Title: Can we ensure that the sacrifice of the mother who was mandated to deliver a child with Down syndrome does not go in vain? The Medical Termination of Pregnancy needs to keep up with technology.

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***ABSTRACT***

*We discuss the case of denial of abortion in the summer of 2017 by the Supreme Court of India. A mother who already had a child with special needs was denied the abortion of her 26-week old fetus who had been detected with Down syndrome at 22 weeks. The Medical Termination of Pregnancy Act of 1971 although well formulated and ahead of its time at inception seems to have not kept pace with technology and is 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. Here, the mother was not able to decide for herself and was forced to abide by the decision taken by the court.*

**Introduction**

On 28th February 2017, the Supreme Court interceded in a case of a 37-year-old mother, who requested for an abortion of her 26-week fetus who had been 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 to a potentially handicapped or malformed child, within the approved 20-week gestational period. Despite such a pertinent clause, the Supreme Court denied the abortion plea once again questioning the stringent abortion laws in India. Under MTP Act, 1972 Section 3, it allows abortion if continuation of the pregnancy would involve a risk to the life of the pregnant woman or cause grave injury 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 she would have been eligible for an abortion under the MTP Act.

The mother, a resident of Alibaug, Mumbai, Maharashtra belonged to a lower middle-class family and was diagnosed during her antenatal confirmatory test at 22 weeks with trisomy 21, a genetic chromosomal aberration more commonly known as Down syndrome. The couple already has a differently abled child in the family, knew the hardships of bringing up such a child, and thus, wanted to go for abortion after they got the confirmatory reports. The reports reordered by the Supreme Court were done at Mumbai’s KEM Hospital and the doctors reported, “There is no harm to the health of the mother. The fetus 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 Justice SN Bobde and LN Rao sympathized with the woman’s plight, but regrettably 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 in Down syndrome, of 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 between 18-20 weeks [3]. The prenatal screening tests include a blood test and an anomaly scan by ultrasound thus providing a possibility of the fetus having Down syndrome. The blood test measures alpha-fetoprotein, inhibin A, plasma protein A, estriol, and human chorionic gonadotropin [4]. Anomaly scan can detect fetal abnormalities only after 18 weeks of gestation and costs around Rs 3650 [5].

In the 22nd week, they received confirmatory test reports for the same.

Current confirmatory tests available for Down syndrome are fetal chorionic villi sampling and amniocentesis. Amniocentesis is done between 15-22 weeks and its results would be available within 2-3 weeks. It has almost 1% chances of spontaneous termination and it will cost around 8110 rupees [5]. It has 100% accuracy [6]. Chorionic villus sampling (CVS) is performed between 9-14 weeks and the reports are available in 10 days. It has a higher risk of miscarriage and infections than amniocentesis and will cost Rs 9290 [5]. CVS has 98% accuracy [7].

Considering the cost and risk of confirmatory tests, they will be done only if the diagnostic tests are positive. The procedure involving diagnostic test followed by the confirmatory test will cross the legal limits of 20 weeks in cases when active investigations are not being sought to rule out congenital anomalies, as in most pregnancies. The socio-economic background of the family and their rural habitat contributed to their unawareness of the application procedure and therefore it took them 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 thus appears that the background of the couple contributed to the delay in decision making and by the time any decision was made, the approved time for abortion according to the Medical Termination of Pregnancy, 1971 had passed. Justice, an important component of medical ethics had been thus denied to the couple due to their background.

**Abortion and Down Syndrome**

Abortions have been carried out in Down syndrome across many countries including the US which has a relatively anti-abortion environment due to religious sentiments. In a systematic review of termination rates published in 2012, it was found that the abortion rates in Down syndrome were in the order of 85% (range 60 to 90%) across six states including the District of Columbia [8]. Similar rates are seen in England and Wales where abortion statistics are published annually. Down syndrome is the most commonly reported congenital anomaly where abortions are performed. In the statistics released in 2016 by England and Wales, about 3208 abortions were performed for congenital malformations of which 7% of congenital anomalies (21 were contributed by Down syndrome) were terminated above 24 weeks of gestation [9].

In a well-argued piece on the moral and ethical reasons for justifying Nuccetelli argues that we cannot use justifications of quality of life of Down syndrome or for that matter any other congenital anomaly as it can always vary and statistics cannot replace individual outcomes. The only factor which can be considered is the procreative freedom which in this case is the right of the parents (who are in agreement) as it receives great moral weight in any ethical argument [10]. Another way of interpreting abortion for Down syndrome would be stretching the timeline to after birth with the same set of conditions and thus argue against abortion. If we are willing to allow abortion for Down syndrome, then would it not be equivalent to allowing infanticide of Down syndrome. It can be an unnerving proposition to advocates of abortion but it is well discussed in a recent viewpoint by Henrik Friberg-Fernros [11].

However, most of the literature on the ethics on abortion has come from developed countries, which have insurance based, or state-sponsored health care 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 [12]. In addition, they would also undergo financial and social turmoil. A poorly adjusted family will definitely impact the unwanted child with a congenital anomaly and as often happens, they will be often denied care in India since healthcare is mostly out of pocket expenses [13].

**Effects on the family**

With the abortion denied the family has to raise the child with its meager financial resources and a dented emotional reserve. The mean medical cost for children 0-4 years is 12-13 times higher than for children without Down syndrome. For infants with Down syndrome and a congenital heart defect, mean cost is 5-7 times higher than for infants with Down syndrome who do not have any heart disease [14]. 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 apnea (50-75%), ear infections (50-70%), congenital heart defects (50%), eye disease (up to 60%), etc. [15]. While many of these can be addressed, it requires immense resources to correct and address the problem while undertaking health risk of procedures. For a country with such stringent abortion laws and claims that Down syndrome children 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 needed to have done this evaluation before passing judgment. Current services in India include [16];

Formals 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 – a programme of the Ministry of Social Justice and Empowerment. Children who are not able to cope with regular schools need a referral to these schools. A disability certificate is needed for admission to such schools. It is issued if there is 40% disability of particular type like hearing impairment, visual impairment, mental retardation and physical disabilities. Special schools are generally run by voluntary organizations and located in urban areas. There are 20 special schools in Maharashtra.

National open schools – its mission is to provide education through an open learning system as an alternative to the formal system.

Down Syndrome Federation of India. It supports the individual along with its family by providing services such as counseling distraught families, training children to overcome their shortcomings, providing physiotherapy, speech therapy, occupational and vocational therapy and spreading awareness about Down syndrome. It has 10 centers in India, one of them being in Mumbai [17].

**Current abortion laws in India**

Medical Termination of Pregnancy Act of 1971 is based on the science present during older times. With changes and recent advances in reproductive science and technology, the act has lost its relevance with the availability of newer techniques and procedures. Decades ago, the only method available for termination of pregnancy was Dilatation and Curettage (D&C). It is an invasive procedure and requires general anesthesia to remove products of conception. It can lead to complications such as bleeding, perforation of uterus, infection, etc. Thus, the law in 1971 took into consideration mother's safety according to what was best available at that time [18]. We are in the second decade of the 21st Century and there are various safer options for abortion including pharmacological treatment, dilatation, and evacuation (vacuum aspiration). It is less invasive and requires only local anesthesia. Even abortion late in pregnancy has become safer with better anesthesia, 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, which proposed many changes that have initiated an important discourse among health care providers and consumers. One of them is to increase the time period for a legal abortion to 24 weeks, keeping in view that modern medicine can detect fetal anomalies only after the 20th week. It will help in decreasing maternal morbidity and mortality and may also help in preventing wastage of pregnancy, women’s health, strength, and above all life [19]. The Supreme Court could have utilized the draft bill while delivering the judgment. While it is not required as it is not a law yet, the draft bill does contain scientific evidence why the period should be extended to 24 weeks. The authors feel that the current case has suffered and fallen between the cracks of the judiciary, the legislative and the executive while the science is currently available. It is a sign that the scientific community needs to engage more with the civil society so that the benefit of science is not withheld from the lower rungs of society.

In addition to these amendments, there is also the need to lay down legal guidelines under MTP Act for doctors and courts to follow while deciding for abortion after 20 weeks. If pregnant women want to terminate the pregnancy after 20 weeks, 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 according to their ethical and moral values, as there are no set rules for the same. In addition, there are no guidelines on how to perform an abortion after 20 weeks of gestation in India. This aspect, which is more technical also, needs attention from professional bodies [20].

**Abortion laws across the world**

Abortion laws across the world are different and about 60 countries prescribe gestational limits. 52 percent, including inter alia France, the UK, Austria, Ethiopia, Italy, Spain, Iceland, Finland, Sweden, Norway, Switzerland and even our neighboring country Nepal, allow for termination beyond 20 weeks on the diagnosis of fetal abnormalities. Some countries go beyond even these limits with laws in 23 countries, including countries as diverse as Canada, Germany, Vietnam, Denmark, Ghana, and Zambia, allowing for abortion at any time during the pregnancy on request of the pregnant woman. The reasons could be social as well as fetal abnormalities [18]. In the United Kingdom, abortions are allowed up to 24 weeks, the Royal College of Obstetricians and Gynecologists has formulated the guidelines for abortion. It also includes procedures for pregnancy more than 20 weeks. It states that, in pregnancy beyond 21 weeks and 6 days, an injection to cause fetal death is given before the fetus is evacuated. Many other countries follow the same procedure for late-term abortions. The guidelines also take into consideration doctors who have an objection to abortion on basis of their religious or moral beliefs. While a doctor can refuse to perform an abortion, he is required to tell the woman of her right to see another doctor [20].

**Ethical Dilemma**

The core principles of ethics are autonomy, beneficence, non-maleficence, and justice. In pregnant women, there are two lives at stake. If the mother’s life is in danger then actions are easy to take. Here the mother’s life was not in danger but the birth of a child with defects will ensure that she will have poor mental health throughout her life, and consequences including mortality [21]. The caregivers of the unborn child are decision makes and parental autonomy is well known except when they set out to make martyrs of their children. In this case, though parental autonomy cannot be invoked it needs to be respected and the parents' decision 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 this trait by overlooking available evidence and expertise. Perhaps accurate information has not been provided and this is the failure of the academic community. Therefore, while parental authority has been disregarded the unborn child has been left unguarded.

The principles of beneficence and non-maleficence, in this case, have also been poorly addressed. If appropriate resources are available, the child after birth may lead an adequate quality of life. In the face of poor infrastructure and availability of resources, the quality of life may indeed be poor and cause untold pain to the child. The parents will suffer from moral distress and poor mental health and thus this decision will ensure that these rights have been violated. It must be argued that the court decision has caused maleficence to the parents. The case cannot be held to against the principle of justice 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 was a couple with good economic resources and hailing from a bigger city, then they would have got an abortion done before 20 weeks as the time duration for various tests would have come down from days to hours. Viewed from this standpoint, we infer that couple suffered injustice that was meted to them by their socioeconomic circumstances.

**Conclusion**:

The case demonstrates that laws that were designed to protect humans have been rendered detrimental in light of current technological changes. Ethical dilemmas are also more prevalent in the socio-cultural milieu and need to be addressed with changing times. We believe that if there was speed in the promulgation of the new act and better availability of evidence to the court, then we may have had a different result than the one that played out.

In this unfortunate story of a mother who was forced to deliver an unwanted baby with congenital issues, we feel that the society has failed the mother and the newborn. 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.

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