

EDITORIAL

The Niketa Mehta case: does the right to abortion threaten disability rights?

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The secular public discussion on abortion in India has generally been centred around the need to prevent sex selective abortion because of its social consequences. Abortion has also been discussed in the context of maternal health, where it is feared that contraception use is substituted by repeated induced abortions. Another concern has been that induced abortions are resorted to by unmarried girls. In all the above circumstances, the key ethical issues are related to gender inequality and the presence of subtle or overt coercion. It needed a person like Niketa Mehta to initiate the ethical discussion surrounding the question of abortion *per se* in India.

Coercion does not seem to be an issue in the case of Niketa Mehta. An educated, middle-class woman, with a supportive husband, having a much longed-for first pregnancy, she was arguably better placed than most women to take a decision about her pregnancy. She was equipped with sufficient information on the foetus' health condition and apparently did not face any coercion from her family. She wanted to terminate a pregnancy which had a high probability of resulting in a miscarriage or the birth of a child with a serious heart defect. This could have been a routine decision, had it not been for the fact that Niketa's pregnancy had advanced beyond the 20 weeks during which medical termination of pregnancy is permitted in India.

Rather than resort to an illegal abortion, Niketa and her husband, along with the specialist who diagnosed a congenital anomaly in the foetus, filed a petition in the Mumbai High Court asking for permission for an abortion in the 23rd week, which was when the problem was detected (1). The argument supporting them is that in several countries, including the United Kingdom, there is no gestational age limit set for abortion in the case of foetal abnormalities (2). Niketa's personal reason for wanting an abortion was that she did not want to give birth to a severely disabled infant and witness its suffering; the trauma caused to her and her family was an additional reason (3).

While Niketa failed to obtain a favourable judgement from the court, her case has prompted the government to announce that it will be considering a review of the law (4). Further, this case raises several ethical dilemmas related to abortion, and also to disability and the role of medical intervention.

Disability and the Medical Termination of Pregnancy Act

Disability-related abortion is actually built into the Indian law (5) which permits abortion up to 20 weeks if there is a pre-natal diagnosis of congenital defects; a pre-natal diagnostic test would be meaningless without the possibility of correcting the problem in *utero* or terminating the pregnancy. Some would argue that once abortion following prenatal diagnosis of foetal abnormalities is legal, a gestational age limit is meaningless. And if we start from the premise that it is a woman's right to terminate a pregnancy that she does not want, even a planned pregnancy can become unwanted once foetal abnormalities are detected, regardless of how far the pregnancy has progressed. Further, a logical consequence of the provision for abortion in the case of foetal abnormalities is that each development in pre-natal diagnostics will necessarily be followed by revisions in the law that the development necessitates. In Niketa Mehta's case, the foetal heart defect could only have been detected after 20 weeks' gestation.

Third, there may be a social context to the choice to undergo an abortion rather than carry a pregnancy to term. Niketa was remarkably unequivocal in her views. Regardless of the offers to support and care for her child when born, she was categorical in the assertion that her decision was a private matter. This is not surprising as disability has remained largely a private concern in India. The family of the disabled child bears almost all the burden of care, support and even financial costs. Unlike other countries, no comprehensive social support system for people with special needs exists in India. As a result, disability is looked upon with a sense of fear and a lack of understanding, which is perpetuated through images in the popular media.

However, removing the social barriers to care, stigma and discrimination would not automatically make disability a "non issue". The decision to give birth to a child who is disabled can never be easy, even in the best of circumstances, though several women choose to continue a pregnancy even when they know that they will give birth to a disabled child, and many willingly adopt a disabled child.

I believe that no law or person can ethically compel a woman to carry on a pregnancy that she does not want. However, when the pregnancy has progressed to a point where the foetus has become viable, one is compelled to view the situation from the point of the woman as well as the potential child. Thus, while a woman's choice *not* to continue a pregnancy which harms her sense of

well-being remains at any point in the pregnancy, it may be impossible to fulfil her choice when a late abortion could amount to a prematurely induced birth of a child. The only exception is when the pregnancy poses a grave danger to the woman's life—her interests take precedence over all other considerations.

The problem arises when the reason for abortion is not the risk posed by the pregnancy but the perceived consequences of giving birth to that child. These risks are not physical but social. It would be incorrect to posit this as a conflict between woman and foetus. One would have to explore the woman's reasons for wanting an abortion. In this case, Niketa was as concerned about the possible suffering of the future child as her own suffering.

This position also runs counter to the legal and political position that has long been accepted in the context of sex selection, where the pregnant woman's own choice is to protect the rights of women as a group. I have also been a participant in the campaign which resulted in legislation to ban sex selection, and its amendment.

At best, this contradictory position could be defended by arguing, as I had done, in an earlier article in this journal (6), that the disadvantages that girls face are *completely* socially constructed and, hence, there is space for and obligation on society at large to intervene in the matter. In contrast, disability poses inherent disadvantages, which although they can be ameliorated by social measures, cannot be removed altogether. In such a situation, one must give the woman the right to decide in her best interest.

Does the right to abortion threaten disability rights?

The question remains: does one's endorsement of the right to abortion on grounds of disability at any point in the pregnancy weaken one's commitment to the rights of the disabled? I argue that the value of living persons cannot be equated with the foetus which is not a person. Thus, the right of a woman to decide on the fate of her pregnancy does not conflict with, or interfere with, the human rights of the disabled. The decision to abort a foetus for no other reason but congenital defects is largely based on the parents' prediction of the quality of life that such a child would have, and their own emotional response to it. These in turn are mostly determined by the existing condition of the disabled. There is little acceptance of the rights of the disabled in society, and scant attention paid to their needs, making disability appear to be a greater tragedy than it needs to be. There is a role for society and the state to minimise the disadvantages that the disabled face due to institutional rules and infrastructural arrangements. This is a question of not merely providing services and resources for rehabilitation, but also of acknowledging the right of the disabled to be part of society, and accepting different definitions of success and fulfilment in life.

The response of parents, and their experiences, after the child is born can be different; at least some parents of disabled children note that the experience of parenthood with that child was as rewarding as with any other child. However, their experiences have still failed to challenge the dominant image of disability, which is also shared by a large part of the medical profession which is responsible for guiding and supporting women such as Niketa.

In this case, one is inclined to vote in favour of Niketa, as an endorsement of her right as a woman to choose whether to give birth or not. There was speculation and there were unobvious hints that she had eventually induced the abortion on failing to obtain a favourable judgment. This was not deserved by a woman who had no need to come out in public with her predicament in the first place, had she not wanted to draw attention to the larger issue at stake.

The development of diagnostic technology which enables better detection of foetal abnormalities will take its own course and have its momentum, as it is well entrenched in the logic of the private medical sector, which is patronised by the middle and upper class. However, the movement for disability rights needs the support of the larger collective, and more comprehensive measures on the part of the state and society, which cannot be commodified as easily. While each family finds its own way of coping with the burden of care, in the search for individual solutions to seemingly personal tragedies, the larger struggle may be lost even before it is begun. This is only symptomatic of the larger situation of healthcare in India, where the more influential middle class has migrated entirely out of the public sector and sees no benefit in devoting its energies to the development of social and comprehensive solutions which would benefit the people at large.

References

1. Kher S. Niketa's miscarriage brings back focus on legal cut off for abortion. *Indian Express* 2008 Aug 15 (online edition) [cited 2008 Sep 30]. Available from: <http://www.expressindia.com/latest-news/Niketas-miscarriage-brings-focus-back-on-legal-cutoff-for-abortion/349199/>
2. Ministry of Justice (United Kingdom). The UK Law statute database. Abortion Act 1967 (c.87). [cited 2008 Sep 30]. Available from: <http://www.statutelaw.gov.uk/content.aspx?activeTextDocId=1181037>
3. Kilpady N. CNN/IBN. Abortion debate: Bombay HC verdict today. IBNlive.com . 2008 Aug [cited 2008 Sep 30]. Available from: <http://www.ibnlive.com/news/abortion-debate-bombay-hc-verdict-today--your-say/70368-3.html?from=search-relatedstories>
4. Sharma S. Niketa effect, government to review abortion laws. *Hindustan Times*. 2008 Sep 4. [cited 2008 Sep 30]. Available from: <http://www.hindustantimes.com/StoryPage/StoryPage.aspx?sectionName=&id=61ed0377-7d6f-4f0a-8f0a-a33a06f99550&&Headline=Niketa+effect%3a+Govt+to+review+abortion+laws>
5. Ministry of Health and Family Welfare, government of India. The Medical Termination of Pregnancy Act, 1971 (Act No.34 of 1971). [cited 2008 Sep 30]. Available from: <http://mohfw.nic.in/MTP%20Act%201971.htm>
6. Madhiwalla N. Sex selection: ethics in the context of development. *Issues Med Ethics* 2001; 9(4): 125-6.