

EMPOWERING CHILDREN THROUGH ASSISTED REPRODUCTIVE TECHNOLOGIES

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ABSTRACT

Assisted reproductive technologies is advancing rapidly with the invention of various technologies that not only allow parents to conceive any child but also enables them to conceive a child with specific traits and characteristics. Preimplantation Genetic Diagnosis (PGD) is one of the techniques that provide a high chance for parents to produce a child who is free from genetic diseases or disability. Without PGD, parents who are at high risks of producing such children may consider adoption, conception using donor gametes or remain childless. If these options are not achievable, the couple may proceed to conceive naturally and leave the matter to chance, hence increasing the risks of giving birth to a child with genetic diseases or disability. PGD is, arguably, a method that can empower children by minimising the risks of being born with debilitating genetic condition. This is the central thesis of this paper where it is argued that modern medical technology such as PGD may be used as a tool to empower children by preventing the risks of being born with serious genetic disability. In promoting this argument, the main critics raised against the practice of selecting against embryos with disability namely 'the disability discrimination claim' and 'the loss of support argument' are analysed and refuted. It is contended that the use of PGD should be supported merely as a preventive tool to assist couples who are at high risks of producing children with genetic condition or disability to conceive a healthy child.

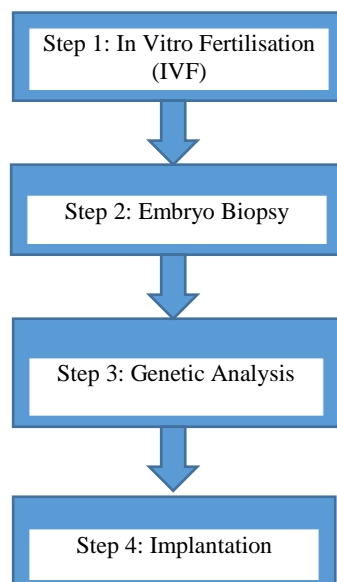
Key words: Bioethics, Assisted Reproductive Technologies, Preimplantation Genetic Diagnosis.

INTRODUCTION

Preimplantation Genetic Diagnosis (PGD) is a technique that allows the selection of embryos that are free from genetic diseases that may cause disability such as Huntington' and Tay-Sachs disease. The technique was introduced in 1968 and its functions have been continuously developed (Franasiak & T Scott 2012). In Malaysia, the use of PGD was revealed in 2006 by a couple in order to produce a son (New Sunday Times, 18 June 2006). To date, PGD is offered in many private healthcare providers in Malaysia (Angelina 2013). Although applauded for the benefits that the technology brings, PGD is not free from critics and concerns. The crucial issues raised against the technology when used to prevent the birth of a child with genetic disability is that it promotes discrimination against the existing disabled people and result in the loss of public support for them. These concerns are the main crux of this paper where such critics are analysed and refuted. In the end, it is argued that PGD should be viewed as a tool to 'empower' children by circumventing the risks of being born with disability and should not be negatively perceived. First, however, the science of PGD is briefly explained.

THE SCIENCE OF PGD

PGD requires the production of embryos *in vitro* where the embryos will be screened at normally three days after fertilisation. Selected embryos are then implanted into the woman's uterus (Taylor 2008). PGD is mainly used to screen for three categories of diseases: single-gene disorders, sex-linked diseases and chromosomal abnormalities (Braude et.al. 2002). Its use may also be extended to select for embryos with HLA tissue-match for bone marrow or cord blood stem cell transplantation (Haniwarda 2014). Essentially, PGD involves four steps:



PGD may be considered as a better alternative to other genetic testing methods such as amniocentesis and chorionic villus sampling as PGD is performed on early embryos before pregnancy is established. Compared to amniocentesis that is performed around 15-22 weeks of pregnancy and chorionic villus sampling at around 10th week of pregnancy, PGD obviates the dilemma of terminating the pregnancy should the embryo found to be affected with genetic disorder as pregnancy has yet to occur (NHS 2015). Nonetheless, its use to screen against embryos with genetic disorder/disability raises a crucial claim that such a practice discriminates against actual people with disability by sending the message that life with disability is not worth living (Steinbock 2002). It also contended that reducing the number of disabled people with the use of PGD will eventually cause a reduction in social funding and support for the disabled (Buchanan 1996). These issues are examined in turn.

‘THE DISABILITY DISCRIMINATION’ CLAIM

Rather than curing disability after birth, PGD is a technique that avoids the birth of disabled child (Bennet and Harris 2007). Disability rights advocates believe that selecting against children with disability is a form of discrimination against actual people with disability. Relying on the ‘expressive’ nature of such an act, they feel that preventing the birth of a disabled child exhibits the thought that life with disability is less worthy than life without disability (Buchanan 1996). Hence, any technology that aims to prevent the birth of such children including PGD should not be condoned. Asch (1989) argues:

“Prenatal diagnosis and selective termination communicate that disability is so terrible that it warrants not being alive. As a society, we do not wish to send the message to all such people now living that there should be no more of your kind in the future.”

Nonetheless, it can be argued that when parents opt not to have a disabled child, such preference need not necessarily imply that they hold negative perceptions against disabled people and their disability. Instead, such a selection could be motivated by the need to avoid physical and financial strain in raising a disabled child and should not be adversely construed (Parens & Asch 1999). Shakespeare (1998), therefore, rightly argues that:

“If we accept that women may wish not to have babies because of the impact on their careers or financial situation, then we must also accept that women may not wish to have babies with impairment, because such children may have more complex needs with major implications for both cost and care.”

Savulesco (2001) further argues that “it would be a drastic step in favour of equality” to expose parents to the risk of having a child with disabilities when they are not in the position to accept one simply on the grounds of promoting social equality. He asks, “should we ban prenatal testing for Down’s Syndrome to reduce discrimination against those with Down Syndrome and so promote equality?” As such, it is equally arguable that preventing the birth of children with genetic disability using PGD need not necessarily carry the message of discrimination against actual disabled people. Nonetheless, critics also fear that by reducing the number of disabled people using medical technologies such as PGD, the social support and funds allocated to the disabled people may be decreased, a claim known as the ‘loss of support’ argument.

THE ‘LOSS OF SUPPORT’ ARGUMENT

Another argument voiced to condemn the act of selecting against embryos with genetic disability is known as the ‘loss of support’ argument. According to this view, choosing not to have a disabled child will inevitably reduce the number of disabled people in a society and in such a situation, social support and funds provided for disabled people will be affected (Buchanan 1996). Shakespeare (1995) further expresses the fear that parents who do not wish to use any medical technology to prevent the birth of a disabled child may be blamed for being irresponsible and their healthcare benefits may be reduced for the reason that they could have prevented their child’s disability.

An argument that can be advanced to reject the ‘loss of support of argument’ rests on the connection between disability and the amount of social support for the disabled. A small number of disabled people need not necessarily caused a reduction in the social benefits allocated for them. In Australia for example, social funds for the disabled has been increased alongside the availability of prenatal diagnosis techniques to select against disability (Kuhse 1999). In Malaysia, the rights of the disabled are secured with the implementation of various policies on social welfare and social services such as the National Welfare Policy 1990, The National Social Policy 2003 and the National Policy for Persons with Disabilities 2007 (Rezau Islam 2015). Hence, Wertz and Fletcher (1993) rightly states that there is no clear and direct connection between a reduction in the number of disabled people and a reduced funding for them. Furthermore, it must be borne in mind that disability need not be genetically caused and detectable at the embryonic stage. Some disabilities may accrue after birth which can be related to non-genetic factors such as accidents or injury. Hence, prohibiting the use of PGD to select against disabled embryos will not necessarily reduce the number of disabled people in a society (Gillam 1999).

CONCLUSION

The use of PGD to select against embryos with genetic disorders that may result in disability has been condemned as an act of discrimination against the disabled people by sending the message that life with disability is not worth living. In addition, it is also feared that a reduction in the number of disabled people in a society from the use of medical technology such as PGD will affect the amount of social benefits and funds allocated for the disabled. The former known as the 'disability discrimination claim' and the latter as the 'loss of support' argument have been analysed and refuted in this paper. On the contrary, it is concluded that children can be empowered through the use of assisted reproductive technologies such as PGD by ensuring that they are born without genetic disorder and disability and such a practice should not be damagingly construed.

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