

Ethical Perceptions with Regard to Pre-implantation Genetic Diagnosis (PGD) from the Perspective of Selected Medical Professionals in Malaysia

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Abstract

Pre-implantation Genetic Diagnosis (PGD) has historically been the subject of heated public controversy because it offers the ability for parents to select their future children genetically. This paper explores the ethical implications of PGD, and discusses the ethical issues associated with the use of PGD from the perspective of medical professionals, whose work involves contact with women or couples undergoing or who plan to undergo PGD and fertility treatment. Consequently, their knowledge, attitudes and views concerning PGD use are critical to allow us to understand the issues involved. Using in-depth interviews, eight medical professionals from three different medical institutions were interviewed. Interviews were recorded, transcribed and analysed using thematic analysis. The findings showed that the participants perceived PGD as an opportunity for couples in the 'high risk' groups to have children who are genetically healthy. However, due to low health literacy, misunderstanding of what PGD is capable of is always a problem, leading to negative perceptions of PGD that give rise to controversial ethical issues including the notion of 'designer babies' and eugenics. The study concludes by highlighted participants' concern with regard to the lack of monitoring of PGD and the quality of the service providers.

Keywords: Low health literacy; Malaysia; Ethical issues; Pre-implantation genetic diagnosis (PGD); Medical professional

Introduction

Pre-implantation genetic diagnosis (PGD) was originally developed as an option for parents having high risk of transmitting genetic disorders to their future children, and also for parents who wished to avoid the trauma of having to go through selective abortion following prenatal diagnosis when their unborn child was diagnosed with a genetic disorder [1]. However, the use of PGD has expanded in the more than 20 years after its inception [2], including the use of PGD for indicating the chromosomal and genetic abnormalities associated with the later onset of disorders among adults [3], rhesus incompatibility, human leukocyte antigens (HLA) tissue type [4] and social sex selection or social traits. However, the expanded uses of PGD have led to concerns and debate regarding its medical appropriateness and its ethical acceptability, as well as the possibility of regulatory oversight [1]. These issues have led to bigger moral, ethical and legal debates, including parental reproductive rights versus the welfare of the child who may or may not be born, and clinical authority or professional responsibility [5]. In fact, the use of PGD can be closely linked to the fundamental issue of what it is to be human [6]. However, for those who condone the act of discarding abnormal embryo, PGD is viewed as a medical miracle because it can be used to avoid serious and life-threatening genetic diseases [2].

For parents or couples who disagreed with the act of discarding embryos due to the fact that they see an embryo as a live human, PGD do not give them the comfort they need. Most couples or parents who are against the act of abortion are so due to personal or religious beliefs [7]. For these parents, suffering is viewed as something that all mankind was meant to go through. This has taken the meaning of 'suffering' to a different level, because for these parents, suffering is not seen as a negative experience but a positive one. In addition, religion seems preoccupied with the issues of suffering because, the act of suffering is very much related to the idea of spiritual growth and to the testing of self-understanding [8]. On the other hand, having children with a genetic abnormality can be very tough on some parents, such that it

is argued that the decision to terminate an 'affected pregnancy' does not indicate a discriminatory statement against people with a genetic abnormality. Parents who request an abortion on such ground do so because '...they cannot, for whatever reason, take on the care of that particular kind of child at that time' [7], and this is when PGD plays an important role. As Furedi points out, the harm associated with the notion of forcing a woman to have and raise a child against her will, far outweighs the harm of abortion [9]. With the proliferation of reproductive technology, the options for couples at risk of transmitting some kind of genetic diseases to their children also increases [10], contributing to the emergence of a profound discussion concerning women's rights with regard to their reproductive choices.

However, increasing the reproductive rights of parents or couples, may lead to another controversial issue related to the setting of boundaries in order to make sure that those rights do not supersede the value of humanity, where children are simply treated as instruments [11]. But despite these concerns, a study conducted by Petersen [12] showed that parents do express their concerns on the possible future of their offspring when making their reproductive decisions with regard to PGD. Therefore, such concerns lead them to consider what is fair or right for their child's future, rather than fulfilling their own desires. On the other hand, the increase of the reproductive rights of parents or couples can cause a dilemma to medical staff when patients' request for PGD clash with their medical principles, such as purposely producing

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a disabled child, or for non-medical gender selection [13]. Working in such situations results in medical staff being faced with difficult decisions and dilemmas.

There is a growing international literature in the field of both social sciences and ethics with regard to PGD that highlights the ethical, clinical and policy dilemmas implicit in the area, from the perspective of medical experts, potential users, or actual users, as well as interested members of the public [14]. The findings show that medical experts support the use of PGD, particularly to avoid serious and life threatening genetic diseases, but are less approving of using it for less serious or late onset diseases and sex selection. In addition, it highlights concerns that PGD should be regulated in order to monitor its uses. There has not been any research done in Malaysia with regards to medical experts' views of ethical and clinical issues that arise from the use of PGD in Malaysia. Therefore, this paper aims to explore the views of medical professionals and medical scientists working in the area of reproductive and genetic medicine, and to provide an understanding of how medical staff or scientists working in a morally contentious, innovative and ever-evolving area such as PGD, view their daily work in connection with the clinical and ethical issues that arise from the use of PGD. It is hoped that this paper can contribute to the existing literature on PGD, and give us an understanding of the extent to which the scientific community in Malaysia accepts PGD, and probably provide information that was not highlighted previously in past literature reviews.

Materials and Method

Using in-depth interviews based on open ended, semi-structured questionnaires, which were designed to examine the ethical and clinical issues posed by PGD. Based on purposive sampling, eight participants were selected from three different medical facilities/hospitals within the Klang Valley (Malaysia). The participants were chosen based on the appropriateness of their backgrounds and characteristics for this study. All participants either work in the reproductive medicine field or in the medical genetic field, and were chosen because 1) they are well versed in treatments involving human reproduction and issues pertaining to the use of reproductive techniques, 2) they have daily contact with patients who are using such treatment, or who want to use the treatment and 3) they basically use or have hands-on experience with PGD. Interviews were conducted at mutually convenient designated venues and times. This research was conducted from April 2010 to April 2011. Interviews were tape recorded and transcribed, and data were analysed using thematic analysis.

Results

Benefits of pre-implantation genetic diagnosis (PGD) for 'at-risk' couples

Generally, most participants viewed PGD as a medical advancement; it was seen to be beneficial, especially women or couples who were at risk of transmitting some kind of genetic disease to their future child. As Participant 6, a feta-maternal subspecialist in a private fertility treatment centre, mentioned:

PGD is saving life. It is a new medical technology to cure genetic diseases and to give an option to parents who are out of options. I believe that everyone should be given the chance to have a healthy baby, especially if they have a strong medical reason to request for it and they can afford it.

Whilst there are no disagreements over the benefits of PGD for individuals who are in the high-risk category over conditions such as single gene disorder or chromosomal abnormality, there is, however, reluctance

when it comes to using PGD for late onset and low penetrance conditions, such as inherited breast or ovarian cancer. Participant 2, another feta-maternal subspecialist who work at a teaching hospital, stated:

I would not highly recommend it to my patients because in the case of breast cancer, it is a low penetrance disorder, which means, even though the patient has a history of breast cancer in the family it does not mean that she will have the gene. Even if the mother decides to eliminate the breast cancer gene from her future child, this does not mean she will be free from other types of cancer. Furthermore, breast cancer is not only inherited but it is also a multi-factorial disease.

However, for Participant 6, he has no qualms in fulfilling his patient's request to use PGD even though the reason might appear trivial.

I have no qualms in providing PGD services to my patient even if their reason for using it seems trivial for some. For me, when patients have made up their mind to use PGD, that means that they have thoroughly understood the risks and the effect involved when using PGD. So, as their physician, I feel that it is my duty to provide them with the service and support they need.

Despite the labyrinth of complexity related to the moral judgment about embryo status, couples worldwide, experts in the field, and members of the general public, who are grappling with moral evaluations about embryo status related to PGD, are likely to agree that PGD is more morally acceptable than the standard clinical option of prenatal diagnosis with subsequent termination of pregnancy. Participant 7, a molecular biologist with a teaching hospital, mentioned that:

I look at PGD as a more humane way to discard embryos as compare to PND because in PGD, embryos are discarded outside the woman's womb whereby in PND, it involve the invasion of the woman's body because the foetus is already growing inside the woman's womb.

Lack of information and knowledge on the capability of PGD leads to negative perceptions of PGD: Low health literacy

The capability of PGD to allow parents to select their future children based on genetic characteristics has given rise to speculation that PGD is trying to override the natural process of human reproduction and thus, allows human beings to act as God. The term "play God" has partly emerged due to the lack of awareness and information on how PGD works and what it is capable of. As Participant 3, an Obstetrician and Gynaecologist consultant in one of the government hospital in Klang Valley explained:

I believe that society think those who used PGD as trying to play God because of lack of information and awareness on the technology. I think through time, this perception might change especially when society knowledge on PGD increases.

Participant 8 (a geneticist), added,

I believe that a lot of people are still sceptical about it because there is not sufficient information available to educate Malaysian society regarding it.

At the same time, most participants feel that it is not right for anyone to judge parents or physicians who provide or use PGD as trying to 'play God' because both parties have one thing in common; to provide the best possible medical care for their patient or future children. As Participant 7 added:

If parents choose to go for PGD, it is merely their personal choice. We can't prohibit or stop them from using it because it's just not right.

This lack of knowledge with regard to how PGD works, and the limitation of PGD might lead to further rejection of PGD, thus making it inaccessible to those who need it. Participant 6, argued that, a lack of access to PGD might lead to an unnecessary burden and pressure on parents, particularly those who already have one or more children with a genetic disease. Furthermore, he argued that, the welfare system in Malaysia is still lacking, and many parents and their sick children might not get the assistance they need to lessen their burden.

Our health care systems do not have sufficient after care for children with genetic disability either to the children itself or the parents. There are some help available but it's just not enough. So, for parents who can avoid having disabled children and they want to use PGD, by all means, do it. I don't think they want to play God. They just have to do what they have to do as parent.

Professional obligation towards patient's right to reproductive autonomy: Freedom

Sometimes there exists tension between a patient's reproductive autonomy, and medical professional responsibility with regard to reproductive decision-making, because medical personnel view the situation from the medical perspective, but patients might see it from a different perspective such as religious, cultural or, personal values, and also in terms of the knowledge they possess with regards to the treatment. Staying true to their profession obligations, all medical professionals in the study are advocated the awareness-promotion of autonomous rights to their patients. As a medical professional, Participant 2, who is a feta-maternal subspecialist with a teaching hospital in the Klang Valley, stated:

I feel that it is wrong not to suggest or even inform patients regarding PGD when as a physician you know that it provides them with the alternative that they desperately need. How they will decide on it is up to them. They will evaluate their decision based on the information that you give, and when they have already made their decision, the physician has to respect it.

Furthermore, Participant 4, an embryologist, stated that it is the parent who is going to face the challenges and struggles in the future in providing care and treatment for the affected child. He stated:

We should not stop parents from their intention to have a healthy child because it is their right as patients and also as parents to do so. All parents want the best for their children, and in their case they want their child to be free from a genetic disease that they might transmit to their child. And if PGD is the best option they have, why not?

Sometimes, the patient's reason for requesting PGD might appear trivial to some, but for Participant 6, he still thinks that it is the patient's right to request for it. He stated that the stress of raising children with congenital genetic diseases could have an impact on the family dynamics. He explained:

Don't look at the consequences of the children alone, but let us look at the consequences it has on the parents and their family too. Who will take care of their needs in raising special children? Who would think about these parents and their needs? This is an essential question that we need to ask ourselves.

Concern regarding the quality of PGD services in Malaysia: Safety

Given the growing interest in PGD and the increasing number of medical fertility centres in Malaysia that provide PGD services, a major

concern among medical professionals is that a specific and restricted regulations should be imposed on the use of PGD. Participant 1, another feta-maternal specialist, mentioned this concern:

I am quite uncertain about my feelings towards the use of PGD because there is no scientific outcome of the result, no transparency in the outcome results and very little or no follows up at all that have been performed for children born via PGD. Furthermore, the thing that has been published is just the success rate of pregnancy, which for me does not represent the total outcome of the technology itself.

The study also highlights participants' concern regarding the quality of services provided by the PGD facilities and the accuracy of information that is being conveyed to potential users. As Participant 2 commented during the interview:

It is very expensive and I am not quite sure about the level of standards of the PGD laboratories in the country. Not only do we need a well -equipped laboratory; we also need experts in the field and highly trained technicians to perform the daily operations of the laboratory to avoid any mistake, especially in the diagnosis.

Discussion

The emergence of PGD is not viewed as something negative but rather as a medical milestone in reproductive and genetic medicine that will allow us to avoid the birth of children with known genetic disorders within the patient's family circle. This technology is a benefit to 'high risk' parents, and provides them with the opportunity to have a healthy child who is genetically related to them [14]. At the same time, these parents can avoid the traumatic experience of having to go through abortion or termination of pregnancy when the child is tested positive for defective genes [15]. Although being labelled as no different from PND, as both treatments involved the discarding of embryo or foetus, those who work in the medical field view PGD as a more humane way to discard unwanted or unhealthy embryos as compared to PND. Consequently, PGD is thought to be a less traumatic experience for the parents [16]. This finding is similar to research previously done by Ehrich et al. [17] where, for some individuals who work in the medical field, the avoidance of termination of pregnancy through PND was their primary priority, and who therefore, have a preference for the use of PGD.

Using the term 'low health literacy', medical professionals in this study described how a lack of information and limitations regarding PGD, has contributed to the misconceptions with regard to PGD, thus, generating a wrong image of PGD. This has either lead to scepticism with regard to the use of PGD, or a total rejection of PGD, as well as a negative attitude towards those who choose to uses PGD. The results from this study were relatively consistent with previous studies involving medical professionals in other countries [18] where they do not see PGD as a negative medical technology but instead see it as one that could have a positive effect on parents or children who really need it. Discussion on the lack of knowledge with regard to PGD that leads to misconceptions about the technology involved and has resulted in negative impression of PGD, is consistent with the findings in previous research done in Japan [19] where, through an educational programme on PGD, knowledge and awareness of PGD has changed. This is also in line with a previous study by Quinn [20], which indicated that low knowledge of PGD leads to a moderate acceptance of PGD and to a high level of need for information about PGD.

When it came to discussing about patients' rights to make their own reproductive decisions, medical professionals are strong advocates of

reproductive rights. The prevailing body of genetic counselling ethics stresses the 'non-directiveness' and 'value neutrality' of decision-making [21]. They (the participants) are sometimes; faced with situations where they feel that PGD is not really necessary, for example when PGD is requested for non-medical sex selection or requested to purposely conceive disabled children such as deaf children, such reasons defeated the purpose of PGD, which is to assist patients to produce healthy children. When faced with such a situation, it will be hard to argue against couples' rights to decide, or to argue against the fact that the parents' personal knowledge of their condition might be seen as outweighing other factors. Despite admitting that the whole process from suggestion to decision-making involved 'teamwork' between clinicians, genetic counsellors and patients, the end results would be solely the patient's decision.

However, the notion of giving parents the ultimate right to their own reproductive decision, raises concerns about the possible misuse of PGD, because parents are no longer restricted by what they should and should not do. This freedom might lead to unintended consequences, and sometimes 'impossible choices' [22]. In contrast, the findings in this study show that participants do not display such concerns. They do not think that an increased individual right to decision-making will contribute to the misuse of PGD such as using PGD for social sex selection. This is consistent with previous study in Australia [23] where using PGD for trivial physical characteristic or social sex selection is of little concern among the participants, but differ in the case of Roberts and Franklin [24] who found that participants thought that it was important to prevent frivolous use of PGD to avoid regulatory backlash that might create barriers for those who need the technology.

Having a vast knowledge in the medical field, particularly in the field of reproductive genetic technology, medical professionals tend to use their expert knowledge when faced with ethical issues, which arise from the use of medical technology. They described that, due to lack of knowledge in PGD, members of the public tend to have negative perception of PGD, thus discouraging its use, either by themselves or on the part of others. One of the disadvantages of PGD is the high cost involved in using it. This might be one of the main hindrances for anyone who wants to use it. However, the high cost of the aftercare of children born with a rare genetic disease and for which treatment is scarce, can also motivate parents to use PGD. This is a significant finding in this study because the high cost involved in the after-care of disabled children has not been associated with parent's motivation to request PGD. Instead, the high cost of PGD is highlighted as one of the disadvantages for parents wanting to use PGD as compare with the high cost of caring for disabled children as disadvantage of not using PGD. This paper also highlights the fact that although there might be agreement that PGD is a great advance in the medical scene, there is acknowledgement that it could create tensions over the issues associated with probable clashes between reproductive autonomy (on the part of parents/clients) and professional responsibilities (on the part of medical professionals), especially in domains which place great rhetorical emphasis on individual freedom of choice.

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