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

M R 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 The draconian Narcotic Drugs and Psychotropic Substances (NDPS) Act of 1985, outdated medical and nursing education, lack of public awareness and lack of clear governmental policy are responsible for this sorry state of affairs.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.

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To cite: Rajagopal MR. Access to palliative care: insights into ground realities post-2014 amendment to NDPS Act. *Indian J Med Ethics*. 2016 Jan-Mar; NS1(1): 25-30.

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 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?

Acknowledgment

I gratefully acknowledge the valuable secretarial assistance of Ms Jeena Manoj.

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India: not a country to die in

ROOP GURSAHANI, RAJ KUMAR MANI

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.

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To cite: Gursahani R, Mani RK. India: not a country to die in. *Indian J Med Ethics*; 2016 Jan-Mar; NS1(1): 30-5.

> *Yaksha: What is the greatest wonder?*
>
> *Yudhishthira: 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