

Advance Directives in India: Seeking the Individual within the Community

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पुनरपि जननं पुनरपि मरणं,
पुनरपि जननी जठरे शयनम्।
इह संसारे बहु दुस्तारे,
कृपयाऽपारे पाहि मुरारे॥

(Born again, dead again, born again to stay in the mother's womb. It is indeed hard to cross this boundless ocean of samsara. Oh Lord! Redeem me through thy mercy.)

– “*Bhaja Govindam*”, Adi Sankara, Eighth Century

6.1 Introduction

The legal regime surrounding advance directives (ADs) and living wills in India took a long journey to reach where it is, and yet the journey remains incomplete. Legal recognition of end-of-life ADs in India is usually seen as closely tied to questions of the legalisation of passive euthanasia and decriminalisation of suicide attempts. Much of the literature has overemphasised the connection between euthanasia and ADs, particularly because they are conflated with do-not-resuscitate orders and enforcement of the right to refuse treatment that ADs may contain.¹ This chapter explores legal developments in relation to end-of-life care and ADs in India, with the aim of decoupling ADs from the euthanasia discourse and focusing on the former. We lay out the current guidelines on ADs laid down by the Supreme Court of India, followed by a

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¹ The authors have themselves been guilty of such overemphasis in the past. See R.B. Ghooi, K. Dhru and S. Jaywant, “The Urgent Need for Advance Directives in India” (2016) 1(4) *Indian Journal of Medical Ethics*, 242.

consideration of ADs in the psychiatric context, and compare some of the crucial elements of each, including the role of the family and the consultation process.

An important thread connecting the legalisation of euthanasia with ADs is the role of individual autonomy. In the landmark case of *Common Cause (A Registered Society) v. Union of India*² in March 2018, which saw the legal sanction of passive euthanasia and legal recognition of ADs, as well as the creation of the aforementioned current guidelines on ADs, the judges explored the value of patient autonomy. In his judgment in the *Puttaswamy v. Union of India* decision, which was quoted in *Common Cause*, Justice Chandrachud said:

Life is precious in itself. But life is worth living because of the freedoms, which enable each individual to live life as it should be lived. The best decisions on how life should be lived are entrusted to the individual. They are continuously shaped by the social milieu in which individuals exist. The duty of the State is to safeguard the ability to take decisions – the autonomy of the individual – and not to dictate those decisions.³

There remain in the background, however, concerns over the social and religious relevance of the notion of autonomy. Whilst the value of individual autonomy may be quite central to Western culture, the cultural context has often been neglected in discussions about ADs in India. For example, the family plays an important role in India's sociocultural context, with respect to decision-making in particular, but there is also a presumption by the courts that the patient has to be protected from the family. We argue in this chapter that the role of doctors and the courts can be seen as protecting patients from their families. The chapter also briefly addresses the questions surrounding autonomy in the religious and medico-cultural context.⁴

In terms of the practice of and attitudes towards ADs, there is very little understanding, although a survey we conducted on the level and

² *Common Cause (A Registered Society) v. Union of India* (2018) 5 SCC 1.

³ See J. Chandrachud in *Puttaswamy v. Union of India* (2017) 10 SCC 1, para. 118 as quoted by C.J.I. Misra in *Common Cause (A Registered Society) v. Union of India* (2018) 5 SCC 1, para. 153.

⁴ While the Indian social milieu is richly diverse, with members of its population belonging to a plethora of religions, this chapter will mainly focus on some of the common themes across Hinduism, Buddhism and Jainism. The authors have no intention of undermining the importance of Islamic, Christian, Sikh or any other faith-based and cultural interactions with the relevant legal developments, or the legal interpretation of the freedom of religion.

extent of knowledge about ADs amongst educated persons with and without a medical background provides some empirical data on the level of AD awareness in India. The last section of the chapter discusses this survey, highlighting that there is a need for greater awareness of ADs. We conclude with reflections on the problems with the current AD regime and recommendations for the way forward.

6.2 The Legal Background: *De Lege Lata*

6.2.1 *The Legal Understanding of Life and Death*

To understand the legalisation of ADs, one must first understand the Indian legal approach to life and death. Article 21 of the Constitution of India guarantees the right to life: “No person shall be deprived of his life or personal liberty except by a procedure established by law”.⁵ Following the case of *Maneka Gandhi v. Union of India*,⁶ Article 21 of the Constitution of India has been given a very expansive interpretation by the Supreme Court of India to embody dignity⁷ and a meaningful, complete life worth living. Since then, Article 21 of the Constitution of India has also been the anchor of many welfare rights.

In the context of patients suffering from terminal illness, the pertinent question is whether the right to life includes the right to die and to die with dignity. The legalisation of end-of-life ADs has been by extension of the right to self-determination involved in the refusal of treatment and withdrawal of life support in this context. As the legal situation currently stands, ADs are seen as a mechanism to ensure death with dignity, as they involve self-determination. What the situation thus demands is translation of the abstract right to death with dignity into concrete regulatory processes to ensure realisation of that right. Accordingly, it is important to understand, as part of the AD context, the journey that led to the legalisation of death with dignity in the form of passive euthanasia.

6.2.2 *The Aruna Shanbaug Case (2011)*

The battle surrounding the legalisation of euthanasia took centre stage and garnered nationwide attention with the *Aruna Ramchandra*

⁵ Constitution of India, Art. 21.

⁶ *Maneka Gandhi v. Union of India* (1978) SCC (1) 248.

⁷ Also found in the Preamble to the Constitution of India.

Shanbaug v. Union of India case.⁸ The case concerned the brutal rape and assault of a nurse at KEM Hospital Mumbai by a ward boy, which left her in a persistent vegetative state. The Supreme Court held that passive euthanasia (understood here as the withdrawal of life-sustaining treatment) could be legalised only through an act of Parliament. The two-judge bench of the court made a distinction between active and passive, and voluntary and involuntary, euthanasia. The procedure it devised required that a high court be approached directly concerning every single case in which life-sustaining treatment was to be withdrawn.

Just as in the *Airedale National Health Service Trust v. Bland* case,⁹ Aruna Shanbaug had made no express provision for an AD. In *Aruna Shanbaug*, a reference to ADs was made in the report submitted to the court by medical experts, who also stated that they had no information concerning the expressed views or wishes of Aruna Shanbaug.¹⁰ The amicus curiae in the case also brought up the link between self-determination, used interchangeably with informed consent, and ADs.¹¹ The court laid down guidelines on the withdrawal of life support, which were to remain in force until Parliament enacted a law. Under those guidelines, the decision to withdraw life support should be taken in the best interests of the patient if she is unable to make a decision for herself.¹² Such a decision could be taken by a person or body of persons acting as “the next friend” and could also be taken by the patient’s doctors. However, the decision required the approval of the high court concerned.¹³ The Supreme Court in this case limited itself to acceptance that there had been no expression of wishes without going into the question of the legality of ADs per se.

6.2.3 Law Commission of India Reports (2006 and 2012)

The next milestone in the development of end-of-life AD legislation was two Law Commission of India reports, specifically the 196th report

⁸ *Aruna Ramchandra Shanbaug v. Union of India* (2011) 4 SCC 454.

⁹ *Airedale National Health Service Trust v. Bland* [1993] 1 All ER 821, a landmark House of Lords case in the United Kingdom dealing with the question of withdrawal of life-sustaining treatment.

¹⁰ J. Katju in, *Aruna Ramchandra Shanbaug v. Union of India* (2011) 4 SCC 454, para. 9.

¹¹ *Ibid.*, para. 24.

¹² *Ibid.*, para. 126.

¹³ *Ibid.*, para. 126.

published in March 2006,¹⁴ which discussed the withholding of life support measures from terminally ill patients, and the 241st report published in August 2012¹⁵ after the *Aruna Shanbaug* decision.

The 196th report recommended allowing passive euthanasia for both competent and incompetent patients. However, despite acknowledging the recognition of ADs in other countries, the report resisted recognising their legal validity, citing “complex legal and factual issues”, such as subsequent changes in circumstances, or changes in technology, and problems of proof in the event of a subsequent withdrawal.¹⁶ The Law Commission, in the 196th report, seems to have been greatly influenced by Justice Munby’s considerations in *HE v. Hospital NHS and Another*,¹⁷ which centred on the efficacy of ADs (in this case in the context of blood transfusions) and a test of their applicability being a matter of proof.¹⁸ The commission seems to have been concerned about the problems of proof in oral ADs, particularly given the level of illiteracy in India. For policy reasons, it thus recommended that ADs not be legalised in India, fearing the huge amount of litigation stemming from conflicting evidence, even if the ADs were in writing.¹⁹

The 241st report of the Law Commission upheld the findings of the previous report. Interestingly, some of the questions concerning the subsequent withdrawal of consent, for example, which are found in contemporary discussions of ADs, were cited as reasons for not accepting their validity. In light of these findings, Section 11 of the draft bill arising from the two reports (i.e. the 2016 draft Treatment of Terminally-Ill Patients (Protection of Patients and Medical Practitioners) Bill) considered ADs to be invalid.

6.2.4 *The Common Cause Decision (2018)*

The *Common Cause* case, which was referred to the Supreme Court with a request that it declare that the right to life includes the right to die with

¹⁴ Law Commission of India, *196th Report – Medical Treatment to Terminally Ill Patients (Protection of Patients and Medical Practitioners)* (New Delhi: Law Commission of India, March 2006).

¹⁵ Law Commission of India, *241st Report – Passive Euthanasia – A Relook* (New Delhi: Law Commission of India, August 2012).

¹⁶ See note 14, pp. 319–28.

¹⁷ *HE v. Hospital NHS and Another* [2003] EWHC 1017.

¹⁸ See, for example, note 14, pp. 321–23.

¹⁹ *Ibid.*, p. 327.

dignity and legalise ADs, dealt more generally with the end-of-life context in India. The court also considered the question of legalising ADs in the case. In light of international developments, in India too there had been repeated requests for the legalisation of euthanasia, many of which ended up on the doorstep of the Supreme Court. Advocacy groups had been writing about euthanasia and ADs and recommending legal sanction for the latter.²⁰ Everything changed in March 2018, however, with the court's ruling in *Common Cause*, which was heard by a five-judge bench comprising Justices Dipak Misra Chief Justice of India (CJI), Khanwilkar, Sikri, Chandrachud and Bhushan.

In the *Common Cause* decision, the court upheld the arguably problematic distinction between active and passive euthanasia²¹ and legalised passive euthanasia, which it understood as the withholding or withdrawal of life support, not as physician-assisted suicide. In relation to ADs, Justice Sikri stated that the fear of misuse cannot be grounds for a blanket ban on ADs.²² The Court laid down a set of detailed guidelines, discussed later, which are the law in place until the Indian Parliament enacts legislation. The guidelines provide for a rather long procedure in the event that the executor of an AD develops a terminal or incurable illness.

In this case, we find at least a *prima facie* reiteration of the right to decisional autonomy in the five-judge bench decision, particularly Justice Chandrachud's judgment.²³ Even the CJI, just before giving the guidelines for ADs, quoted John Rawls from his book *Political Liberalism*, wherein he emphasises choice, holding that between best interests and decisional autonomy, it is decisional autonomy that triumphs.²⁴ It could be said that the legal milieu for the recognition of ADs was established by the Supreme Court's increasing focus on individual decisional autonomy,

²⁰ See Ghooi, Dhru and Jaywant, note 1, and R.K. Mani, S.N. Simha and R. Gursahani, "The Advance Directives and Foregoing of Life Support: Where Do We Stand Now?" (2018) 22(3) *Indian Journal of Critical Care Medicine*, 135.

²¹ The distinction between active and passive euthanasia has been questioned in the literature on ADs and euthanasia in India. See, for example, S. Rao, "The Moral Basis for a Right to Die" (2011) 46(18) *Economic and Political Weekly*, 13.

²² J. Sikri in *Common Cause (A Registered Society) v. Union of India* (2018) 5 SCC 1, para. 130–2.

²³ This is in contrast to the focus on best interests in *Aruna Ramchandra Shanbaug v. Union of India* (2011) 4 SCC 454, where in the entire decision the word "autonomy" appears only twice, and even then in quotations. The focus is clearly on best interests. See in particular para. 27.

²⁴ See J. Misra in *Common Cause (A Registered Society) v. Union of India* (2018) 5 SCC 1, para. 162.

as is highly visible in the recognition of the right to privacy in 2017 by a unanimous decision of a nine-judge bench of the Supreme Court in *Puttaswamy*.

There has also been acknowledgement of the role that the right to privacy played in the court's reasoning in the *Common Cause* case. Justice Sikri, for instance, when formulating the questions concerned states that "with [the] right to privacy now a fundamental right under Article 21 (right to life), the principle of self-determination in India stands on a higher footing than before".²⁵ In the *Puttaswamy* decision, which was quoted in *Common Cause*, Justice Chelameshwar said, "An individual's right to refuse the life-prolonging medical treatment or terminate life is another freedom which falls within the zone of the right to privacy".²⁶ Hence, the domain of privacy has been extended to include end-of-life decisions.

6.3 Current Legal Position on Advance Directives in India

The key guidelines pertaining to ADs²⁷ come from paragraphs 191–4 of the *Common Cause* decision, described previously, under the judgment of the CJI and Justice Khanwilkar, which was reiterated by the rest of the bench.²⁸

- (a) **The format:** Under the guidelines, an AD can be executed only by an adult of sound mind, who is in a position to understand and communicate the purpose and consequences of the directive. The Court decision does not specify how soundness of mind is to be assessed, although soundness of mind in Indian law is a presumption under the Indian Contract Act 1872.²⁹

²⁵ See J. Sikri in *ibid.*, para. 10.

²⁶ See J. Chelameshwar in *Puttaswamy v. Union of India* (2017) 10 SCC 1, at para 38, as quoted by J. Bhushan in *Common Cause (A Registered Society) v. Union of India* (2018) 5 SCC 1, para. 78.

²⁷ While these are the first legal guidelines on the topic of ADs in India, there is some evidence that ADs have already been considered previously as a part of professional guidelines on end-of-life care. See, for example, All India Institute of Medical Sciences, *Guidelines for End of Life Care* (New Delhi: All India Institute of Medical Sciences, 2020). While these guidelines do not refer to the term ADs, they refer to the documentation of a mentally capacitated patient's wishes for withholding life-sustaining support (see p. 4).

²⁸ *Common Cause (A Registered Society) v. Union of India* (2018) 5 SCC 1, at paras. 191–4.

²⁹ Indian Contract Act 1872, s. 12.

Reference is also made to “informed consent” given without any undue influence or constraint. The AD must be clear, unambiguous, with specific terms and instructions, and in writing. It can be withdrawn at any time, and the withdrawal must also be in writing. The format requirement is that the AD has to be signed by the executor (who is an adult of a sound and healthy state of mind) and two (independent) witnesses and counter-signed by a judicial magistrate first class (JMFC). It is unclear what exactly is meant by “independent”, but it presumably means someone with no vested interest in the property of the person making the AD. The JMFC is a post established under Section 11 of the Criminal Procedure Code 1973.³⁰ The JMFC’s role is to preserve the document in both paper and digital form and send a copy to the Municipal Corporation or local Panchayat (local village council³¹) for the appointment of a custodian of the document. The JMFC also needs to inform the executor’s family of the directive, which risks compromising the executor’s autonomy. Finally, the JMFC is required to maintain a copy of the AD in his or her office, with another copy forwarded to the relevant district court. The amount of responsibility placed on the JMFC is concerning given the huge backlog of cases in the courts.

The signature of the JMFC is likely to constitute a major hurdle given that the number of judicial officers of this level is very small in any given city. For example, in the city of Pune, there are only 19 such officials for a population of six million. There is also a huge backlog of cases with the lower judiciary in India, a concern that does not seem to bother the Supreme Court.

- (b) **When ADs apply:** Under the Supreme Court guidelines, an AD can be given effect only in the event that the executor becomes terminally ill and is undergoing prolonged medical treatment with no hope of recovery or cure of his or her ailment or is surviving on life support.
- (c) **The process if there is an AD:** The physician, when made aware of the existence of an AD, must check its authenticity with the JMFC and then inform the hospital, which in turn will form a hospital medical board comprising the head of the treating department and at least three experts from the fields of general medicine, cardiology,

³⁰ Code of Criminal Procedure 1973, s. 11.

³¹ These are not informal institutions, but hold constitutional status through the Constitution (73rd Amendment) Act 1992.

neurology, nephrology, psychiatry or oncology with good standing in the medical profession and at least 20 years' experience.

The experts visit the patient and form a preliminary opinion on whether to execute the directive. If it is to be executed, the JMFC is to be informed, and he or she in turn appoints a medical board consisting of the Chief District Medical Officer as chairperson and three expert doctors (who are not members of the hospital's medical board). If this board agrees with the hospital board that the instructions in the AD may be carried out, it will approach the JMFC, who will visit the patient and "after examining all aspects" authorise the implementation of the board's decision.

If the JMFC-appointed medical board refuses implementation, the executor of the AD, his or her family members, or even the treating doctor or hospital staff may approach the High Court. The two-judge bench of that Court can, if it wishes, form another committee with expert doctors (each again with at least 20 years' experience), although the High Court is to keep in mind "the best interest of the patient".

- (d) **No AD:** In the case of no AD (or an ambiguous AD), the procedure to be followed is this: after consultation with the patient's family, which must give its consent in writing, the hospital's medical board is consulted for a primary opinion, and the JMFC-appointed medical board for a secondary opinion.

This is obviously a highly complex and rather bureaucratic procedure, with too many opinions required to be obtained before life support can be withdrawn. There is also no separate procedure for emergency situations. The power to interpret and give effect to an AD lies largely with the physician and the various boards. There is little or no representation of persons other than doctors in the expert committees. It is likely that in future cases,³² the Supreme Court will clarify the procedure, as well as the convoluted nature of the existing guidelines. In the meantime, however, the value of self-determination that the *Common Cause* decision ostensibly serves is taken away by the lengthy procedure laid out in the

³² For example, the Vidhi Centre for Legal Policy, an independent think-tank, has already filed a clarification application in the Supreme Court as this volume goes to print. See further D. Mehta and A. Agarwal, "End of Life Care in India: A Model Legal Framework", Vidhi Centre for Legal Policy (15 November 2019), <https://vidhilegalpolicy.in/research/end-of-life-care-in-india-a-model-legal-framework/>.

guidelines given by the Supreme Court, which remain the law of the land until the Indian Parliament enacts legislation concerning ADs.

Interestingly, in a different context, India has experienced much less controversy in enacting AD legislation. We now turn to the psychiatric advance directive (PAD) regime in India.

6.3.1 PADs under the Mental Healthcare Act 2017

The recognition of PADs under Section 5 of the Mental Healthcare Act 2017 provides analogical strength in favour of the legalisation of end-of-life ADs. For example, Justice Sikri uses PADs in arguing against the Law Commission's concerns that ADs might be misused, relying on the safeguards in the PAD regime as an example of the safeguards that could be implemented to prevent abuse.³³

Under the procedure for PADs, the power to determine the manner of the directive's implementation is delegated to the Rules and Regulations of the Mental Healthcare Act 2017, of which Part II deals with the same. An AD format is given in Form CR-A of the Mental Healthcare Rules 2017, made under the Mental Healthcare Act 2017. The AD is to be signed by two witnesses, and is to be registered with the Mental Health Review Board of the jurisdiction in which the person resides. There is also an obligation to make the AD available online within 14 days. According to Form CR-A, a person can appoint two or more nominated representatives in order of precedence to make decisions about mental healthcare treatment in the event of incapacity. In some regards, this stipulation renders a PAD more akin to a power of attorney than to an AD. There is also a need for certification by a medical professional that the capacity to make decisions exists at the time the PAD is made.

Whilst there appears to be no apparent basis for distinguishing between end-of-life ADs and PADs on the issue of capacity, there is an established procedure for assessing capacity under the Mental Healthcare Rules 2017, unlike under the aforementioned guidelines laid down by *Common Cause*. The determination of the capacity to consent for patients with mental illness is to be made by the expert committee appointed by the Central Mental Health Authority under Section 81 of the Mental Healthcare Act 2017.³⁴

³³ J. Sikri in *Common Cause (A Registered Society) v. Union of India* (2018) 5 SCC 1, para. 132.

³⁴ Mental Healthcare Rules 2017, Rule 16.

Although PADs were used to provide analogical support for the legalisation of end-of-life ADs in that decision, as discussed previously, there remain crucial differences between the procedures and powers concerning PADs and end-of-life ADs. For example, compared with an end-of-life AD, a PAD confers a duty upon the medical caregiver to follow the directive.³⁵ Less discretion thus lies with the medical practitioner. The AD format is also specified by the Mental Healthcare Rules 2017, which constitute a much more detailed legislative scheme.³⁶

The media attention surrounding euthanasia and ADs has been greater than that surrounding PADs. Because the legalisation of PADs generated little controversy, discussion or resistance in India, they may well have been easier than ADs to legislate. The law under which they were legalised, the Mental Healthcare Act 2017, received cross-party support, as it recognised the legal right to mental healthcare.³⁷ There is also a greater role for the family under the PAD regime, which will be discussed in the next section.

It thus seems that whilst ADs in the psychiatric and end-of-life contexts both aim to provide individuals with the opportunity to exercise autonomy in relation to decisions about medical treatment if and when they lose capacity, the respective regimes are very different, although the differences (in relation to the assessment of mental capacity or enforceability, for example) do not appear to be based on principle.

6.4 Advance Directives in Context

6.4.1 *The Role of the Family*

Illness in India, scholars have argued, is a family matter, and hence the role of the family is the most crucial for healthcare decision-making.³⁸ The role of the family is central in the epics that scholars often cite as

³⁵ Mental Healthcare Act 2017, s.10.

³⁶ Mental Healthcare Rules 2017, Part II s. 1.

³⁷ See, for example, S. Pathare, "Mental Healthcare Act: A Paradigm Shift", *Mint* (27 December 2017), www.livemint.com/Opinion/BdVVXjyKWDhAAcU1ulHwSI/Mental-Healthcare-Act-A-paradigm-shift.html.

³⁸ See S. Chattopadhyay and A. Simon, "East Meets West: Cross-Cultural Perspective in End-of-Life Decision Making from Indian and German Viewpoints" (2008) 11(2) *Medicine, Health Care and Philosophy*, 165, 169. For a very insightful discussion on end-of-life concerns and the role of family in the Hindu and particularly the British Hindu population, see particularly chapters 4–13 of S. Firth, *Death, Dying and Bereavement in a British Hindu Community*, PhD thesis, School of Oriental and

creating the landscape for Indian ethics.³⁹ In an interaction between the Indian legal landscape through personal laws and Hindu religious-cultural practices, the law itself allows for the fictional unit of the “Hindu Undivided Family”, particularly in the context of the ownership of family property and inheritance under the Hindu Succession Act 1956.⁴⁰ Under this system, the eldest male of the family, that is, the father, husband or eldest son, has traditionally been considered to be the *Karta* or “manager” (or, by extension, the decision-maker). The definition of *Karta* has now been extended to include females.⁴¹ Family lies at the heart of Indian society, and yet the treatment that ADs afford it is bittersweet. Under the Supreme Court guidelines, doctors have a greater role to play than family members. Nevertheless, the JMFC is to inform the family of the person making the AD that such a document has been made. How is one to interpret this apparent discrepancy?

Given the country’s huge young population and cultural norms against the abandonment of one’s parents in their old age, one would expect the family to play a crucial part in this context in India. Yet, the legal battles around who gets to make a decision on behalf of the patient in the case of ADs have centred on the roles of the courts and doctors. In light of the importance of the family in other law and ethics contexts, as demonstrated in the way decisions are to be made by the head of the family, and legal recognition of the Hindu Undivided Family, one can only wonder at the lack of any role for the family in the end-of-life context.

It is possible that the situation arises from concerns over the potential for abuse in that context. Such concerns are apparent in court decisions pertaining to ADs, as well as in the aforementioned Law Commission reports. Hence, one can argue that the main reason for the resistance is the potential misuse of ADs by family members. In light of this

African Studies, University of London (1994), <https://library.soas.ac.uk/Record/eprints-28921/Description#details>.

³⁹ Consider, for example, B.K. Matilal and J. Ganeri, *Ethics and Epics: Philosophy, Culture, and Religion* (New Delhi: Oxford University Press, 2002). See also G. Das, *The Difficulty of Being Good: On the Subtle Art of Dharma* (New York: Oxford University Press, 2010). Both of these authors build on the ethical dimensions within the characters and conflicts in *The Mahabharata*, which centres on a family feud over the rightful inheritance of a kingdom.

⁴⁰ The Hindu Succession Act 1956, in turn, is based on the *Dayabhaga* and the *Mitakshara* systems.

⁴¹ The amendment to the Hindu Succession Act 1956 was brought about by the Hindu Succession (Amendment) Act 2005.

scepticism of the role of the family, the state or third-party agencies perceive themselves as having a crucial role in preventing such abuse and preserving the autonomy of the individual, even though that perception may be unwarranted given the lack of empirical evidence on such abuse.

Scepticism about the role of the family is also reflected in the *Aruna Shanbaug* decision. The hospital and her caretakers were considered to be the next of kin rather than Aruna Shanbaug's family or even Pinky Virani, the humanistically intentioned person who filed the case. It was because of the decision of the staff and nurses at KEM hospital who had looked after Aruna Shanbaug in a persistent vegetative state for 37 years that she was kept on life support.⁴²

In the *Aruna Shanbaug* decision, the role of the family in giving consent on behalf of the patient was also resisted. Justice Katju, for instance, said the following:

The question arises, as to who should give consent for withdrawal of life support. This is an extremely important question in India because of the unfortunate low level of ethical standards to which our society has descended, its raw and widespread commercialisation, and the rampant corruption, and hence, the Court has to be very cautious that unscrupulous persons who wish to inherit the property of someone may not get him eliminated by some crooked method.⁴³

Justice Katju discussed the appointment of a guardian in the *Aruna Shanbaug* case. He cited chapter IV of the 196th Law Commission Report, which considers the family and relatives to be just one consideration, placing power with the High Court as *parens patriae*. As with the High Court's authority to make decisions regarding the withdrawal of life support, there is strong jurisprudence on the role of the state, particularly that of the High Court as *parens patriae*. Somehow, the Supreme Court under *Common Cause* and Law Commission of India under the reports seem to view themselves as the protectors of individual patients from their own families. Under the new procedure resulting from the *Common Cause* case, the focus seems to have shifted from the role of the High Court to that of medical practitioners and the JMFC, with the family still placed in a secondary position. The sentiment remains similar: to protect the individual from his or her family.

Interestingly, concern over the potential for abuse is less evident in the PAD context, in which there appears to be a larger role for the family. In

⁴² J. Katju in *Aruna Ramchandra Shanbaug v. Union of India* (2011) 4 SCC 454, para. 126.

⁴³ *Ibid.*, paras. 101–2.

the PAD regime, for example, a relative or the caregiver of the person concerned can make an application to the hospital board to review, alter, modify or cancel the AD.⁴⁴ The greater role for the family in this regime may be the result of dialogue with stakeholders, who expressed scepticism about PADs. The Standing Committee Report on the Mental Healthcare Bill, which resulted in the Mental Healthcare Act 2017, attributes PADs to the Convention on the Rights of Persons with Disabilities, to which India has been a signatory since 2007.⁴⁵ In the report,⁴⁶ which, as noted, resulted from dialogue with stakeholders, there is scepticism regarding the creation of PADs, as well as resistance on cultural grounds, namely, that they may be in conflict with the role of the family in decision-making in India.

Whilst there has been no similar dialogue with stakeholders in the end-of-life context, and it is therefore unclear whether a similar concern would be raised, the foregoing discussion of the importance of the family in Indian culture and other legal contexts suggests that despite court scepticism about that role, there may be cultural reasons for the family to be given a larger role in the context of end-of-life ADs.

6.4.2 *Autonomy, Pain and Desire: The Role of Religions*

Law operates in the context of its society, which, in the case of India, brings together the peculiarities of that society owing to its highly diverse, pluralistic nature. In fact, doubts have been expressed in the past concerning whether a unified “Hindu” bioethics can exist given the plurality of Indian culture. The management of patients at the end-of-life is also influenced by religious and cultural beliefs, although there appears to be little discussion of personal will and desire in the context of end-of-life treatment.⁴⁷

⁴⁴ See Mental Healthcare Act 2017, s. 11.

⁴⁵ See Department-Related Standing Committee on Health and Family Welfare, *74th Report on the Mental Healthcare Bill 2013* (New Delhi: Rajya Sabha Secretariat, November 2013).

⁴⁶ The inclusion of the PAD provision has an interesting history in the consultations, as described in the *74th Report on the Mental Healthcare Bill 2013* (ibid.).

⁴⁷ This may be because there is no clear “individual” or “auto” in Hindu or Buddhist phenomenology, which may cause difficulties when attempting to use autonomy as a ground value (cf. Ganeri, who argues that there may be space for autonomy; see J. Ganeri, “Buddhism and Bioethics: A Theravada Defence of Individual Autonomy” in S. Grätzel and E. Guhe (eds.), *Life, Body Person, and Self: A Reconsideration of Core Concepts in Bioethics from an Intercultural Perspective* (Munich: Verlag Karl Alber, 2016), pp. 176–92).

For a significant number of people belonging to the Hindu, Buddhist and Jain faiths, amongst others, there is the concept of an ongoing cycle of birth, death and rebirth. In these traditions, societal existence, or *Samsara*, sees its outer boundaries in the pursuit of the attainment of *Moksha* or *Nirvana*. According to this view, death is not the end, and there are many ideas pertaining to renouncing all material desires, and eventually the body itself.

Interestingly, the judgment of the CJI and Justice Khanwilkar in *Common Cause* holds that although Buddhism, Jainism and Hinduism are against euthanasia in the strict sense, the concept of the “good death” in each of these religions can be seen as reflecting the concept of dying with dignity.⁴⁸ More broadly, death can be seen within Indian religious tradition and philosophy as a union with the Divine, the greater Self.⁴⁹ In the Hindu epic of *The Mahabharata*, Bhishma, who had decided to remain celibate owing to various circumstances, was given in return the boon of *Ikcha-mrityu*, or “the death of desires”, meaning that he could choose the time of his death “as per [his] desire”. This example demonstrates that a good death is considered the highest of rewards.

What about alleviation of the suffering of the Self? As per the famous bhajan *Bhaja Govindam* quoted at the beginning of this chapter, whilst the individual is to embrace pain, it is left to God to save the individual from pain and suffering. In Hindu and Buddhist philosophy, suffering is considered to be an eternal truth about life, to the extent that it is one of the noble truths of Buddhism. Hence, the desire to avoid pain is not celebrated. Pain is to be embraced and may depend on past-life deterministic forces such as *karma*, and freeing oneself of pain is not sufficient justification for bringing about death. Accordingly, the rejection of life-sustaining treatment to alleviate pain

⁴⁸ See J. Sikri in *Common Cause (A Registered Society) v. Union of India* (2018) 5 SCC 1, para. 54. However, for the view that there is a more sympathetic view of sacrificing one’s life in Hinduism, as well as the spiritual, religious and political significance of doing so, see P. Bilimoria, “The Debate on Euthanasia in India” in P. Bilimoria et al. (eds.), *Gender, Justice, and Ecology*. Vol. II of *Indian Ethics* (New Delhi: Oxford University Press, 2015).

⁴⁹ For an account of end-of-life spirituality in various branches of Indian philosophy, see H. Inbadas, “Indian Philosophical Foundations of Spirituality at the End of Life” (2018) 23(4) *Mortality* 320. For an account of the different religious attitudes of Hindus towards the end of life, see S. Firth, “End-of-Life: A Hindu View” (2005) *Lancet* 366, 682–6.

and suffering, which will in turn bring about the person's death, would not be seen as in line with these religious beliefs.⁵⁰

6.4.3 *The Medico-cultural Context*

In ancient India, physicians took an oath after completion of their studies. One of the commitments they made was that they would not try to prolong life in end-of-life situations or resort to what is known today as futile treatment.⁵¹ In the West, however, medicine evolved on different principles. The original Hippocratic oath placed two important conditions on the practice of medicine. The first was to disallow euthanasia, and the second was to never conduct an abortion, with no exceptions.⁵² In India, the Indian medical tradition was replaced by an interpretation of the Hippocratic formulation of doctors' duties in ways that stress the need to act paternalistically towards patients. Doctors in India, who may even have been favourably inclined towards self-determination at the end-of-life, were taught that life has to be preserved, at all costs if necessary.

The greater role of doctors and medical paternalism also have roots in Ayurvedic systems, where great faith is reposed in the medical community despite the issues of medical malpractice and institutional problems concerning hospital infrastructure. One can see a reflection of Ayurvedic ideas in doctors being seen as a rebirth of Dhanvantari, the lord of medicine. In Ayurvedic systems, there were codes of ethics, which can be found in the *Sushruta Samhita* and *Charaka Samhita*. The *Charaka Samhita*, for example, makes reference to autonomy and consent, although preference is afforded the physician in the case of, for instance, withholding the truth from the patient in his or her best interests, as opposed to full disclosure in order for him or her to make an informed

⁵⁰ In any event, the identification of a self with a body that is suffering is questionable. As the texts of the dominant *Advaita* (non-dual) tradition, which focus on the emancipation of the individual *Aatman* or "self" from the illusion of the duality of the self and the larger consciousness (*Brahman*), suggest, the self should not be conceived of as attached to the physical body.

⁵¹ I.A. Menon and H.F. Haberman, "The Medical Students' Oath of Ancient India" (1970) 14(3) *Medical History* 295.

⁵² M.A. Faria Jr., "Utilitarianism and the Perversion of the Ethics of Hippocrates" (2000) 172(4) *The Western Journal of Medicine* 224.

decision.⁵³ Although medical paternalism and a larger role for doctors may in some jurisdictions result in greater reluctance to accept ADs (as individuals would presumably expect to defer to doctors about decisions at the end of life), this has not been the case in India. Instead, preference for the role of the physician in overseeing and enacting a bureaucratic process of reviewing the place and applicability of an AD has interestingly been accepted as a key component of the AD regime laid down by the Supreme Court, wherein medical practitioners have the greatest say in decision-making. This situation may well result from the fear of abuse by family members, as discussed previously, but is also consistent with the Indian medico-cultural context.

6.5 Survey Mapping the Level of AD Awareness

Autonomy, if it is to be realised, presupposes the knowledge required for an informed decision. Despite the legal permissions given by the Supreme Court, the common person in India remains unsure about the implications of AD legislation and the *Common Cause* ruling.

The question we come to now is this: to what extent is there awareness of the law as it currently stands? One way to understand perceptions of ADs is to conduct a survey amongst a broad swathe of people. To the best of our knowledge, no such survey had previously been undertaken in India since the *Common Cause* decision.⁵⁴

6.5.1 Demographics

We conducted an online survey using Google Forms. The survey collected information from individuals who were internet users and had obtained at least a graduate degree in any field. Our respondents do not represent the Indian population in any way; rather the population we selected was a highly educated, elite group of people.⁵⁵ Our final sample

⁵³ See K.A. Tawalare et al., "Contribution of Ayurveda in Foundation of Basic Tenets of Bioethics" (2014) 35(4) *Ayu* 366.

⁵⁴ There have been a very small number of surveys, however, on the effectiveness of PADs. See, for example, B. Tekkalaki et al., "How Do Our Patients Respond to the Concept of Psychiatric Advance Directives? An Exploratory Study from India" (2018) 40(4) *Indian Journal of Psychological Medicine* 305.

⁵⁵ Graduates and above account for only 6.92 per cent (92 million) of the total population; see further Ministry of Human Resource Development, *All India Survey on Higher Education (AISHE: 2018-19)* (New Delhi: Government of India, 2019).

of 411 responses reflected a healthy mix of male and female respondents from the fields of medicine, science, the arts, engineering and law, with a mean 18.16 years of work experience. The responses were sorted by gender, qualifications and field of education for detailed analysis using simple statistical measures.

6.5.2 *The Findings*

In relation to their awareness of ADs, only 115 (27.9 per cent) of the respondents reported having some knowledge of ADs, meaning that 296 (72.1 per cent) had no such knowledge. Further questions about ADs were therefore not directed towards those with no knowledge of the subject matter. Amongst those who knew about such directives, 100 reported having thought about making them, but only 21 (18.2 per cent) had actually done so. Taking all respondents as a whole, only 5.1 per cent had prepared an AD.

We analysed the knowledge of respondents from the medical profession separately. Of the 147 medical professionals, 92 (62.6 per cent) had heard of ADs, whereas 55 (37.4 per cent) had not, and only nine (7.8 per cent) had actually made one. One question that we asked all respondents was whether, if they were unable to voice their preference about medical treatment, they would like to nominate someone as their proxy. We received a response from 226 respondents. Most (133, or 58.8 per cent) said they would want their spouse to act as their proxy. Seventy-one (31.4 per cent) chose their parents, and 18 chose family or their children. Only three said they would like a doctor to make decisions on their behalf if they were unable to do so. It is alarming that the doctors in our sample were only slightly better informed about ADs than our other respondents; roughly half were clueless.

Several findings emerge from these data. First, despite all of the benefits of ADs, not all are inclined to make them. Second, considerable effort is required to make ADs acceptable. Our survey revealed that although most of our respondents wanted autonomy over their medical treatment and the way in which they were treated, very few had an understanding of ADs, their legality or the process of making them.

The inference that can be drawn from our survey is that the likelihood of a well-educated Indian making an AD is rather slim. An added worry is that there appears to be little knowledge of ADs amongst medical professionals. Thus, the likelihood of a patient who has prepared an AD being treated by a medical practitioner with knowledge of ADs is remote.

This situation, added to the fact that responsibility lies with the medical practitioner, makes AD implementation a challenge. There is thus an urgent need for a campaign by governmental and non-governmental organisations to spread awareness of ADs, their advantages and the need for them. The Indian courts seek legal grounding in other common law jurisdictions, and yet ground-level adoption is often neglected. Whilst the governments of other countries have put huge effort into popularising ADs, no such effort has been seen in India. Without knowledge of ADs, they will remain an unrealised right.

6.6 Conclusion

India has come a long way in jurisprudence concerning end-of-life care, culminating in the current guidelines on ADs laid down by the Supreme Court of India, which remain the law of the land. There remain, however, various concerns about this regime. The first is in relation to the lengthy, bureaucratic and unrealistic procedure that the court has laid down for the creation of an AD. Whilst at first glance, the court's decision in *Common Cause* seems to have furthered decisional autonomy, the complex procedures it put in place may actually serve to disempower patients, reducing their control over decisions about their care and discouraging them from undergoing the AD process.

The second concern relates to the institutional dimension surrounding the legalisation of ADs. The *Common Cause* decision, a result of India's activist judiciary, raises questions about the separation of powers by showering rights on people without any democratic dialogue. Implementation is also a challenge, especially when new legal requirements are introduced without careful consideration of what is practically feasible in a healthcare context. Because of the different workings of the legislature and the judiciary, the idealism of the judiciary seldom translates into ground-level practices. The Health Ministry, for instance, has yet to hold a consultation meeting with stakeholders concerning the procedure for ADs.⁵⁶

A third concern relates to how the law sits uncomfortably with the social reality of India, which is communitarian and family-based. Interestingly, despite the importance of the family being recognised in the PAD context, the courts have expressed concerns about the potential

⁵⁶ We are grateful to Dr Dhvani Mehta for this point.

for abuse by family members in the end-of-life context. Such concerns have not, however, translated into an endorsement of the person-centric approach that ADs encapsulate. Instead, a key role for healthcare professionals is envisaged, and looks to have been generally accepted.

In terms of the way forward, our survey demonstrates a significant lack of awareness of ADs, which needs to be remedied. Concerns over the lack of AD knowledge have also been expressed in the context of PADs.⁵⁷ One of the potential solutions has been to set up legal aid centres to spread awareness and afford access to vulnerable populations.⁵⁸ Such centres may be a way to educate the public about ADs, although the bureaucratic procedures will need to be streamlined if such directives are to be widely taken up by the population. At the hospital level, ethics committees could be empowered to keep a check on futile treatments and even make decisions where necessary.

⁵⁷ See A. Sarin, P. Murthy and S. Chatterjee, "Psychiatric Advance Directives: Potential Challenges in India" (2012) 9(2) *Indian Journal of Medical Ethics* 104, 106.

⁵⁸ *Ibid.*, p. 107.

