

Ethics and Reproductive Technologies for Discussion (to be read prior to class)

Case 1

The year is 2014. June and Jerry Smith, ages 30 and 31, very much want a child. Unfortunately, last year Jerry lost his reproductive capacity as the result of an automobile accident. June and Jerry are uncomfortable with the alternatives of sperm donation or adoption. They learn of research at the Jorge Bush Fertility Center. A cell can be taken from Jerry's body. Its nucleus will be inserted into June's enucleated egg cell and the resulting embryo will be placed in her womb, as in a standard IVF procedure. The child born to June will be Jerry's twin. Although the couple is not entirely comfortable with this idea, they feel it is the best alternative they have for ensuring some genetic continuity in their offspring. ***The Ethics Committee at the Bush Fertility Center is meeting to decide the risks and benefits of June and Jerry's case. For this activity, you are asked to role-play a member of the Ethics Committee. The object is not to take sides, but rather to look at the safety and ethical issues, and the implications for society if they decide to approve June & Jerry's case.***

Case 2

Sally Moore and Mary Jones, ages 30 and 31, are a lesbian couple that have lived together for five years. Sally and Mary very much want a child. Sally and Mary are uncomfortable with the alternative of sperm donation and they face formidable obstacles in trying to adopt. They learn of a program at the Howard Fertility Center. After five years of research, scientists are prepared to offer the option of cloning to couples like Sally and Mary. They are confident of the safety of the procedure. A cell will be taken from Sally's body. Its nucleus will be inserted into Mary's enucleated egg cell and the resulting embryo will be placed in Mary's womb, as in a standard IVF procedure. The child born to Mary will be Sally's twin. Although the couple is not entirely comfortable with this idea, they feel it is the best alternative they have for ensuring some genetic continuity in their offspring and for keeping third parties out of their relationship. If the couple succeeds with this first child, they plan to reverse roles and have a second child. They feel that with this technology, they can approximate the shared union in their offspring experienced by heterosexual couples. ***The class will be divided into 2 groups of 4. One group will take the pro perspective and the other group will take the con perspective. Each group will consider the ethical and societal implications involved and come up with arguments as to why Sally and Mary's case should/should not be approved.***

Case 3 -- Five "designer babies" created for stem cells

Five healthy babies have been born to provide stem cells for siblings with serious non-heritable conditions. This is the first time "saviour siblings" have been created to treat children whose condition is not genetic. The five babies were born after a technique called preimplantation genetic diagnosis (PGD) was used to test embryos for a tissue type match to the ailing siblings, reports the team, led by Anver Kuliev at the Reproductive Genetics Institute in Chicago, US.

The aim in these cases was to provide stem cells for transplantation to children who are suffering from leukemia and a rare condition called Diamond-Blackfan anaemia (DBA). "It's a big step, because it gives people another option," says Mohammed Taranissi, at the Assisted Reproduction and Gynaecology Centre, London, UK, one of the team. "Before that the only option was to look in the siblings and immediate family to see if you had a match or alternatively to just keep trying [to have a baby which matches]." He told **New Scientist** that people trying to conceive a child naturally as a tissue match for a sick sibling had only a one in five chance. This method can also lead to terminations where the fetus is not a tissue match for the sibling. "If you do it this way, the chance of finding a match is 98 per cent."

A UK couple (the Whitakers) involved in this study travelled to the US for treatment after the UK's Human Fertilisation and Embryology Authority (HFEA) ruled that they could not create a tissue-matched sibling as a stem cell donor to their son. In-vitro fertilisation (IVF) and tissue-typing was used in the US to give the Whitakers a perfectly matched baby boy to help their son Charlie, who suffers from DBA. The Whitakers were banned from the procedure in the UK because DBA could not be identified genetically in any embryos created. The HFEA deemed the procedure would be "unlawful and unethical" as although Charlie might benefit, the embryo would not and might even be at slight risk. The technique has been allowed in the UK where the embryo itself has been at risk of a genetic disorder.

Some experts believe that the process of tissue-typing an embryo could itself carry risks. In the US study, a single cell was taken from each three-day old embryo, which consists of a ball of just eight cells. The DNA was then analysed to find the tissue-type. --Journal of the American Medical Association 2002, 291(17): 2079

Case 4 -- Genetically selected baby free of inherited predisposition to early-onset Alzheimer's disease

The application of preimplantation genetic diagnosis to select against early-onset Alzheimer's has been criticised on several grounds. Some critics think it is wrong to reject an embryo because it may develop a disease later on in middle age and some question whether a woman who will soon become incapacitated and unable to provide for her child should be a candidate for assisted reproductive technology.

A 30 year old woman with the gene for early-onset Alzheimer's disease, who seems certain to develop the disease by the time she is 40, has used IVF and preimplantation genetic diagnosis to select an embryo that is free of the mutant gene. The woman, a geneticist, has given birth to a mutation-- free child. This marks the first time that preimplantation genetic diagnosis has been used to "weed out" an embryo with the defect.

Early-onset Alzheimer's is an inherited, incurable disease striking people in their 30s and 40s. The woman's sister developed the disease at 38 and has been placed in care. Their father was suffering from memory problems when he died at 42 and a brother who also carries the gene had short term memory problems at 35.

Critics of preimplantation genetic diagnosis think there is something morally unacceptable about selecting and rejecting embryos by genetic preference. And the application of preimplantation genetic diagnosis for Alzheimer's is seen as more controversial still because an embryo is being rejected on the basis that it may develop a disease in middle age. Prior to this, preimplantation genetic diagnosis has been used only to select against embryos with disorders that strike in childhood. Some people think that trying to prevent people who are likely to have 40 years of normal healthy life from being born is wrong.

Other critics of preimplantation genetic diagnosis question whether we should be helping the woman have a child at all. Dena Towner and Roberta Loewy question the choice of "bringing into the world a child for whom the mother will, with near certainty, be unable to provide care". They concede that conceiving a child free of the genetic predisposition for early-onset Alzheimer's disease is a "laudable goal" but argue that the mother's "ethical responsibility" entails more than disease prevention. They ask whether reproduction is a "privilege" or an "inalienable right" that trumps the rights and needs of others.

Yury Vertlinsky, who published a report on the family in the Journal of the American Medical Association, is reported to have said that any difficulties the family might face are "outweighed by the fact that the family's next generation will be free of the problem. The JAMA report recommends informing parents at genetic risk about the possibility of preimplantation genetic diagnosis "so they can make a choice about reproduction" and maintains that this approach is more ethical than suppressing information on the availability of preimplantation genetic diagnosis. -- Journal of Medical Ethics 2002, 28(5):290