

## LAW AND BIOETHICS

## The Medical Termination of Pregnancy Act: Need to keep pace with technology

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**Abstract**

*In the summer of 2017, the Supreme Court of India denied permission to abort a 26-week-old foetus, detected with Down syndrome at 22 weeks, to a family which already had a child with special needs, on the grounds that the 20-week mark specified in The Medical Termination of Pregnancy Act of 1971 had been crossed. An Act well formulated and ahead of its time at inception seems not to have kept pace with technology and to be in need of change. We argue that by denying the abortion the Court did not adhere to the core principle of ethics—respect for autonomy, beneficence, non-maleficence, and justice—as the mother was not allowed to decide for herself and was forced to abide by the decision taken by the court.*

**Introduction**

On February 28, 2017, the Supreme Court interceded in the case of a 37-year-old mother, who requested abortion of her 26-week-old foetus detected with Down syndrome at 22 weeks. According to the Medical Termination of Pregnancy Act, 1971 (MTP Act), grounds for granting abortion include, but are not limited to, women facing the birth of a potentially handicapped or malformed child within a 20-week gestational period (1). Under Section 3 of the MTP Act, 1971, abortion is allowed if continuation of the pregnancy could involve a risk to the life of the pregnant woman or cause grave injury to her physical or mental health, or there is a substantial risk that if the child were born, it would suffer from such physical or mental abnormalities as to be seriously handicapped (1). Thus, if the mother had not crossed 20 weeks of gestation, she would have been eligible for an abortion under the MTP Act. Despite such a pertinent clause, the Supreme Court denied the

abortion plea, once again bringing into question the stringent abortion laws in India.

**Case background**

The mother, a resident of Alibaug, Maharashtra, belonged to a lower-middle-class family. The foetus was diagnosed via an antenatal confirmatory test at 22 weeks with Trisomy 21, a chromosomal aberration more commonly known as Down syndrome. The couple already had a differently-abled child in the family, knew the hardships of bringing up such a child, and thus, wanted an abortion after receiving the confirmatory reports. The tests were reordered by the Supreme Court, which the family could only approach at 24 weeks, and were conducted at Mumbai's KEM Hospital. The doctors reported, "There is no harm to the health of the mother. The foetus has the possibility of being born with mental and physical abnormalities but has chances for survival, and thus abortion is not warranted."

The Supreme Court bench consisting of Justices SN Bobde and LN Rao "sympathised" with the woman's plight but regretfully claimed they could not permit her to abort as "it was a life in their hands". The bench observed that though "everybody knows that children with Down syndrome are undoubtedly less intelligent, they are fine people" (2). It is inexcusable that the Supreme Court used terms like "everybody knows" rather than relying on scientific evidence of the quality of life of someone with Down syndrome, detailing which there is plenty of literature available.

**Unpacking the issue**

In the 18th week, the couple first discovered the possibility of a Down syndrome diagnosis during their antenatal screening tests, which are advised at between 18 and 20 weeks (3). The antenatal screening tests include a blood test and an anomaly scan by ultrasound, which can reveal the possibility of a foetus having Down syndrome. The blood test measures alpha-fetoprotein, inhibin A, plasma protein A, estriol, and human chorionic gonadotropin (4). An anomaly scan can detect foetal abnormalities only after 18 weeks of gestation and costs around Rs. 3650 at the Apollo Centre of Fetal Medicine (5). The cost will range between Rs 2500-3500 anywhere in India (6). In the 22nd week, the couple received confirmatory test reports for the same.

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To cite: Nimbalkar SM, Patel DS. The Medical Termination of Pregnancy Act: Need to keep pace with technology. *Indian J Med Ethics*. 2019 Jan-Mar;4(1) NS: 59-64. DOI:10.20529/IJME.2018.096.

Published online on November 30, 2018.

Manuscript Editor: Veena Johari

Peer Reviewer: Leena Gangolli

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Current confirmatory tests available for Down syndrome are foetal chorionic villus sampling (CVS) and amniocentesis. The amniocentesis procedure is used to obtain a small sample of amniotic fluid. It contains cells shed by a foetus which can be used to detect chromosomal disorders (7). It is done at between 15 and 22 weeks, and its results are available within two to three weeks. It comes with an almost 1% chance of spontaneous termination, cramps, preterm labour, bleeding/leaking of amniotic fluid from puncture sites. It costs around Rs 8100 at the Apollo Centre for Fetal Medicine (5). The cost ranges from Rs. 8000-12000, generally, in India (8)<sup>1</sup>. It has 100% accuracy (9). CVS is a prenatal test in which a sample of chorionic villus is removed from the placenta for testing (it can be transcervical or transabdominal) (10). It is performed between nine and 14 weeks, and the reports are available in 10 days. It carries a higher risk of miscarriage and infections than amniocentesis and costs around Rs. 9290 at the Apollo Centre for Fetal Medicine (5). It costs Rs 3500 at AIIMS, New Delhi (11). CVS has 98 % accuracy (12).

Considering the cost and risk of confirmatory tests, they are performed only if the screening tests are indicative. The process timeline involving screening tests followed by the confirmatory test could easily cross the legal limit of 20 weeks in cases when active investigations are not being sought to rule out congenital anomalies, as in most pregnancies. The socioeconomic background of the family and their rural habitat contributed to their lack of awareness of the application procedure and it therefore took them a further two weeks to appeal to the court for the right to abort. To add to this delay, the Supreme Court ordered another medical report, which was completed by the 25th week of pregnancy. During the 26th week, the Supreme Court passed its judgment.

It is clear that the background of the couple had played a major role in the delay in decision making along with the medical and legal systems that denied quick access to affordable tests, thereby further delaying decision making. By the time any decision could be made, the approved time for abortion as per the MTP Act had passed, leading to a miscarriage of justice.

In contrast to this, on January 16, 2017, the Supreme Court allowed a 22-year-old to terminate her 24-week pregnancy (13). The woman had been undergoing treatment in KEM Hospital and had been detected with foetal abnormalities during her 21st week of gestation. She was allowed to undergo abortion on the grounds that continuation of the pregnancy would have endangered the mother's physical and mental health. The family faced many legal hurdles and was mentally and emotionally exhausted by the whole process. However, due to their better socioeconomic means and because of being treated in a reputed hospital, the family had slightly easier access to and better awareness of the legal procedures (13).

### **Abortion and Down syndrome**

Of the about 26 million births that occur in India yearly, approximately 2–3% involve severe congenital or

chromosomal defects. Many suffer intrauterine foetal death (IUFD). Certain abnormalities may be detected before the 20-week mark but are confirmed only after that period (14).

Abortions of fetuses with Down syndrome have been carried out across many countries, including the US, where the environment is largely against abortion, due to religious sentiments. In a systematic review of termination rates published in 2012, it was found that the abortion rates in fetuses with Down syndrome were in the order of 85% (ranging from 60% to 90%) across six states including the District of Columbia (15). In England and Wales, where abortion statistics are published annually, Down syndrome is the most commonly reported congenital anomaly where abortions are performed. Statistics released in 2016 by England and Wales reported about 3208 abortions performed for congenital malformations, of which 7% were for congenital anomalies (21 were contributed by Down syndrome) and were terminated at above 24 weeks of gestation (16).

In a well-argued piece on the moral and ethical reasons for justifying abortion (17), Nuccetelli contends that we cannot use justifications of quality of life with Down syndrome, or for that matter any congenital anomaly, as it can always vary and statistics cannot replace individual outcomes. The only factor that can be considered is that of procreative freedom, which in this case, is the right of the parents (who are in agreement with each other), as it receives moral weight in any ethical argument (17). However, another way of interpreting abortion in case of Down syndrome would be that of stretching the timeline to after birth with the same set of conditions and thus arguing against abortion: If we are willing to allow abortion on the grounds of a Down syndrome diagnosis, would it not be equivalent to allowing infanticide on those very same grounds? That can be an unnerving proposition to advocates of abortion that is well discussed recently by Henrik Friberg-Fernros (18). This extension of the argument essentially plugs for euthanasia, but that is a separate topic and out of scope of the current paper.

However, most of the literature on the ethics of abortion has come from developed countries, which have insurance-based or state-sponsored healthcare that can ensure the quality of care for the mother and child. Birth, death, and abortion have different socio-religious connotations in various cultures. The literature for Indian conditions is almost absent, and making legal decisions based on a different milieu is fraught with danger. Another aspect of this ethical conundrum is the fact that there is little focus on parents. We do know that parents of children with chronic disease have poor mental and physical health (19). In addition, they also undergo financial and social turmoil. The attitudes of a poorly-adjusted family will definitely impact the treatment of the child with a congenital anomaly, and as often happens, they will likely be denied care since healthcare is mostly an out-of-pocket expense in India (20).

### **Effects on the family**

With abortion denied, the family has to raise the child within its meagre financial resources and a dented emotional reserve. The mean medical cost for children with Down syndrome aged

0–4 years is 12–13 times higher than for children at that age without Down syndrome. For infants with Down syndrome and a congenital heart defect, the mean cost is a further 5–7 times higher than for infants with Down syndrome who do not have heart disease (21). Compared to children without Down syndrome, children with Down syndrome are at higher risk for many conditions. These include hearing loss (up to 75%), obstructive sleep apnoea (50–75%), ear infections (50–70%), congenital heart defects (50%), eye disease (up to 60%), and so on (22). While many of these can be addressed, it requires immense resources to correct and address the problems and the procedures are not without their own health risks. For a country with such stringent abortion laws and which claims that children with Down syndrome can lead adequate lives, it is imperative to evaluate the services provided in order to facilitate the mental and physical development of such special-needs children. The Supreme Court should have assessed these services before passing its judgment.

Current educational services in India include the following (23):

- *Formal schools:* The Ministry of Human Resource Development has been implementing “integrated education for the disabled children” in formal schools since 1982, wherein education is provided to differently abled children in normal schools to facilitate their retention in the school system.
- *Special schools:* The Ministry of Social Justice and Empowerment runs a special-school programme. Children who are unable to cope with regular schools are referred to these schools. A disability certificate is needed for admission to such schools, issued if there is a 40% disability of a particular type, such as hearing impairment, visual impairment, mental retardation, or physical disability. Special schools are generally run by voluntary organisations and located in urban areas. There are 20 special schools in Maharashtra alone.
- *National open schools:* The mission of the national open school system is to provide education through an open learning system as an alternative to the formal system.

The Down Syndrome Federation of India supports the individual along with their family by providing services such as “counselling for distraught families; training children to overcome their shortcomings; providing physiotherapy, speech therapy; and spreading awareness about Down syndrome.” It has 10 centres in India, one of them in Mumbai (24).

### Current abortion laws in India

Decades ago, the only method available for termination of pregnancy was dilatation and curettage (D&C), an invasive procedure that requires general anaesthesia to remove the products of conception. This procedure can lead to complications such as bleeding, perforation of the uterus, infection, and so on. The MTP Act took into consideration the mother’s safety according to medical technology available at that time in 1971 (25). It is based on old science. We are now in

the second decade of the twenty-first century. With the recent advances in reproductive medicine and technology, newer techniques and procedures have become available. There are several safer options for abortion, including pharmacological solutions and dilatation and evacuation (D&E or vacuum aspiration). D&E is less invasive than D&C and requires only local anaesthesia. Even abortion in later stages of pregnancy has become safer with the availability of better anaesthesia, good intensive care, and newer gases.

On October 29, 2014, the Ministry of Health and Family Welfare released a draft of the MTP (Amendment) Bill (26), which proposed many changes that have initiated an important discourse among healthcare providers and consumers. One of these is to increase the time period for a legal abortion to 24 weeks of gestation, keeping in view that modern medicine can detect foetal anomalies only after the 20th week. This will help in decreasing maternal morbidity and mortality and may also help in preventing wastage of resources invested in a pregnancy and preserving the woman’s health, strength, and above all, life (27).

The Supreme Court could have utilised the draft bill while delivering its judgment. While this is not required as the bill has not yet been enacted into law, the draft bill does contain scientific evidence on why the period for legal abortion should be extended to 24 weeks. The authors feel that the current case has suffered and fallen through the cracks between the judiciary, the legislature, and the executive while the science is currently available (27). It is a sign that the scientific community needs to engage more with civil society so that the benefits of advances in science are not withheld from society, the lower rungs of which are most impacted.

In addition to these amendments, there is also the need to lay down legal guidelines under the MTP Act for doctors and courts to follow while deciding on abortion after the 20-week mark. If pregnant women want a termination after this point, they need to appeal to the Supreme Court, which relies on the advice of medical boards appointed to examine the women petitioning for an abortion. Decisions of the doctors on the medical board appointed by the Supreme Court may vary, and one does not know if their decisions are guided by their ethical and moral values, as there are no set rules for the same. Thus, if the doctors personally have morality-based opinions about abortion, then such a report could be challenged as not being a report based on the Constitution and rights but one based on personal values and judgments. When medical professionals publish papers or write reports, they sign conflict-of-interest statements. It is important for experts and judges as well to sign such statements with respect to their comments on cases. Otherwise we will never know, as in this case, whether their moral/spiritual/religious standpoint is part of the opinion expressed or judgment made. Judgments should ideally be based on scientific data, which are not yet available in India as no studies have reported on such outcomes.

However, judgments may vary on a case-to case-basis as seen in these recent examples:

- In July 2016, the Supreme Court had allowed a 26-year-old alleged rape victim to abort a 24-week-old foetus with severe abnormalities as the medical board formed for the case had opined that continuing the pregnancy posed a danger to the mother's life (12).
- In November 2016, the High Court of Kerala had allowed termination of an over 20-week-old pregnancy of a rape victim (28).
- In May 2017, the Patna High Court denied abortion of a 26-week-old foetus of an HIV-positive rape victim as the court felt that it was the responsibility the court to keep the child alive. After which, the victim appealed to the Supreme Court who heard her plea but denied her an abortion (29).

With no medical guidelines on how to perform an abortion after 20 weeks of gestation in India, this aspect, which requires more advanced technical knowledge, also needs the attention of professional bodies (30).

### Abortion laws across the world

Abortion laws vary across the world, and about 60 countries prescribe gestational limits. 52 % including France, the UK, Austria, Ethiopia, Italy, Spain, Iceland, Finland, Sweden, Norway, Switzerland and even Nepal, allow for termination beyond 20 weeks on the diagnosis of foetal abnormalities. Some countries go beyond even these limits with laws in 23 countries—Canada, Germany, Vietnam, Denmark, Ghana, and Zambia—allowing for abortion at any time during the pregnancy on the request of the mother (31). The reasons could be either social or the evidence of foetal abnormalities (31). In the United Kingdom, abortions are allowed at up to 24 weeks, with abortion guidelines formulated by the Royal College of Obstetricians and Gynaecologists including procedures for termination of pregnancies older than 20 weeks. It states that, in pregnancy older than 21 weeks and 6 days, an injection to cause foetal death is given before the foetus is evacuated (32). Many other countries follow the same procedure for late-term abortions. The UK guidelines also take into consideration doctors who have an objection to abortion on the basis of their religious or moral beliefs: While a doctor can refuse to perform an abortion, he is required to inform the woman of her right to see another doctor (32).

### Ethical dilemma

The core principles of ethics are autonomy, beneficence, non-maleficence, and justice. In pregnancy, there are two lives at stake. If the mother's life is in danger, then actions are easy to take. In the case under discussion, the mother's life was not in danger, but the birth of a child with defects would commit her to poor mental health throughout her life, including the possibility of self-harm and suicide (33). The caregivers of the unborn child are decision makers, and parental autonomy is well established except when they set out to make martyrs

of their children due to their beliefs or religious practices (34). In this case, though parental autonomy cannot be invoked, it needs to be respected; the parents' request may be denied if there is clarity that the birth of the child will not affect the health of the parents. Competence is an integral part of autonomy, and in this case, the Supreme Court has not demonstrated application of mind by overlooking available evidence and expertise. Accurate information has perhaps not been provided, and this is a failure of the medical community. As a result, parental autonomy has been disregarded and the unborn child's quality of life has been left ignored.

The principles of beneficence and non-maleficence, in this case, have also been poorly served. If appropriate resources are available, such a child may lead a life of adequate quality. In the face of poor infrastructure and questionable availability of resources, however, the quality of life may indeed be poor and cause untold pain to the child. The parents are then likely to suffer from moral distress and poor mental health, and thus, this decision has likely violated these rights. It must be argued that the court's decision has caused maleficence to the parents. In this case, the principle of justice is upheld as far as the courts are concerned as they may have given the same decision with the same set of findings. However, it can be surmised that if this were a couple with good economic resources and hailing from a larger city, they could have performed an abortion before the 20-week mark as the time taken to receive the various test results would have come down significantly, possibly from days to hours. Viewed from this standpoint, we infer that the couple suffered an injustice due to their socioeconomic circumstances.

On July 3, 2017, the Supreme Court allowed a woman who had crossed 24 weeks of gestation an abortion as her foetus suffered from pulmonary atresia (14). The right of a woman to have reproductive choice is a part of personal liberty, as per Justice Mishra, the judge on the bench in that case. The court also quoted a petition filed in 2015 on behalf of a 14-year-old rape victim, which said, "Woman's right to make reproductive choices is also a dimension of personal liberty as understood under Article 21 of the Constitution." "It is important to recognise that reproductive choices can be exercised to procreate as well as to abstain from procreating. The crucial consideration is that a woman's right to privacy, dignity, and bodily integrity should be respected." (28, 35)

Just as termination of pregnancy is not allowed without voluntary consent of the woman, continuation of pregnancy should not be forced on her without her consent. Forced continuation of a pregnancy is an infringement of right to privacy and dignity of a woman and a violation of the right to a healthy and dignified life of the new born (36).

### Conclusions

This case demonstrates that laws that were designed to protect have been rendered detrimental in light of current technological changes. Ethical dilemmas are also more prevalent in an economically disadvantaged sociocultural

milieu and need to be addressed in line with the changing times. We believe that if the promulgation of the amendment and the presenting of evidence to the court had been promptly conducted, there could have been a different outcome than the one that played out. In this unfortunate story of a mother who was forced against her will to deliver a child with congenital defects, we feel that society has failed the mother and the new born. The scientific community needs to engage more in the public space so that the legislative, executive, and judicial arms of the government do not disregard medical ethics.

**Acknowledgements:** We would like to thank Dr. Ameer Amin for reviewing the manuscript and for performing a language check.

**Conflict of interest and funding:** None to declare

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### **ANNOUNCEMENT**

#### **Maiden Bioethics Essay Competition for 'IJME Young Bioethicist and Change-makers Award' by the Bioethics Centre, Forum for Medical Ethics Society, Mumbai**

We at Bioethics Centre, Forum for Medical Ethics Society, Mumbai, are pleased to announce the **maiden Bioethics Essay Competition titled 'IJME Young Bioethicist and change-makers Award'** aimed at creating spaces for young scholars to engage with bioethics matters and share their views with the larger peer community.

#### **Who can submit essays?**

Post graduate, MPhil and Doctoral students studying in India from a range of disciplines including Medicine, Nursing, Biomedical sciences, Public health, Health management, Law, Social sciences, Humanities, Journalism, and Engineering are welcome to submit essays.

#### **What does the award comprise?**

- a. The first three winning essays will be posted on the *IJME* website and be considered for publication in *IJME*.
- b. FMES will support authors of the first three winning essays for a two-week-long internship (cost of travel and stay upto INR 25K) with grass-roots level organisations in India which contribute to enhanced access to quality care as an ethical obligation.

#### **Guidelines for essay writing:**

**Word count:** About 1500 words;

**Language:** English;

**Essay content:** Innovative, thought provoking essays with fresh perspectives on the issue at hand will be preferred;

**Focus:** Must centre-stage ethical, social, cultural and legal aspects;

**Citation style:** Must use a single citation style consistently through the essay; **Type of file:** Microsoft Word document and named as author's FirstName\_LastName\_DateofSubmission.docx;

**Insertion of pictures:** If any are inserted, must be sourced appropriately;

**Inclusion of contact information:** Must mention - Name, Postal Address, Contact number, Brief Bio-sketch in the covering email.

**Timelines: (a) Essay submission:** By midnight of March 21, 2019; (b)

**Notification to winners:** April, 2019;

**Submit to:** [fmescentre.essay@gmail.com](mailto:fmescentre.essay@gmail.com) with a cover email explaining briefly (upto 200 words) your motivation for participating in the competition; **Jury:** Jury members will be drawn from the network of FMES and *IJME*.

**Essay themes: (1)** Health care professionals and the death penalty in India: Ethical obligations and challenges; **(2)** Ethical challenges and responsibilities in health journalism; **(3)** Artificial Intelligence in health care: Ethical and regulatory quandaries. **[please visit [www.ijme.in](http://www.ijme.in) for more information]**