family members is another dilemma for the health professional in the case of a stigmatising illness. Does one respect the wishes of the patient and put the others at risk? Should one suppress the wishes of the individual for the sake of the greater public good? There is also the effect of "courtesy stigma", described by Goffman as the rub-off effect of stigma from the discredited individual to the family (20). Counselling the patient and caregivers and being there in case of a negative fallout require time, effort and going beyond a comfort zone that is traditionally defined by the health professional.

Stigma is not just a process of labelling that hinders treatment and creates a public health risk, but is in a sense, an infringement of human rights, which requires a response. To help eliminate stigma, the health professional, whether a

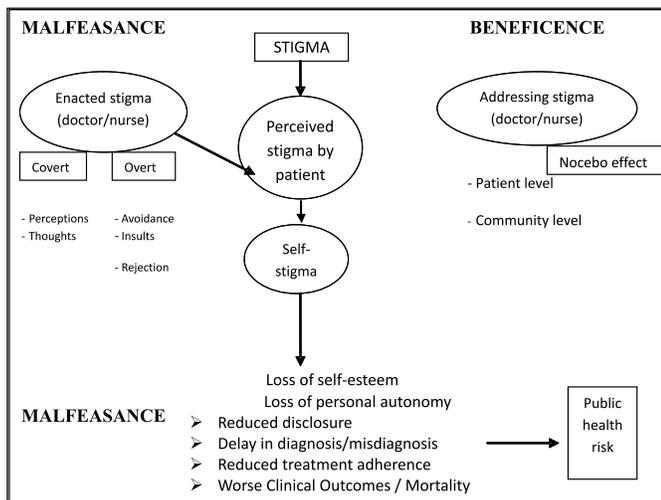


Figure 1: An ethical construct of stigma

doctor or nurse, has to be an agent of social change, address issues of discrimination, stand up for social justice and acknowledge that the voices of a minority (in this case, the stigmatised), however small, are not insignificant.

In Levinas' paradigm on stigma, "radical responsibility for the other" suggests that we must go beyond recognising and understanding the issues related to stigma; we must commit ourselves to doing something about it and realise that stigma, even if experienced by the other, is our responsibility. Hence, we recommend incorporating the topic "Handling stigma in illness – the role of the health professional" in the medical and nursing curriculum for undergraduate students. While various other studies and reviews of health-related stigma have recommended interventions at the community level, in public health research and in social and health policy, our view is that interventions in the curriculum, which is taught during the formative years, will equip health professionals to have the sensitivity and skills required to reduce stigma and avoid exacerbating it both at the subconscious and conscious levels.

## Conclusions

The main finding of this study is the excessive stigma attached by medical and nursing students to patients with TB and DM. The stigma appears to be related to socioeconomic conditions, such as the class, educational level and living conditions of the patient more than the illness per se. Precautionary measures, such as wearing of gloves and masks, are often confused with discriminatory behaviour and stigma. While a greater knowledge of the disease would help to improve the clinical judgment of health professionals, the higher perception of stigma among them could influence their behaviour towards their patients, and this has several ethical implications. We feel that there is a need to provide students with a socio-cultural-ethical understanding of stigma, and to increase their sensitivity and skills so that they can address discriminatory biases within themselves and their peers, towards their patients, and towards the public. We recommend that the topic

"Handling stigma in illness – the role of the health professional" be included in the undergraduate curriculum of medical as well as nursing students. An ethical response on the part of the doctor or nurse to discrimination against "the other" will go a long way in addressing stigma and its adverse consequences.

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## Iranian patients' perspective of patients' rights: a qualitative study

SHAHNAZ KHALEDI, GOLROKH MORIDI, SINA VALIEE

### Abstract

*There is an increasing emphasis on "protecting patient rights", which has a great influence on the patient's well-being. This study aimed to explore patients' perspectives of patients' rights in the hospitals of Kurdistan University of Medical Sciences in Iran. This qualitative study used the content analysis method. The data were collected through in-depth interviews, conducted in Persian at the internal and surgical wards from 2012 to 2013. Consequently, interviews continued to be conducted on 20 patients, using content analysis, until data saturation. The findings highlighted aspects of patients' rights and five themes emerged from the interviews: having one's dignity respected, receiving care of the requisite quality, being shown financial consideration, receiving adequate information, and having a desirable and pleasant environment. The patients believed that for their rights to be upheld, it is necessary that together with the provision of enough facilities and equipment, they need to be respected and offered ideal healthcare services. This could be achieved by removing barriers and facilitating procedures.*

### Introduction

Human beings have physical, mental, social and spiritual dimensions, from which arise certain rights, whether they are in good or bad health (1). These rights cannot be achieved, defended and supported without assistance (2). Contemporary ethical thinking on "human rights" places increasing emphasis on the concept of "ethics" within different professions, especially those that directly involve human beings, and forces the

authorities in these professions to take fundamental human rights into consideration to achieve citizenship rights, consider patients as vulnerable human beings with special needs, and stress their rights more seriously than before (3). Years ago, professional health practitioners, especially physicians, used to think that they could determine the patient's destiny just because they were aware of his/her health (4). However, in the light of the international community's growing concern about human rights, great emphasis is now being placed on "protecting patient rights" as well (3).

The World Health Organization (WHO) considers patients' rights as rights which individuals possess and which must be maintained by health service providers (2). Some of these are: right to appropriate and fair treatment and care, right to information, right to confidentiality, right to allow intervention only after giving informed consent, right to autonomy and freedom of choice, right to receive instruction on health, right to make complaints, and right to compensation (5). In other words, patients' rights touch upon legal and reasonable physical, mental, spiritual and social needs; these have been turned into medical rules and standards which a responsible treatment team must follow (6).

Nowadays, health systems take into consideration a "patient's bill of rights", which is announced at the administrative level, and healthcare personnel are urged to follow it. The content of these bills is almost the same: they all try to protect patients' rights (7,8). In most countries, such as Canada, the UK, the USA, Germany, Switzerland, Australia and Sweden, patients' rights are taken into consideration (8). In Iran as well, the Ministry of Health and Medical Education has issued a patients' bill of rights, which consists of 10 statements and is meant to be put into practice (9).

Most patients and doctors in the developed countries are familiar with patients' rights (10). Studies indicate that there are differences among different countries regarding these rights. Zolfaghar and Alvasvi concluded that 45% of patients in Turkey were completely unaware of their rights and did not know the concept of patients' rights (11). In Iran, Hooshmand and Joolaei stated that 73% of patients were moderately aware of their

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rights (12). A study in Iran indicated that patients' rights were enforced inadequately (7). Moreover, Eshkevari et al concluded that patients' autonomy and freedom of choice are taken into consideration in 36% of cases, while secrecy of information and confidentiality are taken into consideration in 56% of cases (13). In a qualitative study, Joolaee et al reported that in the view of patients and their companions, the most important areas in which patients' rights are honoured include: being offered fair healthcare services, having their and their family's respect and dignity maintained, being given information on their disease and the activities related to it, and being provided with medicines and basic facilities in the hospital (1).

All in all, studies show that patients' awareness concerning their rights is increasing; therefore, if their expectations are not met, they react (13,14). Support is considered a necessary part of nursing activities. This includes helping patients to diagnose their disease, informing them about their rights, and protecting these rights and interests (5,7,14,15). Whatever the form of support and expectations, the patient is the locus of the medical team's activities. All medical activities should be characterised by a high level of attention to the patient because the need to follow medical procedures can increase the patient's vulnerability and need for comprehensive support (11,15,16).

Finally, it should be stated that the principles of humanity and respect for human rights apply to the entire world. In Iran, due to the moral lessons of Islam and the setting in cultural and human terms, special attention is paid to human rights, in general, and patients' rights, in particular. Several quantitative studies have been carried out on patients' rights; however, it is necessary to understand the concept of "rights" as seen by patients, based on their specific cultural and social setting. This study aimed to understand the perspectives of Iranian patients' on patients' rights in the government-run teaching hospitals of Kurdistan University of Medical Sciences.

## **Methods**

### **Design**

We used the qualitative content analysis method, which offers instruments for examining experiences and results in the acquisition of valuable and in-depth data from the samples (17,18).

### **Participants**

The participants were selected using the purposive sampling technique. The participants were chosen from among patients admitted to educational-governmental hospitals, all of which have health insurance that partly covers medical expenses. Consequently, those recruited were hospitalised patients who were admitted to the internal surgical wards, were at least 18 years of age, did not suffer from dementia, had stable general health, and consented to participate in the study.

### **Data collection**

The patients were given an introductory letter which mentioned the purpose of the study, assured them that the

information they parted with would be kept confidential, informed them that they had the right to abandon the study, and contained the informed consent form. The data required were collected through deep and semi-structured interviews. The interviews were conducted in Persian in the internal and surgical wards from 2012 to 2013. Twenty patients continued to be interviewed until data saturation. The interviews started with a general question on the patients' experience of how their rights were being observed in the hospital, after which further details were explored. The interviews took 45–60 minutes, and were recorded, transcribed and manually analysed.

### **Ethical measures**

This research was ratified by the Ethics Committee of Kurdistan University of Medical Sciences. The method to be used and the objective of the research were explained to all the participants. The participants were all volunteers and written informed consent was obtained from them before starting the interviews. The names of the participants were converted into codes while transcribing the interviews, and the data related to each interview were stored safely. The participants were informed that they could withdraw from the study at any time.

### **Data analysis**

The Graneheim and Lundman (19) procedure for qualitative content analysis was used to analyse the data. For this purpose, the researchers listened to the recorded interviews after data collection and studied the transcribed data to gain a general understanding. The contents of the transcripts of the interviews were studied frequently. The text was divided into meaning units and reviewed frequently. The meaning units were condensed, abstracted and labelled with a code. Then various codes were compared based on similarities and differences with the initial texts specified and final conclusions were made by the researchers for driving sub-themes. The opinions of experts and the panel of judges were elicited to investigate and confirm the contents of the interviews. Their viewpoints also directed the researchers to arrive at the deep meanings of the concepts put across by the participants and thence, to formulate the final themes.

### **Trustworthiness**

Trustworthiness in content analysis studies, as in other qualitative studies, means methodological soundness or adequacy (17,18). To increase the trustworthiness of collecting data, data collection was carried out at an appropriate place and time, the participants were treated well, the complementary views of the co-workers were taken into consideration, the notes were revised with the patients' help, and other researchers' comments were utilised. In addition to interviewing the patients, we actively observed and made a note of their behaviour and interactions during the recorded interview so as to gain important information.

## **Findings**

During the analysis of the data, five themes emerged with regard to the patients' views on "patients' rights". These were:

having one's dignity respected, receiving care of the requisite quality, being shown financial consideration, receiving adequate information, and having a desirable and pleasant environment (Table 1). The following quotations from the participants have been presented on the basis of what they indicate.

### **Maintaining dignity**

Most of the participants mentioned the theme of "maintaining dignity", which consisted of two sub-themes: observing professional ethics and showing respect. They saw professional ethics as an important dimension of honouring patients' rights. In the words of one patient, "Doctors must establish a good relationship with a patient and keep the oath they have taken, even if the patient cannot afford to pay the hospital costs [code 3]." Another participant stated, "In the first place, a good nurse or doctor is characterised by a commitment to observing professional ethics and valuing human principles, so a good doctor or nurse is someone who is more committed to ethics [code 14]." According to another patient, "A medical team should prioritise the patients' well-being over money [code 6]."

Another important dimension which most patients referred to was respect for the patient and honouring his/her dignity. This included themes such as listening to patients, establishing an appropriate relationship with them, and treating them as human beings rather than just patients. One of the participants said, "Not all doctors, but most of them do not even bother to listen to the patient, let alone establishing a good relationship with him/her and this is a disaster because doctors can only diagnose on the basis of the disease history [code 4]." Another said, "The personnel, especially doctors, don't behave well, which makes us feel inferior, insignificant and taken advantage of because we are treated like objects [code 12]."

Another theme that emerged in this study was that of respecting and valuing the patients' and their families' time. Almost all participants spoke of how the patients' and their families' time and energy were wasted – something which they equated to a failure to honour their rights. One of the participants said, "They hospitalise our patient, operate him and discharge him whenever they like to [code 4]." Another said, "Valuing the patient's time and avoiding wasting his/her time are really important to me, which should be considered by all the hospital personnel [code 1]." According to another participant, "We waited for a long time until the doctor came and examined me. We were under great pressure. How long should we wait unattended? [code 3]" This complaint was echoed by a participant, who said, "The emergency ward was very crowded and we were not attended to until after a long delay, when the specialist doctor came to visit us. Later, twice I was sent for taking X-rays and both times the machine was not working. [code 5]" According to one participant, "I've been waiting for three days to be operated. I was taken to the operating room three days ago. To be honest, I was really scared and stressed out, and after waiting for 4 hours, they told me that the doctor will not operate. He hasn't turned up until now."

### **Quality of care**

Most of the participants stated that they had the right to be provided with complete healthcare, which was considered under the theme of "having quality of care". The sub-themes of this theme included access to experienced personnel, facilities and equipment (such as sheets, clothes, medicines, and diagnostic and treatment equipment), as well as appropriate medical and nursing services. The participants said that access to specialist doctors and equipment was the most important. One of the patients stated, "Every Iranian should have access to health and medical facilities; however, for the most part, they have to go to Tehran and other big cities [code 15]." Another patient said, "We still lack facilities and experienced doctors in most cases" [code 18].

Patients thus feel that access to the necessary facilities and appropriate services is a significant factor when it comes to regard for their rights. The lack of basic facilities and medicines make specialised diagnosis difficult. Speaking about the lack of facilities, one of the participants said, "My family took a lot of trouble trying to procure a medicine that was finally found in Tehran, whereas it was supposed to have been available in the hospital [code 13]." Another patient said, "The food we eat isn't of good quality and I won't eat hospital food. My family brought me food from home [code 17]." One of the patients spoke in rather strong terms: "Patients' rights are nonsense; we are even deprived of a proper room and clean clothes [code 10]." Another said, "In the hospital where I'm hospitalised, there are few doctors compared to the number of patients. In addition, they are not specialists [code 15]." Yet another participant said, "The doctors are too busy and always have a large workload and a large number of patients. They have little time for their patients and are always pressed for time [code 2]."

### **Financial considerations**

Another important dimension highlighted by the participants was that they had a low level of financial support, including insurance. One of the patients said, "Patients who have financial problems should be helped by some organisations [code 19]." Another said, "Those who are not financially able and are not supported by any insurance organisation need to be protected more so that they are not stressed out by the hospital and medical costs [code 4]."

### **Receiving information**

Another theme that emerged from this study was the patients' wish to have the right to be aware of their disease and the treatment procedure. The sub-themes of this right, which were mentioned frequently by the participants, included the right to be seen by trained health personnel who devote enough time to the patient, explain the patient's treatment procedure to him/her and seek his/her cooperation in the procedure. Another important sub-theme was the right to receive complete information about the disease. Most patients felt that this right was not honoured properly. One of the patients said, "Nurses and doctors should frequently tell

me about my disease and whatever they have done, but it's not so. Most illiterate patients don't even know their disease and their doctor's name, and no one gives them appropriate education [code 11]." Another participant stated, "A doctor should establish a relationship with the patients and give the necessary explanations, but unfortunately most doctors don't observe the patients' rights and don't care [code 3]." According to another patient, "I'm satisfied with the nurses and doctors with regard to their professional knowledge, but regarding a good relationship with patients, I'm not satisfied. I can't feel at ease and tell them my needs and talk about my problems freely. There's no communication between the personnel and the patients, there's no education about my disease, and I'm complaining about this [code 8]." Yet another patient said, "I didn't receive an education on my disease, its progress and treatment. I don't know what diet suits me [code 9]." Finally, one of the interviewed patients said, "If we know what will happen, we can decide what to do, but they don't tell us about our disease at all and don't consider us as human [code 4]." In addition, an important sub-theme of this theme was allotting enough time to patients to diagnose their disease and answer their probable questions. In this context, one of the patients said, "We're hardly given the right to ask any questions and if we ask, doctors don't respond or they even get upset and say that we're talkative. They don't explain. I think they're of a higher social class and we're not even important in their eyes [code 11]." Another participant said, "Here it's not important if someone is sick. Everyone wants to do their business and leave. No one asks who you are or what you want or even what the heck happens to you. And if we ask, no one responds [code 13]."

#### ***Need for a desirable and pleasant environment***

Another theme that emerged from the study was the right to be hospitalised in a desirable and pleasant place. In the patients' view, the sub-themes of this theme included that they should have a relaxing place in the hospital to rest in and that the structure of the hospital wards should be appropriate. Most participants felt that the structure of the wards left much to be desired. One of the patients stated, "If they put fewer patients in a room, it would be a better place to relax in. If they planted trees and flowers in the hospital yard, it would be better for the hospitalised patients [code 7]." Another participant said, "I'm not satisfied with the hospital environment at all. The rooms are really crowded. There's a lot of noise and we're not relaxed at all [code 8]." According to another participant, "There's no peace by any means. For example, suddenly a cleaner comes to our room at midnight and makes noises and disturbs us. Unfortunately, nurses and even doctors speak loudly and disturb us when we're resting [code 1]." Another patient said, "Regarding the general environment of the hospital, it should be said that it's crowded inside the rooms and corridors and there's not enough peace. Regarding aesthetics, there has been no plan [code 20]." An important factor mentioned by the participants was the role of the hospital's personnel in providing the patients with a calm environment. One of the patients said, "The hospital

environment should be clean and aesthetically pleasing, and the nurses and doctors can try to provide a peaceful and desirable atmosphere for the patients to loosen up [code 17]." Going back to the question of the structure of the hospital and its wards, one of the participants said, "In our room, there are four beds. Due to limited space, our room is always crowded and we never relax [code 9]." Another participant said, "The hospital and the wards are not maintained well. The ward does not have enough toilets. They're not clean and I'm reluctant to use them. This is really frustrating [code 3]."

Finally, on the basis of the themes that emerged from the interviews, the study defined the observance of patients' rights as patient-centred and comprehensive healthcare, which can be offered through a cooperative process and effective communication, together with efforts to understand the patients. Meeting the patients' basic needs and protecting them extensively are essential elements of healthcare, and these goals can be fulfilled only in an appropriate and desirable environment, given adequate information about the patients and their needs, and at the same time, upholding their dignity and respect.

#### **Discussion**

The results of the study increased our understanding of patients' perspectives of their rights in hospitals and provided us with information on their unique experiences.

All the participants of the study had health insurance which covered their medical charges partially. In Iran, there are four main kinds of public health insurance, which cover more than 90% of the people. These are the Social Security Organization, The Medical Service Insurance Organization, The Military Personnel Insurance Organization and The Emdade-Emam Committee. The first one is for all people employed in the formal sector, except for government officials and members of the armed forces. The second is for government employees, students and rural dwellers. The third kind of health insurance is for military personnel, while the fourth is for the uninsured poor (20). The participants in the study had the first two kinds of insurance, which cover the same levels of service and costs.

As shown by the results of the study, the patients believed that respecting the dignity of the patient is among the major features of patient-centred healthcare systems. Many studies have had a similar finding (1,12,13). The right to receive healthcare with respect and attention was one of the main themes that emerged also in a qualitative study conducted by Joolaei et al (1). The study conducted by Waterworth and Lucker (16) stresses the results of the present study in the context of the importance of respect for and attention to patients and the need to give these priority. Bucken and Bucken (21) noted that honouring patients' rights to provide healthcare characterised by respect and empathy had to be different from the past, when it was based on the individual will of healthcare providers. According to these researchers, the support and attention provided to patients by doctors, nurses and other healthcare providers should be based on

national and international principles and rules that clearly outline patients' rights and specify ways of observing them. It is important to have rules and principles that specify certain punishments for healthcare providers who ignore the rights of patients. Bills of patients' rights usually set out patients' expectations and rights without clarifying the healthcare providers' duties. Thus, the practical obligations of those practising medicine are not specified (21). The authorities and policy-makers probably need to adopt approaches that are more creative than sticking the patients' bill of rights on the walls of hospitals and medical centres.

In this study, the participants felt that the main element of patients' rights is the provision of good quality of care, which was associated with other themes such as effective communication, cooperation, comprehensive support, and fulfilment of their mental and spiritual needs. In their opinion, receiving care of good quality meant more than the mere physical presence of health personnel and routine medical and nursing activities. They were interested in the improvement of healthcare. Mrayyan (22) believes that quality nursing is based on nursing standards. The criteria of good-quality nursing care include: sufficient skills, a caring attitude, effective communication, efficient organisational and managerial systems, and effective cooperation among the members of society (16). Therefore, physicians and nurses should acquire knowledge and skills to provide quality care to patients.

A large number of scholars have highlighted care as the essence and basis of nursing. In this regard, Tschudin (23) states that, "Although care is not unique to nursing, it is regarded as a unique activity in this field." The main elements of everyday nursing care include experience, emotion, kindness and communication. They could all be summarised in one word, which is "care".

As shown by the participants' responses, the lack of necessary resources, whether qualitative or quantitative (such as time and manpower), was an important issue which was seen by many as obstructing the provision of appropriate healthcare. In their study on patients' understanding of appropriate healthcare, Larrabee and Bolden (24) concluded that in the view of patients, good healthcare is based on the patient's needs, associated with respect and warmth, patient-centred and, timely and appropriate, and should be provided by a skilled person. Other studies mention the right to receive appropriate healthcare, which emphasises the essence of care and not just its appearance (1,12,22). Appropriate and effective policies can create appropriate circumstances for the observance of patients' rights. Informing patients about their rights and responsibilities can effectively influence the observance of these rights. Joolaei et al (1) stated that a greater effort is required to stabilise patients' rights and improve their cooperation when taking health decisions related to them. It is not possible to observe patients' rights merely on the basis of ethical principles. Laws, instructions and mechanisms are necessary for the purpose. Nursing textbooks lay much emphasis on the content of healthcare; and providing

good-quality nursing care is one of the main rights of patients. Two important factors affecting patients' rights are a lack of information forthcoming from the people, patients, nurses and physicians, as well as unclear statements. In addition to the efficiency of the healthcare provider, care includes dimensions such as attention, respect and warmth, which are not measured using the typical methods.

Providing good-quality care to patients relies on ethical attitudes in healthcare providers and is possible only following comprehensive practical education in the nursing departments of universities (11,25). An insufficient number of healthcare providers, especially nurses, and an excessive number of patients can also affect the quality of care. Implementing patients' rights is the responsibility of all the personnel of the healthcare delivery system. It is a matter that is sociocultural and contextual in other ways as well, and a strong will and commitment are required on the part of the healthcare personnel.

There is always a gap between the expectations and rights of patients. However, policy-makers should be aware of the people's perspectives and expectations. A modicum of awareness can help them coordinate the perspectives of patients and the codification of their rights.

The issue of patients' rights has been a controversial one since the last decade. Health rights are specified in patients' bills of rights. These bills of rights usually mention patients' rights without clarifying the responsibilities of healthcare providers. Thus, no practical obligation is specified for anyone (3). The Iranian Patients' Bill of Rights was approved by the Ministry of Health and Medical Education in 2009 and has five axes.

- A patient has the right to receive optimal healthcare.
- Patients must be provided adequate information, in a proper manner.
- A patient's right to have a free choice and autonomy of decision-making must be respected in matters concerning his/her health.
- Health services should be based on respect for the privacy of patients and respect for the principle of confidentiality.
- Access to an effective system of complaints is a patient's right (25,26).

The first statement in the Iranian Patients' Bill of Rights, says, "A patient has the right to be provided with appropriate care and treated immediately, with complete respect and without considering racial, cultural and religious factors." It is clear that there is no trace of realism in this statement because it does not guarantee the fulfilment of patients' expectations with respect to their rights. A patient can harbour many expectations, but what remains vague is who will respond to these expectations (1,25).

The Iranian Patients' Bill of Rights has nine principles in common with the bills of other nations.

- The right to appropriate care and treatment, which should be of high quality and offered without any discrimination

- The right to medical information related to the disease status
- The right to privacy in relation to health and therapeutic information and to have healthcare providers maintain confidentiality
- The right to allow any health/ therapeutic intervention only after giving informed consent
- The right to decide independently on the type of healthcare service to be availed of
- The right to a hospital environment that offers privacy
- The right to peace
- The right to express objections and complaints
- The right to fair compensation (25,26).

When one compares patients' rights in Iran with those in other countries, it is clear that Iran's Patients' Bill of Rights could be more comprehensive with the addition of the right to independent decision-making on the type of healthcare services to be availed of, the right to a hospital environment that offers privacy, the right to peace, the right to express objections and complaints, and the right to fair compensation. If these elements were incorporated, we could expect effective and efficient service delivery to people in need.

Since there is no appropriate forum for patients to voice their views on their rights in Iran and there is no responsible non-governmental organisation, establishing such organisations is necessary, so that the patients' voices can be heard by the authorities and their opinions considered while designing a bill and instructions aimed at protecting their rights. Further, patients' lack of adherence to the recommendations of treatment teams result in poor outcomes and lead to the sense of lack of optimal healthcare services. Therefore, other than expecting their rights to be upheld, patients should, as far as possible, adhere to the recommendations and prescriptions of the healthcare system that guarantees their rights.

**Limitations of the study**

As this was a context-based qualitative study, the generalisability of the results is limited. Therefore, more studies are necessary for further exploration of patients' rights, especially among patients hospitalised under different systems and in different wards. Moreover, it would be helpful if additional studies were carried out to explore the various aspects of patients' rights as perceived of by nurses and physicians.

**Conclusion**

The results of this study show that patients believe that for their rights to be upheld properly, adequate facilities and equipment need to be complemented by respect and the provision of ideal healthcare services. They do not have an adequate knowledge of their rights, which makes it difficult for them to know how to go about things and how to exercise different aspects of their rights. The patients' viewpoints are important because their ideas can be utilised as a basis for further research and to design a bill of rights that is

appropriate for their needs and expectations, with Iran's social, economic and cultural context as the general backdrop. Further, it is essential to understand the patients' opinions on their rights as it would not be possible to satisfy them otherwise. Their satisfaction could be increased by removing barriers and facilitating procedures that help in upholding their rights.

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**Conflict of Interest**

*The authors declare that there is no conflict of interest.*

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**Table 1. Summary of themes and sub-themes**

| Main themes  | Sub-themes  |
|--|---|
| <b>Having one's dignity respected</b>              | Receiving care from professionally ethical personnel      |
|  | Being respected   |
| <b>Receiving good-quality care</b>                 | Having access to experienced personnel                    |
|  | Having access to adequate facilities and equipment        |
|  | Having access to appropriate medical and nursing services |
| <b>Being shown financial consideration</b>         | Receiving financial support                               |
| <b>Receiving adequate information</b>              | Being given complete information on the disease           |
|  | The right to be trained and being given enough time       |
|  | Having one's questions answered                           |
| <b>Having a desirable and pleasant environment</b> | Being in a place in the hospital that is relaxing         |
|  | Structure of wards should be appropriate                  |

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### ***IJME* now in The Philosopher's Index**

*Indian Journal of Medical Ethics* has been accepted for inclusion in The Philosopher's Index (TPI). Citations for the journal will now appear in the world's most comprehensive bibliography of writings on philosophy. All volumes dating back to 2011 (vol. 8) up through the current volume (vol. 13) are in the process of being indexed and all future issues will be included. Citations for the journal will be available to search in TPI's online index in March or April, 2016.

## THEME: HEALING AND DYING WITH DIGNITY

### The caregivers' point of view

**SHEELA JAYWANT**

I worked in the customer service department of a multispecialty tertiary care private hospital in an Indian metropolis. Whenever the staff/doctors did not know whom to call, they would page me to sort out matters, for example:

- when someone was throwing a tantrum because he or she felt the bill was unfair,
- when there were no sheets/gloves/wardboys available, or, worst of all for me,
- *when they had no time to spend on or deal with the relatives of dying patients, either admitted or coerced into getting discharged.*

*The last was relegated responsibility.* Since I was middle-aged and grey-haired, it was assumed that I would know what to say or do. As I was untrained to counsel, I was often at a loss when it came to finding comforting words. I went by personal experience and that of family and friends who had dealt with loved ones who were dying.

A few incidents stand out.

- An old man who was dehydrated was brought into the casualty ward. He said that for many days his daughter-in-law had not given him water, tea or coffee, except a sip or two with which to swallow his medicines. I confronted her with this and she agreed: "We live in a *chawl*. My husband is out from eight to eight. I fill the drum with water, do the shopping, cutting, chopping, dusting, sweeping, mopping and cooking, and wash the clothes... I have to feed both my children and my father-in-law. My father-in-law can't hold his urine. I can't keep taking him to the toilet. I tried to put a mug and a plastic bottle next to him. His hands shake. The urine spills. In the beginning, I helped him change his pyjamas. Then I tied a lungi around him because that was easier to handle. Our house stank of urine. The neighbours complained. Finally, I stopped giving him liquid." His end was near and she was hoping it would come soon. She could neither keep him in hospital, nor did she want him at home. They could not afford disposable diapers and part-time help. "He's been good to me," she wept, with guilt written all over her face. "My husband is caring; it's my

*naseeb* (fate) that's at fault." The *naseeb* factor seems to help people tide over severe difficulties, or at least accept them uncomplainingly. For caregivers like this one, organised associations could help with time-sharing or pooling of some chores, such as shopping and dropping children to school.

- An 11-year-old girl with a congenital problem was admitted for respiratory distress. However, she moaned for 24 hours due to her contracted muscles and constant pain. Her parents had come to Mumbai, having sold all they had for her sake. The doctors had told them that there was no hope for the girl, but with good care, she could live for another two years. "I don't want her to," the mother said within the girl's hearing. "If she has to go, let her go. Why this *natak* (drama)?" I was appalled by her cruel attitude. She said, "The girl knows she's going to die; she's been hearing doctors say it for years. (I was more shocked still that some doctors had said this in the girl's presence.) We've reduced ourselves to poverty for her, fasted, prayed. This child has brought us nothing but misfortune. Even my goat is more valuable." Her voice spoke of despair and deep sorrow. Nothing – whether it is family support or community backing – works when there is a shortage of finances. For such patients, we need volunteer-based residential or at least day-care institutions, run privately or by the government, possibly at the taluka level.
- A stench hit my nostrils as I entered a ward one morning, as if there was a putrefying rat somewhere. The patients and relatives pointed to a corner of the room. On the bed indicated by them lay an end-stage tongue cancer patient, whose family had paid a deposit and abandoned him. Everyone did their best to alleviate his agony. He gestured, moving the handle of a spoon across his throat, to tell me to kill him. We moved him to an end-of-life care home. He was tired of the suffering and his own people were tired of him. In contrast, my sister-in-law died of breast cancer in the USA, by chance over a weekend, knowing what to expect, with her pain controlled, on her own bed, with her husband, children and grandchildren by her side. Her end reminded me of all the paralysed/bedridden elders I had seen in the middle-class homes of my relatives or neighbours during my childhood. They were made to lie in an inner room, but were still kept up-to-date about the happenings in the community. Even when very ill, they were seldom transferred to hospital. There would be no tubes and ventilators, no chance of prolonging life/death. Some of them might have lived longer, but the philosophy

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was that “it was better they (went), their time was up”.

- An intelligent and aware patient had guessed the “secret” that her condition was grim and was miserable about it. She got no counselling and had no happy moments, and was not prepared by anybody for the inevitable. Those looking after her lied when she asked, “Am I going to die?” They said, “no” even hours before she died. For a long time, one of her children felt guilty about having lied. There was no need to. The patient wanted to know and had a right to know. However, there was no one who could give appropriate guidance to the relatives.

Families which can afford to keep their end-stage patients in hospital tell themselves, “*Sab kuch theek hone vala hai* (Everything’s going to be fine).” It is only in rare cases, mostly if the patient is very old, that the family takes the patient home willingly. This happens when a family “elder” takes the call.

As for the medical team, even after it has told the patient’s relatives that death is near, it often continues treating the patient without consent. Patients’ relatives have often asked me, “If nothing’s going to improve, why are they taking blood/urine for tests, giving medicines and charging consultation fees?” One woman with end-stage liver failure had to undergo routine checks with her finger pricked thrice a day for assessments of her blood sugar levels. One hospital told a patient it was compulsory for him to buy a thermometer, even though he had but a few days of life left in him. (The compulsory sale of thermometers is unethical anyway. When I asked the assistant director of that hospital’s administration why this rule existed, I was told “to prevent infections”. I want to know which infection travels from armpit to armpit via properly cleaned thermometer bulbs. However, more on that in another article.)

When my 84-year-old father-in-law neared his end, our general practitioner politely told us that we could transfer him to a nursing home if we wanted to, but reminded us that there would be zero outcome. On the other hand, a friend’s father, who was of the same age as my father-in-law, had tubes inserted into him, underwent a tracheostomy, and was pumped with plenty of complicated-sounding drugs. He lived for almost a month after the ambulance had brought him to the intensive care unit (ICU). He was unconscious and his life’s savings went into that final bill. The serious-faced doctors must have known that nothing could be done. No lay relative would have the courage to say, “Stop,” if a doctor said, “...let’s try this...” Some doctors do not openly say that the end is near. Sadly, we also have cruel staff/doctors who bluntly say, “*Ghar le jao, kuch nahin hone wala. Khattam* (Take him home. Nothing is about to happen. It’s all over).” Sensitivity matters. Soft skills matter.

For the NABH certification, I had tried to find priests of different faiths for last-minute religious counselling/prayers for the relatives of patients. Only the Roman Catholic Church was organised in this respect. The Protestants had many sects, the Muslims did not know what I was talking about, the Parsis said they would handle the case after the death and the Hindus

looked at me blankly. Let a family member put *tulsi* leaves or *gangajal* in the mouth, a practical Brahmin advised. There was no religious support for caregivers.

The mother of a patient with Duchenne muscular dystrophy told me she had called a psychiatrist and a Hindu priest home to prepare him for the end. She kept those visits private and did not ask her son about the conversation, allowing him to dwell on his thoughts. However, she did not get any counselling for herself and was shattered when her son was gone. In nuclear families, those who are left behind definitely need counselling. I used to get calls from parents/widow(er)s/middle-aged children that had some sentences in common, such as, “I feel the presence,” and, “I can’t stand the silence/lack of routine.” We have no support groups to deal with loneliness or the sense of guilt that especially the bereaved feel. In my experience, families often worsen the situation/condition of the bereaved because of their social conditioning and their expectations regarding behaviour. No hospital that I know of encourages post-death calls from the recently bereaved or, for that matter, from those who are desperate to know that the patient is not dying. The parents of D, who had been a quadriplegic since the age of 18 years, looked after him through four decades. When his mother passed away and his ageing father could barely cope, even with the help of paid servants, there was a time when the thought of killing the son crossed the father’s mind. This is not uncommon (the thought, not the deed). In another case, the mother of a middle-aged severely spastic, mentally retarded and profoundly deaf daughter asked me whether I could request one of the doctors to “give the daughter an injection.” In both the instances cited above, the stage was not “the end” for the patients, but the parents wanted it to be lest they were outlived by their children.

Special training should be given to those who deal with caregivers. In the case of a brain-dead donor, the family had nearly accepted a brain death, but a young nurse said, “Don’t worry, we’re doing our best, no?” There was havoc after that; the furious family disbelieved every word I said about cadaveric organ donation. All the doctors/nurses/technicians should say the same thing about a patient and there should be two representatives from the family so that there’s no misunderstanding about what the doctor has said. Go-between general practitioners are a great help. The medical records file should contain a counselling paper, which should bear the signature of all present.

I think the following measures are necessary.

- a. There should be an audit of dying patients so that with professional inputs, families can decide when and how to tackle the end, whether in hospital or at home.
- b. Retired nurses should be employed as “death-midwives”.
- c. Simple information on end-of-life care should be painted on the walls or printed on posters, which should be prominently displayed (like the “no smoking” signs) outside ICUs and health check areas (where the healthy

- spend a curious but bored day). Do not resuscitate(DNR) directives should also be displayed, as should information on the withdrawal and withholding of expensive and futile therapies, as well as terminal care. Pamphlets are not effective. The relatives of patients who are temporarily admitted and likely to recover will also read about and possibly discuss palliative care and euthanasia with other visitors/relatives, and become aware of the differences between administering no treatment, some treatment and aggressive treatment.
- d. The contact details of nursing bureaus that have trained palliative care nurses, charitable trusts that help with money, shops that sell/rent special beds/oxygen cylinders, those who undertake home delivery of diapers and

medicines,etc. should also be displayed prominently.

- e. As a rule, except in acute, unexplained conditions that lead to death or in fatal trauma cases, the relatives of patients listen to physicians. Other than knowing what to say, doctors and their teams must be taught *how* to say it. The tone is a give-away. It is useful to activate volunteers from among those who have been through the experience of caring for an end-stage patient.

Caregivers must know what *can* be done at home, together with which services are available and their prices, and should be encouraged to reach out and help others. Unless the people are involved, the onus of end-of-life care falls on the already burdened healthcare professionals.

## Access to palliative care: insights into ground realities post-2014 amendment to NDPS Act

MR RAJAGOPAL

### Abstract

*Medical practice today is disease-focused, ignoring the universally accepted definition of health as not just the absence of disease, but the promotion of complete physical, social and mental well-being. Generations of doctors in India have not studied modern pain management, and palliative care is practically unknown in most parts of the country, causing patients to be rejected by hospitals and doctors when they need help the most. The draconian Narcotic Drugs and Psychotropic Substances (NDPS) Act of 1985, outdated medical and nursing education, lack of public awareness and lack of clear governmental policy are responsible for this sorry state of affairs.*

*The development of a community-oriented palliative care network eventually led to the formulation of a state palliative care policy in Kerala. The acceptance of palliative care as a medical specialty by the Medical Council of India and introduction of a postgraduate degree course in palliative medicine in 2010, the development of a National Programme for Palliative Care in 2012 by the Ministry of Health of the Government of India, and the amendment of the NDPS Act in 2014 have been major positive developments which have the potential to change the current state of affairs. However, these recent achievements represent but one step in the right direction. An improvement in palliative care education, a realistic palliative care policy and implementation of*

*the NDPS Amendment Act are necessary for doing away with the gross, needless violation of the human right to life with dignity.*

### Introduction

For centuries, medical students have learned the 15th century aphorism that a doctor's duty "is to cure sometimes, relieve often and comfort always" (1). In 1948, the World Health Organisation (WHO) defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (2). This definition is still valid.

However, do these principles translate into clinical practice? With the advent of technology, healthcare has become so disease-focused as to ignore domains of disease-related suffering, including symptoms and sociocultural and humanistic factors (3). The situation is particularly bad in developing countries. While access to palliative care is admittedly difficult to measure, the per capita consumption of opioids does provide an index. There is virtually no opioid consumption among 66% of the world's population. Among 10%, it is very low, among 3% low, 4% moderate, and only among 7.5% is it adequate. India ranks among the lowest, with only 0.22% of its citizens having access to opioids for pain relief (4, 5).

Along with the growth of technology and therapeutics came commercialisation of medicine. The average doctor in India had seldom heard of the phrase "healthcare industry" till the 1970s; in those days, we knew about "health service". Today, we do not hide the fact that healthcare is an industry. The very purpose of an industry is to make profit. Unfortunately, in the context of healthcare, the profit has to be made out of human suffering. The pharmaceutical industry is the most profitable business

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sector, with an average profit of 16.2%, ahead of financial companies (11.6%) and beverages (10%)(6). The magnitude of this problem can be gauged from the recent report that 26,426 people in India who were suffering from various ailments, including cancer, AIDS and paralysis, chose to end their lives in the year 2013(7).

Apart from the social and financial implications, the unrelieved physical suffering is usually profound. About one million people in India suffer from moderate to severe pain because of cancer (8). The prevalence of such pain has been shown to be approximately 47% among those living with HIV, and India, with over two million people living with HIV, must be having close to one million people in moderate to severe pain (9). We still do not have statistics for the numerous others who would be suffering pain from other causes. The pain is often overpowering, destroying the person physically and emotionally and exhausting the resources of the family, which pursues needless and ineffective treatment because access to simple pain relievers is denied them. As the United Nations Special Rapporteur on Torture mentioned in a joint report with the UN Special Rapporteur on the right to health in 2013, the failure of member states "to ensure access to controlled medicines for the relief of pain and suffering threatens the fundamental rights to health and to protection against cruel, inhuman and degrading treatment"(10). The UN Committee on Economic, Social and Cultural Rights states that providing access to essential medicines is one of the core obligations deriving from the right to health. The International Covenant of Economic, Social and Cultural Rights recognises access to essential medicines as a human right (11). The WHO has included oral morphine among "essential medicines" (12). It is also on the Government of India's list of essential medicines (13).

Once we accept the proven fact that unrelieved pain has major physiological, psychological, economic and social ramifications for the patient, family and society (14), the question arises whether access to pain relief is affordable. In fact, the cost of palliative care is low and it helps in several ways, not only to improve the quality of life, but also to reduce the cost of treatment by avoiding unnecessary and expensive treatment. In the bargain, it has also been shown to improve survival (15).

Most pain can be relieved by the simple application of inexpensive medicines. In 1986, the WHO brought out the "three-step analgesic ladder", which revolutionised cancer pain treatment all over the developed world (16). For severe pain, the ladder recommends opioids such as morphine. Though medical science has proved that neither addiction, nor abuse and diversion to illicit sources are problems if reasonable skill and care are applied (17), professionals, the public and administrators have an unrealistic fear that opioids would cause addiction, while medical professionals fear respiratory depression. The result has been poor access to opioids, leading to lack of familiarity with opioids among professionals, and finally, to needless pain. Today, there is a paradoxical situation in India, where the poppy is grown under licence and the

country has been the world's largest exporter of legal opium for medical purposes, but denies opioids to more than 99% of its needy citizens (18).

In an obviously misguided attempt to curb the misuse and abuse of opioids, the Narcotic Drugs and Psychotropic Substances (NDPS) Act of 1985 brought in unrealistic licensing procedures for accessing opioid analgesics. Each state had different rules and in every state, usually four to five different licences were required before morphine could be procured and dispensed to patients. These licences required the concurrence of multiple government departments and all needed to be valid at the same time. In addition, the Act imposed very stiff penalties, some of them applicable to even minor errors in bookkeeping. The result was that after the passage of the Act, the consumption of morphine in the country dropped from 573 kg in 1985, which was already very low, to 17 kg in 1997(8). A study by the Economist Intelligence Unit and Lien Foundation has found that India ranks an abysmal 67th among 80 countries (19). In the absence of palliative care, the end of life becomes particularly agonising in India.

Often death is over-medicalised, and a system seems to have evolved in which a lot of people die in intensive care units on artificial life support even in the face of obvious futility of treatment, without the ethical alternative of withdrawal of artificial life support and introduction of palliative care (21). While death was preceded by the withdrawal of artificial life support in up to 90% of cases in intensive care units in the USA(20), the Indian figure for the withdrawal of life support among cancer patients was only 29% (21). To quote Sankha Mitra, "The poor die in agony in neglect, the middle class die in agony in ignorance and the rich die in agony on a ventilator. No one gets a dignified and pain-free death."(22).

In the absence of psychosocial support, treatment-related debt and the loss of a livelihood push families below the poverty line, and children often drop out of schools (23). Poor awareness of palliative care prevents people from accessing it even where available. Sometimes, palliative care is also confused with euthanasia, though the palliative care community has generally held the view that a society which does not provide palliative care to the needy does not have a moral right to consider euthanasia.

In short, the medical system in India, while offering high-tech disease-specific treatment, seems unable to take care of physical symptoms or cater to the psycho-socio-spiritual issues affecting patients and their families. This situation makes us wonder whether Ivan Illich was not right when he said, "The medical establishment has become a major threat to health."(24) Have we already come to the point which Alain Enthoven, the health economist, spoke of when he said, "increasing medical inputs at some point will become counter-productive and cause more harm than good"(25)?

## The advent of palliative care

In the 1960s, Dame Cicely Saunders, the pioneer of palliative care, founded what is now recognised to be a healthcare revolution. Her initial attempts to care for the dying eventually evolved into the specialty of palliative medicine. Dame Cicely Saunders recognised suffering as total pain, and a mix of physical symptoms, the psychological consequences of disease and symptoms, the social implications and spiritual pain, each with the potential of worsening the others. Though a 1986 definition of palliative care restricted it to situations in which “the disease is no longer responsive to curative treatment” (16), in 2002, the definition was changed to the currently prevailing one (Box 1) (26).

It has already been shown that the concurrent provision of palliative care and curative treatment improves the outcome not only qualitatively, but also quantitatively. A study by Temel and colleagues on people with non-small-cell cancer of the lung, found that the addition of palliative care into definitive cancer treatment increased life expectancy by an average of three months (27).

The cardinal feature of palliative care is a shift from disease-oriented treatment alone to person- and family-oriented treatment. The focus, in addition to the disease, is also on the quality of life, not only of the patient but also of the family; because palliative medicine recognises that when one person suffers from a life-threatening disease, the whole family suffers. Typically, pain is managed by an initial assessment, particularly to distinguish nociceptive pain from neuropathic pain. Appropriate medical management is instituted wherever possible, by mouth, by the clock and by the ladder (the WHO three-step analgesic ladder). For moderate to severe pain, opioid medicines of step III, such as morphine, are used when indicated, in doses adequate for pain relief. There is a widespread misconception among doctors that the administration of morphine results in a vegetative existence. This is not true, and the aim of palliative care is to bring the person’s functioning as close to normal as is possible. If the dosage of opioids is titrated according to the degree of pain, more often than not, the patient has a reasonable quality of life and may sometimes be able to get back to work.

Other symptoms are assessed and treated scientifically. While such symptom management would go hand in hand with disease-specific treatment if the disease is potentially curable, it focuses on the quality of life in the case of incurable diseases. The scheme of management could be different from that in acute medical or surgical practice. For example, a person with breathlessness from a life-threatening, incurable condition would not be isolated in an intensive care unit. The person would be encouraged to be with the family, and interventions would be aimed only at his/her well-being. Morphine would then become the mainstay of pharmacotherapy as it decreases the sensation of breathlessness (28).

To take another example, the intestinal obstruction in malignancy is recognised to be sub-acute in nature and

can often be overcome without resorting to the typical management strategy of draining the contents of the stomach with a nasogastric tube and providing intravenous fluids or, in some extreme cases, total parenteral nutrition. Instead, dexamethasone to treat the peri-tumour oedema may help (29) and gastrointestinal motility is increased by the use of 40–80 mg per day of metoclopramide, often given as a subcutaneous infusion (30). With these measures, a significant majority of patients with gastrointestinal obstruction arising from malignancy may continue to take oral feeds, often till the very end.

The diagnosis of a life-threatening condition often causes intense distress to the patient. Sensitive disclosure of the bad news, coupled with the reinforcement of realistic hope, help the person and the family to overcome the initial shock and to make intelligent decisions regarding future treatment. A large number of patients with cancer or HIV, as with many other diseases, suffer from clinical depression or states of anxiety. Efforts are made to identify these conditions and treat them early. Whether or not the emotional problems qualify as disease states, such as clinical depression, the principles of communication are vitally important. It is a matter of grave concern that training in communication skills is not a part of the undergraduate medical curriculum in India even today.

Palliative care includes the identification and management of social issues, both at the micro and macro levels. At the micro level, the issues that come to the forefront are those concerned with relationships in the family and with friends. Appropriate counselling helps to identify and resolve them when possible, paving the way for peace of mind. At the macro level, financial issues are particularly troublesome in India, as families have often been destroyed by the cost of previous treatment. Many palliative care centres make an effort to provide vocational rehabilitation to families destroyed by disease. They also recognise that the children in such families often drop out of school. Many centres raise resources to give educational support to the affected children.

On the spiritual front, essentially two kinds of exploration are made. One, an effort is made to find out what connects the person most to the world. It can be his/her environment, as is evidenced by the oft-mentioned request from patients not to take them to hospitals but to keep them at home at the end of life. Two, it may be his/her connection with God. Appropriate religious support may then be needed, but should be provided with caution and sensitivity in India’s multi-religious society. Insensitive attempts at spiritual support may be perceived of by the patient and family as attempts at conversion and could be resented. They may cause suffering at a vulnerable time. The spiritual evaluation also involves reviewing the patient’s life story with a view to discovering the meaning of life in his/her eyes and reinforcing the patient’s achievements. The person who feels that “my life has not been wasted; my legacy will live” is likely to be at much greater peace than others at the end of life.

### Box 1: WHO definition of palliative care, 2002

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten, nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

### History and current status in India

Palliative care was born in India in the form of Shanti Avedna Sadan in Mumbai, the result of pioneering activity by Dr Lucito D'Souza, an oncosurgeon. The initiative of the Pain and Palliative Care Society in 1993 in Calicut and the formation of the Indian Association of Palliative Care in 1994 can be seen as two major landmarks in the development of palliative care in the country. In the early years of its activities, the Pain and Palliative Care Society became a known entity in Kerala for its humane approach, the active involvement of volunteers, its outreach into the community and community participation. However, the reach of palliative care was very inadequate in the rest of the country and in 2003, the organisation Pallium India was created to catalyse the development of palliative care centres in those states in which it was particularly deficient. During the first 10 years of its activity, Pallium India was able to catalyse the development of such centres in 11 states, which had next to no palliative care earlier.

In 2005, Pallium India submitted a proposal for a state palliative care policy to the government of Kerala. After wide deliberations, in May 2008, Kerala declared a palliative care policy which, in principle, endeavours to integrate palliative care into routine healthcare.

Two major factors contributed to the success of the palliative care movement in Kerala. One was the creation and demonstration of a viable model of care and the fact that the pioneers were keen on others replicating the first palliative care service started in Calicut. The other was perhaps the state's high literacy rate, which helped the people to imbibe a powerful socio-medical message.

In 2007, the palliative care community approached the Supreme Court of India contending that denial of access to palliative care violated the right to life with dignity and asking

for central and state palliative care policies, legislation to ease availability of opioids for pain relief, and inclusion of palliative care in medical and nursing education. A public interest litigation in the Supreme Court could be a very expensive affair, but Mr Ashok Chitale, a senior lawyer and a trustee of Pallium India, and his colleague, Mr Niraj Sharma, took it upon themselves to provide their services *pro bono*, and the case was filed at practically no cost and registered by the Supreme Court in 2008. Though the final hearing is yet to take place, the questions that the Supreme Court has asked the governmental agencies during the periodical hearings have acted as a catalyst for the further growth of palliative care.

In the meantime, several international developments have helped the palliative care movement in India. In 2009, the Human Rights Watch published the results of their research, namely "Unbearable pain: India's obligation to ensure palliative care" (31). The International Narcotics Control Board (INCB) took up a suggestion by the Human Rights Watch to visit India and study the problem. An INCB delegation visited India and interacted with government officials and representatives of civil society organisations. Its recommendations played a major role in persuading the government to take further action (32). The Pain and Policy Studies Group in Madison-Wisconsin included three fellows and two Central government officials in its fellowship programme and this, too, had a catalytic effect (32). Finally, the World Health Assembly (WHA), the decision-making body of WHO, passed a ground-breaking resolution calling upon its member states to integrate palliative care into healthcare at all levels (33).

These landmark global activities, as well as persistent advocacy over the years, bore fruit and led to the following developments.

1. The Medical Council accepted palliative medicine as

- a medical specialty and announced an MD course in palliative care in 2010.
2. In 2012, the Ministry of Health announced a National Programme for Palliative Care (NPPC) in the current Five-Year Plan (34). Unfortunately, the proposed budget allocation did not materialise. However, a small part of the NPPC – corresponding to approximately 2% of the originally proposed budget – is being rolled out to those states which would like to start palliative care services.
  3. After 19 years of advocacy, in 2014, Parliament passed an amendment of the infamous and draconian NDPS Act (35). It shifted the power for legislation regarding opioid analgesics from the state governments to the Central government. Following this, in May 2015, the Department of Revenue of the Government of India notified the new state NDPS rules (36). As the situation stands in 2015, all states would have a uniform rule and only a single governmental approval issued by a single agency for procuring and dispensing morphine, would be necessary.

### The way forward

The three developments mentioned above have been important steps, but contrary to the expectations of many, are unlikely to change access to pain relief immediately. True, some hurdles have been overcome in theory, but several others lie ahead. Though the rules for the states have been simplified, previous experience tells us that unnecessary procedural hurdles are likely to be raised by the state government departments during the phase of implementation. This is something to guard against and the role of the civil society will be vital in this context.

Even if the NDPS Amendment Act is implemented both in letter and principle, access to pain relief still depends on the medical community. As doctors and nurses are unfamiliar with modern principles of the pharmacological management of pain, and as the current and past medical and nursing curricula do not include palliative care, translating the legal change to clinical practice will require a major shift in the attitude, knowledge and skills of medical professionals. Though the Medical Council of India has started postgraduate programmes, pain management and palliative care are still not a part of undergraduate medical or nursing education. The result is the gross violation of the fundamental right to life with dignity. In this case, this violation becomes particularly unacceptable because an inexpensive solution is available even to the poor and it is only lack of government action which is standing in the way.

It is essential now to implement the WHO strategy of concurrent education of professionals and the public, improvement of access to essential medicines, and the creation of a realistic policy and its implementation (37). With the major barriers to opioid access having been overcome by the NDPS Amendment Act, the greatest need of the moment is action by the Medical Council of India and Indian Nursing Council to include pain management and palliative care in their

undergraduate curricula. The resurrection of the NPPC in full and its modification and adoption as an essential part of future Five-Year Plans is also essential.

But can the medical profession leave it all to the government? If there is a violation of the right to dignity and right to health of the individual, does not the medical profession have the moral and ethical responsibility to advocate for patients and their families and demand that medical and nursing councils must include the essentials of pain management and palliative care in their curricula? Is it not for them to demand that while preventing abuse, needless regulatory barriers to opioid analgesics be removed? Do they not have the moral and ethical duty to advocate that as the WHA demands, palliative care should be integrated with routine medical care?

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## India: not a country to die in

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### Abstract

*This commentary addresses the issue of disproportionate medical interventions for end-of-life patients. A complex mix of sociocultural and medical factors, against the backdrop of the legal milieu, has an impact on the quality of death. The barriers to appropriate end-of-life and palliative care in India are multilayered and not easy to dismantle. To raise the level of care for the dying in India, currently rated among the worst in the world, it would require no less than a nationwide movement. This paper attempts to bring into the open the areas of concern for*

*discussion, and proposes appropriate legislation for a realistic solution.*

*Yaksha: What is the greatest wonder?*

*Yudhishtira: Day after day countless creatures reach Yama's abode, yet those who remain behind believe themselves to be immortal. What can be more extraordinary than this? (1)*

### Dignity in death

Death is not a welcome topic for conversation anywhere in the world. In India, it is “*apshagun*”(inauspicious) to even speak of mortality, even though India's religious traditions emphasise the dignity and spiritual significance of the end of life. Yet, discussions on the end of life are essential when patients, families and medical professionals come face-to-face with the inevitable. Without clear decision-making, the default option is an unnecessarily prolonged death. If one goes about the process the right way, intensive care can overlap

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and segue into palliation and withdrawal/withholding (WD/WH) of futile care. In this regard, it is known that the choices made by medical professionals are somewhat different from those made by the lay public with regard to themselves and their families (2). Anecdotal evidence suggests that “for all the time they spend fending off the deaths of others, they tend to be fairly serene when faced with death themselves”(3). In the questionnaire-based ETHICATT study from Europe (4), physicians and nurses assigned greater value to the quality of life and death than to the length of life. There is now widespread public awareness in the developed world of the futility and burden of intensive care in the last few days of life and jurisprudence is rapidly taking this into account. In the USA, since the early 1970s, legislation and case law have evolved into fairly settled legal positions with respect to limitation of treatment, palliation and living wills (5,6). Canada and the state of California have recently seen the legalisation of physician-assisted dying, building on more than three decades of public acceptance and debate. It is, therefore, not surprising that WD/WH of treatment or “do-not-resuscitate” (DNR) orders were found to precede most intensive care unit (ICU) deaths in North America and Europe (7,8). Both physicians and families now accept such decision-making as routine. Even in the case of neonates and children, 40%–60% of ICU deaths are preceded by limitation of treatment (9,10). The question of managing one’s own death is now also reaching a tipping point in mainstream social media. Death Over Dinner and The Conversation Project (11,12) are two examples of beginning what has been called “the most important and costly discussion America is not having”. India, to the best of our knowledge, has somewhat limited medical literature on this topic (13,14). There is not a semblance of a mention of it in either legislation or public policy, leave aside the private conversations which can then be facilitated.

### **When the end is near: beginning an essential discussion**

The prediction of an individual’s mortality is inexact. In the Indian context, it may not be advisable to depend on western models of prediction, especially because the quality of the data is uncertain. Nevertheless, some trends can be discerned from international literature. In a seminal study from 1993 to 1998, Lunney et al (15) analysed a random sample of United States Medicare beneficiaries and developed a profiling strategy that captured 92% of deaths. Excluding sudden deaths, which accounted for only 7% of deaths, the dying process from the medical point of view was dominated by three distinct trajectories. Malignancy (22%) peaked in the 6th–7th decade of life, initially with functions maintained and followed by a quick but definitive terminal phase. Organ failure (16%) was associated with a slower descent, often punctuated by recurrent acute episodes, and the peak of mortality was in the 7th–8th decades. Beyond the 70s, a good many people (47% of this sample) had an interminably slow decline, with a poor and inexorably deteriorating functional status. In the case of all three scenarios, objective clinical criteria largely developed and used in Europe and North America can identify those with

a greater than 50% risk of dying within a year (16). Even in the case of younger patients, including neonates and children with acute or incurable illnesses, the inevitability of death can be predicted after a period of interventions (9,10). As in the rest of the world, more and more of these deaths are likely to occur in a technology-laden hospital setting. In addition to the evident waste of personal and societal resources, poor quality of life and family stress, this kind of death is actually associated with a lower level of satisfaction with the care received (17). In India, 80% of healthcare is privately financed and in our experience, this often feeds into a narrative of exploitation, especially when futile medical care leaves the family deep in debt. Worldwide, including India (18), home is the preferred place of death for a huge majority of lay people, not just medical professionals (4). To allow patients to make their choice, whether in the acute ICU setting or in the outpatient encounter, it behoves the responsible clinician to openly, honestly and explicitly communicate the prognosis to the capable patient and/or family. The SPIKES (Setting up the interview, assessing patient’s Perception, obtaining patient’s Invitation, giving Knowledge, addressing Emotions, Strategy and Summary) protocol (19) was developed to enhance the content and quality of the communication between the clinician and patient and/or family in a structured fashion. It can be applied in most settings and has been taught successfully to medical students (20). Japanese culture has a major taboo against informing terminally ill patients of their condition and the use of SPIKES has been documented there (21). In Kerala, Narayanan et al have developed and used a simpler version (22), termed BREAKS (Background, Rapport, Explore, Announce, Kindling, Summarise).

### **Improving the quality of death**

Many attempts have been made to define a good death (23, 24) and perhaps it is better to accept a somewhat messy reality (25) as individuals and families come to terms with dying. The basic elements of individual control, dignity, privacy and pain/symptom relief should be available to all as a basic human right, consistent with the first principle of bioethics: the autonomy of the patient. Advance care planning (ACP) is the process by which individuals can align future medical care with their wishes and values, especially if and when they can no longer make decisions or communicate them. It is best seen as a dialogue that allows for an exploration of one’s priorities, especially as these relate to quality of life. These values are then translated into medical care plans and documented in written forms (“living will”) (26), and surrogates are appointed (“medical power of attorney”). The latter assume responsibility for implementing the documents. Optimally done, as the culmination of a series of conversations with the family and clinicians sometime towards the end of life, the ACPs are emotionally satisfying both to patients and caregivers (27). Not everybody is comfortable with the decision-making that this involves. For instance, some individuals are specific about making their own decisions for either altruistic reasons or a felt sense of personal autonomy. Others would prefer to leave the final choice to identified

surrogates by specifically transferring authority or by default (28). Also people's preferences may change over time, although one study found that the preferences are reasonably stable (29). Anecdotally, the will to survive may outlive the will to die with dignity (30). Another issue is that in specific circumstances, the patient's best interests may clash with their previously documented preferences (31). In the absence of a medico-legal framework this is uncharted terrain, even for those Indian physicians who are earnestly engaged in end-of-life care (EOLC). Once legislation is in place, we will probably find that in this regard, too, Indian exceptionalism is just another myth, as the human issues surrounding death are universal. Documentation and legal validity of EOLC would remain unclear without relevant laws.

### Understanding medical futility

The related question of medical futility and how to resolve disputes burst into attention in India in 2011 (32). Futility has been defined as excessive (in terms of effort and finances) medical intervention that has little prospect of altering the ultimate clinical outcome (33). The reference is to the case of Aruna Shanbaug, a nurse who was a victim of sexual assault and existed in a persistent vegetative state (PVS), meticulously maintained by the devoted attention of her former colleagues for over 40 years. A public interest litigation (PIL) in the Supreme Court of India (SCI) sought that she stop being fed and be allowed to die. The judges refused the plea and wrote a long judgment including a review of the Indian legal literature. The only definite contribution the judgment made was the explicit decriminalisation of the withdrawal of medical care in the specific circumstances of the PVS, given certain procedural safeguards. There was vague extrapolation to consider all forms of treatment withdrawal as "passive euthanasia", with a cursory reference to the current concepts of bioethics. As a consequence, the judges were led to prescribe an unrealistic pathway of resolving futility questions, whether disputed or not, by involving the local High Court. As expected, in four years, the Aruna Shanbaug case has not influenced even one death, not even her own! In the USA, most EOLC decisions are made at the bedside and disputes are resolved by empowered hospital ethics committees. It is only when local mediation fails that the courts are involved (34). A broad international consensus has evolved in the last decade on the definitions and ethical foundations of EOLC (35, 36). In most cases, the process is now part of standard medical decision-making which occasionally requires legal guidance and only rarely formal authorisation. The case of brain death is even more interesting. The general understanding in India is that brain death can be declared only when organ donation had been planned. Till the Aruna Shanbaug judgment, it was perceived without basis that if the deceased was not an organ donor, disconnecting life support could even attract murder charges. Since there is no case law and no explicit legal recognition of the equivalence of brain and circulatory death, this perception is widespread. The USA promulgated the Uniform Determination of Death Act in the late 1970s to legally recognise declaration of death by neurological criteria

(37). A joint international panel is collaborating with the World Health Organisation to develop a unitary concept that does not distinguish between brain and circulatory death (38). Even in India, the Organ Transplantation Act 1994 (assented to on July 8, 1994, Act No. 42 of 1994, Bill No. LIX-F of 1992) has already recognised the deceased state to be either cessation of brain or cardiac function. However, this fact needs to be made more explicitly known to medical professionals to alter the perceptions that govern our clinical practice.

### Keeping in step with change

India is developing and changing rapidly in many ways. The generation that came through Independence believed that their children would see to their end-of-life concerns. Decisions about EOLC are still largely a matter of a family consensus. However, within a few decades, joint families have given way to nuclear families and in the large cities, many people live alone. To understand how the balance between the individual and family/community is likely to change, it is necessary to take a look at some of the unexpected demographic dividends of rapid economic growth in our neighbourhood. East Asians are marrying later and fewer of them are marrying. In Japan and Hong Kong, about 20% of women between the age of 35 and 39 years are single and are expected never to marry. In China, it is projected that in two decades, 10% of men will not find brides as a consequence of the skewed sex ratio (39). Currently, less than 5% of Indians live alone, whereas single-person households already constitute 15% of households in China, 25% in South Korea and 35% in Norway (40). Indian society is deeply uncomfortable with individual choice, or what film-maker Anand Gandhi evocatively calls the "landscape of the individual" (41). To us, this is the fundamental barrier to evolving EOLC legislation. The term passive euthanasia sharpens this conflict with connotations of control outside the individual. The foundation of EOLC is preservation of autonomy irrespective of capacity. As one of us put it, "Animals are euthanised, but sentient human beings take charge of their own deaths." As Gandhi cogently argues, "The individual is the sole owner of the self (and is) entirely responsible for the self. We have to accept and establish that the law has no moral right whatsoever to legally interfere with the lifestyle, sexual, reproductive or death choices of informed, consenting adults, even if they are beyond the understanding of presumably well-intentioned state representatives."

The autonomy of the patient is the first principle of bioethics. Self-determination is fundamental to this autonomy. It cannot be emphasised enough that EOLC and ACP are both the right and the responsibility of the individual, well within the ambit of the Constitution of India. Within the next decade or two, more and more Indians will demand this constitutional right.

### Legal and social complexities

The title of this commentary is from an evocative blog by Jo Chopra, who speaks of the difficulties a Dehradun family faced in letting their mother die in peace at home (42). In 2010 and 2015 (43,44), the Quality of Death Report published by the

Economist Intelligence Unit rated India as having amongst the poorest EOLC amongst the major countries that it surveyed. We believe this is because of the lack of any legal framework, government support or community involvement. The only bright spot is the state of Kerala, thanks to the voluntary organisation, Pallium India, and the Neighbourhood Networks in Palliative Care project (43, p24). At the time of the Aruna Shanbaug judgment, one of us had hoped (32) that the Indian judiciary would evolve case law that could perhaps substitute for the lack of suitable legislation. That has not happened and as we have realised in the case of Article 377 (decriminalisation of homosexuality), the judges, too, carry the cultural biases of the Indian establishment. As late as 2012, the 241st Law Commission report (45) concluded that "living wills, whether written or oral, are controversial and can lead to mischief and, therefore, should be made legally ineffective, overriding the common law right of self-determination". This position implies that extraneous considerations would trump the citizen's fundamental right to autonomy and privacy in a decision on something so personal as his/her manner of dying. As in the Aruna Shanbaug case, this document quotes purely legal formulations, most of them dating back to two or even three decades ago. It is oblivious of the varied scenarios in EOLC, published professional guidelines or the existing bioethics literature, and makes no mention of even Beauchamp-Childress! (46). Obviously, checks and balances are in order, but to deny the patient's autonomy in so cavalier a fashion is unacceptable. Elements of this paternalistic attitude can be seen in the Rajasthan High Court judgment on *Santhara*, which has now reached the SCI. Not many are aware that voluntarily stopping eating and drinking is legally valid all across the USA (47). The Indian legal system already accepts the curious concept of "civil death" in the case of someone renouncing the world and taking *sanyasa*, as per Hindu religious tradition (48). Perhaps all that is required is the secularisation of *Santhara*, with safeguards to prevent misuse.

The Indian situation can best be understood as an evolving conceptual continuum in a matrix that incorporates medical capabilities, the legal situation and societal attitudes. At one extreme is a position that emphasises the sanctity of life with no reference to patients' rights. The other limit is a utilitarian argument based entirely on autonomy. To understand how this plays out in a given politico-cultural setting, it is instructive to consider two examples of the bioethics of death in two markedly different nations and political systems. The Netherlands and the People's Republic of China (PRC) are polar opposites. Physician-assisted death has been legal in the former since 2002, but with very strict safeguards. If the conditions are not met, the medical practitioner concerned can be charged with homicide (49). The Dutch are largely Christian Protestants/Lutherans (not Roman Catholics) and the country has been a parliamentary democracy since 1848. At the other extreme, in the last decade, the PRC had the world's highest rates of execution of "criminals" as well as of organ transplants. Supposedly most of those facing execution would offer their organs "as a present to society"! In a sting, a BBC journalist

was offered a liver for transplant from a scheduled execution for about 50,000 GBP (50). As a vigorous democracy under the rule of law, there is little doubt about the direction in which the Indian situation can and will evolve.

### Harbingers of reform in India

Some barriers to effective EOLC are obvious (51). Medical training, both here and worldwide (52), is focused on curative therapies and imparts little knowledge of palliative care and when to overlap or switch. The concept of the autonomy of the patient is weak among Indians in general. This is further compounded by the prevalent paternalism and low level of professional accountability. When limiting therapy, physicians here are often wary of being accused of providing suboptimal care and consequent criminal liability. So what is the way forward? Over the past few years, professional societies have filled some of the gaps with detailed guidelines for the responsible practitioner (13, 53). In its new edition, the National Accreditation Board for Hospitals has included proposals for EOLC quality assessment. In its Code of Ethics, the Medical Council of India proscribes euthanasia, but has made it clear that brain death is a valid reason for withdrawal of care, provided due process is followed (54). There is, however, no mention of DNR or WH/WD of treatment in contexts other than brain death. This position needs to be updated to include the current developments in bioethics. However, legal validation must also be aligned and there is thus no alternative to a comprehensive, forward-looking legislation that can serve both doctors and their patients in the coming decades. A PIL requesting such legislation has been pending with the SCI (Common Cause vs. The Union of India, Writ petition civil no. 215 of 2005) for a decade, to which the Indian Society of Critical Care Medicine (ISCCM) has filed an impleadment petition as a party respondent.

### The way forward: why we need an EOLC law

Ideally, EOLC legislation should arise out of a wide debate and a felt public need. However, it must also be recognised that India's diversity makes a nationwide conversation next to impossible. For example, it is unrealistic to yoke the self-financed medical choices of an urban, middle-class individual with those of a below-poverty-line rural villager who is often subject to brutal triage in India's grossly underfunded public health system. To us, it is self-evident that the various strands that we have alluded to make for a Gordian knot that can only be cut through by legislation. On August 15, 2015, three medical societies – the Indian Academy of Neurology, the ISCCM and the Indian Association of Palliative Care – came together to try and evolve such a law and to push for having it debated and passed by Parliament. This law would have the following basic components: (i) uniform recognition of death, including death by neurologic criteria; (ii) legal validation of ACP, including living wills and medical power of attorney; and (iii) the establishment of due process for resolving medical futility and WH/WD treatment issues. This law would then allow responsible and willing citizens to take charge of their last days.

The law would have built-in and adequate safeguards against misuse. It would be simple and applicable in all systems, public and private. It would enable the good doctor to give morally and ethically sound end-of-life and palliative care without fear of litigation. The field of palliative medicine would be able to develop India-specific protocols and processes. Far more importantly, the law would help evolve public, professional and personal attitudes to the many choices and shared decision-making that must define medical care at the end of life. Such a law would allow Indians to begin having those necessary conversations with each other about death and dying, well before Yama comes calling!

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## Passive euthanasia in India: a critique

ROHINI SHUKLA

### Abstract

*Given its preoccupation with the doctor's agency in administering euthanasia, the legal discourse on euthanasia in India has neglected the moral relevance of the patient's suffering in determining the legitimate types of euthanasia. In this paper, I begin by explicating the condition for the possibility of euthanasia in terms of the following moral principle: the doctor ought to give priority to the patient's suffering over the patient's life. I argue that the form of passive euthanasia legally permissible in India is inconsistent with this moral principle, owing to the consequences it entails for the patient.*

*Inevitably, it is acts of commission on the part of the doctor that can provide the best possible death, which is the moral objective of euthanasia. To meet this objective, doctors must be seen as agents who possess the moral integrity and technical expertise to judge when and how the patient's life ought to be terminated,*

*depending on the patient's medical condition. They are not bound to save lives and provide care unconditionally.*

### Introduction

For over 40 years – precisely 41 years and 173 days, for not a moment of suffering ought to be discounted, Aruna Shanbaug remained locked up in ward number 4 of KEM hospital, Parel, Mumbai. Her struggle to die ended on May 18, 2015. The absence of bed sores on Aruna's dying body was celebrated and the nurses' tremendous "attachment" to her was much exalted. All this, despite the bitter fact that Aruna lived a life, to use Peter Singer's words, "so miserable as not to be worth living" (1).

In March 2011, owing to Pinky Virani's indefatigable efforts, the Supreme Court of India deemed passive euthanasia legal. A detailed discussion of the different ways of implementing passive euthanasia is due, given the equivocality of the term in the legal document. I hope to throw some light on several inconsistencies in the verdict's arguments in favour of passive euthanasia (and against active euthanasia). Beyond the legal debates that ensued, euthanasia needs serious moral reflection in India.

We seem to intuitively understand that the pain of aching knees is qualitatively different from the pain of chronic cancer,

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paralysis or coma. Perhaps it is impossible to analyse and define what this difference really is, both in medical and moral terms. Despite this ambiguity, the medical fraternity must deal intimately with pain – by studying its causes as well as the preventive, curative and healing measures, by treating it and by simply witnessing it. By virtue of their profession, are doctors morally obliged to “care” for patients, “heal” their pain and thereby, sustain their lives “unconditionally”? It is important to note at the outset that the discourse on euthanasia begins by answering this question in the negative; thence follows another, more perplexing question. What are the morally permissible methods of implementing euthanasia, given that the patient is certain to die a slow and painful death because of her/his irreversible medical condition (like that of Aruna)?

In this paper, I begin by explicating the condition for the possibility of euthanasia in terms of the following moral principle: the doctor ought to give priority to the patient’s suffering over the patient’s life. I argue that the form of passive euthanasia that has been legally permissible in India since 2011 is inconsistent with this moral principle, owing to the consequences it entails for the patient. Inevitably, it is acts of commission on the part of the doctor that can provide the best possible death, which is the moral objective of euthanasia. In order to meet this objective, doctors must be seen as agents who possess the moral integrity and technical expertise to judge when and how the patient’s life ought to be terminated, depending on the patient’s medical condition.

### **Moral integrity and euthanasia**

Imagine a reckless doctor, who does not care whether her/his patients die or continue to live in pain. S/he will neither take responsibility for the consequences of her/his actions, nor will s/he feel morally implicated if the patient expresses her/his wish to die. Regardless of whether doctors perceive their decisions as morally fraught however, they remain moral agents because their actions (commissions and omissions alike) affect the patient’s condition in some way or the other. Taking as a given the essential moral agency of the doctor, whether reckless or otherwise, we must begin by inquiring into what makes euthanasia an ethical dilemma in the first place.

Euthanasia presupposes what Dhanvanti Nayak and Sundar Sarukkai call “integrity”(2) in medical practice and discourse. A person with moral integrity, unlike our imagined reckless doctor is “one who sticks to her/his principles despite other pressures and temptations” (2).The important question then is: what are the moral principles implicit in euthanasia that guide the actions of doctors with integrity? The etymology of euthanasia does not make any such principle explicit, for it leaves unanswered the practical question of how an easy and painless death is to be delivered.

The fundamental moral principle – fundamental in the sense that it is the very condition for the possibility of euthanasia as a medical practice – is that the patient’s suffering ought to be prioritised over the patient’s life. In this sense, the concept of euthanasia stands as an exception in medical discourse; the

patient’s aliveness is presupposed by the effectivity of medical treatment, but with respect to euthanasia, there is an intended reversal. Euthanasia considers the act of ending life to be the treatment, for it alone leads to the end of suffering desired by the patient. Life is not presupposed but surrendered, to make the treatment possible. It is important to note that the irreversibility of the patient’s condition is central to this reversal. As we will see, this moral principle of prioritising the patient’s suffering over the patient’s life, given the irreversibility of her/his medical condition, provides effective guidelines for deeming only certain ways of implementing euthanasia morally legitimate.

Let us begin by revisiting some of the arguments made in the 2011 verdict that legalised passive euthanasia in India.

### **Revisiting the 2011 verdict**

In 2011, the verdict of the Supreme Court bench comprising Justices Markandey Katju and Gyan Sudha Misra distinguished between active and passive euthanasia in the following manner.

*Active euthanasia entails the use of lethal substances or forces to kill a person, eg a lethal injection given to a person with terminal cancer who is in terrible agony. Passive euthanasia entails withholding of medical treatment for continuance of life, eg withholding of antibiotics where without giving it a patient is likely to die, or removing the heart lung machine, from a patient in coma (3).*

Besides making a deliberate attempt to debase active euthanasia by using words such as “force” and “kill”, the verdict is flawed on two serious counts regarding the distinction it makes between active and passive euthanasia. First, no distinction is made between the different types of passive euthanasia. Throughout the document, the words “withholding” and “withdrawing” are used interchangeably. There is, however, a subtle difference between the two, which is relevant to the larger distinction between active and passive euthanasia. Withholding life support implies that crucial medical intervention is restrained, for example, not performing a kidney transplant when it is necessary for the patient’s survival. This would involve acts of omission on the part of the doctor. Withdrawing life support, on the other hand, implies suspending the medical intervention that is already operative to sustain the patient’s life. This would involve acts of commission; in Aruna’s case, the legal document acknowledges that withdrawing medical intervention would include stopping food supply. We must note that the doctor is fully aware of the fact that death is a highly likely consequence of withholding or withdrawing medical support.

Now, if the criterion for distinguishing passive from active euthanasia is the doctor’s agency, that is, if in passive euthanasia the doctor only passively commits acts of omission, while in active euthanasia the doctor actively commits acts of commission, then withdrawing medical treatment would be a

form of active and not passive euthanasia. In the section titled "Legal Issues: Active and Passive Euthanasia", the verdict focuses on the question of the doctor's agency in distinguishing between active and passive euthanasia. This is evident in the crude analogy drawn between a doctor conducting passive euthanasia and a person who is (merely) witnessing a building burn. Passive euthanasia as per the verdict is equivalent to "simply not saving" (3) the patient, which is presumably morally unproblematic because failing to save is "normally" (3) not condemned, whereas killing is. By implication, just as a person who is watching a building burn, and is not actively saving trapped people cannot be prosecuted "for failing to save a life," (3) a doctor cannot be prosecuted for failing to save the patient after medical support has been withdrawn or withheld.

The point is if the doctor's being an active agent in performing euthanasia is the reason for condemning active euthanasia, then the same reasoning deems passive euthanasia as defined in the verdict condemnable. How then does the verdict claim that passive euthanasia is morally justifiable, while active euthanasia is not?

In both cases, the doctor is aware that her/his omissions or commissions will in all likelihood lead to the patient's death. One can never predict with indubitable certainty that death will be the only consequence in passive euthanasia, and as we will see, this uncertainty makes defending passive euthanasia all the more problematic; nevertheless, the likelihood is crucial. The verdict, rather conveniently, sidesteps discussing the moral relevance of the difference between active and passive euthanasia in terms of the doctor's agency (which is highlighted elsewhere in the verdict through the analogy mentioned above). Instead, the verdict holds that only the latter is morally justifiable based on a dubious deontological claim that in passive euthanasia the doctor's intention is to continue the patient's life, rather than to end it intentionally. Now, if the intention of the doctor is to continue the patient's life, then why should s/he withhold or withdraw medical treatment as a kind of euthanasia?<sup>1</sup> Besides if the moral justifiability of passive euthanasia is based on the doctor's wishing to continue the patient's life, then it is not a form of euthanasia at all. Since euthanasia implies that the doctor intends to deliver the best possible death for the sake of releasing the patient from suffering, then by virtue of the doctor's intention to continue the patient's life, that particular treatment ceases to be euthanasia.

Interestingly, the verdict discusses physician-assisted suicide or "physician-assisted killing" (3) very briefly, without attempting a moral evaluation. The laws allowing physician-assisted suicide operative in the Netherlands, Switzerland, Belgium and the American states of Washington, Oregon and Montana are reviewed in the verdict, but only in a sketchy manner. The verdict dismisses physician-assisted suicide as irrelevant to the discussion of euthanasia in India because Section 309 of the Indian Penal Code considered any form of suicide a criminal offence in 2011.<sup>2</sup>

The second, and to my mind, the most crucial flaw in the legal discussion about the types of euthanasia is reflected through what is considered the most persuasive argument against passive euthanasia. The patient slips far into the background, and it is as if the effects of euthanasia on everyone but the patient are important.

*In case hydration or food is withdrawn/withheld from Aruna Ramchandra Shanbaug, the efforts which have been put in by batches after batches of nurses of KEM Hospital for the last 37 years will be undermined. Besides causing a deep sense of resentment in the nursing staff as well as other well wishers of Aruna Ramchandra Shanbaug in KEM Hospital including the management, such acts/omissions will lead to disheartenment in them and large scale disillusionment (3).*

This reasoning is followed by absurd claims and sweeping generalisations, such as "Indian society is emotional and care-oriented"(3) and the "unfortunate low level of ethical standards to which our society has descended, its raw and widespread commercialisation, and the rampant corruption" (3) is lamented.

Owing to an undeserved preoccupation with the doctor's agency in administering different types of euthanasia, the verdict ignores the two most fundamental ethical concerns of euthanasia, the patient's suffering, and the moral principle that guides the doctors' integrity in treating such suffering. If the doctor is to maintain her/his integrity, the patient's suffering must be accorded priority over the patient's life, which in turn, needs to be given priority over the doctor's agency. Only then can the different types of euthanasia be evaluated in terms of which method is best suited for a particular patient's medical condition. For instance, a patient who has cancer of the digestive tract cannot swallow the lethal drink, so the lethal injection would perhaps be the best way of carrying out euthanasia. If, on the other hand, a patient is paralysed, or is unable to inject her/himself for other reasons, then the lethal drink might be better suited.

### **Passive euthanasia: is it really euthanasia?**

Going back to the question of passive euthanasia, one may ask, what happens to a patient when medical support is withheld or withdrawn? This remains an important question because, despite the inconsistencies in the arguments put forward by the verdict, passive euthanasia is the only way to legally administer euthanasia in India. The 2011 verdict considered Aruna's case as the model case to evaluate the morality of euthanasia. She was partially brain dead and in all significant aspects, could be said to have been in coma (6).<sup>3</sup> Withholding life support was not possible in her case, because KEM hospital had been providing her medical support for about 42 years. Withdrawing medical support was the only option, and if it had been done, Aruna would have, in all likelihood, suffocated to death, or died after suffering in other excruciating ways. Thus, passive euthanasia would have led to an unnecessary amplification of her pain for an indeterminate period of time. In what way could this

be the best possible death? And how would it uphold the moral principle of prioritising the patient's suffering over her life? Had the Supreme Court taken into account these consequences of passive euthanasia for the patient, perhaps active euthanasia and physician-assisted suicide might have seemed worthy of more than a quick dismissal.

Since Aruna was unable to communicate there would have been no scope for us to know what she went through had medical support been withdrawn. The case of Cody Curtis (4) will help us understand better. Cody was diagnosed with liver cancer. Despite multiple operations and regular medications, she suffered a relapse and at the age of 52, she expressed the wish to discontinue living. At first, she thought she would allow life to take its natural course by asking for medical support to be withdrawn, and instead of killing herself artificially by drinking the lethal drug, she preferred to just "slowly drift off" (5). But she realised eventually that drifting off by allowing nature to take its course was too unbearable to live through. Her body was dependent on an equivalent of 10 mg of intravenous morphine per hour, for three weeks, and yet she was unable to bear the pain. She revised her decision and opted for physician-assisted suicide, using Oregon's Death with Dignity Act.

One's decision to opt for euthanasia is not solely based on the present experience of pain; it is made in anticipation of a miserable death. The verdict does not acknowledge the value of legalising euthanasia to give patients who are chronically ill (like Cody Curtis) and older patients, who fear slipping into a state in which they would be unable to communicate the kind of death they desire, the security of dying with dignity. Euthanasia allows patients to gain control over the way death occurs when medical conditions pose a real threat to their future well-being. Passive euthanasia, however, owing to its consequences for the patient, fails to confer such control.

### Concluding remarks

Notwithstanding the verdict's arguments in favour of passive euthanasia, acts of commission on the part of doctors are

inevitable, if the best possible death is to be provided. Only if the patient's suffering is prioritised over the patient's life, would it become clear that passive euthanasia defeats the very purpose of euthanasia by unnecessarily prolonging a miserable life till death finally takes over. We need to abandon the overwhelming preoccupation with the doctor's agency in administering euthanasia, to ensure that euthanasia is not reduced to another way of dying in misery.

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### Notes

- <sup>1</sup> The verdict is not consistent regarding what the doctor's intention is in performing passive euthanasia. To begin with it says the intention is "continuance of life" (3) and later it says, "Passive euthanasia is usually defined as withdrawing medical treatment with a deliberate intention of causing the patient's death" (3).
- <sup>2</sup> Suicide was decriminalised in 2014.
- <sup>3</sup> For a detailed description of Aruna's medical condition, see: Virani Pinky. *Aruna's story: the true account of a rape and its aftermath*. Pune: Penguin Books; 1998. 18-84 pp.

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## Aruna Shanbaug and the right to die with dignity: the battle continues

RR KISHORE

### Abstract

*Aruna Shanbaug's protracted continuance in a persistent vegetative state (PVS) for nearly 42 years needs to be viewed*

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*seriously by all those who believe in a person's inalienable right to dignity in dying. A terminally ill and/or incapacitated individual is a helpless person confronted with perpetual risk of intrusion in to his autonomy by the moral paternalists, owing to false notion of human virtues. Legislative inadequacy coupled with judicial heterogeneity has exposed the decision making process to unwarranted ambiguity. Misapplication of moral and juristic principles is a global challenge. 29-year-old Brittany Maynard's recent act of ending her life by migrating from California to Oregon has ignited a fierce debate and nearly half of the states*

*in the USA are contemplating enactment of death with dignity legislation. Across the Atlantic, the European Court of Human Rights judgment on June 5, 2015, endorsing Vincent Lambert's right to end medical support, is a resounding affirmation of an individual's right to die with dignity. This article is an attempt to explore various dimensions of one's right to dignity in dying, in the global as well as the Indian context*

## Introduction

After being in a persistent vegetative state for nearly 42 years Aruna Shanbaug died of pneumonia, on May 18, 2015, in King Edward Memorial Hospital, Mumbai where she had worked as a nurse until 1973. Earlier, an attempt to terminate her life remained unsuccessful as the Supreme Court of India, on March 7, 2011, rejected the petition filed by Ms. Pinki Virani, a journalist claiming to be Shanbaug's next friend, praying for directions to stop feeding Shanbaug as it amounts to continuing "her existence in sub-human condition" which "violates her right under Article 21 of constitution of India to live with dignity" (1). The rejection notwithstanding, the Court's verdict was a landmark decision in the Indian context as the Court, for the first time accepted a person's right to assisted dying and recognised another person's authority to act as surrogate on behalf of an incapacitated individual. However, in practical terms, the decision did not offer much relief to many persons suffering from unbearable and irreversible agony due to terminal and incurable illness and waiting for assistance in dying. The Court, in effect, allowed only non-voluntary passive euthanasia ie withholding or withdrawal of life support in case of patients who are terminally ill and unable to consent due to loss of cognitive abilities, which too was made subject to mandatory approval by the High Court concerned. The consent of the individual and the medical opinion supporting the withholding or withdrawal of life support are not treated as final determinants.

Before Aruna Shanbaug, during the last four decades, four young women, Karen Ann Quinlan [1976] (2), Nancy Cruzan [(1990)] (3) Terri Schiavo [2005], (4) and Eluana Englaro [(2008)] (5) have been the subject of intense debate and long judicial campaigns concerning their right to end of life. In order to avoid lengthy and arduous judicial battle, on November 1, 2014, 29-year-old Brittany Maynard, suffering from glioblastoma moved from California to Oregon to take advantage of Oregon's Death with Dignity Law, (6) and ended her life saying that "death with dignity was the best option for me and my family." (7)

From Karen Quinlan [1976] (2) to Lee Carter [2015] (8) there have been numerous judicial pronouncements recognising one's right to assistance in dying by the Courts in the USA, UK, Canada, Australia, France, Italy, Germany, Switzerland and European Court of Human Rights and certain jurisdictions such as the Netherlands, Belgium and Luxembourg in Europe and the states of Oregon, Washington and Vermont in the USA have also enacted distinct legislations to regulate the process of assisted dying but the jurisprudence with regard

to end of life decisions continues to be hazy. This is partly because the operational spectrum of assisted dying includes several acts of omission and commission on the part of several players such as the individual, family members, physician, administrators and policymakers, each having his/her own imperatives, priorities and stakes. Furthermore, the values and moral perceptions differ according to cultural, religious, political and socio-economic milieu, making unanimous paradigms difficult.

In this article, I try to define death with dignity, discover its core values, explore the arguments for and against assisted dying, provide a glimpse of legislative strategies and judicial decisions across the world, go through the emerging voices and offer a brief account of the Indian scenario. I conclude that the right to end life is inherent in one's right to self-determination. In the practical context, end of life decision making is a multidimensional exercise involving a wide range of disciplines, including religious, cultural, economic, moral, ethical and legal perspectives. In such a pluralistic milieu, legislative wisdom provides better resolution than judicial deliberation. It is therefore imperative that comprehensive and fine-tuned legislative strategies are evolved in order to concretise a person's right to die with dignity.

## Core values and conflicting arguments

Controversy about a person's right to end his life is not new. The debate has been "ranging from Plato and Aristotle in ancient Greece to Augustine and Thomas Aquinas in the Middle Ages, and Hume and Kant in the more modern times" (9). Plato found suicide disgraceful but he made several exceptions including the self-killing "compelled by extreme and unavoidable personal misfortune" (10) Aristotle concludes that self-killing does not treat oneself unjustly so long as it is done voluntarily because the harm done to oneself is consensual (11). The Roman Stoic, Seneca, claimed that since "mere living is not a good, but living well", a wise person "lives as long as he ought, not as long as he can." (12) Thomas Aquinas disapproved self-killing "because it injures other people and the community of which the individual is a part; and because it violates God's authority over life, which is God's gift." (13, 14, 15)

In the modern context, the act of assistance in dying may manifest itself in various forms such as killing by physicians by administering deadly drugs, withdrawal of nutrition and/or life sustaining medical treatment, withholding of nutrition and/or life sustaining medical treatment and non-persuasion to take nutrition and/or life sustaining medical treatment. The moral and legal discussion concerning assisted dying, therefore, revolves around the core values such as love, trust, compassion, autonomy, sanctity of life, human dignity, rationality and equity. At the core of the argument supporting assisted suicide are the twin goals of maximising individual autonomy and minimising human suffering. Autonomy is a long cherished concept found in moral, political and bioethical philosophy. It is the capacity of a rational human being to exercise his/her self-determination,

free from external authority and influences. At times, self-governance may appear to be tainted with subjectivity and the acts of a self-directing individual may be disagreeable to others. But, we ought to realise that others cannot impose their norms, standards and choices to define and regulate the sufferings of an individual. Concepts of dignity vary from person to person. What may be dignified to one may appear to be false or hypocritical to others. To many, the British Supreme Court's decision to withhold life sustaining treatment from "a gravely ill man" (16) as being in his best interest, may appear to be an expression of excessive judicial paternalism. To others, it may appear a pragmatic judicial approach founded in the imperatives of individual and societal good.

For the proponents, the most compelling reason for providing assistance in dying is love and compassion. It is for this reason that the request for assistance in dying has come in the case of several incapacitated individuals from the closest family member, namely parents or spouse, not from any distant relative or some other person acting as guardian. In the UK, in Anthony Bland's case (1993), the parents requested withdrawal of life support from their son who was in a persistent vegetative state (PVS) (17). In Robert Wendland's case, his wife Rose sought intervention to get his feeding tube removed (18). In the case of Eluana Englaro, an Italian woman, who entered into a persistent vegetative state following a car accident, her father requested that her feeding tube be removed and she be allowed to die "naturally" (19). In the case of Terri Schiavo, a resident of Florida, in PVS following respiratory and cardiac arrest, her husband Michael filed a petition to remove her feeding tube (4). In France, in the case of Vincent Humbert, a mute and blind quadriplegic, his mother Marie Humbert campaigned for her crippled son's right to die and having failed in her efforts, she attempted to kill her son with an injection of barbiturates, which sent him into a coma which was followed by switching off his life support by Dr Frederic Chaussoy leading to his death (20). Such compassion is a response to the intensity of suffering of a loved one and it overtakes the desire to keep the loved one alive. There are occasions when assistance in dying is the most humane act that can be performed by those who are responsible for care of their loved ones. However, some continue to argue that assistance in dying "denies the inherent value of humanity and of human life by trading life for comfort." (21).

Undoubtedly, the State possesses an essential interest in the preservation of life of its citizens. Based on this interest attempted suicide or assistance in suicide is an offence in many jurisdictions. However, the State's interest needs to be balanced against a person's right to refuse medical treatment or to have treatment withdrawn. As early as 1905, the US Supreme Court had balanced an individual's liberty interest in declining an unwanted smallpox vaccination against the State's interest in preventing disease. (22) This has been followed by several other decisions. As such, a person's right not to be subjected to medical intervention outweighs the State's interest in the preservation of life. While the State's interest lies in the preservation of life of its citizens, the individual interest

is best served by freedom of choice and non-violation of privacy. Viewed in the context of equity too, one may not find it wise to continue the life sustaining treatment of a person, endlessly. In a world where even primary health care is not available to millions of people, and even safe drinking water is a luxury in certain parts, how far is it equitable to spend resources on prolonging the life of a person in an irreversible vegetative state? According to some estimates, "Expenditure at the end of life seems disproportionately large" (23). "Out of every four Medicare dollars – over \$ 125 billion – is spent on care near the end of life, and the financial burden on families can be staggering" (24). "About 25 per cent of all health-care costs are devoted to the caring of patients in the last year of life" (25) and "the high cost of dying" is emerging as an area of concern for healthcare policy makers (26). We ought, however, to appreciate that fast advancing biotechnology, growing institutionalisation of healthcare and increasing material value of the human body has imparted new dimensions to end of life issues, contemplating a delicate balancing of individual and societal perspectives. Decisions regarding prolongation and termination of life are now linked to the imperatives of necessity. At times, the dictates of utility may reduce continuance to futility. Such an apprehension is not unfounded when we see the recent debate about the healthcare reform legislation in the United States, initiated by President Barak Obama, wherein the old, infirm and chronically ill are being targeted as the main consumers of healthcare budgets. There are scholars who feel that the "potential for costs to spiral out of control is particularly acute with regard to life-extending interventions for the elderly." (27). Viewed in a wider context, "only a state or society or community in which all necessary medical attention was absolutely guaranteed to all—and in which, therefore, anyone ever seeking to extend his or her life to the last instant of bare existence would be both entitled and able to do so—could be said to bring a practical rationality to the ethical principle of "always to care." (28).

The debate notwithstanding, there may be times in one's life when the decision to die may provide the greatest relief and it may be the most dignified act of her/his life. There are occasions when dying provides an acceptable resolution to unending suffering. The German philosopher Friedrich Nietzsche was perhaps closest to the reality when he wrote, "There is a certain right by which we may deprive a man of life, but none by which we may deprive him of death" (29).

### Legislative strategies

The issue of assistance in dying is inherently complex and formulation of legislative strategies is a challenging task. Several vital questions need to be addressed such as:

1. When is a person dead?
2. If a brain-dead person is treated as dead, at what point of time can the life support system be withdrawn?
3. Does a person have a right to choose the time and manner of his death?.
4. How can one ensure that the desire to die is truly informed and free from extraneous considerations?

5. Who is competent to take a decision on behalf of a brain-dead individual?
6. How can one determine the best interests of an incapacitated individual?
7. How can it be ensured that the process of assisted dying is not abused?
8. Who will take a decision on behalf of an unborn child of a pregnant woman in PVS?
9. In the event of conflicting maternal-fetal interests, whose interest should prevail?

The intricacies notwithstanding, the compelling nature of the issue of dying with dignity has prompted certain jurisdictions to evolve suitable legislative strategies. The legislations are based on the common law doctrines, national constitutions, judicial pronouncements and international covenants such as the Universal Declaration of Human Rights, the European Convention on Human Rights, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. The legal foundations of one's entitlement to assisted dying can be traced to the right to autonomy which includes informed consent, privacy, right to refuse medical intervention, right to religious freedom and right to dignified death; and all these perspectives are reflected in the legislative enactments. The Netherlands, (30) Belgium (31) and Luxembourg (32) in Europe; and the states of Oregon (6) Washington (33) and Vermont (34) in the USA, have enacted legislations to regulate the process of assisted dying. In two US states, namely Montana (35) and New Mexico (36) the process has been legitimised by judicial mandate. In Switzerland, although there is no separate law on euthanasia, article 115 of the Swiss Criminal Code, 1942, provides that: "Any person who for selfish motives incites or assists another to commit or attempt to commit suicide shall, if that other person thereafter commits or attempts to commit suicide, be liable to a custodial sentence not exceeding five years or to a monetary penalty." Consequently, assisting suicide is a crime only if the motive for doing so is selfish such as personal gain, and this protects those providing assistance to any person in the act of dying. Swiss law only allows for providing the means to commit suicide, and the reasons for doing so must be altruistic.

In France, the Patients' Rights and End-of-Life Act (number 2005-370)15 was passed into law by a unanimous vote on April 22, 2005. "The law's major provision concerns conditions that define and authorise passive euthanasia practices. Withholding and withdrawing of "all treatment" (including artificial hydration and nutrition) is not only legal and morally unproblematic but even obligatory when treatment amounts to "unreasonable obstinacy," that is, when "treatment appears as useless, disproportionate, or having the sole effect of artificially sustaining life" (Article L 1110-5 du CSP al. 2)." (37).

The major perspectives reflected in the legislations are presence of terminal and/or incurable illness, a bonafide patient-physician relationship, the patient's best interest, the patient's unimpaired judgment and valid consent, a legitimate surrogate decision maker in case of incapacitated individual, freedom from undue influence and absence of abuse.

In the UK, the Commission on Assisted Dying under the Chairmanship of Lord Charles Falconer published a Briefing Paper, in January 2012, entitled "The effectiveness of legal safeguards in jurisdictions that allow assisted dying," by Penney Lewis and Isra Black. The briefing paper identifies "eight categories of safeguard that are used in jurisdictions that permit assisted dying and specifies how each of these safeguards is applied in the Netherlands, Belgium, Oregon and Switzerland. These categories are: the type of assistance; the person's condition and/or experience of suffering; making the request for assistance; the age of the person requesting assistance; consultation and referral requirements; the identity of the assistor; due medical care; and the reporting and scrutiny of cases." (38).

Different jurisdictions have adopted different methodologies to achieve the above objectives. The biggest challenge arises while determining the best interest of an incapacitated patient. One may feel that a person suffering from terminal and incurable illness, with loss of cognitive abilities, may be best served by withdrawing life sustaining treatment. This will give him freedom from misery, distress and indignity. But, this is just one view. There can be another view, namely, that shortening life is no solution. The effort should be to ameliorate a patient's suffering by providing the best possible medical care, not by withdrawing life support because elimination of pain, not the person, is the goal. As such, best interest may be interpreted either way. It is a matter of individual choice. In this context, it may be enlightening to note what the Supreme Court of New Jersey said in Karen Ann Quinlan's case (2).

*"We have no doubt ... that if Karen were herself miraculously lucid for an interval (not altering the existing prognosis of the condition to which she would soon return) and perceptive of her irreversible condition, she could effectively decide upon discontinuance of the life-support apparatus, even if it meant the prospect of natural death."*

Since it is not practicable to give a detailed account of all the legislations in this article, some reflections may suffice. The Oregon Death with Dignity Act 1997, the first legislation in the world to permit terminally ill patients to determine the time of their death, permits a capable adult Oregon resident to request his or her physician to write a prescription of a lethal dose of medication for the purpose of ending his/her life, subject to the following conditions:

- The person has been diagnosed, by a physician, with a terminal illness that will kill the patient within six months
- The request is confirmed by two witnesses, at least one of whom is not related to the patient, is not entitled to any portion of the patient's estate, is not the patient's physician, and is not employed by a health care facility caring for the patient.
- After the request is made, another physician must examine the patient's medical records and confirm the diagnosis.
- The patient must be determined to be free of a mental condition impairing judgment.

- If the request is authorised, the patient must wait at least fifteen days and make a second oral request before the prescription may be written.
- The patient has a right to rescind the request at any time.
- Should either physician have concerns about the patient's ability to make an informed decision, or feel the patient's request may be motivated by depression or coercion, the patient must be referred for a psychological evaluation.

Similarly, in the Netherlands, the Termination of Life on Request and Assisted Suicide (Review Procedures) Act which took effect on April 1, 2002, legalises euthanasia and physician-assisted suicide in very specific cases, under very specific circumstances. The law allows a medical review board to suspend prosecution of doctors who performed euthanasia when each of the following conditions is fulfilled:

- the patient's suffering is unbearable, with no prospect of improvement
- the patient's request for euthanasia is voluntary and persists over time (the request cannot be granted when under the influence of others, psychological illness or drugs)
- the patient must be fully aware of his/her condition, prospects and options
- there must be consultation with at least one other independent doctor who needs to confirm the conditions mentioned above
- the death must be carried out in a medically appropriate fashion by the doctor or by the patient, in which case the doctor must be present
- the patient must be at least 12 years old (patients between 12 and 16 years of age require the consent of their parents)

A regional review committee assesses whether a case of termination of life on request or assisted suicide complies with the due care criteria. Depending on its findings, the case will either be closed or, if the conditions are not met, brought to the attention of the Public Prosecutor.

### Judicial decisions across the world

From Karen Quinlan [1976] (2) to Lee Carter [(2015) (9)] there have been several judicial pronouncements by the apex Courts across the world on one's right to end his/her life. However, despite in-depth judicial deliberations during the last four decades, the issue continues to reflect heterogeneous approaches. It may be worthwhile to quote some of the decisions of the courts in the USA, Canada, the UK, Ireland, Switzerland, France, Germany, Italy, the European Court of Human Rights, and Australia.

### Unites States of America

The Supreme Court of New Jersey, in Karen Ann Quinlan's case in 1976, was the first to hold that the right to privacy includes a patient's right to refuse medical treatment in some situations. The New Jersey Supreme Court ruled that "Karen's

right of privacy may be asserted on her behalf by her guardian under the peculiar circumstances here present." (2) In 1977, the Supreme Court of Massachusetts in *Superintendent of Belchertown State School v. Saikewicz* upheld a person's right to refuse medical treatment under the common law right to informed consent, as well as on the basis of a constitutional right to privacy(39). In 1980, the Supreme Court of Florida in *Satz v. Perlmutter* ruled that a competent adult patient, with no minor dependents, suffering from a terminal illness has the constitutional right to refuse or discontinue extraordinary medical treatment where all affected family members consent (40). In 1981, in *re Storar*, the court in New York upheld a person's right to refuse medical treatment under the common law right to informed consent(41). In 1986, in *Brophy v. New England Sinai Hospital*, the Supreme Judicial Court of Massachusetts held that the "State's interest in the preservation of life does not overcome [the patient's] right to discontinue treatment," and that such a position is not contrary to the "State's interest in the prevention of suicide."(42).

The US Supreme Court, in 1990, in *Cruzan v. Director MDH*, while interpreting the Due Process Clause, held that "a competent person has a constitutionally protected right to refuse lifesaving hydration and nutrition" (3). The Supreme Court of Massachusetts, in a case of a competent adult who was a Jehovah's Witness and a mother of a minor child, ruled that the patient had the right to refuse to consent to the blood transfusion even though such refusal would, in all probability, lead to her death due to haemorrhage (43).

In a momentous pronouncement the Supreme Court of the United States, on June 26 1997, in *Vacco v. Quill*, issued a unanimous (9-0) decision holding that a New York ban on physician-assisted suicide was constitutional, and preventing doctors from assisting their patients even those terminally ill and/or in great pain, was a legitimate state interest that was well within the authority of the state to regulate (44).

In 2001, in *Wendland v. Wendland*, the California Supreme Court ruled that the wife of a physically and mentally disabled person lacked the legal authority to refuse tube feedings on her husband's behalf, in the absence of durable power of attorney for health care, because the constitutional right to life and right to privacy required that the incompetent person receive special protection.(18)

In the case of Florida resident Terri Schiavo, who was in a PVS, the Supreme Court of Florida, on a petition filed by her husband Michael Schiavo, struck down the Florida legislation and ruled to disconnect Terri Schiavo from life support, despite opposition from Terri's parents. After a prolonged legal battle, lasting seven years, Terri Schiavo's feeding tube was removed on March 18, 2005, and she died on March 31, aged 41 years (45).

In 2006, the United States Supreme Court, in *Gonzales v. Oregon*, ruled, by a 6-3 decision, that the United States Attorney General could not enforce the federal Controlled Substances Act against physicians who prescribed drugs, in

compliance with the state law namely, the Oregon Death with Dignity Act for the assisted suicide of the terminally ill (46).

The Supreme Court of Montana, on December 31, 2009 upheld the Helena District Judge Dorothy McCarter's decision of December 5, 2008 in favour of Robert Baxter, holding that assisted suicide is an acceptable defense to any homicide charges against the doctor. Justice William Leaphart writing for the Court, stated, "In physician aid in dying, the patient, not the physician, commits the final death-causing act by self-administering a lethal dose of medicine." Robert Baxter, who was diagnosed with leukemia 12 years ago, died of lymphoma on December 5, 2008 — the day McCarter issued her ruling (34).

On January 13, 2014, Ms Nan G Nash, judge of the 2<sup>nd</sup> District Court in Albuquerque, New Mexico, ruled that terminally ill residents have a constitutional right to obtain "aid in dying." The judge said, "This court cannot envision a right more fundamental, more private or more integral to the liberty, safety and happiness of a New Mexican than the right of a competent, terminally ill patient to choose aid in dying." With this pronouncement, New Mexico becomes the fifth state in the USA to allow doctors to prescribe fatal drugs to terminally ill patients in order to end their lives. (47).

On January 24, 2014, a judge in Texas, directed a hospital not to keep Ms Muñoz, a brain-dead pregnant woman, on life support against her family's wishes. Ms Muñoz, 33, was 22 weeks pregnant and had been on life support since November, 2013. The Texas law bans abortion after 20 weeks of pregnancy. However, the judge ignored the state's compelling interest in protecting the unborn children, as reflected in the Texas legislation which treats an unborn child as alive "at every stage of gestation, from fertilization until birth." The judge said the law did not apply to Ms Muñoz because she was dead (48).

### **United Kingdom**

The House of Lords, in 1992, *in Re T*, held that "if a patient, while competent and properly informed about the consequences of refusing or agreeing to treatment (in the circumstances of his or her present condition) had given a clear direction, then that direction is binding (49). In 1993, in the case of Anthony Bland who was in a persistent vegetative state, the House of Lords held that in making the decision whether or not to provide medical treatment, the question to be asked is whether it is in the best interests of the patient that his life should be prolonged. The previously expressed wishes of the patient should be taken into account in the assessment of best interest. The court ruled that it was in the patient's best interests for treatment to be withheld and that its discontinuance was in accordance with good medical practice. As a result, he became the first patient in English legal history to be allowed to die by the courts through the withdrawal of life-prolonging treatment (17).

In 2002, in *Re B* the House of Lords while deciding the fate of a 43-year-old woman who had become tetraplegic, and who no

longer wished to be kept alive by means of artificial ventilation, held that a competent patient has the right to refuse treatment and their refusal must be respected, even if it results in their death (50).

The British Supreme Court, on October 30, 2013, in *Aintree University Hospitals NHS Foundation Trust v. James*, allowed the withholding of life-sustaining treatment from "a gravely ill man". The Court's affirmation of a terminally ill person's right to end his life is clearly manifest in the judgment. In para 357, the Court, inter-alia, asks the question: "More importantly, is the sanctity of life protected or enhanced by insisting that those who freely wish to but are physically incapable of bringing their lives to an end, should be required to endure untold misery until a so-called natural death overtakes them?" (51). However, the same Court, on June 25, 2014, in a divergent pronouncement, dismissed Nicklinson's and Lamb's appeal holding that "no assistance could be given to a person who wishes to die unless and until a Judge of the High Court has been satisfied that his wish to do so was voluntary, clear, settled and informed" (52). This decision disappointed many who were expecting a rather affirmative decision from the UK Supreme Court in view of their earlier pronouncements.

### **Ireland**

A 59-year-old woman, suffering from multiple sclerosis since 1989, who was immobile, in great pain and distress, and wanted assistance in dying, approached the High Court of Ireland with the prayer to declare section 2, subsection (2) of the Criminal Law (Suicide) Act 1993 as contrary to the Constitution of Ireland and violative of her rights as enshrined in the European Convention on Human Rights and Fundamental Freedoms. After thorough deliberation, in a detailed judgment on January 10, 2013, the Irish High Court rejected her prayer (53).

### **The European Court of Human Rights**

In 2002, Mrs Diane Pretty, who was paralysed and suffering from a degenerative and incurable illness of the nervous system, called motor neuron disease, challenged the decision of the House of Lords in the European Court of Human Rights at Strasbourg, France, alleging that the refusal of the Director of Public Prosecutions to grant her husband immunity from prosecution if he assisted her in committing suicide, and the prohibition in domestic law on assisting suicide infringed her rights under Articles 2, 3, 8, 9 and 14 of the European Convention on Human Rights. The European Court, on April 29, 2002, dismissed her application holding that there has been no violation of the Convention (54).

However, following Diane Pretty's case, the European Court of Human Rights adopted a more liberal approach in three successive decisions between 2011 and 2013 holding that article 8.1 of the European Convention on Human Rights encompasses the right to decide how and when to die, and in particular the right to avoid a distressing and undignified end to life, provided that the decision is made freely. In Haas

v Switzerland the Court ruled, "In the light of this case-law, the Court considers that an individual's right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence, is one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention" (55). In *Koch v Germany*, the Court held, "Having regard to the above considerations, in particular to the exceptionally close relationship between the applicant and his late wife and his immediate involvement in the realisation of her wish to end her life, the Court considers that the applicant can claim to have been directly affected by the Federal Institute's refusal to grant authorisation to acquire a lethal dose of pentobarbital of sodium (56). In *Gross v Switzerland*, the Court held, "Having regard to the above, the Court considers that the applicant's wish to be provided with a dose of sodium pentobarbital allowing her to end her life falls within the scope of her right to respect for her private life under Article 8 of the Convention." (57).

### **Canada**

In Canada, the Ontario Court of Appeal in *Malette v. Shulman* (1990) held, "The doctrine [of informed consent] presupposes the patient's capacity to make a subjective treatment decision based on her understanding of the necessary medical facts provided by the doctor and on her assessment of her own personal circumstances" and "a doctor is not free to disregard a patient's advance instructions any more than he would be free to disregard instructions given at the time of the emergency." (58). In 1992, the Quebec Superior Court, while deciding the case of Nancy B, a competent woman with an incurable neurological disorder praying for withdrawal of artificial ventilation, without which she was incapable of breathing independently, held that she was entitled to the relief sought, and ordered that the treating doctor be permitted to stop ventilation if and when the woman so instructed. The Court found that the woman's right to refuse treatment was almost absolute, subject only to the corresponding right of others not to have their own health threatened (59).

However, in 1993, in *Rodriguez v. British Columbia*, the Canadian Supreme Court, by majority, upheld the blanket prohibition on assisted suicide (60). However, 22 years later, on February 6, 2015, the Canadian Supreme Court through a landmark decision in *Carter v. Canada*, reversed their earlier stand and recognised an individual's right to end his/her life (8) The judgment is unique as the Court has not only recognised an individual's right to end his/her life at will; but has also relaxed the existing parameters like 'terminal illness that will kill the patient within six months' (6) to "grievous and irremediable medical condition causing enduring suffering", offering a much wider latitude in the decision-making process.

### **Australia**

In 2003, the Supreme Court of Victoria, Australia held that the Public Advocate (who had been appointed guardian) had the

power to refuse further nutrition and hydration administered via percutaneous endoscopic gastrostomy (PEG) to a 69-year-old woman in the advanced stages of dementia (61).

On August 14, 2009, the Supreme Court of West Australia ruled that a nursing home in Perth must respect the wish of 49-year-old Mr. Christian Rossiter, suffering from quadriplegia and he may be starved to death. Chief Justice Wayne Martin in his order said, "Mr. Rossiter is not a child, nor is he terminally ill, nor dying. He is not in a vegetative state, nor does he lack the capacity to communicate his wishes. There is therefore no question of other persons making decisions on his behalf. "Rather, this is a case in which a person with full mental capacity and the ability to communicate his wishes has indicated that he wishes to direct those who have assumed responsibility for his care to discontinue the provision of treatment which maintains his existence." (62).

On June 17, 2010, Supreme Court of South Australia granted to a South Australian woman confined to a wheelchair, the right to die by refusing to take food and medication. South Australian Supreme Court Justice Chris Kourakis in his judgment said a competent adult was not under a duty to take life-sustaining medication and a refusal to do so was therefore not suicide. The judge held that "Once that proposition is accepted it is difficult to maintain the proposition that self starvation is suicide as a matter of logic or by reference to consistent ethical principles," (63)

### **Switzerland**

On November 3, 2006, the Swiss Federal Supreme Court opened a new chapter in the debate over assisted suicide and euthanasia. While recognising the right to self-determination of a 53-year-old manic depressive under Article 8 of the European Convention on Human Rights, the Swiss court responded with a sweeping opinion upholding the right of those suffering from "incurable, permanent, severe psychological disorders" to terminate their own lives. The Court held that the right to decide on the method and date of one's own death is a part of the Right of Self-Determination, guaranteed by article 8 of the European Convention on Human Rights (64).

### **Germany**

In June 2010, the Federal Court of Justice, the highest court in Germany, ruled that "it was not a criminal offense to cut off life-sustaining treatment for a patient." "The court overturned the conviction of a lawyer who "was found guilty of attempted manslaughter for advising a client to sever the intravenous feeding tube that was keeping her mother alive, although in a persistent vegetative state. The mother had told her daughter that she did not wish to be kept alive artificially." (65).

### **Italy**

On November 13, 2008, in the case of Eluana Englaro, a woman who entered a persistent vegetative state on January 18, 1992, following a car accident, the Italian Constitutional Court

awarded Eluana's father the right to stop his daughter from being fed (19).

### France

On June 24, 2014, The Council of State, France's top administrative court, ruled that doctors had the right to end the medical support that has kept Vincent Lambert, 38, brain-damaged and quadriplegic, alive since 2008 following a road accident. Vincent's deeply religious Catholic parents challenged the Council's judgment in the European Court of Human Rights at Strasbourg. (66) However, the European court in its judgment delivered on June 5, 2015, upheld the ruling of the French court (67).

### Indian scenario

There is no legislative enactment in India concerning one's right to end life. However, in a positive development, Section 309 of the Indian Penal Code which criminalised attempt to commit suicide is expected to be repealed. However, section 306 of the Indian Penal Code which says "If any person commits suicide, whoever abets the commission of such suicide, shall be punished with imprisonment of either description for a term which may extend to ten years, and shall also be liable to fine" will remain intact. Hence, any act of providing assistance in dying will continue to be a criminal offence. This is almost similar to the British law where suicide was decriminalised by the Suicide Act, 1961; but under Section 2(1) "A person who aids, abets, counsels or procures the suicide of another, or attempt by another to commit suicide shall be liable on conviction on indictment to imprisonment for a term not exceeding fourteen years."

It is noteworthy that after the repeal of Section 309 of the Indian Penal Code, a patient's right to refuse medical treatment, which is a universally accepted right of an individual emerging out of the right to self determination, shall stand vindicated in India too. Thus, a patient's refusal to take medical treatment will not constitute an offence.

Before the case of Aruna Shanbaug, the issue had been deliberated by the Supreme Court in 1996, rejecting a person's right to end his/her life (68). Another case filed in 2005 is pending before a constitution bench of the Court (69). In view of the large proportion of vulnerable population in India, one of the biggest objections against assisted dying is founded in concern against its misuse by the family members, near relatives, surrogates and unscrupulous physicians. This is what the Hon'ble Supreme Court of India has also said in their aforesaid judgment in Aruna Shanbaug's case. In fact, this is one of the main reasons why the apex Court has subjected the right to passive euthanasia to mandatory approval of the High Court. The possibility of misuse is undoubtedly a valid concern but it needs to be understood in a more practical context. If a family member or close relative looking after the patient wants to kill him for greed or some other unlawful motive he can easily do it by not providing the medical care which is due, or by diluting such care, which does not constitute any

offence, rather than colluding with the physician and resorting to euthanasia. Why will a family member or a surrogate seek judicial intervention by the High Court, when an easier option is available to him?

### Conclusion

The protracted continuance of Aruna Shanbaug in PVS is not a solitary instance. Many individuals across the world have suffered --- and are still suffering -- such colossal indignity during the last days of their life, owing to undue extension of the dying process, in utter violation of their autonomy and the right of self-determination and callous disregard for their pain and agony. Legislative inadequacy coupled with judicial heterogeneity has exposed the decision making process to unwarranted ambiguity. A pious and humane act of providing assistance in dying to a terminally and incurably ill person is treated as an offence owing to antiquated and proscriptive laws rooted in religious misinterpretation, a false notion of virtue and undue moral paternalism. Many lives are forced to linger aimlessly prolonging the suffering of the individual, and heavily burdening the already stressed families. The Canadian Supreme Court's pronouncement, on February 6, 2015, in *Carter v. Canada* (8) affirming a person's right to die with dignity, reversing the law in vogue for almost a quarter of a century, has come as an oasis in the sultry desert of denial and negativity. It is equally heartening to know that, following Brittany Maynard's death, in the USA, "More than a dozen states, plus the District of Columbia, are considering controversial medically assisted death legislation this year" (70).

No doubt, end of life decision making is an intricate exercise involving careful assessment of the veracity of the individual's consent, scientific evaluation of the severity and course of his/her illness, exclusion of extraneous forces, knowledge of evolving utilitarian notions, risks involved in the event of a potentially wrong decision and the possibilities of other options. One of the biggest challenges continues to be the determination of consent which contemplates a valid purpose and truly informed consent in the case of conscious individuals and the assessment of best interest in the case of those who are incapacitated. In view of the profound and irreversible stakes involved, the matter calls for thorough and deep deliberation. At the core of the argument supporting assisted suicide are the twin goals of maximising individual autonomy and minimising human suffering. An incapacitated individual is a helpless person confronted with the perpetual risk of intrusion into his autonomy by the social paternalists. Incessant infliction of pain and agony on a person is not consistent with human dignity, which is an essential element of sanctity of life. An act violating the dignity of life is, therefore, contrary to the sanctity of life. The possibility of abuse of vulnerable persons is a valid concern; but it can always be curbed by appropriate legislative and regulatory mechanisms. This is clear from the fact that in jurisdictions where assisted dying has been practised for decades, not a single case of abuse has been reported so far. Judicial decisions may fill the vacuum for some time; but they cannot be a substitute for

legislative enactments. The situation calls for the enactment of comprehensive and fine-tuned legislative strategies in order to relieve the suffering of many awaiting a dignified exit from the unbearable agony of living with death.

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## COMMENTS

# Aruna Shanbaug and workplace safety for women: the real issue sidestepped

**SREELEKHA NAIR**

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### Introduction

Aruna Shanbaug (born 1948) passed away on May 18, 2015 and the coverage that the news got on the front pages and the primetime news slots surprised everyone. One wonders whether this news would have got so much coverage had it not involved the sensational euthanasia debate. That Aruna should have been projected as the face of the euthanasia debate in India disturbs those who have been following her "story". The fact remains that it was a debate set off by Pinki Virani – for people like Aruna – with due respect to the former's earnest intentions and efforts. That Aruna was subjected to violence in November 1973 was nothing but the potential experience of every working woman in India. Aruna should be remembered for that reason – a cause much more bitter than passive euthanasia. She has been and will remain the face of working women in India against whom male prejudice has remained unabated even 42 years after Aruna became a victim. How many Arunas were assaulted, murdered and violated physically, emotionally and mentally during this period? To a substantial number of Indians, women still belong to the hearth and the harem, and the rapist of the Delhi girl whom we nicknamed Nirbhaya told us this impudently from within the Tihar jail in Delhi (1)<sup>i</sup>. India as a society seems to refuse to recognise the ethical issues associated with denying women their right to be safe at their workplaces.

Newspaper reports were eloquent on the relentless care that generations of nurses provided with devotion to Aruna; they, however, did not talk about the medical treatments that she received. There were a few reports on how she was not taken out of the hospital for some diagnosis because she was uncomfortable being taken out of the familiar environment<sup>ii</sup>. The details of Aruna's service as a nurse in the hospital are not known and as of May 21, 2015, we know that the hospital does not have any records that can be placed before the public (2).

For every known Aruna assaulted in the workplace whose story becomes known, there are thousands who are unknown. The public space of every woman in India is subject to violence of some sort; it is just that there is disagreement on what constitutes violence. When it is physical assault amounting to rape and murder, there is some acknowledgement that there was violence. While men's crimes are often excused as "their unavoidable biological tendency" or as a product of their "playful nature", the responsibility for "being at the wrong place at the wrong time" is thrust upon the women who are subjected to violence. It has been so very convenient for all of us – the media, the government, the judiciary, us women who go to work every day and make sure we return before it gets dangerous, and the general public – to evade the real issue. Is it because there is no solution? Or is it that we do not want to face the reality as it is too harsh?

### Women's safety at the workplace: the real issue

As mentioned earlier, the safety of women at the workplace is a difficult issue and yet so easy to sidestep. Physical and sexual violence are definitely imminent threats for every working woman<sup>iii</sup>. Women in workplaces like hospitals, where they work in proximity to men in various capacities, such as colleagues, patients and the companions of patients, face issues that result from the nature of their work and the widely prevalent norms on gender roles. When it comes to women workers, violence of a sexual nature is the predominant form of crime. The sexual nature of the violence discourages women from reporting the crime as they fear that their reputation will be tarnished, given the importance of women's "sexual purity" in our society. In a study on health workers in the private and public sector hospitals of Kolkata, conducted over the last decade, Chaudhuri (3) identified a cross-section of men as perpetrators of violence, of which sexual harassment was a significant form. The men included doctors, patients, non-medical staff who were assistants to the medical staff, administrative staff and outsiders.

It has also been observed that the organisational structure and hierarchy of a workplace like a hospital play an important role in the way a crime such as sexual harassment is identified and reported. Seeking redress and finding solutions to the issue also depend on the position, status and power of the perpetrator, rather than that of the harassed person<sup>iv</sup>. It has been found that when male doctors are the perpetrators,

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harassment is far less likely to be reported than when other male staff members harass women (3: p 230). Similarly, actions taken on complaints of harassment depend on the hierarchy and the power of the perpetrators. Interestingly, gender is an important factor that mediates the processes of the act of violence, reporting and redress. Gender becomes the greatest deciding factor when there is educational and occupational equivalence between the harassed and the perpetrator. That is why women doctors, especially juniors, and nurses often find themselves experiencing the same kind of harassment despite their occupational and social differences.

Nurses, as a group of professionals, are the greatest sufferers when it comes to violence, especially of a sexual nature, within the hospital space. Nair and Healey (4) found that the history of the development of nursing as a profession in India contributed towards the low status of the profession and the way its practitioners are mistreated. Another study in the context of Delhi found that the perceptions of patients and others regarding power and hierarchy are very important in their dealings with nurses (5). It was found that while doctors were seen as professionals who kept a social distance from the patients due to their language and class, nurses shared the same language and social location with a majority of patients and hence, it did not come naturally for the latter to respect nurses (5: p 87).

Evidence found by the committee<sup>v</sup> appointed to look into the problems in the nursing sector in Kerala reveals that even after an acceptance by the wider society that hospitals as workplaces are not always safe for women, the conditions have not improved much. The committee (6), therefore, recommended that "adequate basic facilities such as changing room with dining and toilet facilities for male and female staff, sick room, transportation at odd hours of duty shifts, quarters and canteen facility shall be ensured for nursing staff"(6:p 29).

### **Hospitals as workplaces and sexual violence: some observations**

It has been widely reported that women workers in hospitals experience sexual harassment on a daily basis. Interviews with women of diverse social standing – whether they are highly qualified professionals or simply eking out a living with few opportunities for professional growth – reveal an insecurity regarding their physical safety at their workplaces that their male colleagues do not share. Hospitals have been one of my fieldwork sites for more than a decade. They illustrate the daily connotations of gendered living at a workplace. A hospital, a public place like all workplaces, is distinct from the others in various respects. It is a place characterised by a sense of urgency among the patients as well as workers, regardless of their working hours and personal circumstances. In the latter category, nurses care for patients even when other medical staff members are not available. They are, therefore, supposed to command immense power at their workplaces. They are in a majority in any hospital. A numerical majority should rid one of some degree of insecurity, but despite all this, nurses

experience a sense of insecurity at their workplaces. On the contrary, the omnipresence demanded of them by the nature of their work seems to devalue their work and dehumanise their persona. This makes it important to analyse hospitals as workplaces for nurses in the context of the frequent occurrence of sexual violence.

Often, the lack of a sense of safety and security is due to the structural powerlessness that nurses feel within hospitals. As workplaces, hospitals are supposed to provide them with adequate comfort within the physical environment. Staff nurses working in Delhi and Kerala disclosed that certain physical and material circumstances of their work encouraged misbehaviour by men and, therefore, such conditions inhibited them. In most cases, changing rooms are not available for nurses and the individual nurse is forced to find the privacy to change her uniform. Often, store rooms and toilets are used for changing clothes before and after duty. In many cases, it is not possible to lock doors from the inside. Some reported that the male staff deliberately damaged the locks. Toilets may not have lights and enough space to manoeuvre while dressing and undressing without the clothes getting soiled. Just to avoid getting into embarrassing and sometimes fatal situations, many travel to and from the hospital in their uniforms, making a mockery of the high standards of hygiene that are supposed to be maintained in hospitals.

Nursing is an extremely gendered job, but the care aspect of the work is considered feminine and devalued and those who do nursing work are deprived of the qualities of a "worker". Numerous nurses who reported violation of the physical body or attempts at such violation – whether of their own body or those of other nurses known to them – pointed out that the attack occurred merely because they are female. The numerous cases that I came to know of through interviews point, without doubt, towards the fact that sexual violence is a manifestation of power. And the attackers range from representatives of managements, superior or subordinate colleagues, patients and their companions to contract employees who come for electrical or plumbing jobs. When men of a low professional status attack a woman of a higher designation, it is intolerance towards her official superiority and affirmation of their male supremacy. The claim of Sohanlal Walmiki, the criminal who attacked Aruna, that he did not assault her sexually is irrelevant; he was filled with vengeance because she had shouted at him. It is clear that he would not have dared to attack a male colleague under such circumstances. As argued elsewhere, sexual harassment is often an extreme manifestation of low status and the dehumanisation and devaluation of women in our society (7).

Chaudhuri (8) found that even when sexual harassment is reported, it does not always take the shape of a formal complaint. There are many informal obstacles in the way of filing complaints. Women file complaints if they think that they are going to be heard without any prejudice and that they will not be misunderstood. Inaction on the part of the authorities is an important obstacle, but such inaction is not always due to

sympathy for the harasser; it is that the authorities simply do not want to get involved in what they see as a time-consuming matter. It is easier, instead, to ask women to show restraint, dress “properly” and behave in a way that does not attract the “unwanted attention” of men. Thus, the onus of the harasser’s act is placed on the harassed. Described below are two cases to which I was a witness, and which illustrate the ways in which the process of redress is sought and managed.

**Case 1:** I had gone to the female ward of a Delhi government hospital much before regular office hours to interview nurses. As I entered, I noticed that there was a commotion. The nurse who had been on duty at night was waiting to complain about a drunken electrician who had attempted to harass her and misbehave with her. She was bent on speaking to the senior representative of the nurses’ union. Here are some important facts that I learnt of subsequently.

1. The nurse was confident that she would be heard and understood without having to give explanations. She believed that union leader would not be dismissive about her experience.
2. The nurse said she decided to complain because she did not have to deal with the administrative authorities directly.
3. She was sure that the Medical Superintendent (MS) and other authorities would respond differently to the union representative than to the “harassed”, that is, herself.

Later, the union representative called the MS directly. The latter was polite and responded positively, promising immediate action. The action taken in this case was a “win-win” situation for everyone for the following reasons.

1. The allegation was against a worker who was on contract and had no formal affiliation with the hospital.
2. It was easy to take action: the company which had contracted the worker was asked not to send the worker to work in the hospital again.
3. It did not create any trouble for the hospital hierarchy as an outsider was the perpetrator.
4. If the perpetrator had been an outsider who happened to be a patient or a patient’s relative, the authorities would have been hesitant to take action. In this case, no one was going to question the decision as it was not really going to hurt anyone. It would most probably not hurt even the harasser, who would simply be barred from working in the hospital and face no further action.

**Case 2:** A female nurse in a well-known charitable hospital in Delhi was sexually harassed by a senior physician. After the incident, the woman learnt that the perpetrator was a habitual offender and no action had been taken against him in the past. By then, she had already complained verbally to the Nursing Superintendent (NS). The NS assured her that her complaint would be considered seriously and asked her to give a written complaint through her ward in-charge. Meanwhile, the nurse shared the incident with her friends among her colleagues. They advised her against lodging a formal complaint as the

doctor was an “indispensable” member of the hospital staff; the best “solution” would be to ignore it and avoid the person. However, our respondent felt that she had to “do something” if she had to continue working there. She wrote a formal complaint and went to her immediate superior. The lady in charge appeared surprised by her allegation and said that the doctor was a senior person who had been working there for several years. When the “harassed” insisted that she wanted to file a formal complaint, she was asked to come the next day.

The next morning, judging by the seemingly “casual and innocent” chat with some senior colleagues, it was clear that the news had reached everyone and that no one was in favour of anyone creating a problem in that “peaceful” workplace. The fact that it was an atmosphere in which a harasser ruled the roost did not seem to disturb anyone. The threatening body language of the perpetrator showed that he had come to know about the nurse’s complaint. When she went to file the complaint, the in-charge was unusually busy and made her wait for hours. When they finally met, her superior literally refused to accept her complaint. In a matter of one month, she was asked to leave the hospital for dereliction of duty, the details of which were never specified. She was told that it would be better for her if she resigned as this would leave her career record intact; on the other hand, she would be given a suspension letter if she resisted. By one month after the incident, she had lost all confidence in herself and in the system. All the while, she tried to avoid the perpetrator and act meek so as to prove that she was nice and not a “troublemaker”.

During the fieldwork conducted among health professionals in Kerala during 2012–2013, I tried to explore the differences between the situations of the nurses and other female hospital staff. My research revealed that nurses are more vulnerable than the others to the gender prejudices of men (predominantly) as they are often closeted with men due to their work. Nurses are direct and first points of contact for patients, their associates and other health professionals during cure and care. The other women professionals in hospitals are doctors, pharmacists, laboratory technicians, receptionists and technicians, none of whom visits patients alone. They see patients mostly in their own work rooms, mostly in the daytime. Even when night pharmacies in hospitals employ women, they are often locked in their rooms and the pharmacies are situated in more open spaces. Women doctors visit patients either as a part of their routine visits or rounds, and are accompanied by junior doctors and the nurses in charge of the patients. When they visit them in emergency situations, they never go alone. It has been reported that in England and Australia, women doctors face fewer sexual advances from other doctors and patients than do nurses and their presence acts as a deterrent for nurses (9). Nurses in charge of wards often have to handle patients’ associates, canteen workers, electricians, plumbers and other such workers, especially at night. They express relief when the non-medical staff takes charge of administrative and housekeeping duties. Such comforts are becoming scarce due to cutbacks in staffing and budgets. There is a new pattern of employment of

contracting private security agencies to cut down the number of hospital staff on the permanent payroll, and this has resulted in inadequate security arrangements, which have no relation with the rest of the hospital staff and leave much to be desired in terms of moral obligation. The security personnel take on the role of "bouncers" who would make sure that the hospital is run as a business, without any disturbance from any source, especially aggrieved patients.

There are some formal obstacles that prevent women from filing complaints. Despite the Supreme Court order, the service rules have not been amended to spell out the procedures to be followed in the aftermath of sexual harassment. The Complaints Committee has not been constituted in most workplaces. Where it has been constituted, it has not been done so as per the guidelines in the *Vishaka v The State of Rajasthan* case of 1997. Where it has been constituted as per the guidelines, meetings are not held regularly. Most importantly, the members of the committee selected from civil society organisations may not be favourably disposed towards women in cases of harassment, contrary to the general perception.

It has been reported that a search for the keyword "nursing" in the literature and newspapers brings forth reports on sensational events, such as protests and violence (10). The image of nurses still carries a sexual flavour and the images thrown up by the media seem to have contributed to this. Over the last decade, I have observed that caricatures of nurses with overblown lower lips and breasts, in tight tops and short frocks, appear alongside news items which are unrelated to nurses and/or are remotely related to health issues – such as a rise in drug prices or waste management in hospitals. There have been positive changes in the portrayal of nurses in serials and movies, but as Mrs Khurana, the founder GS of DNU stated: "In our country, no woman can say with a sense of pride that she is a nurse by profession" (7: p 80).

Questions on sexual harassment elicited an interesting response from a handful of young women nurses during my fieldwork. They argued that emphasising the sexual nature of violence against nurses would only make them look more like sexualised objects. They felt that this focus would detract from the other issues that needed urgent attention. This clearly shows that sexual assault and fear of sexual violence are not the only threats that women nurses face in their workplaces. This view was expressed by young, articulate nurses. These women also stressed individual responsibility in raising their status, as well as the need to maintain the dignity of nurses and their profession. For many of them, the nature of the work of nurses is part of the issue! They feel that doing "menial jobs" such as cleaning and washing patients only adds to the perception that "these women will do anything to make a living"<sup>vi</sup>.

### **Discussion: is there a way forward?**

Experience elsewhere in the world shows that collective action is the best method to combat the problem (11)<sup>vii</sup>. The problem

of violence against nurses is not confined only to India. According to a study by the International Council of Nurses (2004), as many as 72% of nurses do not feel safe from assault at work (12). A report by the United States Occupational Safety and Health Administration in 1998 showed that healthcare workers in the USA were assaulted more frequently than workers in any other occupation, including law enforcement officers (12). Most northern countries have adopted measures intended to prevent and redress violence at work. Considerably stringent implementation of the rules and measures against violence in these countries has ensured that the crimes against healthcare workers have become less atrocious in terms of severity and nature, if they have not been eliminated altogether. India can, therefore, learn from these examples to adopt useful strategies to tackle such violence.

Most of the hospital communities in these countries have adopted a policy of "zero-tolerance" of violence at the workplace as the standard (13). This means that they have addressed the contributing factors to violence, such as allowing female personnel to work in isolated units, inadequate staff coverage, lack of staff training, a poor work environment, such as one characterised by lack of empathy on the part of superiors, and the presence of drunk people or those who take drugs, workers or patients in states of mental or emotional duress, and violent or revengeful people. Should violence occur, countries like the USA and Canada put the potential liability on the employers (14) and in my opinion, this seems to be acting as an important deterrent in countries such as Canada. Employers are expected, without fail, to have policies on workplace violence and harassment and on prevention and redress in place. If the employer has more than five employees, the policies must be exhibited in writing at an open place at the workplace. In the USA, the gravity of the problem is recognised to such an extent that 30 States have made violence against emergency nurses a felony; convicted violators have to spend up to three years in prison (14).

More than legislations, it is social attitudes towards and perceptions of the issue of harassment that have undergone a significant transformation in these societies. An important aspect of the change in attitude has been the acceptance of nursing as an essential service by the governments and civil society, and the subsequent recognition of nurses' right to equality and dignity at the workplace as an ethical matter. Moreover, the acceptance of women as first citizens, just like men, and their freedom has to become more universal. The fight against violence in healthcare organisations has become part of a broader work culture that encourages gender equality as a moral principle. Such a culture includes policies that eliminate all forms of discrimination and exploitation, especially in terms of the participation of traditionally underrepresented groups in civic life and their occupying non-traditional positions, thus demonstrating that prejudices against women and other marginalised sections are unfounded and illogical. Professional development opportunities that include formal or informal networking and mentoring programmes for women at all levels, including

women working in non-traditional fields, have been found to be successful in countries like Australia (15). Violence has been seen as a work hazard and, therefore, a focus on its prevention as an ethical duty has yielded results.

In India, the Sexual Harassment at Workplace (Prevention, Prohibition and Redressal) Act 2013 (16) has provided considerably clear guidelines on the prevention of violence and redress for victims in workplaces. The role of the employers and district officers has been outlined quite explicitly. What is distressing is that even after the Act has come into force, women employees are neither aware of the law, nor of the options for redress. Even when they seek redress, they encounter the formal and informal obstructions discussed earlier. Discussions on the Vishaka judgment had brought the issue to the fore among activists and lawyers. That judgment was an important milestone as it was for the first time that sexual harassment was institutionally recognised as the violation of a woman's right to equality rather than a simple personal harm. Nevertheless, my research indicates that we require measures that go beyond legislations and judgments; stricter enforcement of the existing laws is what has made some of the northern countries a better place for nurses to work in.

Policy statements such as the health policy should contain provisions aimed at making the workplace safe and optimal for women. The Draft National Health Policy, 2015 did make a beginning. It states:

*"4.2.6.5. Nirbhaya Nari – Action against gender violence ranging from sex determination, to sexual violence would be addressed through a combination of legal measures, implementation and enforcement of such laws, timely and sensitive health sector responses, and working with young men."*(17)

Concrete and systematic measures are needed to put an end to violence against women in the workplace, as it is a systemic issue. The role of professional councils, such as the Nursing Council, is underestimated and they have been underutilised until now, even if one accepts the argument that their role is limited to the education and training of professionals. Interventions in the clinical settings become the area of activity more of the states' department of labour. Even with such limitations, training programmes and awareness campaigns can be conducted during the registration process every five years, now that the pattern of "once-in-a-lifetime" membership has been changed in the cases of nurses. The councils can network with the respective state governments, especially the department of labour, to make sure that all hospitals constitute the mandatory complaints committee in a manner that is intended to function effectively and ethically. We have seen that the government and civil society insist on the enforcement of nurses' duties even in adverse conditions of work and nurses are asked to forego their right to protest and strike, citing ethical issues (18). However, the same conviction about ethical issues is somehow not in evidence when they are mistreated at their workplaces.

Nurses themselves have suggested some measures very specific to Indian settings. These include reducing the non-medical burden on them by appointing non-medical staff to take charge of administration and housekeeping. Administrative mechanisms to ensure adequate staffing patterns and security measures are essential. Programmes that train workers to recognise and manage potential assaults, safety training that may include martial arts, alertness and precise reporting are important. Travel to work for night shifts has been an area of concern and poses much risk for women as reported in newspapers. Ensuring safe transport for professionals who travel for night shifts should become the employers' responsibility<sup>viii</sup>. Factors like poor lighting and inadequate facilities should be identified by the administrators. Countries such as Canada have adopted measures like assigning more security staff to psychiatric units, making provision for personal alarm pendants and security cameras, and carrying out risk assessment of potentially violent patients and co-workers. These could mitigate the risk of violence against nurses to some extent. Given the lifelong physical and emotional scars that result from violence, the need for providing counselling to the victim cannot be overemphasised. Societal attitudes, as well as the mass media's portrayal of nurses as "loose" and "sexually oriented", will have to change to create safer workplaces for nurses.

Our duty to Aruna's memory lies not just in allowing humans who are in a vegetative state to die with dignity, but in ensuring that women are safe in their workplaces. We can no longer sidestep the issue, be it with reference to public sector institutions such as the one where tragedy befell Aruna or private sector institutions, where such matters are hushed up even more vehemently. The only way forward is to cultivate a culture in which workers are treated ethically, with dignity and equality. In the present era, in which the health sector is market-oriented, ethical issues are reportedly being relegated to the background; however, unless all the stakeholders take an ethical stand, many more Arunas will be lost to our society. Last but not the least, drawing a distinction between women's honour and their sexual identity and purity may help matters farther than we imagine at present.

### **Acknowledgement**

*This comment is dedicated to all the working women of India, who in spite of the many abuses inflicted on them, struggle on from strength to strength, and from whom our society benefits and learns much. The author would like to thank the anonymous peer reviewers for their help in improving the article.*

### **Notes**

- <sup>i</sup> "A decent girl will not roam around at nine o'clock at night. A girl is far more responsible for rape than a boy," Mukesh Singh, one of the killers of the woman whom we nicknamed Nirbhaya, told the interviewer.
- <sup>ii</sup> Since she was attacked in November 1973, she had been cared for in the King Edward Memorial Hospital, where she worked as a nurse.
- <sup>iii</sup> In no way is it an argument that those who just move around idly deserve to be assaulted; everyone has a right to be safe in our public space, whatever their reason for being there.
- <sup>iv</sup> The word "victim" is consciously avoided in order to indicate that an

act like sexual harassment should not be the burden of the woman but that of the perpetrator. The concept of so-called sexual "purity" should be debunked. Every woman should be reminded that after sexual harassment, she has many options and the ultimate aim of the employers and the immediate society should be to help women exercise these options.

- v The committee for studying the problems being faced by Nurses in Private Hospitals of the State of Kerala, chaired by the late Dr S Balaraman, the former acting chairman of the Kerala State Human Rights Commission. This committee was appointed by the Department of Health and Family Welfare in response to the state-wide strikes by nurses in private hospitals.
- vi Interview with a 23-year-old Delhi-born Malayali nurse working in a private hospital in Delhi,
- vii Unionisation is an important factor as far as collective bargaining and action are concerned. As affirmed by Ms Molly OS, a member of the Indian Nursing Council and General Secretary of the Kerala Government Nurses Association, it is the absence of a forum for collective action that makes the private sector nurses much more vulnerable in comparison to their counterparts in the public sector.
- viii Hospitals sometimes use ambulances to transport nurses, but this can be a control mechanism that restricts their movement. Moreover, when there are shortages of nurses in some shifts, especially at night, an ambulance is sent without any prior notice to fetch nurses for duty

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## The Allied and Healthcare Professional's Central Council Bill, 2015: more of the same

GEORGE THOMAS

The Medical Council of India (MCI) is a statutory body established in February 1934 under the Indian Medical Act, 1933. This act was repealed in 1956 and replaced by the Indian Medical Council Act, 1956. The objectives of the MCI are:

1. Maintenance of uniform standards of medical education, both undergraduate and postgraduate.

2. Recommendation for recognition/de-recognition of medical qualifications of medical institutions of India or foreign countries.
3. Permanent registration/provisional registration of doctors with recognised medical qualifications.
4. Reciprocity with foreign countries in the matter of mutual recognition of medical qualifications.

The main task of the MCI is to oversee the standards of medical education in India. The council has performed this task fairly well, though there are constraints. Health being a state subject, the council has to work with state governments. It has no mechanism to ensure compliance with its directives other than not recognising degrees. Besides it has an unwieldy

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structure, which consists of members nominated by the Central government, several state governments and members elected by medical practitioners. Like the MCI, similar councils for other allied healthcare disciplines—such as those for dentistry, nursing and physiotherapy—also have problems in their functioning. These problems will not be solved by creating yet another council.

One must, therefore, wonder as to why the Central government wishes to introduce a new Bill to establish another council above the MCI and the various other allied healthcare councils (1).

The stated objects and reasons for establishing a new council are:

“Maintenance of proper standards in the training and education of allied and healthcare professionals is considered essential as these personnel play a crucial role in healthcare delivery. With a view to regulating these professions, it is considered necessary to set up a Council on the lines already existing for pharmacy, nursing, etc. To begin with, it is proposed to set up an overarching Council for all the categories prescribed under the Rules by the Central Government with individual committees for each professional. The Council will be responsible, inter alia, for maintenance of uniform standards of education in the respective disciplines and registration as well as licensing of qualified personnel for practicing the professions.”

In the Preamble, it is stated: “To provide for regulation and maintenance of the standards of education and practice of Allied and Healthcare Professionals through the constitution of Central and corresponding State Councils of the Allied and Healthcare Professionals and for matters connected therewith or incidental thereto.”

These are precisely the functions of the MCI, the Dental Council of India and the others, none of which are going to be replaced. In the recent past, the MCI has come under a cloud mainly because it has been perceived that there is corruption in its function of recognising medical colleges established in the private sector. There is widespread concern that medical graduates from some private institutions are not properly trained. There is basis for these apprehensions.

It is not clear, however, how another council, above the existing councils, will make any difference. The structure of the new council mirrors that of the old council with members nominated by the Central government, various state governments and a few elected by the various professional societies. A point of extreme concern is item 3 (l) in Chapter II;

“One-third members from total categories as prescribed under the rules by the Central Government at any given point on biennial rotation to be elected from amongst themselves in such a manner that they represent such organisations which can represent the interest of allied and healthcare professional cadres, as the case may be.”

It is not difficult to imagine that such a vague clause will enable

governments to allow whichever organisation it wishes to categorise as those “representing the interests of allied and healthcare professional cadres.” With one-third of the members likely to be committed to the government in power at the time, besides the fact that a bulk of the others are bureaucrats, it is entirely possible that the council will follow the diktat of the government, instead of charting an independent course in the interest of medical education.

This apprehension becomes stronger, as, for the first two years of its existence, the new council will be full of nominated members because clause (l), under point 3 in Chapter II concludes: “Provided that each of the categories to be represented at least once (for period of two years) in the duration of six years and that in case of constitution of the Council for the first time after the commencement of this Act, the members of this category shall be nominated by the State Government till the assumption of office by the elected members.”

It appears that the present government wishes to create a body entirely under its control, at least for the remaining period of its term in office. This method is unlikely to bring about any of the changes that are needed to help achieve the sustainable development goals in health (2). We will now have yet another layer of bureaucratic control with no reason to believe that it will be any better than the existing councils. This Bill serves no public purpose. It should be scrapped. If the government is serious about improving public health, it should:

- Establish an academic body to continually study public health and medical care so as to provide data which will form a solid basis for public policy.
- Ensure clarity in the rules for opening, running and licensing of educational institutions in the medical sector. The present confusing maze of rules and procedures makes it difficult for even well-meaning institutions to comply.
- Close all loopholes in admission procedures to medical institutions so that justice is seen to be done. For example, the provision for allowing “deemed universities” to conduct their own admission tests has been widely misused.
- Bring clarity into the career path for graduates of these institutions. At present, young graduates are forced to accept demeaning working conditions, at least in the early years, resulting in loss of morale.
- Plan human resource requirement for the country on the basis of studies so that the young graduates can fully utilise their training for the welfare of the public.

It is not difficult to ensure proper functioning of the existing councils. Their poor functioning is the result of collusion between the politician, the executive and the judicial system.

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# When corruption becomes the norm and ethical conduct an exception

SUJATHA RAO

## Introduction

India's health sector is facing a credibility crisis contributing to the growing trust deficit in the competence and integrity of our caregivers. This shift from trust to distrust within the span of two decades needs to be understood within the broader context of a rapidly changing macroeconomic environment and the shifts in values and perceptions governing social relations.

Neoliberalism, an economic term associated with Ronald Reagan and Margaret Thatcher, is used to signify the reduction in state spending and the creation of a *laissez faire* environment for promoting privatisation. Such an ideological shift that saw its beginnings in the mid-1980s became more pronounced in the health sector during the 1990s with India reducing its public spending on health (1) and extending financial and non-financial incentives to promote the privatisation of medical practice without putting in place a regulatory framework to contain and control the scope of perverse market behaviour.

Prior to the 1990s, India's health sector had a vastly spread out private sector. However, this was fragmented and consisted of small-sized hospitals and nursing homes where most doctors took fee for service but valued patient care and never really envisioned medical care as a means of multiplying money power. The launching of the Apollo hospital in 1983 in Chennai (2) in the mid-1980s introduced the corporatisation and financialisation of the medical sector that separated investment from the rendering of services. Part of the reason for this development was the advancements in medical technology that required institutionalisation of treatment and care, besides large investments. While corporate hospitals raised substantial resources from capital markets, brought in modern technology, better diagnostic capabilities, and improved quality of care saving many lives in the process, they also made healthcare into an industrial enterprise entailing changes in the way medical care is organised. While the autonomy of the doctor got reduced, that of the investor became centre stage. The focus too shifted towards declaring dividends to shareholders and from patient care to generating profits. But unlike other sectors, technology and the investment for supporting infrastructure resulted in increasing

the price of medical services, while competition entailed a "race to the bottom" with the "kickback" culture taking roots. The rampant spread of this practice by doctors of kickbacks and cut-practice from pharmacy shops, diagnostic centres and hospitals in return for unnecessary referrals was recently elaborated in an article by Dr David Berger (3), attracting much media attention. The increasing trend towards prescribing a battery of tests, irrational medication, or unnecessary procedures and surgeries that have been well documented in the literature, are all facets of this process of commodification of healthcare.

## The case of medical education

In this changing scenario, the commercialisation of medical education was only a matter of time. Widening disparities between supply and demand for doctors created conditions of scarcity making education a profitable enterprise. With government withdrawing investment, control shifted into the hands of the private sector, as can be seen from the fact that 85% of the 106 medical colleges established during the period 1995–2005 were privately owned. As of today, of the 333 medical colleges, over 65% are private (4).

Given the weak regulatory environment, medical education is today a lucrative investment opportunity where risk is negligible and the return on capital very high. What is, however, significant, is the institutionalisation of the process of politicising this sector, with the 1993 amendment (5) to the MCI Act of 1956, under which section 10 (A) was introduced that made opening of any medical colleges, introduction of new courses, or expansion in the intake of students incumbent upon the explicit approval of the central government. This amendment centralised policy-making in the hands of the political executive using discretionary power. Often, colleges were sanctioned and established on grounds of political expediency. Accordingly today, several medical colleges function without the requisite faculty, or have hospitals without patients, or are fake to a large extent, yet are allowed to continue. The recent revelations in the media of the Vyapam scam where entrance examinations were written by others or undeserving candidates got admission on fake degrees signifies the extent of the rot (6). If running fake colleges is one aspect, the official policy of allowing half the medical seats to be auctioned to the highest bidder is yet another aspect of legalising fraud, in the process effectively undermining the system and making the health system unsustainable (7). That the system of governance does not necessarily comprehend these developments and policies as contradictory to ethics; or is unaware of the larger consequences it may have for the health system, signifies the large-scale failure of the system.

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With resorting to courts of law as the only option (available for a few) and the absence of any institutional mechanisms that positively encourage complaints or feedback on adherence to norms or any systems that would ensure quality such as, for example, an All India National Exit Examination for obtaining the licence to practice or go abroad, there is no incentive for colleges to provide education as per standards laid down.

### **The Medical Council of India**

To check the abuse of patients for commercial considerations, a strong regulatory environment was seen as a prerequisite to containing the impact of market failures. For the purpose of regulating physician practice along ethical norms and ensuring the quality of medical education, the Medical Council of India (MCI) was constituted in 1933 by an Act that was amended in 1956, as a self-governed elected entity functioning as a watchdog body against unethical practices and safeguarding the social trust and professional interests through peer pressure.

With the politicisation of professional education, the stature of the MCI gradually degenerated into being perceived as a corrupt and unreliable entity with serious conflicts of interest. With an estimated requirement of Rs 300 crore for establishing a medical college, only persons with financial muscle could establish them. With no prequalifying criteria laid down by the government regarding investors or management, moneyed persons have invested in medical education as a business proposition, not necessarily for creating doctors to treat the sick.

It was a matter of time before the nexus between politicians, investors and the MCI developed. MCI is the only regulator, as compared to other sectors such as the telecom, banking and financial sectors or power, to have been suspended twice in the course of less than a decade – the first time by the Supreme Court, and the second in 2010 by the government by way of an ordinance, and to have faced the ignominy of having its president jailed (8) for corrupt practices. Between the political system and business interests there is today a vicious cycle of corruption that is difficult to untangle, even while anecdotal evidence, as reported in the media from time to time, estimates that the illegal market could be in the order of Rs 25,000 crore per year.

### **Impact on the health sector**

The impact of commercialising a service sector like health had an adverse impact on increasing corruption and unethical practices. In 2013, Transparency International declared that according to a survey in 17 countries (9), the health sector was perceived by 70% of the households interviewed to be the most corrupt. It was estimated that of the \$7 trillion global health spending, corruption in government procurement accounted for about 10% to 25%; and about 3.29% to 10%, with an average of 5.6%, was lost to fraud. Nearer home, in early 2000, in the erstwhile Andhra Pradesh, an internal survey was undertaken by the government (unpublished) that showed

that after police and revenue, the most corrupt was the health department. It is undoubtedly a profitable sector registering a cumulative annual growth rate (CAGR) of 10.3% during 2007–2010 when the global economy was reportedly facing a recession; and set to have a CAGR of 15% during 2012–2017 (10).

Corruption in the health sector takes the form of bribes in cash or kind - to physicians by pharmaceutical companies to prescribe banned or expensive drugs; in the public sector for manipulating the tender system so as to buy cheap drugs from the lowest bidder, and not check the quality or expiry dates, for allowing counterfeit and falsified drug markets to flourish; or in the realm of human resource management for appointments, promotions, transfers and siphoning off money as seen in Uttar Pradesh, where the scam in the National Rural Health Mission resulted in an inquiry by the Central Bureau of Investigation (CBI), the murders of five persons, and the imprisonment of the health secretary, the resignation of the health minister, etc (11).

### **Market failures in the health sector**

Unlike other sectors, the health sector has inherent market failures and scope for conflicts of interest. First, there are barriers to entry as only those with certain qualifications can practise and administer medicine. Such authority is self-certified – bestowed by a body of doctors, chosen by themselves, that then create a situation where self-interest determines supply – what to teach, who to teach and for how long. The banning of the perfectly relevant Licentiates of Medical Practice on the recommendation of the Bhole Committee, or the refusal to allow nurse practitioners, or delegating some functions to other co-workers and disciplines are essentially motivated by such considerations resulting in keeping the numbers of entrants small, and prequalifying criteria opaque and mystifying in the name of science and patient safety.

The second is the psychological behaviour that surrounds this sector. No matter how educated and knowledgeable, when sick, the person becomes acutely vulnerable, willingly surrenders his judgement, and implicitly trusts the treating physician. The power play between these two individuals – the patient and the doctor – is asymmetrical and it is in such a moment of trust that the doctor is faced with the ethical dilemma. He is undoubtedly in a better position to judge the real situation of the patient who, at times may need some counselling and encouragement, at times some simple diagnostic tests, and at other times a thorough examination. It is then that the temptation overtakes discretion —ordering unnecessary tests that may not necessarily harm the patient, or resorting to irrational drug prescriptions —a patented or a branded drug when a generic would do as well—or admitting the patient for inpatient treatment when an outpatient consultation would have been adequate. An even more worrying trend is the increasing loss of doctors' autonomy to take decisions on matters related to patient care, which

is being taken over by insurance companies and hospital managers. Further, though not documented, it is reliably learnt that doctors working in private (particularly corporate) hospitals are required to order a targeted number of tests or surgeries, irrespective of need, with their employment often dependent upon the achievement of targets.

### **Role of the state**

With the imprisonment of the president of the MCI, the Ministry of Health, Government of India, in 2010 initiated three strategies<sup>1</sup>: (i) It took the unprecedented step of setting aside the elected body of the MCI with a nominated body of governors by way of an ordinance. (ii) It submitted a draft law to curtail the powers of the elected body of MCI only to registration of doctors and regulating physician practice. (iii) It introduced the requirement of a nation-wide entrance exam (NEET) for students desirous of pursuing a career in medicine.

The fact that the government was unsuccessful in implementing any of these measures is a reflection of how deep are the conflicts of interest. The ordinance was issued and a Board of Governors consisting of six experts was established. This board took several initiatives to bring in transparency and probity in the process of approval of colleges, seats or courses; sought to radically redraft the curricula for MBBS and MD, under which a student would need to study the social sciences and gain a broader understanding of the importance of values in medical practice and social dynamics that influence patient behaviour and bring in ethical standards in practice; developed the proposal for the national entrance examination, etc. Unfortunately, since the flexing of muscles by this body as a regulator was politically inconvenient, the Board of Governors was changed twice over the next two years with some members having controversial reputations or conflicts of interest and subsequently going back to the status quo with an elected body in 2013<sup>(12)</sup>.

Likewise, the government failed to process the proposal to establish a National Commission for Human Resources for Health (NCHRH). The NCHRH was envisioned as an overarching body with nominated members to look after physician practice, accreditation, and academic matters related to curricula of medical doctors, nurses and paramedical personnel. The idea was to ensure complementarity, modernisation and adherence to standards. In October 2012, the Parliamentary Standing Committee returned the draft NCHRH bill to the Ministry of Health to reexamine three major concerns: (i) the states' autonomy and potential violation of federal principles<sup>(13)</sup>; (ii) excessive bureaucratisation and centralisation; and (iii) faulty selection procedure of regulators, providing scope for abuse. Rather than seizing the opportunity to come up with a better draft, the ministry, for the third time, reconstituted the Board of Governors with a retired Director General of Health Sciences as chair and kept the main proposal in cold storage<sup>(14)</sup>.

The NEET examination was an equally sad story. As students are subjected to multiple examinations for an admission

into a medical college entailing stress and expense, and also because it was found that the standards of basic education were of varied quality, it was felt that one national entrance examination for qualifying for admission into a medical college would be in the interests of the meritorious and deserving. The proposal provided for a merit list out of which the students were to be selected based on merit and in adherence to the various quotas.

The NEET was to be followed by another national examination at the end of training to qualify for being registered by the MCI. By these two measures, it was envisioned to standardise the quality of the Indian doctor – ie certify to the people that the doctor licensed by the MCI had basic capabilities, skills and competencies needed for a doctor, irrespective of which college he or she was trained in. This was an attempt to smoothen the huge disparities in educational standards in different medical colleges of the country and give the Indian doctor a brand value.

The MCI orders on conducting NEET were challenged by 90 medical colleges in the Supreme Court. A three-judge bench, with one judge dissenting<sup>(15)</sup>, declared by a strange logic that the MCI had no authority to impose this test and more so in the case of minority colleges, as it amounted to interfering with the rights accorded by the Constitution. Even though this proposal benefited students, promoted standards and ensured better patient care and enhanced social benefit, yet it could not be implemented as in effect it would curtail the freedom of private managements to cherry pick their students based on their ability to pay.

Crass commercialisation of medical education apart, what is of equal concern is unethical practice. This is related to the process of becoming a doctor. After paying Rs one crore for a seat, the graduating doctor has to earn it back not by ethical practice but by resorting to dubious means of kickbacks and cut-practice, made easier due to lax oversight over such deviant behaviour.

An overall decline in values has also affected the public health system. The policy of permitting government doctors the right to private practice is one that has vitiated and undermined the delivery system in the public sector. The logic of this policy is that since the government is unable to provide market determined salaries, doctors should be allowed to practise privately during their off hours to increase their earnings. It should be noted that no other government employee or professional enjoys such consideration. Yet, the doctors have abused this trust: absenteeism is high, with facilities having no doctors when needed, treatment in the public facilities is abrupt and unkind so as to push the patient to avail of good treatment to their private clinics; equipment and drugs to be supplied to the poor free of cost are diverted to their clinics, while in hospitals, expensive equipment is deliberately spoilt so as to force the patients to go to their preferred diagnostic centres for tests and so on; making the creeping privatisation of the public system inevitable. In order to permit such deviant behaviour, bribes are paid to the supervising officers and

an array of politicians, making transfers, appointments and promotions that are routine administrative matters, the most political action due to the huge possibilities for rent-seeking. So no matter what the government does, provides and aspires for, the public health system continues to be in a crisis, with the poor who rely on it continuing to incur huge expenses in seeking private care.

### What next?

Policy-making is politics and an arena of huge conflicts of interest. For example, Members of Parliament or their associates running medical and nursing colleges or private nursing homes create a conflict of interest in discussing reform of the professional education in health or any policy measures that could hurt the commercial interests of their constituency, such as supporting the creation of a community doctor. And when there is rent-seeking behaviour by the ruling powers then it is ensured that no laws are either enacted or enforced. In several government committees, eg those on food safety or regulation of medical devices, under the guise of partnership with stakeholders, lobbyists and those to be regulated are made members, leading to the charge of regulatory capture. Such people then do not allow laws to be stringent.

What is needed today is to bring ethical values back to centre-stage by raising peoples' awareness and encouraging greater transparency and public disclosure. What is required is a public policy that strongly incentivises ethical behaviour and reward those several doctors, nurses and officials who have not allowed themselves to be lured by money and find satisfaction in rendering service. What is needed is for the government to enact a strong public health law and regulations that would bring in greater accountability and curtail malpractice.

Of equal importance is the need to reform and revamp the MCI on the lines of the British General Medical Council (GMC), which not only ensures academic standards but also enforces physician behaviour along ethical norms. Most urgently, the elected body must be replaced with a nominated one. The Board of Governors of the BMC are selected by a public authority, like the Union Public Service Commission, from out of applications received. The Body is also much more diverse containing representatives of the lay public, patient groups, medical college student representatives, doctors, etc. The BMC also enjoys functional autonomy while all its proceedings are placed in the public domain. Unlike India, college inspections are not a one-time event but held throughout the year to ensure that the quality of education being provided is consistently maintained. Government control is confined to the appointment of the Board and intimating the Council the number of doctors and specialists, discipline-wise, that are required to be produced.

### Conclusion

There is an urgent need to reform the health sector; yet, the system is unable to undertake the process. While the struggle for probity and high ethical standards has to be led by the medical profession, there is an equal need for the political system to respond to the issues mentioned above and so eloquently described by MacAskill et al in their article (7) that talks of rampant fraud in medical schools. For the future sustainability of the health system in India, there is an urgent need to initiate the process of reform and restructuring in such a manner that distortions are minimised and health outcomes realised.

**Note**<sup>1</sup> This was during the author's tenure as Union Health Secretary.

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## REVIEWS

## India's development story: unfounded apprehensions?

VACHASPATI SHUKLA

**Jean Drèze and Amartya Sen. *An uncertain glory: India and its contradictions*. Penguin India, 2013. ISBN 9781846147616. Hard cover. INR 699.**

This book attempts to evaluate the implications of the recent economic growth in India for improvement in the living standards of the masses. According to Drèze and Sen, India's recent economic growth is, indeed, quite remarkable; however, its celebration is contemptible, given its limited translation into better living conditions for the people. One indication that something has been wrong with India's development strategy is the fact that it has started falling behind every other South Asian country in terms of social indicators, despite doing so well on the economic front. A comparison between Bangladesh and India offers evidence of this. India experienced higher economic growth than Bangladesh in the last two decades, in terms of per capita income, which was 60% higher than that in Bangladesh in 1990 and 98% higher in 2010. However, during the same period, Bangladesh overtook India in terms of a wide range of basic social indicators: life expectancy, child survival, fertility rates and immunisation rates. Bangladesh surpassed India even in certain educational indicators, such as the estimated "mean years of schooling". The authors present their analysis mainly in chapters 3–8. Chapter 3 deals with how poorly India fares on social development indicators in relation to poorer nations of the world. Chapter 4 discusses the lack of accountability in India's public sector and the prevalence of corruption. The next three chapters (5–7) discuss education, the healthcare crisis and poverty. In Chapter 8, the authors discuss the various forms of inequality in India.

The authors recognise the neglect of education in India, judging by international standards, both in terms of coverage and quality. They argue for universalisation of high-quality education. The proper evaluation and monitoring of teachers and students, along with the provision of an adequate number of teachers and basic infrastructure are ways to accomplish this. The evaluation of teaching should be aimed at restoring the accountability of the schooling system; this would certainly facilitate the attainment of the larger educational goal. Students' evaluation

tests need not be intended mainly to put pressure on children; they should aid us in determining the kind of help, attention or encouragement particular children or schools need. The poor health outcome, attributed to State negligence, is identified as another sector that requires serious attention.

The central message of the book is that growth per se is not sufficient to transform the living conditions of the underprivileged. Adequate attention must be paid to how the growth is shared or how far it visibly changes the quality of life. It is also important to recognise that the nature of the growth process – sectoral composition and employment intensity – as well as of public policy designed to enable the common people to experience the benefits of growth have a crucial influence on the impact of economic growth on living standards. In addition, Drèze and Sen emphasise the needs and rights of the underprivileged to receive greater attention in public discussion and policy-making. The authors put part of the blame on the media as well. They allege that rather than trying to diagnose the issues related to the lives of the Indian masses, the media celebrates only the rich and powerful, perhaps because it is an advertisement-driven business.

One could say that the book presents facts without providing any in-depth analysis of the same. For instance, it is a well-known fact that India has failed to perform well on many fronts despite its higher economic growth in relation to the rest of the South Asian countries, and evidence of this can be found in the various reports of the World Bank. However, what is expected of a scholarly exercise in terms of offering probable explanations for the observed state of affairs is largely missing in the book. Prior to offering any policy suggestion, it is necessary to undertake an in-depth analysis to discover the reasons behind such poor performance. It is possible that the reason for the slow progress with respect to some indicators is that the earlier regimes were negligent about making promotion efforts. An apt example could be the abysmal performance of the healthcare system, which cannot be set right unless it is duly regulated and monitored. Such measures remained a neglected domain even during the pre-reform periods. While a book of this kind serves as a glossary of evidence, it would be more rewarding to locate the factors responsible for the disappointing evidence and measures to alleviate them.

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# Making those hard decisions – for people and the environment

ADITHYA PRADYUMNA

**Resnik DB. *Environmental health ethics*. New York: Cambridge University Press; 2012. ISBN 9781107617896. 305 p. Paperback. INR 1994.**

Ethics in the field of environmental health deals not just with dilemmas involving individuals and groups of people, but also between people and the rest of the natural world, compounding the challenges. Resnik's *Environmental health ethics* is written to serve as a "starting point," "calling attention to important issues...and dilemmas," and to provide a framework for ethical decision-making on issues relevant to environmental health. On each of those grounds, the book delivers well and in a succinct manner. This is also probably the first book devoted exclusively to this important subject, moving as it does beyond the traditional boundaries of public health ethics. While the bulk of the book is on the application of the proposed ethical framework to issues concerning environmental health, ethical theory, too, is discussed. The author includes other environmental thinkers' critique of his framework, thus displaying a good deal of transparency about his line of thought.

With regard to decisions that concern economic development on the one side and human and environmental well-being on the other, the author opines that some degree of mutual compromise is necessary. He holds that this can be the objective result of an ethical framework dealing with multiple competing values. His approach is based on an "enlightened form of anthropocentrism," one that gives a higher value to human concerns but also gives independent value to concerns of animal welfare and the larger natural world. It is akin to a critical type of environmental pragmatism, encouraging discussion on deeper moral differences and avoiding quick-fix solutions (1). The principles on which the framework is based: human rights, utility, justice, animal welfare, stewardship, sustainability and precaution.

Resnik goes on to discuss the realistic options available in each case, scrutinising them using current evidence and his framework. The apparent short-term benefits are weighed against longer term consequences, and it is suggested that decisions be revisited in the light of new evidence. While recommending a balance between competing values, he adds that decisions should be consistent, withstand criticism from

the public, and be based on distributive and procedural justice.

He starts with a familiar issue – vector control and the use of pesticides – in which the conflict between the health impacts of vectors against those of pesticides is apparent. Importantly, other issues such as population size or the consumption of meat, which are either relatively challenging or unfamiliar to the average public health professional, are included in this discourse.

Some of Resnik's conclusions are debatable. For instance, questionably, he allows for the use of genetically modified foods (after "adequate measures" have been taken to mitigate and prevent risks) for their role in food security and economic growth. The inappropriateness of this technology for developing countries (2) and the threats posed (through direct and indirect mechanisms) to global food security and health are known (3). In that context, the author's application of the principle of "precaution" also needs further discussion – which may be the most contentious part of the framework. Mainstream technology has assumed the guise of a saviour in dealing with social problems in developing countries, and the zeal for its promotion (4) has superseded any need for reflection, or for stringent checks and balances (5). There is a need to learn from previous developmental programmes which had disastrous consequences on biodiversity and communities (6).

In the author's words, "much more work remains to be done." Environmental health concerns range from individual well-being to the survival of life in general. More than any other time in history, we have reached a stage in which people are having a catastrophic impact on the global environment, and are also systematically oppressing groups of people and other species, in the name of efficiency, development and the greater good. It is very difficult to be aware of latent prejudices (7), and this may hold true in the context of how people perceive of the environment as well. It is possible and not unlikely that in the near future, the priority given to each of the competing ethical principles will be different, with several authorities already recommending an urgent paradigm shift in development thinking (8). The Sustainable Development Goals are potentially the first global step towards such a shift.

This book is relevant to practitioners and students of public health, the environmental sciences, engineering, the agricultural sciences and philosophy, as well as industrialists and policy-makers. It provides first-time readers with a technical input on the subject, and would serve to stimulate a debate among professionals. There is, indeed, a gigantic gap between ethics and decision-making, which necessitates discussion striving to narrow the gap.

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# To believe or not to believe: the onlooker's role in cases of sexual boundary violations

RAKHI GHOSHAL

**Who would you believe? Director: Sunita Simon Kurpad. Supported by: The Institutional Ethics Review Board, St John's Medical College, Bengaluru, 18 minutes**

Available from: <http://sjri.res.in/hhResources>

This triple-tiered 18-minute documentary explores the issue of sexual boundary violation (SBV) in the healthcare setting. SBV is a complex terrain and the evaluation of the incidents falling in its domain rely on the imperatives of objective, rational and legal decision-making as these incidents are often considered an individual's subjective perception of a gesture, an activity or spoken words. Consequently, it is not uncommon to find those acting as decision-makers and the jury getting caught in the slippage between *their* perception of the accuser's "perception" and the objectivity warranted by the law. In the process, the "reality"/"truth" of SBV gets lost.

It is this complexity that the documentary captures. It decidedly portrays rather "grey" character, ie it abstains from portraying a voiceless, meek victim against an obviously evil perpetrator. Instead, it makes use of a somewhat reverse characterisation, thus approximating to real-life situations as closely as possible.

In the first section of the film, a 20-year-old female patient narrates how her 62-year-old male surgeon came to check on her on the eve of her surgery, but without a chaperone. The doctor did not record this examination in the case notes either. The patient was left initially confused, and then shaken when he used "more hands than stethoscope" to palpate her chest. The conversation that follows takes place in an interesting mode, with the characters talking about themselves in the third person. It is a triologue between the surgeon, the patient and a nurse (who forwarded the patient's complaint to the hospital authorities), and it acquaints us with certain facets of each character.

The surgeon has a very clean record, his female secretary has never reported having had any problems in working with him, and he argues that he is being targeted as he comes from a different state. The nurse allegedly holds a grudge against the surgeon for he had reprimanded her for her work some time ago; also, she is a local person. The patient is apparently vivacious and admittedly flirted with the ward boys, male patients and doctors. Having thus significantly "greyed" the characters, the first section of the film ends here, leaving the audience uncertain as to who to believe.

Taking this uncertainty regarding "who to believe" as the point of departure, the next section acquaints us with a "real life case". A close friend and colleague of the Canadian doctor, Dr Paul Garfinkel, had been accused of gross sexual misconduct by a female patient. However, Dr Garfinkel unquestioningly supported him, believing that he knew his friend thoroughly. When he eventually learnt that the sexual violation had indeed

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taken place, he was left devastated. The accused had not only violated the trust of his patient, but also that of his friend, who felt that he had contributed to the violation of the woman by initially believing her to be a fabricator. In this case, Dr Garfinkel was an involved onlooker, and it is indeed easy for such people to get caught in the slippage between what an unknown victim claims and what they believe they know about their own friend(s).

The final section explores this emotional quandary through an interview with a clinical psychologist, Dr Tanya Machado, who speaks of a similar experience she had had. Dr Machado shares the plight of the involved onlooker, who is often fooled by the outward charm of the seemingly respectable perpetrator, and the former ends up re-victimising the victim by denying her/him even the benefit of the doubt.

The documentary examines the location of a very crucial player in cases of SBV – of the involved onlooker. S/he is an engaged party, who has the power either to strengthen the voice of victims by believing them or to make them feel doubly violated and let down. The involved onlooker is a microcosm of

society, which tends to commonly err even when something seems apparent, and is known for its inclination to reject claims made by women who are “too” lively, “too” friendly and who defy social stereotypes in any way.

So, who to believe? The documentary provides no definite answer, but serves its purpose well through its very open-endedness. This film can be used as a potent tool in courses/sessions on medical sensitisation and medical humanities. SBV is an alarmingly widespread malaise that is eating into the integrity of several professions, and the higher the power imbalance between the service provider and the recipient, the more intense it tends to become. It is much more a question of a display of power than of sexual gratification. The power relation between the two parties is clearly skewed, and it is the responsibility of society – commonly individualised and embodied by a few people who are close to either the accused or accuser, or both – to decide on action so that justice is delivered, the victims are not further abused, their rights are restored, and finally and most importantly, instances of such violations are reduced.

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## LETTERS

**Non-psychiatrists practising psychiatry in India: ethical concerns**

The deficit of psychiatrists in India is about 77%, which is a huge gap especially in the context of the enormous burden of psychiatric morbidity (1). Unfortunately, this gap is being filled by an under-skilled or unskilled workforce. Self-proclaimed/unqualified psychologists, psychotherapists, life coaches, social workers and counsellors are not authorised in their professional capacity to deliver mental healthcare. Similarly, practitioners of alternative medicine and traditional/religious/faith healers are not competent to provide mental health care. Finally, non-psychiatric non-specialist/specialist/super-specialist doctors who are not sufficiently trained to diagnose and treat psychiatric disorders treat mentally ill patients. To attract patients, these practitioners inadvertently or intentionally take advantage of the stigma associated with being treated by psychiatrists (2). In the process, inadequate and inapt care is meted out to a lot of mentally ill patients.

There is no provision for licensing/regulation of clinical psychology and its practice. No accreditation or proof of adequate supervision is deemed necessary for offering psychological services (3). Bonafide clinical psychologists merely form the tip of the iceberg, with MA-level psychologists, counsellors, special educators, teachers, anganwadi workers and others offering similar services (3). As against this, psychiatrists are required to register their postgraduate qualification with the Medical Council of India, as well as obtain a license before offering inpatient services. Given the poor state of mental health literacy in India, most people do not appreciate the difference between a "psychiatrist" and a "psychologist". It is not uncommon to find mental health departments of multispecialty hospitals in metropolitan centres being headed and run by psychologists (with or without the required expertise) as convenient and cheaper substitutes for psychiatrists. A recent newspaper report also indicated the illegitimate and rampant practice of the mental health profession by ill-qualified persons posing as counsellors and life-coaches (4).

About 25% of patients that consult general physicians have active, diagnosable psychiatric illnesses; and neurologists in adult ambulatory settings can expect this proportion to be 40% (5). Though increasingly the border between neurology and psychiatry is getting blurred (6), the fact is that the two remain distinct specialties, as is clear from the 10th revision of the International Classification of Diseases, where Chapter V deals with psychiatric disorders, and Chapter VI with diseases of the nervous system. Although assessment of mental status is an integral part of a neurological examination, neurologists are not sufficiently trained to analyse behavioural elements (6). Neurologists are not entitled in their capability to diagnose

and treat primary mental illnesses. Treatment in psychiatry involves much more than just prescribing psychotropic agents and reducing overt symptoms. However, it is widely known that several neurologists in India treat psychiatric patients; this is subtly accepted by the society as well as the medical fraternity. Is this practice not a breach of professional ethics by neurologists?

Ideally, optimal mental health services are best delivered by a team led by a psychiatrist. Based on the setting, the team may have a clinical psychologist, a psychiatric nurse, an occupational therapist and a psychiatric social worker. After a thorough diagnostic assessment that incorporates physical, mental and social factors, the psychiatrist may recommend initiation of psychological or social intervention delivered by a member of the team with the most appropriate skills (7). Clinical psychologists practising independently should collaborate and liaise with psychiatrists for diagnostic and pharmacological considerations, and in a best-case scenario should only consider diagnosed cases referred to them by psychiatrists, rather than assessing and diagnosing patients first-hand. Mandatory regulation and licensing for clinical psychologists could be a way to check the quack practice of psychology by unqualified individuals.

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## Indie insanity – misrepresentation of psychiatric illness in mainstream Indian cinema

Indian cinema has progressed in the recent past. Many directors have broken the mould of the typical “masala” film and their cinema resonates with real life. However, the representation of psychiatric illnesses and psychiatrists in Indian films still reflects the populist melodrama.

Indian films often follow a template comprising elements of heroism, romance, villainy, song and action sequences randomly strung together without any attempt at showing reality (1). In this background, psychiatric illnesses lend themselves to a colourful portrayal. Psychiatric patients are often depicted as “psycho-killers” in mainstream Indian films. They show traits of psychosis, dissociative personality, dis-social personality disorder and poly-substance abuse. These individuals are devious, fiendishly clever and capable of maintaining an intact alter-ego which the people closest to them cannot penetrate. For instance, the Tamil film *Nadunisi Naygal* caricatures a patient with schizophrenia as a serial killer. Conversely, psychiatric patients are at increased risk of being the victims of homicide, perpetrated by their “sane” counterparts (2). The few murders committed by mentally ill individuals are often characterised by lack of secrecy, planning or a clear motive (3).

On the large screen, psychiatric patients who are not homicidal maniacs are either a source of comic relief or serve as objects of horror and pathos. Their symptoms are often shown as transient mood swings associated with complete amnesia, three-dimensional “audio-visual” hallucinations or childish regression. The Tamil film *Three* showed all the above symptoms as representative of bipolar disorder in the protagonist, who finally ends up killing himself, to save his beloved from his “madness”.

Aetiology of mental illness is another area of gross misrepresentation. While the “nature versus nurture” debate is well known, vernacular films implicate life events as the cause of all psychological symptoms. Raving cinematic insanity is produced by stressors ranging from childhood adversities, being jilted by one’s romantic interest or a blow to the head, as in the Hindi film *Tere Naam*.

While doctors are often reduced to caricatures in Indian films, psychiatrists are further relinquished to the realms of the bizarre (4). Psychiatrists are sometimes rendered as naively comical characters, devoid of common sense. More sober representations of psychiatrists depict them as incompetent jargon-spouters administering intrusive and ineffective treatments. The Hindi film *Kyon Ki*, set largely in a psychiatric hospital, depicts different psychiatrists engaging in unethical behaviour ranging from singing romantic duets with patients, rendering them brain dead by dubious scientific procedures to mercy killing them in secret to relieve them of “unbearable” symptoms. A recent film *Kick* even depicts a “psychotherapy session” providing a prelude to a song and dance number between the patient and the therapist set in a bar.

The cinematic “management” of psychiatric patients involves

seclusion and often includes highly sedative and debilitating drugs. In *Kyon Ki*, a “joint-therapy” session by two psychiatrists focuses on helping patients re-live traumatic life events through a song sequence. Such interventions lead to dramatic resolution of symptoms and cure through reunion with loved ones. In other cases, a bleak prognosis is depicted with life-long institutionalisation or death through suicide. While such turn of events may lead to box office success, they do not reflect reality.

Specifically, electroconvulsive therapy (ECT) has been portrayed cinematically as a form of torture used by the medical community as a means of punishing the patient or as a means to induce insanity among healthy individuals (5). As in *Kyon Ki*, ECT is mostly administered cinematically without consent and is completely unmodified. Patients are depicted as developing mental disturbance with the treatment and are seldom shown to benefit from ECT. Such a depiction of a potentially safe, life-saving intervention, will only serve to decrease its acceptance among patients and their caregivers.

Films tend to influence the masses and such depiction reinforces stigma and misconceptions about a vulnerable population. Sometimes, however, actors do their homework before performing such roles. For example, *Taare Zameen Par* portrayed dyslexia with sensitivity and scientific credibility. Such films get critical acclaim as well as commercial success.

In the UK, the “Time to Change” campaign has addressed the misrepresentations of psychiatric illnesses by the media. This campaign has reported success in reducing discrimination experienced by individuals using mental health services (6). Similar efforts are required in India to discourage gross misinformation and misrepresentation. Film-makers should treat these subjects with the respect and sensitivity they deserve.

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### Continuing dental education (CDE) points: serious concerns

This letter raises some serious issues about continuing dental education (CDE) points instituted by the Dental Council of India (DCI) – the apex body that regulates dental education. The DCI has recommended 150 CDE points over a period of 5 years with a minimum of 20 points a year and a maximum of 50 points annually (1).

In India, CDE points are awarded to dental professionals only for attending lectures or conferences or workshops (1), whereas CDE points should also be awarded for publishing and reviewing articles in indexed national and international journals (2). Since August 1, 2011, the American Association of Oral and Maxillofacial Surgeons is offering CDE credits for reviewing manuscripts for the *Journal of Oral and Maxillofacial Surgery* (3). Reviewers may earn 1.0 CDE credit per review and up to a maximum of 12 reviews per volume, ie 12 credits per year (3). The Academy of General Dentistry is also offering CDE credits for reviewing manuscripts for the *Journal of General Dentistry* (4). These journals are also offering CDE points for readers (3,4).

In India, dental professionals in the government health sector (ie in dental colleges and hospitals) are working with feasible salary and fresh younger dental undergraduates work with meagre salaries in the private health sector, and many opt for other better-paying jobs (5). On the other hand, some dental colleges, after they get recognition of BDS/MDS degrees, remove their teaching staff abruptly leading to vacant staff positions for a considerable time. They deprive the students of jobs and lower teaching standards (6).

Postgraduates in dentistry have to spend an exorbitant sum for attending national and international specialty conferences to

get the essential CDE points (7). It was observed that specialty national conferences were accredited with 18 CDE points for a 3-day conference (8).

The DCI should conduct a study on the living standards of dental surgeons working in the private health sector in India. Based on the results, the DCI should revise the CDE points for dental professionals.

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## OBITUARY

### Dr Ranjit Roy Chaudhury (1930–2015)

Dr Ranjit Roy Chaudhury passed away on October 27, 2015 at the age of 85, literally with his boots on. He breathed his last after having just arrived in Chennai to deliver a speech on pharmacovigilance at a local medical college hospital.

The several awards he received during his long and active life included the Vishisht Bihari Samman in 2012, an award that came just in time to honour and reclaim the distinguished son of Bihar. For it was in Patna's (then) Prince of Wales Medical College that Dr Roy Chaudhury took his first degree (medicine in 1954), before going on to Oxford on a Rhodes scholarship for his D Phil degree. Decades later, in an interview to NDTV, he was to say, "The person I admire *the* most is Professor EP Abraham, who was my tutor at Oxford. He was a member of the team which discovered 'penicillin' at Oxford and then went on to discover cephalosporin. He remained a simple, unassuming person till the end and donated all the earnings from cephalosporins and his own house to the University of Oxford." (1).

On his return to India, Dr Roy Chaudhury was associated with the All India Institute of Medical Sciences (AIIMS), New Delhi; with the Post Graduate Institute of Medical Education and Research (PGIMER), Chandigarh, where he became the head of the Department of Pharmacology at the age of 34 years and together with his colleagues, set up India's/Asia's first DM course in clinical pharmacology in 1978; with the ICMR, where he helped in the clinical evaluation of medicinal plants; with the National Institute of Immunology (NII), New Delhi where he was Emeritus Scientist since 1991; and with the Government of India as part of several committees over the past four decades. He was a member of the committees that drafted the ICMR's ethical guidelines for research on humans in 1980, and again, in 1994. The 1980s saw him holding a series of responsibilities and carrying out several assignments on deputation with the WHO, including in Geneva, Burma and Thailand.

He published regularly: he had 275 publications in national and international journals, and authored 25 textbooks on medical education. The last book I know of was titled *The healing powers of herbs* (Sterling; 2007, reprint 2011) dedicated to his better half.



The first time I met him was around 1980 in PGI in Chandigarh, where he was Dean and Professor of Pharmacology. I had gone for some work to PGI and the director of the organisation I was working for in Delhi, an American Chinese Jesuit, had insisted that I meet his most brilliant student, whom he had taught in St Xavier's School in Class 8. (Subsequently, when I narrated this to Dr Roy Chaudhury, he said the Jesuit priest had taught him in Class 1!). When I finally met Dr Roy Chaudhury at PGI, he was the Herr Professor in full bloom. He gave the impression that he would suffer no fools and would not tolerate even the most negligible non sequiturs in articulation. My host, a senior professional in his own right, got a severe dressing down in my presence as I had dragged him in, leaving me red-faced. In the light of this incident, I tried my best to avoid Dr Roy Chaudhury in later years – to my loss, as it turned out – despite the fact that several friends spoke of what a wonderful person he was and how he was not your typical lofty, high-handed medical college don.

My next exposure to Dr Roy Chaudhury was around 1993, when I read a WHO monograph, *Herbal medicine for human health* (SEARO, No. 20, 1991), authored by him. It was a short 94-page monograph that laid out the canvas of issues and challenges involved in making the wealth of traditional medicinal plants available in regular clinical practice. The passion for making traditional knowledge available was to return and this issue became a recurring theme in the next 20 years of his life.

Dr Roy Chaudhury was a good committee man and a good chair, who knew how to wring out something that could be implemented even when it came to difficult issues. Inevitably, therefore, he was a member or chair of government committees the key words of which were medical teaching, pharmacology, toxicology, medicinal plants, rational use of medicine, etc. A former health secretary who was a schoolmate of mine confirmed in an informal chat on some contentious issue that if Dr Roy Chaudhury was the chair, "Don't worry, he will find a way out."

Almost the last of the committees that he chaired came out with the Report to Formulate Policy and Guidelines for

Approval of New Drugs, Clinical Trials and Banning of Drugs (July 2013). The report covered a wide range of issues, but received a mixed reception from various stakeholders. I, too, disagreed on certain points. I wrote about these in the *Hindu Business Line* and much to my chagrin, the business paper provocatively titled my piece "A muddled view of clinical trials." (2).

Muddled it was not, at least for the most part. It was an understandable compromise, but nevertheless a statement of intent. Dr Roy Chaudhury was clear that notwithstanding the 2500-plus deaths in clinical trials in recent years, deaths and serious adverse events (SAEs) could be minimised, despite problems in establishing causal links between the clinical trials, SAEs and deaths. The report did not worry about trials of new chemical entities (NCEs) originating abroad. It endorsed the Schedule Y amendment of 2005 allowing concomitant phase 2 and 3 trials of NCEs. According to some of us at least, the removal in 2005 of the phase lag in clinical trials was the major cause of the more than 2500 deaths in the post-2005 clinical trials of NCEs discovered abroad. The report also recommended accreditation of clinical investigators, ethics committees in institutes and research institutes for carrying out clinical trials. It endorsed audiovisual recording of the informed consent process, recommended bridging phase 3 trials and bio equivalence studies for first-time generics and made many remarks on compensation for SAEs and deaths related to clinical trials.

Soon afterwards, the government introduced desultory, assorted measures to regulate clinical trials, often tagged with the phrase "as recommended by the Ranjit Roy Chaudhury Report." However, various industry lobbies and a few well-meaning civil society organisations have wrongly considered these measures to be responsible for the decrease in clinical trials and the inflow of new useful drugs into the country.

Dr Roy Chaudhury was justifiably proud when in January 2015, he narrated to me how he and his fellow Governing Board members (of 2010-13) at the Medical Council of India (MCI) had almost made history of the "whole scandal of borrowed faculty, fake patients, floating libraries and borrowed equipment which had made our assessment [of new medical colleges] a farce" (3). This was when the Government of India made an attempt to clean up the mess in the MCI. This scandal in medical education, which continues today, would indeed have been history if he and his colleagues had been allowed to continue for another couple of years.

Twenty years earlier, in the mid-1990s, this kind of let-us-do-what-we-can spirit had resulted in the establishment by Dr Roy Chaudhury and younger colleagues of the Delhi Society

for Promotion of Rational Use of Drugs (DSPRUD). The DSPRUD was the first body with full-time medical college professors, in contrast to civil society activists, and it took the lead in actively promoting the rational use of medicines through advocacy, training and consultation to state governments (4). About the same time, Dr Roy Chaudhury's association with the then Health Minister of the Delhi state government, Dr Harsh Vardhan, resulted in the announcement of the state government's drug policy (1994). This included, among other things, a pooled procurement system for efficient and cost-effective procurement of medicines. It also covered several other ingredients of a comprehensive, rational drug policy (5,6, 7). For a long time, the Delhi government experiment, now in need of resuscitation, was cited, together with a similar effort of the Tamil Nadu government, as a model for pooled procurement of medicines.

"A good doctor," Dr Roy Chaudhury said in the NDTV interview (1) "has to be good and up-to-date in his professional work. Therefore, he should be a competent doctor. The second most important attribute is compassion. You cannot be a good doctor without compassion." He had both qualities.

Dr Roy Chaudhury is survived by his life companion, Dr Mandakini Roy Chaudhury, three sons, and his devoted and beloved dog, Wolfie.

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