- 3. Bhaumik S. Unbanked direct blood transfusions should be legal, say Indian surgeons. *BMJ*. 2013;347:f5623. doi:10.1136/bmj.f5623.
- Dogra B. Blood for health's sake. The Hindu [Internet], September 8, 2013 [cited 2016May 16]. Available from: http://www.thehindu.com/ todays-paper/tp-miscellaneous/tp-others/blood-for-healths-sake/ article5105867.ece
- Tongaonkar RR. Scope and limitations of rural surgery. Ind J Surg. 2003;65(1):24–9
- American Red Cross. Autologous and Directed Donations [Internet] [cited 2016 May 16]. Available from: http://www.redcrossblood.org/donating-blood/types-donations/autologous-and-directed
- New York Blood Center.Autologous and Directed Blood Donation. [Internet] [cited 2016 May 16]. Available from: http://nybloodcenter.org/products-services/blood-products/
- Blood transfusion: Medicines Sans Frontiers, 2010. Available from: http://refbooks.msf.org/msf_docs/en/transfusion/transfusion_en.pdf[Accessed on Nov 7, 2013
- Dhot PS. Amendments to the Indian Drugs and Cosmetics Act and Rules pertaining to Blood Banks in Armed Forces. Med J Armed Forces India. 2005;61:264–66.
- 10. Kataria R, Jain Y. Blood transfusion services in India safety or access do we need to choose? Submitted to NMJI, 2013, In press.
- 11. World Health Organization. Towards 100% voluntary blood donation, a global framework for action. Geneva, Switzerland: WHO; 2010.
- 12. Weiskopf RB, Ness PM. Transfusion for remote damage control resuscitation. *Transfusion*. 2013;53(1):8–12. doi:10.1111/trf.12018.
- 13. Vidal CA. Appropriate health technology. *Bull Pan Am Health Organ*. 1978;12(3):201–10.
- National Vector Borne Diseases Control Programme. Training module for malaria technical supervisor. New Delhi: DGHS, Ministry of Health and Family Welfare; 2012.
- DGHS, Ministry of Health and Family Welfare. Job functions of health worker female/ANM. Indian Public Health Standards. Guidelines for Subcenters, Revised 2012. New Delhi: MoHFW; 2012
- Mavalankar D, Vora KS. The changing role of Auxiliary Nurse Midwife (ANM) in India: implications for Maternal and Child Health (MCH), WP no: 2008-03-01, Indian Institute of Management; 2008.
- Kihaile PE, Mbaruku G, Pemba S. Improved maternal and perinatal mortalities by trained medical assistant staffs in Rural Tanzania. J Health Med Informat. 2013:S11:007. doi:10.4172/2157-7420.S11-007
- 18. Lassi ZS, Cometto G, Huicho L, Bhutta ZA. Quality of care provided by

- mid-level health workers: systematic review and meta-analysis. *Bull World Health Organ*. 2013,91(11):824-833. doi: 10.2471/BLT.13.118786.
- 19. Wilkinson D, Sach ME. Cost-effective on-site screening for anemia in pregnancy in primary care clinics. South African Med J. 1997;87(4):463–5.
- Anemia detection methods in low resource settings, A manual for health workers, by PATH. December 1997 [cited 2013 Nov 20]. Pp 17–20.
 Available from: http://www.path.org/publications/files/TS_anemia_ guide_health_workers.pdf
- Tongaonkar RR, Sanders DL, Kingsnorth AN. Ten-Year Personal Experience of Using Low Density Polyethylene (LDPE) Mesh for Inguinal Hernia Repair. Trop Med Surg. 2013; 1:136. doi: 10.4172/2329-9088.1000136.
- Mulholland EK, Simoes EA, Costales MO, McGrath EJ, Manalac EM, Gove S.Standardized diagnosis of pneumonia in developing countries. *Pediatr Infect Dis J.* 1992;11(2):77–81.
- National guidelines on the use of rapid diagnostic tests (RDT) in the diagnosis of malaria [cited 2016 May 16]. Available from: http://www.gov.bw/Global/MOH/NATIONAL%20GUIDELINES%20 ON%20THE%20USE%20OF%20RAPID%20DIAGNOSISTIC%20TESTS. doc
- 24. Malhotra S, Zodpey SP, Chandra S, Vashist RP, Satyanaryana S, Zachariah R, Harries AD. Should sputum smear examination be carried out at the end of the intensive phase and end of treatment in sputum smear negative pulmonary TB patients? *PLoS One.* 2012;7(11):e49238. doi: 10.1371/journal.pone.0049238. Epub 2012 Nov 9.
- 25. Arbyn M, Sankaranarayanan R, Muwonge R, Keita N, Dolo A, Mbalawa CG, Nouhou H, Sakande B, Wesley R, Somanathan T, Sharma A, Shastri S, Basu P. Pooled analysis of the accuracy of five cervical cancer screening tests assessed in eleven studies in Africa and India. *Int J Cancer*. 2008;123(1):153–60. doi: 10.1002/ijc.23489.
- Supreme Court of India: Common Cause vs Union of India and others on 4 January, 1996, Case No: Writ Petition (civil) 91 of 1992 [cited 2016 March 28]. Available from: https://indiankanoon.org/doc/1449517/
- Friedman M. Medical licensure. In: Capitalism and Freedom; 1962, excerpted in Freedom Daily 1994 [cited 2016 May 16]. Available from: http://fff.org/explore-freedom/article/freedom-daily-classic-reprint-medical-licensure/

The urgent need for advance directives in India

RAVINDRA B GHOOI, KELLY DHRU, SHEELA JAYWANT

Abstract

Many individuals at the end of life are unable to convey their wishes regarding medical treatments. Advance directives (ADs) or living wills (LWs) allow them to crystallise their wishes in a written form so that these can be carried out if the relevant situation arises. In many countries, ADs are legally valid and enforceable;

Authors: Scientia Clinical Services, G 801, Rohan Nilay, Aundh, Pune 411 007, INDIA – Ravindra B Ghooi (corresponding author - ravindra.ghooi@gmail.com); Research Foundation for Governance, 3, Brahmin Mitra Mandal Society, Mangaldas Road, Ellisbridge, Ahmedabad – 380 006, Gujarat, INDIA – Kelly Dhru (kellydhru@gmail.com), Director and Advocate; Freelance writer and columnist, 96/6, Mae de Deus, Sangolda, Bardez, Goa, 403 511, INDIA – Sheela Jaywant (cmjaywant@gmail.com).

To cite: Ghooi RB, Dhru K, Jaywant S. The urgent need for advance directives in India. *Indian J Med Ethics*. 2016 Oct-Dec;1(4) NS:242-9.

©Indian Journal of Medical Ethics 2016

they reduce the use of life-sustaining treatments, which often merely prolong life without improving or even maintaining the quality of life. Such treatment puts a financial burden on the patient's family, often leading to penury. Resources are limited, the more so in countries like ours, and should be spent only when/ where they can make a difference. The general public is not well versed in the advantages and disadvantages of life-sustaining treatments and needs to be educated on how to distinguish between them. A well-designed legislation for legalising ADs would help society at large. In addition to legalising ADs, some countries are contemplating making them compulsory. We could learn from them and empower our citizens by giving them the right to self-determination at the end of life.

Introduction

An advance directive (AD) or living will (LW) is a document prepared by a person to instruct doctors and caregivers on what must be done and not done if and when that person is no longer able to take decisions on their own health on account of illness or incapacity (1). Such a document is important because a person's life may reach a point at which attempts to prolong it are futile, and may only compromise the dignity and quality of life (2). An AD is not to be confused with a normal "will", which becomes operational after the death of an individual. An AD becomes operational when the individual is still alive, albeit incapacitated, and is, therefore, also known as the "living will".

An AD is legally valid and enforceable in the USA (3), Canada, Australia and many countries across Europe (4). ADs have been endorsed by the United Nations Convention on the Rights of Persons with Disabilities (5). Whereas more than half of the citizens of the USA have ADs, the concept is virtually unknown in India. We have no statute on ADs; thus a person may prepare one, but it is not legally enforceable. Doctors and caregivers are not bound to follow it, and there is no legal recourse in a court of law. In fact, the fear of the law is a crucial reason for ignoring ADs, even if they exist (6). There is also a possibility that the treating doctors and the patients or their families have different perceptions of what can be considered futile treatment (7). Since there is no law on ADs, and the legal implications of end-of-life care are not taught in medical schools, there is ignorance and doubt regarding how to react under such circumstances (8).

There are strong reasons to support the legalisation of ADs. ADs lighten the burden on the family members and medical personnel when crucial decisions need to be taken at the end of life. These documents also help to make scarce resources available for the treatment of needy patients with curable conditions, instead of wasting the same on futile therapy. In India, where most medical expenses are out of pocket (9), such directives may ease the financial strain on the patient's family due to mounting medical bills (10). They also ensure the autonomy of the patient at a time when the individual is at his most vulnerable.

The Supreme Court recently asked the Central Government whether "a terminally ill person, medically diagnosed to be in the last stages of life, could be kept alive on life support system, even though he had willed against it." The Court felt that such an action could amount to torture and be financially draining for the person's family, thus opening the inconclusive debate on passive euthanasia, which the Bombay High Court had initiated in the Aruna Shanbaug case (11). A detailed analysis of legal implications and the status of cases like those of Aruna Shanbaug has appeared recently (12), In the on-going case of Common Cause vs Union of India, a Constitutional Bench of the Supreme Court has stated that the matter has to be debated in Parliament first. In the light of this, the Ministry of Health and Family Welfare has released a draft Bill on the medical treatment for terminally ill patients for public consultation, which expressly makes ADs void (13).

History

At the heart of the debate lies the question of whether we can make a choice about our own death. One strand of thought mentioned in the Aruna Shanbaug case is that our society is too emotional to allow for such a choice. This concern is not valid.

Indian mythology is replete with stories of people who had been given the boon of "ichha mrutyu". Such persons could choose the time and place of their death. Though there are major differences between "ichha mrutyu" and ADs, the similarity is that an individual can control the circumstances of his last days and death. Certain saints took "samadhi", inviting death by forsaking food and water or burying themselves alive. In Indian culture "samadhi" is a respected method of dying that is never equated with suicide, though the end result is the same.

Different philosophies have viewed the issue of ending life very differently. While the concept of choosing death is found in ancient Greek philosophy (14), Judaism and Islam do not support suicide in any form (15). Suicide was unlawful in the country and any attempt to take one's life was treated as a crime, though this has come under criticism for a long time (16). The Rajya Sabha has passed a bill to decriminalize suicide in August this year. Among western cultures, too, support for suicide is sporadic. No one is brought into this world at their request, nor should they be forced to continue here against their wishes.

ADs were first proposed by Luis Kutner (17). The concept evolved as a corollary to property law, under which a person can control property affairs after his death. It was suggested that somewhat similarly, persons could express and control their healthcare wishes when they were not in a position to do so. Since the contents of the document were to be made operational while the person was alive, it was called the "living will".

LWs soon became popular in the USA and most states passed laws in their support. These were embraced by the population and the Patient Self-Determination Act was passed in 1990. The provisions of this Act ensure that healthcare providers:

- Provide all adult patients, residents and enrollees written information on their rights under state law to make decisions concerning medical care, including the right to execute an AD, as well as maintain the policies of the provider on the implementation of ADs
- Document in the patient's medical record whether they have an AD
- Educate the staff and community on ADs
- Do not make the provision of care dependent on whether a patient has an AD or discriminate otherwise on this basis
- Ensure compliance with the state's law on ADs.

Any discussion on ADs usually brings passive euthanasia into focus, and many recognise that the AD could eventually lead to this practice (18). Three cases in the USA brought the issue of ADs and euthanasia centre stage. To a large extent, they helped establish the role of ADs while defining the circumstances in which passive euthanasia could be considered. The Karen Ann Quinlan case helped to strengthen the link between ADs and passive euthanasia (19), which is the logical extension of the

AD. In the Nancy Cruzan case, the appointment of a proxy by a patient, in the absence of an AD, was considered legally valid (20). In the Terry Schiavo case, there was a conflict between two close relatives – the husband and the parents. The US courts upheld the petition of the husband (21). These cases helped to clarify the concept of ADs. In time, these documents were modified to make them more relevant.

Legal conflicts also brought home the fact that ADs had certain lacunae. They had limited scope, were often in conflict with the standard of medical care, and reflected the thinking of the person at one particular point in time. ADs made in the 1980s or 1990s may have been at variance with the individual's thinking at a later time in their life and needed to be regularly updated. Legal proceedings in these cases and the lacunae that had been identified gave rise to the second generation of ADs.

The second generation of ADs had an added feature, the power of attorney. Any individual could name a relative or friend to take proxy decisions, in case the individual was incapable of doing so. Here, the proxy plays the same role as that of the "legally authorised representative" in the consent process for research. Two problems remained unsolved. First, how correctly and clearly did the proxy understand the wishes of the individual? Second, would the proxies substitute the patient's wishes with their own? Some studies showed that the instructions given to proxies were vague and guesswork by the relatives was often inaccurate (22).

Third-generation ADs were introduced to overcome the deficits. Predictably, the length of ADs grew and many variants were prepared. One of the most acceptable is "Five Wishes", prepared by Aging with Dignity, an NGO (23). The body of this directive addresses five major concerns in the form of wishes. They are:

Wish 1: The person I want to make care decisions for me when I can't

Wish 2: The kind of medical treatment I want or don't want

Wish 3: How comfortable I want to be

Wish 4: How I want people to treat me

Wish 5: What I want my loved ones to know.

Five wishes is one of the most widely known and accepted ADs, and has been endorsed by a variety of organisations, including Mother Theresa's Missionaries of Charity.

Role of the AD

In the USA, nearly two million people are confined to nursing homes (24) and over 1.4 million survive only with the help of feeding tubes and other aggressive medical interventions (25). As many as 30,000 persons are kept alive in comatose and permanently vegetative states (26). Many of them have no ADs which would allow doctors to withdraw or withhold life-sustaining treatments. The USA is among the few nations to have both federal and state laws on ADs, which, if used

judiciously, could help to avoid the expense of keeping people in a persistent vegetative state (27).

A typical AD says: "If I suffer an incurable, irreversible disease or condition and am unable to convey my wishes to the doctors, I direct that life-sustaining measures that serve only to prolong my life be withheld or discontinued." ADs are essential and become effective if the subject is unable to express their wishes at the relevant time. Thus, old ADs cannot override the wishes of patients if they are competent to convey them to the medical team. ADs may require certain actions to be taken or not taken; they may demand one of the following courses of action.

- 1. The AD asks for life-prolonging measures.
- 2. The AD asks for life support to be withheld or withdrawn.
- The AD opts for "do not resuscitate (DNR)".

The first option does not fall foul of the law, but the subsequent ones do in countries like India, which do not allow withholding or withdrawal of life-sustaining treatments or euthanasia. Thus, any discussion on ADs leads to a discussion on euthanasia. It is, therefore, pertinent to examine the various types and the legal status of euthanasia.

As discussed in the Aruna Shanbaug case, euthanasia is classified as either "active" or "passive". In the former, the patient's death is brought about by the administration of a toxic substance, while in the latter it is brought about by withdrawing or withholding life-prolonging treatment. Active euthanasia is allowed in very few countries and the following discussion is only about passive euthanasia.

Another classification divides euthanasia on the basis of the patient's wishes, into involuntary, non-voluntary and voluntary euthanasia. In the first, death is brought about against the wishes of the patient or his/her near relatives. This is considered an offence in most countries. In non-voluntary euthanasia, the patient or relatives have not specifically asked for euthanasia, but death is brought about. This contentious form of euthanasia was the core issue in the Aruna Shanbaug case. In voluntary euthanasia, death is brought about at the request of the patient or near relatives. Most activists are seeking the legalisation of this form.

ADs in India

ADs have no sanction in India. Indian law does not recognise the AD as a legally enforceable document. Even in the new draft bill, Section 11 explicitly states that ADs are void. Various organisations are pressing the government to make ADs legally acceptable. There are very few studies or reports on this issue, since people hesitate to voice their opinions due to fear of punitive action (28).

Unfortunately, the issue is nowhere near resolution in spite of the draft bill. The principle of euthanasia has been tested in India. The Supreme Court has pronounced its opinion at least thrice, but in no case has the principle of euthanasia received legal acceptance in its entirety, and there has been no decision on the status of ADs.

In the existing jurisprudence, the Supreme Court has held that active euthanasia is not compatible with Articles 14 and 21 of the Indian Constitution. The status of passive euthanasia is still unclear. In the Naresh Marotrao Sakhre vs Union of India case (1994), the Bombay High Court held: "Euthanasia or mercy killing is nothing but homicide, whatever the circumstances in which it is effected" (29). In another case, the court clearly mentioned that Article 21 guarantees only the right to life and personal liberty and the right to die cannot be included in it (30). The court made a significant departure from practice by declaring that passive euthanasia was permissible in the Aruna Shanbaug case in 2011. The matter is now before the Constitutional Bench, which has referred it to Parliament (31). In the Aruna Shanbaug case, there was no record of the patient having made an AD and she could not convey her wishes when in a persistent vegetative state (PVS). Her relatives had forsaken her and she was cared for by the staff of the KEM Hospital, Mumbai. In the expert panel's deposition, ADs were mentioned, but the Hon'ble Justices Katju and Mishra made no reference to them in their judgment.

Energetic debates on passive euthanasia followed the Shanbaug case judgment. There was a need to clarify concepts such as end-of-life care, medical futility, palliative care and proxy decision. The need to clarify these concepts was brought out by Chakravarty and Kapoor (7). They defined the circumstances in which a therapy could be judged as futile; however, there was a doubt as to whether medical futility can be accurately predicted. Mishra et al (32) showed that preventilation variables and indications for respiratory support can be used to predict medical futility accurately in 77% cases, which should be considered a good level of predictability, given the uncertainty of life.

Even though ADs have no legal sanction in India, the demand for them has been sustained in psychiatry. The Law Commission, in its 241st report, made strong observations on the existing law (33), and Sarin et al wrote about the role of ADs in psychiatry and the challenges faced in this regard in India (34). Due to the pressure from practising psychiatrists and the obsolescence of the Mental Health Act of 1987, the new Mental Healthcare Bill, 2013, was introduced in Parliament. The Bill, which is still under consideration, permits one to prepare an AD for use, if and when affected by a mental disorder. It provides every person the right to make an AD, empowering them to decide how s/he should and should not be cared for/ treated in the event of a mental illness in the future (35). It provides detailed procedures for registering/revoking such directives and the conditions in which they may be overridden. This Bill could be an indication that the government may not be as opposed to ADs as before.

It is widely believed that passive euthanasia is practised in India, but since its legality is questionable, there are no reports or confessions from physicians who have practised it. Withholding and withdrawing life-sustaining measures are by definition clubbed together as passive euthanasia, though physicians withhold rather than withdraw such treatments

more often. This differential preference means that there is a need to separate the two. Clubbing them together is not in line with the perspective of physicians (36). Palliative experts seem to reject the concept of passive euthanasia, and practise the same while calling it terminal or palliative sedation (37).

Decades ago, the doyenne of palliative care, Dame Cicely Saunders, expressed strong opinions against euthanasia, partly because she was a devout Christian and partly because it is always possible to control pain (38). She felt that specialists in palliative care could use their knowledge to prevent pain and distress towards the end, and that the term "passive euthanasia" was both confusing and unfortunate (39). It was the term rather than the act that she objected to.

Pallium India, an NGO working in the field of palliative medicine, wrote in its newsletter (December 2011) that ADs would be an appropriate way to prevent inappropriate treatment. The newsletter added that it is not too early for Indians to start thinking about ADs (40). Semi-structured interviews showed that psychiatric ADs are associated with positive outcomes for some service seekers, but the tool may require adaptation to make it more suitable for the Indian environment (41).

In India, many people have limited resources and the public-funded health service is poor. Almost 80% of outpatient and 60% of indoor healthcare is controlled by the private sector (42). The public sector is by and large overburdened and inefficient, and provides poor service. The private sector is superior but expensive, and treatment may continue beyond a reasonable period if patients or their families are paying for it. The duration and cost of treatment is in the hands of the attending physicians; there is no way of preventing the administration of futile treatment.

Studies on the impact of serious diseases have shown that 10% and 25% of the families of patients with cardiovascular and neoplastic disease, respectively, are driven to poverty due to out-of-pocket health expenses, because 30.5% of healthcare expenditure is made by the government while 69.5% is privately funded (43). It becomes necessary to carefully balance the need to prolong the life of the patient against driving the family to penury.

In the absence of ADs, many critically ill patients receive aggressive medical interventions for a variety of reasons. In some cases, private corporate hospitals see this as a means of boosting their income. Some physicians believe it is their moral duty to deploy every means in their possession to prolong life. The financial impact of this "futile" treatment is so severe that people with little or no health insurance seek medical help in public hospitals rather than expensive private ones (44).

The principle of autonomy demands that the patient alone has the right to decide what is done to them. Recent studies in South Korea have shown that towards the end, the patient is more concerned with the quality rather than the quantity of life. When the ADs of patients were recorded in a hospice, 89%

chose palliative sedation in favour of aggressive life-sustaining treatment. A large number of patients wanted their spouse to decide their fate, demonstrating that there is a high level of acceptance of proxies (45).

Though ADs have no legal sanctity in India, some people prepare them nonetheless. A few studies revealed that end-of-life preferences were closely associated with age and religion, and healthcare professionals emphasised aspects that were different from those stressed by patients (46). People of Indian origin appeared less inclined to prepare ADs than Caucasians (47).

The Supreme Court's verdict in the Aruna Shanbaug case has clarified that passive euthanasia involving the withholding or withdrawal of life-prolonging treatments will be allowed with the caveat that it is done only with the permission of the high courts. Some things are unclear. If an individual asks for withholding of life-prolonging treatments, should the doctors first comply with the patient's request or seek the high court's opinion? What is to be done in the interim period? In any case, the applicability in such cases of the *parens patriae* doctrine, which views the State as the "parent", is itself debatable.

DNR is another related concept, which applies in only certain cases. A DNR order in a patient's file means that resuscitation is not required if the heart stops. It is designed to prevent unnecessary suffering. The usual circumstances in which DNR is appropriate are:

- when efforts to restart the heart or breathing will not succeed
- when there is no benefit to the patient
- when the benefits are outweighed by the burdens.

The last option of an AD (to continue treatment till death overtakes the patient) will be honoured if the patient or family are paying for the treatment. What will happen in publicly funded hospitals is anybody's guess. It is worth mentioning that Aruna Shanbaug was being looked after in a publicly funded hospital for 42-odd years. She was a staff nurse when she was attacked and slipped into a PVS. The hospital staff members looked after her meticulously for such a long period possibly because she had become an icon for them. Whether the hospital would have taken so much trouble for a patient who was not connected with it is a matter of speculation, particularly since such hospitals have few resources and beds.

Risks of ADs

A common argument against ADs and passive euthanasia is that India is not developed enough or that our people are not mature enough to prevent their misuse. This argument is put forward whenever there is no other rational argument against change. In most situations, Indians claim to be superior to others due to their cultural heritage, but when confronted with change, they talk about the immaturity of the Indian population. The claim of immaturity is one that cannot be adequately challenged due to its obscure nature.

As for the possible misuse of ADs, any AD has the potential to

be misused, particularly in countries with large socioeconomic inequalities and a high rate of illiteracy. However, the mere existence of the possibility of misuse should not deter us. In India, there are three ways in which we can bring about the required changes: (i) through the bureaucracy, (ii) through the legislature, and (iii) through the judiciary. The last is often the best, if not the fastest. With the current case pending before a Constitutional Bench of the Supreme Court (referred to it by a smaller bench), the buck is being passed, and the judiciary has been waiting for the legislature to draft a law.

Among the arguments against adopting ADs is the slippery slope hypothesis. Once logical ADs become acceptable, slowly less logical ones and finally, illogical ones would become the norm. People would make more and more bizarre directives and the medical profession would have no option but to follow them. A comprehensive legislation defining acceptable and unacceptable directives will need to be put in place before ADs can be made effective. However, unless ADs are considered seriously, no legislation is likely to be drafted on permissible directives, and ADs cannot be made legal till such legislation is in place. This harks back to the old chicken or egg problem: which comes first?

An important clause in ADs in the USA is the appointment of a proxy. Any individual can appoint a proxy to take a decision on their medical management in case the individual is not in a position to do so. Opponents of ADs doubt the honesty and integrity of proxies, particularly in situations in which the proxy may have vested interests. It has also been shown that proxies do not necessarily understand the directions of the patients who, in any case, may not be clear about their wishes. Thus, there is a risk that proxies substitute their own wishes for those of the patients. This risk is universal and not restricted to India.

Another argument used to counter ADs is that life is a gift of God and shall not be terminated without His will. The authors do not claim to be religious experts, but would like to point out that religious texts support both sides of the same argument. One part of a text recommends "an eye for an eye and a tooth for a tooth"; elsewhere, the same text suggests that one should proffer the other cheek when one is slapped. The interpretation of religious canon has had unfortunate outcomes in many countries. To cite one, abortion is prohibited on religious grounds even if the life of the mother is in serious danger.

In India, no debate on ADs and euthanasia has reached an acceptable conclusion. The attempt to prevent euthanasia from becoming a way of life leads to the denial of the right to self-determination in the form of ADs.

The death of Aruna Shanbaug on May 18, 2015 sparked a fresh debate on euthanasia. For the KEM nurses, her survival was an act of faith that cannot be challenged on a scientific or legal basis. Setting aside their selfless devotion to Aruna, a few questions beg answers.

1. The care of Aruna entailed the use of resources that could have been put to better use for other patients. If the

- hospital had more such cases, would it have been able to devote the same support, care and resources to them?
- 2. By keeping her in a PVS, what did the hospital, doctors and nurses achieve?
- 3. She was very well cared for. In all those years, she did not develop a single bed sore. Was there, however, any improvement in the quality of her life?
- 4. The report of the expert committee said she was aware of her environment. Was she in pain or any physical distress that she could not convey to her caregivers?
- 5. Is it moral to condemn an individual to a vegetative state for 42 years, denying the escape of death?

Some believe that Aruna was provided palliative care, but this is stretching the definition of palliative care too far. Palliative care in its true sense must improve the quality and not the quantity of life. In Aruna's case, the quantity of life was increased without an iota of improvement in its quality. The care that she received, whatever it may be known as, was not palliative care.

The new Bill: salient features

The Ministry of Health and Family Welfare has placed The Medical Treatment of Terminally III Patients (Protection of Patients and Medical Practitioners) Bill for public consideration. Section 3 of the Bill allows competent patients to make an informed decision on the withholding or withdrawal of medical treatment. It provides that death resulting from this choice would not be punishable under the Indian Penal Code.

However, in Section 11, ADs are declared void. A patient is allowed to make a choice at the time of illness, but not in advance. This section takes away all the powers that the Bill intended to give patients, and should be deleted. The Bill makes it mandatory for people to seek the court's permission before taking such decisions on behalf of incompetent patients. This Bill looks upon the court as *parens patriae*, which is problematic.

Challenges ahead

One of the biggest challenges in this field is the inconsistency in the definitions of different types of euthanasia and even palliative care (48). There is confusion between passive euthanasia and physician-assisted suicide. Not many are clear about the difference between the two, if any exists (49). In fact, passive euthanasia can be practised even where it is not allowed. Some practitioners deny this, merely by calling it by another name. It is necessary to emphasise that the use of terminal sedation, sometimes known as double effect, is challenged on the basis of the intention of the practitioner (50). If the practitioner knows that terminal sedation can cause death, then it would be more appropriate to call it euthanasia and more accurate to call it active euthanasia. The argument that the intention was not to cause death is specious. Even in Belgium, a survey showed that terminal sedation is used when

passive euthanasia is not practical, showing the similarity between the two (51).

It is recognised that passive euthanasia means bringing about death either by withholding supportive therapy or withdrawing it (52). One is an act of omission and the other an act of commission. A survey of physicians serving in intensive care units (ICUs) in Asia revealed that 75% of them perceived that there is a difference between withholding and withdrawing support. Most of them accepted withholding rather than withdrawal of treatment (36). There is a debate on whether the withdrawal of treatment causes death or allows death to take place, thus raising the doubt as to whether it constitutes active or passive euthanasia. Such debates need to be settled so that the physician in the ICU is free to decide, rather than getting bogged down with these arguments (53). Most physicians reject the ethical analysis that withholding and withdrawing treatment are the same (54).

The presently accepted definitions and understanding of death and dying have been constructed by professional bodies, or arrived at through surveys and interviews of focus groups. The understanding of issues such as euthanasia changes over time and the perceptions regarding them are dynamic (55). In India, care for dying individuals is very poor (56); it has been suggested that retired nurses be employed as "death midwives", perhaps with a better title (57). Yet in each of these models, the need to empower the patient by allowing for self-determination is keenly felt. Doctors also have a duty towards the dying patient and must decide when to terminate the patient's life. They should not and are not bound to consider that it is their duty to prolong life and provide care indefinitely (11).

Conclusions

There is a need for ADs and directives such as DNR, as they benefit patients, their families and institutions too. Patients have to be educated on ADs and DNR policies, their import, and their risks and benefits before they can make a choice or prepare them. These need to be made legal and enforceable even if it becomes necessary to re-examine passive euthanasia or the withholding or withdrawal of treatment, or similar practices called by another name. It is illogical to deny people the right to take decisions on end-of-life care because of the existing rules. There is also a need to differentiate between the withholding and the withdrawal of life support; the two are clubbed together at present, but need to be separated. Withholding is an act of omission; the other is an act of commission. ADs are expected to give patients and their families a say in what is to be done in case artificial means become necessary for prolonging life. The draft bill on the medical treatment of terminally ill patients should be amended by dropping Section 11, which makes ADs legally void. Just because a person is incapable of conveying their wishes in a medical crisis, previously drafted ADs cannot be declared void. People must have a right to decide whether or not lifeprolonging treatment should be used in the terminal stage. The Constitution gives us the right to life; this should be extended to give us a say at the end of life, too. Individuals should be permitted to record their wishes in advance or nominate a close relative/friend to take a decision on their behalf, when necessary.

The authors are aware that not everyone will agree with their views. That is not the expectation either. Even if our paper gives rise to arguments and debates about ADs, it would have served its purpose.

Declaration: Competing interests and funding support: None.

This work is not a part of another work that is either published or is to be published here or elsewhere.

References

- Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EJ. Advance directives for medical care – a case for greater use. N Engl J Med. 1991;324(13):889–95.
- Cherniack EP. Increasing use of DNR orders in the elderly worldwide: whose choice is it?[Internet]. J Med Ethics. 2002 Oct;28(5):303-7 [cited 2016 Sep 10]. Available from: http://jme.bmj.com/content/33/5/261.full
- Cornell University Law School. Legal Information Institute. 42 CFR 422.128 – Information on advance directives [cited 2016 Mar 13]. Available from: https://www.law.cornell.edu/cfr/text/42/422.128
- 4. Barta H, Kalchschmid G. Advance directives in Europe. *Wien Klin Wochenschr.* 2004;116(13):442–57. German.
- UNCRPD India. United Nations Convention on the rights of persons with disabilities: an advocacy initiative for its implementation in India [Internet], October 2007 [cited 2016 Mar 13]. Available from: http:// uncrpdindia.org/
- Mani RK. Constitutional and legal protection for life support limitation in India. *Indian J Palliat Care*. 2015;21(3):258–61. doi: 10.4103/0973-1075.164903.
- 7. Chakravarty A, Kapoor P. Concepts and debates in end-of-life care. *Indian J Med Ethics*. 2012; 9(3):202–6.
- 8. Parker M, Wilmot L, White B, Williams G, Cartwright C. Medical education and law: withholding/withdrawing treatment from adults without capacity. *Intern Med J.* 2015;45(6):634–40. doi: 10.1111/imj.12759.
- Patel V, Parikh R, Nandraj S, Balasubramaniam P, Narayan K, Paul VK, Kumar AK, Chatterjee M, Reddy KS. Assuring health coverage for all in India [Internet]. Lancet. 2015;386 (10011):2422–35. doi: 10.1016/ S0140-6736(15)00955-1[cited 2016 Sep 10]. Available from: http:// www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)00955-1/fulltext
- Quintussi M, Van de Poel E, Panda P, Rutten F. Economic consequences of ill-health for households in northern rural India. BMC Health Serv Res. 2015;15:179.doi: 10.1186/s12913-015-0833-0. Available from: http://link.springer.com/article/10.1186/s12913-015-0833-0
- 11. Shukla R. Passive euthanasia in India: a critique. *Indian J Med Ethics*. 2016:13(1):35–8.
- 12. Kishore RR. Aruna Shanbaug and the right to die with dignity: the battle continues. *Indian J Med Ethics*. 2016 Jan-Mar;1(1) NS:38-46.
- PTI. No order on euthanasia, Supreme Court leaves it open for government to take call [Internet]. February 15, 2016 [cited 2016 Mar 13]. Available from: http://www.dnaindia.com/india/report-no-orderon-euthanasia-supreme-court-leaves-it-open-for-government-to-takecall-2178136
- Laios K, Tsoukalas G, Kontaxaki MI, Karamanou M, Androutsos G. Suicide in ancient Greece. Psychiatriki. 2014;25(3):200–7.
- Isgandarova N. Physician-assisted suicide and other forms of euthanasia in Islamic spiritual care. J Pastoral Care Counsel. 2015; 69(4):215–21. doi:10.1177/1542305015616099.
- 16. Trivedi JK. Punishing attempted suicide anachronism of twentieth century. *Indian J Psychiatry*. 1997; 39(2):87–9.
- 17. Kutner L. Due process of euthanasia: the living will, a proposal. *Indiana Law Journal*. 1969;44(1):539–54.
- Lappé M. Dying while living: a critique of allowing-to-die legislation. J Med Ethics. 1978;4(4):195–9.

- 19. Quinlan J. History of Karen Ann Quinlan and the Memorial Foundation[Internet] [cited 2016 Mar 13]. Available from: http://www.karenannguinlanhospice.org/history
- Cruzan v Director, Missouri Department of Health. 497 U.S. 261; 110 S. Ct. 2841; 111 L. Ed. 2d 224; 1990 U.S. LEXIS 3301; 58 U.S.L.W. 4916.
- 21. Mamdani B. The Terry Schiavo case: possible implications for India. *Indian J Med Ethics*. 2005; 2(3):97–8.
- Hare J, Pratt C, Nelson C. Agreement between patients and their self-selected surrogates on difficult medical decisions [Internet]. Arch Intern Med.1992 May;152(5):1049–54. [cited 2016 Sep 10]. Available from: http://archinte.jamanetwork.com/article.aspx?articleid=616257
- 23. Aging with Dignity. Five wishes, aging with dignity [cited 2016 Mar 13]. Available from: http://www.agingwithdignity.org/five-wishes.php
- 24. Wilkes JL. Nursing home nightmares. USA Today. August 20, 1996.
- 25. American Academy of Neurology. Practice parameters: assessment and management of patients in the persistent vegetative state (summary statement). *Neurology*. 1995;45(5):1015–18.
- Covinsky KE, Goldman L, Cook EF, Oye R, Desbiens N, Reding D, Fulkerson W, Connors AF Jr, Lynn J, Phillips RS. The impact of serious illness on patients' families. *JAMA*.1994;272(23):1839–44.
- Links to State-Specific Advance Directive Forms, 2014 [cited 2016 Mar 13]. Available from: http://www.americanbar.org/content/dam/aba/ administrative/law_aging/Links_to_State_Advance_Directive_Forms. authcheckdam.pdf
- 28. Datta R, Chaturvedi R, Rudra A, Jaideep CN. End of life issues in the intensive care units [Internet]. *Medical Journal Armed Forces India*. 1993 Jan;69(1):48-53.[cited 2016 Sep 10]. Available from: http://www.mjafi.net/article/S0377-1237(12)00163-3/pdf
- Naresh Marotrao Sakhre and Ors vs Union of India and Ors.1996 (1) Bom CR 92, 1995 Cri LJ 96, 1994 (2) Mh Lj 1850[cited 2016 Sep 10]. Available from: https://indiankanoon.org/doc/1453319/
- Smt Gian Kaur vs State of Punjab (1996) [cited 2016 Mar 13]. Available from: http://indiankanoon.org/doc/217501/
- Court Ruling, Aruna Shanbaug vs. Union of India, March 7, 2011 in the Supreme Court of India [cited 2016 Mar 13]. Available from: http://indiankanoon.org/doc/235821/
- 32. Mishra S, Bhatnagar S, Gupta D, Goyal GN, Agarwal R, Jain R, Chauhan H. Respiratory support in oncology ward setting: a prospective descriptive study. *Am J Hosp Palliat Care*. 2009;26(3):159–64. doi: 10.1177/1049909108330032.
- Law Commission of India. Report No 241. Passive euthanasia a relook [Internet]. Aug 2012[cited 2016 Sep 10]. Available from: http://lawcommissionofindia.nic.in/reports/report241.pdf
- 34. Sarin A, Murthy P, Chatterjee S. Psychiatric advance directives: potential challenges in India. *Indian J Med Ethics*. 2012;9(2):104–7.
- 35. Dhanasekaran S, Kar SK, Tripathi A, The Mental Health Care Bill: changes and appraisal. *Delhi Psychiatry J.* 2014;17(1):160–6.
- Phua J, Joynt GM, Nishimura M, Deng Y, Myatra SN, Chan YH, Binh NG, Tan CC, Faruq MO, Arabi YM, Wahjuprajitno B, Liu SF, Hashemian SM, Kashif W, Staworn D, Palo JE, Koh Y; ACME Study Investigators and the Asian Critical Care Clinical Trials Group. Withholding and withdrawal of life sustaining treatments in intensive care units in Asia. *JAMA Intern Med*. 2015;175(3):363–71. doi: 10.1001/jamainternmed.2014.7386.
- Indian Association of Palliative Care. Position statement on euthanasia [Internet] [cited 2016 Mar 13]. Available from: www.palliativecare.in/wp-content/uploads/2014/10/IAPC-position –statement-on-euthanasia. pdf
- 38. Richmond C. Dame Cicely Saunders. BMJ. 2005;331:238.
- Saunders C. Euthanasia definition, dangers and alternatives. Ann Acad Med Singapore. 1994;23(2):300–3.
- Pallium India. Avoiding inappropriate health care with advance directives. Pallium India Newsletter December 20, 2011.
- Shields LS, Pathare S, van Zelst SDM, Dijkkamp S, Narasimhan L, Bunders JG. Unpacking the psychiatric advance directive in low-resource settings: an exploratory qualitative study in Tamil Nadu, India [Internet]. Int J Ment Health Syst. 2013;7(1):29. doi: 10.1186/1752-4458-7-29 [cited 2016 Sep 10]. Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3877945/
- 42. National Health Policy 2015 Draft [Internet][cited 2016 Mar 13]. Available from: http://www.vhai.org/ceo/Draft-NHP-2015.pdf
- 43. Thakur J, Prinja S, Garg CC, Mendis S, Menabde N. Social and economic

- implications of noncommunicable diseases in India. *Indian J Community Med*. 2011;36(Suppl 1):S13–22. doi: 10.4103/0970-0218.94704.
- 44. Savitha S, Kiran K. Health seeking behaviour in Karnataka: does microhealth insurance matter? *Indian J Community Med.* 2013;38(4):217–22. doi:10.4103/0970-0218.120156.
- 45. Kong BH, An HJ, Kim HS, Ha SY, Kim IK, Lee JE, Park YJ, Kang YJ, Kim YR, Kim HK. Experience of advance directives in a hospice center. *J Korean Med Sci.* 2015;30(2):151–4. doi: 10.3346/jkms.2015.30.2.151.
- Chacko R, Anand JR, Rajan A, John S, Jeyaseelan V. End-of-life care perspectives of patients and health professionals in an Indian healthcare setting. *Int J Palliat Nurs*. 2014;20(11):557–64. doi: 10.12968/ ijpn.2014.20.11.557.
- 47. Doorenbos AZ, Nies MA.The use of advance directives in a population of Asian Indian Hindus. *J Transcult Nurs* 2003;14(1):17–24.
- 48. Radbruch L, Leget C, Bahr P, Müller-Busch C, Ellershaw J, de Conno F, Vanden Berghe P; board members of the EAPC. Euthanasia and physician-assisted suicide: a white paper from the European Association for Palliat Care. *Palliat Med.* 2016 Feb;30(2):104–16. doi: 10.1177/0269216315616524.
- Cuervo Pinna MÁ, Rubio M, Altisent Trota R, Rocafort Gil J, Gómez Sancho M. Qualitative research about euthanasia concept, between Spanish doctors. Rev Calid Asist. 2016 Jan-Feb;31(1):18–26. doi:10.1016/j. cali.2015.07.002. Spanish.
- Ngo L, Kelly M, Coutlee CG, Carter RM, Sinnott-Armstrong W, Huettel SA.
 Two distinct moral mechanisms for ascribing and denying intentionality.

- Sci Rep. 2015 Dec 4;5:17390. doi: 10.1038/srep17390.
- Robijn L, Chambaere K, Raus K, Rietjens J, Deliens L. Reasons for continuous sedation until death in cancer patients: a qualitative interview study. Eur J Cancer Care (Engl). 2015 Oct 29. doi: 10.1111/ ecc.12405.
- Barilan YM. Rethinking the withholding/withdrawing distinction: the cultural construction of "life-support" and the framing of end-of-life decisions. *Multidiscip Respir Med*. 2015;10(1):10. doi: 10.1186/s40248-015-0004-5.eCollection 2015
- McGee A. Does withdrawing life-sustaining treatment cause death or allow the patient to die? Med Law Rev. 2014 Winter;22(1):26–47. doi: 10.1093/medlaw/fwt034.
- 54. Wilkinson D, Savulescu J. A costly separation between withdrawing and withholding treatment in intensive care. *Bioethics*. 2014 Mar;28(3):127–37. doi: 10.1111/j.1467-8519.2012.01981.x.
- Raisio H, Vartiainen P, Jekunen A. Defining a good death: a deliberative democratic view. J Palliat Care. 2015;31(3):158–65.
- 56. Gursahani R, Mani RK. India: not a country to die in. *Indian J Med Ethics*. 2016;13(1):30–5.
- 57. Jaywant S. The caregivers' point of view. *Indian J Med Ethics*. 2016;13(1):23–5.

A reproductive justice perspective on the Purvi Patel case

RAJANI BHATIA

In the spring of 2015, news media across the world displayed images of a young, South Asian American woman in handcuffs, her long, untied black hair flowing forward and shielding her face as a Caucasian male police officer led her into a US court room. In another image, mug shot frontal and profile views of her face as a criminal, dotted online press reports, blogs and the social media. Although criminalised people of colour occupy a permanent space in the US media, her image jars. What is a young woman from a so-called "model minority" doing in handcuffs?

Early reports focused on the technicalities of the case. In the summer of 2013, Purvi Patel visited a hospital in South Bend, Indiana, in need of care. The doctors, recognising the signs of a recently terminated pregnancy, somehow suspected Patel of wrongdoing, and called the police. What followed was a series of attempts to locate the foetus and interrogate Patel. Patel has maintained that she suffered a miscarriage. Prosecutors in Indiana charged her with two crimes – foeticide and child neglect. Convicted for both, she will serve 20 years in prison (1,2).

Author: Women's, Gender and Sexuality Studies, **State University of New York at Albany**, Social Science-353, 1400 Washington Ave., Albany, NY 12222, USA – Rajani Bhatia (rbhatia2@albany.edu), Assistant Professor.

To cite: Bhatia R. A reproductive justice perspective of the Purvi Patel case. *Indian J Med Ethics*. 2016 Oct -Dec;1(4) NS:249-53.

Published online on May 19, 2016.

© Indian Journal of Medical Ethics 2016

The case was remarkable for two major reasons. First, Patel holds the unsavoury distinction of being the first woman in the US convicted of the crime of foeticide. Second, the Indiana state prosecutor managed to successfully convince the jury of two apparently contradictory felony charges against her – that she conducted an illegal abortion and that she neglected her live baby. While the jurors deliberated on whether the recovered dead foetus had once lived, media commentary in the aftermath of Patel's conviction tried to make sense of the stunning success and convergence of two separate antiabortion strategies. Among these, a very small number focused on the relevance of Patel's national/ethnic identity.

Conceptualised by women of colour activists in the USA, reproductive justice takes as its central concern the consistently devalued reproduction of disadvantaged groups. Advocates focus on the right to have and raise children in supporting environments just as much as the right not to have them. Broad-based by definition, reproductive justice movements in the USA account for multiple and intersecting oppressions faced by communities of colour (3). To contrast reproductive justice from a service delivery model of reproductive health, and a legal and advocacy model of reproductive rights focused on the individual, Asian Communities for Reproductive Justice (ACRJ) elaborated as follows.

The Reproductive Justice framework is rooted in the recognition of the histories of reproductive oppression and abuse in all communities, and in the case of ACRJ, in the histories of Asian