

# Genetic privacy: Resolving the conflict between the donor and the child

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*An attempt has been made to analyse the issue of genetic privacy arising out of the medically assisted reproductive techniques. The conflict between the donor's 'right to privacy' and the child's 'right to know' has been sought to be harmonized by adoption of a proposed statutory framework.*

With the mushrooming of IVF (*in vitro* fertilization) clinics all over the country, an important ethical, moral and legal question has come to occupy the centre stage in the debate. Should the child born as a result of the medically assisted reproductive techniques (MART) have the right to know the identity of his genetic parents? Practicality suggests that MART children would benefit from access to genetic and medical information about their biological father's family, and that knowledge of the donor's identity would help prevent the possibility of marriage between two persons with the same donor and also unleash a whole host of preventive medicine benefits. On the other hand, offspring might wish to contact their genetic parents and may end up intruding on another family's right to privacy.

This commentary seeks to examine the legal position with regard to the right of the child to know the identity of his genetic parents. Further, it attempts to lay down the parameters for a new statutory framework, regulating the 'right to know' of the MART-child.

## Artificial insemination

Artificial insemination is a process whereby semen from an anonymous donor is placed near the cervix of a woman whose husband is infertile or at risk for a genetic disorder. The secrecy of the artificial insemination process allegedly protects the donor, the child and the parents from stress or embarrassment. It also purportedly protects the donor from legal responsibilities in the areas of legitimacy and inheritance.

## In vitro fertilization

IVF<sup>1</sup> is a technique where one or more ova are removed from a woman's body, combined with semen, allowed to mature

through two or three cell divisions and then inserted into the uterus through the cervical canal<sup>2</sup>. It is a complicated process requiring accurate timing and extensive monitoring. The procedure is most commonly used for women who are able to ovulate, but who cannot conceive because of blocked or diseased fallopian tubes. The wife's ova and the husband's sperm are combined and hopefully, pregnancy results. Complications arise in situations where either the husband or the wife is unable to provide the germinal material, which must then be obtained from a donor.

Therefore, both in cases of artificial insemination and IVF, the services of an anonymous donor of genetic material may be used. It is here that the legal question arises whether the child should have a right to know the identity of the person who supplied the genetic material.

## Why is genetic information necessary?

The need to keep accurate records for genetic paternity is increasingly becoming apparent. For the children, the records may be critical to the process of genetic counselling, which is an increasingly useful tool in preventive medicine<sup>3</sup>.

The secrecy that cloaks artificial insemination and IVF is baffling to many geneticists. Increasingly, people are seeking a geneticist's advice prior to the birth of their first child. Before counselling can begin, a detailed family history must be compiled. All parties are adversely affected when access to medical records is prohibited. For example, children born through the use of artificial insemination or IVF cannot give or receive accurate family information, which may affect their health as well as that of their loved ones. Donors of biological material, eggs or sperms, are unaware of the number or medical condition of the children result-

ing from these procedures and cannot later make informed family-planning decisions. Any common medical history form, insurance policy or other medical document is not accurate so long as records remain sealed<sup>4</sup>.

The most often touted justification for secrecy is in 'the best interests of the child'. This justification seems outdated given the recognized significance of heredity in all aspects of life. How can it be in anyone's best interest to withhold vital medical information from them? It is time to reassess strict secrecy requirements and to create a system allowing each person access to his or her own medical records by the age of majority, if not before.

## Conflict between donor's privacy and the right to know

Genetic information has been recognized to be entitled to the highest expectation of privacy<sup>5</sup>. Statutes have been enacted in some places, which provide that genetic information is confidential and privileged<sup>6</sup>. A further refinement that has been brought into this sphere is that any entity that receives genetic information may not use or keep that information for any non-therapeutic purpose<sup>7</sup>.

The secrecy of donor and surrogate transactions is a contested issue in collaborative reproduction. The interests of offspring in knowing their genetic and gestational roots conflict with the desire of donors, surrogates and recipients for privacy, and their freedom to collaborate anonymously for reproduction.

It has been said that duty to disclose information would be a complete breach with the original theory and purpose of MART<sup>8</sup>. Further, it is also argued that if the 'right to know' is pressed too far, it may inhibit the use of artificial reproduction techniques<sup>9</sup>. Factors such as social stigma, the effect on other people's will-

ingness and the patient's reasons for failing to disclose, should assess the harm in disclosure. The courts in the United States have held that curiosity alone would not satisfy the 'good cause' requirement, which is required to be satisfied prior to disclosure of genetic information<sup>10</sup>. However, where it has been established that a clear overriding interest exists in the disclosure of genetic information, it must be seen to transcend confidentiality requirements<sup>11</sup>.

By satisfying the need of the offspring to know their roots, the law might prevent the birth of future children through collaborative arrangements. Without guaranteed anonymity, donors and recipients may not enter into collaborative transactions. But this is not a sufficient argument for frustrating the need of existing persons to know their genetic roots. The welfare of offspring is a sufficient basis for limiting reproductive contracts.

### The Indian scenario – the Apex Court and ICMR guidelines

In India, the Supreme Court has held that disclosure of confidential medical information may be justified in some circumstances<sup>12</sup>. When the right to health is weighed against the right to privacy, the right to health will override because privacy interest must be placed in the context of other rights and values<sup>12</sup>. Where life, safety, well-being or other important interests are in jeopardy, it will be justified to disclose the information<sup>12,13</sup>.

In India, the Ethical Guidelines for Biomedical Research on Human Subjects of the Indian Council of Medical Research (ICMR) have clearly laid down that children born from use of donor gametes and their social/adopted parents have the right to know whatever medical or genetic information about the genetic parents that may be relevant to the child's health<sup>14</sup>.

Therefore, a clear trend is seen across nations that where non-disclosure of genetic information can possibly have harmful effects on the health of the child, it will be justified to disclose such information. What is significant is that the Guidelines framed by ICMR also provide this right to the adopted parents in order to safeguard the health of the MART-child.

But what about *non-therapeutic* usage of genetic information? Section 31(4)(a) of the Human Fertilization and Embryol-

ogy Act, 1990 in United Kingdom imposes an obligation upon the authority to provide genetic information to those who have discovered that they are MART-children<sup>15</sup>. The Human Fertilization and Embryology Act, 1990 in United Kingdom embodies this right in Section 31(3), which allows a person who has attained the age of 18 years to check records maintained by authorities if the applicant has received counselling<sup>16</sup> and was born as a result of treatment services<sup>17</sup>. Therefore, in the United Kingdom genetic information is allowed to be disclosed even for non-therapeutic purposes. This is in sharp contradistinction to the prevailing position in India, where disclosure would only be permissible for therapeutic purposes. The new law should further clarify that disclosure of genetic information would be permissible only for purely therapeutic reasons.

### Is there an internationally recognized right to know one's genetic origin?

The right to information about one's genetic origins has been expressly recognized in the context of MART<sup>18</sup>. Various international conventions have expressly recognized this right<sup>19</sup>.

The international conventions and norms are to be read into municipal law in the absence of domestic law occupying the field, when there is no inconsistency between them<sup>20</sup>.

It is submitted that with regard to assisted reproductive technologies, the Guidelines for Assisted Reproductive Technologies in India of the ICMR regulates and provides accreditation to all MART clinics and hospitals. The Guidelines of the ICMR have laid down the legal, ethical, scientific and technical norms with regard to MART in India and its consequences thereof<sup>21</sup>. The Guidelines issued by the ICMR are in conformity with the international conventions in this area and therefore should be enforced for the benefit of the MART-child.

### Should the right to know one's genetic origin be made a fundamental right?

The question that arises is whether the right to know should be raised to the

level of a fundamental right. The test to be satisfied before being elevated to the level of a fundamental right is whether the right claimed partakes of the same basic nature and character as the named fundamental right, so that the exercise of such a right is in reality and substance nothing but an instance of the exercise of the named fundamental right<sup>22</sup>.

It becomes the duty of the Court to apply the Directive Principles in interpreting the Constitution and the laws, and they should serve the Court as a Code of Interpretation<sup>23</sup>. Article 39(f) exhorts the State to give children opportunities to develop in conditions of dignity and be protected against moral abandonment. Thus, Article 39 can be read into Article 21 to give expansive meaning to it.

However, the question which requires to be answered, is whether the right to know should be elevated to the level of a fundamental right. Given the fact that this technique of new biology is still in its nascent stage and not all outcomes are fully known, this right cannot be said to be in reality and substance nothing but an instance of the exercise of the right to life. Therefore, it would be far more prudent to adopt a regulatory legislation similar to UK's Human Fertilization and Embryology Act, 1990 to monitor the exercise of this right.

### Conclusion – signalling a new legal framework

As the use of noncoital technology increases, the need for more explicit public policy in several areas must be addressed. Since few laws explicitly address the new reproduction procedures, and professional norms and codes remain inchoate, the current public policy is implicitly laissez-faire. Implicit policies, however, create uncertainty for doctors and patients about proper conduct with embryos and collaborators. The result may leave too much room for private reproductive agendas, causing preventable injury to collaborators, offspring or the society. Legislation to assure the well-being of offspring in collaborative transactions could take many forms. Most important is to establish certainty about who the rearing parents are, by clearly defining the rearing rights and duties of donors, surrogates and recipients. Recording information about donors and surrogates will be essential, if information about

these persons is to be provided to the offspring who require this information for therapeutic purposes.

All children must be allowed access to their medical and adoption records. There can be serious medical consequences if access is denied. The significance of heredity in various diseases is well known and continues to gain even greater recognition. A uniform law must be enacted to protect the rights of these children and their parents. This law must provide for accurate record-keeping and record maintenance, a right to access this information on it satisfying a suitably defined 'good cause' requirement analogous to the law prevailing in some states in the US and a provision which clarifies the legal status of the child, making him/her the legal offspring of the adoptive or recipient parents.

1. In the 26 years since its birth, IVF has improved greatly and diffused widely. With more than two thousand children born worldwide, the technique is now recognized as 'an acceptable treatment for achieving pregnancy for couples in which the wife has absent or irreparably damaged fallopian tubes'.
2. Annas and Elias, *Fam. Law Q.*, 1983-84, 17, 199.
3. Curie-Cohen, M., Luttrell, L. and Shapiro, S., *N. Engl. J. Med.*, 1979, 300, 585.

4. Lamport, A. T., *Am. J. Law Med.*, 1988, 14, 109.
5. Bloodsaw vs. Lawrence Berkeley Laboratories, No. 96-16526, 9th Cir. 3 February 1998.
6. Georgia Code Ann §33-54-3; Missouri Rev. Statute §191-317; Florida Statute Ann §405.01-405.03.
7. Maryland Code Ann §223.1.
8. Committee of Inquiry into Human Fertilization and Embryology Report, 1984.
9. Deech, R., *Mod. Law Rev.*, 1998, 61, 697.
10. In Re Linda M, 409 NYS 2d 638; In Re Assalone, 512 A. 2d 1383; Rhodes vs. Laurino, 444 F. Supp 170.
11. Mills vs. Atlantic City Department of Vital Statistics, 372 A.2d 646.
12. Mr. X vs. Hospital Z, 1998, 8 SCC 296.
13. Berry vs. Moench, 331 P.2d 814.
14. Ethical Guidelines for Biomedical Research on Human Subjects, Indian Council of Medical Research, 2000.
15. O'Donovan, K., *Int. J. Law Fam.*, 1996, 4, 27; See also Freeman, M., *Int. J. Child. Rights*, 1996, 4, 273.
16. Section 50, Adoption Act, 1976 of the United Kingdom.
17. Davies, M., *Textbook on Medical Law*, Blackstone Press Limited, London, 1998, 2nd edn, p. 241.
18. Proceedings of the Third Session of the International Bioethics Committee of UNESCO, September 1995.
19. Arts. 7 and 8, Convention on the Rights of the Child, 1989; Art 8. European Convention on Human Rights, 1950. See also

- Preamble to the Council of Europe, Convention on Human Rights and Biomedicine; UNESCO's Universal Declaration on Human Genome and Human Rights.
20. Vishaka vs. State of Rajasthan, 1997, 6 SCC 241; Gramophone Company of India Ltd. vs. Birendra Bahadur Pandey, AIR 1984 SC 667.
  21. Guidelines for Assisted Reproductive Technologies in India, Indian Council of Medical Research. See also Dental Council of India vs. Subharti Charitable Trust, 2001, 5 SCC 486; Goa Foundation vs. Diksha Holdings Pvt Ltd, 2000 (7) SCALE 390; State of Himachal Pradesh vs. Ganesh Wood Products, AIR 1996 SC 149. (The Court upheld guidelines of the regulating agencies in each of the above-mentioned cases.)
  22. Per Bhagwati, J., In Maneka Gandhi vs. Union of India, AIR 1978 SC 597; All India Bank Employees Association vs. Union of India, AIR 1962 SC 171. See also Bhattacharjee, A. M., *Equality Liberty and the Property under the Constitution of India*, Eastern Law House, Calcutta, 1997, p. 60.
  23. Chandra Bhavan vs. State of Mysore, AIR 1970 SC 2042; A. B. S. K. Sangh vs. Union of India, AIR 1981 SC 298.

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