

ETHICAL IMPLICATIONS OF PREIMPLANTATION
GENETIC DIAGNOSIS (PGD): A QUALITATIVE
STUDY ON THREE SELECTED
GROUPS IN MALAYSIA

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ABSTRACT

Pre-implantation genetic diagnosis or PGD refers to procedure performed on embryos prior to implantation in IVF trials. The technology enables the embryo to be screened for genetic disease and is usually applied when parents have risk of genetic diseases. Ethical issues raised from the utilization of PGD include gender biasness and discrimination towards people with disabilities often linked to societal obsession with perfectionism. This study explores participant perception of ethical issues posed by PGD, by focusing on four key themes: sanctity of life, play God, perfectionism and freedom of choice. Three focus groups were selected; medical personnel, religious representatives and potential users. Key findings show significantly differing views of each study group. For example, members of the medical fraternity alluded to biological interpretations such as ‘mere accumulation of cells’ when declaring limited moral rights of the embryo. On the theme ‘play God’ doctors argue that PGD is merely a form of medical but necessary intervention and do not agree with the idea of ‘meddling with nature’. Perception of both religious figures interviewed and potential users show mixed and almost similar reactions, whereby some consider PGD as an act of playing God because of the belief that such actions will bring upon unknown and undesirable (but God-ordained) consequences while others believe that actions that prevent dangerous diseases in children would not entail playing God.

ABSTRAK

Pra-implantasi genetic diagnosis atau PGD merujuk kepada prosedur yang dilakukan ke atas embrio sebelum implantasi dalam ujian IVF. Teknologi ini membolehkan embriodisaring untuk penyakit genetic dan ini biasanya digunakan apabila ibu bapa mempunyai risiko penyakit genetik. Isu-isu etika yang timbul dari penggunaan PGD termasuk diskriminasi terhadap individu yang berlainan jantina dan individu kurang upaya yang sering dikaitkan dengan sifat obsesi masyarakat dengan kesempurnaan. Kajian ini meneroka persepsi peserta mengenai isu-isu etika yang timbul dari penggunaan PGD, dengan member tumpuan kepada empat tema utama; kesucian hidup, bermain Tuhan, kesempurnaan dan kebebasan pilihan. Tiga kumpulan focus telah dipilih; kakitangan perubatan, wakil agama dan bakal pengguna PGD. Penemuan utama menunjukkan peserta dari setiap kumpulan mempunyai pandangan yang ketaranya berbeza apabila berbincang mengenai isu-isu yang timbul dari penggunaan PGD. Sebagai contoh, anggota dari kumpulan perubatan merujuk kepada tafsiran biologi seperti ‘pengumpulan sel semata-mata’ apabila mengisytiharkan hak moral terhadap terhadap embrio. Pada tema ‘bermain Tuhan’ pula, para doctor berhujah bahawa PGD adalah campur tangan perubatan yang perlu bagi segelintir kumpulan individual dan tidak setuju dengan idea ‘campur tangan dengan alam semulajadi’. Persepsi tokoh agama dan bakal pengguna yang ditemuramah menunjukkan reaksi yang bercampur baur serta hamper sama, di mana ada di antara mereka yang mempertimbangkan PGD sebagai perbuatan bermain Tuhan kerana percaya bahawa tindakan itu akan membawa kepada kesan yang tidak diketahui dan tidak diingini (tetapi di izinkan Tuhan) manakala yang lain percaya bahawa tindakan yang mencegah penyakit berbahaya di kalangan kanak-kanak adalah bukan perbuatan yang mempunyai niat untuk bermain Tuhan.

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CHAPTER 1

INTRODUCTION

1.1 Background

For many parents, children are perceived as a gift; to appreciate them is to simply accept them as they are. We can choose our life partner depending on our preferences, but this is not the case when it comes to children. It is the dream of every parent to have a healthy and able child. However, in some cases, it might not be possible, especially for couples that have a history of inherited genetic disorder within the family. The situation places them in the high-risk group.

It is a tough decision for these couples to have children of their own because they are at risk of transmitting the diseases to their children, which in some situations could cause severe suffering to the children. In order to avoid this problem, some parents choose not to have children of their own, being aware of the high probability of passing the genetic disease to their children. If they still decide to have children, there are other alternative ways such as adopting a child or accepting gamete and eggs donation. The last resort is to terminate a pregnancy or simply play a game of 'reproduction roulette' with spontaneous conception (Lavery et al., 2002).

However, the emergence of pre-implantation genetic diagnosis (PGD) has provided the affected parents with reproductive choices that were unavailable previously. This has given them a solution to avoid the birth of a child with genetic abnormalities. PGD enables parents to select embryos based on their genetic characteristics before implanting the selected embryos into the mother's womb, which increases the chances of having a healthy child.

The introduction of sophisticated genetic reproductive technologies such as PGD in the clinical setting is a double-edged sword. These technologies have great potential to prevent illnesses and diseases in novel ways, but at the same time bring about clinical, ethical and social dilemmas (Williams et al., 2007). This scenario forces us to face new dilemmas that are unique to state-of-art technologies while simultaneously revisiting older dilemmas, which revolve around; fundamental arguments about the definition of life itself.

With increasing genetic selection and manipulation of children, PGD is a hot topic for ethical debate, commentary and speculation about the future (Robertson, JA., 2003). The development of PGD is aimed at fostering the creation of healthy children but, at the same time, it has also caused additional concerns about its ability to end life. The more prevalent use of PGD has intensified debates and discussions on the ethical and clinical issues posed by PGD on individuals, families and society.

Due to the rapid growth of genetic tests for genetic diseases, predispositions, and other characteristics, use of these genetic tests in combination with PGD only fuels the existing controversy (Kalfoglou et al., 2005). New uses of PGD also bring about increasing ethical concerns on the potential abuse or misuse of PGD (Damewood, MD., 2001). At the same time, some couples that choose to use PGD are accused of choosing a child to order (Braude et. al., 2002). Parents' ability to select their future children through PGD has reignited the debate and fears of designer babies (Spriggs, M., 2005) and has spurred further development of eugenics technology.

Studies have been conducted in different countries in order to assess the acceptability of and demand for PGD, attitudes, and experiences among potential PGD users, actual PGD users and PGD providers as well as other medical or ethics experts (Kalfoglou et al., 2005). The findings of these studies indicate that attitudes, acceptance

and decision towards the use of PGD have been rather ambiguous and complex (Meister et al., 2005).

Based on these findings, the researcher feels that there is a need to explore and investigate the ethical implications of PGD in Malaysia. The purpose of this study is to establish an understanding of how physicians and potential PGD users confront the ethical and clinical issues posed by PGD, how they view the ethical issues and challenges that arise, and the approaches to these issues. Subsequently, the study explores whether their perception on the ethical issues, will or will not contribute to the final decision in regard to the reproduction choices.

This study also explores the views of religious organisations and their understanding of PGD as well as implications on people of various faiths. To the best of the researcher's knowledge, this study represents the first qualitative study on ethical and clinical issues of PGD that includes physicians, potential users and representatives from three different religious organisations in Malaysia. This is because most of the studies concerning PGD in Malaysia are related to medical or scientific research such as the use of PGD to identify genes that cause beta- thalassaemia (Nasri, NWM et al., 2009). The findings from this study will therefore, be a huge contribution to the existing studies that have been carried out elsewhere.

1.2 Research objective

Studies on ethics and PGD have been actively carried out in other countries (Hershberger and Pierce, 2010) but it is a growing research area in Malaysia. The use of PGD is also not common in Malaysia except among those who are susceptible to genetic diseases and have been informed by their physicians in regard to the available choices.

Therefore, limited information is available concerning how Malaysians feel about PGD and the ethical issues that could arise as well as how well it is accepted in this country. The objectives of this study are:

1) To explore participants' (medical representatives, potential PGD users and religious representatives) perceptions on the ethical and clinical issues that arise from the use of PGD. This information can be obtained by investigating on how do the participants confront and approach these issues.

2) To investigate participants' mind-sets regarding the use of PGD by identifying factors that may influence their views or decisions on PGD.

3) This study also presents ethical implications of PGD, which may be useful for the development of guidelines and policies, future scholarships and researches, and also educational programs in this field of study.

1.3 Theoretical framework

Theoretical framework for this study has been developed in tandem with the methods chosen. The key concepts are ethical theories, bioethical issues, public perceptions, ethics, decision-making and perspectives.

The ethical theories for conducting ethical analysis have been used in several ethical researches related to some of the ethical issues that triggered ethical dilemmas among the professions, groups or societies. Ethical theories such as utilitarianism theory, virtue theory and deontological theory were used to evaluate ethical issues. In 1988, Hedner and Hansson from Sweden wrote an article that outlined the ethical theories and systems determining what ought and ought not to be done in the prevention of cardiovascular diseases. According to both of them, the correctness of ethical guidelines

for medical interventions can only be properly evaluated in retrospect. In the prospective consideration of various interventions, one can act based on different general principles.

In their evaluation, Hedner and Hansson (1988) used ethical theories of utilitarianism and deontology to elaborate and compared different ethical approaches; they endeavoured to find the best and the most appropriate approach, which could be used for the purpose of medical interventions in cardiovascular diseases. Based on utilitarian theory, medical intervention is morally right and justified if it leads to the greatest possible balance of good consequences or the least bad consequences as judged by the world as a whole (Hedner and Hansson, 1988).

On the other hand, in some respects of deontological approach, a medical intervention or moral act may be independent of the utilitarian concepts of maximal benefits. Thus, in terms of strategy of primary prevention of cardiovascular diseases, there may be moral disagreement about whether we should consider the strategy from the perspective of population or individuals¹. In conclusion, the authors advocate risk factors reduction. In theory, interventions for cardiovascular patients should be performed according to the utilitarian principles only if they are strictly guided by the maxim of beneficence (Hedner and Hansson, 1988).

At the same time, ethical theories are also applied to assess ethical dilemmas for policy considerations in different situations. One example is the ethical analysis of HPV (Human papillomavirus) vaccine policy options in the United States. The researchers debated on the construction of policies regarding the vaccination of HPV based on the feedback they received from a survey, which was conducted among various groups of people (Zimmerman, RK., 2006). According to Zimmerman (2006), the arguments that

¹ According to Hansson (1988), population strategy is a strategy applied primarily to maximise benefits for the whole population; individual strategy, is primarily applied to maximise good results for patients that have binding physician-patient relationships.

were used in his study are analogies between hepatitis B vaccine (HBV) and human papillomavirus vaccine (HPV).

This is because similar to HPV, hepatitis B vaccine targets viruses that are transmitted from one person to another, mostly through sexual contacts although hepatitis B is commonly transmitted by exchange of blood products. He argued on the appropriateness of comparison between HBV and HPV, and the necessity of a state mandate on vaccination for school registration especially in the case of HPV.

Zimmerman (2006) used ethical theory of utilitarianism, theory of Natural Law, principlism, as well as religious and cultural ethics. Based on his evaluation and ethical analysis, Zimmerman stated that ethical analyses using utilitarianism theory, Natural Law theory (Principle of double effect) and principlism support universal vaccination, including children aged between 11 and 12 years. Zimmerman made this statement when a routine vaccination visit was indicated in the United States Recommended Childhood Immunization Schedule. However, some theoretical concerns about the harmful side effects must be considered seriously.

Ethical analysis is also employed to evaluate dilemmas concerning funding of drugs research and development for some selected drugs used for certain types of diseases. Conflicting moral obligations of beneficence and distributive justice, seem to demand a different level of funding for orphan drugs research (Gericke, CA., 2005). Orphan drug is a pharmaceutical agent that has been developed to treat a rare medical condition. According to Gericke (2005), pharmaceutical companies are generally reluctant to produce orphan drugs because rare medical conditions do not open up profitable markets; besides, the conditions are prevalent mainly in developing countries where the majority of the population are too poor to buy the drugs.

On one hand, orphan diseases only represent a small number of individuals and investing a substantial amount of resources in rare conditions could be considered unethical from the utilitarian point of view; such investments do not maximise the long-term social benefits due to the population. However, on the other hand, many would uphold that society has a moral obligation not to abandon individuals who have the misfortune of being afflicted with serious but rare conditions.

Furthermore, medical professionals also have the obligations to tap into scientific knowledge in developing new-therapies. Gericke (2005) argued and analysed these ethical dilemmas according to four principles of biomedical ethics. He added that for his study, he believes that the principles of beneficence and justice are particularly relevant, where the principle of justice covers the utilitarian and a right-based approach.

The principle of beneficence covers the discussions on moral obligations for non-abandonment; it also includes professional obligations of medical doctors to promote scientific advancement. In his conclusion, Gericke (2005) stated that both principle of justice and beneficence support a stronger role for the public sector in deciding the priority of funding for orphan drug research.

Public health constantly encounters serious ethical dilemmas, such as rationing scarce resources, influencing individuals to change their behaviours, and limiting freedom to reduce disease transmissions (Roberts and Reich, 2002). In their study, the authors conducted ethical analysis based on a framework, which used approaches that were premised on ethical theories of utilitarianism, liberalism and communitarianism.

They argued and explored critical variations within each approach, and identified practical problems that arose in addressing the ethical dimensions of health policies. According to Roberts and Reich (2002), public health professionals need to enhance their

knowledge regarding the application of philosophy to develop coherent positions on these issues and contribute to the democratic deliberations of public policies.

The above mentioned and several other researches show that ethical analysis using ethical theories and principles has successfully analysed the ethical issues that are being discussed, thus provide understanding and conclusion to the ethical dilemmas faced. Ethical analysis not only helps researchers to deal with ethical dilemmas or issues but also guide them to find the best solutions to address the problems. At the same time, ethical analysis contributes to understanding what ought and ought not to be done when one faces certain situations.

Therefore, based on these literature reviews and arguments the researcher decided to conduct the ethical analysis of this research by using ethical theories of consequentialism and deontology. The moral rightness of a specific decision is dependent on its ultimate consequences and/or the fact that decisions under certain circumstances are always right, irrespective of the possible consequences of the decisions or acts (Hedner and Hansson, 1988). Both ethical theories will help in the exploration and understanding of the rationales behind the participants' responses, when the identified ethical issues of PGD are discussed. Thus, it is pertinent to identify the dominant thinking patterns of each group of participants, and at the same time, relate the rationality of the thinking with the chosen ethical theories.

The findings of this study are expected to display some similarities and differences in terms of the participants' views and opinions on ethical issues related to PGD because they may view the issues discussed from different perspectives. Therefore, by using both of these ethical theories, we can holistically and constructively build an understanding regarding the participants' perceptions of PGD. Conclusively, this will lead to the formation of a general conceptual framework representing participants' perceptions in

regards to PGD and how it might influence their final decision-making on PGD. Figure 1.1 is a theoretical diagram, which summarises the arguments, presented in this chapter.

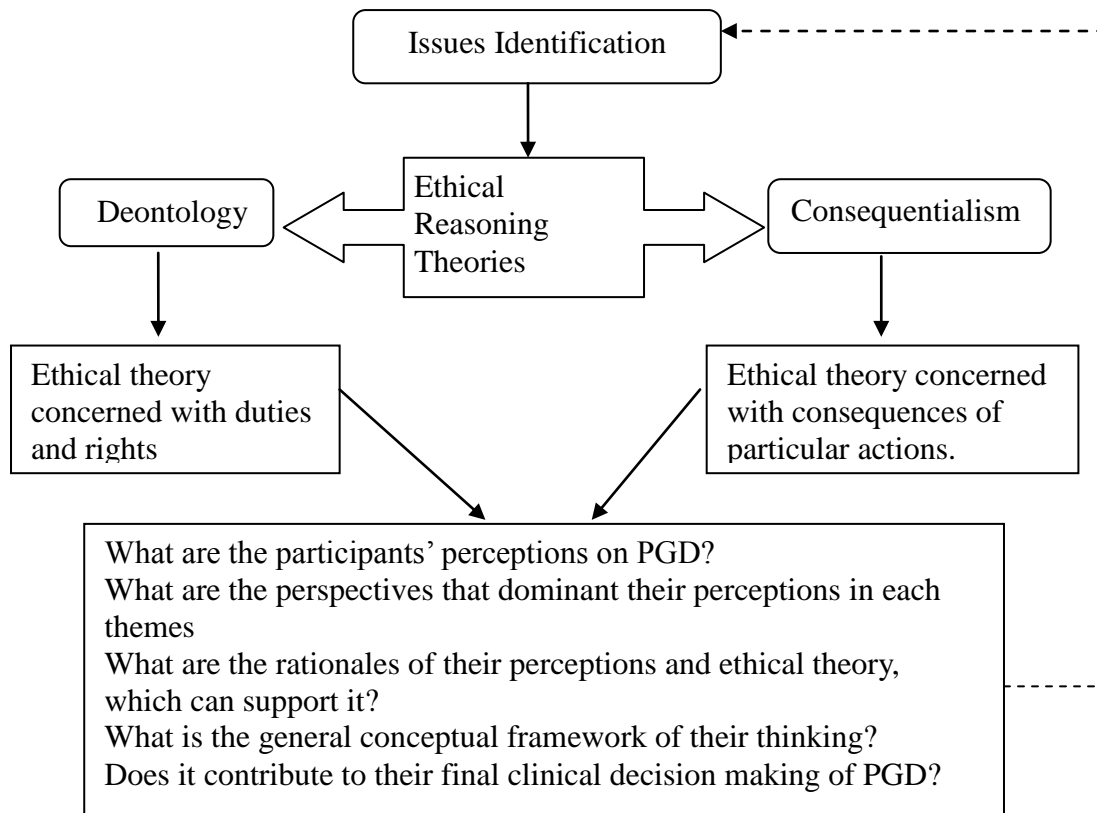


Figure 1.1: Theoretical framework for ethical perceptions on PGD

1.4 Significance of study

The number of PGDs performed each year is rising and it is estimated that over 1000 children worldwide have been born following PGD (Kalfoglou et al., 2005). However, these have led to concerns about medical inappropriateness; it creates concerns whether medical reasons alone are enough for individuals to demand for PGD or for physicians to provide PGD, ethical acceptability; looks on how well accepted are the ethical issues that arise from the use of PGD such as moral status of the embryos or issues of discriminations and adequacy of regulatory oversight; whether the government or medical community has

done enough monitoring and supervision, coupled with the existing regulations on the use of PGD, in order to avoid the possible future misuse of the technology (Shenfield et al., 2003). These issues are the reason why in some countries, PGD is only allowed for selected medical conditions or is totally prohibited by law (Knoppers and Isasi, 2004) such as in Germany and Austria.

PGD is a technique that was developed as an alternative to prenatal testing in order to avoid selective abortion among women and couples at high risk of having children affected by genetic diseases (Krones et al., 2005). It improves reproductive choices for these couples, and at the same time provides reassurance and reduces anxiety associated with reproduction.

There is a growing number of private fertility centres in Malaysia, which provide genetic testing services and these include PGD. Although the exact number of centres that are equipped with this technology is unknown, it shows there is growing interest among Malaysian parents or couples to consider the use of or to even try out this technology. This indicates that Malaysian parents or couples are aware of the available reproductive choices, and this information might influence their reproductive decisions.

When the first case of PGD in Malaysia was published in 2004², it was still a new medical technology that was unknown to most Malaysians; this explains the negative perceptions of Malaysians towards PGD. However, these perceptions might change in the coming years as more parents or couples become better informed on their reproductive choices through consultation with their physicians or self-education. Therefore, it is important to conduct this study in Malaysia in order to find out how Malaysians feel about the use of PGD and ethical and clinical issues that could arise from its use.

² Government won't allow 'designer babies'. The Daily Express, 27th June, 2006 (Retrieved from <http://www.dailyexpress.com.my/news.cfm?NewsID=42814>)

This study will provide information on participants' perceptions of the ethical and clinical issues posed by PGD, and at the same time, provide insight on how they confront and approach these issues. These findings will be crucial because they will help us to understand what the Malaysian society thinks of the technology.

Most of the previous studies were conducted in order to assess the acceptability of, and demand for PGD, as well as attitudes towards PGD among potential users, actual users and providers, and other medical or ethics experts. Findings of these studies show that attitudes, acceptance and decision towards its use can be seen as rather ambiguous and complicated (Meister et al., 2005). This is because the attitudes and decision making of couples, individuals or parents' regarding PGD are normally based on their critical evaluation of the technology, emotional responses and moral judgements (Hershberger and Pierce, 2010).

In their paper review on the previous qualitative researches on PGD, Hershberger and Pierce (2010) noted an interesting finding, which showed that the existing studies do not really focus on the elements that could influence respondents' views on PGD and how it relates to their reproductive decisions, as well as how couples or parents weight the ethical issues that arise from using the technology in their own decision- making. Furthermore, most studies have been done mainly in the Western countries, which portray views based on the Western culture. These views may differ from those of the Eastern culture.

Therefore, there is a need to conduct this study in Malaysia in order to gain knowledge regarding participants' views and opinions on this new technology, and to further expand the existing literature of the subject. It is worth noting that this study will provide a different perspective since it will include the views of three groups of participants from various backgrounds. Besides, physicians and potential users as well as,

representatives of the three major religions in Malaysia are also included as participants to provide religious understanding of PGD and implications for people of various faiths. Involving various religions in one study is certainly a new attempt, but it is essential to this study because of the country's diverse religious and cultural backgrounds. This approach differentiates the present study from the previous studies done on the issues of PGD. At the same time, their views on the issues could provide an explanation why individual from different religious background represent different understanding or explanation on the same ethical issues pertaining to the use of PGD.

Furthermore, the findings of the study could be used in educational programmes in this area. The information is very useful in terms of patient counselling; it will help in understanding patients with different medical experiences who have different views towards PGD. This will enable counsellors or physicians to use different approaches when discussing issues related to PGD. At the same time, this study will be useful in terms of developing guidelines and policies related to new reproductive technologies in the country as the findings from this study will give insights on the ethical implications of PGD in Malaysia from the perspective of different segments of Malaysian society.

1.5 Research questions

The availability of PGD is a new and exciting alternative for many affected parents who can benefit from the treatment. However, it poses greater challenges for parents or couples in terms of clinical decision- making because of ethical issues related to its use. In Malaysia, the use of PGD is only permitted for medical purposes (Guidelines by the Malaysian Medical Council [MMC] 2006), and it is only available at private fertility medical centres where other types of reproductive treatments are also available. The

Ministry of Health has acknowledged that there is a need to properly regulate and monitor the use of PGD or other new genetic reproductive technologies in the country. Nevertheless, it is inappropriate to completely ban PGD because it is medically beneficial for families who need it.

Despite having the technology in Malaysia, the rate of acceptance pertaining to the use of it among Malaysians is unknown. Therefore, it is important to conduct such a study in Malaysia, in order to explore ethical implications of PGD within the medical fraternity and society. The aim is, to understand the factors that influence their attitudes towards PGD. This information will be useful when assessing further needs for guidelines, policies or professional and patient education programmes in the country.

This study is guided by the following research questions:

- How do the participants confront the ethical and clinical issues posed by PGD?
- How do the participants approach the ethical issues that arise from the use of PGD?
- What are the factors that could possibly influence the participants' perceptions on PGD?
- Do their perceptions contribute to their final clinical decision- making in regard to PGD?
- What are the ethical implications of PGD in Malaysia?

1.6 Limitations

The possible limitations of this study that are beyond the researcher's control are race and ethnicity. The participants, except for the religious representatives from the three main religions were not selected based on their religious beliefs. They were instead selected based on their different medical situations and experiences. Since this study requires participants to give an account of their personal experiences of having to raise a

child with genetic disorders, it may be a sensitive topic of discussion; this is a possible limitation to open and honest discussions.

Qualitative research is used when the researcher needs to explore and investigate issues, which can only be established by talking to the persons who have gone through or is currently going through the experience themselves (Creswell, JW., 2007). This can be a good way to gain insight on a specific topic, but the subjective description of the affected person's experience can also be a limitation to this study.

Another limitation of this study is the reactions of the interviewees towards the interviewer, such as the emotional state of the interviewees at the time of the interview. This study only involves the potential users of PGD instead of the actual users, which is another limitation of this study. This is because the researcher does not have any access to any information of the actual users of PGD, which is guarded by the respective medical centres that provide PGD services.

Therefore, this study is unable to explore and provide the experiences and perceptions of people who have actually used the technology. At the same time, another limitation of this study is the restrictive area of sampling because the study is only conducted within the Klang Valley and Selangor. Therefore, the findings of this study is not representative of the Malaysians population, but represent the perceptions of only a small number of Malaysians on ethical issues related to the use of PGD.

1.7 Organisation of study

This study is divided into five chapters and a brief explanation on each of the chapters is provided as below.

Chapter 1 is the introduction to the study and provides an overview of the theoretical framework of the study. It also includes the objectives of the study and research questions used to guide this study.

Chapter 2 summarises the literature reviews that were to develop the theoretical framework of this study, which was used to execute this research. This chapter also examines previous studies on PGD conducted in other countries, which provide the initial basis of this study. In addition, the chapter discusses the divergent religious views in regard to PGD, current dilemmas of PGD and the development of PGD internationally, as well as in Malaysia.

Chapter 3 outlines the research methodology employed in this study and provides an explanation on why this methodology was used. This chapter also describes the selection process of participants for this study and why it is necessary to include them. The last section discusses the methodology adopted to analyse the data collected during the interviews.

Chapter 4 is dedicated to discussion and analysis of data obtained from the interviews with the 21 participants selected for this study. This chapter also includes discussions of the findings and how does it differ or support previous findings or studies on PGD.

Chapter 5 concludes the study through presentation of the research findings; its implication for theory and for policy. The chapter also discusses the limitations of the research, ethical considerations that were taken into account during the research,

implications for the practice of PGD in the future and recommendations for future research in this field in Malaysia.

1.8 Conclusion

PGD can help to reduce the number of babies born with genetic disorders and serves as an alternative for parents who are at high-risk of transmitting genetic disorders. However, it does generate fears of designer babies and eugenics. In certain countries, the use of PGD is either controlled or totally prohibited due to the nature of the technology that enables parents to select the genetic characteristics of their future offspring.

However, the emergence of new uses for PGD has brought the discussion and debate on PGD to another level as the clinical, ethical and social dilemmas become more acute. These dilemmas may influence the reproductive decisions of couples or parents on whether or not to use PGD. Therefore, this study is important because it helps the researcher to understand the influencing factors of the participants' perceptions on PGD. It is also important for us to understand how these perceptions affect the reproductive decisions of the couples or parents as to whether or not to proceed with PGD, and the rationale of their decisions and formation of general conceptual framework the thinking of each group of participants.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction to ethical theories

Ethical theories and principles are the foundations of ethical analysis because they are the viewpoints from, which guidance can be obtained along the pathway to making decisions. Each theory emphasises different points, such as predicting the outcome and fulfilling one's duties to others in order to reach an ethically correct decision (Ridley, A., 1998). At the same time, ethical theories also have common goals, which are to achieve the most basic ethical principles, including beneficence, non-maleficence, respect for autonomy, and justice (Penslar, RL., 1995).

Ethical theories are based on the ethical principles, each of which emphasises different aspects of an ethical issue, which tends to be the most ethically right solution, according to the guidelines within the theory itself. Ethical theories are often used in the field of bioethics as moral reasoning for individuals to decide or determine whether an action ought to be ethical. It is an idea or a set of ideas that tries to explain a person's reaction towards selected ethical issues in any given situation. Ethical theories sometimes are used as a supportive argument when explaining why some people have contradictory views when faced with the same ethical situation.

Bioethicists have used ethical theories to conduct ethical analysis on the emerging ethical issues associated with genetic testing, animal and human cloning, genetic enhancement and modification, or existing ethical issues related to abortion, gender selection and embryonic stem cell research (Kuhse and Singer, 2009). Discussions and

debates using different ethical theories have led to multiple views of how one should evaluate whether their actions are right or wrong.

There are two fundamental types of ethical theories: those based on the notion of choosing one's actions so as to maximise the value or values to be expected as consequences of those actions, and those based on the notion of choosing one's actions according to standards of duty or obligation that do not refer to consequences but to the nature of actions and motives that are held by those performing them (Hull, RT., 1979).

2.1.1 Normative ethics

Normative ethics provide a general theory that tells us how one should live his or her life. However, it does not mention what moral properties are or what comprises the specific things that have those properties. Generally, normative ethics provide a framework for ethics. Normative ethics (Kagan, S., 1998) generally can be divided into three categories: consequential, deontological and virtue ethics.

Deontology and consequentialist ethics are considered as an action based theory because it focuses on actions which people take and the consequences of their actions. On the other hand, virtue ethics focus on the character of the person performing the action or the inherent character of a person, rather than on the specific action he or she performs. Basically, a person makes moral decisions based on the action, which make them a good person.

2.1.1.1 Consequentialism theory

Consequentialism refers to moral theories that are based on the consequences of a particular action, which form the basis for valid moral judgment on the actions. Therefore, from the consequentialist's ethical view, a morally or ethically right action is an action that ends up producing a good outcome (Darwall, S., 2003). In consequentialist moral theories, the consequences of an action outweigh other considerations because the deciding factor of whether an action is ethical is the outcome of the action itself. If the actions produce consequences that seem to be the best for the situation and the people involved, it is therefore, claimed by consequentialist as ethically right.

However, the definition of good or bad may differ from one individual to another, which creates conflicts in deciding which actions to take in a given situation in order to maximise good outcomes. This leads consequentialist to agree that the best overall consequences will not only bring goodness but also bring happiness to the individuals or parties involved. Therefore, for proponents of consequentialist theory, acting on the said basis is considered to be ethical actions.

Utilitarianism is the most influential consequentialist theory. It is an ethical theory, which holds that the proper course of action is the one that maximise the overall 'happiness' for the greatest number of people. According to utilitarian concept, an action is considered as ethically right if the action chosen produces good consequences, which are favourable to a lot of people or society, rather than to just one individual. Good consequences in terms of utilitarian concept mean consequences that will bring great happiness and pleasure to a great number of people. Jeremy Bentham and John Stuart Mill, with the former living in the 18th century and the latter in the 19th century, are two main scholars of utilitarian thinking, who formulated this way of thinking.

In assessing the consequences of an action, utilitarianism depends on the theory of intrinsic values. This means something is held to have good in it, apart from further consequences, and all other values are believed to derive their worth from their relationship with this intrinsic good as a means to an end (Darwall, S., 2003).

Jeremy Bentham presented one of the earliest fully developed systems of utilitarianism. Two features of his theory are noteworthy. First, he proposed that we tally the consequences of each action we perform and thereby determine on a case-by-case basis whether an action is morally right or wrong. This aspect of Bentham's theory is known as act utilitarianism or situational ethics. Secondly, he proposed that we tally the pleasure and pain, which result from our actions. For him, pleasure and pain are the only consequences that matter in determining whether our conduct has moral. This aspect of Bentham's theory is known as hedonistic utilitarianism (Hull, RT., 1979).

The other proposal of utilitarian theory is known as rule-utilitarian, which was proposed by John Stuart Mill in the 19th century. Rule-utilitarian theory claimed that actions are ethically right when they conform to the rule, which end up producing the greatest good (Hull, RT., 1979). This differs from act-utilitarianism because rule-utilitarianism stresses that the correctness of a rule is determined by the amount of good it brings when it is followed.

Therefore, an action that is proposed has to not only produce the greatest amount of happiness to a great number of people, but it also needs to conform to certain rules and regulations in order for the action to be defined as ethically right. Conclusively, rule-utilitarianism defines a system as ethically acceptable as long as there are no rules being broken unless there is a strong reason to do so.

A normative system provides a standard by which an individual should act and how the existing moral code within the society should be evaluated and improved. However,

utilitarianism cannot be verified and confirmed in the same way as descriptive theory although for exponents of utilitarian theory, it is also not totally arbitrary. Bentham believes that only in terms of utilitarianism, such words like 'should', 'right' and 'wrong' have meaning, and that whenever anyone attempts to go against the principles of utility, he or she does so with reason drawn from the principles itself.

Bentham and Mill are both advocates of utilitarian theory, and they believe that human actions are motivated entirely by pleasure and pain. At the same time, Mill saw pleasure and pain as a basis for his motivation to argue that since happiness is the sole end of human actions, the level of happiness is the test to judge all human conducts.

However, Bentham's theory on utilitarianism received much criticism from other scholars, who claimed that these aspects have some limitations. One of the fundamental criticisms of Bentham's theory of utilitarianism is that it does not offer an obvious way of how to decide between distributions of good consequences, some of which are just and unjust (Hull, RT., 1979).

For example, according to utilitarian theory, it is ethically wrong for someone to gain pleasure and happiness by doing what they like instead of doing what they like less but results in giving a lot of pleasure and happiness to a great number of people. However, prohibiting an individual from experiencing happiness and pleasure from the things they love to do does seem unreasonable.

Most significantly, according to act utilitarianism, specific acts of torture would be ethically permissible if the social benefits of doing so outweigh the disbenefits. This can occur during interrogation of a criminal where the interrogators are under pressure to get information from the criminal in a very short time in order to make sure the lives of civilians are protected. Some will question whether the need to protect civilians justifies the act of torture towards a person.

Suppose a man's wife needs a certain type medication, which is produced from a certain kind of drugs that can be bought from one of the drug dealers in town. Due to the nature of the medication, it is illegal to purchase or sell it in the local pharmacy at the hospital. Desperate to save his wife, the man goes to the drug dealer, asking to buy the particular drug.

However, being a greedy person, the drug dealer will only sell it at a high price, in which the man cannot afford to pay. Determined to get the drug, the man goes to the drug dealer's house and steals the medication so that he can save his wife. From the utilitarian point of view, this action is ethically right because the man saves another life by stealing the drug. However, stealing is morally wrong because we take what is not ours.

For those who oppose the act of stealing or torture, they think that both actions are ethically wrong and morally impermissible, resulting in the refutation of utilitarianism. However, for those who favour both actions, they think that it is ethically right as the actions benefit a lot of people and should be permissible, which shows how good utilitarianism theory is.

However, this does not mean that the exponents of utilitarianism agree on the notion of torturing a human being or the act of stealing. In response to these critics, exponents of utilitarianism theory claimed that the moral rightness of distribution of good consequences, and what is the just and unjust, should be evaluated and analysed using rule-utilitarianism rather than act-utilitarianism.

According to rule-utilitarianism, there are some rules that tell us what to do in a particular situation, in which the consequences of acting based on those rules will bring benefits to many people. However, rule-utilitarianism also claimed that there are general exceptions rules that allow the breaking of other rules if such rules breaking increases happiness.

For instance, when a husband steals medication that can save his wife, the act gives happiness to both of them but not the drug dealer (Houser, R., 2006). Based on Mill's Weak Rule utilitarianism, he stated that although some rules should be framed based on previous examples that benefit society, it is possible, under specific circumstances, to do what produces the greatest happiness while breaking the rules (West, HR., 2006).

Another criticism of utilitarian theory is that it does not serve justice and fairness to the individual, which indicates that the rights of individuals are less important than the good of many. This indicates that it is acceptable to violate the rights of individuals in order to make sure that society at large would benefit from this violation.

If the evaluation is done based on utilitarian theory, then the act of a doctor killing a healthy person in order to gain access to his viable organs is ethically right. The man's organs can save the lives of several people who desperately need organ transplants to stay alive. Thus the doctor's decision has given happiness and pleasure to a great number of people.

However, when we take into account the principles of autonomy and individual rights, the above-mentioned action is ethically wrong considering the method that was used to obtain the organs. Moreover, some of the recipients might not be happy when they come to know how the organs were harvested. As Rawls mentioned in his justice theory, he rejected the utilitarianism's idea that the happiness of a few separate individuals could be meaningfully counted together (Blackorby et al., 2001). Rawls argued, as written by Blackorby et al (2001) that it indicates as if we are treating a group of many people as a sentient entity and ignoring the separation of consciousness.

Utilitarian theory according to Rawls, has denied the idea of individual rights of each of the individuals involved including the man who acted as the organ donor. However,

proponents of utilitarian theory claimed that justice is served when the benefits and burdens of society produces overall utility, as justice is defined in terms of utility.

In addition, utilitarianism believes that in some situations, the needs of many do matter most, rather than the needs of one individual (Hull, RT., 1979). Furthermore, according to Blackorby et al (2001), Bentham himself had never believed in individual or human rights, or known as nature rights during his time, because he thought that it was ‘nonsense upon stilts’, which often than not would lead into conflicts and not harmony.

Another criticism of utilitarian theory is regarding the motivation of the person who performs the action. Critics of utilitarian theory claimed that the rightness or wrongness of actions should include the motives that motivate the individual to choose the action. For example, consider a situation when a few people help or sacrifice their time in order to help in a charity event, which will bring joy and happiness to the society at large. The end results in this situation might be the same; however, each person might have different motives to choose to volunteer in the charity event.

Some individuals might do it to glorify themselves but for another person, they might do it because they genuinely want to help. Critics of utilitarian theory believe each person’s actions do not have the same value, by considering the fact that there are many others motives that motivate individuals to choose, such as their obedience to law enforcement and, obligation to their duties or religions.

Based on Mill’s argument, the rightness or wrongness of the actions does not depend on the motives of the person who performs it, but it depends entirely on the intentions of doing so (Ridge, M., 2002). He added that motive has nothing to do with the morality of the actions, or whether the actions are ethically right or wrong, but it is focused on the worth of the agent.

According to exponents of utilitarianism, motives are normally actions that are influenced by or initiated from emotions of approval or disapproval that vary from one person to another, or obedience to different understandings of what God or conscience requires (Ridge, M., 2002). Furthermore, if we use motive to decide whether an action is ethically wrong or right, it might lead to negative consequences.

Utilitarian theory has also being criticised for its lack of personal integrity. One of the critics, Bernard William, claimed that utilitarianism does not distinguish what we ourselves do from that which we only allow to happen (Norcross, A., 1997). In his criticism of utilitarian theory, William mentioned that sometimes, a person might be pushed or placed in a difficult situation where he or she is forced to commit some spectacular unjust or problematic crime.

Although this might sound hypothetical, it cannot be denied that humans are sometimes put in an uncomfortable situation. An example is, when a person is asked to kill an innocent man in order to stop the killing of 20 other people who are involved in a protest against the government. According to utilitarian principles, the person will end up killing a human being because he believes that the death of one person will save the rest of the captives, although he personally thinks that it is wrong to kill an innocent man.

Basing on this situation, Williams claimed that utilitarianism indirectly controls a person's commitment to himself as moral agent, and the need to care about people who are close to him, in order to maximise desirable outcome. This, according to William Bernard is the weakness of utilitarian theory; he suggested that there should be a sense of personal integrity and commitment in order to make sense of justifying any morality and not merely based on the maximising the outcome. In his reasoning, William highlighted the important aspects of what it means to be human (Norcross, A., 1997).

Throughout the years, there have been modifications of each view to avoid the contradictory conclusions, and proponents of utilitarianism have developed some new defences against these criticisms (Hull, RT., 1979). It is no longer the relatively simple, straightforward rubric that Bentham and Stuart Mill take it to be. However, it is important to note that utilitarian theory does not state that moral action is one that maximises the benefits or happiness of the person who is performing the action.

It must be for the benefits and happiness of everyone, where each person is equally considered. Another common misconception is the belief that utilitarianism takes into account only the immediate consequences of an action. This is wrong because utilitarianism clearly states that all consequences must be accounted for, including both short and long term consequences.

2.1.1.2 Kantian ethics: Duties and Rights

Deontological ethics or deontology is an approach to ethical issues, which determines the goodness or rightness of the action by examining the act itself, rather than the consequences (Waller, BN., 2005). Deontology theory states that people should adhere to their obligations and duties when analysing an ethical dilemma.

Deontologists make decisions based on their obligations towards another individual because of their duties, and this is considered as ethically correct (Penslar, RL., 1995). The term deontology was first used in this way in the 1930s, in C.D. Broad's book entitled, "*Five types of Ethical theory*" (Beauchamp, TL., 1991). Deontologists believe that one has a duty to act in a way according to the rules and regulations.

The best-known deontological theory is the one established by Immanuel Kant in the 18th century, which is now known as the Kantian Ethics. In his theory, Kant argued that

in order for one to act in a morally or ethical manner, one has to act out of duty because he or she agrees that the consequences of the action are not as important as the intention of the person who performs the action (Bowen, SA., 2004). Deontological theory provides a basis for special duties and obligations to specific people, which can be observed clearly in a doctor-patient relationship. In this specific relationship, a doctor's most important duty is to assist their patients medically in any way they can, and making sure that no harm is done towards their patients.

However, one may argue that it is difficult for people to know exactly what their duties are. This is because unlike the medical profession, some duties and obligations are not written but are based on understanding; for example, one's duties within the family. Kant defended his argument by explaining that our understanding regarding our duties can be derived from our unique nature as human beings because unlike any other living things, humans are uniquely rational.

Based on this rationality, Kant derived the basic morality, which he later called the *categorical imperative* (Bowen, SA., 2004). According to Kant, rules should comply with categorical imperatives which hold that: (1) moral rules should be universal where it will apply to all rational moral members of the community rather than to just some, (2) all persons should be treated never simply as means but also always as ends in themselves and (3) members of the community should join hands in making the law as well as living by them (Hull, RT., 1979). Kantian ethics has inspired others to develop their own ethical theory based on Kant's ethical theory, such as discourse ethics that was suggested by German philosopher, Jurgen Habermas; theory of justice by John Rawls and theory of psychoanalysis by Jacques Lacan.

In contrast to consequentialism, deontological theory is less morally demanding and its law is absolute and largely non-negotiable, which makes it easy to live a normal life

while still adhering to the philosophy. At the same time, deontology is very much straightforward in the sense that every action is considered as neutral as long as it does not breach one's duty. According to Hull (1979), deontological ethics are also enforceable because there are clear violations of duty which will be punished by whoever has been wronged. Although deontological theory may seem to contain positive attributions, it is not free from criticisms.

One of the main arguments against deontological theory is that sometimes, a person's duties can cause conflicts within the person. This is because often at times, duty can lead people to do things that they might not want to do, and sometimes they need to make choices (Singer, P., 1993). Hegel mentioned this argument in his criticism against Kant, and Hegel thinks that this will force individuals to have an internal conflict between reason and desire (Brooks, T., 2012). Deontologists are criticised for their support of unbending obedience at the expense of the original intent of the rules.

Thus, no effort is shown in developing moral character like virtue ethics. In support of this argument, Schopenhauer claimed that ethics should not just be legislative and imperative, but should concern what actually occurs and attempt to explain and interpret it (Manninon, G., 2003). In addition, he explained that ethics should be about the construction of moral frame based on the understanding of the world.

Contradictory to consequentialism where the welfare of many is a major concern, deontological theory is criticised for not having concern for the welfare of others. For deontologists, conforming and following rules as well as obligations to one's duty are grave concerns, rather than paying much attention to the outcome of the actions.

Another criticism of deontology theory is that sometimes, different rules can contradict each other, specifically rules in *divine command theory*, a theory that places morality as whatever God says it is (Austin, MW., 2006). According to divine command

theory, all ethical propositions can be directly inferred from the contents of the scripture, which is believed as the word of God.

Kant sees his ethics as applying to all, and only rational beings. It was clear to him that animals are not rational beings, thus our duties to them could not be decided using his ethics. These rational beings also include babies, the insane, the comatose and the severely retarded. Kantian ethics do not offer any basis for limiting what we may do to such beings or indicate what our positive obligations to them are.

2.1.1.3 Virtue ethics

Virtue ethics lie in the work of Plato and Aristotle, and the tradition's key concept is derived from ancient Greek philosophy (Devettere, R.J., 2002). Virtue ethics concentrate on the moral character of the agent instead of the consequences of the action. Virtue ethics has been developed in three main directions: Eudaimonism, agent-based theories and the ethics of care (Darwall, S., 2003). Eudaimonism describes virtue ethics in terms of human flourishing that associates ethics with human rationality leading to a well-functional human being.

According to Aristotle, the most distinctive function of human beings is their capability for moral reasoning; therefore, stating that life that is 'worth to living' is an example the one where one can reason well (Hursthouse, R., 1999). An agent-based theory of virtue ethics emphasises on human's common-sense intuitions, which is viewed as admirable traits in others (Pojman and Fieser, 2009). Finally, feminist thinkers who believe in the idea that ethics should focus on justice and autonomy, has proposed a new kind of ethics, which known today as the ethics of care.

Subsequently, virtue ethics focus on human characters such as compassion; generosity or courage, which will virtually manifest in the decision a person makes that, would justify their state of action in ethical situations as ethically correct. This shows the difference of virtue ethics with consequentialism that focuses on consequences, and deontology, which emphasise on duties and obligations rather than the consequences.

The differences of these theories lie more in the way each theory approaches the moral dilemmas rather than the moral conclusion that it intends to reach. Virtue ethics emphasises more on the moral agent rather than the moral agent's actions, which bring about the consequences. It also argues that developing morally desirable virtues will help in deciding the moral action when a decision needs to be made (Taylor, R., 2002).

2.1.2 Ethical principles

The principles of beneficence guide the ethical theory in defining what is good. The priority to do good, provides an ethical perspective and possible solution when someone is faced with ethical dilemma. The principle of beneficence is also related to the principle of utility, which demonstrates that one should try to generate the largest ration of good over evil (Penslar, RL., 1995). This principle explains that ethical theories should strive to obtain the greatest amount of good because a lot of people can benefit from it. This principle is mainly associated with the ethical theory of utilitarianism.

The principle of non-maleficence is similar to beneficence but deals with situations where neither choice is beneficial. In this situation, a person should choose a decision that would impose the least harm to fewer people. This principle can clearly be observed in a physician's daily duty towards his patients. Bonded by the Hippocratic Oath physicians

have the responsibility to ‘do no harm’ to the patients as their primary duty, to provide helpful treatment rather than to inflict more suffering upon the patients.

The principle of autonomy states that an ethical theory should allow people to reign over themselves and be able to make decisions that apply to their lives. This means that people should have control over their lives because they are the only ones who completely understand their chosen lifestyle.

Everyone deserves to be respected for their decisions made because they have those exact life experiences and understands their own emotions, motivation and body in such an intimate manner. However, there are two ways of looking at this principle, which is from the paternalistic or libertarian view. In the paternalistic view, the dependent’s best interests are the priority rather than the dependent’s wishes.

In the libertarian’s view, the dependent’s wishes are the priority, which indicate that the parents have total control over their lives and they should be contented with their choices in life because they have chosen the path with the greatest amount of personal beneficence (Ridley, A., 1998).

The justice ethical principle states that ethical theories should present actions that are fair to those involved.

2.2 Introduction to bioethics

Perhaps the first ‘modern’ work of bioethics was by Joseph Fletcher, which was written in his book entitled “*Moral Medicine*” published in 1954. In “*Moral Medicine*”, Fletcher wrote about his controversial approach to ethical questions, which had more things in common with consequentialist ethics than with traditional Christian views (Kuhse and Peter, 2009). It was only in the 1960s that bioethics really began to take shape as a field of

study.

During the 60s, most countries in the Western Hemisphere were going through some important cultural and social changes, which led to the rise of civil rights movement, renewed questioning of war and nuclear weapons, resurgence of feminism, and availability of safe abortions and modern contraceptives (Kuhse and Peter, 2009). All these developments subsequently contributed to questions about women's and individuals' rights. In part, all these social happenings were the results of new and sometimes revolutionary advances in biomedical sciences and in clinical medicine, which raised questions that no one had needed to answer before.

In 1971, Van Rensselaer Potter published an unnoticed but very significant volume entitled; *Bioethics: Bridge to the Future*. Following the publication of this book, he was perhaps the first person, or among the first, to formally employ the term 'bioethics'. His intention was to identify a field that could combine both biological and humanistic concerns within the scientific realm that would establish a system of medical and environmental priorities at an acceptable level of quality of life (Levine, C., 2007). The original meaning of the term never became widely established; instead, bioethics regarded as growing interest in the area of ethics arising from health care and biomedical sciences (Kuhse and Singer, 2009).

Since then, the advent of modern medical marvels such as dialysis machine, ventilator and organ transplant, offers new hope of life to patients who would otherwise have been unable to survive. In vitro fertilisation and other related reproductive technologies have enabled a new kind of relationship between parents and children, which include women giving birth to children who are genetically unrelated to them.

One of the most publicised medical breakthroughs during the 60s was the first heart transplant in 1967, performed by South African surgeon Christian Barnard (Lederer, SE.,

2008). Although the patient only survived for 18 days after the surgery, it did not dampen the spirit of those who hailed a new era of medicine, but with attendant ethical dilemmas. According to Lederer (2008), the ability to perform heart transplant was linked to the development of respirators which were introduced to hospitals in the 1950s. The development of transplantation, respiratory and other life extending technologies in medical sciences, raised not only questions about when a patient should be declared dead but also where to draw the line for this technology's application in attempting to prolong a patient's life.

Duff and Campbell (1973) published an article regarding issues related to ethical dilemmas that health care workers, specifically nurses, encountered in the special care nursery. In their article, Duff and Campbell revealed that a doctor's decisions not to provide life- prolonging treatments to severely ill infants had raised a central question whether these non-treatment decisions were morally or legally sound.

Questions and debates regarding the limits of treatment for those who are unable to decide for themselves were not only raised in the United States but in other countries as well, such as Britain and Australia (Kuhse and Singer, 1985). It was not until 1976 that the first trial was held in order to release doctors' legal authority in making the decision on behalf of their patients whether the patients should be given life -prolonging treatments (Quilan and Quilan, 1977). This case became another landmark within the medical fraternity because it lent support to the view that doctors had no legal duty to prolong life under any circumstances. At the same time, this case also led to the development of formal ethics committees in hospitals, hospices and nursing homes as well as, development of advance health directives.

The main ethical issues in science and technology normally centre on human genetics. Important ethical issues relating to the ethics of human experimentation were

already raised in the USA by Henry Beecher in 1966 (Harkness and Wikler, 2001). Beecher's writing, entitled "*Ethics and Clinical Research*" revealed that there were ethical lapses in researches carried out by physician-scientists in renowned universities. His publication was deemed as the most influential single paper written on experimentation involving human subjects. As a results, this prompted consideration of research practices that laid the groundwork for today's ethical codes and review committees, including the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research³.

Although there is general consensus on the acceptability of human-subject research under the safeguards of informed consent, voluntary consent of the subject, patient or proxy, careful balancing of the risks and benefits as well as, being fair in the selection of research participants, there is still a good deal of disagreements on the justification of research when human subject is involved (Ryan, AE., 1999). Concern was expressed when discussing issues pertaining to the manipulation of human genetic material even though the medical benefits were evident especially relating to the use of genetic information (Ab Majeed, AB., 2001).

The 20th century has shown that there is rapid advancement in the field of bioethics, particularly in the area of human biology, and its related field, biotechnology. Numerous achievements within the field of science and technology are being showcased in this era (Ab Majeed, AB., 2001). Modern technology is still considered to be something new and has yet to stand the test of time. Therefore the rapid advancement in this field has caused some doubts, fears and concerns as well as intense debates worldwide on the potential risks to human health, the environment and society (Amin, L., 2009).

³ National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research was established in 1973 by the US Congress with the task of drawing up regulations that would protect the rights and interests of subjects of research. One of the most well known reports written by the commission was the Belmont Report. In the Belmont Report, it clearly stated the ethical principles that should govern research are respect for persons, beneficence and justice.

According to an American study on “Public Perception on Biotechnologies”, the public accepted science and technology in general but they revealed an ambiguous attitude toward biological research (Ab Majeed, AB., 2001). Modern biotechnology or biological researches are classified as complex emerging issues, which are of high salience to the public but of which they have limited knowledge (Amin, L., 2009).

There are also plentiful source materials written on bioethics as almost everyone involved in the field has written something about clinical dilemma, legal ruling, policy option, philosophical analysis, or personal experiences regarding bioethics. At the same time, some advisory boards such as the Ethics Committee or Institutional Review Board (IRB), and several public commissions, that have examined specific ethical issues and also have produced a large volume flood of documents concerning bioethics (Levine, C., 2007). Levine also mentioned that there are several publications or books written by researchers regarding bioethics, such as books by David Rothman⁴ and, H. Tristram Engelhardt Jr.⁵ as well as, articles by Stephen Toulmin⁶ and Daniel Callahan⁷, among others.

However, the field of bioethics also received criticism from several individuals: based on the writings of these people, their criticisms were mainly directed at its founding principles and current practices. In the book entitled “*Bioethics in America: Origins and Cultural Politics*”, Steven (2000) highlighted his criticisms concerning the origin of bioethics movement in America, the history and influence of Hasting Centre⁸ towards the development of the field of bioethics, the definition of ‘death’ in the medical field and issues related to patients who are in a persistent vegetative state (PVS).

In his book entitled “*Culture of Death: The assault of medical ethics in America*”,

⁴ Rothman, D. (1992) *Strangers at the Bedside: A history of how law and Bioethics Transformed Medical Decision Making*, New York: Basic Book

⁵ Engelhardt, HT Jr. (1996) *The Foundations of Bioethics*, 2nd ed. New York: Oxford University Press

⁶ Toulmin, S. (1982) How Medicine save the life of ethics, *Perspective in Biology and Medicine* 25(4): 736-750

⁷ Callahan, D. (1999) The Hasting Centre and the early years of Bioethics, *Kennedy Institute of Ethics Journal*, 9(1):53-71

⁸ Hastings Centre is formally known as the Institute of Society, Ethics and the Life Sciences, which was founded by Daniel Callahan, a philosopher and Willard Gaylin, a psychiatrist. Hastings Centre convened research groups from among its fellows, who were elected from scholars and others around the country and led by a staff member.

Smith, WJ. (2002) argued that a small but ‘influential group of philosophers and health care policy makers’ is working to bring about a culture in which ‘killing is beneficence, suicide is rational, natural death is undignified; caring properly and compassionately for people who are elderly, prematurely born, despairing, disabled, or dying is a burden that wastes emotional and financial resources’.

Criticism on bioethics also came from John Evans (2002) in, “*Playing God? Human Genetic Engineering and the rationalization of public bioethical debate*”, in which he explored the social forces that led to the thinning out of the public debate over human genetic engineering. In his book, he rejected the deep assumption of the Western intellectual that formal rationality⁹ will inexorably replace substantive rationality¹⁰. He instead argued that formal rationality is not historically inevitable or predictive but a culturally constructed product of particular actors pursuing a particular interest.

These books and publications which discussed past ethical issues within biotechnology still stir controversies today or even create new ethical dilemmas regarding modern biotechnology. This scenario shows that opinions and views on bioethical issues are varied. Bioethics has now become more global in its focus and the growth of international bioethics; media attention on bioethical issues is one of the important ways to widen the reach of bioethics.

At the same time, international bioethics can incorporate a range of views from different bioethicists in different countries when discussing the same or different ethical issues or situations; this allow diversification of, the discipline and views among bioethicists which in turn enrich the field of bioethics. On the other hand, there might be less agreement on what constitutes the field and how its goals should be attained, described as ‘*pandora box*’ by Stephen Toulman in an articles entitled “Pandora Box” cited by

⁹ Formal rationality is a type of decision making which is subject to calculation that goes into an action to increase its chances of success.

¹⁰ Substantive rationality is a type of decision making which is subject to values and appeal to ethical norms.

Levine (2007). There are situations in which the problem of medical ethics can take years to resolve before they are rounded up, labelled and properly corralled once they are known to the public.

2.3 Ethics and Reproductive Technologies (RTs)

In 1978, the world's first 'test-tube' baby was born in England, and that made Louis Brown as the first baby born using in vitro fertilisation. This required the fertilisation of the sperm and egg outside the human body, which took place in a Petri dish, in a science laboratory. Some cases involve only couples (usually married), and there may be other cases which involve single or unmarried couples who utilised bodily products or services of third parties (Purdy, LM., 2009).

Among the methods used by the former are artificial insemination by husband (AIH), standard IVF and related technologies of gamete intrafallopian transfer (GIFT) and zygote intrafallopian transfer (ZIFT) as well as intracytoplasmic sperm injection (ICSI) and preimplantation genetic diagnosis (PGD). The methods employed by the latter including AID, IVF and PGD using donor eggs or sperms as well as various forms of contract pregnancy or 'surrogacy'. Since then, nearly one million babies have been born worldwide as the result of various assisted reproductive technologies (Soini et al., 2006).

For more than 30 years after this first birth through in vitro fertilisation, the development of new reproductive technologies (NRTs) has evolved rapidly. However, this advancement has given rise to a variety of social, cultural, legal and ethical responses. New reproductive technologies have diversified, globalised and denaturalised the taken for granted binaries of, among other things, sex/procreation, nature/culture, gift/commodity, biology/sociality and human/non-human (Inhorn and Birenbaum-Carmeli, 2008). Such

challenges indicate that there is much to consider and think through of what is 'new' about these so-called new reproductive technologies.

Ethical aspects of human reproduction and assisted fertilisation are based on respecting life of an individual even before establishing a conception, from pre-embryonic stage, through embryo stage, stage of foetus and a newborn infant (Dragojevic et al., 2008). The new reproductive technologies involve the use of human specimens. This situation raises crucial questions regarding the moral status of this material, such as whether the embryo in the dish in the laboratory is a human person or the foetus in the womb is a human person, and any attempts have been made to answer these questions (Velle et al., 2002).

The debate regarding this status still persists today as views on this topic vary from one group to another. In fact, there is already a huge range of possible permutation of these methods, which have raised new questions about family relationships and what it is to be human. Of late, more options are starting to emerge at the forefront of ARTs such as human cloning, eggs using material from more than one individual and artificial womb (Inhorn and Birenbaum-Carmeli, 2008).

The new form of reproductive technologies (RTs) available today not only allow parents to have children who are genetically related to them, but also give parents the opportunity to select their future children in order to avoid a certain kind of genetic disease; these technologies even allow parents to purposely create another child who will be a positive match to the child who is sick ('saviour sibling'). At the same time, contract pregnancy or '*surrogacy*' also gives women the ability to have children without having to go through the normal pregnancy stages, either by their own choice or due to health issues.

It is evident that the demand for RTs is increasing rapidly. This is probably due to the increasing number of infertile couples, either because of the advanced maternal age or

deterioration in the quality of gamete owing to lifestyle habits and environmental factors (Soini et al., 2006). Touching on the issue of infertility, Soini et al (2006) stated that infertility is a topical problem in gynaecology and regarded as health problem which affects approximately one in every six couples in the Western countries. Nevertheless, in some countries it might not be viewed as a public health issue. Besides, lifestyle habits and environmental factors as well as genetics factors such as chromosomal translocations or sex-chromosomal abnormalities have also been frequently associated with infertility problems in both men and women.

Couples who are unable to have children on their own, either due to infertility or other causes can now opt to use the new reproductive technologies which are available today. At the same time, widespread social values also play a role in promoting the use of ARTs as in some societies; many people believe that having one's own biological children is a natural and important part of human life, especially for women (Soini et al, 2006). Individuals who are in the high- risk group also could benefit from these new reproductive technologies and be able to conceive healthy children of their own. With the emergence of these powerful and sophisticated technologies, parents are now able to select the genetic characteristics of their future children for those who wish to make sure that their future offspring do not carry the defective genes that are can be genetically passed on.

The development of new reproductive technologies can change the reproductive landscape and changing the basic requirement of the notion of procreation. Although it can bring medical benefit to those who need it; parent at risk of giving birth to disabled child, couples with infertility problem or couples who wish to gain control of their procreation, these development excite both huzzas of approval and homilies of despair (Robertson, JA., 1994). According to Soini et al (2006), the attitudes towards NRTs vary substantially not only in the Western countries but also in other parts of the world, due to scientific, cultural

and religious differences. Some of the assisted reproductive techniques are prohibited in some countries or are only allowed for specific medical indications; this situation has forced some couples to travel elsewhere to other countries which allow the application of these techniques in order to gain access to the techniques in other countries where it is allowed.

The opposition regarding the use of ARTs may come from two different groups of people, the conservatives or the feminist groups (Purdy, LM., 2006). Conservative objections mentioned by Purdy (2006) are normally based on the idea that ARTs separate sexual intimacy and reproduction, which could lead to the alteration of traditional relationship between husband and wife, and also between parents and children. On the other hand, feminist groups object to the use of ARTs because it is feared that ARTs would promote and reinforce sexism among the population. Many feminists believe that it is better to eradicate the source of infertility and the underlying sexism especially in extremely patriarchal cultures (Kuhse and Singer, 2009). There are other ethical issues that arise when discussing ARTs including issues related to informed choices, embryo status and commercialisation of reproduction (Shanner and Nisker, 2001).

2.3.1 Artificial Insemination (AI) & egg donation

Assisted reproduction process normally begins with artificial insemination (AI), either using the spouse's own sperm (AIH) or other donor's sperm (AID). Artificial Insemination Husband (AIH) first opened up the possibility of separating sex and reproduction, whereby Artificial Insemination Donor (AID) involves a third party in human reproduction without sexual intercourse (Purdy, LM., 2009).

AI was first administered to humans in 1790 although it was not reported until 1799,

and it was performed (pioneered) by John Hunter. AID per se does not appear to harm the individuals it produces, although it does raise ethical questions about the non-traditional family relationship that the procedure has created. According to Purdy (2009), the ethical issues that arise from AID does not stem from the relationships themselves, but from the lies and secrecy about them. Another underlying ethical issue in the use of donated sperms or eggs is the right of privacy of the donor as opposed to the right of the resulting child to know his or her genetic parent (Zawawi, M., 2010).

At the same time, ethical questions were also raised on the real intention of the sperm or egg donors when they agreed to become donors. One might well question whether it is in the individual's interest to donate eggs or sperms, and not due to coercion or monetary reasons (Zawawi, M., 2010). Nevertheless, eggs market is flourishing in some developed countries such as the US. According to Zawawi (2010), this creates concerns that it theoretically might lead to some marital problems when fathers do not have close relationship with the future children to whom they are not genetically related. Besides ethical issues, AI also raised some concerns regarding the clinical and safety aspect of the procedure. According to Baratt and Cooke (1989), the retrieval of eggs for eggs donation from women's ovaries could pose some medical risks including suspected risk of cancer. However, most physicians are uncertain on the relationship between egg retrieval and cancer as the side effect.

2.3.2 In Vitro Fertilisation (IVF) and other ARTs

Although it has been more than 30 years since the success of IVF among humans, ethical questions and concerns, which were raised at that time, are still being debated today. One of the ethical questions that still remain at the forefront of intellectual discourse on

IVF today is the moral status of the embryo created during the procedure. For those who confer the same moral status to human embryos as to children and adults, they believe that the destruction of living embryos for research is immoral and necessary right to life (McMahon et al, 2003). The ethical and legal status of human embryo has long been a core ethical concern in RTs, including IVF. The range of legal definitions of embryo includes embryos as persons, embryos as property or objects and embryos as a unique category (Shanner and Nisker, 2001).

According to Shanner and Nisker (2001), all major religions, attach special meaning to embryo although significant disagreements exist about the details of embryo status. Differences in terms of their definitions on the moral status of embryo also contribute to their perception of IVF and other kind of RTs. The Vatican considers embryo as persons from the moment conception happens, therefore, rejecting the use of IVF as it separates sex and reproduction (Shanner and Nisker, 2001).

For Protestant Christians, consideration of personhood can vary widely, from time of conception to time of birth. Meanwhile, the conservative and Orthodox Judaism attach a great significance to embryos after 40 days of conception (Nikolaos, M., 2008). According to Islamic belief, ensoulment only happens after the 4th month of gestation, therefore, considering embryo as a person after 120 days of fertilisation (Serour, GI., 2008).

Women's consent might also raise another ethical question specifically on feminist grounds because sometimes, women feel pressured and are forced to opt for IVF or any other RTs (Warren, MA., 1988). This might be mainly due to societal pressure or family pressure, that as a woman, one needs to be able to give birth naturally to your own child. The thought of being labelled as barren is so great for some women that they are willing to undertake IVF or other RTs at any cost (Warren, MA., 1988). In addition, Warren (1988) mentioned that in such circumstances, these women are basically compelled by society's

sexism and pro-natalism, causing them to be under immense pressure to go for IVF or other ARTs instead of just getting on with their lives.

Ethical issues on IVF are also related to the increasing chances of multiple pregnancies, which is very risky to both mother and child. In addition, parents are sometimes forced to perform selective abortion to reduce the risk or protect the remaining child, which is likely to increase the chances of losing the whole pregnancy (Purdy, LM., 2009). Multiple pregnancies are always associated with pre-term delivery, low birth weight, congenital malformation, fetal and infant death as well as long term morbidity and mortality of survivors (Fathalla, M. 2001).

Due to these existing risks, some countries which offer IVF have limited the number of embryos which can be transferred into women's wombs; in some cases, a maximum of two embryos are allowed to be implanted. However, the number of embryos implanted inside the mother's womb has also raised ethical debate for some people because implanting more than two embryos should be able to increase the success rate of implantation and pregnancy (Fathalla, M., 2001). On the other hand, some people might disagree stating that implanting more than two embryos would lead to multiple pregnancies and thus, have a psychosocial impact and a heavy burden on the mother to care for more than one immature baby.

Another controversial use of ARTs is in assisting pre-menopause women to have children. Women who have already experienced menopause are able to give birth to children using IVF and eggs donation (Caplan and Patrizio, 2010); this number has been growing for the past decade. These women seek to become pregnant through ARTs, using eggs donation either from family members or strangers. This condition contributes to ethical debate on whether it is suitable to allow these women to conceive when their capability to raise the children might be limited due to their age and physical state. Caplan

and Patrizio (2010) also mentioned that some critics also raised concerns that due to the women's advanced age, they might not be able to take care of their children, physically, emotionally and financially.

IVF technique involves several steps and procedures, which also has been the subject of ethical concern. According to Soini et al (2006), there is evidence that IVF babies have roughly double the risk of birth defects compared with those of normal pregnancies, although different studies produced different results. At the same time, the risk towards women such as those associated with the extraction of the eggs by super-ovulation, and the use of fertility drugs in order to increase the number of fertilised eggs, have also raised some concerns among ethicists. Cases of ovarian enlargement, neural tube defects and congenital malformations have also been reported in connection with the use of fertility drugs (Nor, SNM., 1999). Given all these facts, one might question whether women who undergo IVF fully understand its risk-benefit ratio (Kuhse and Singer, 2009).

In gamete intrafallopian transfer (GIFT), fertilisation is performed in the uterus whereas in zygote intrafallopian transfer (ZIFT), fertilisation is performed outside the woman's uterus before implanting it into the woman's womb. Both of these techniques raised similar ethical issues, which is the identity of the future children, specifically children who are created through eggs or sperms donation. According to Toner (2002), theologians raised concerns that GIFT might replace the role of traditional marriage and family in the future, thus, changing the whole concept of traditional family. At the same time, ZIFT is already considered as controversial because this technique has made Pre-implantation Genetic Diagnosis (PGD) possible, thus giving parents the ability to select their offspring based on their genetic characteristic before implantation (Toner, JP., 2002).

Fathalla (2001) claimed that generally, ethical concerns regarding the use of ARTs cannot be lumped together in one basket. First, there is what he called the 'moral panic',

which he described as direct reactions from the general population when traditional moral beliefs associated with family and reproduction appear to be threatened by perceived dangers. The second ethical concern of ARTs is based on ideology and religious belief that mostly revolve around the moral status of embryos, and this varies widely from one religion to another. In addition, this second ethical concern also includes the sanctity of a family's genetic lineage in some religions including the Islamic faith. Finally, the third ethical concern is based on utilitarian considerations, which are built on utilitarian principles, are about what is best for the society and what is in the best interest of the children.

2.3.3. Prenatal Diagnosis (PND)

The history of modern forms of prenatal diagnosis is not a very long story, but it is longer than most people think as it started around the 1950s, which is about 60 years ago. The idea of prenatal diagnosis through studies of foetal cells in amniotic fluid was already presented in the 1950s. It was inspired by prenatal sex determination that was performed by Danish researcher Fritz Fuchs (Macer, DRJ., 1998). The intention of PND is to provide expecting parents with genetic information regarding their unborn children in order to rule in or out foetal anomalies and genetic disorders; at the same time, parents are given the opportunity to modify pregnancy management or post natal care.

However, ethical principles are intertwined with prenatal genetic testing. This situation has caused those who are seeking and providing this testing to often be faced with critical decisions and ethical dilemmas. When performing prenatal diagnosis, patients are not only exposed to a certain amount of risk but they are also faced with dilemmas when supplied with the results of the diagnosis (Modell, B., 1990). At the same time, opting for

prenatal diagnosis also puts the foetus in a dangerous position because spontaneous abortion could happen due to the invasiveness of the procedure itself, such as chorionic villus sampling (CVS) or amniocentesis (Pauker and Pauker, 1977).

A conflict or dilemma arises from PND when a pregnant woman is faced with problematic test results. It places her in a position where her wish to give birth and raise a cognitively, mentally and physically healthy child, is confronted with test results that might provide something different. She is in a dilemma whether to terminate the pregnancy and bear the thought of killing another human being or face long -term commitment of having to raise the child who will require her devotion more than she might be able to give (Purdy, LM., 2009).

From the ethical point of view, biotechnology caused evoked both a shift of natural borders and a crossing of natural borders, which sometimes transformed biotechnology into a technique of selection, thus forcing individuals to make tough decisions (Hildt and Fischmann, 2011). Moral conflicts or dilemmas may come from making a ‘simple’ decision such as whether to go for PND, or opt for termination of pregnancy (TOP). When one talks about PND, one cannot avoid talking about the possibility of TOP, either spontaneously or planned, which is a decision to be made after getting the results. However, women reproductive right in regard to their decision on TOP might collide with different religious and philosophical views on the moral status of foetus. The ethical questions of when a foetus becomes a human being, and has all the rights of a born human being, will necessarily arise when it comes to making decisions related to TOP.

Each religion, be it Islam, Christianity, Buddhism or others, will each evaluate its decision based on the utilitarian or deontology point of view; hence, decisions on PND or termination of pregnancy will have different outcomes depending on the point of view taken (Hidlt and Fischmann, 2011). At the same time, these viewpoints might also portray

how different people handle and cope with their situations. Although decisions before or after going through PND are made voluntarily on the part of individuals, society can also influence the individuals in making these decisions (Macer, DRJ., 1998). Opponents of PND believe in the preservation of life. Therefore, they claim that until cures for genetic diseases are available, terminating the lives of inflicted foetuses will remain prevalent within our society (McLean, S., 1997). In addition, McLean (1997) in her articles mentioned that, for the opponents of PND, terminating foetuses is not a substitute to finding cures for genetic diseases. Instead, it leads to other ethical issues and concerns such as selective breeding, eugenics and value judgments.

However, there are also people who favour the use of PND and agree that it should be made available to foetuses with severe abnormalities. Some believe that having a child with a severe genetic disorder may bring the mother or family distress, psychological harm, emotional harm and suffering, the loss of a child, loss of opportunities, loss of freedom, isolation and costly financial expenses (McLean, S., 1997).

Prenatal diagnosis also poses another ethical and moral concern regarding one aspect of the testing, which is the possibility that the tests may yield false positives or false negatives results, or simply fail to provide the certainty that would be helpful in deciding how to act in response to them (Purdy, LM., 2009). Some techniques in PND are highly reliable but others merely suggest a higher than average probability of a given condition. This situation can particularly burden women as they need to make decisions based on the test results. Additionally, it also raises moral concerns that when the testing yields false positive or negative results, it could lead to undesirable situations, which are the terminations of healthy children or the birth of severely ill children, which the couples want to avoid.

2.4 Preimplantation Genetic Diagnosis (PGD)

Preimplantation genetic diagnosis (PGD) was developed as an alternative to prenatal diagnosis (PND) and possible terminations of affected pregnancies for couples at risk of passing on serious genetic diseases to their children (Braude and Flinter, 2007). PGD has been available since 1990 for testing aneuploidy in low prognosis infertility patients, and for single gene and X-linked diseases in at-risk couples (Robertson, JA., 2003). Initially, PGD was used to select against embryos carrying mutations for severely disabling and usually causing lethal monogenic conditions that have complete penetrance and often paediatric onset (Klitzman, R., 2008).

However, with the development of modern genetic technology, the use of PGD has changes. Today, the use of PGD includes the following: detecting mutations for susceptibility to cancer, detecting late onset disorders like Alzheimer's disease, gender selection, and hematopoietic stem cell transplants to ensure that the child born is free from disease and is a good match for the existing child (Robertson, JA., 2003). However, the emergence of PGD has also contributed to the rise of old and new ethical dilemmas such as the moral status of the embryos, rights, commodification of children and designer babies.

According to Hershberger and Pierce (2010), since the inception of PGD, there has been considerable interest in research that helps to address the impact of new genetic reproduction technologies such as PGD that alters the basic human elements of reproduction and genetics. They added that such research by scholars from different disciplines is essential to understand how the merging of genetics and advances in reproductive technologies affect the lives of individuals, couples, families and society. The review paper by Hershberger and Pierce (2010), listed quite a number of qualitative researches performed in different countries in regard to the use of PGD for various medical

conditions. These are found to be important and beneficial to both scientists and clinicians as they attempt to understand further new technologies in order to provide accurate and relevant information to the public.

Longstanding issues that have always been a matter of debate are the ethical and clinical aspects, and challenges posed by the use of PGD as well as the attitudes of different groups of people towards those issues. Opinions and views regarding ethical issues of PGD are varied as they are shaped by different factors such as cultural values, religion and professional duties. This sometimes can create overwhelming stress for couples, parents or families when making reproductive decisions. Most early research focused on the acceptability of PGD among potential or actual users of PGD. The researchers investigated the attitudes and, experiences of couples, parents and medical experts in relation to PGD (Kalfoglou et al., 2005). Previous qualitative research also included the attitudes of respondents when discussing sensitive topics such as the moral status of the embryos, attitudes of respondents about the use and regulation of PGD (Kalfoglou et al, 2005) and views and opinions on PGD among BRCA (BRest CAncer) gene mutation carriers on the use of PGD for hereditary breast and ovarian cancers (Menon et al., 2007).

2.4.1 Ethical aspects

The philosophy of PGD is to provide couples who are at high-risk of transmitting an inherited genetic disorder to their future children, with the alternative and assurance of having selectively healthy or unaffected children. The emphasis is on the provision of life for new children who may otherwise never have been born (Fasouliotis and Schenker, 1998). This is one of the great advantages of PGD for couples that want to avoid the

implantation of defective embryos and eliminate the need for future termination of pregnancy. PGD provided couples at risk of transmitting defective genes to their future children to avoid the transfer of the genes as well as abortion because affected embryos are detected before the implantation of the embryo. However, this has raised ethical concerns that the technology might change the natural concept of human reproduction and lead to societal change in terms of how society views people with genetic diseases or disabilities (Petersen, TS., 2005).

There are two sets of objections that make this technology and proposals for its extension controversial, which have led to the rise of several ethical concerns. According to Robertson (2003), the first set of objections arises from the need to create and select embryos based on chromosomal or genetic grounds, where the unselected embryos are usually discarded. The second set of objections is concerning the selection process itself. He added that the debates on the use of PGD give rise to issues such as the moral status of the embryo, issues on rights of the parents or the rights of the embryo, sexism and also the controversial topic of 'designer babies'. In addition, the capability of PGD to create another child for the sole purpose of saving another child's life by donating his or her cell, gives rise to another concern regarding the possible misuse of the technology.

The researcher will discuss further the ethical issues and shall try to explain why the selected issues raise so many concerns and debates, leading to ambiguous feelings among different groups of people. The discussions will start with issues on the moral status of embryos and of the sanctity of life, issues of justice and rights of the parents, issues related to sibling donors via PGD, ethical issues and concerns on sex selection using PGD, and finally issues regarding 'designer babies'. Through the information conveyed, it is the researcher's aim and hope that readers will be able to understand better all the controversies surrounding the issues of the role, reason and ethical arguments in PGD.

2.4.1.1 Moral status of the embryo

The discussion on ethical issues will begin with the moral status of embryo by stating the position of those who believe that the embryo is a representation of human life, and thus disagree with the notion of discarding it through PGD. This will be followed by discussion on the position of those who have liberal responses to the issue of the moral status of embryo, and the reasons behind their stand will be presented. Due to these differences, the debate regarding the moral status of embryo can be a difficult and sensitive issue; the foregoing disagreements will be examined. Discussion will also cover how the views on the moral status of embryo relate to other issues including reproductive rights, sibling donors, sex selection and eugenics technology.

Those who opposed to the destruction of embryo displayed their support to both of the objections because it has direct effect on embryos. In the selection process, several embryos are discarded because they are unfit for implantation. Thus regardless of the reasons for selection, the consequences towards deselected embryos are the same. The embryos end up being destroyed when parents make their decisions.

Previously, high-risk couples would have to go for prenatal diagnosis (PND) to perform genetic testing in order to know the medical conditions of their unborn child. PND, as well as PGD, have also been closely linked to the heated issue of abortion. Until 1967, abortion was considered illegal in almost all Western democracies except Sweden and Denmark (Singer, P., 1993). Few years later, a few countries also liberalised their abortion act in order to make it less stressful for those who really need to undergo abortion.

Abortion and destructive embryo experimentation pose difficult ethical issues because the development of human beings is a gradual process (Singer, P., 1993) where each stage of the development represents different meanings to different groups of people.

The arguments against the status of embryo normally centre on issues, which include whether the foetus is real, whether human hood or personhood is immeasurable, the notion of equal protection to include disabled individuals and prolife choice where there is compassion towards the individual foetus regardless of its handicap (Fasouliotis and Schenker, 1998).

However, these opinions vary from one person to another based on their own beliefs or understanding of the definition of human life. According to Singer (1993), the central arguments against abortion or destruction of embryos if put in a formal argument format, would go something like this:

*“First premise: It is wrong to kill an innocent human being
Second premise: A human foetus is an innocent human being
Third premise: Therefore, it is wrong to kill a human foetus” (pg138)*

The response from those who oppose the idea of abortion or destruction of embryo would agree with the second premise. For this group of people, embryo does represent a person who is not only innocent but deserves to be protected just like any other full-grown human being. Using the excuse that PGD only involves destruction at a pre-embryonic stage and is therefore not a human being is unacceptable to those who agree with the second premise. The opinions of this group are hard to change because of their conservative beliefs or upbringing that normally centres on their religious understanding of when life begins (Singer, P., 1993).

According to Singer (1993), the conservative group challenged the liberal group to pinpoint, where along the gradual process, from the moment of fertilisation to the point the child is born, that marks a morally significant dividing line. This dividing line refers to a ‘visible’ line where one can decide whether the embryo is considered an innocent human

being. If there is no such dividing line, the conservative group believes that there are two options: to upgrade the status of the earliest embryo to that of a child or to downgrade the status of a child to that of the embryo. It is more acceptable to agree with the former view rather than the latter as no one would want to allow children to be dispatched on the request of their parents (Singer, P., 1993).

One of the main reasons that resulted with the rejection of PGD is based on religious conviction on life. The term 'sanctity of life' has always been used to refer to the sacredness and holiness of human life, which demands that life, should be treated with respect. According to Christian belief, human life begins as soon as the fertilisation process happens and to disrupt this process, amounts to deliberately choosing to end an innocent human life, which is unacceptable (Cole-Turner, R., 2003).

Based on this understanding, most Christian people view embryo as a human being, which 'draw a line' between what is acceptable and unacceptable with respect to the legitimate role of science in assisted human reproduction (Doolin and Motion, 2010). According to his study, the findings of Doolin and Motion (2010) showed that participants who believed that embryo has the same status of a full-grown human being, disagreed on the destruction of these embryos during the process of PGD. They were perturbed by this act as embryos are discarded or flushed away just because potentially, there might be something wrong with them. Other religions such as Buddhism & Islam also have their own beliefs and stand regarding issues related to the moral status of embryo. According to Buddhism, embryo is considered as a human life because Buddhism views human life to begin when the conception happens; thus technically, the moral status of an embryo is moral status as that of a human being (Roberts, M., 2009). However, the Jewish and Islamic religions believe that newly fertilised embryo has no moral status as it does not

carry any soul at such an early stage until after 40 days of fertilisation for the latter, and 120 days for the former (Kerridge et al., 2010).

It is worth noting that some disagreement on the destruction of embryo during PGD selection process is not due to reason that the embryo is having the same moral status as that of a human being, but based on viability. This mean, embryo has the potential to develop into a full-grown human being and therefore, we should not disturb the developing process but allow it to develop naturally. According to Singer (1993), some of the opponents of PGD argued that their opposition towards PGD and the fact that several embryos are being discarded during the selection process is not due to their religious beliefs. Instead, Singer (1993) claimed that the basis of their objection is because parents are destroying potential lives that might have something wrong with them after birth. Using this statement, he argued that equating the moral status of embryo to that of a potential human being is a stronger argument because it cannot be denied that embryos or foetuses are potential human beings.

However, it differ with those are of the opinion that embryos do not have any moral status, the act of selective abortion or discarding of defective embryos through PGD is viewed as acceptable. In fact, it could help couples to avoid the task of having to raise severely sick or disabled children. In addition, allowing the birth of severely defective children could cause more injury and suffering to the children, and could even lead to suicide (Savulescu and Kahane, 2008). According to Savulescu and Kahane (2008), the relevant moral principles that underlie these widely accepted opinions are not that we should have healthy children, but that we should have children who could have better lives. It is deemed important to care about the potential wellbeing of the future children.

At the same time, PGD could help parents avoid the hassle of having to go through one or several terminations of pregnancy or selective abortion when the child is diagnosed

with defective genes. Some individuals are more reluctant to discard an older foetus compared with a few days old embryo because the latter is less developed (Ehrich et al, 2007). This view will change as the embryo develops further with more body features and vital organs. Ehrich et al (2007) called it the gradualist approach where the view regarding the moral status of embryo changes significantly as it develops further. Proponents of the gradualist approach would have no problem accepting the use of PGD because the discarding of embryos in PGD only involves embryos that are a few days old or also known as the pre-embryonic stage. For this group of people, a few days old embryos hold very limited moral status compared with a few weeks old foetus (Enrich et al., 2007). Therefore, they opine that PGD is ethical and permissible for those who need it.

However, the limitation of rights and status of the embryo do not mean that it should be handled without care. Ehrich et al (2007) showed in her study that individuals who hold this approach do think and believe that the embryo does require some respect throughout the handling and discarding procedures. Additionally, the study also indicated that most medical staff working in the field of reproductive technology are more reluctant to terminate a few weeks old foetus compared with just a few days old embryos. The cells that will eventually become the proper embryo are at this stage indistinguishable from the cells that will become the placenta and amniotic sac. Furthermore, medical experts claimed that up to about 14 days after fertilisation, we couldn't even tell if the embryo is going to be one or two individuals. This is because splitting can take place, leading to the formation of identical twins (Singer, P. 1993), and this stage is medically known as the primitive streak.

Generally, individuals who build their perceptions on PGD are principally driven by their views on the moral status of the human embryo, and two different outcomes are possible. The first group would agree on the use of PGD as they view embryo as not

having the moral status as that of a full-grown human being. On the other hand, the second group would disagree on the use of PGD because of the possible consequence towards embryos, which they view as having the same moral status of a full-grown human being. Those who favour the former view also argue that since prenatal diagnosis is general widely accepted, there is no reason to single out PGD and ban it (Penning et al., 2002). Those who believe in the latter view are, normally people with religious conviction, who view embryo as a focal point for profound concerns about human dignity, identity and manipulability (Cole-Turner, R., 2003).

2.4.1.2 Reproductive rights

Reproductive rights have given parents the right and flexibility to make clinical decisions in regard to their reproductive decisions based on the choices available to them. Respecting individual autonomy rights has been strongly practised within the Western tradition and has established its position in Western bioethics (Zeiler, 2004). According to Zeiler (2004), the importance of reproductive rights has been frequently raised and emphasised in arguments relating to prenatal diagnosis. This is because parents and doctors might have different views regarding the situation, leaving both parties frustrated.

The expanded uses of PGD have raised discussions related to the issues of individual or parental reproductive rights. At the same time, there are on-going discussions on the right of the unborn child, from groups who believe that individual rights should also be extended to include the right of the unborn child to live. There is mixed feelings about the issues of rights and PGD among different groups of people. The discussions on rights are normally centred on either the rights of the parents to select their unborn child via PGD or whether the unborn child has the right to live or if it has any rights at all.

In PGD, parents are given the right to decide whether to use the technology, and to decide what to do with the remaining embryos that are in healthy or unhealthy condition. Parents have the right to decide whether to preserve the remaining healthy embryo for future use, donate the unhealthy or unused embryos for medical research, or destroy the remaining embryos. At the same time, parents who are susceptible to transmitting the defective genes to their unborn child are also no longer clueless on whether the child will be affected.

PGD not only increases the reproductive choices of parents, but it also provides them an alternative to do something in the best interests of their unborn child; for example, stopping their newly born child from being affected by inherited genetic disorder (Green, RM., 1997). In his articles, "*Parental autonomy and the obligation not to harm one's child genetically*", Green argued that parents not only have the rights to autonomy regarding their reproductive decisions, but they are also the best protector of their children's best interests.

In addition, Petersen (2005) also found in his study that parents do express their concerns on the possible future of their offspring when making their reproductive decisions in regard to PGD. This situation conclusively leads them to favour what is fair or right for the child's future, rather than fulfilling their own desires. Therefore, it can be seen that parents do not only try to exercise their rights to choose, but at the same time they make sure that their final clinical decisions regarding the use of PGD will give maximum benefit to their unborn child.

In a study conducted among women who have breast cancer, had breast cancer or are susceptible to breast cancer, Quinn et al (2009) showed that women with susceptibility conditions do feel that it is their right to make sure that their future children are free from the disease. According to the study, some women were concerned about passing on the

mutation to their children and felt that PGD was an acceptable option for BRCA1/2 (cancer gene) carrier. The study also showed that some of the women would feel guilty to give birth to a child who has possibility of getting affected with the disease. This forced them to search for other reproductive choices like PGD. The women felt that it is their right to make sure that they do their best in order to provide the best for their children, and this starts with making sure they are born healthy.

Previously, according to Savulescu & Kahane (2008), parental rights are not only concerned with their obligation to heal their sick child, but they also include the obligation to enhance the child's health in order for the child to enjoy the happiest time in life. He added that 'health is not intrinsically valuable', but only 'instrumentally valuable', a 'resource' that allows us to do what we want. Thus, parents are morally obligated to genetically modify the genes of their future children (Savulescu and Kahane, 2008).

The use of PGD for susceptibility conditions has created a strong and controversial ethical debate (HFEA, 2005) on whether it is necessary to allow parents to undergo such procedure in order to make sure their future offspring are free from diseases that might or might not manifest through the children. The increasing reproductive choices in reproductive genetic technologies have led to some doubts about the unequivocal benefits of these choices in general, and create awareness that multiple reproductive choices might be morally problematic rather than morally beneficial (Scully et al, 2006).

It has also led to the realisation that increasing awareness of parental rights and the need for them to practise their reproductive rights could collectively lead to the 'slippery slope' of PGD (Ehrich et al., 2007). At the same time, increasing parental rights raised concerns regarding the possibility of abusing the technology because parents are no longer confined to restrictions on what they should and should not do. This might lead to unintended consequences, and sometimes 'impossible choices' (Kerr, A., 2004).

However, with the increase of parental reproductive rights, a medical practitioner's responsibility sometimes gets more complicated due to potential tension and misunderstanding between the doctor's professional advices on what would be best for their patients and parents' wishes (Bredenoord et al., 2010).

The notion of reproductive rights creates fears that PGD might lead to the misuse of the technology by parents who want a child with a specific genetic characteristic or specific medical condition. PGD can allegedly be misused by putting pressure on people to select against embryos that do not have severe genetic diseases (Peterson, TS., 2005). One example is in the case of Duchesneu and McCollough, where they requested for PGD in assisting them to have a child who will be born deaf, just like the both of them (Savulescu, J., 2002). Sharon Duchesneau and Candy McCullough both considered deafness as a cultural identity and not a disability to be cured. Their decision is not unique to deafness alone, because people with a particular disability may wish to have children like them, such as dwarves who may wish to have dwarf children (David, DS., 2001). Their decision, which was published on BBC News Online on 8 April 2002, caused widespread condemnation, and they were accused of deliberately causing disability to their child even before he was born. According to David (2001), this event has raised questions on the initial purpose of using PGD.

If parents are allowed to use PGD to purposely produce a disabled child, it might lead parents to request to use PGD for a trivial reason (Baruch, S., 2008). However, exponents of individual rights believe that the choice of parents to produce a deaf child like themselves is acceptable because of their strong commitment to the wellbeing of their child and the rich culture of the deaf community, which according to Baruch (2008) is a culture and community united by sign language. Contrary to this statement, there are others who disagree with the notion of purposely causing disabilities to future offspring. This is

because regardless of how committed the parents seem to be to their unborn child, their action to purposely cause a disability to their child by making them deaf or becoming dwarfs like themselves remains unjustifiable (Petersen, TS., 2005).

The increase of reproductive rights of parents can cause a dilemma to medical staff when patients request for PGD and want to use it to produce a child free from adult onset conditions such as Alzheimer or Huntington disease. In 1999, PGD was used to help a woman who was a carrier for an early onset of Alzheimer's disease, to give birth to a healthy baby girl who is free from the condition (Verlinsky et al., 2002). She was tested positive for the defective gene through predictive testing of a family with a history of early onset of Alzheimer's disease, which reportedly affects adults in their 30s. Late or early onset condition is categorised as a high penetrance medical condition.

This means if a person is tested positive to having the mutation gene, he or she is highly likely to contract the disease in some stage of their life without knowing when the first symptom will show up. The ethical issues that were raised in such situation is whether it is right to allow the parents to go for PGD when it is clear that they would not have the physical and mental ability to raise the child in a few years time and whether it is right for medical practitioners to allow these parents to undergo PGD knowing that their life span will be shorter (Robertson, JA., 2003).

For the proponents of individual rights, they argued that the decision whether to use PGD for this purpose is the sole right of the parents. For those who oppose the sole rights of the parents, they argued that we should think about the rights of the unborn child as they also have the right to be raised by both of his or her parents (Robertson, JA., 2003). The ability of the parents to raise the child is being questioned, knowing that their medical condition will deteriorate as they age.

The loss of both parents might affect children emotionally and psychologically because they have to grow up as orphans or as young children who have to watch their parents suffering. At the same time, Robertson (2003) mentioned that some critics argued that it is unnecessary to disallowing parents with late onset condition from having children using PGD. They argue that trauma of losing a parent through death or illness does not make life so miserable, and does not justify the decision to forbid these parents to have children. Some believe that the essential ethical question that should be asked is not with regard to the patient but on the part of medical practitioners when patients request for PGD (Towner and Loewry, 2002). The decision of medical practitioners who decide to offer help to these patients to have children, knowing that they are at risk of have premature death, is raising ethical concerns.

Alternatively, medical practitioners argue that the decision to allow these parents to go for PGD does not rest with the medical practitioners but is entirely up to the parents. This situation triggered off a debate associated with the reproductive rights of parents in regard to their own reproductive decisions based on the available reproductive choices. However, Wolf et al (2003) argued that using PGD to avoid early onset of illness in a child would be widely acceptable because the screening of the embryo will reduce the chances of parents having a child affected by the disease. This will avoid the traumatic experiences of having to go through a termination of pregnancy (TOP) when the child is tested positive with the disease.

Reproductive rights also led to the rising ethical concerns of increasing intolerance towards people with disabilities or people who have inherited genetic diseases (Petersen, TS., 2005). When choosing to use PGD, parents normally have made the decision to give birth to a healthy child, instead of a child who might suffer from genetic disabilities. This has led to the rise of society concerns on further discrimination towards people with

disabilities or parents who have children suffering from genetic diseases or disabilities (Childress, KD., 2003). Although parents' intention to use PGD is not to discriminate children with disabilities but to make sure their future child is free from some kind of genetic disorder, some argue that regardless of any reason, parents are already showing discrimination by performing the act (Robertson, JA., 2003).

According to Krahn (2007), increase of reproductive rights could have a huge effect on the structure of the global healthcare system as well as the market for cures, where there will be little incentives for pharmaceutical companies to develop drugs to treat conditions, many of which are eliminated by PGD. Particularly, wealthier families will likely be the first to have widespread access to this expensive technology. However, restricting the rights of the parents to decide is not only a violation of their rights, but it also encourages them to seek PGD elsewhere where the use of PGD is more liberalised (Krahn, T., 2007).

Conclusively, reproductive rights of parents to decide whether to use PGD can be viewed as having positive and negative consequences towards the society and also the parents involved. On one hand, reproductive rights have allowed parents to make decisions regarding their reproduction. On the other hand, the increased rights of the parents to decide could also give rise to a number of concerns and complications toward the future society. It is feared that the increased rights of parents would lead to the misuse of this technology when parents start to make various demands in order to have the 'perfect' child that they desire.

2.4.1.3 Creating a sibling donor using PGD

According to Liu (2007), one of the latest and controversial uses of PGD involves selecting embryos with a specific tissue type in order to have a healthy child who will act

as a donor to an existing sibling, who requires a haematopoietic stem cell transplant. Based on Liu's articles (2007), PGD for a sibling donor involves two phases: PGD is first used to select embryos that are free of a familial genetic disease, and it is then used to screen for embryos that are a tissue match for an existing sibling who carries that genetic disease and requires a cell transplant. Before the emergence of PGD, the only option for parents was to conceive the child through the traditional way. Sometimes, parents had to go through several times of termination of pregnancy (TOP) when the child conceived was tested positive to have the same genetic disease as the other child. Therefore, PGD provides an alternative for these parents while enabling them to avoid going through TOP.

Using PGD for sibling donors has led to ethical concerns of treating children not as a gift but more as a commodity and instrument in order to get what they need (Spriggs, M., 2002). Children are akin to manufactured goods that are created in a production line to fulfil the demands from customers (Boyle and Savulescu, 2001). However, just like other uses of this technology, PGD for sibling donors also creates ambiguous and conflicting views among parents, medical professionals, religious organisations and society because of the ethical issues that arise from it. Among others, treating children not as a gift but as commodity, debate regarding individual rights, issues related to using children as an instrument rather than for who they are and psychological effects to the created child are some of the frequently mentioned ethical issues in arguments about sibling donors using PGD (Sheldon and Wilkinson, 2004).

According to Hashiloni-Delov and Shkedi (2007), there are already several objections to the use of PGD in general. However, the use of PGD for sibling donors raises more specific concerns that relate to the possible changes it can bring to the traditional family relationship between children and parents. When discussing the use of PGD for sibling donors, Hashiloni-Dolev and Shkedi (2007) stated that the frequently asked

questions include, what can families rightly expect of their future children? Are the family's present needs synonymous with those of the future child, or do they conflict? Should it be permissible to create a child not merely for her own sake but to save the life of another child? Or what unique emotions may the relationship between the futures siblings involve and finally, if the transplantation fails, whether the donor child will still be loved. These questions further led to continuous discussions and debates on the use of PGD for sibling donors.

Despite these ethical objections and questions, PGD for sibling donors does have an advantage, which is to save lives. Children have been conceived to provide stem cells for their siblings even without the use of PGD. For example in the case of Ayala, Marissa was conceived in 1989 to provide stem cells for her sister, Anissa (Boyle and Savulescu, 2001). In this case, both children have grown up and become healthy young women. There are other cases where parents have used PGD to conceive the donor child, like the Nash family (Boyle and Savulescu, 2001), where Adam Nash was conceived in 2000 through PGD to be a donor to his sister Molly, who suffered from Fanconi Anaemia. The Whitaker family also used the same technique in 2002, to save their son Charlie who was suffering from Diamond-Blackfan Anaemia (Spriggs and Savulescu, 2002). In Israel, the Harari family had also used PGD to save their son who was suffering from Fanconi Anaemia (Hashiloni-Delov and Shkedi, 2007).

These cases indicate that the use of PGD for sibling donors is acceptable for some parents, at least in the case of regenerable tissues in providing the transplant to their sick child, which is also in the best interests of the donor (Watt, H., 2004). According to Watt (2004), it is morally defensible to take tissues from the child if the tissue is able to save someone whom he or she might become siblings with, someone he or she loves such as in the case of sibling donors. Watt (2004) added that there is nothing wrong with treating a

child as someone who can save someone else's life, providing the child donor is also respected as an end in him or herself.

Those who do not oppose the use of PGD for sibling donors view it as a moral act where another life is saved with the birth of a child. It is not seen as an immoral act of using the child as an instrument for the benefit of the other child (Liu, CK., 2007). It is argued that conceiving a child to save another child is a morally defensible decision on the condition that the operation performed on the future child is beneficial to the existing child (Watt, H., 2004).

Liu (2007) also mentioned that PGD is commonly used and accepted when it is used to save the child from living a life filled with pain and suffering. In addition, Liu (2007) claimed that since PGD for sibling donors also involves screening against a genetic disease, it could be argued that parents do care about the donor child and consider his or her wellbeing. They do not regard him or her as solely a source of stem cell. At the same time, groups that represent support groups for family with genetic conditions disagreed with any attempt to restrict the use of PGD, especially for the range of medical conditions that PGD could help to rectify (Boyle and Savulescu, 2001). This is because banning the use of PGD to create sibling donors will lead to the death of several children who could have been saved by sibling donors through PGD (Sheldon and Wilkinson, 2004).

The use of this technology to purposely create another child to be a cell donor to another existing child who needs it has led to the concern that it might bring a dynamic change to the traditional family relationship. Children are conceived for a reason and are no longer conceived by chance but by choice, depending on the situation that the parents are facing at the time the decision was made (Robertson, JA., 2003). However, Liu (2007) stated that it is worth noting that there are many reasons why parents choose to have children, including fulfilling their desire to become parents or to provide their children

with another sibling. In addition, they may simply wish to have someone to take care of them when they are old. Therefore, it should not be a matter of concern that PGD for sibling donors would lead to a change in the traditional family or husband-wife relationship.

As mentioned by Knopper (2006),¹¹

...Most parents have a broad range of reasons and expectations when they decide to have children, which also instrumentalizes them to a degree, leading some authors to conclude that, as long as the tissues donation would be ethical if performed on an existing child, bringing a child into the world to serve as a tissues donor is ethical if the child is also valued for him or herself.

According to the opponents of PGD in general, the objections towards sibling donors using the technology are based on the thought that children are used to fulfil the needs of others. These children are seen to be valued more as an instrument to accommodate the ends of others, and not valued for who they are (Sheldon and Wilkinson, 2004).

Treating others as means to someone's ends was described in Immanuel Kant's theory of categorical imperative, which is one of the fundamental rules that underlie Western moral thinking. According to Kantian's theory in the second rule of categorical imperative, it states that, 'Act in such a way that you always treat humanity, whether in your own person or the person of any other, never simply as a means, but always at the same time as an end' (Pennings et al., 2002). Based on this theory, Pennings et al (2002) explained that parents' decision to conceive and select a certain embryo would fail to show respect for the future child if their only reason for creating the child was to extract the tissues. Therefore, this theory strengthens the basis of argument from the opponents of PGD regarding their objection to the use of it for sibling donors.

¹¹ Cited from Fasbender, W. (2009) The Savior Child: Having a Child to Save a Sibling. Is this right?, The journal of Undergraduate Nursing Writing, 3(1):pg21

The opposing view on PGD for sibling donors also comes from religious groups where they object both PGD and IVF. They claim that both techniques involve offensive manipulation of human life by changing the nature of these children to fulfil the parents' desires (Dickens, BM., 2005). PGD for sibling donors is not only seen as treating a child as a commodity, but it might also impose some pressure on the created child to donate his or her tissues again in the future when the need arises (Gitter, DM., 2006). Those who oppose to the use of this technology for sibling donors, are not only concerned that children are conceived for the wrong reason but are also concerned about the way these children will be treated by their parents (Sheldon and Wilkinson, 2004).

The second objection against permitting the deliberate creation of sibling donors is that to do so would be to step onto a slippery slope towards allowing 'designer babies' (Sheldon and Wilkinson, 2004). Currently, the use of PGD for sibling donors is allowed on a case-by-case basis. However, as explained by Sheldon and Wilkinson (2004), the reason to use PGD might change in the future, and it might be the start of what they called, 'slide down' the 'slope' towards permitting the selection of embryos on wholly frivolous grounds.

In support of Sheldon & Wilkinson's explanation on 'slide down the slope', Gitter (2006) added that expanding the frequency and scope of genetic screening on prospective children would move us towards a eugenic world. Thus, this situation might usher us into the world of 'designer babies' where the use of genetic engineering for future offspring becomes a norm. Allowing parents to choose their future offspring based on their genetic characteristic could lead to higher demands from parents where they might request the use of PGD for choosing a child with their desired social traits and features (Sheldon and Wilkinson, 2004).

However, there is some objection to this 'slope' argument in which critics argue that PGD for sibling donors should not cause society to be permissive about 'designer baby'

(Sheldon and Wilkinson, 2004). As mentioned by Sheldon and Wilkinson in their articles, this is because those who propound the empirical slippery slope argument rarely support it with hard evidence but merely speculate that it is the first step towards allowing parents to choose their children based on social traits. Furthermore, currently, strict regulations are imposed on the use of PGD where it is only allowed for certain purposes; thus, the 'slide down the slope' can be averted. In addition, to create a full-fledged 'designer baby', one would need a very large pool of pre-implantation embryos, thus incurring significant additional cost, discomfort and inconvenience to the parents- to- be (Boyle and Savulescu, 2001). Finally, those who oppose the deliberate creation of sibling donors often make claims about the welfare of those children who will be created for this purpose (Sheldon and Wilkinson, 2004). According to Sheldon and Wilkinson (2004), there are two types of ethical dilemmas suggested by the proponents of child welfare objection. They are harm to physical health caused directly by the PGD process and psychological ramification to the donor child, knowing he or she was selected and conceived for the sole purpose of saving another life.

In relation to the first objection, medical experts claimed that embryo biopsy in PGD does not seem to produce adverse physical effects in the short- term, although it is too early to exclude the possibility of long-term effects (Devolder, K., 2005). Based on this statement, it can be concluded that as far as direct effects on physical health are concerned, PGD for sibling donors is no worse off than other children created using PGD. Thus, the argument based on physical health is considered invalid due to inadequate evidence of harm (Devolder, K., 2005).

The second ethical dilemma related to the welfare of the child is the belief that the sibling donor will be psychologically scarred. There are two kinds of concerns related to psychological harm. According to Sheldon and Wilkinson (2004), the first concern is on

the possibility that the created children may suffer psychological harm if they come to know that they were not born for natural existence but to save the life of another sibling. The second concern is related to the children's relationship with their siblings or parents. However, both of these concerns were rejected by Hashiloni-Delov and Shkedi (2007) based on their study on couples who had used PGD for sibling donors. Generally, the discussions concerning the use of PGD for sibling donors show that there are three different opinions: people who agree on the use of PGD for sibling donors, those who totally oppose the use of PGD for any kind of purposes and those who oppose the use of PGD for sibling donors but support its use for genetic testing (Devolder, K., 2005). For the participants from the third group, they believe that genetic testing to detect genetic diseases in an embryo is done in the best interest of the embryo or the person whom it will become, whereas in sibling donor, PGD only benefits the existing child.

Earlier on in this section, it was mentioned that sibling donors using PGD can also have effects and cause changes to the traditional family values because of the nature of the technique. However, views on family values vary among individuals, groups or societies because of the differences in terms of cultural understanding on family values (Hashiloni-Dolev and Shkedi, 2007). These differences can influence their views on sibling donors using PGD. In a study conducted by Hashiloni –Delov and Shkedi (2007), they came across an interesting finding where parents' decision to use PGD for sibling donors in Germany was criticised as being selfish while in Israel, these parents were viewed as heroes who tried their best to do whatever they could to make sure their future child is healthy and free from genetic diseases. The study showed that critics are more receptive in one country compared with another. This proved that individual beliefs and values in regard to family values and traditions do affect their views on issues pertaining to genetic technologies.

Philosophically, different views between cultures and their understanding on the same issue can be explained using Franz Boaz's ethical theory of cultural relativism. This theory suggests that what appear to be patterns or structures in a culture is not a product of a conscious design, but rather diverse mechanisms that produce cultural variation, shaped by the social environment in which people live and act (Rosado, C., 1990). With reference to the study comparing German and Jewish society on issues pertaining to the use of PGD for sibling donors, the findings show that cultural differences do play a part when people form views on sibling donors. These differences were described by Hashiloni –Delov and Shkedi (2007) as one of the reasons why PGD (in general) and PGD for sibling donors (in particular) have been banned in Germany, but endorsed without hesitation in Israel. In general, cultural values sometimes do contribute to how individuals or societies respond to issues pertaining to reproductive technologies.

Conceiving a child by way of embryo selection and tissue matching to benefit a sick sibling is generally justified on the grounds that in addition to the potential to save the sick child, there are benefits for the new baby (Spriggs and Savulescu, 2002). However, we ought to interfere with individual liberty by preventing the use of such procedure for no good reason, using it for the benefit of one individual or for social reasons. According to Boyle and Savulescu (2001), if the procedure of using PGD for sibling donors is accepted, it is reasonable to use PGD to bring a new person into the world and to help save an existing life at the same time.

2.4.1.4 Sex selection

The use of PGD has been extended to not only medical sex selection but also for non-medical sex selection to serve parental preferences in having a healthy child of a

particular gender (Robertson, JA., 2003). Interest in sex selection has a long history dating back to ancient cultures, and methods have varied from special modes and timing of coitus to the practice of infanticide (ASRM, 1999)¹². However, recent development in biomedical technologies has made possible the determination of foetal sex, prior to conception or implantation (Strange and Chadwick, 2009). According to Strange and Chadwick (2009), sex selection using PGD gives couples a better and higher chance of success in conceiving the baby of their desired gender because it is a reliable and effective technology that yields a new zero chance of pregnancy with a foetus of the non-chosen sex.

PGD for sex selection is used to provide information regarding the sex of embryos either as a by-product of testing for genetic disorders or when it is done purely for sex selection (ASRM, 1999). Within the medical and scientific community, some people have expressed the view that sex selection is intuitively acceptable to society. Some patients may feel that if the option is available, and it is possible to achieve their goal, there is nothing wrong in using it (Sills and Palermo, 2002). This option involves the use of PGD to avoid the birth of children with serious genetic disease, if they were born of one particular gender (Robertson, JA., 2003). The presence of serious medical concerns goes some way towards justifying the use of this medical sex selection, and criticisms tend to focus on the use of reproductive technology (RT), rather than the sex selection process itself (Strange and Chadwick, 2009).

However, non-medical sex selection still causes some controversy in society. The central argument put forward is that non-medical sex selection is a sexist practice, which promotes socially restrictive conceptions of sex, gender and family (Strange and Chadwick, 2009). Request for PGD for sex selection comes from two different groups; the first group comprises people who wish to select the sex of their first -born child and the second group

¹² ASRM is also known as the American Society for Reproductive Medicine

consist of those who already have a child of one gender and wish to have a child of the opposite gender. According to Robertson (2003), PGD for non-medical sex selection is seen by some people as a less compelling reason to request for PGD. In addition, he claimed that PGD for non-medical sex selection has received negative criticism from various individuals and organisations because there is insufficient evidence to support the importance of gender variety in a family that justifies the act of creating and destroying embryos for this purpose.

The criticisms against the use of PGD for non-medical sex selection include unnecessary medical burdens and cost for parents, inappropriate control over nonessential characteristics of children, inappropriate and potentially unfair use of limited medical resources for sex selection rather than more genuine and urgent medical needs as well as its contribution to society's gender stereotyping (ASRM, 1999). For the opponents of non-medical sex selection, they believe that performing sex selection basing on personal or social needs, and for the first- born, could lead to imbalance of the world population in terms of sex ratio (Eckholm, E., 2002). Sex selection has become a national crisis in countries such as India and China because of parents' preference for children from one particular gender (Allahbadia, GN., 2002), which has led to gender disparities.

The choice of a particular gender may mean a great deal to an individual or family. However, if this gender preference is fulfilled on a large scale through PGD for sex selection, it may contribute to society's gender stereotyping and overall gender discrimination (ASRM, 1999). Non-medical sex selection only exemplifies sexism because parents place their central value on the children's gender, prior to any physical, social or psychological development, before they even know anything about their future children (Berkowitz, J. and Snyder, 1998). In addition, parents are already stereotyping their children by putting a value on them based on their gender, thus reinforcing possibilities of

unfair discrimination. Zilberberg (2007) added that parents, especially women, would be harmed by widespread sex selection and subsequently continue to suppress the position and status of women in the society. Furthermore, non-medical sex selection appears unjustifiable when weighed against unnecessary bodily burdens and risks for women (ASRM, 1999).

At the same time, Bumgarner (2007) also indicated that PGD for non-medical selection might lead to issues of controlling children characteristics that are perceived as nonessential, and children will be chosen based on these traits before they are implanted. Those who argued against non-medical sex selection believe that choosing future offspring is based on unnecessary characteristics; they used ‘slippery slope’ argument and contended that it might lead to complicated ethical issues of ‘designer babies’ (ASRM, 1999). This concern is not unreasonable in this modern culture with availability of sophisticated technologies; in the past, no one would ever think that fertilisation of human beings can happen outside the body, as in the case of Louis Brown.

However, restrictive legislation that bans all identification and selection of foetal sex in some countries is viewed as morally inappropriate because it imposes restrictions on women’s reproductive rights or the fundamental principle of autonomy (Strange and Chadwick, 2009). Proponents of reproductive rights often argue that as long as the child and parents are not harmed, others have no right to interfere with parents’ choices (www.hgalert.org)¹³. At the same time, some might disagree, saying that it is unlikely that PGD will contribute to the disparities between sexes because it is unlikely to be used widely due to the costs involved and the accessibility of the technology (Savulescu and Dahl, 2000). In addition, Robertson (2003) argued that sex selection for family balancing is

¹³ www.hgalert.org is Human Genetics Alert (HGA). A secular and independent public interest group that is based in London, UK. Until 2005, The Joseph Rowntree Charitable Trust funded the group. Since 1999, the group has been committed to informing people about human genetics issues, and to putting forward clear policies that serve the public interest

less criticised because parents want to have a child that has gender different from that of their existing children. According to Savulescu and Dahl (2000), gender imbalance may not be detrimental to women because there will be increase in influence of rarer gender, reduced population growth and interbreeding of different populations.

2.4.1.5 Eugenics technology and designer babies

Recent breakthrough in the study of genetics and genetic technologies raise the hopes and expectations of many that humans will soon be more able to manage, cure and eliminate diseases of all kinds (Childress, KD., 2003). Genetic research is rapidly progressing into the genetic basics of complex traits like intelligence and the identification of a gene that causes criminal behaviour in one family (Savulescu, J., 2001). According to Savulescu (2001), once the decision to use IVF is made, PGD is just a small ‘cost’ to pay, for couples or parents. They are more inclined to use it to select less serious medical traits, such as a lower risk of developing Alzheimer disease or even for non-medical traits. PGD has enabled parents to select the characteristics of their future children including selecting the gender of their children without the existence of sex- linked diseases in the family history. This has led to increased concerns and fears of eugenics and ‘designer babies’.

Eugenics is the study of selective breeding of humankind that aims to improve human species. The term was used in 1883 by Sir Francis Galton, a cousin of Charles Darwin, who applied statistical methods to the study of heredity (Sandel, MJ., 2007). Eugenics was a popular term in the 20th century but began to have a negative connotation when it was associated with Nazi Germany during World War II. With new developments in genetic reproductive technologies and the emergence of PGD, eugenics has once again been highlighted as it triggers public concern that history might repeat itself.

Advancements in PGD, together with cloning and genetic engineering, have led to a new era of eugenics that is claimed to be the new eugenics.

Basically, PGD is doing what is expected of it, which is to assist parents to conceive a healthy child. However, the request to use PGD has varied, and it is feared that the need for PGD might change from medical to social traits, thus leading to the creation of 'designer babies' (Simoncelli, T., 2003). At the same time, the expanded use of PGD such as for sibling donors, sex selection for non-medical traits, susceptible conditions and adult onset conditions, has further reignited the debate on 'designer babies'. This situation has led to public speculation that PGD is a new form of eugenics that is used for selecting socially desirable characteristics in human embryos (Fasouliotis and Schenker, 1998). In addition, using PGD to allow parents to select their future children has also brought about accusations that it is a tool of eugenics more powerful than any of its predecessors and perhaps more acceptable than any form of PND; thus, it is more alarming (King, DS., 1999). In addition, King (1999) added that some people argued against the use of PGD for genetic selection claiming that accepting the logic of eugenics in the context of PGD would open the door for justifying more controversial practices, such as selecting embryos for cosmetic traits like eye colour. He concluded and believed that if PGD becomes widely accepted and becomes user friendly, it might pose new implications that might cause changes in society regardless of their perception on human reproduction.

The fact that PGD does not involve abortion, as the procedure is done on an embryo rather than an established pregnancy would subsequently put enormous social pressure on parents to avoid genetic disorder and undergo testing (King, DS., 1999). Societal pressure and the widespread use of eugenics or 'designer babies' according to Le Bris (1998), would most likely reduce sympathy for parents who reject the opportunity of using PGD, simply on the ground of wanting to leave things to Mother Nature. This would

lead to the spread of the culture of prevention. She added that this culture would abolish the desire to proceed with the pregnancy because implanting an unhealthy embryo will be viewed as cruel and purposely imposing suffering on the child once it is born (Le Bris, S., 1998).

Additionally, PGD could also weaken the argument related to 'a woman's right to choose' because embryos are created outside the woman's body, thus allowing the decisions over the embryo's fate to be open for intervention from the male partner or spouse, doctors and society at large (King, DS., 1999). This situation creates further dilemma because individuals' views and opinions are varied and may subsequently influence the decisions of the parents. Eugenics also raises concerns that it could lead to the race perfection when parents use PGD to produce a 'perfect child' (Green, RM., 2007). In tandem with the race for perfection among members of society and the current trends in society where cosmetic surgery is increasingly prevalent, and the desire to be better than the rest, Kahn (1997) fears that children might no longer be seen as a gift but as selected products, expressing their parents' expectations, desires and whims. In support of Kahn's claim, Childress (2003) added that unless we become aware of the factors that lead us into acceptance of what amounts to a basic eugenics philosophy, critically examine them, and actively determine at society level the direction we want to take, it seems quite possible that we could be moving into eugenics actions.

The term 'designer babies' also see the emergence of issues associated with discrimination towards people with genetic disabilities. Sometimes, the term 'designer babies' is also labelled as selective breeding. This is because in both situations embryos are selected based on the desired genetics that will give them an advantage over the deselected embryos (Spriggs, M., 2002). Due to this fact, Spriggs (2002) stated that PGD holds the potential for the stimulation of many major discriminatory issues including discrimination

towards people with genetic diseases or disabilities. This will impose further pressure on prospective parents to use PGD to have children without any genetic abnormalities because society already regards disability as a terrible thing (Earnshaw, M., 2003). At the same time, PGD could increase public intolerance towards children who may currently have disabilities or are born with disabilities. The prospect of being able to limit the development and birth of embryos with a wide range of functional physical impairments has led some critics to speculate that PGD might lead to intolerance towards differences, variations and the handicapped (Harper, JC., 2001). Proponents for the rights of disabled people oppose the notion of 'designer babies' because they believe any usage of PGD to obtain the desired child by the parents might eventually end up denigrating or hurting disabled people (Robertson, JA., 2003).

The notion of having the tools to design the perfect child creates high expectations towards prospective parents to use PGD in order to avoid the birth of children with disabilities (Krahn, T., 2007). Therefore, with the emergence of PGD, giving birth to a child with a genetic disease is no longer a matter of chance but a matter of choice. Parents in the high-risk group would feel that they are being judged or blamed when they choose not to use PGD despite knowing the consequences to their child. A situation that once was dominated by fate, has now become a matter of choice, as stated by Sandel (2007) in his book, *The Case against Perfection*,

Whatever one's believe about which, if any, genetic condition warrant terminating a pregnancy (or selecting against an embryo, in the case of PGD), the advent of genetic testing create a burden of decision for parents that did not exist before (p88)

However, the notion that PGD is the next eugenic technology and parents who decide to use it are claimed as trying to 'play God', does not sit right with supporters of individual rights who believe that parents should be allowed to make decisions on their

reproductive choices. According to Dworkin (1996), he argued that there is nothing wrong with the ambition 'to make the lives of future generations of human being better'. For those who support the use of new reproductive technologies (NRTs), they argued that parents should use technology, including PGD to genetically enhance their children's memory, temperament, sense of humour and other characteristics in order to give them the best in life (Savulescu and Kahane, 2008). Proponents of eugenics believe that enhancing a child's capability using PGD is no different than enhancing a child through rigorous education or training because the aim is the same (Green, RM., 2007). Furthermore, from the standpoint of liberal eugenics, neither the training nor education or PGD violates the autonomous rights of the child or hinders the child from experiencing bright future.

However, some people argued that PGD would not lead to the development of eugenics technology. Society need not be concerned because PGD at its present stage is unlikely to make a strong impact in terms of the development of eugenics technology (Fasouliotis and Schenker, 1998). According to Earnshaw (2003), the term 'eugenics' and its association with PGD, is a gross misuse of language that comes easily to those who are uncomfortable with genetic technology. It is thus claimed that modern reproductive technology and eugenics are two different things. Citing Furedi's words in an article written by Earnshaw (2003), eugenics was primarily the product of the late 19th or 20th century years of racial degeneration. In addition to this, Siddiqui (2006) stressed that the potential for abuse of PGD as a tool for eugenics that give rises to the idea of 'designer babies' is not a valid reason to stir up fear and concern, and to deem it as inherently unethical. Additionally, eugenics that parents are searching for through PGD is nearly impossible to create in the genome. It is impossible to use PGD as tool of eugenics to choose desirable traits because most of these traits are controlled by not one, but multiple genes, and this make an optimal gene combination almost impossible to achieve from a

statistical standpoint (Siddiqui, 2006). However, political philosopher, Habermas believes that PGD should remain prohibited or strictly monitored to avoid replay of German dark history with eugenics experiments during World War II (Wilkinson, S., 2008). He added that any use of PGD for genetic testing or medical enhancement for non-medical purposes should not be initiated to avoid any opportunity of misuse of PGD. However, one should not place absolute restriction on parents' rights to decide.

According to Mameli (2006), individuals should also be given the freedom to choose, by claiming that anyone should pursue his or her own perceptions of a good life but, it should be done in a way where we do not impose harm on others. According to Mameli (2006), when parents intervene in the genetic makeup of their future children and decide what they should become when they grow up, parents are changing the child's life history according to what they desire.

It cannot be denied that the availability of PGD today might have a direct effect on family dynamics because it is able to reduce the family's physical, emotional and financial burden of having to take care of a disabled child or children with genetic disorder. However, medical scientists still believe that human gene modification using PGD is just a scientific theory that needs to be thoroughly studied due to the complexity of human DNA (Green, RM., 2007). Additionally, Green (2007) stated that, "We're not close enough to understand the issues to make wise decisions or predict the outcomes." Many molecular geneticists, who work at the forefront of genomic science today, share this view. Those who are concerned that the use of PGD could lead to eugenics technology have every reason to worry, but it should not mean that the use of PGD should be banned altogether. Rather than banning PGD, we should allow the use of PGD under strict regulations that embody the appropriate moral constraints.

2.5 Religious views on Reproductive Technologies (RTs)

Religious elites, operating through organised religious groups, are attempting to influence the popular debate over reproductive technologies (Evans, JH., 2006). One of the reasons for this situation as mentioned by Evans (2006), is because many of these technologies resulted in the death of embryos or foetuses, thus linking this debate to the issue of abortion, which many religious groups have spent much energy trying to influence. Many religious groups are opposed to the use of many of these reproductive technologies, especially the conservative Christians like the members of Roman Catholic churches. On the other hand, more liberal Christians like the Protestants as well as the Jewish groups are not opposed to almost all of the RTs (Evans, JH., 2006). However, other religious groups such as Jewish, Islamic or Buddhist have debated and established their own religious understandings and stands when it comes to reproductive technologies. For example, one of the reasons reproductive technologies are encouraged in the Jewish society is because Jewish religion emphasised the importance of procreating healthy children (Hashiloni-Delov and Shkedi, 2007).

In Islamic religion, reproductive technologies for treating infertility are encouraged to preserve humankind as long as it is done within the frame of marriage (Serour, GI., 2005). Meanwhile, Buddhism generally has no specific opposition to the use of any reproductive technologies. This is explained by its different views on the creation of life, where it believes that the creation of life is not fixed or not an unequivocal process (Frazzetto, G., 2004). This places Buddhism's view on the world and its relationship with mankind uniquely; it is different from the views of other monotheistic religions. In this subchapter, discussions will cover the views of different religions on reproductive

technologies including PGD, based on previous research that has been conducted internationally or in Malaysia.

2.5.1 Islamic perspective on RTs

Islamic scholars often refer to their religious texts for guidance, mainly the Qu'ran, when considering the ethics of reproductive technologies for Muslim couples (Frazzetto, G., 2004). Reproductive technologies that are currently available have opened the way for several other practices including gender selection, PGD, genetic manipulation, cryopreservation of gametes, embryos and cloning (Serour, GI., 2005). These new practices have challenged the old idea of traditional human reproduction and have provoked debate that still continues until today. According to Serour (2005), the teaching of Islam covers all the fields of human activities; spiritual and material, individual and social, educational and cultural, economic and political, national and international.

Until recently, the treatments of infertility were mainly by medication or surgery to correct hormonal deficiencies or anatomical defects. These treatments are mostly non-controversial from ethical and religious point of views (Fadel, HE., 2002). However, with the emergence of new reproductive technologies, the scenario has changed. This is because these new technologies are seen as changing the natural process of human procreation, and at the same time bringing dynamic changes to the traditional family relationship. Fadel (2002) expressed that these changes are not only challenges to the basic human relationship, but they also pose challenges to the basic religion and ethical concepts. In Islam, infertility and its remedy with the unforbidden is allowed and encouraged if it involves preservation of procreation, and the treatment is within the frame of marriage (Serour, GI., 2005). He added that if the use of reproductive technology is indicated as a

necessary line of treatment, it is permitted during the validity of the marriage contract without the mixing of genes. This literally means that when performing the treatment, couples are prohibited from accepting sperms or eggs donation from third parties. Couples should be legally married at the time of the treatment. If the marriage falls apart or when one of the spouses passes away, the remaining process of the reproduction cannot be performed. Thus, the preserved embryos have to be destroyed.

Islam also encourages scientific developments as long as they benefit humankind and do not contradict basic Islamic rulings (Fadel, HE., 2007). Therefore, it does not prohibit the treating of infertility because it is not seen as defiance of God's will. Instead, it is seen as discovery of the truth about the capability of couples to have children of their own (Ahmad, NH., 2003). Islam even allows the use of excess embryos from ARTs treatment, with the consent from the couples, to be used for medical research; this is for purposes of gaining advanced scientific knowledge and benefitting humanity (Fadel, HE., 2007). Moreover, the interests of embryo research also include further improvement of knowledge related to assisted reproduction, the diagnosis and prevention of genetic diseases as well as development of better contraception methods (Ahmad, NH., 2003).

Fadel (2007) explained that the controversies that revolved around the issues of moral status of the child regarding the discarding of unhealthy embryos, is not a big issue in Islam. This is because in Islamic teaching, an embryo at such an early stage is not considered as having any moral status. Furthermore, in Islamic religion, ensoulment of the foetus only occurs after 120 days of conception. Hence, it is generally accepted by most Muslim jurists that the pre-embryo before implantation is not a human being, as it does not have an independent life. However, research on embryo should be limited to therapeutic research. It should not be used for personal gain, and the embryo should not be replaced in the uterus of the owner of the eggs or other women. Islamic law however, forbids the use

of PGD that includes research in changing the genetic characteristics of the embryos, such as sex selection or future social traits (Serour, GI., 2005).

Reproductive technologies such as PGD and other types of assisted reproductive technologies (ARTs) is permissible in Islam as long as the following conditions are satisfied: first, the treatment must involve a married couple; secondly, the sperms must be from the husband and the eggs from the wife; thirdly, the treatment must take place in the context of a valid marriage; finally, the treatment must be conducted by competent teams in order to reduce the chances of failure (Fazzetto, G., 2004). According to Abdul-Majeed Alaro (2010), if the reason for using any reproductive technologies is to cure the couple's infertility or purely for medical reasons, the act is completely permissible provided that no other law of Islam is contravened in doing so. Based on this understanding, ARTs such as IVF, ICSI, GIFT, ZIFT and AI as remedies to infertility are adjudged permissible by Muslim jurists. This is provided that these treatments are not predicated on frivolous medical reasons, and are free from any introduction of a third party donor (Abdul-Majeed Alaro, AR., 2010).

Most Muslim scholars approve the use of PGD. This is because it involves a pre-embryo before it is implanted and is beneficial to the couple involved. For example, PGD can help to prevent the birth of a severely sick child. However, Islam does not permit PGD to be used for sex selection for non-medical reasons (Fadel, HE., 2007). PGD for sex selection in Islam is acceptable only under certain circumstances. For instance, for purpose of family balancing, where the married couple has three daughters and it is in the couple's best interest that another pregnancy should be the last. Hence, it is acceptable that they use PGD to ensure the birth of a baby boy. In this situation, the use of PGD is permissible as the application comes under the sanction of religion; it also helps the family to meet the obligation and saving the woman from increased risk in further pregnancies (Schenker, JG.,

2002). In addition, Schenker (2002) explained that the application of PGD for sex selection should not be encouraged but should be resolved based on particular merits of each case. Islamic perspective on reproductive technologies is firmly grounded on the fundamental tenets of Islamic Law. With the emergence of new reproductive technologies, it provides guidance in moderating the extremes of conservatism and liberalism.

2.5.2 Christian perspective on RTs

Religion and science have been interrelated since the beginning of human history. Nowadays, religious groups still exert influence in the field of reproduction, such as in the areas of prevention and procreation as well as issues such as abortion and infertility treatment (Schenker, JG., 1992). Again, since many of the techniques in reproductive technologies require the destruction of embryos, many religious traditions including Christianity officially oppose RTs on these grounds and try to influence the views of their constituencies (Evans, JH., 2006). Firstly, one must be cognisant that the church does not reject any particular procedure in the new reproductive technologies on the grounds that they are artificial (Alvare, HM., 2002). Rather, the church evaluates these technologies based on the dignity of the human person. Christian (Doolin and Motion, 2010) authorities believe that the fertilisation of both the egg and sperm is a sign of the beginning of life, and thus indicate that embryo has a soul and should not be destroyed. This has become the basis of their main argument regarding their thoughts of when life begins and giving moral status to the embryo the same as that of a full- grown human.

The Roman Catholic Church has explicitly placed a limitation on the use of PGD, thus curbing the reproductive rights of future parents who wish to go for it. The reason is the fact that the technology would result in the destruction of not one but several embryos

(Evans, JH., 2006). The Catholic Church and most Evangelical and Protestant groups imposed limitation on PGD. This is because PGD involves the destruction of embryos or innocent lives as far as the church views are concerned. Such action according to Evans (2006) is drawn into the abortion debate. Due to this view, most Roman Catholic churches oppose the use of any kind of reproductive technologies including PGD (Alvare, HM., 2002). However, for the Protestant Christians, they do not totally oppose the use of reproductive technology because children who are born through this method can spring from love between a man and a woman; it is a deep and intimate relationship of a couple whose reproductive channels bear fruit without any medical assistant (Cohen, CB., 2002).

A biblical defence of the human embryo is based on the idea that human beings are made in the image of God and belong to God. Therefore, no human being should be killed except under very special circumstances (Saunders, P., 2006). The Catholic's traditional belief is unequivocal on the subject of the moral status of the embryo, saying that it is sacred, inviolable & should not be destroyed (Sinclair, K., 2008). In addition, they believe that the soul is present from the moment conception happens. Therefore, to destroy embryos is unacceptable; in fact, it should not be treated any differently from embryonic Christ. From a certain perspective within some Christian groups, the appropriateness of technical intervention in human reproduction such as PGD is often characterised as humanity's hubris in 'playing God' (Doolin and Motion, 2010). This is because they view people as trying to change the natural process of human reproduction when children's genetics are altered using PGD.

Most Christian denominations including the Roman Catholics do not oppose the use of medical technologies that heal and improve the embryo's health because the treatment is in consistence with the dignity of the human being. However, they are opposed to non-therapeutic operations on human embryos. Instead, they call for a moral certainty of

not causing harm to the life or integrity of the unborn child and the mother (Alvare, HM., 2002). Most of the new reproductive technologies impose great risk or involve the deliberate destruction of embryos. This explains the reason why most Christian groups are opposed to reproductive technologies, especially when they are used for non-therapeutic purposes. The destruction of embryos occurs during the selection process when parents choose embryos based on certain genetic characteristic, which they believe will be in the best interests of the unborn child.

However, destruction of human embryos also happens when a large number of embryos have been implanted in the woman's womb, and more than one begin to develop. In this kind of situation, Alvare (2002) mentioned that doctors sometimes advise that certain number of the developing lives be aborted or selectively reduced for the benefit of the child. The theologically liberal Catholics are inclined to agree with the Catholic Church that the use of third party genetic materials violates the sanctity of the marriage covenant. Some fundamentalist Protestants even deems it as tantamount to adultery (Greil, AL., 1989).

It is worth noting that not every possible use of new reproductive technologies is justifiable and accepted within the circle of Protestant believers. For the Protestant Christians, parents are seen as the procreators rather than creators of their children. This means that children are entrusted to parents; children are not parents' possessions, products or some projects that they can do whatever they wish (Cohen, CB., 2002). According to the Protestants, children should be accepted as a gift and cherished as a person that has integrity and dignity. Children are not tool that parents should use to gain some sort of identity within the community. According to Cohen (2002), Protestants maintain that it is wrong to use any kind of reproductive technologies to purposely alter the biological features of children, as made- to- order children have been shaped to fulfil arbitrary

parental and societal standard of beauty and perfection. He added that it is feared that such act will lead to discriminatory and harmful stereotypes that already exist in society. Subsequently lead to possible eugenics movement among such perfectionist parents.

2.5.3 Buddhism perspective on RTs

In Buddhism, the beginning of life is at conception when stream of consciousness from a previously deceased being enlivened an egg in the process of being fertilised (whether in the womb or in an IVF test tube) (Sinclair, K., 2008). The question of when the developing embryo ‘becomes a person’ is not really an issue. This is because Buddhists believe that an embryo at any stage is considered alive, conscious and human, though its physical and mental faculties will take time to fully develop (Sinclair, K., 2008).

According to Roberts (2009), Buddhist dictum mandates that any choice be exercised with the greatest compassion for all who are involved. Buddhism allows the use of PGD if the psychological or spiritual damage caused by caring for a disabled or severely sick child outweighs the negative aspects of discarding the unhealthy embryos (Roberts, M., 2009). However, this is only allowed for extreme medical cases where the disease shortens the life of the child. Thus, for Buddhists, the main motivation to use any reproductive technologies including PGD is to benefit the parents by enabling them to have a healthy child. Mahmoud (2010) mentioned that according to the teaching of Buddhism, it does not prohibit the use of reproductive technologies (RTs). Buddhists believe that a child conceived through RTs is no different from a child who is born naturally, where the man, woman and the child have a *karmic* connection. Buddhists believe that life can enter the world through many ways and forms; sexual reproduction is just one of the ways, so it has no divinely sanctioned priority over other modes of procreation (Frazzetto, G., 2004).

Therefore, Buddhism does not oppose the use of IVF, GIFT or ZIFT. At the same time, there are no issues pertaining to the use of third party donation in terms of gametes, zygotes, sperms or eggs because they viewed it as blessings (Mahmoud, F., 2010).

Buddhism does not oppose the use of new reproductive technologies (NRTs) such as PGD that has the capability to allow parents to choose their future offspring. According to Harvey (2008), Buddhism is more concerned with the spiritual and psychological being of the parents when raising a disabled child. Hence, they pay more attention to the second motive of using PGD, which is to avoid bringing into the world a child suffering from severe illness. He added that as soon as one has a living embryo, one has a very early stage human being with the genes in it. Therefore, clearly if a person has a group of embryos and is only going to implant one, or perhaps two, it is better to implant those that are known to be genetically healthier, if this knowledge is available. Buddhism encourages the use of assisted reproductive technology or reproductive genetic technology if it brings happiness to the families.

2.6 Ethics of Reproductive Technologies (RTs) in Malaysia

Advances in biotechnology specifically include reproductive technology, medical imaging, genetic and DNA technology, and most recently cloning of mammalian tissues and organisms. These biotechnological advancements have brought to the fore pressing ethical issues in biomedical research and medical practice (Chan, CK, 1998). Undoubtedly, these concerns will in time emerge in policy and ethical discourse in Asian countries including Malaysia, if it is not already a matter of concern in Malaysia. In 1996, the National Advisory Committee on Genetic Manipulation (NACGM) published its Guidelines for the Release of Genetically Modified Organism (GMOs), which became an

early institutional expression of bioethical concern in Malaysia (Chan, CK, 1998).

In recent years, reproductive issues have made up a major part of bioethical studies and discussions in most study centres of the world. Abdul Majeed, AB (1998) stated that abortion and sterilisation used to be the foremost reproductive ethical issues which generated controversies and debates throughout the world. At present, topics of assisted reproductive technologies (ARTs) and prenatal diagnosis (PND) have emerged as important reproductive ethical issues in the developed world (Arshat, H., 1989). There are multiple forms of assisted reproductive technologies available in Malaysia, including artificial insemination and in vitro fertilisation.

Assisted reproductive technology (ART) was initiated in Asia, in the early 1980s and in Malaysia; the technique of IVF was first conducted by a group of researchers and physicians in 1984. This was followed by a live birth in 1987 (Nor, SNM., 1999). The first instance of government support for problems of infertility management began with the establishment of the MAC Project (Medically Assisted Conception) in Kuala Lumpur. This project was undertaken by a team of specialists and researchers from the National Population and Family Development Board (NPFDB). However, no form of official regulation exists in Malaysia on ARTs, despite the fact that there are between 15-20 ARTs centres within the country that have been functioning since the 1980s (Arshat, H., 1989). According to Arshat (1989), lack of official regulation in certain Asian countries is probably due to the multi- religious composition of the population in the country. This diversity makes it difficult to implement and regulate uniform practice guidelines. In addition to the said reason, most ARTs centres in Malaysia are set up in non-governmental medical centres in the private sector, with minimum supervision and monitoring.

In a country with a multi-religious population, the introduction of ARTs into the medical scene has created some concerns regarding the use of the technology and the

consequences of the technology to society. In a society where importance is placed on marital relationships and on the traditional concepts of family, Malaysians are very careful when selecting from various forms of assisted reproductive treatments available to them (Zawawi, M., 2003). According to Zawawi (2003), although ARTs could help parents to conceive their own children, it must still be restricted such that the application involves sperm taken from the husband and ova taken from the wife, and later to be carried by the wife.

The issues of ARTs in Malaysia normally raise ethical concerns related to medical and religious ethics (Arshat, H., 1989). The maintenance of religious beliefs and a strong sense of respect for rich Asian culture is a strong influence on reproductive perception and choices in Malaysia (Zawawi, M., 2003). It is also largely influenced by the make-up of the country, which houses the majority of Muslims as well as Christians, Buddhists, Hindus and other religions. At the same time, ethical concerns were also raised by certain groups of people who were influenced by their surrounding community. According to Zawawi (2003), this is because Asian or Malaysian views are totally different compared with the West, where the idea of fundamental rights is injected with individual freedom. In Asian community, rights are coupled with responsibilities and the collective rights of society.

2.6.1 Artificial Insemination (AI) & egg donation in Malaysia

Artificial insemination is a technique in which sperms are placed in the female reproductive tract by mechanical methods that precludes sexual ejaculation into the woman's vagina. This technique is available in Malaysia as one of the services provided to couples who choose to get pregnant through medically assisted methods such as IVF

(Zawawi, 2010). Similar to AI, eggs donation is one of the techniques used to help couples to conceive their own children either using their own bodies or another woman's body, a method known as 'surrogacy'. In both techniques, the sperms or eggs of the couple's own spouse can be used but in some situations, a third party donor is required when the husband or wife is not able to produce eggs or sperms.

When the eggs or sperms come from their own spouse, it does not contribute to a big ethical debate because there is no third party involved in the procedure. However, ethical questions are raised when donor eggs or donor sperms are involved. According to Islam et al (2007), Islam prohibits the use of donor eggs or sperms as it obliterates the lineage; therefore adultery is a punishable crime in Islam in order to preserve the lineage. He quoted the statement below in his paper (2007), "*Ethics of Artificial Insemination: An Islamic Perspective*", an opinion from Dr. Yusuf al-Qaradawi,

"Islam safeguards lineage by prohibiting adultery and fornication and legal adoption, thus keeping the family line unambiguously defined without any foreign element entering into it. It likewise prohibits what is known as artificial insemination if the donor of the semen is other than the husband."

This is because not knowing the correct lineage may cause a person to marry his or her sibling or any other close relatives with whom marriage is forbidden. Subsequently, this situation will cause harm not only to the individuals involved, but in the long run to the society as a whole. However, a famous jurist, Mustafa al-Zarqa claimed that AI using sperm donor does not fulfil the prerequisites of *zina*. Therefore, the punishment is not applicable in this case. In addition, he added that although AI via donor is not legally or morally *zina*, it is morally wrong and prohibited from the perspective of Islamic ethics (Islam et al, 2007).

Another ethical concern that has arisen from Artificial Insemination Donor (AID) and

eggs donation is the impact of these techniques on the traditional family concept, and the changes it brings to the natural process of conception. For some individuals, AI and eggs donation are viewed as 'unnatural' because fertilisation happens due to mechanical help instead of normal sexual intercourse between husband and wife (Tang, A., 2006). Traditional family relationship refer to the parent-children relationship in which, using AID or eggs donation may lead to weakening or questioning of the relationship since one of the parents is natural and the other is a stepmother or stepfather (Nikalaos, M., 2008).

2.6.2 In Vitro Fertilisation (IVF) & other ARTs in Malaysia

IVF has been available in Malaysia since the 1980s. The first IVF was conducted in 1984, followed by the first live birth in 1987 (Nor, SNM, 1999). However, the emergence of new reproductive technologies (NRTs) such as IVF raised several ethical concerns regarding the possible ethical implications of the technology to individuals, families and societies. Furthermore, when IVF was introduced in the medical scene, there was very limited information available to the public in order for them to be well-informed. In 1992, when the media relayed a wide public perception on the technology, there was mixed feelings among the Malaysian public as they started to question the development of this project (Nor, SNM, 1999). The revelations by the media showed rapid development of reproductive medicine. At the same time, this development indicated that it had the resemblance of a form of eugenics in the midst of the Malaysian culture.

Due to the public uncertainties and lack of knowledge regarding IVF, the Malaysian Fertility Society conducted a forum in 1993 to educate the public on IVF and other kinds of fertility or ARTs services available in Malaysia (Nor, SNM, 1999). Since Malaysian society has very much embedded their life with their religious beliefs, knowing

only the technical aspect of IVF or other ARTs is not enough. Furthermore, religious councils or organisations have always stated their religious stand in regard to this technology. These stands are different from one religion to another, where one religion might be more flexible than the other.

One of the most discussed ethical concerns in IVF is the moral status of the embryo. During the procedure, several embryos are created and some of the embryos will be implanted inside the woman's womb. For one reason or another, some of the embryos might be discarded. Thus, ethical questions have been raised of what should be done with the spare embryos which were created during the procedure, for both healthy and unhealthy embryos. These spare embryos reignite the old question of when human life begins and contributes to the dilemma faced by parents on what they ought and ought not to do regarding this issue (Nordin, MM., 2011). Tang (2006) explained that those who hold to the idea that human life starts at fertilisation or conception are left with the question of what would be the most ethical decision to make in regard to the extra little persons. For devout Catholic believers, they believe that the soul enters the body at conception and the fertilised ovum is a human person with full rights. Tang (2006) added that, with this belief, it explains why most Christian organisations, especially the Catholic Church are normally opposed to and reluctant to allow the use of IVF among their followers.

Another ethical concern among Christian organisations when it comes to IVF is concerning 'embryo reduction'. Due to the high cost involved in IVF technique, physicians are sometimes pressured to produce a viable pregnancy; the more you implant, the higher the success rate (Islam et al., 2005). This theory resulted in doctors implanting more than three embryos although most regulations regarding IVF only allow a maximum of three implantations, leading to multiple pregnancies. When women have multiple pregnancies, there are bound to be cases where the women need to make a decision on the embryos,

which need to be selectively aborted due to medical conditions. This poses a difficult situation for parents, and creates an ethical conflict and dilemma for Christian couples who wish or opt to go for IVF treatment (Tang, A., 2006). Besides religious obligation, multiple pregnancies also raise concerns regarding the risks to the mother and also to the unborn child, including pre-term labour, congenital malfunction, blindness or learning disability (Purdy, LM., 2009).

On the other hand, it is widely accepted in Islam that the 120th day of pregnancy is the time of ensoulment, thus permitting the use of RTs (Serour, GI., 2005). However, it is stressed that although ensoulment occurs at a later point in time, the embryo should be respected from the onset of fertilisation and is considered as a human foetus after implantation (Nordin, MM., 2011). It is also indicated that in Islam, IVF is not prohibited as long as it is performed for medical reasons, and spare embryos are either preserved using cryopreservation technique or donated to be used in clinical research. In addition, the treatment must also be performed within a legal marriage frame (Ahmad, NH.,2003). Cryopreservation is still experimental in humans, and the long-term risks to children are unknown. During IVF or PGD, there is an option for spare embryos to be cryopreserved when the couple decides not to implant them inside the womb, and request that the embryos be kept for future use. However, cryopreservation has led to the debate of ownership when the couple's circumstances have changed and they need to decide what to do with the 'kept embryos'. This subsequently gives rise to the issue of posthumous reproduction that involves the welfare of the child (Samani et al., 2008).

The Malaysian society is also concerned when reproductive procedures involve the use of a third party individual, where the particular individual is the egg or sperm donor because importance is placed on marital relationship and on the traditional concepts of family (Zawawi, M., 2003). When both parents have the difficulties to produce their own

sperms and eggs but still want to try and conceive a child, they would definitely need to engage the service of ‘materials donor’. When parents engage the service of ‘material donors’, it raises ethical concerns on the genetic information of the future child, and also concerns regarding possible violation of the marriage constitution (Tang, A., 2006). Consequentially, the child’s genetic information might no longer be restricted to just one set of parents but probably two sets of parents. This is because on some rare occasions, parents might need to engage a surrogate mother to gestate the child for them when the wife is unable to have a pregnancy due to some medical condition. In this situation, the matter becomes much more complicated and raises not only ethical and religious concerns but also legal concerns especially after the child is born (Zawawi,M., 2003).

2.6.3 Prenatal diagnosis/testing in Malaysia

Prenatal diagnosis or screening or testing, counselling and preventive procedures raise many legal, moral, ethical and religious issues in Malaysia. Ethical questions usually revolve around the following areas: beneficiaries of prenatal diagnosis; whether it is carried out for parents to allow them to make informed decisions; for physicians to provide optimal care to avoid legal liability; for society to minimise the burden of suffering or health care costs; or for the baby to be provided with a ‘good’ start in life (MOH, 2003).

Based on the documentation that was published by MOH (2003) regarding RTs, there are several types of prenatal diagnosis techniques available in Malaysia, including ultrasound, amniocentesis and chorionic villus sampling (CVS). Prenatal diagnosis techniques can be very invasive and it could lead to spontaneous abortion and pregnancy loss for patients with healthy foetus. Therefore, this issue cause dilemma for women when they decide on whether to go for the testing (Nazimah et al., 2010). Some women refused

to go for prenatal diagnosis because they associated it with abortion (MOH, 2003), whereas for some, refusal to undergo prenatal diagnosis was associated with their religious beliefs (Wong et al., 2011). In general, abortion or termination of pregnancy is not a favourable consideration among Asians including Malaysians because of the complex web of moral, cultural, traditional and religious values of the family and community (Wong et al., 2011).

Unfortunately, Wong et al (2011) claimed that there are very few studies that have examined societal perspective on the acceptability of abortion in the Malaysia context. However, there are several studies which show religious beliefs to be associated with refusal for prenatal diagnosis and termination of affected foetuses among high-risk couple (Wong et al., 2011).

2.6.4 PGD in Malaysia

In Malaysia, the monitoring of PGD is under the legislation of the Ministry of Health (MOH), and only a few fertility clinics in the country have been able to provide the services to the patients. According to the guidelines that were published by the Malaysian Medical Council (MMC) in 2006, PGD is only allowed when it involves the prevention of the birth of a baby, which will have severe genetic disorders or when both parents are carriers of a genetic disorder, and wish to have a healthy baby. Prospective parents with a history of genetic disorder are able to request for PGD, provided they have gone through a series of counselling sessions with a qualified counsellor.

The use of PGD for sex selection for social reasons is banned in Malaysia and is viewed as an unethical decision because the child is in no danger whether it is born as a boy or a girl. Therefore, in 2006, a law was proposed by the Malaysian government to

prohibit the practice of PGD for social sex selection, whereby PGD will only be permitted to avoid severe and life threatening genetic diseases (Yaakob, H., 2012). However, he added that until today, the law has not been passed although currently, guidelines are available, which were prepared by the MMC. PGD facilities are currently only available in Malaysia at selected private fertility clinics, and not in the government hospitals. Due to the high cost, the service is only accessible to a limited number of people. Setting up a well- equipped laboratory and providing expertise to perform the procedure needs huge financial resources, which explains why these services are only offered at privately owned fertility centres.

Research on pre-implantation genetic diagnosis in Malaysia is mainly related to medical or scientific progress, or recently in regard to PGD and non-medical sex selection. In 2006, a group of medical scientists from two local universities worked together and conducted a research using PGD to identify the gender of pre-implantation mice embryos (NorAshikin et al., 2006). By performing this research, this group of scientists were trying to show that gender identification can be done using a single blastomere, and by using PCR it was optimised into several DNAs for diagnosis. This method is important in a situation where parents are trying to avoid the birth of a child from a particular sex to avoid the birth of a child with X-linked diseases. Conclusively, the results showed that six mice were successfully sexed within 6 hours using 8-cell embryos.

At the same time, these groups of scientist also explored the effects of biopsy and cryopreservation by vitrification of 8-cell mouse embryos. Biopsy of embryos in PGD is normally at the 8-cell stage because it has been reported that a biopsy at this stage has less detrimental effect on subsequent in vitro development. It was observed that through blastomere biopsy and vitrification procedure, intact and biopsied embryos could be successfully cryopreserved. However, the survivability of the embryos declined steadily

with advancing developmental stage, irrespective of the treatment used. Therefore, when taking into account the effect of cryopreservation on the embryos' developmental stage, it is better to extract two blastomeres for biopsy instead of just one blastomere; this is the current practice to increase the chances of survival.

In another medical research on PGD, a group of physicians from a local university performed a research using PGD; they used PGD with polymerase chain reaction (PCR) technique in order to identify the beta-globin genes that cause beta-thalassaemia (Nasri et al., 2009). A whole genomic amplification (WGA) was performed to yield enough DNA to allow PCR analysis for Codon 17 and Codon 26 of beta-globin genes that cause beta-thalassaemia disorder. The amplified DNA was from a single blastomere, which was extracted from unwanted pre-implantation human embryos that were donated by infertile couples that agreed to be part of the research. The study showed that the method used had successfully amplified both Codon 17 and Codon 26, and found no mutation. Therefore, this research indicates that PGD is considered a suitable and non-invasive clinical tool compared with prenatal diagnosis (PND), for identifying genetic disorder to reduce selective miscarriages. According to the team of researchers, they hope that the use of PGD would help to reduce moral dilemma associated with abortion when using PND.

In another study on PGD, the researcher analyse public rejection against the use of PGD for non-medical sex selection and determine that such rejections should not be taken into consideration in formulating legal policy on PGD for social sex selection in Malaysia (Yaakob, H., 2012). This is because according to Yaakob (2012), public intuition on PGD for SSS has been proven to change over time and may also be associated with a lack of public trust in scientists, and fears over technologies such as cloning. Therefore, she concluded that public intuition alone should not be the basis of legal prohibition or restriction of PGD for SSS in Malaysia.

Qualitative research that involves the investigation and exploration of how the Malaysian society perceives PGD as part of the emerging new reproductive technologies has yet to be conducted. Thus, little information is available on the opinions and views of the Malaysian society about PGD. As a country with diverse backgrounds, it is crucial to acknowledge the differences of views and opinions on the use of PGD in today's medical scenario. Therefore, it will be important to conduct such research in Malaysia to enable us to understand how different individuals perceive the ethical and clinical, challenges posed by PGD. At the same time, the research results obtained can explain the elements that contribute to people's views and perceptions, and explore whether these perceptions would influence their clinical decision- making in regard to PGD.

2.7 Conclusion

Ethical issues concerning the use of reproductive technologies (in general) and PGD (in particular) have long been discussed and debated among bioethicists, scientists and societies (Evans, JH., 2006). The expanded use of PGD has raised fears of eugenics and 'designer babies' (Childress, KD., 2003). Some claim that, whoever considers or uses PGD are merely trying to 'play God' by selecting their future children according to their genetic characteristics (Jones, G., 2004). Initial research on PGD indicates that the use of PGD has increased concerns on further discrimination and intolerance towards disabled people (King, DS., 1999).

On the contrary, some people believe that PGD is a positive development in the medical field, particularly in the field of reproductive genetic technologies (Kalfoglou et al., 2005). PGD is also a good alternative for parents to have healthy children, and enables prospective parents to avoid passing on inherited genetic diseases to their children,

eventually eliminating the diseases from the family line. With the proliferation of reproductive genetic technologies, the range of options for couples at risk also increases. This has subsequently contributed to the emergence of profound discussions concerning parental rights with regard to their reproductive choices (Watt, H., 2004). Increased parental rights lead to another ethical issue, that is, 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 'goods' (Pennings et al., 2002).

This study was initiated and constructed based on previous studies conducted in other countries, which involved different groups of people from diverse different backgrounds regarding issues pertaining to the use of PGD. This study aims to explore how the participants confront and approach ethical and clinical issues posed by PGD, the factors that contribute to their perceptions, and whether their perceptions play a role in influencing their decisions in regard to PGD. Ethical analysis using consequentialist and deontological theories seem to be most appropriate theory to be used to analyse the findings based on the previous ethical research that was conducted in some countries as was mentioned in the later section of this chapter. Furthermore, an analysis that applies ethical theories such as consequentialism and deontology is necessary for ethical consideration on the issues of reproductive technology. A summarization of the literature analysis is shown in Figure 2.1 where it also showed the literature gap that this study aiming to fulfil, thus obtaining the objective of the study.

In the next chapter, I will explain the research methodology used for this study, reason for selection of this methodology, and basis for choosing participants for this study.

Below is Figure 2.1, a summary of literature review analysis;

Ethical theories are based on the ethical principles, each of which emphasizes different aspects of ethical issues. Bioethicists have used ethical theories to conduct ethical analysis on the emerging ethical issues associated with genetic testing, animal and human cloning, genetic enhancement and modification, or existing issues related to abortion, gender selection and embryonic stem cell research (Kuhse & Singer, 2009). Therefore, it is relevant to use ethical theories to conduct analysis in this study.



The field of bioethics has really taken shape as a field of study during the 60s where most countries in the Western hemisphere were going through some important cultural and social changes, which was led by the advances in biomedical sciences and in clinical medicine. The main ethical issues in science and technology are normally centered on human genetics, which has shown rapid advancement in the 20th century. Since modern technology related to human genetics is still considered to be something new and has yet to stand the test of time, it raised doubts, fears and concerns as well as intense debate worldwide (Amin, L. 2009). Therefore, studies that involve the investigation of individuals' views on these ethical issues are important to understand their fears, concerns and hope. Thus, contribute to the expansion of the diversification of existing research findings.



Since the birth of the world first test tube baby, the development of new reproductive technologies has evolved rapidly. Thus, lead to the rise of variety of social, cultural, legal and ethical responses. New reproductive technologies have diversified, globalized and denaturalized the taken for granted binaries of, among other things, sex/procreation, nature/culture, gift/commodity, biology/sociality and human/non-human (Inhorn & Birenbaum-Carmeli, 2008). The new form of reproductive technology available today not only allow parent to have children who are genetically related to them but also give parents the opportunity to select their genetic combination; it change the basic requirement of the notion of procreation. At the same time, bring with it a new set of ethical concerns, which varied due to scientific, cultural and religious differences (Soini et al. 2006).



One of the new reproductive technology that was developed as an alternative to prenatal diagnosis (PND) is pre-implantation genetic diagnosis (PGD). Initially, the use of PGD is to diagnose single gene disorder, chromosomal translocation or X-linked disease. However, its use has expanded to new indications such as for susceptible condition, late onset condition, social sex selection and HLA typing in the case of sibling donor. Thus, this creates new fears and concerns that this technology could lead to dynamic changes in parent-children relationship or increasing intolerance toward people with genetic disease. Since PGD allow parent to select their future children, this has increase parental right to make decision regarding their reproductive choices, thus raise concern that this might be the 'slippery slope' of the technology where it can be misuse to gain personal profit. It has not been known how do Malaysian views and responds to these ethical issues brought about by the use of PGD although the technology has been actively used in the country for the past few years.



Religion has been contributed as one of the most important factor that influence one's view on the use of new reproductive technologies. This is because religious elite, operating through organized religious groups, is attempting to influence the popular debate over reproductive technologies (Evans, JG 2006). One of the reasons for this situation is because many of these technologies resulted in the death of embryos or fetuses, thus linking this debate to the issue of abortion. However, it is understandable that different religious beliefs have different views regarding these new reproductive technologies, which are influence by their religious teachings. Due to these varieties of views and factors that shape the view of people from different religious conviction, it is important to include the opinion of religious representatives of leader in this study; their views and opinions could potentially influence member of their congregation. (Evans, JH 2006).



Assisted reproductive technology was initiated in Asia, in the early 1980s including Malaysia. However, no form of official regulation exists despite the fact that there are between 15-20 ARTs centers within the country that have been functioning since the 1980s (Arshat, H. 1989). The issues of ARTs in Malaysia normally raise ethical concerns related to medical and religious ethics as well as concerns on the future impact of these techniques on the traditional family concept and changes that it might bring to the natural process of procreation. Unfortunately, there are very few studies that have examined social perspective on the acceptability of ethical issues associated with the use of ARTs such as issue of abortion in the Malaysia context (Wong et al 2011).



One of the new reproductive technologies that is currently available in Malaysia is pre-implantation genetic diagnosis or known as PGD. The monitoring of PGD is under the legislation of the Ministry of Health (MOH) and only a few fertility clinics in the country have been able to provide the services. Normally, research on PGD in Malaysia is mainly related to medical or scientific progress. There is very limited knowledge on the view of Malaysian on the technology as well as how far do they actually accept the technology. At the same time, there is also very limited information on how do Malaysian response to the current ethical issues arise from the use of PGD. Therefore, conducting this study is one of it's kind in the field of bioethics in Malaysia and this will be an important study because it provide information concerning public perception on PGD. This information could be very useful especially when constructing policy and regulation on the use of PGD in order to make sure that it is accessible for those who need it and at the same time, prevent the possible misuse of the technology by irresponsible party.

Figure 2.1 Summary of the literature analysis

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

Qualitative method is chosen for this study because it is well suited to the needs of the study to understand participants' opinions and views in regard to ethical implications of PGD. This method is considered appropriate because the emphasis of qualitative research is to explore and understand why people have certain mind-sets and to identify the factors that contribute to their decisions; less emphasis is placed, on testing a hypothesis (Pope and Mays, 1995). The study was conducted between April 2010 and May 2011 in the region of Klang Valley. Three different sets of open-ended, semi -structured interview questions were designed for the in-depth-interview to be conducted among 21 participants from selected organisations.

In-depth qualitative interviews are appropriate to be employed for a wide range of topics, particularly when a researcher intends to understand participants' concerns and feelings on sensitive issues such as human reproduction. This approach is useful for explanatory and descriptive research purposes. The use of qualitative interviews enables the researcher to develop deeper understanding about the participants' experiences and perceptions.

However, it is important to note that the opinions expressed by the participants involved in the study cannot be generalized too far. The interviews explored how participants would approach and confront ethical and clinical issues posed by the use of PGD; this included the participants' perceptions on ethical issues of reproductive choices,

moral status of embryos, intolerance towards people with genetic disabilities and playing God. The interviews were audio- taped and later transcribed.

3.2 Qualitative methodology

The qualitative method seeks to explore and explain events happening in the world through observation, by appreciating the subjective experiences of social actors and by revealing data that are not easily accessible by quantitative methods (Power, R., 2002). This method comes into play in providing access to areas not amenable to quantitative research, particularly in areas that have received little research interest. Qualitative methods have been used to study human behaviours or reactions towards a particular topic of discussion or research. This is because qualitative methods enable the researcher to have personal touch in dealing with the participants and to explore their views and opinions on the research area concerned.

In area of bioethics, qualitative research methods are believed to be particularly well suited to aid in understanding values, personal perspectives, experiences and contextual circumstances (Hull et al., 2001). Qualitative interviews differ from experiments and surveys because human participants are treated as complex entities with special ethical concerns (Jorgensen, DL., 1989). This type of interview has been used in various fields; examples of its use are in sexually transmitted infections (STI) and HIV/AIDS research because many of the social phenomena being studied require personal and private discussions, sometimes illicit, to obtain the participants' views and opinions. Manhart et al (2000) performed qualitative research on the study of STI in Morocco, and this enabled him to unearth the conceptualisation and indigenous understanding of STIs among the Moroccans. Results indicated that there are clear gender differences in

understanding sexually transmitted diseases (STIs) and also differences in health-care-seeking behaviour between men and women participants.

Rogers (2001) used qualitative method to investigate attitudes of General Practitioners (GP) towards respect for patient autonomy in consultation for low back pain. The study aimed to explore GP's attitudes in dealing with patient autonomy using the ethical framework, and focused on four main issues that commonly occur in management of low back pain. Findings showed inconsistencies in GP's attitudes toward respect for patient autonomy; GP's attitudes toward patient autonomy are modified by ethical and pragmatics factors, and varies depending upon the nature of the issues in question.

By using qualitative methodology, the researcher was able to gain insight into possible factors that influenced GP's' attitudes towards respect for patient autonomy. In order to explore the opinions and views of individuals within society on issues related to the latest reproductive technologies, McMahon and Jones (2003) adopted qualitative methods in carrying out their study. In the study, the authors examined public's perception on stem cell research and pre-implantation genetic diagnosis (PGD) using semi-structured interviews. Their findings showed that the participants gave better rating to stem cell research than PGD.

New reproductive and genetic technologies such as PGD have been at the centre of controversial debates as different individuals have different perceptions on the use of these technologies. In fact, Kalfoglou et al (2005) performed a qualitative study in order to explore these differences. The study focused on the participants' attitudes towards the use and regulation of PGD; the findings were then analysed using thematic analysis and categorised into three main themes; benefit for patients, concern for safety and concern for society. In addition, another semi-structured interview was conducted among women in Holland who were offered prenatal screening tests in a fertility clinic (Garcia et al., 2008).

The study focused on how these women made clinical decisions after the screening and the variables that influenced their decisions; participants mentioned that they make decisions based on their personal perspectives but at the same time, preferred to share the responsibility of taking decisions, and its consequences for other family members, with their partner and close persons.

The above mentioned findings from previous researches show that qualitative method is a very useful and appropriate method for this study because it intends to explore the opinions and views of participants in regard ethical and clinical issues of PGD as well as, challenges related to its future use. By using open-ended, semi-structured interviews, this study will be able to explore and understand the implications of PGD in Malaysia based on views and experiences of the participants, who were selected and grouped into three different categories. The qualitative method will also help the researcher to understand the possible factors that shape participants' perceptions in regard to PGD and explore whether these perceptions will influence their reproductive decisions. Therefore, the qualitative methodology that is used in this study enables the researcher to collect a wide range of data, which helps in the development of comprehensive understanding regarding participants' perceptions on PGD and the ethical implications to the society and country.

3.3 Participant selection

This study involves three focus groups from different selected organisations and institutions in Malaysia. It is essential to include different groups in this study because the researcher intends to explore and investigate their opinions and views, which might be different from one another because of their background variety. The three focus groups

comprise medical practitioners and scientists, potential PGD users and representatives of religious organisations.

Samples for this study were collected using a sampling method known as purposive sampling where the participants were chosen based on the appropriateness of their backgrounds and characteristics for this study (Crabtree and Miller, 1992). Purposive sampling is also used to aim at maximizing diversity (Rogers, WA., 2001). For example, the group of medical practitioners that were chosen for this study comprise physicians who are currently working in the field of reproductive medicine such as feta maternal sub-specialist, fertility specialist and embryologist. In addition, this group of physicians were chosen because they are well versed in treatments involving human reproduction, and issues pertaining to the use of reproductive techniques. At the same time, convenience sampling was also used where suitable participants were recommended by their colleagues or individuals; these potential participants have been identified because of their abilities to contribute significantly, to this research based on their vast experience in the field.

The sample size, which is not fixed prior to data collection, depends on the resources and time available, as well as the study's objectives. The number of participants recruited for this study is determined on the basis of data saturation, the point in data collection when new data no longer provide additional information to answer the research questions. According to Baumberg, "most qualitative researchers aim to keep getting data until they have saturation, which I take to mean sufficient depth on the full range of the phenomenon they're interested in"¹⁴. In order to reach saturation level, expert mentioned that there is no specific number of participants because it all depending on what does the researcher want to achieve (Baker & Edward, 2012). This is because if saturation is the criterion for sample size, specifying minima or maxima for sample size is pointless. Essentially, the criterion

¹⁴ Cited from Baker, SE & Edward, R. (2012), How many qualitative interviews is enough? Expert voices and early career reflections on sampling and cases in qualitative research, National Centre for Research Methods Review Paper (pg 37).

for sample size is whatever it takes to achieve saturation (Bryman, A., 2012). For example, Guest et al (2006) conducted a study on a corpus of transcripts from interviews with women in two West African countries and found that saturation was attained after twelve interviews, although basic elements for meta themes were present as early as six interviews. It is important to emphasise that due to the limitation of the sample size, the findings of this study do not represent the general perception of the whole Malaysian population.

3.4 Description of the sample

21 participants were selected for this study, which included eight medical professionals, seven potential PGD users and six representatives from religious organisations. These groups are categorised as Group 1 for medical professionals, Group 2 for potential PGD users and Group 3 for religious organisations.

3.4.1 Medical professionals

Medical professionals are chosen for this study because of their experiences and expertise in the field of reproductive medicine in general, and specifically in PGD. This will provide a unique perspective about ethical and clinical issues of PGD. It is also good to have a wide range of medical professionals involved in this study such as geneticists, obstetrician and gynaecologist, as well as embryologists and molecular scientists because their work involves contact with women or couples undergo or planning to undergoing PGD and fertility treatment (Ehrich et al., 2007). According to Enrich (2007), previous researches also showed that involvement of variety of medical professionals has

successfully examine their concern and views in regard to social, ethical and clinical issues posed by NRTs such as PGD and its impacts on professional policies and practice.

Three medical institutions were selected namely, University Malaya Medical Centre (UMMC), Kuala Lumpur General Hospital (KLGH) and Fetal-Maternal & Gynaecology Centre (FMGC), in order to have a variety of medical professionals from different medical institutions involved in the study. For the medical professionals, their contact information was obtained from the institutions' websites or online organisation charts, or through referrals given by the contact persons of the organisations based on their expertise or positions in the organisations. Additionally, other participants were suggested by the medical practitioners themselves because of their prominent contributions to the field of reproductive medicine in the country.

This group of participants is made up of eight medical professionals consisting of three fetal maternal specialists, three fertility specialists, two medical scientists, a human geneticist and a molecular biologist. All the six medical practitioners have extensive patient contact but other professionals, notably the geneticist and molecular biologist, whose jobs are mostly done in separate laboratories, have limited patient contact.

Participant 1 is a Maternal- Fetal Medicine sub-specialist at University of Malaya Medical Centre (UMMC), Kuala Lumpur. Maternal- Fetal Medicine is a medical field that focuses on the medical and surgical management of high- risks pregnancies. Participant 2 is also a Maternal-Fetal Medicine sub-specialist at UMMC. Participant 3 is an Obstetrician and Gynaecologist (O&G) and also the Head of the O&G Department at Kuala Lumpur General Hospital (KLGH). Participant 4 is an O&G and sub-specialist in fertility at UMMC. Participant 5 is also an O&G Specialist and sub-specialist in fertility at University Kebangsaan Malaysia Hospital (HUKM), in Cheras. Participant 6 is a Maternal- Fetal Medicine sub-specialist at Fetal Medicine and Gynaecology Centre (FMGC), in Petaling

Jaya. It is a private medical centre that provides services related to women's health including high- risk pregnancy. Participant 7 is a molecular biologist with UMMC and an academician at the Faculty of Medicine, University of Malaya (UM). Finally, Participant 8 is a human geneticist and an academician at Jeffrey Cheah School of Medicine and Health Sciences, at Monash University, Sunway.

3.4.2 Potential users of PGD

Potential users of PGD were selected among people who have had experiences with disabilities syndrome such as Down syndrome and Thalassaemia. The potential users for this study were recruited through two non-governmental organisations dealing with two different genetic disorders. Subsequently, two NGOs were selected for this study namely, Kiwanis Down Syndrome Foundation, Petaling Jaya and Thalassaemia Association of Malaysia, Kuala Lumpur.

Contact was established with these two NGOs using the contact details available on their websites. Potential users from the Kiwanis Down Syndrome Foundation were chosen randomly among parents of children attached to the foundation. On the other hand, whereby potential users from the Thalassaemia Association of Malaysia were selected based on the availability of the members of the association. There are seven potential users of PGD involved in this study. All potential users who were recruited through non-governmental organisations (NGOs) gave their informed consent to participate in this study. Four of the respondents were parents (participant 9, 10, 11 and 12) with children suffering from genetic diseases; the other three respondents were individuals afflicted with some form of genetic diseases (participant 13, 14 and 15). These NGOs were selected because

they represent people with different genetic disorders: Down syndrome, a non-inherited genetic disorder and Thalassaemia, a blood disorder that is genetically inherited.

Participant 9 (A) is a mother of two, whose first child is diagnosed with Down syndrome but her second child is healthy and free from the disease. Participant 10 (B) is a mother of one, and her daughter is diagnosed with Down syndrome. Participant 11 (C) and participant 12 (D) are both Thalassaemia minor: both are mothers to one or more children affected with the disorder. D has two sons who are both Thalassaemia major patients: one of her sons passed away a few years ago at the age of 19 years due to the illness. Participant 13 (E) is a medical student in his 20s and is affected with Thalassaemia, and he is D's son. Participant 14 (F) also in his 20s and has Thalassaemia, and is C's son. Participant 15 (G), in her 20s, is a close friend of E and F, who is also affected with Thalassaemia. Participants 11, 12, 13, 14 and 15 were all interviewed at the same place and at the same time.

It is important to include the opinions of these participants because they are the future or possible 'consumer' of the technology. Therefore, it is important to explore their perceptions on the technology and how do they approach ethical and clinical issues related to the use of PGD.

3.4.3 Representatives of religious organisations

This group was selected from three different religious groups in the country: Islam, Christianity and Buddhism. It is important for this study to include the opinions and views of members from different religious groups because Malaysia has diverse cultures and religions that are reflected in the daily life of the Malaysians society. Evans (2006) conducted a research involving religious organisations in the USA, and explored their

religious beliefs and perceptions towards reproductive genetic technologies (RGTs) based on the idea of human suffering. The author found that religious understanding of human suffering influences the religious organisations' support or opposition on the use of RGTs. Their views and opinions therefore, potentially influence the views of members of their groups or their congregations regarding RGTs.

This situation is similar to the debate among some religious groups on the issues of abortion. Based on this finding, the researcher believes that it is necessary to include the views of the different religious organisations in this study, and observe the influence of their opinions on the members of their groups. The involvement of Christian, Buddhist and Muslim representatives in this study will bring about interesting and informative findings because it helps us understand why followers of different religions have certain mind-sets on the ethical issues of PGD.

Representatives from the religious organisations were contacted through emails or phone calls. This study involves six representatives from three religions in Malaysia: Islam, Christianity and Buddhism. Three of the representatives are Christians, two are Muslims and one is Buddhist. The Christian representatives represent three Christian organisations, which are Kairos Research Centre, a Christian research centre in Damansara (participant 16); Christian Council of Malaysia (participant 17) and the Roman Catholic Church of Malaysia (participant 18). The two Muslims are from two organisations namely, the Department of Fiqh and Usul in University of Malaya (participant 19), and Jabatan Kemajuan Islam Malaysia (JAKIM) (participant 20). The Buddhist representative in this study is from the Young Buddhist Association of Malaysia (YBAM) (participant 21).

Participant 16 is the Research Director at Kairos Research Centre. This research centre seeks to encourage Christian scholars to work together in an interdisciplinary venture, drawing knowledge and information from a variety of fields including philosophy,

theology and science. Participant 17 is the Executive Secretary for the Council of Churches of Malaysia (CCM), an ecumenical fellowship of churches and Christian organisations in Malaysia. Participant 18 is a Catholic priest at the Church of Our Lady Fatima in Kuala Lumpur, and is also an ethicist for the Roman Catholic Churches in Malaysia. Participant 19 is a religious scholar and also an academician in the Department of Fiqh and Usul, the Academy of Islamic Studies, University of Malaya. Participant 20 is an Assistant Director of the Research Division at JAKIM. Participant 21 is a consultant to the Young Buddhist Association of Malaysia (YBAM), who is also an engineer by profession.

The summarizations of all the three participants are listed in Table 3.1, which include the organisations they belong as well as their background.

Table 3.1 Summarization lists of all participants in this study

Participant	Background/Position	Organisation
Participant 1	Feta-maternal sub-specialist	UMMC
Participant 2	Feta-maternal sub-specialist	UMMC
Participant 3	Sr. Consultant O&G	GHKL
Participant 4	Fertility sub-specialist	UMMC
Participant 5	Fertility sub-specialist	HUKM
Participant 6	Feta-maternal sub-specialist	FMGC
Participant 7	Molecular Biologist	UMMC
Participant 8	Human Geneticist	Monash University
Participant 9	Mother with children afflicted with genetic disease	KIWANIS Down Syndrome Foundation
Participant 10	Mother with children afflicted with genetic disease	KIWANIS Down Syndrome Foundation

Table 3.1 Continue

Participant	Background/Position	Organisation
Participant 11	Mother with children afflicted with genetic disease	Thalassemia Malaysia Association
Participant 12	Mother with children afflicted with genetic disease	Thalassemia Malaysia Association
Participant 13	Individual living with Thalassemia	Thalassemia Malaysia Association
Participant 14	Individual living with Thalassemia	Thalassemia Malaysia Association
Participant 15	Individual living with Thalassemia	Thalassemia Malaysia Association
Participant 16	Christian Evangelist and scholar	Kairos Research Centre
Participant 17	Representative	CCM
Participant 18	Catholic priest & ethics	Roman Catholic Churches
Participant 19	Academician/Religious scholar	UM
Participant 20	Religious scholar	JAKIM
Participant 21	Buddhist consultant	YBAM

3.5 Data collection

Data for this study were collected through in-depth interviews using open-ended semi-structured interview questions. Questions were selected based on ethical and clinical issues posed by PGD such as the moral status of embryos, discrimination issues, safety issues and parental reproductive rights. The interviews also included discussions on challenges that could arise from future use of PGD in Malaysia. After each interview was concluded, data analysis was performed to determine common patterns or issues highlighted by the participants.

3.6 Theme selection

The questions for the interviews are based on the four key themes namely, play God, sanctity of life, perfectionism and freedom of choice. The four key themes are selected based on the current ethical issues of PGD that actively being discussed in the social media as well as in the academic scene; particularly in the field of bioethics pertaining to the used of new reproductive genetic technologies including PGD. The development of PGD is aimed at fostering the creation of healthy children but at the same time, it has caused additional concerns about its ability to end life (Robertson, JA. 2003). In fact, according to Robertson (2003), one of the most frequently discussed or debated ethical issues of PGD are concerning the moral status of embryo. The destruction of embryo posed difficult ethical issues because the development of human beings is a gradual process (Singer, P. 1993). The arguments against status of embryo normally focus on issues, which include whether the foetus is real, whether personhood is immeasurable, the notion of equal protection that include disabled individuals and prolife choice where there is compassion towards the individual foetus regardless of its handicap (Fasoulitis and Schenker, 1998). It is understandable that these opinions vary from one person to another based on their beliefs or understanding of the definition of human life. It is based on this reason that this theme was selected as the first key theme for this study because the researcher intends to understand the participants' views regarding moral status of embryo, which might reflect their reason to accept or reject the notion of using PGD. The term 'sanctity of life' is chosen because it has always been used to refer to the sacredness and holiness of human life, which demands that life should be treated with respect.

The fact that PGD has enable parent to select their children based on their genetic combination and allow parent the choice to have children who will be born free from

genetic disease has led to the accusation that the technology is trying to replace or meddle with the natural process of human procreation. This led to the rise of ethical concerns that is based on deontological theory, which stressed that human procreation should be allowed to perform its duty to naturally select whether the child will be born healthy or unhealthy (Robertson, JA 2003). The interference of parent with the natural selection process using PGD is considered as treating children more as a manufactured good rather than a 'gift' or accused of choosing a child to order (Braude et al. 2002). Thus, led to ethical concerns that not only the technology might change the natural concept of human procreation but also might lead to societal change in terms of how society views people with genetic diseases or disabilities (Petersen, TS 2005). From a certain perspective within certain religious groups such as Christian groups, the appropriateness of technological intervention in human reproduction such as PGD is often characterised as humanity's hubris in 'playing God' (Doolin and Motion, 2010). The term 'play God' is chosen as the second key theme in this study because the study attempts to investigate participants' views on the capability of PGD to genetically select children according to the parent's desire rather than leaving it to Nature; a metaphor used to convey images of humankind transgressing its role in nature and trying to become God-like (Jones, G. 2004).

Due to rapid growth of genetic tests for genetic diseases, predispositions and other characteristics, use of these genetic tests in combination with PGD only fuels the existing controversy (Kalfoglou et al. 2005). The expanded uses of PGD has brought about new fears on the possible misuse of PGD that give rise to the term 'designer babies' and the notion that PGD might be the new form of eugenics (Damewood, MD 2001). Since PGD allow the predetermination of preferred genetic combination while avoiding natural birth, it sometime create perception that the technology provide parent with a tool to create the perfect child; children who will be born with zero defect, be it physical, emotional, mental

and in term of genetic. Subsequently, this can create unrealistic expectation by parents when they wish to use PGD. Furthermore, these days, overly ambitious parents are prone to carried away with transforming love; promoting and demanding all manner of accomplishment from their children; seeking perfection (Sandel, MJ 2007). This could encourage intolerance towards individuals possessing genetic disabilities as well as parent who have children with genetic disability, thus raise concern on the possible effect toward society in general (Kalfoglou et al 2005). Therefore, the term 'perfectionism' is chosen as the third key theme in this study; the notion of creating or designing an optimal quality of life in term of physical, mental and genetic well being of their child using PGD.

The expanded uses of PGD have raised discussions related to the issues of individual or parental reproductive rights, which is strongly practised within the western tradition and has established its position in Western bioethics (Zeiler, 2004). This technology not only increases the reproductive choices of parents but it is also provides them an alternative to do something in the best interests of their unborn child; for example, stopping their newly born child from being affected by inherited genetic disorder (Green, RM 1997). However, the increasing reproductive choices in reproductive techniques have led to some doubts about the unequivocal benefits of these choices in general, and create awareness that multiple reproductive choices might be morally problematic rather than morally beneficial (Scully et al. 2006). The increase reproductive right has also led to the realisation that it could collectively lead to the 'slippery slope' of PGD (Ehrich et al. 2007). This give rise to concern regarding the possibility of abusing the technology because parents are no longer confined to restrictions on what they should or should not do, thus lead to unintended consequences, and sometimes 'impossible choices' (Kerr, A 2004). Subsequently, increase society concerns on further discrimination toward people with disabilities or parent who have children suffering from genetic disease (Childress, KD 2003). It is based on these

arguments that the fourth and final key theme was chosen for this study that is the freedom of choice. In the discussion on this theme, the study intended to investigate participants' views on the notion of individual or parental reproductive right including who should have the right to make the final reproductive decision, why should these individuals be allow to do so and what kind of factor that shape their views on the theme.

After conducting extensive reading and discussion between academic peer as well as my supervisor, it is decided that the four key themes that has been chosen based on the current issues of PGD are the most appropriate themes that will direct the research in obtaining its objective. At the same time, these themes are also used to construct the interview questions as well as assisting researcher to answer research questions that subsequently lead to the success of this research. Table 3.2 indicate list of literature review as well as a brief description or statement taken from the articles just to provide reader with an idea on how the themes were established.

Table 3.2 Summary of literature review used to establish themes for this study

Theme	Brief description of statement from which the themes are established
Sanctity of life	<ol style="list-style-type: none"> 1. Robertson, JA (2003) <ul style="list-style-type: none"> - The development of PGD is aimed at fostering the creation of healthy children but at the same time, it has caused additional concerns about its ability to end life - One of the most frequently discussed or debated ethical issues of PGD are concerning the moral status of embryo. 2. Singer, P (1993) <ul style="list-style-type: none"> - The destruction of embryo posed difficult ethical issues because the development of human beings is a gradual process 3. Fasoulitis & Schenker (1998) <ul style="list-style-type: none"> - These opinions vary from one person to another based on their beliefs or understanding of the definition of human life.
Play God	<ol style="list-style-type: none"> 1. Robertson, JA (2003) <ul style="list-style-type: none"> - Stressed that human procreation should be allow to perform its duty to naturally select whether the child will be born healthy or unhealthy 2. Braude et al (2002) <ul style="list-style-type: none"> - The interference of parent with the natural selection process using PGD is considered as treating children more as a manufactured good rather than a ‘gift’ or accused of choosing a child to order 3. Doolin & Motion (2010) <ul style="list-style-type: none"> - The appropriateness of technological intervention in human reproduction such as PGD is often characterised as humanity’s hubris in ‘playing God’ 4. Jones, G (2004) <ul style="list-style-type: none"> - Trying to change the natural process of human procreation is viewed as trying to ‘play God’. A metaphor used to convey images of humankind transgressing its role in nature and trying to become God liked.

Table 3.2 Continue

Theme	Brief description of statement from which the themes are established
Perfectionism	<ol style="list-style-type: none"> 1. Damewood, MD 2001 <ul style="list-style-type: none"> - The expanded uses of PGD has brought about new fears on the possible misuse of PGD that give rise to the term ‘designer babies’ and the notion that PGD might be the new form of eugenics 2. Sandel, MJ (2007) <ul style="list-style-type: none"> - These days, overly ambitious parents are prone to carried away with transforming love; promoting and demanding all manner of accomplishment from their children; seeking perfection 3. Kalfoglou et al 2005 <ul style="list-style-type: none"> - Thus raise concern on the possible effect toward society in general
Freedom of Choice	<ol style="list-style-type: none"> 1. Scully et al. 2006 <ul style="list-style-type: none"> - The increasing reproductive choices in reproductive techniques have led to some doubts about the unequivocal benefits of these choices in general, and create awareness that multiple reproductive choices might be morally problematic rather than morally beneficial 2. Ehrich et al. 2007 <ul style="list-style-type: none"> - The increase reproductive rights has also led to the realisation that it could collectively lead to the ‘slippery slope’ of PGD 3. Kerr, A. 2004 <ul style="list-style-type: none"> - This give rise to concern regarding the possibility of abusing the technology because parents are no longer confined to restrictions on what they should or should not do, thus lead to unintended consequences, and sometimes ‘impossible choices’ 4. Childress, KD 2003 <ul style="list-style-type: none"> - Increase society concerns on further discrimination toward people with disabilities or parent who have children suffering from genetic disease

3.7 Interview protocol

Based on these themes, the constructed interview questions were then pilot tested twice before the questions were considered to be appropriate for this study in providing the interviewer with the necessary information. After gaining approval for the interview questions to be tested, the pilot test was conducted through a separate interview session with five individuals who have similar background as the selected group in this study. However, the first set of questions was found to be inappropriate for this study because it could not provide sufficient information to answer the research questions.

Based on the finding of the first pilot testing, improvements were made in constructing the second set of questions. Three different sets of interview questions were used to interview participants from Group 1 (physicians), Group 2 (potential users of PGD) and Group 3 (religious organisations). Three different sets of interview questions were needed because some questions used for one group might not be appropriate to be used during the interview with another group. However, during the pilot testing some pertinent questions might surface, these questions were then incorporated into the new set of interview questions as deemed appropriate. After the first stage of the interview session with one participant from each of the groups, it was concluded that the newly modified set of interview questions was able to provide enough information to answer the research questions.

Thematic analysis is used to analyse the data collected in this study. Thematic analysis allows the researcher to identify all data that relate to the existing classified pattern (Aronson, J., 1994). The questions in the interview will allow the participants to give their views on the ethical and clinical issues, and also challenges posed by the use of PGD in Malaysia. The patterns that surfaced from the interviews were pieced together to

form a comprehensive representation of their perceptions on the technology. The interview questions are as follows:

- 1) Have you heard of PGD?
- 2) What do you think of PGD?
- 3) What are your views on issues pertaining to the moral status of the embryo?
- 4) Do you think of parents/couples/doctors who decide to use PGD either for themselves or performing it on their patients as someone who is trying to play with nature?
- 5) Do you think that PGD is about perfection or elimination of genetic diseases?
- 6) What do you think of parents who choose to go for PGD in their quest for conceiving the perfect child?
- 7) What do you think of using PGD for sibling donors? Why?
- 8) Who should make the final decision on whether to use PGD? Why do you think so?
- 9) As parents with children who are diagnosed with genetic disorder, describe how you feel about PGD?
- 10) Do these experiences influence your perception on PGD?
- 11) As individual living with genetic disorder, how do these experiences contribute to your view on PGD?
- 12) Do you think parents should be given the freedom to decide whether to use PGD? Why?
- 12) Based on your religious understanding, what should be considered when making the decision whether to use PGD?
- 13) Do you think PGD would influence society in relation to their views on people with genetic disorder? Why? How?
- 14) What would be the possible impact of PGD on the Malaysian society in the future?

15) Would you consider of using PGD? Why?

Conclusively, the themes that were established help researcher to construct the interview questions, which are based on the selected themes. These interview questions provide researcher with the sufficient information that will assist the researcher in answering the research questions, thus obtaining the objective of the research. For example, interview question “What are your views pertaining to the moral status of embryo?” is related to the theme sanctity of life. Participants’ responses to this interview question will assist researcher in the attempt to provide answers and explanations to the research questions; how do participant confront the issues discussed, what kind of approach they used, what are the factors that could dominate their perceptions or view on the issue and do their perception influence their decision-making on PGD. Obtaining the answer for the research questions will assist the researcher to reaching the objectives of the research that is to investigate and understand why people have certain mind-set, and to identify the factor that contribute to their views or decision. This flow is indicated in Figure 3.1

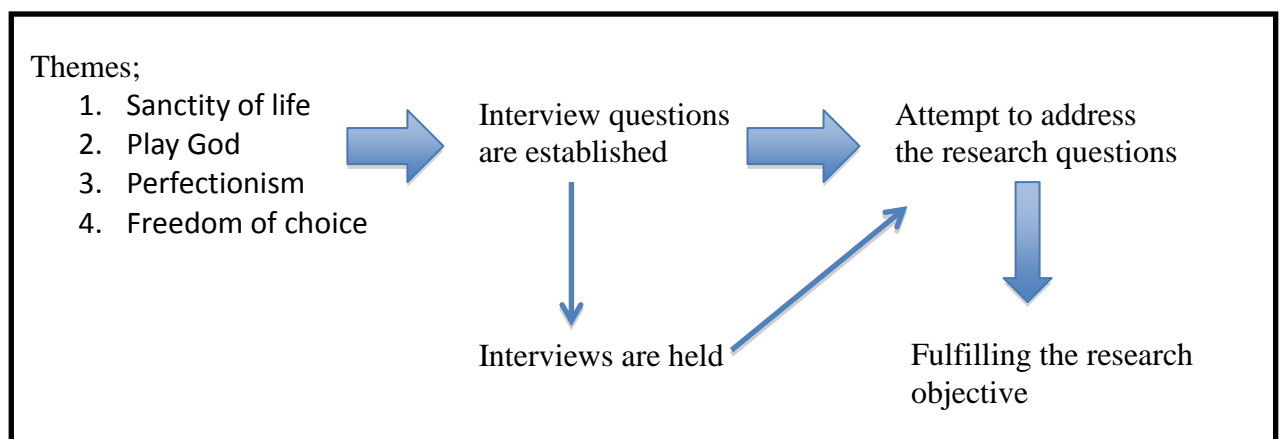


Figure 3.1 Diagram showing the flow of the interview protocol

3.8 Method of analysis

It is important that the method chosen for a research is fit to answer the questions being asked and also well suited for the purpose of the study (Holm, S., 1997). Based on previous research done using qualitative methods, there are a few methods that are frequently used to analyse the data collected. Thematic analysis is chosen for this study as the most appropriate method of analysis because it identifies, describes, analyses and reports themes and patterns within data (Braun and Clarke, 2006).

Furthermore, according to Clarke, thematic analysis is a flexible technique that can be used to analyse data obtained under a number of qualitative theoretical frameworks because it is relatively easy for new researchers to use it. However, the drawback of using thematic analysis is that it is not well described and thus, the interpretation is debatable, especially at higher level of analysis. Nevertheless, after much consideration and evaluation, thematic analysis is considered the most appropriate method for this study.

Thematic analysis either allows a rich description of the data set related to a broad research question or a detailed description of a particular theme within the data. In the first situation, researchers normally want to gain a cross-section of experiences related to their research questions. To achieve this purpose, researchers use an inductive approach in which patterns and themes are linked to the data collected and are not fundamentally driven by the researchers' pre-set theories (Braun and Clarke, 2006).

In the second situation, researchers are normally interested in a particular idea or issue that is derived from previous literature, or from their previous research studies and their own clinical experiences. Therefore, these researchers tend to use a theoretical or deductive approach in their thematic analysis derived from their pre-existing ideas. All

thematic analyses include not only a description of the themes identified but also interpretation of these themes, often in relation to previous reports in the literature.

A number of qualitative researches on the public's opinion on ethical and clinical dilemmas posed by PGD, have used thematic analysis as their method of analysis: this includes research on attitudes of patients and PGD providers on PGD (Kalfoglou et al., 2005), the opinions of medical staff working in the reproductive field on widening the scope of PGD in the UK (Williams et al., 2007) and views of medical professionals in regard to the moral status of the embryo (Ehrich et al., 2008). Thematic analysis was also used to analyse interview data, which were collected from the interview sessions with selected individuals from different Christian denominations in regard to their views on PGD (Doolin and Motion, 2010).

Using thematic analysis, Ehrich et al (2008) illustrated the findings in four main themes. The themes were used to demonstrate views of medical staff on the status of the embryo, their opinions on the issues pertaining to the discarding of unused embryos that includes donating embryos for research and how they manage the issues in order to achieve shared work goals.

Findings showed that in contrast to the image painted by the mass media that portrayed polarised stances regarding the 'embryo question' in PGD, the group of staff in one of the fertility clinics held a variety of beliefs about the following aspects: when life begins, when an embryo becomes morally significant, and the acceptability of discarding embryos or donating them for research purposes (Ehrich et al., 2008).

Therefore, thematic analysis will enable the researcher to identify themes throughout the interviews, which evolve into a comprehensive view of patterns that provide the data needed for the study. By having the recorded tapes of the interviews transcribed and making notes during or at the end of each interview, the researcher is able to store the data

more easily. Once all the interviews have been transcribed and analysed using thematic analysis, the data will be reviewed. The common information will be inserted under the existing theme as the data is reviewed.

Upon completion of the above task, the researcher can now build valid arguments for the selected themes and relate them back to the literature to develop a storyline. Once the literature or previous studies on the related topic have been interwoven with the findings of this study, the story that is constructed by the researcher will be one that stands with merit. The findings of this study, which are based on the participants' interviews can add new insight to research on PGD or reaffirm existing research findings on this topic.

At the same time, ethical theories are also used to ethically analyse the findings in order to understand the participants' responses on the issues discussed in terms of their ethicalities. By using these ethical theories, the researcher hopes to help readers understand the rationales of the participants' perceptions of PGD. Thus, the ethical theories applied may create understanding on why different individuals react differently to certain situations.

3.9 Ethical considerations

The first consideration is to obtain participants' informed consent. The first task in achieving informed consent is by providing participants with the necessary information regarding the research in a simple and understandable manner. At the same time, participants were also brief on the kind of information that was expected from them during the research. For participants from Group 1 and Group 3, informed consent was obtained directly from them either through phone calls or emails. Once they agreed to be interviewed, appointments for the interview sessions were arranged.

However, for Group 2, informed consent was obtained from the participants through the association, where interested participants were provided with the necessary information on the research. The requirements of the research were explained to the potential participants beforehand: they were briefed on the aspects such as the purpose of the research, what was expected of a research participant including the amount of time likely to be required for participation, the fact that participation was voluntary and that the participant could withdraw anytime and how confidentiality of a participant's information would be protected. Once the targeted participants agreed to be interviewed, their consent for the interview was conveyed to the researcher by the association's representative, either through emails or phone calls.

At the same time, other issues that should be taken into consideration while conducting the interview include respecting the privacy, opinions and sensitivity of the participants. In terms of privacy, some of the participants wanted to remain anonymous and some felt more comfortable to proceed with the interview without having their voices recorded. This was because some of the participants were uncomfortable to have their voices recorded although no specific reasons were mentioned.

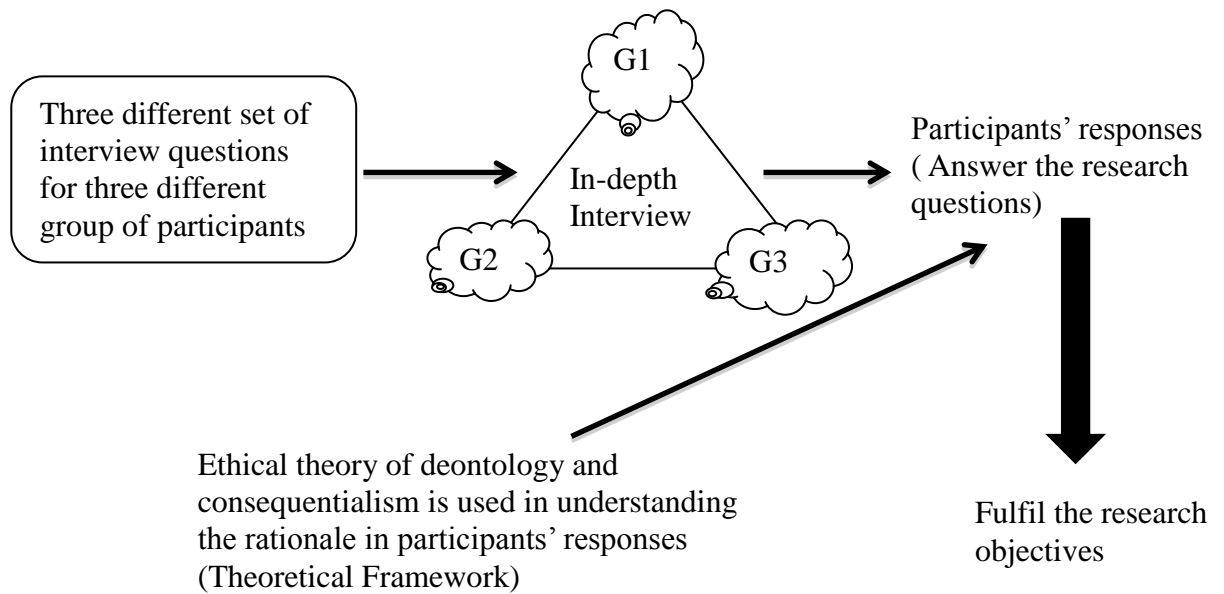


Figure 3.2 Diagram of research flow

3.10 Conclusion

Based on previous research that used qualitative methodology, the researcher decided that it is the most appropriate method for this study because it enables the researcher to understand participants' reactions regarding the issues being discussed. Qualitative methodology using open-ended, semi-structured interviews can provide answers to questions like, "why the use of PGD is acceptable to some but might not be acceptable to others?" and "what do individual means when they refer to using PGD as 'playing God?'"

The participants' inputs and responses during the interviews will lead to better understanding of why different individuals view some issues or situations as ethical issues or situations while others do not share the same view. Qualitative research such as this study will also help researchers to explore the reasons or factors that influence the

perception of the participants, which indirectly shape their understanding on the ethical issues of PGD. At the same time, this methodology is also the appropriate method to be used in a multicultural society such as Malaysia as it might reflect the diversity of the country's population in terms of their responses during the discussion of PGD. Cultural values are one of the possible influences on a person's final decision when considering whether to use PGD.

By using thematic analysis, the findings are presented in themes, which are representative of the participants' perceptions on ethical implications of PGD in Malaysia. However, it is worth noting that these findings do not represent the general views of the Malaysian population. Instead, the findings reflect the views of selected groups of Malaysians on ethical issues pertaining to PGD who have been interviewed by the researcher.

CHAPTER 4

RESULTS, DATA ANALYSIS AND DISCUSSIONS

4.1 Introduction

The purpose of this study is to explore participants' perceptions on ethical and clinical issues of PGD and the influence of their perceptions on their final decision-making on the technology. The study involved 21 participants, categorised into three main groups; The first group is PGD providers, which consists of medical professionals and medical scientists; The second group is potential PGD users, which comprises representatives of Thalassaemia Association of Malaysia and Down Syndrome Foundation or Kiwanis; The third group consists of representatives from various religious organisations: Young Buddhist Association Malaysia or YBAM; three different Christian organisations including the Roman Catholic Church, National Evangelical Council & Christian Council of Malaysia; and two Islamic representatives from two different organisations, which are Jabatan Agama Islam Malaysia or JAKIM and Dept of Fiqh and Usulludin, University of Malaya.

All the interviews were carried out at the following venues respectively: the participants' offices, their personal homes or the association's office compound; the aim was to find the most comfortable place for the interviewees. A typical interview session would start when the time and the venue for the interview were fixed and agreed by the interviewer and interviewee. However, one interview had to be done through email because the interviewee was too busy to spare some time for the interview sessions; she was willing to answer and explain her responses to the interview questions via email.

The interviews were recorded using voice recorder or note form because some of the interviewees preferred not to have their voice recorded. The recorded interviews were then transcribed. Information related to the identity of the participants, in particularly the potential PGD users, was removed as requested, in order to keep their anonymity. Thematic analysis was used to analyse the data collected and identified the themes, which were developed into a comprehensive view of patterns that provide the data needed for the study. Colour scheme table (Refer to Appendix A) are used to explain the overall findings in term of the participants' responses during the interviews, which were based on four key themes.

The four key themes are sanctity of life, perfectionism, playing God and freedom of choice. Briefly, the four thematic descriptions are as the following: 1) Sanctity of life, explore the participant's value toward human life, which might be destroyed during the process of PGD; 2) play God, an attempt to assess participants' perceptions on a technology that enabled human to take full control of their own procreation instead of leaving it to Nature or God 3) Perfectionism, assess participants' perceptions on a technology that allows the predetermination of preferred genetic combination while avoiding natural birth ; 4) Freedom of choice, assessing participants' perceptions on technology that increases the rights of individual to make decision on their reproduction process.

4.2 Thematic Analysis Phases

This research has followed closely the phases of thematic analysis as mentioned by Braun and Clarke (2006) and is tabled below;

Table 4.1: Phases of Thematic Analysis

Phase	Description of the process
1. Familiarising yourself with your data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing	Checking the details of themes in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis
5. Defining and naming Themes	Ongoing analysis to refine the specifics of each theme, and the overall story unfolded by the analysis; generating clear definitions and names for each theme.
6. Producing the report	The final phase of analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating the analysis back to the research questions and literature, producing a scholarly report of the analysis

Source: Braun, V. & Clarke, V. (2006), Using Thematic Analysis in Psychology

4.3 Results

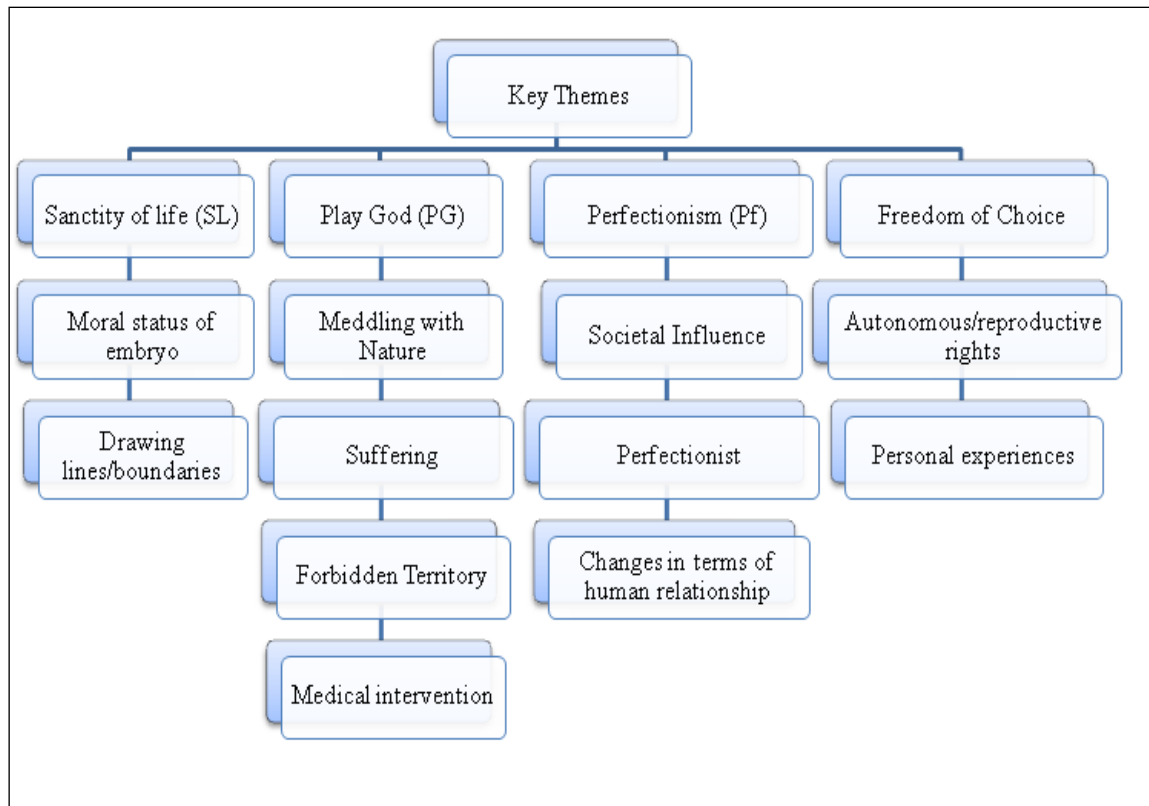


Figure 4.1 Chart illustrating four key themes and summarisation of pattern of discussion arise within each theme

Based on the findings presented in Appendix A, a new diagram is created to show how participants discussed the themes during the interview sessions (Figure 4.1). As an overview, Figure 4.1 above demonstrates the pattern of discussions that constantly emerged during the interviews with the participants. In theme ‘sanctity of life’, participants’ discussions were mainly focused on issues related to the moral status of the embryo.

Subsequently, the discussions progressed to creation of boundaries on what is acceptable and unacceptable when it comes to handling embryos. Their opinions on moral status of embryos covered not only creating a boundary between acceptable and

unacceptable actions towards embryos, but also placing limitations on how far they would accept PGD.

In contrast, in theme 'play God', participants centred their discussions on PGD as an attempt trying to meddle with the natural process of human reproduction or simply as a medical intervention that seems necessary for certain groups of individuals. As mentioned by some participants and shown in Figure 4.1, the notion of trying to 'play God' is like trying to enter a forbidden territory, which might result in occurrence of unfortunate events or uncovering unanticipated consequences that can bring misfortunes to humanity.

It is like opening a Pandora box where the content is unknown to the opener. Discussions on this theme also showed that participants included some talks on the idea of suffering. Some participants describe suffering as something that is necessary in human life; others opined that it is something that should be avoided if they have the means to do so.

The third theme, 'perfectionism' is a discussion centred on the idea of creating or designing an optimal quality of life in term of physical, mental or genetic wellbeing of their child using PGD. Some participants highlighted that the notion of creating the optimal environment or conditions in order to have the perfect child, can exert societal pressure on prospective parents to produce children who are free from genetic diseases. Thus, this social expectation may force prospective parents to make decisions not based on their own desires but on what are acceptable in the community where they reside.

Discussions on societal pressure for prospective parents to produce healthy children also included fear that it might lead to the creation of a perfectionist, both from the perspective of parents and society. This subsequently, raised concerns on the possibility of changes in terms of human values, which are measured by having the right physical or genetic combinations; such deviation can possibly have negative impacts on parent-child relationship.

Finally in theme ‘freedom of choice’, participants’ discussions were mainly focused on the issue of parental reproductive rights. Discussions on this theme also showed that some participants related their views on parental reproductive rights to their own experiences, as parents to children suffering from genetic disorder or individuals who are living with genetic disorders.

4.3.1 Sanctity of Life (SL)

Ethical issues pertaining to sanctity of life have a long history of debate whenever PGD is discussed (Doolin and Motion, 2010). Sanctity of life is always associated with the sacredness and holiness of human life. This has brought the discussions concerning sanctity of life to the question of when life begins, thus leading to the long-standing debate regarding moral status of embryo.

Based on the research findings, the participants’ explanations regarding sanctity of life were underpinned by religious doctrines, personal belief or by their scientific knowledge on human embryo. The discussion on sanctity of life brought about various perceptions on issues pertaining to the moral status of embryo, which subsequently becomes guideline for participants and thus, placing limitations when considering PGD. Therefore, the discussion on this theme is discussed in two part; moral status of embryo and boundaries.

4.3.1.1 Moral status of embryo

Most medical professionals in this study unanimously claimed that embryo is an accumulation of cell that has limited moral rights but deserving to be respect. Therefore, it

is ethically allowed to discard embryos that are unhealthy but the process of destroying this embryo has to be conducted in a delicate and respectful way. In medical profession, physicians are trained to follow medical guidelines.

According to one physician in this study, embryo is an accumulation of cells that is lacking distinct individual moral status but worthy to be respected and protected. Therefore, he does not think that by discarding embryos, we are violating the lives of another.

For another physician, embryo is viewed as something that does not have moral status as well as having limited rights when compared to a newborn child. Subsequently, he believes that legally, discarding unhealthy embryos are not a violation to human life as well as the law. So, technically and legally, the discarding of unhealthy embryos during PGD is acceptable.

“Legally in Malaysia, embryos do not carry any status of their own. Decision whether to discard it is at the hand of the parents. So, it is up to the parent to decide and we don’t get to say that they are violating the rights of the embryo.” (Participant 3, O&G Consultant, HKL)

In support of the above statement by the two physicians, it is also stated by the medical council that there is no worldwide agreement as to when human life begins or when it acquires moral significance as well as there is no agreement on moral status of embryo (Malaysian Medical Council, 2006). Nor is there any agreement as to whether discarding an embryo with a genetic disorder, prior to implantation, is equivalent of an abortion.

Therefore, based on the above excerpt and the given guideline by MMC, it is shown that the physicians are using their medical knowledge regarding moral status of embryo coupled with the mentioned guideline, when discussing on the issues of life.

Using a different approach, another two physicians explained their views on moral status of embryos by comparing the process of PGD with that of a conventional process of prenatal diagnosis (PND). They both feel that PGD is more humane when compared to PND. PGD enabled the discarding of the embryo within a few days of conception rather than at 11 weeks via the conventional PND procedure.

“When you compare PGD and PND, which one is worst? Is it more acceptable to discard a few days old embryo or few weeks old foetus where the human feature and function is more visible? I believe when we talk about violating a human life, it is more prominent when we use PND.” (Participant 1, Feta-Maternal sub-specialist, UMMC)

“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 involves the invasion of the woman’s body because the foetus is already growing inside the woman’s womb.”(Participant 7, Molecular biologist, UMMC)

In addition, the termination of pregnancy will get very complicated not only medically but also emotionally, especially for the mother. These views expressed by both participants above, which in some cases are influenced by the feeling of distress that they attributed to women or couples facing the possibility of termination, which were also mentioned in previous study reported elsewhere (Ehrich et al, 2008).

Despite the labyrinth of complexity of 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 (Hershberger and Pierce, 2010).

Although all the medical professionals in this study think that embryo is just an accumulation of cell that do not carry any moral status, they do not want to imply their

views on it to influence their patient's view on the matter. They do not deny that their patient might have a different view on moral status of embryo, thus for one medical professional she mentioned that,

“Although in my opinion that embryo do not have any moral status, I do not deny that some might have different opinion. It's depends on ones definition of when does life begin. Some people might view that discarding of embryo during PGD as an act of abortion and some might not. This is just because we have different opinion on when does life begin. If in my opinion that PGD can be an advantage but my patient against the destruction of embryo due to their religious or personal belief or moral value, then I won't push it. I respect their view on embryo and its status.” (Participant 7, Molecular Biologist, UMMC)

On the contrary, two medical professionals mentioned that when patients come to them to request for PGD, it is very clear that they have made up their mind over it and they must have discussed it very carefully prior to their decision to use it. For both of the participants, it is clear that the patient has also overcome the issues of embryo's status.

“I am not so particular on the issues regarding moral status of embryo in PGD because I think embryo is not a human life. Furthermore, when parents choose to go for PGD, they must have already thought about all the related ethical and clinical issues of PGD before making their final decision. So, I believe, at this stage, there should be no fuss unless parents change their mind, which also they have the right to do.” (Participant 4, Fertility sub-specialist, UMMC)

“Well, it's depend on each person beliefs or values because some will see it from the perspective of their religion or personal values. So, it is not right to tell someone that their views are not right just because you do not have the same view.” (Participant 8, Human Geneticist, Monash University)

Supporting patients right to their own opinion, one physician mentioned that sometimes parent has to make drastic decision such as resorting to PGD because they want the best for their children. He believes that by choosing to avoid the birth of a sick child, the parents are thinking about the welfare of the child after birth. Rather than letting the child suffer, the prospective parents chose to use PGD and avoid future suffering to their unborn child; this could be in the form of countless painful surgeries, cost of treatments or medication, which the parents might not be able to afford. Creating and destroying embryos to have a healthy child are not acts of treating embryos in a frivolous way; they are handled with respect (Robertson, JA., 2003).

However, one participant described the destruction of embryos during the use of PGD as direct killing of human life and not an act of abortion. She describes that the action of discarding embryo outside the human body indicate that the embryo is not even given the chance to live unlike foetus that was aborted when the pregnancy was terminated. This indicated that she believes embryo has a life and moral status as a born human being. Therefore, this particular participant became the anomaly in this group.

Most medical professionals in this study showed that their perceptions on moral status of embryo are grounded in the argument that the landmark of human life is when the blastocyst is implanted in the uterine wall. Indeed, this is the first stage at which the individual is defined because the embryo is past the stage in which it can split to form twins. It is only after this stage has past that the life of one individual starts as a recognizable one (Hug, K., 2006). It is based on this argument that most medical professionals in this study conclude that embryo is not a life and do not have moral status.

On the contrary, the discussion with potential PGD users (Group 2) regarding theme 'sanctity of life' showed a rather interesting finding. The first two potential PGD users are both mothers to children afflicted with Down syndrome. For both mothers, they

are not so particular when it comes to issue related to the moral status of embryo. They both believe that regardless what society or others opinions on the issue, if the parents already decide to use PGD they will just go for it.

“Actually, that ‘issue’ has not crossed my mind. For me, embryo is embryo. I do not think it as anything else. The destruction of embryo happens during the process because it is part of the procedure. Furthermore, the embryo is unhealthy right? Would you place an unhealthy embryo inside your womb when the purpose of using PGD is to implant the healthy one?” (Participant 10, mother with a daughter afflicted with DS)

“I am not so sure how would I feel about moral status of the embryo because I never thought of it as a possible living thing. For me, it is just embryo. I guess I could refer to my Pastor to know what my religion says about embryo status.” (Participant 9, mother with a son afflicted with DS)

On the contrary, for two other potential PGD users, they prefer to consult their religious leader on issues such as the embryo status because they want to ensure that they know and understand what does their religion’s stand on the issue. They both feel that religion is as an authoritative body that provide them with guides when they are facing tough and conflicting medical decisions; it becomes a benchmark that is used to evaluate their available choices before they make the final decision.

“I would prefer to know what does the Fatwa said about moral status of embryo.” (Participant 11, mother with a son afflicted with Thalassaemia)

“Yes. I agree. I will feel better when I know what does the Fatwa said about it and also their opinions on PGD in general. It is better to know what Islam stands on the issues of PGD or other new reproductive technologies before I make any rash decision.” (Participant 12, mother with two sons afflicted with Thalassaemia)

These findings differ with the two potential PGD users mentioned earlier (Participant 9 & Participant 10) where they are not so particular on issue concerning moral status of embryo as compare to another two potential users (Participant 11 & Participant 12). Unlike the latter two potential PGD users, the first two participants' perceptions on embryo status are based on their personal belief on embryo and its status. Although one of the participant would like to know what does her religious leader's view on embryo status, she personally think that embryo is just an embryo.

For both potential PGD users, they are more focus on the practicality of the technology, which explained why one of them mentioned that the destruction of embryo during PGD is just part of the procedure and more of the consequences of using the technology. On the other hand, Participant 11 & 12, prefer to know the opinion of their religious leader in order to state their own views on embryo status.

Three other potential PGD users are individuals living with genetic disorders and in their mid 20s. All three of them agreed that they would like to know their religious leader views on moral status of embryo. This is because they are not sure how does the religious authority's view on issues related to embryo status. Although knowing the benefit that PGD can provide them, they still acknowledge the important of religion and how it can impact their view on embryo status, and their decision on PGD. However, for them, these views might not be the only factor that contributes to their decision on PGD, as they also will include other relevant information such as the costs involve, safety issue, quality issues or the success rate of the technology.

"I am not sure what does the Fatwa says about moral status of embryo. But I would like to know. It will be good to know anyway. Furthermore, knowing their opinion on embryo status will more or less be a good guide when I'm making decision on PGD

although, I will not deny other factors that I might include when making my decision.”
(Participant 14, individual living with Thalassaemia)

“I agree that I would like to know what they think about the issue of embryo’s status when it comes to new reproductive technologies. But whether my decision is depending on their opinions, is another matter”. (Participant 13, individual living with Thalassaemia)

Potential PGD users displayed two different perceptions; 1) perception on embryo that is based on the practicality of the technology, which view destruction of embryos during PGD is part of the process; they do not place embryo status higher or having the same status of that of a born baby, 2) perceptions that is based on religion; the view of religious ruling body on embryo status ranked higher than their own view on embryo. However, for three potential PGD users, perceptions on embryo status goes hand in hand with the practical aspect of the technology and religious ruling on embryo status; it is displayed that both aspects to be equally important in their perception on PGD.

This is an important finding because frequently presentations on perceptions of individual on embryos status are generally based on personal, religious or professional belief, which eventually lead to their perception on PGD. But this finding suggest that religious belief do not necessarily reflect participants perception on PGD although it is highlighted as important in term of providing them with a guideline. It is suggested that while religious views on embryo status is important; this is not the only factor that concerns the participant when making their perceptions on PGD, which was displayed by three potential PGD users.

Almost all religions express ambiguous understanding in regard to the moral status of embryos (Cole-Turner, R., 2003). This ambiguity is also shown in the findings of the discussions with the six participants from the third focus group in this study, representing different religious organisations in Malaysia. For three Christian representatives, the notion

of sanctity of life show that every human life are all sacred and holy, therefore deserve to be preserve and respect. Embryo that is created during the process of PGD is a human life because Christian believes that life start when conception happens.

They stressed that even though the embryo might be unhealthy and would probably be affected with some kind of genetic disorder, it does not give us the right to destroy it because they are creation of God. Their views on embryo status are based on Christianity belief in sanctity of life, which is derived from its doctrine of God as Creator (Tang, A. 2008). According to this belief, God has made man in His image and each individual is precious to Him and made for internal destiny.

“In Catholicism, it is a firm belief that life begins as soon as the fertilisation process starts. Therefore, we view embryo as life itself that does have a moral status and needs to be respected. I do understand that parents want to have a healthy child by choosing to go for PGD, but they need to be aware at the same time that, they have committed a grave sin by destroying not one but several innocent lives.” (Participant 18, Ethicist and a priest for the Roman Catholic Church)

According to the New Testament, it teaches that God died for ‘the world’ that is everyone, people from all states, conditions, nations and orientations toward God and neighbours. It reminds us that God lay down His life not just for his friend but his enemies (Roman 5:6-11). The universality of life’s dignity is affirmed and it is written in 1 Cor 8: 1-13 that, “Who am I to harm one for whom Christ’s died.”¹⁵

“The process of conception itself is a process which already has a moving direction or development towards personhood. Therefore, it should be allowed to grow and develop naturally. It should be allowed to grow to its potential as human regardless of how it will turn out to be. It is not appropriate to destroy the lives of these embryos just because they

¹⁵ All Bible verses are taken from NIV bible.

might be disabled. Who are we destroying what God has created” (Participant 16, Christian Evangelist & scholar, Kairos Research Centre)

For Christian, human life is view differently compares to the life of an animal or a plant because human share something of nature with God as written in the Holy Scripture where God created Adam and breathed into his nostril the breath of life and this did not happen to plant or animal. It is also mentioned that human are made in the image of God, which means that human are somehow a reflection of God (Tang, A. 2008). So no matter how imperfect the child will be when they are born, as Christian parents, they should accept them as who they are and believe in the providence of God.

These findings showed that Christian representatives are discussing issues regarding sanctity of life from the perspective of Christian belief that life is derived from the doctrine of God as Creator. Therefore, any human including unborn children are precious and special because they are all God’s creation. To destroy it will mean, destroying God’s creation, which human should not do.

It is based on this perspective, that Christian representatives reject the notion of using PGD because of its negative consequences toward embryo; in this case, the destruction of unwanted embryos. One Christian representative explained that only God has the sovereignty on life over death. Therefore, he thinks that it is not right for human to decide who get to be born and who don’t, thus, explained his discouragement toward the use of PGD among Christian parents.

However, for two Islamic scholars, they do not view embryo as a life because in their opinion, embryo do not have any soul. This is accordance to Islamic views on life, which stated that life only begins when it has soul and the soul only enter the body 120 days after fertilization happens.

“According to the Islamic Law, the spirit or soul of the foetus will only enter the foetus, 120 days or approximately 4 months after conception. Therefore, before 120 days, embryo is not considered as human life. This explains why in Islam, PGD is permitted as long as it is done for medical purposes.” (Participant 19, Islamic Scholar, UM)

“In Islam, life is considered as sacred and should be respected. However, embryo is considered as living human only after 120 days of conception in which in this period the spirit (‘roh’) is breathed into him. So you can see, embryo that is use in PGD is not considered as life yet.” (Participant 20, Islamic scholar, JAKIM)

For one participant from the Buddhist association, he believes that life begins during conception as in accordance to the teaching of Buddha. Therefore, any action that resulted in the destruction of life is prohibited.

“In Buddhism, as soon as a child is conceived, it is the beginning of life. Therefore, embryo is a form of life. Destroying it will be unacceptable. PGD for me is acceptable if the remaining embryos are not discarded. They can be frozen for future use by the parents.” (Participant 21, consultant to YBAM-Young Buddhist Association of Malaysia)

However, he understands that at some situation parents are forced to find an alternative in order to avoid the transmission of inherited genetic disease to their future children, which sometime can cause severe suffering to the child. The intention of the parents to avoid the suffering of their future child and the effort that they do to avoid such thing from happen is view as having a good intention toward another human being.

Helping others who are suffering can also be explained using the Law of Karma, which means, our actions have consequences. So basically if you help others now, probably in other time or life, the favour will be return to us in other forms.

“If the decision to use PGD can end up with happiness for both the couple and their desire fulfilled by having a healthy child, then it is fine. There is no reason to prevent

them from using PGD. After all, Buddhism emphasise on personal happiness and fulfilment and also, the need to relief other from suffering.” (Participant 21, consultant to Young Buddhist Association of Malaysia [YBAM])

4.3.1.2 Boundaries

Creating a boundary and delineate what are acceptable and unacceptable in terms of human existence is important for new reproductive technologies such as PGD (Doolin and Motion, 2010). Not only it will guide participants when evaluating their decision on PGD, boundaries that they created also place limitation on how far they are willing to accept the use of PGD or how far are they willing to go in term of providing PGD to their prospective patients.

According to medical professionals in this study, there are two type of limitation that they place when providing PGD to their patient; 1) when the procedure might end up imposing harm to the child and 2) if the purpose of the request has nothing to do with the medical conditions of the child or parent.

“For me, if the parent has very strong medical histories of repeated genetic diseases in the family and they do not wish to pass it to their future child; I do not feel why I should not provide them with the service. As physician, my aim is to provide patients the best medical care that I can afford to do. ” (Participant 6, Feta-Maternal sub-specialist, FMGC)

“I would not provide the service if the patient reason to use it is very lame. For example, in the case of susceptible condition because I think in susceptible condition like breast cancer, the disease is preventable if detected earlier. Furthermore, there are treatments for the disease. So, there is no need for anyone to go through such an invasive

procedure like PGD for something that is treatable and preventable. As much as I wanted to help my patient, I place my limit there.” (Participant 2, Feta-Maternal sub-specialist, UMMC)

For potential PGD users, their boundaries on PGD are decided by two main factors that are based on the aspect of religion and, safety and quality of PGD. For two potential PGD users, their religious leader’s perception on PGD is important that it become a benchmark in regard to their acceptance of PGD. However, this differs from two other potential PGD users where the acceptance and limitation on PGD is not influence by the religion aspect but instead, the safety and quality aspect of PGD dominates it. They will use PGD as long as there is no harm done to their child.

However, touching on the issues of limitation on the use of PGD, one potential PGD user mentioned that sometime the limitation on PGD could be very restricted that it prevents parents from accessing it. Such overly restrictive boundary will deny them to receive the only medical treatment that can help them. She argued that sometimes, organisations or institutions place too many restrictions on some medical technologies. Eventually, these restrictions become a major obstacle for prospective parents to even consider using the technology.

The concern that is highlighted here is consistent with the concern that was highlighted by participants in a study conducted in the USA (Kalfoglou et al., 2005); governmental regulations are too restrictive and those who could benefit from PGD will not have access to it. But despite this concern, she still feels that restriction is still needed in order to avoid the misuse of the technology.

Participants’ discussion in theme ‘sanctity of life’ can be best described and rationalized using two ethical theories; the ethical theory of deontology and consequentialism. In deontological theory, it described that some people adhere to their

duties when they analyse ethical issues (Beauchamp, TL., 1991). This can be observed in the responses from some participants where it highlights their duties to their profession and religion.

Commitment toward one's duties and obligations are demonstrated among medical professionals where they feel the need to respect and protect the embryo although viewing it as non-human life; handling and discarding the unhealthy embryo after the diagnosis. In another finding, participants also displayed their duty to the higher power; perceptions on the sanctity of human life are solely base on their religious teaching on life. They described that it is more important than their own personal views on the issue.

On the other hand, some of the responses can also be rationalized using the ethical theory of consequentialism, which stated that the consequences of one's conduct are the ultimate basis for any judgement about the rightness of that conduct. This can be observed among Christian representatives where, their disapproval on PGD is not just because it against the Christian belief in the sanctity of human life but also, due to its negative consequences toward human life; the destruction of several human embryos, which to them is a life. Consequentialist theory can also explained why some potential PGD users place limitation on PGD, particularly, if the technology shows possibility of harm to their child.

The participants overall perceptions on moral status of embryo showed diverse responses, which are influenced by several factors that allowed them to discuss the issue from different perspectives. For medical professionals, their perceptions on the sanctity of life are generally influenced by their medical knowledge on human reproductive health, which stated that human life is only considered as recognizable one when the embryo are implanted at the uterus wall. Thus, indicate their support for the use of PGD and their disregard on the notion that PGD is destroying human life.

For the potential PGD users, their perceptions on the issue are varied and interesting because they are divided by their outlook on the issues into three small cluster within the group itself; 1) perception that focused more on their personal value on embryo status; embryo is not a life thus, accept the destruction of embryo during PGD as part of PGD process, 2) perception on sanctity of life are dominated by the view of their religious ruling body on the issue, which influenced their acceptance on PGD as well and 3) perception on sanctity of life are equally influence by both aspect of religion and practicality of the technology, although decision on PGD might only reflect one of those aspect.

The findings also highlight the differences of perceptions on the theme by representatives from different religious organisations; Christian perspectives on this theme are based on Christian's belief in the sanctity of life, which is derived from the doctrine of God as Creator; Islamic scholars' perceptions on sanctity of life is very much based on the notion of human ensoulment that stated human life only begins when the soul has entered the body; and Buddhist representative's perceptions on sanctity of life is based on Buddhism teaching of good intention, where the destruction of embryo is acceptable if the intention is to avoid the suffering of the child.

4.3.2 Play God (PG)

The second key theme in this study is 'Play God'. This theme describes how PGD is viewed as trying to override the natural process of human reproduction and allowing humans to act as God by selecting the child they desired. Trying to 'play God' is a metaphor used to convey images of humankind transgressing its role in nature and trying to become God liked; refusing to accept God's ordained limitations (Jones,G., 2004). The

theme ‘play God’ is also used to demonstrate participants’ concerns, especially on the new applications such as PGD for sibling donors and late onset medical conditions; they believe the said practices would increase the demand for PGD to be used for social purposes.

Thus, this theme is discussed in four parts: PGD view as human meddling with nature and entering a forbidden territory, PGD as medical intervention and the use of PGD to avoid the notion of human suffering.

4.3.2.1 Meddling with Nature

The finding shows that all medical professionals (Group 1) claimed that PGD is not playing God. They argued that parents who choose to use PGD or physicians, who decide to provide PGD to their patients, are not trying to meddle with natural process of human reproduction. This is because PGD is viewed a medical intervention that seems necessary for certain group of people. For two medical experts, they feel that it is not right for anyone to judge parents or physician who provide or use PGD as both party only has one thing in common; to provide the best possible medical care for their patient or future children.

“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.” (Participant 7, Molecular Biologist, UMMC)

“I do not see it as trying to play God nor do I think that parents who choose to go for PGD is trying to play God. This is because it is an individual choice.” (Participant 1, Feta-Maternal sub-specialist, UMMC)

Another physician viewed PGD as medical intervention that provide necessary help to parents who require intervention in order for them to have healthy children. In fact, he views parent’s decision to go for PGD as an act of courage. This is because not everyone is

brave enough to come forward and take their chances to try new medical technologies such as PGD. Not to mention that it is still risky and the invasive procedure involved, and with the possibility that the technology might fail them in term of getting a success live birth (Hershberger and Pierce, 2010).

“In fact for me, that is an act of courage. Parent is willing to go through an expensive, invasive and risky procedure such as PGD, knowing there is still a small change that it might fail. There are such cases you know although not that many. I mean, what kind of parent will you be when you know that you are able to do something to save your child and yet you do nothing about it.” (Participant 1, Feta-Maternal sub-specialist, UMMC)

In another response, one physician claimed that he do sympathize and understands why some parents might be willing to go through PGD despite the ethical controversies attach to it. He thinks that the country health care system is not sufficient as compare to the Western countries in term of providing the moral and financial support that these parents need; parents with disabled children.

“Our health care systems do not have sufficient after care for children with genetic disability either toward the child itself or to 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.” (Participant 6, Feta-Maternal sub-specialist, FMGC)

For two other medical experts, the term play God partly emerged due to the lack of awareness and information on how PGD work and what is it capable of. They believe that the general public lack of information on PGD, which resulted in their perception that PGD, is trying to play God. Media portrayals and public perceptions about negative social consequences of using reproductive technologies like PGD are sometime exaggerated due to lack of knowledge on the technology (Kalfoglou et al., 2005).

“I believe that society think 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 3, O&G Consultant, GHKL)

“I believe that a lot of people are still sceptical about it because they are not so much of information available to educate Malaysia society regarding it.” (Participant 8, Human Geneticist, Monash University)

On the contrary, potential PGD users displayed mixed responses. For two potential users, the notion of PGD as trying to play God by changing the natural process of PGD has not occurred in their mind. This is because for both of them, they see PGD as medical technology and an alternative treatment for parent like themselves; parent who has children afflicted with genetic disabilities. Having to raise children with genetic disability, they do understand why some parents choose to go for PGD. They do not look at PGD as trying to change the natural process of procreation but to help those who are out of option.

“What important to me is that my child is healthy. Whether people want to say that PGD is playing God is up to them. As for me, such comment is not important as compare to the health of my kid.” (Participant 10, mother with daughter afflicted with DS)

However, this differs with two other potential users who do view PGD as playing God. They do not think that it is right for us to choose our children even before they were born. Parents should accept their child as they are instead of trying to change their genetic combination in order to have the child that they desire. Sharing her experiences of raising a child affected by genetic disorder, she explained that it has taught her how to be persevering and accept God’s plan in her life. She mentioned that even a severely ill child or disabled child could have positive impact on one’s life.

“Sometimes, although our children are sick, they always manage to give us joy and happiness despite the struggle we have to go through by taking care of them. I am talking based on my own personal experience of raising my son who is also a Thalassemia patient.”
(Participant 11, a mother with one son with Thalassemia)

They both feel that everything that happened in their life, happen for a reason. They accept it as God’s plan in their life and if God already plan that they will face such challenges in their life, they trust that He also provide them the strength to go through it. As Muslim, they both place their faith in God’s hand and just trying their best to make the best out of the situation; they will not resort to PGD.

Using their own personal experiences living with genetic disorder, three of the potential PGD users described PGD as not trying to meddle with nature, less more trying to take over the work of God. According to one of them, sometimes, parents are forced to ‘play God’, not because they want to but due to urgent needs of the situation. He understands why some parent may choose to use PGD as he might consider it too because he do not wish to pass down the Thalassemia genes to his future kid. At the current situation, PGD is the only one that can provide parent with that option.

“You can view it as trying to play God or meddling with nature but it depends on the individuals as well because they have their own reasons to do so. And due to my own circumstances, I tend to understand why & I do not want to pass judgement on those who use it.” (Participant 13, individual living with Thalassemia)

“I also do not want to judge couple who use PGD as trying to play God. Personally for me, these couples are not trying to play God but just want to do the best they can for their child. As in my case, I won’t totally reject the idea of using it but at the same time, I am not saying that I will use it. At the end of the day, a decision has to be made.”
(Participant 14, individual living with Thalassemia)

“I don’t really bother for those who want to use PGD, nor will I judge their action or decision as trying to play God. To each is their own.” (Participant 15, individual living with Thalassaemia)

In Christianity, it teaches its follower to accept things that happen in their life as God’s plan for them. Christians are encouraged to believe in the providence of God and it is based on this perspective that the three Christian representatives argued on the issue of PGD and play God. They argued that children should be accepted unconditionally, regardless of how imperfect the child might be because every child is special.

Trying to change children based on the parent’s desire is like rejecting God’s gift and plan in our life. One participant opined that interfering with the work of God is like messing around with nature and this might bring unfortunate events to humanity in the future.

“The term playing God is always associated with the use of PGD because it has the ability to allow parents to select their child. As for me, I rather leave it to nature and just accept it as it is.” (Participant 16, Christian Evangelist & scholar, Kairos Research Centre)

Another Christian representative mentioned that only God has the authority and right to choose who gets to be born and who does not, and who will be born healthy and who doesn’t. When one changes the natural genetic characteristic of a child instead of just accepting it as it is, it is considered as trying to play God.

“How can you not say that they are not trying to play God when clearly for me, they have the ability to select and discard embryos. If they are not trying to play God, then no need to indulge in such technology and just accept the child as it comes.” (Participant 18, ethicist and a Catholic priest)

On the contrary, Islamic representatives do not view PGD as trying to meddle with nature but more as a medical technology that was designed to help improve human kind.

Both of the Islamic scholars in this study stated that God urge its follower to use available medical technologies that can treat and cure a person from sickness including, children. Both feel that if the technology is use for medical purposes and it does not result in harm to the child, then it should not be label as trying to play God but as an attempt to cure a disease.

“If it is done for social reasons, it is forbidden in Islam because it does not have any necessity. The act of choosing indicates that we are not pleased with what God has given to us. But if it is done to avoid any disease, it is not trying to play God but rather our efforts to ensure that our generation is fit enough and will not spread any genetic disease.”
(Participant 20, Islamic scholar, JAKIM)

Islam permitted therapeutic research as long as it has not reach the blastocyst stage and since PGD testing is done before this stage, therefore, it is allowed to use it (Hug, K. 2006). However, it is forbidden if the purpose of using PGD has nothing to do with medical condition (Fadel, HE., 2007), but for producing children that is at advantage socially. This is because by changing the social feature of a child, it looks as if parent is not happy with what God has given them, as what the Scripture tell us,

“O Men! Truly We have created you from a male and female, and made you into nations and tribes that you might get to know and be kind to one another. The noblest of you in the sight of Allah is the one most deeply conscious of Him among you (not accordance with the nobility of lineage or ethnicity). Truly Allah is most knowing. Most Aware (of your state and deeds).”(Al-Hujurat, 49:13)[Participant 20, Islamic scholar, JAKIM]

Therefore, the colour of our hair, the type of our eyes and other part of our body has its own purpose exclusively created differs from one another.

One male representative from the Buddhist organisation stated that it is entirely up to the parents whether they want to use PGD. He believes that other people are not in the position to judge them as trying to play God by doing so. This is because he believes that every parent has good intention when they decided to use PGD as well as trying to make everyone in the family happy.

Thus, if PGD can provide them with the happiness they are looking for, he argued that others should not criticise the decision of these prospective parents. They are just trying to become parent and trying their best to provide the best to their child.

4.3.2.2 Suffering

The term ‘suffering’ is vaguely used in public discourse. Cassell (1991) defined it as the state of severe distress associated with events that threaten the intactness of a person. A few participants related the use of PGD as a tool to relieve pain and suffering for both the child and the parents. However, not everyone agree that the notion of human suffering is good enough a reason to use PGD, as suffering is something that is unavoidable. It is part of the norm of being human.

According to one physician, PGD is not only a medical technology that enable parent to have healthy child but it is also a technology that can relieve the suffering of both the parent and the child.

“It can stress both the parent and child. It is also an emotional suffering for parents to see their children struggling and unable to lead a normal life like healthy child. Thus, if PGD can avoid both parent and children from suffering, we should not prohibit them to use it and accused these parents as trying to play God. I do not think that it is fair to do so.”
(Participant 1, Feta-Maternal sub-specialist, UMMC)

However, for two potential PGD users, having to raise one or two children who are afflicted with incurable genetic disease, is indeed a journey of ‘suffering’ for both the children and themselves. But they did not refer the term ‘suffering’ as negative experience. Instead they described the experiences as ‘special’, which have made them tougher and enriched their life in so many ways.

Both potential PGD users look at the ‘suffering’ that they been through as destined by God and accepted it as ‘takdir’. This finding shows that both potential PGD users believe that human suffering is something that is bestowed by God in order to bring human closer to their faith and be humble.

Any religion seems preoccupied with the issue of suffering because the act of suffering is very much related to the idea of spiritual growth and testing of self-understanding for most religious communities (Evans, JH., 2006). Based on this understanding, one Christian representative stated that he believes that suffering is not only part of human experience but also the ‘will of God’. At the same time, he also mentioned that suffering is very subjective because it differs from one person to another.

“How do you define suffering? Is it just because the child was born with one leg or because they need to go through medical examination every month? And who gets to decide whether the child is suffering from his or her medical conditions? Just because parents believe that a severely sick child could not enjoy a care-free life and enjoy the same thing as other healthy children, it does not justify the act of terminating their life by discarding the embryo.” (Participant 18, Ethicist & a Catholic priest)

Therefore, he concluded that using PGD for the purpose of avoiding suffering is unacceptable.

4.3.2.3 Forbidden territory

For some, trying to change human genetic combination is like entering a forbidden territory where previously, only God has the authority to decide (Doolin and Motion, 2010). As Doolin (2010) stated, the term of trying to ‘play God’ generally has connotations of going where we should not be going and inquiring of things that lie outside the scope of our interests.

It looks like humans are aiming to become God-like in their own power. For one participant, he argued that we should not use scientific powers for superficial and frivolous ends; using these scientific interventions for minor gains is dangerous and irresponsible.

“For humans like you & me...trying to play God or becoming God is a very dangerous thing because human beings are very unpredictable. Greed can overcome anyone and this will not lead to a good ending. I guess that is why the churches have their doubts on PGD. It’s like playing God. No one can be God or even trying to be one because God is God.”
(Participant 18, ethicist and a Catholic priest)

The above excerpt highlighted the way one participant described why he thinks that trying to play God is a dangerous game because it might result in negative consequences, such as the misuse of the technology for personal gain; raising the point why one should not manipulate or mess around with genes. These words were used in a pejorative sense, indicating that such interventions are something that human beings were not really capable of doing without ‘messing up’ (Jones, G., 2004).

4.3.2.4 Medical intervention

For one physician, he viewed PGD as a means to provide options for parents to avoid the traumatic experience of going through termination of pregnancy; the procedure is required if the child is tested positive to carry the defective genes. In another discussion, one medical expert suggested that PGD is the best option in terms of medical intervention to prevent the birth of children with severe genetic diseases.

“I do not view it as trying to play God because for me, it is medical interventions that help parents to choose their future children that are going to be healthy and be able to enjoy their life without having to depend constantly on medical treatment.” (Participant 7, Molecular Biologist, UMMC)

Knowing the benefits of this technology, most medical professionals agreed that there should be a balance in evaluating between the positive and negative consequences of PGD. However, putting a stop to it can also pose danger to society because we need technology development in order to maintain stability and improve the health of the population. This technology is considered as medical advancement and a milestone in both reproductive and genetic technology.

Most medical professionals feel that PGD can bring more positive outcomes, thus saving more lives, if it is monitored closely. According to Kalfoglou et al (2005), using the technology frivolously can result in a backlash against PGD and subsequently, lead to overzealous regulation that might limit appropriate access to PGD.

Conclusively, medical professionals' perceptions on PGD in this theme are dominated by their knowledge in the field of genetic and reproductive medicine. This can be observed in their views regarding PGD; it is not view as trying to play God but medical intervention to save lives and avoid the suffering of both children and parents. Furthermore, lack of

knowledge on PGD is also highlighted as one of the main reason why member of the public have wrong impression on PGD. As for potential PGD users, their approach to the theme 'play God' are including; 1) from the perspective of Islamic teaching about accepting the will of God, 2) from the perspective of their children's health and 3) from their own personal experiences living with genetic disorder.

Finally for the representative of various religious organisations, they are using religion based approach such as Christian teaching on the providence of God, Islam teaching on seeking treatment and cure for diseases and Buddhism teaching on good intention and suffering.

4.3.3 Perfectionism (Pf)

The term 'perfectionism' is referring to the persistence of will in obtaining the optimal quality of spiritual, mental, physical and material being. It is used here to describe the quest for perfection, where parents trying to obtain the highest quality of life for their child using PGD, thus fulfil the desire of their own version of perfect child. Discussions on perfectionism normally triggered off talks on the topic of discrimination and issues related to the marginalisation of certain groups of people.

This could encourage intolerance towards individuals possessing genetic disabilities of inhibited by such disabilities. Marginalisation is defined as a social process of becoming or being made marginal or relegated to the fringe of society (Crossley, M. 2004). In this theme, the discussions included the following topics: the possibility of creating parents who are so obsess with perfection, influence of society towards human perfection and PGD as agent causing changes to human relationship among one another or between children and parents.

4.3.3.1 Perfectionist

Participants who work in the medical field (Group 1) stated that PGD does not only help to eliminate genetic disease but also, a medical tool that parent can use to provide their children with a good quality of life.

“I don’t think that parents will use PGD to create this so called superhuman but they just want to have healthy children and PGD is able to help them. As parents they just want to make sure that their children have the best possible life at the moment they were born. They do not wish to see their children suffering from diseases that might not have any cure, and PGD might be the only medical treatment that can assist them.” (Participant 7, Molecular Biologist, UMMC)

“Personally, I don’t believe that PGD can be the ultimate tools to create extraordinary human but it can facilitate parent’s desire to provide the highest quality of life to their children especially when previously they have children suffering from genetic disease.” (Participant 1, Feta-Maternal sub-specialist, UMMC)

The emergence of PGD is viewed as an alternative for parent who wish and willing to explore new medical technologies in order to prevent the passing of mutated genes to their future children. For parent who had a child afflicted with genetic disease, it can be a traumatic experience for them thus, push them to be resourceful in order to make sure that their subsequent child does not get affected with the disease. For one physician, he does not look at this as negative desire. This is because it is the parent responsibility to make sure that they have try their best to make sure that their children are able to enjoy their life as much as possible.

According to him, some diseases are very rare and treatments are sometimes very expensive or access to medication is very limited. Therefore, he opined that PGD might be

the best solution for these parents who wish to avoid the said predicaments. In a situation where the genetic disease is very rare, technology such as PGD, enable parents to select healthy embryo for implantation, thus avoiding the need to deal with the after care and treatment of the child.

This in return could be a cheaper option for them instead of having the need to go for expensive treatment and medication for a long duration of time, and yet do not provide any cure for the disease. At the same time, he also mentioned that the insufficient support in term of the welfare of the genetically disabled child or parents with genetic disabled children from society, can fuels the desire of parents to use PGD. He believes that PGD can medically benefit the prospective parent and lighten their future burden and responsibilities of raising disabled children, which in some cases might cause further psychological damage to both parents and the children.

Another physician stated that PGD is mainly request by parents to eliminate genetic disease that they do not wish to pass down to their children, especially for those parents who know their genetic history. However, their intention to do so is sometimes misinterpret by other as trying to produce the perfect child with extra ordinary characteristics, resulted with accusation that parents are designing their children for personal benefit.

“PGD can give parent the perfect child, in term of their health but it does has its limitation. Don’t misinterpret PGD as having the ability to produce a child that will be free from any kind of disease. Yes, PGD can eliminate certain type of genetic diseases but it is important to know that it can’t eliminate all kind of genetic diseases and parents/couples has to know what kind of diseases to be eliminate. PGD only work for those who know about their genetic combination and history because it is not a genetic screening but genetic diagnosis.” (Participant 2, Feta-Maternal sub-specialist, UMMC)

These misconceptions regarding how PGD works and limitations of PGD are due to lack of knowledge on the technology. His perspective on perfectionism and PGD is based on the approach of low health literacy; a medical perspective that describe individuals who has none or limited medical knowledge. It is a term that is generally used within the medical fraternity. Due to this lack of knowledge, PGD is sometimes view negatively by member of the public.

Supporting his statement, six other medical experts also stating that PGD has been misunderstood as this ‘perfecting machine’ that can produce any kind of children as per desire. But instead, PGD can only be any help to parents if they know what kind of disease that they want to avoid. Therefore, it can’t assure parents that the child will not get affected with other genetic diseases that is unknown to the parent and child, or a sporadic genetic disease, which can happen to anyone due to gene mutation, triggered by various factors.

Using their own personal experiences with genetic disorder, three of the potential PGD users displayed a common understanding toward parent who decided to use PGD. This is because they believe any parent want to provide the best they can to their child and making sure that their child is healthy at the moment they are born.

“I can understand the parent desire to have a perfect child. PGD is an alternative for them to have their perfect child so yes it is a tool for perfection. But I don’t think that parents place higher priority on creating ‘super child’ as compare to the health of their child. I don’t think that they even think about it from that angle.” (Participant 13, individual living with Thalassaemia)

“For me, PGD is a medical tool used to eliminate genetic disease, thus provide parents like me with the perfect child that we long for. I do believe that when parent said that they want the perfect child, it does not refer to a child that is perfect from every aspect but rather a child that is healthy both physically and genetically. Like myself, after having

a child with DS, I am afraid to have another child until I am very sure that I can avoid the same thing happen to him/her. We just want to give the best to our child and try to provide the optimal lifestyle for them.” (Participant 10, mother with a daughter afflicted with DS)

On the contrary, two other potential PGD users described parent who use PGD as not appreciating their children as who they are. Furthermore, these days, overly ambitious parents are prone to get carried away with transforming love; promoting and demanding all manner of accomplishments from their children, seeking perfection (Sandel, MJ., 2007).

As a person who believes in God’s plan, one potential user preferred to leave the matter of procreation to the Maker rather than taking it into her own hands. In her situation, she thinks that the need for perfection might send a message to her son that he is not good enough.

“If I focused on getting the perfect child, how would my son feel about it since he has genetic disability? How about my other children? They might also suffering from lack of parental attention, which might make them feel less important. Or financially deprive if I channelling all the money we have into funding these new genetic technologies because we all know that they are all very expensive. Is this fair for them? It makes me feel like a selfish person.” (Participant 11, mother with a son afflicted with Thalassaemia)

The above excerpt supported what Watt (2004) mentioned in her study that there is no such thing as ‘good enough children’ on the view of parent-children relationship; all children are ‘good enough’ for their parents to love and respect them unconditionally.

On the other hand, all Christian representatives showed that it is not appropriate to claim that PGD is a tool for perfection because they believe there is no such thing as the perfect child. Explaining the idea of perfection from Christian perspective, three Christian representatives described perfection as being without sin and it is more related to human relationship with God rather than physical appearance or their state of health.

Therefore, no one is perfect because all human have sin. When relating PGD with perfection, two of the representatives claimed that PGD might be able to eliminate some genetic disease but it definitely can't produce the perfect child because human alike, be it children or adults, are not meant to be perfect.

Wanting to provide good quality of life to their future children is considered as natural need of every parent. However, for one Christian representative, he argued that good quality of life for one person might not represent the same quality to another. He argued that it is unacceptable to discard unhealthy embryos just because it is deem to be unfit for implantation and would have low quality of life after they are born. We can't basically know whether the embryo will or will not have a good quality of life simply base on medical diagnosis.

“There are some people who have some sort of disease, which restricted their movement and limiting their daily activities, or people with disability that make them dependent on others but still enjoy their life. In fact, I do not see anything low about their quality of life. PGD was design to eliminate disease and save life but are we actually saving life when we destroy several lives along the process?” (Participant 18, Ethicist and a Catholic priest)

In contrast, two Muslim scholars' viewed parent's desire to provide the optimal quality of life to their child, to a point where they are willing to try anything or placing their trust in new technology is view as parent's love for their child. They mentioned that Islamic religion has always encouraged its follower to conceive healthy children and try their best not to tarnish the family line with genetic abnormality.

It is also encourage in Islam that Muslims should find the best cure or treatment for their medical condition (Fadel, HE., 2007). Base on this perspective, the use of PGD or any medical technology that seek to maintain the lineage clean and cure for diseases is

permitted in Islam. In fact, the decision of parent to use PGD in order to make sure that their child is free from genetic disorders is view as the parent 'ikhtiar' or effort to cure their children. However, it will be unethical and forbidden if PGD is used to change the child physical feature to give them an advantage socially.

“Islam acknowledges any new technology and welcomes any effort to upgrade our lifestyle but it should be in line with Islamic teachings without marginalizing the role of God in our life.” (Participant 20, Islamic scholar, JAKIM)

However, awareness of the possible effects of the technology triggers off precautions about the potential harm that medical technology can do to the future of humanity. For one Muslim scholar, she did not think that parents who opt for PGD are trying to create the perfect child; however, it can possibly lead to the use of PGD for more trivial reasons. Thus, such non-essential practices can lead to the misuse of this technology.

“From my point of view, selection of embryo can lead parents to be perfectionists, in a sense that they are willing to try anything regardless what are the consequences of their actions, which might probably lead to unforeseen incident. Therefore, I believe clear guidelines should be provided to ensure that this technology will not be misused.” (Participant 20, Islamic scholar, JAKIM)

Perfectionists are individual who do not believe that one can attain a perfect life but they do practices steadfast perseverance in obtaining the best possible state of living. There is down side of being perfectionist; parent might subconsciously making decision without thinking of the possible consequences of their action toward people around them or the surrounding community. One Christian representative expressed his concern on the possibility of such desire toward the already deteriorating societal attitude towards disabilities.

People may have less tolerance or zero tolerance for those with congenital genetic disorders, showing further disrespect for disabled people. At the same time, others might view parent's decision not to resort to new medical technologies as not giving much effort to save their own child.

“Society emphasise too much on perfection that in the near future, parents are willing to do anything without any human conscience just to make sure their child is perfect. Life might not mean anything to them anymore and destruction of embryos would not give them any guilt, and this is what we will teach our younger generation, that life means nothing if it is not perfect.” (Participant 18, ethicist and a Catholic priest)

4.3.3.2 Societal influence

Influences from society and various views on people with physical and genetic disabilities could have an impact on participants' view on the need for perfection. One potential PGD user stated that she would consider PGD because of the pressure from society and her own relatives. They expect her to have son without Down syndrome because she already has a daughter with Down syndrome. She is under enormous pressure to try any kind of treatment or seek medical assistant that can help her to produce the perfect child from a particular gender. This effort is deemed necessary to make her feel accepted within the family and community.

“My first-born has Down syndrome (DS) & I am pressured to produce a son that I hope will not have DS. I am afraid to have a child again after my daughter was born with DS. But coming from a culture that emphasises having a boy, I am pressured to have another child, preferably a healthy boy. If PGD can do that and is accessible to me, I guess this is the best solution in my situation or else, I might be label as a mother who don't

place much effort in providing the best health care for my child.” (Participant 10, mother with a daughter afflicted with DS)

At the same time, one Christian representative strongly believes that societal influence can compound further the negative attitudes towards people with physical or genetic disabilities. The effect of the need for perfection on society is not being assessed in this study but the same concern was also highlighted in a study in the USA where the participants raise concern that PGD might lead to the lack of tolerant of the disabled and their parents (Kalfoglou et al., 2005).

This according to Kalfoglou et al (2005) resulted with the couples feeling pressured to use PGD to avoid having an affected child. This is consistent with the view of one Christian representative in this study. He mentioned that the pressured that is exerted by society on prospective parents to attain optimal living for their child, led parents to choose PGD, although initially preferred to leave procreation to nature. He is concerned that through the years, becoming parent will no longer be occasion of joy but rather a choice that people make based on convenience.

“I fear that in the future, having a sick child no longer depends on your chance but a choice that parents have to make. Parents are being pressured to have healthy children and parents who choose not to go for PGD are viewed as selfish parents.” (Participant 17, executive secretary at Council of Churches Malaysia)

4.3.3.3 Change in human values and relationship

It is fear that with the emergence of PGD changes in terms of human values and human relationship can take place among one another or between parents and their children. This might cause negative impacts on human values and relationship in the future.

People will be valued by their abilities to perform in society, and by their genetic characteristics. Such scenario can change the traditional meaning of procreation and turns pregnancy into a biological process; children become products that are made perfect through technology (Boyle and Savulescu, 2001).

Deliberately terminating embryos just because they might be affected by genetic disorder seems unrealistic and unacceptable to three Christian representatives in this study. Permitting the act of terminating life of embryos during PGD could possibly result in changes to people's perceptions on what it means to be human (Spriggs, M., 2002).

Children are treated as a commodity and instrument (Sheldon and Wilkinson, 2004). They exist to fulfil parents' desire to have children with the ability to make them stand out in the crowd, or they function as sibling donors, who are purposely created to save another.

“Is it acceptable to create another human life specifically for a reason to intentionally save another life but during the process sacrifices a number of other lives? This is like the concept of utilitarianism, sacrificing numerous lives, each of which has the potential to become a full human being. They are terminated just because they are deemed unfit to be qualified as donor.” (Participant 18, ethicist and a Catholic priest)

In his opinion, children created via this technology are carefully selected genetically like the process of selecting products. These 'manufactured' children are expressions, in part, of their parents' aspirations, desires and whims in their need to have the child they desire. Whichever embryos do not fit into that desire is deliberately destroyed. The changes in terms of human values and relationship do not start at the selection process but rather at the initial step of choosing to go for PGD.

However, another participant who is also a physician, differs in his opinion regarding changes in family relationship. He mentioned that not choosing to use PGD may also lead to changes within the family. This is because he claimed that the difficulties in

raising and living with a child suffering from a specific genetic disorder can create tensions within the family.

Stress and strain between family members can lead to breakdown in the family bonds. Such situation will generate adverse effects on the family. The aspects of family life affected can be financial, emotional or psychological.

“I have seen many family structures crumple down due to having a disabled child. They blame each other and in some cases, which I witnessed, the issue could break up a family. Having a disabled child or having to deal with children with severe genetic disorder has caused them great emotional distress.” (Participant 6, Feta-Maternal sub-specialist, FMGC)

Conclusively, medical professionals’ discussions on this theme showed that they mainly discussed it from perspective of cost, low health literacy and welfare system. Whereby for potential PGD users, they discussed it from the perspective of parental natural instinct to provide the best for their child, religious concept of ‘takdir’ and also their own personal experiences with genetic disorder.

On the contrary, religious representatives discussed it from the aspect of religious teaching on perfection; Christianity perspective of perfection is focus more on living without a sin, which related to human relationship with God. Islam on the other hand encourage perfection because Allah has told His creations to strive for perfection, mind, body and spirit, therefore, view perfection as parent’s ‘ikhtiar’ to provide the best for their children. Whereby Buddhism perspective on perfection is parent’s determination to save their child, at the same time showing their undying love for their children, which demonstrated their good intention toward their children.

4.3.4 Freedom of Choice (FC)

Freedom of choice in this study refers to the rights of parents to consider or choose PGD. Discussion on this theme mainly centred and focused on the ethical issue concerning the rights of parents to their own reproductive choices and decisions. Discussion on this theme constantly highlighted the issue of parental reproductive rights, which witnessed some participants associated it with their personal experiences dealing with genetic disabilities. This also includes the experience of medical professionals dealing with their patient when assisting them when making the decision.

4.3.4.1 Reproductive rights

Findings showed that all medical professionals, potential PGD users and one Buddhist representative believe that individuals, couples or parents should be given the freedom to make their own decisions regarding their own reproductive health. However, for three Christian and two Muslim representatives, they believe that autonomous rights of parents only exist if they confine to the religious rulings on the issue. Therefore, indicating that in Christianity and Islam, total autonomous rights do not exist because there are other religious aspects that need to be considered before making the final decision.

Most medical practitioners in this study advocate awareness-promotion of autonomous rights to their patients. This is extremely important when patients consult them on medical issues including reproductive issues. However, they are some medical or genetic professionals who feel that restriction on parental access to information should be practice in order to avoid the rising of eugenics or authorizing unjustified parental interventions in a child's life (Green, RM., 1997).

But for one physician in this study, it is extremely important that parents are informed of their right to decide and allow them to exercise their right. This is because reproductive issues are always very sensitive and complicated as the matter involves many parties. The issue become more complicated and complex when other factors such as religion and culture are involved.

“I feel that it is wrong not to suggest or even inform parents regarding PGD when as physician you know that it provide 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 already make their decision, physician has to respect it.” (Participant 2, Feta-Maternal sub-specialist, UMMC)

Another physician believes that parent has every right to make the final decision on whether to use PGD, even for a low penetrance disease such as susceptible conditions because as parent they do have the utmost right to decide. At the end of the day, it is the parent and the family, who are going to face the challenges and struggle in the future in providing care and treatment for the affected child. Furthermore, using the principle of beneficence, he explained that if the technology helps my patient to be free from genetic disease then by right as physician, I should not stop them from requesting for it.

“Even in the case of susceptible conditions or sibling donors, I do think that it is the right of the parents to choose whether to go for PGD. As long as there is no harm inflicted toward the child, then I think it should be good enough to allow them to use PGD.” (Participant 4, Fertility sub-specialist, UMMC)

In fact, most medical professionals in this study, constantly mentioned in their discussions concerning the right of parents to decide what is best for their child, especially when the child is still under their guidance, or when the child is not yet born. Parent would

want the best for their children and do whatever they can in their power to make sure the children have the best possible life when they come into the world (Green, RM., 1997).

Approaching the issue of freedom of choice and parental right, one medical expert explained her opinions by stating that individual have the right to make their own decision without duress. Therefore, using the theory of deontology, she concludes that it is her duty as medical expert to provide the available information to her patients, thus allowed them to make their own decision base on the given information.

However, with the availability of PGD, sometime physician can indirectly influence the patient when providing them with information regarding the technology. Physician might have their own prejudices toward certain conditions, which they indirectly convey to their patients when assisting them in the decision-making process.

“In Malaysia, doctors’ suggestions most of the time is being taken seriously even though they do not make any decision on behalf of the patients.” (Participant 8, O&G Consultant, GHKL)

However, sometime patient’s reason to request for PGD might appear trivial to some but for one physician, he still think that it is the patient’s right to request for it. He just wants to help his patient to have the children they desire and bring happiness to his patient’s life as well as giving them a healthy child. He commented that the stress of raising children with congenital genetic diseases could have an impact on the family dynamics. Based on his experience as physician, he observed that some family just could not handle having a disabled child.

“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? How will they go through and carry their burden of raising children with special needs? This is

an essential question that we need to ask ourselves.” (Participant 6, Feta-Maternal sub-specialist, FMGC)

Increasing autonomous right of parent to make the final decision regarding PGD create fears and concerns that it could be the down fall or ‘slippery slope’ of the technology (Sheldon and Wilkinson, 2004). It raises concerns that when parents are given the ultimate rights to decide, they might end up misuse the technology, resulted in the creation of designer babies, thus rising concern on further development of eugenics technology (King, DS., 1999).

But for most medical professionals in this study, concerns and fears regarding PGD and its relationship to eugenics technology is baseless. This is because they feel that there are other more important issue to be concern of such as the quality and safety issue of PGD facilities rather than thinking about the possibility of eugenics technology in Malaysia.

“I would not think that by allowing parents to practice their rights to decide will actually do any damage or leading to slippery slope of PGD because for now, we have a cheaper technology to diagnose whether the baby is healthy or free from any genetic disorder such as PND. PGD is very expensive and not everyone can afford it even if they want to use it. I personally think that we’re still far off in term of perfecting the technology to even be able to create a designer child.” (Participant 2, Feta-Maternal sub-specialist, UMMC)

“I do not think that by allowing parents to have the freedom of choice, it will be a slippery slope for PGD as long as there is a proper regulation on the use of PGD.” (Participant 3, O&G Consultant, GHKL)

Giving parent the right to make their own reproductive decision would allow those with inherited genetic disorder to avoid suffering and the painful experience of having to go through TOP. Termination of pregnancy is a very traumatic experience for both husband

and wife. Thus the advent of PGD is viewed as an alternative for those who do not wish to go through TOP, especially for those who been through it previously.

Therefore, if the parent thinks that it is less stressful to discard few days old embryo rather than few weeks old foetus, then it is the parents' rights to make that decision. In both situations, parent is still left with daunting decision to make, to discard a few weeks old foetus or a few day embryo.

Generally, all potential PGD users in this study claimed that parents should be given the rights and freedom to make their own reproductive decisions. It is the parent responsibility to make sure that they are able to provide the best health care to their children or future children. Therefore, they believe that the decision on PGD should be the sole right of the parent. This particular finding showed that most potential PGD users displayed some sense of responsibility toward the people under their care or will be under their care.

“We do not walk in their shoes so we have no idea actually what they go through every single day. We can feel sympathy on them but we're not the one who has to carry the burden. So, why not let them the one who make the call. It's not enough to tell them what to do but we should allow them space to think and come out with the best solution for their situation.” (Participant 9, mother with a son afflicted DS)

“Parents should have the freedom of choice, which include practicing their right to choose because as parents and guardian of their unborn child, they have the right to decide. After all, what they want is the best for their child.” (Participant 10, mother with a daughter afflicted DS)

But for one potential PGD user, she would prefer not to use PGD although knowing she has the right to do so. She insisted that she would prefer to leave the matter to God and just accept whatever God has destined for her life, including medical condition of her

future children. She believes that everything that has happened and will happen in her life is God's will, and she believes that it will be fine as long as she continuously puts her faith in her religion. However, this does not mean that she expects others to do the same. Most people have their own view in regards to PGD and despite their own strong point of view, stressed the important of individual decision making (Kalfoglou et al., 2005).

On the contrary, only one representative from the religious organisation claimed that reproductive right is the sole right of the prospective parent. He believes that parent know what is best for their child. He expressed his belief that all parents want and try to give the best to their children, and at the same time trying to maintain happiness within the family.

“Buddhism teaches personal happiness. If having a severely sick child causes great emotional and psychological effects on the family, and the only way to avoid that is by using PGD, it is up to the parents to make their choice. What important is that the family is happy.” (Participant 21, Buddhist consultant for YMBA)

For three other participants who represented the Christian organisations, they believe that parent do not have the sole right to make the final decision on PGD. This is because Christian belief that embryo is a life, which mean, it also has the right to live. Therefore, it does not give the parent the right to terminate it.

Since Christianity believes that embryo is a life, any decision to deliberately terminate it should be carefully considered or should not be practised by those who hold the same belief. When it comes to Christianity, there is no absolute autonomous parental right because we have no say over when we are born, who our parents are, which gender we will be or when we will die as all these are God's prerogatives (Tang, A., 2008).

“As Christian parent, we should not only think about the end result but also the possible consequences toward the entire embryo that was created during the process.”
(Participant 16, Christian Evangelist and scholar, Kairos)

“Christian couples or parent should use their conscious mind and their conscience and ask themselves, why do they want to use PGD? Do they have other alternatives? To what extent do they want to be involve in a technology that end up destroying lives? These are the questions that they need to ask themselves before making the final decision.”
(Participant 17, Executive secretary of CCM)

Christian representatives also mentioned their concern on the effects of increased reproductive right of parent might have on the society at large. They fear that the increase of reproductive right might lead to what they describe as the ‘slippery slope’ of PGD. It can lead to misuse of PGD to gain personal benefit by using it for reasons other than for medical purposes.

For instance, using PGD for non-medical sex selection raises arguments and concerns on issues related to the potential for inherent gender discrimination, inappropriate control over non-essential characteristics of children as well as inappropriate and potentially unfair use of limited medical resources for sex selection rather than for more genuine, and urgent medical needs (Hershberger and Pierce, 2010).

On the other hand, two Islamic scholars in this study viewed PGD as medical advancement that can help parent who are in great need of it. Although having no qualm allowing Muslim couples or parents to use PGD, they however, do not think that parent has the total right to decide. This is because in order for parent to be allowed to make decision on PGD, they first need to make sure that their reason to use the technology, comply with the religious ruling on the matter. Its use is also restricted to applications within legal marriage frames according to Islam.

4.3.4.2 Personal experiences

On a number of occasions during the interview session with the potential PGD users, they constantly related their views on the theme with their own personal experiences. The interpretations of their views on the theme are accompanied by expressions of empathy and compassion for those who might be in a position to medically benefit from PGD. Using the metaphor of walking in someone's shoes, the participants illustrated their deepest sympathy towards families who are also experiencing similar suffering.

For one potential PGD user and also a mother, she wanted others to understand the circumstances that these parents have to go through in terms of taking care of these children special needs.

“You know, having a disabled child is hard work. It is also a burden for parents because they have to readjust their life and sacrifice a lot of things so that they can make sure their disabled child can have a good life. So, if anyone wants to avoid this ‘burden’ by using PGD, they should be allowed to make decision which befits their medical situation.”
(Participant 11, mother with a son afflicted with Thalassaemia)

Sympathising with parents, who have to go through the same ordeal, is one of the reasons why this group of participants believe that parents should be given the freedom of choice regarding their own reproduction. Beliefs about and attitudes to medical genetic technologies such as PGD can shift ‘when the context is changed from abstract appraisals to involvement of the life and death of oneself, close friends or relative’ (Doolin and Motion, 2010).

In fact, some potential PGD users even highlighted the pain, suffering, joy and happiness in raising children with genetic disorder, and these experiences have significantly shaped their views on the issue of reproductive rights.

“If I had known about PGD, I might opt to use it. Having a child with disability makes me worry all the time about her wellbeing. You just have to be prepared all the time in case something seriously happens to her.” (Participant 10, mother with a daughter afflicted with DS)

The influenced of personal experiences on decision-making of PGD is clearly highlighted by the same potential PGD user when she mentioned that she would seriously consider using PGD in her next pregnancy. This is because she is afraid that she might end up conceiving a child with Down syndrome, just like her first child. Her first few years of raising and dealing with her daughter’s medical complications and complexities were very difficult for her, and this indirectly created fears of having to deal with the situation again.

Another potential PGD user spoke out that the freedom to exercise her reproductive right does not only enable her to use PGD without being judged as selfish, but it also enables her to avoid having to go through termination of pregnancy if her child is tested positive with the same genetic disease that is affecting her elder son.

“My son’s Down syndrome condition might not be the worst, but he does have certain medical conditions that could be detrimental to his health. For me, if a couple chooses to go for PGD, they should be allowed to make those choices especially for women who have been trying to have a child at an advanced age. When I was pregnant with my second son, my husband and I decided that if he was tested positive for Down syndrome, just like his brother, we would abort the pregnancy. We can’t deal with another child with DS. But with PGD, it gives us or other parents a choice, which was unavailable previously.” (Participant 9, mother with a son afflicted with DS)

Another potential user related his own personal experience of living with genetic disorder when assessing his views on the notion of individual right. In his response he described the difficulty and constant fear he has all his life not knowing what could happen

to him in the future. Thus, strengthen his argument that parent or individual like him should be given the freedom of choice when it comes to their reproductive decision because only those have gone through the same situation would understand how it feel like.

Due to his own experience, he does not wish his future children to go through the same ordeal as he has. So for him, if parent wish to use PGD because they previously have children with genetic disability or they themselves are carrier of some genetic abnormality, then they should be allowed to make that decision without the interference of others.

“Everyone has a story in their lives, which sometime motivate them to come to their final decision. So, it is also the same with the decision to choose PGD or any other medical technologies. As long as the intention is right, that is for medical purposes, they should be allowed to make their own choices, just like I would appreciate it if people allow me to make my own reproductive choices.” (Participant 13, individual living with Thalassaemia)

Generally, the findings show that all potential PGD users relate their own personal experience when discussing on the theme ‘freedom of choice’, which explained their main approach to the theme. They unanimously agreed that parent or couple who wish to consider PGD should have the right for individual decision-making.

4.4 Significant findings

Pertaining to the results analysis, it is found that there are a number of similarities and differences among the three focus groups in terms of their perceptions on PGD. These similarities and differences were shown in the way they confront and approach the issues discussed. These differences and similarities described the factors and thus, perspectives that shaped their perceptions on PGD, which might influence their final decision-making on PGD.

4.4.1 Similarities

Results showed an interesting similarity between all focus groups; they displayed a need to fulfil some kind of responsibility towards certain groups of people, which best described using the ethical theory of deontology. These responsibilities are either as medical professionals, parents, future parents or religious leader. Using ethical theory of deontology, it helps to understand the rationale of their responses to the topic discussed.

Medical professionals' obligations and duties to their patient, observed physicians need to place their patient's welfare before their own. They are obligated to make sure that the treatment they are suggesting or providing will bring medical benefit to their patient as well as eliminate or at least minimizing any harm toward their patient. They also feel that it is their responsibility to provide their patient with unlimited information and knowledge in regard to PGD, in order for their patient to understand about the technology.

Therefore, enabled them to practise their right and make their final decision on the available options. This is shown in theme 'freedom of choice'. Another example of this responsibility is in theme 'play God', where medical professionals agreed that PGD is not trying to play God, nor is it tool to create superhuman; it's just a medical technology to prevent, treat and eliminate genetic disorder, thus save the life of their patient and their future children, which serve the purpose of using PGD.

Similar finding are displayed where potential PGD users shown sense of responsibility toward the welfare of their children or future children. However, it differed from medical professionals because their responsibility is more toward their roles as parent or future parent. Responsibility to their children or future children played an important part in their response toward PGD, which are reflected in most of their approaches when discussing the theme. This can be observed in their explanations in theme 'play God',

‘perfectionism’ and ‘freedom of choice’. For example, in theme ‘perfectionism’, most potential users believe that not only PGD provide them the tool to eliminate genetic diseases, it is also a medical alternative that they can use to provide an optimal quality of life to their children.

Again, in theme ‘freedom of choice’, potential PGD users demonstrated their responsibility as parent when they relate their own experience as parent or individual living with genetic disabilities, which prompted them to support the need for individual decision-making. They highlighted their struggle and hardship in term of raising their children who suffered from genetic disability or their personal struggle living with genetic disease, which provide them a strong reason to support the practise of reproductive right for individual or parent with the same situation. They stressed that by allowing parent to freely decide on their reproductive choices, it allow parent to fulfil their duty to their children that is to avoid the transmission of genetic disease and prevent further suffering to their children.

Another type of responsibility that was highlighted in this finding is one’s responsibility to religion and God. For a couple of potential PGD users, they demonstrate their responsibility to their respective faith; obeying and accepting God’s plan in their life and this is observed in theme ‘sanctity of life’, ‘play God’ and ‘perfectionism’. This explained their responses on the need to seek the opinions of their religious ruling body on embryo status before making their own judgment on the issue, which subsequently lead to their decision on PGD.

It indicates that they both prefer their final decision on PGD will not go against the teaching of their religion, thus avoid from defying their relationship and duty to their faith. In theme ‘play God’ they both displayed their trust and believe in God’s plan in their life, reflecting their faith and obedience to their religion, which is their most important duty as

Muslim. Again during their discussion on theme 'perfectionism', both participants stressed an utmost faith in God's will and plan in their life, which they accept with an open mind. If it is God's will that they have to go through the struggling and hardship in raising children with certain type of medical condition, they also believe that He will provide the strength for them to make the best out of the situation. These responses are typical among individuals with religious conviction where they place their duty toward their religion higher than their personal or scientific belief because of the strong influenced of their faith in their life.

Similar to the first two focus groups, participants in Group 3 also displayed the need to fulfil their responsibility, and for this group, the responsibility is to God as well as their religion. In doing so, most religious representatives in this study displayed an utmost loyalty and support to their own religious beliefs. This can be observed when they used their religious beliefs to justify their responses on the four main key themes that were discussed during the interview sessions. Although their approaches toward the issues might be different as these approaches are based on the teaching of their respective faiths, their obligations are the same that is to perform their duties toward higher power. In some of the theme, they might responded differently due to the differences in the teaching of their religion, which see either they accept or reject the notion of using PGD for medical purposes. For example, on theme 'play God' where findings showed that Christian representatives reject the notion of using PGD and view it as human trying to play God, but Muslim representatives opined that parent is not trying to play God when using PGD but merely doing what they should do in order to find cure for their children.

These differences are due to the fact that in Christianity, it is believe that only God has the right to decide who get to live or die, and when parent used PGD to select or deselect embryo for implantation, it is view as parent having the authority that supposedly

only belong to God. According to Christian representatives, as dutiful follower of God, Christian should accept the will of God rather than trying to change it in order to avoid suffering. Thus, explained their rejection on the use of PGD because their duty is to accept God's will and not changing it to suit their need. On the other hand, Muslims are encouraged to seek cure for any kind of disease because it is expected of them to do so. Islam encouraged parent to seek treatment or cure for their children as their duty as parent as well as good Muslim. Hence, demonstrate their acceptance on the use of PGD for medical purposes. For both representatives, their discussion on this theme is dominated by their duty to their Creator and religion, thus show a similarity that is supported by one theory, which is ethical theory of deontology.

Another similarity that was highlighted in the study among the participants is the need to evaluate the consequences or possible effects of their reproductive choices and decision toward others, which can be described using ethical theory of consequentialism. Generally, participants' discussion on PGD indicated that they do think about the possible consequences of PGD and the decision they made in regard to the technology toward their child, patient and society. For example, in theme 'perfectionism', Christian representatives highlight the possible negative consequences of PGD toward society; among others, increasing discrimination toward people with genetic disabilities, the need for the perfect child can lead parent to misuse the technology and changing the value of human relationship where human will be value more on their physical and genetic feature rather than accepting them as who they are. The quest for perfection in their children could lead to the creation of perfectionist, both from the perspective of society and parents. Consequently, increase pressure on prospective parent to used PGD when initially they preferred to leave the procreation process to Nature.

On the contrary, some potential PGD users viewed PGD as technology that could bring happiness into their life where they and their children do not have to suffer physically, mentally, financially and emotionally. This view is based on their personal experience with genetic disease, which explained their determination not to allow the same situation happen to their future children. Therefore, PGD is viewed as an alternative for these participants to give birth to healthy children as well as providing their future children with an optimal quality of life. These positive consequences that resulted from the use of PGD, explained the rationale on why some potential PGD users do not mind using PGD. In fact, for some of the potential PGD users, PGD is viewed as the best option possible.

The similarities displayed among the participants from the three focus groups are summarized and illustrated in Table 4.2 on the following page (181).

Table 4.2 Summarizations of similarities among all focus group

Groups of participants	Ethical theory of Deontology	Ethical theory of Consequentialism
Medical professionals	<ol style="list-style-type: none"> 1. Providing patient with the correct and current medical information or medical alternatives that assist could them in making the best decision for themselves and also for their children. 2. Allowing their patients the freedom to choose from the available reproductive genetic technologies without having any influence on their decision. 3. Emphasize on the welfare of their patients by making sure they benefit from PGD and no harm or minimize any harm toward their patient. 	<ol style="list-style-type: none"> 1. Opined that PGD resulted in positive outcome to their patients, both the parent and child; having healthy child and living life without genetic disabilities. 2. PGD help to eliminate and treated genetic diseases.
Potential PGD users	<ol style="list-style-type: none"> 1. Their parental duties to make sure they provide the best for their child from the day they were born. 2. Their duty toward their beliefs and the need to follow it. 	<ol style="list-style-type: none"> 1. PGD has positive consequences to their child by enable them to provide optimal quality lifestyle to their future child. 2. At the same time, some potential PGD users also think about the possible consequences of PGD toward their relationship with their beliefs.
Representatives of religious organisations	<ol style="list-style-type: none"> 1. Their duty to God and obligation to follow their religious teachings or rulings. 	<ol style="list-style-type: none"> 1. Discussion regarding possible negatives consequences of PGD toward society, faiths and human relationship and values. 2. One participant talked about positive consequences of PGD in term of providing happiness to the parents, child and other family members.

4.4.2 Different approach and perspectives

Table 4.3 Summarisation of the different approaches and perspectives on PGD by three focus groups

Themes/Group	Medical professionals (G1)	Potential PGD users (G2)	Religious representative (G3)
Sanctity of Life (Theme 1)	<p>1. Using scientific approach in regard to moral status of embryo, which stated that embryo, is an accumulation of cell with no moral status but deserving respect.</p>	<p>1. Their approach is base on their personal belief on embryo status, which showed that they believe embryo is not a life. 2. Opinions on moral status of embryo are depending on the religious ruling on it.</p>	<p>1. Using the approach of theological principles of holiness of life; Christian perspective on life that all human are made by God in His own image. Thus, should not be destroyed. 2. Using the approach of ensoulment; a perspective that considered embryo as a life after a soul is breathed into it. 3. Using Buddhist approach of respecting life; one of the five precepts. Thus, believe that all things have life & should not be discard including few days embryo.</p>
Play God (Theme 2)	<p>1. Low health literacy; a perspective that explained misconception on PGD due to lack of knowledge on it. 2. Individual choice; a perspective that individual is free to make their own judgment and decisions on whether to use PGD and whether PGD is trying to play God.</p>	<p>1. Based on their personal experiences with genetic disorders, which see their support to the use of PGD and disregard that PGD is trying to play God. 2. Based their trust in God's plan in their life, therefore, rather leave the faith of their child at the hand of God and refuse to use PGD to change their genetic combination; thinking that PGD is trying to play God.</p>	<p>1. Using biblical principle of providence of God; Christian perspective that God intervene in all aspect of human life in order to bring out the best out of them and believe that only God has the right to decide who live and die. 2. Base on the belief that God create disease and treatment for the disease. Thus, human should try to find treatment and cure for any diseases they are suffering from. 3. Based on Buddhism teaching on suffering and happiness; a perspective that teaches in order to stop suffering, one should prevent suffering on others and bring happiness to others.</p>

Table 4.3, continued

Themes/Group	Medical professionals (G1)	Potential PGD users (G2)	Religious representative (G3)
Perfectionism (Theme 3)	<p>1. Their approach is based on low health literacy, which explained their view on the theme. They also include high cost involve in raising children with genetic disabilities as one of the approach to describe their views on the theme.</p>	<p>1. Using the approach of religious teaching of believing in God's plan in one life and accepting things that happen in one life as destiny.</p> <p>2. Approach the issue using personal experience, in which emphasize on parental desire for providing quality lifestyle to their child.</p>	<p>1. Based on biblical teaching on the sovereignty of God, a perspective that God is in control of everything. Therefore, we should have faith despite anything.</p> <p>2. Based on Islam teaching on perfection; a perspective that a human we should strive for perfection in mind, body and spirit. Therefore, the need for perfection is considered as 'ikhtiar'.</p> <p>3. Determination and love is included in Buddhism teaching of the 10 type of perfection.</p>
Freedom of Choice (Theme 4)	<p>1. Using the approach of professional duty as physician; allowing their patients to practice their right to their own decision</p>	<p>1. Using the approach of 'walking in their shoes'; a perspective that emphasize on personal experiences with genetic disabilities.</p>	<p>1. Using the religious teaching on individual rights.</p>

Based on Table 4.3 on the previous page, results showed that medical professionals, potential PGD users and religious representatives confront and approach issues on life, play God, perfection and freedom of choice differently. These approaches shaping and differentiate their perceptions on PGD, thus could play influence their evaluation during final clinical decision-making regarding PGD.

There are four type of difference views pertaining to the issue on moral status of embryo, which is the focused discussion in theme ‘sanctity of life’; 1) embryo is an accumulation of cell, 2) it is a life, 3) it is a life after certain period of time and 4) it is not a life. The first view emphasized embryo as not a living human and do not hold full moral status but deserving respect. The medical professionals in this study used scientific approach when describing their views on embryo status. Their view on moral status of embryo is based on the perspective of medical science, which is dominated by their strong medical background and knowledge within the field of reproductive and genetic medicine. It is based on their medical knowledge on embryo, which defines that embryo at the pre-embryonic stage, a period from fertilization up to the determinant of the primitive streak at the age of 14 days, is not a life. This embryo is unable to feel pain or pleasure and therefore has no moral status. During this stage, they may be cryopreserved, discarded or used for research purposes (Ehrich et al., 2008).

In the second view, it emphasized that embryo is a life, which is the main view of representatives from Christian organisations. This view is based on the Christian perspectives on theological principles on holiness of life, which described that every human life is considered as sacred and holy because human is created by God in His own image; perspective that is derived from Christian doctrine of God as Creator (Knowles, L 2000). Since Christian believes that human life begins at conception, embryo that is

created during the process of PGD, is given the same moral status as that of a born human person; holy and sacred, thus should not be destroy.

Third view emphasized that embryo is considered as human life when it has a soul, which happen after certain period of time. This approach is based on the Islam perspective on the notion of ensoulment, in which the soul is 'breathed' in to the embryo 120 days after fertilization. Therefore, witnessed a majority of Islam accept that the foetus is accorded the status of a legal person only at later stage of its development, when perceptible form and voluntary movements appear (Hug, K., 2006). The last view emphasized that embryo is not a life, therefore; do not have moral status compared to born human. This view was mentioned by a couple of potential PGD users, which displayed their personal belief on the issue. Personal belief is very subjective because it changes accordingly, based on individual understanding on certain issue, which could be influenced by various factors.

In theme 'play God', medical professionals involved in this research, discussed the issue mainly from the perspective of medical science, which was displayed in their approach; low health literacy and individual choice. Using the approach of low health literacy, they emphasized that due to lack of knowledge on PGD, member of the public tend to have misconception on the technology. Having no or limited knowledge on PGD such as how does it really work and what are the limitation of PGD, tend to create wrong image on PGD, which mostly resulted in negative perceptions on PGD that lead to rejection or objection to the use of PGD. At the same time, labelling it as the new eugenic technology that can be used to genetically modify children.

In another approach, medical representatives argued that parent who chose to use PGD should not be judge as trying to play God because as parent, they do have the right to make their final reproductive decision on their choice of reproductive method. This approach is based on the same perspective that is dominated by the same factor, which is

their professional experience working in the field of reproductive and genetic medicine or assisting patients during their reproductive decision-making.

Unlike medical professionals, potential PGD users approach the issues using their personal experiences of living or raising children with genetic disabilities, which resulted in two different views. They either 1) think that PGD is trying to play God and prefer to leave their faith in the hand of God, and trusting that everything that happen in their life is God's plan or 2) think that PGD is not trying to play God but simply an option for parent or individual like themselves to avoid the transmission of inherited genetic diseases to their future children. Both of these views are influenced by the role of suffering in their life but their arguments are based on two different perspectives; secular and religion perspective. For potential PGD users who argued their approach based on secular perspective, they stressed that suffering is something that should be avoided, particularly to their future children if parent has the means to do so. This is the reason why they do not viewed PGD as trying to play God but more as a medical intervention that is necessary for certain group of individual. On the contrary, potential PGD users who based their argument on the religion perspective, they view suffering as part of human life, which is bestowed by God in order to bring human closer to their Creator. Therefore, they view PGD as trying to play God because by avoiding suffering, human is trying to change the will of God in their life.

On the other hand, religious representatives are using approaches that are based on their religious teaching; 1) Christian perspective on the providence of God, which believe that only God has the right to decide who live and die, 2) Islamic belief that God provide human the means to heal diseases, therefore they should use it to treat and cure diseases that can impose pain to themselves and others and 3) Buddhist perspective on the notion of good intention and Law of Karma, which stated that for every event that occurs, there will be follow another event whose existent was caused by the first and this second event will

be pleasant or unpleasant. Therefore, if PGD is used to avoid suffering of another human, it is acceptable to use it as it is viewed as having good intention toward others.

In the third theme, 'perfectionism', medical professionals are again, using the approach of low health literacy when describing their responses on the theme. However, there is another new approach that was used by this group of participants when discussing the theme; costing, which argued from the perspective of high medical cost involved in raising genetically disabled children. In both approaches, they displayed strong domination of medical knowledge in term of reproductive genetic technologies as well as high medical cost of treatment or medication. Based on these approaches, they stressed that most parent who do not have to face the same situation will not understand the anguish and high cost involve in raising children with genetic disease particularly, a rare type of genetic disease.

On the contrary, potential PGD users mentioned two types of approach when confronting the issue of perfectionism; first approach is based on religion where they believe that any child is perfect regardless their medical conditions and they will accept the child as gift from God; the second approach is based on potential PGD users own personal experiences with genetic disorder. For those who used the first approach, the used the term 'redha' where they believe everything that happened in their life is God's plan. They will accept it and make the best out of the situation and try their best to provide an optimal quality of life for their children, with or without PGD. For those who argued it using the approach of personal experience with genetic disease, they view PGD as the best option for them to avoid further suffering to their future children; an option that is previously unavailable. Potential PGD users displayed two different approaches, which they argued based on two different perspectives but was dominated by one main factor; their parental instinct to provide the best to their children although the methods might be different.

For representatives of religious organisations, their approaches are including; Christianity biblical teaching on the sovereignty of God, which based on the perspective that God is in control of everything and that include controlling who get to be born healthy or unhealthy. At the same time, added that in Christianity, perfection is more toward one relationship with God rather than being perfect in term of physical, mental or genetic; Islam teaching on 'ikhtiar', which emphasize that human should strive for perfection, mind, body and spirit. Therefore, parent's desire to provide the best quality of life to their child is viewed as their effort to save their child; Buddhism teaching on having a good intention, which he described that parent's intention to use PGD is to bring happiness to the child and other member of the family, thus view as parent's love and determination to prevent their child to suffer from genetic disorder.

In the final theme, 'freedom of choice', medical professionals and potential PGD users are both using the approach of individual right, which centred on the right of parent or couple to make final decision regarding their reproduction health. For medical professionals, their approach on reproductive right is based on the perspective of professional duty, which is influenced by the requirement of the medical profession; patient has the right to make final decision in regard to their reproductive choice and they should be allowed to practise this right.

Whereby for potential PGD users, their approach are based on the perspective of their own personal experience with genetic disorder, which prompted them to argued that parent should have the final say in regard to their reproductive choices. On the other hand, representatives from religious organisations demonstrated a rather ambiguous approaches; 1) Christianity do not believe in total right because everyone has right including few days old embryos. Therefore, associating the discussion on parental reproductive right with the sanctity of human life and resulted with the limitation of right of parent to decide

especially if it involve the destruction of embryos, 2) Islam teaching of right, which emphasize that parental rights are confine to religious ruling on reproductive technologies and 3) Buddhism teaching on personal happiness, where it emphasize on decision that bring ultimate happiness to the parents, children and other members of the family. Therefore, if the parent's decision can bring happiness to the whole family, then they should be given the right to decide.

Conclusively, the similarities and differences between the focus groups highlight findings in this study, which provide interesting information regarding participants' perceptions on ethical issues posed by the use of PGD. Their perceptions on the themes described their rather unique approach to the issues that are based on several perspectives, which emphasize their commitment to their profession, patients, children and religion. Some of these perspectives may or may not have been highlighted in previous research regarding PGD and public perceptions on the technology. These differences create a pool of information that can be useful in future studies on public perception on new reproductive genetic technologies.

4.5 General discussion

The study has assessed the perceptions of the participants on four main themes. This study revealed that participants' perceptions on PGD were based on several different approaches, which were based on several different perspectives that are influenced by various factors. When addressing the ethical issues on medical technology that might have a direct effect on the society, other kinds of perspectives besides the medical perspective can be more relevant (Doolin and Motion, 2010). For this reason, two others focus groups are included in the study, which are the potential PGD users and representatives of

religious organisations. Most of the participants only have little knowledge or just basic understanding of PGD except for participants from Group 1, which consists of participants working in the medical professions.

One of the most frequently discussed or debated ethical issues of PGD is concerning the moral status of embryo (Robertson, JA., 2003). PGD has a tremendous effect on embryos because during the selection process in PGD, embryos are either being implanted or discarded depending on the genetic test results. Scientifically, the definition of moral status of embryo is very straightforward, which defines embryo as an accumulation of cells that does not carry any moral status; thus it has limited rights compared with normal humans (Ehrich et al., 2008). Therefore, it justifies why discarding, cryopreserved and research is allowed when it involved the use of embryo that has not past beyond the primitive streak stage is acceptable within the scientific paradigm (Nordin, MM., 2011).

However, the discussions on moral status of embryos and the effects of PGD on embryos might be more complicated and complex when religious opinions on the issue are taken into account, where circumstances have changed. This is because between the science and politics, the hindrance is religion and its views on moral status of embryos (Cole-Turner, R., 2003). The effects of reproductive technologies on embryos have subsequently led to the determination of what is acceptable and unacceptable; how research is done; who approves it; who might benefit and what the long-term implications might be (Cole-Turner, R., 2003).

Participants' views on the moral status of embryo are varied. Medical professionals in this study referred to embryo as an accumulation of cells with no special interest. They do not think embryo carry any moral status. However, some care and respect must be given when embryos are handling for purposes of research or disposal (*Declaration of Geneva,*

1946). At the same time, *International Code of Medical Ethics*, (1949) stressed that medical doctors are obligated to preserve human life from conception.

Those participants who work in the medical field relied upon these beliefs when explaining why they accepted discarding of embryo during PGD (Ehrich et al., 2008). Similarly, medical professionals involved in this study are also using this approach when responding to issues on the sanctity of life. Thus, explained their perceptions on embryos and what is acceptable and unacceptable when dealing with embryos either for implantation or destruction. Discussion on moral status of embryo among medical professionals also witnessed a spontaneous comparison between PGD and PND. In this comparison, PGD is viewed as a more humane way to discard unwanted or unhealthy embryos as compare to PND, thus thought to be a less traumatic experience for the couples or parents.

For some individual who work in the medical field, the avoidance of termination of pregnancy through PND was their primary priority, which see the preference toward the use of PGD (Ehrich et al., 2008). PGD is seen as ‘the lesser of two evils’. It is the practice of terminating the pregnancy and destroying a foetus and disposing of an *in vitro* embryo that differentiates PGD and PND, and one is harder to perform compare to another for some individual. According to Ehrich et al (2008), sympathizing on the effect of having to go through termination of pregnancy also explained why some medical professionals feel that PGD is a better option compare to PND.

A further position among medical professionals when discussing on moral status of embryo is that to prioritise couples or parents choice as a work goal over personal feelings. For these participants, they feel that when parents or couples already decided to use PGD, it means that they already make decision on how do they feel on moral status of embryo and accepting the fact that PGD would end up destroying several embryos. At the same

time, when parents already make up their mind of using PGD, they normally know that they are at risk of having a child with what they considered as serious condition. This could make it difficult to argue with the request of these parents due to their experiential knowledge about such conditions (Williams et al., 2007). In this case, the overall commitment is to support the rights for the individual choice rather than the immediate consequences of the embryo.

Opinions on the moral status of embryo are also varied when religious aspects are included. It is understood that people of different religious beliefs have little consensus on the controversial issues related to the use of reproductive technologies including PGD (Frazetto, G., 2004). This is because different religions have different views on matters pertaining to what constitutes human life. For some religions life begins when conception happens but for other religions, embryo can only be considered as an early-stage human being, 120 days or 40 days after conception.

In simpler times, so little is known scientifically about the nature of prenatal life, and limited of technology also puts a limit of what can be done about it in any case. Thus, religious people feel there is no need to have opinions, much less to choose sides (Cole-Turner, R., 2003). There is a general religious understanding on issues of respecting life and doing what we can to protect and nourish it as well as general opposition to abortion. However, there is no unanimity of opinions about embryo's status or condition. Ethical discussions on moral status of the human embryos are central to contemporary debates on the ethics of new reproductive technologies including PGD (Saunders, P., 2006).

Discussion on the moral status of the embryo in Christianity often involved the notion that life started at the moment the conception process occurs. Therefore, embryo is a human life and it should be protected and respect. This is because human is made in the image of God by the Creator Himself therefore; every life is precious and is to be

embraced with joy (Tang, A., 2008). For someone to destroy it is considered as destroying another human life. This is consistent with the finding that is shown in this study where all the three Christian representatives, claimed that a few days old embryo created during the PGD process is a human life and should be treated with respect and not be discarded. Using the theological approach on the sanctity of human life, they argued that regardless its conditions embryo should not be deliberately created and to be destroyed when not needed.

According to the Christian Holy Scripture, every human life is special and different from that of a plant or animal because human share something in nature with God (Genesis 1: 26-27). As Vorster (2011) has noted, the human being is invested of something of God himself, namely His spirit. With the gift of this life, the human being is ensouled. Therefore, as a human being, created and ensouled by God, the embryo is ontologically an object with a moral status (Vorster, 2011). This subsequently strengthens the Christian representatives' arguments that deliberately destroying the human embryo is tantamount to the deliberate destruction of a human being.

On the contrary, both the Islamic scholars in this study showed that they do not have any qualm to allow the use of PGD among Muslim when their medical conditions require them to do so. They both do not view embryo as a living human because embryo do not have any soul; it is believe that the soul is 'breathed in' to the human embryo on the 120th day after fertilization and this is when life become sacred (Hug, K., 2006). They both also think that it is permitted to conduct a genetic testing on an embryo prior to implantation if the testing is done in order to avoid the transfer of severe genetic disease. Hence, diagnosis aids should be provided for couples at high-risk for selected inherited diseases and the treated embryo may only be implanted into the uterus of the wife who is

the owner of the ova and only during the span of the marriage contract (Nordin, MM., 2011).

Furthermore, according to both of the Islamic scholars, Islam religion encourage its follower to try to avoid illness and is allow to use the best treatment or the most effective treatment to cure the disease. This finding is consistent with previous research where according to Fadel (2007), most Muslim jurist will accept that pre-embryo before pre-implantation is not a human being because it cannot have independent life thus, permitted the use of PGD. Islam has always encouraged men to contemplate, explore new horizons, and make use of all things Allah has created for them (Hug, K., 2006) and this include new reproductive technologies such as PGD.

Similar to religious representatives, potential PGD users in this study also displayed different range of views on issue related to the sanctity of human life. The findings in this study demonstrate that for some potential PGD users, they personally think that embryo does not represent a human life therefore it is acceptable to discard the unhealthy embryo. Another group of potential PGD users showed strong dependence on the religious rulings in regard to their views pertaining to the moral status of embryo; the view of their religious ruling body on the issue ranked higher than their own personal view regarding the issues discussed. This might contribute to their final decision on whether to use PGD.

Education about religious rulings on issues pertaining to new reproductive technologies including PGD has significantly affected parents or couples' attitudes towards the notion of using it (Alkuraya and Kilani, 2001). This scenario is commonly found where religion provides people with religious beliefs containing some kind of guidance and epistemic authority in terms of their lay knowledge of PGD, and provides a basis to interpret new information (Doolin and Motion, 2010). This is consistent with the finding that is shown in this study where some potential PGD users depend solely on the opinions

of their religious leader when assessing moral status of the embryo, thus contribute to their perception on PGD. As noted by Cole-Turner (2003), religion provides boundaries for its followers when they make their reproductive decisions.

According to Zawawi (2003), the maintenance of religious beliefs and a strong sense of respect to rich Asian cultures is a strong influence to reproductive choices in Malaysia. However, in contrast to this statement, this study showed that some potential PGD users place religious views on embryo status and the practicality of the technology side by side when making decision on PGD. They showed that although religious opinions are important, it is also equally important for them to include other aspects related to the technology, particularly, aspects that might have impact on them or their child either physically, emotionally or psychologically. This finding indicates that the strong influence of religion to reproductive choices in Malaysia could not be generalized because there are other factors that might have a stronger influence on individual reproductive choices.

The second theme raises another concern that PGD is trying to 'play God' by providing parents the ability to select their future children based on the desired genetic characteristics. Most of the time, this term is used in a negative way whereby trying to 'play God' is associated with humans trying to interfere with the natural process of reproduction (Jones, G., 2004). This attempt for some may yield unpleasant results in the long run. However, Jones (2004) stated that normally discussion and interpretation of 'play God' in PGD tends to reflect hostility towards the procedure rather than presenting a clear rationale.

Opinions and views on PGD and accusations that it is meddling with natural process of human reproduction are most of the time are ambivalent. Medical professionals in this study indicated that they feel PGD is not about humans trying to 'play God' but is instead a medical technology that can help parents to give birth to healthy children. It is

also viewed as medical intervention that deem necessary for certain group of people. At the same time, their sense of responsibilities to their patient led them to feel the need to protect the unborn children from any kind of diseases (Williams et al., 2007).

Furthermore, it is normal for parents wanting to have healthy children, especially those who are in the high-risk group or who have previously given birth to children afflicted with a severe genetic disorder (Ehrich et al., 2008). Due to the possible medical benefits that PGD can offer to both the unborn child and also his or her parents, most medical professionals viewed PGD as another stepping stone in medical advancement in the field of reproductive technology rather than technology that destroys lives. This also provide rational explanation to why they think that using or providing PGD is not trying to play God; it is needed in order to save lives and cure genetic diseases. This finding is similar to previous research conducted among medical professionals in the USA where PGD providers and other experts support the use of PGD to avoid serious, life-threatening genetic disease (Kalfoglou et al., 2005). Another research in Germany also reflecting similar finding where the PGD providers think that PGD fit the purpose of a technology that was created to help others in need of medical assistant but require it to be regulated (Krones et al., 2005).

Lack of information and knowledge on how does PGD actually work and what it capable of, contribute to incorrect perception on the technology, thus give rise to the term 'play God'. This is another important finding in this study where the medical professionals highlight the main reason that contributes to the negatives impression that member of the public had on PGD. They believe that due to the insufficient information available on PGD, public tends to make their own speculation on the technology base merely on hearsay or through media. However, this low health literacy can be improved through educational program on PGD and this might change the public perception on PGD. Discussion on lack

of knowledge on PGD that lead to misconception of the technology and resulted in negative impression on PGD is consistent with the finding in previous research done in Japan (Shirai, Y., 2001). Similar findings are also highlighted in Germany (Meister et al., 2005) where the study showed that there is very little knowledge about PGD among the German general population, thus creating incorrect assumption about the diagnostic possibilities of PGD coupled with lack of basic genetic knowledge. Therefore, the misconceptions on PGD as trying to play God, which is due to the public low health literacy mentioned by the medical professionals in this study, is consistent with the findings in previous studies by Shirai (2001) and Meister et al (2005).

It is interesting to know that potential PGD users involved in this study displayed two different views in regard to play God, either PGD is trying to play God or PGD is the alternative that they need to eliminate possible suffering to their children. However, potential PGD users unanimously mentioned that regardless whether they think PGD is playing God, they do not want to judge others who choose to go for it. Not wanting to judge others' choices on PGD is not uncommon among parents or individuals who have genetic diseases or have children suffering from genetic diseases. This is because they tend to understand the situation that these parents are facing (Doolin and Motion, 2010). Parents or individuals who are in the same situation generally show more empathy and compassion towards other parents who are in the same situation. This is because they know what these parents had or are going through; raising children with genetic disabilities that require special care is not an easy task that some parents are willing to resort to unconventional treatments.

All potential PGD users in this study do not have any formal education in regards to reproductive and genetic field. But they need to make decision regarding the best medical treatment for their children either physically, genetically, mentally & psychologically; they

only want to give the best they can to their children. As mentioned by Jones (2004), these are ordinary people, without any sophisticated scientific or theological knowledge, having to determine the fate of embryos and children who will one day become adults.

Jones (2004) highlighted that these parents have no control over the underlying genes of this condition and it is not their choice to deal with such tragic disease. The finding in this study, support the statement made by Jones (2004) where most potential PG users argued that as parent or future parent, they do not purposely used PGD for trivial reason; their medical history compelled them to search for alternative and PGD seem to be the most appropriate treatment for it. The main factor that influence and motivate their need to search for alternative for their children is the notion of human suffering. Most potential PGD users in this study are either parents with genetic disabled children or individual who are afflicted with genetic disability. Therefore, they view PGD as an option to avoid further suffering to their future children after witnessing the suffering of anyone close to them or experiencing their own suffering living with genetic disability.

This is consistent with previous research done among women who had, have or susceptible to breast cancer; those who favour the use of PGD associated the notion of avoiding suffering in their child as one of the reason for their choice (Quinn et al., 2009). However, for potential PGD users that view PGD as human trying to play God, the influence of religion is stated as one of the reason for their perception. Although these participants believe that the prospective parents should be allowed to make their own choices regarding PGD, they themselves are not willing to use it.

For these participants, they believe that God has decided everything that happens in their life. As staunch believer in their religion, they both believe that their faith in life is already been decided and they will dutifully follow it through. They place their trust in their faith in God and just accept the child as it is; changing the child according to their

own desire is seen as being ungrateful of God's gift to them. This finding and decision by the two potential PGD users is not something new because according to Watt (2004), some parents are willing to let nature take its course and leave the health of their future offspring to chance rather than making the choice to use PGD.

When addressing the notion of playing God, some religions do not encourage or forbid the use of PGD because selecting children based on their genetic combination in order to avoid the birth of disabled children is sometimes seen as not accepting what God has given to them (Doolin and Motion, 2010). This statement is supported by the findings shown among the three Christian representatives where they stated that they believe in the providence of God; therefore, seeing the use of PGD as human attempting to take over the work of God by creating their own child according to their pre-chosen criteria. Believing that everything is God's prerogative, they believe that children should be accepted as they are and parents should not change them into a person that they desire. There are some things, which we cannot control or 'play God' but have to leave in His hands (Tang, A., 2008).

In this study, PGD is also labelled as interfering into the natural order of things or human trying to enter into a forbidden territory, which only God should enter. For example, the ability to select who gets to live and die, should be dealt by God and not human. This finding is consistent with previous study by Kalfoglou et al (2005), which mentioned that objection to new reproductive technology including PGD was that people do not have the right to decide who gets to be born based on an assessment of potential quality of life.

It is also stated that everything in life happens for a reason as part of God's divine plan and that using NRTs reflects a lack of faith in God's plan for one's life (Kalfoglou et al., 2005). The notion that humans are dealing with technology that they should not indulge in created fear that this action can lead to negative consequences toward human lives. This

concern is also highlighted in a study conducted in New Zealand where individuals from various Christian denominations claimed that PGD is inappropriate interference with God's work or purpose, an unwarranted and potentially dangerous 'meddling' with a divine order that was 'out of bounds' (Doolin and Motion, 2010). These previous studies are consistent with the findings in this study and it showed that people who practise the same faith tends to display similar perception on certain ethical issues.

However, some religions do not encourage the use of PGD although it does not completely forbid it. For two Islamic representatives, PGD is God given knowledge to human kind, which can be used to heal genetic diseases and save lives. PGD is not view as trying to take over the work of God and Islam encourage its followers to find cure and treatment for any kind of diseases that they have. This is consistent with an articles written by Fadel (2007) in which he mentioned that theologically, Islam encourage men to contemplate, explore new horizon and make use of all things God has created for them, and this include seeking cure for their diseases. Thus, explained the reason why PGD or other new reproductive technologies is permitted in Islam as long as it is used for medical purposes and no harm imposes to the child. Consistent with Fadel (2007)'s statement, the two participants also mentioned that if PGD is use for medical purposes, then it is not playing God but it is view as playing God if the reason to use PGD is to simply changing the social features of their child.

Discussion on PGD has brought about the ethical issue of perfection, in which parent are accuse as trying to create the perfect child using PGD, thus creating the term 'designer babies'. The term perfectionism means the persistence of will in obtaining the optimal quality of spiritual, mental, physical and material being. The use of PGD has brought the topic of perfection to a higher level. The quest for perfect babies starts as early as the pre-embryonic stage. Through the procedure of PGD, only the 'perfect' embryos are

transferred to the mother's wombs (King, DS., 1999). This raises fear and concerns on the possible misuse of PGD that might lead to potential full-blown free market eugenics. King (1999) added that since the conception of the future children are done outside the women's wombs, the decision over the embryos' fate becomes much more open to interventions from other parties such as the male partners, doctors and society at large. Thus, impose unnecessary pressure on prospective parents when they make decisions on PGD.

However, the findings showed that the fears of 'designer babies' and 'eugenics technology' through PGD is an unnecessary and should not be a reason to completely banned the use of PGD. Although PGD is able to help parents to conceive healthy child, it will not be able to eliminate all kind of genetic diseases particularly if the parent do not know about their family genetic history. This is because according to medical professionals in this study, PGD can only eliminate genetic disease that is known to both the parent. It is a technology to detect a known genetic disease, which place limitation on the capability of PGD. But, due to the lack of knowledge on PGD; how does it work, what can it do and what are the limitations of PGD, triggered misconception on the technology, leading to the rise of fears associating PGD with eugenics technology. Subsequently, this can create unrealistic expectation by parents when they wish to use PGD. This is also highlighted in a research conducted by Kalfoglou et al (2005) in the UK where the effect of not having the right and accurate information on PGD might led to parent unrealistic expectation of their children, thus raise concern on the possible effect toward society in general.

Having the perfect child is sometimes associated with having children from a particular or preferred gender. PGD has a reputation to be use by parent for selecting their future children based on their gender. Selecting children base on gender give rise to concern that it can lead to the imbalance of the population sex ratio, which has been witnessed in China and India even without the use of PGD (Purdy, LM., 2009). However,

this is not a major concern among participants in this study because they believe that most parents who request for PGD is not because they are particular about the gender of their child. Instead they just want to make sure that their child is born healthy. This is consistent with another study conducted in Australia by Katz et al (2002) where findings showed that PGD users in Australia have little concern that PGD might be use for non-medical sex selection. Instead priority of using PGD is given to the needs to avoid single gene disorder, which reflect their desire to have healthy children. Furthermore, as mentioned by medical professionals in this study, social sex selection is a trivial reason to request for PGD as compare to avoiding the birth of a child with sever genetic diseases.

One of the disadvantages of PGD is the high cost involve in using it and this could probably be one of the main hindrances for anyone who want to use it. However, high cost of the aftercare of children born with genetic disabilities particularly, genetic diseases that are very rare and treatment is scarce, can also motivate parent to use PGD. This is a significant finding in this study because high cost involved in the after care of disabled children has not been associated with parent's motivation to request for PGD. In this finding, one physician stated that the cost of taking care of a child with genetic disabilities might be in the long run exceeding the price of going through PGD, thus some parent might feel that it is a small price to pay in order to have a healthy child. This differ with previous study by Lavery et al (2002) where high cost of PGD is highlighted as one of the disadvantage for parent wanting to use PGD whereby, this study highlight the cost of caring for disabled child as the disadvantage of not using PGD.

Parent desire to provide a good life to their children is nothing new. According to Savulescu and Kahane (2008), most people will agree that there is a moral defect in parents who intend to conceive but are indifferent to whether their future child will be born with the potential for a good life. Previously, prospective parents might have limited option to

enhance the well being of their child but this has been made possible with the emergence of the new reproductive genetic technology such as PGD. Furthermore, the need to provide a good quality of life and to avoid further suffering to their future children is also related to individual or parent's own personal experience with genetic disease. This is highlighted in this study where a number of potential PGD users used their own personal experience with genetic disease to expressed their need to end further suffering to their future children. They view PGD as a mean to provide them with the alternative that they need to avoid the transmission of genetic disease to their child, thus provide them with a good life. Similar to previous review by Hersberger and Pierce (2010), which stated that personal experience with genetic disease, either living with genetic disease or taking care of children with genetic disease, and the tremendous emotional stress dealing with the situation, can influence individual or parent perception and decision on PGD.

However, for few potential PGD users, their religious faith ranked higher than their personal need to have the child that they desire. Although PGD provide them the alternative to have healthy children and be able to avoid the transmission of genetic disease to their future children, they still prefer to leave the procreation process to Nature. Using PGD to have the child we desire is like sending a message to your child that they are simply not good enough. Instead of needing to intervene with the medical condition of their child by changing their genetic combination using PGD in order to provide them a good life, they argued that even children living with genetic disease are able to have a good life. This is base on their own personal experience raising children with severe genetic disease. No doubt it is a constant struggle and suffering for both parent and child, it nevertheless a very valuable learning experience. They do not wish to change anything and accept the medical condition of their child as God's plan. A displayed of religious conviction when discussing issues related to technological intervention in procreation is

common among participants with religious affiliation. It is also has been reported by Kalfoglou et al. (2005) that for many Evangelical and Mainline Protestant participants, having an affected child is a test of faith for the parents or testimony of faith to others.

However, parent's desire to use PGD to conceive children free from genetic diseases, received criticisms from Christian representatives in this study. These religious conservatives claimed that parental aspiration for the perfect child could lead to the new era of eugenic. According to Abraham (2012), religious conservative claimed parent's desire to have the 'perfect child' is to avoid the task to care for children with special needs, which come with possible burden and troubles. PGD is no longer be a technology to eradicate genetic diseases but is instead, becoming a technology to create children whose future depends on their social features and genetic combination, which are purposely design to provide them with the extra edge compare to the rest of their peers.

In addition, parent's desire to avoid the transmission of genetic disease to their future children in order to avoid suffering and subsequently, providing a good life to their children is a lame excuse to use PGD. Having certain kind of genetic disability does not make one life to be less perfect as compare to those who do not have genetic disability. This reason alone could not be a good enough reason for parent to discard embryos. In fact, people do not have the right to decide who gets to be born based on an assessment of potential quality of life (Kalfoglou et al. 2005). Using Christian teaching on perfection, a perspective that see perfection on human relationship with God rather than our physical or genetic feature, Christian representatives stressed that regardless what technology that we apply to help us create the 'perfect child', the child will never be perfect if she or he do not have an intimate relationship with God.

In Islam, Muslims are encouraged to search for perfection in mind, body and spirit. Thus, permitted the used of PGD in order for parent to avoid the transmission of genetic

disease to their future child and prevent the family lineage from being tarnish. However, social 'perfection' is not permitted because it showed that we are not grateful with God's gift to us. Similarly, Fadel (2007) stated that, while there are no specific fatwa (religious decree) issues, PGD for the enumerated acceptable indications appears to be permissible, while PGD for the questionable and the unacceptable indications, including sex selection other than in the context of X-linked disease, is not. Additionally, Nordin (2011) stated that the spirit of the exhortations of the Prophet SAW and his companion was to secure normal and healthy babies, protection of their early well being, endowed with the benefits of good genes from both parents and the prevention of congenital malformations and its consequent disabilities. Therefore, indicating that Islam religion encourage Muslim to find the best cure or treatment for their medical conditions (Fadel, 2007). Thus, explained the reason why the two Muslim scholars in this study do not see any reason why PGD should not be permitted if the technology is use for medical purposes.

The good intention of parent to prevent their child suffering from severe genetic disease and willing to invest their need in modern medical technology such as PGD is seen as parent's determination and love to their child. Based on Buddhist representative's perspective on parent's decision to use PGD, he stated that in Buddhism teaching, it always emphasizes on the good intention of the doer toward the receiver; it has a strong emphasis on ethics and non-violence, on the intention not to harm and compassion (Harvey, 2008). According to Harvey (2008), although Buddhism against the destruction of embryo because they believe that life start at the moment of conception, the destruction of embryo in PGD is permitted when the motive behind the act if not to bring into the world a child suffering from a severe illness. At the same time, prevent the intolerable possible psychological and spiritual damage to the parents as well as other member of the family, in which, has outweigh the negative aspect of PGD.

However, parent's desire to provide a good life to their children via PGD can lead to potential harm to society; leading some parent to become perfectionist. Therefore, it raises concern among some participants particularly Christian representatives because when human is willing to do or try anything to have the 'perfect child' it can lead to the misuse of PGD. Furthermore, as the technology expands, so will the reason to use it; the 'determinations of destructible foetuses may be extended from clear genetic categories to categories of social desirability or usefulness (Childress, KD 2003). Subsequently, leading to changes in term of human value and relationship because children end up being treated more as manufacture goods that is manufactured according to specification in order to satisfy the need of the parent (Boyle and Savulescu, 2001).

Another concern on the frivolous use of PGD is the accessibility of PGD, which can create a widening gap among society because the limitation in term of the access and price. Therefore, make it accessible only to the wealthy group of individual and for those who really need it might not be able to use it. The same concern was highlighted in Hudson (2004) article where she also stated that due to the high cost of PGD, it could create a society gap where only the poor is sick and the rich is healthy. However, the concern on societal effect bring about by PGD uses is regarded as just mere theory by most medical professional because of two reasons; there is still a cheaper and accessible alternative to conduct genetic testing for unborn child in the country such as PND and most PGD services are control and provided by private medical centre, which make it pretty accessible to anyone without restriction.

Therefore, they feel that parents are provided with the available options and it is only a matter of parental choice; choosing PGD and avoid TOP or go for PND and facing chances of having to go through TOP when the child is tested positive for the genetic disease. Unlike in other study, the traumatisation of going through termination of

pregnancy is not being assessed in this study. However, according to other studies, the traumatisation of having to go through TOP especially for those who have gone through it before, give them the more reason to go for PGD (Hui et al., 2002). Even though most participants had strong views in regard to their perception on ethical issues posed by the use of PGD, they do stress the important of freedom of choice and individual decision-making. Because of the sensitivity of reproductive issue and different factors that might influence their views on the issues, most participants ultimately felt that only the couple themselves could or should make the decision to use PGD.

When it came to discussing about patients rights to make their own reproductive decisions, medical professionals are strong advocates of parental rights. The prevailing genetic counselling ethics stress the ‘non-directiveness’ and ‘value neutrality’ of decision-making (Green, RM., 1997). All medical professionals generally identify reproductive rights as a core value during counselling with their prospective patients before using the treatment (Bisecker, BB., 2010). Noted in Green (2007), parents not only have the right to their reproductive decision-making, but they are usually also the best protectors of their children’s interests, including in giving them a healthy start in life.

Participants who have personal experience with genetic disorder strongly endorse the right for couples to make their own decision regarding PGD. They applied their own personal experiences and knowledge to reinforce or reaffirm their support for individual decision-making. They relate their own personal struggle and suffering having to raise children with genetic disabilities or living with genetic disabilities themselves, to support their argument that couples should make the decision on PGD.

When individuals use their own experiences to justify their perception of PGD, it changes the way they look at the technology. A study by Van Rij et al (2011) showed that personal experiences and reproductive history are more important determinants of eventual

PGD use than the mode of inheritance or the expected clinical impact of the disorder. At the same time, personal experiences and reproductive history are found to contribute to the reason why some parents believe that they know what is best for themselves and their future children, thus influencing their reproductive decisions (Hershberger and Pierce, 2010). The finding in this study supported previous study by Van Rij et al (2011) and Hershberger and Pierce (2010) where potential PGD users indicate that their personal experiences with PGD do contribute to their decision making on PGD. However, the finding highlight a new information in which, this study show the link between participant's personal experience with genetic disorder and their belief about the appropriateness of individual decision making on PGD. This is notably one of the most important finding because frequently presentations on personal experience with genetic disorder are generally associated with their decision-making or motive to use PGD but not as a contributing factor to support the appropriateness of individual decision-making on PGD for others.

However, the notion of freedom of choice subsequently might lead to the increasing reproductive rights of parents, thus raise concerns on the possible misuse of PGD. This 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' (Kerr, A., 2004). With increased reproductive rights, medical practitioners' responsibility sometimes gets more complicated. Tension and misunderstanding might arise between the doctors' professional views on what would be the best for their patients and parents' wishes (Bredenoord et al., 2010). At the same time, there are concerns and fears that the increasing rights of prospective parents might lead to a new form of eugenics (King, DS., 1999).

In contrast, finding in this study showed that most participants do not displayed such concern. They do not think that the increasing individual right to decision-making

will contribute to the misuse of PGD such as using PGD for social sex selection. Using PGD for choosing embryo based on trivial physical characteristic or social sex selection is a little concern among the participants involved in a study conducted in Australia (Katz et al. 2002). However, it is agreed that proper regulation should be properly set up to prevent frivolous use of PGD and to avoid future unanticipated incident. This differ with Roberts and Franklin (2004) where they found that participants thought that it is important to prevent frivolous use of PGD to avoid regulatory backlash that might create barriers for those who need the technology.

Although most participants showed an inclination toward individual decision-making, there are few participants who believe that the final reproductive decision should not be the sole right of the prospective parents. The finding showed that Christian and Muslim scholars argued that according to their beliefs, there is no absolute individual freedom. Humans do not have the right to determine when a child will be born, who the parents will be, which gender the child will be or when a child will die as these are all God's prerogatives (Tang, A., 2008).

In Christianity, everyone has the right to live including an unborn child. When discussing the right to live, once again, issues pertaining to the moral status of embryo were brought up. Most Christians view embryo as a representation of life. If parents are given total rights to make decisions concerning their reproduction, there are concerns that such laxity might lead to the misuse of the technology and become the 'slippery slope' of PGD. This is because acceptance of the benefits of medical advances such as PGD is often tempered by concerns about the potential unforeseen consequences of the misuse (Doolin and Motion, 2010). Given the existing trends in our society, such as the increasing prevalence of cosmetic surgery, it is naive to expect that misuse of the technology will not happen (King, DS., 1999).

On the other hand, Islamic religion does not have any qualms regarding the rights of parents to make the final reproductive decisions, as long as it is not against the teaching of Islam. As much as religions allow the use of assisted reproductive technology among its followers, they place a certain level of limitation in order to make sure that decisions are made within the boundaries of the religious teaching. There are always certain levels of acceptance that religions can tolerate when it comes to reproductive technology.

4.6 Conclusion

Participants in this research had robust discussions and appeared to be very interested in the topic. This might attribute in part to the presentation of issues in which participants were able to discuss the issues that arise from the use of this technology, confront them directly and depersonalize their approach on the issue based on several perspectives. These discussions resulted in detailed, picture of participants' beliefs and values that shaped their overall perceptions on the use of PGD.

The significant findings between the focus groups highlight and provide interesting information regarding participants' perception on ethical issues posed by the use of PGD. Their perceptions on the themes described their rather unique approach to the issues that are based on several perspectives, which emphasize their commitment to their profession, patients, children and religion. Some of these perspectives may or may not have been highlighted in previous research regarding PGD and public perceptions on the technology. These differences create a pool of information that can be useful in future studies on public perception on new reproductive genetic technologies.

Based on Table 4.3, which highlighted the difference approaches, thus the difference perspectives of the three focus groups, the general findings of this thesis may be illustrated on the following flow chart (Figure 4.2).

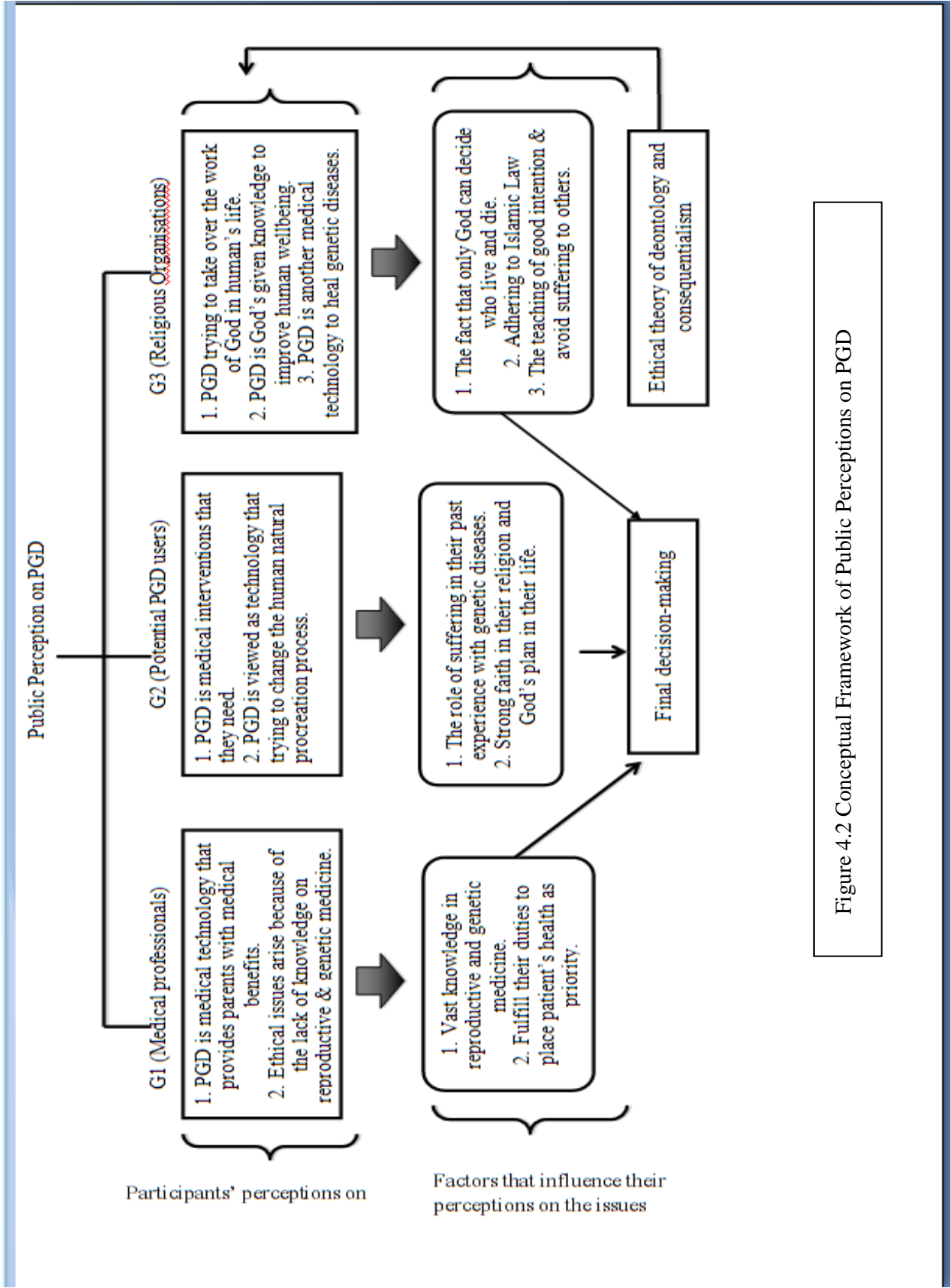


Figure 4.2 Conceptual Framework of Public Perceptions on PGD

Figure 4.2 highlighted several key factors that influence their views on ethical issues pertaining to the use of PGD, which in turn influence their perceptions on PGD. Subsequently, might contribute to their final decision making on PGD. The first focus group consist of medical professionals who have extensive medical and scientific knowledge on reproductive technologies as well as genetic technologies. Therefore, explained their perceptions on PGD; it is a technology that provide parents or couples with medical benefits and ethical issues such as ‘play God’ and ‘perfectionism’ are mainly arise due to the lack of knowledge on the technology among members of the public.

Subsequently, give rise to the misconception that PGD is trying to play God, has the capability to create ‘extra ordinary’ children or ‘designer babies’ and associating it with eugenics technology. The key factors that influence their perceptions are their strong medical knowledge in reproductive medicine and genetic technologies, which is the same factor that influenced their discussion on all the four key themes; sanctity of life, play God, perfectionism and freedom of choice.

On the contrary, potential PGD users in this study demonstrate two different perceptions where PGD is either view; 1) as a medical alternative for individuals with genetic histories and assisting parents to avoid the transmission of genetic diseases and produce healthy children, thus avoid suffering to their children or 2) PGD is a technology that trying to take over the natural process of human procreation, thus can reduce our faith in God and not being thankful of His gift.

The first perception is influenced by the role of suffering in both parent and children, where potential PGD users believe that the technology could enable them as parent or future parent to avoid their children having to go through the situation that they had to go through previously. At the same time, PGD is also view as a mechanism for parent to provide their future children with an optimal environment in order for them to

have good quality of life. The technology is viewed as a medical alternative that their parent does not have the privileged to use previously. The second perception is influenced by potential PGD users strong faith and belief in their religion and God's plan and will in their life. This was highlighted few times during their discussions on the selected theme. For example, in theme 'play God' where they believe that children should be accepted as who they are instead of being changed genetically into a child that the parent's desired. These potential PGD users quoted the term 'redha' and 'takdir' as a proclamation of their faith by accepting their child's medical condition and the experience they have to go through raising their 'special need' children as part of the Divine's plan in their life. They viewed it as part of the Divine intervention that will enrich their life as well as the rest of the family.

However, in Figure 4.2, the flow chart showed that religious representatives have rather ambiguous perceptions when it comes to ethical issues posed by the use of PGD. For Christian representatives, PGD is viewed as trying to take over the work of God and interfere with the natural process of human procreation. This perception is influenced by basic teaching in Christianity on the sovereignty of God; the notion that only God has the authority to decide between life and death, a perspective that God is in control of everything that happens in the world.

This differs with Islamic scholars in this study because they believe that PGD is God-given knowledge to humans and it is to be used to cure and treat diseases in order to save lives including the lives of unborn children. This perception is adhered to with the Islamic Law, which becomes the main factor that influenced their approaches to the ethical issues on PGD, which were discussed in this study.

For Buddhist representatives, he viewed PGD as another new medical technology to heal genetic diseases; therefore, he believes that PGD should be permitted if the intention

to use it is to save lives, avoid the notion of suffering toward others and bring happiness to the whole family. This is because Buddhism teaching emphasize on the teaching of good intention, as well as the welfare of not only the future children but also the prospective parents.

Generally, the findings demonstrated by participants in this study fall neatly into classic ethical theory of deontology and consequentialism. For instance, religious representatives, medical professionals and potential PGD users described their perception based on their responsibilities toward their religion, patients and children or future children. Whereby, their concerns on the kind of future that they desire or fears are very much related to the possible consequences of the technology to human kind. The flow chart also indicated that their perceptions on ethical issues on PGD could influence in their final clinical decision-making on PGD.

CHAPTER 5

CONCLUSION

5.1 Introduction

The final chapter attempts to draw together the key findings of the participants' perceptions on ethical issues pertaining to the use of PGD to provide a comprehensive insight into the ethical implications of PGD in Malaysia. The main findings are presented as responses to the research questions of the study. Ethical and clinical issues pertaining to the use of PGD as well as its important to the sectoral policies are also addressed in the discussion. The limitations and future direction of research in the area are addressed at the final part of the chapter.

5.2 Implications for theory

The emergence of PGD is an important milestone in the field of reproductive genetic technologies (RGTs). Its provide parents with an alternative to avoid the birth of children with genetic disabilities as well as going through termination of pregnancy when the child is tested positive for the mutation genes. However, it creates ethical concerns and fears that it might lead to unanticipated consequences toward individuals and children. Generally, the overall results of this study tends to support previous studies by Pergament (1991), Snowdon and Green (1997), Krones et al. (2005) and Kalfoglou et al. (2005), where individuals perceived PGD to provide an incredible opportunity to have a healthy child as well as an alternative to avoid the risk of having to face a pregnancy termination; and studies by Hui et al. (2002), Alsulaiman and Hewison (2006) and Menon et al. (2007) on

attitudes of individuals toward the use of PGD for those who has experience with genetic disabilities; and Krones et al. (2005) and Kalfoglou et al. (2005) on the important of individual decision-making by the affected families or individuals or couples as well as studies by Alkuraya and Kilani (2001) on the effect of religious educational intervention about religious rulings on individual's attitudes toward PGD.

In the following parts of this chapter, the major findings of this study are presented as responses to the research questions determined in the earlier chapter (Chapter 1.5) of this study.

1) What are the medical professionals' perceptions on ethical and clinical issues posed by PGD?

Findings in this study showed that medical professionals viewed PGD as a medical intervention that is used to prevent and eliminate genetic diseases as well as saving innocent lives. It is not a technology that enables parents or couples to create neither 'designer babies' nor does it has a moving direction toward eugenics technology. The notion that PGD is able to allow parents to select their future children, create a perception that PGD is trying to play God and trying to create 'superhuman'; parents having unrealistic expectation when using the technology. For medical professionals, this misconception from member of the public indicates that there are lacks of knowledge on PGD, how does the technology actually work and what are its limitations.

This finding concurs with previous study by Shirai (2001) in Japan where it showed that there were significant attitudinal differences between the experts and the layperson concerning PGD. However, the significant differences are reducing, as knowledge on PGD increases and it is noteworthy that people showed more cautious attitudes toward PGD.

Also this finding is in accordance with the observation made by Kalfoglou et al (2005) where misconception on PGD could lead to unrealistic expectation of parents on their children when they used PGD. This is in line with previous study conducted in Germany by Meister et al (2005) where knowledge deficiency about PGD lead to an overestimation of the potential of PGD with half of the respondents stating that PGD can diagnose ‘any kind of diseases or handicap’. This cause fears and feeling of insecurity regarding the use of PGD.

This is in line with previous study by Quinn et al (2012), where the study indicated that low knowledge on PGD lead to the moderate acceptance of PGD and high levels of need for information about PGD. This draw attention to the issue of low health literacy among laypersons regarding PGD, as compared to individuals who are working in the medical field especially in the field of reproductive genetic.

It also highlights the way medical professionals approach ethical issues regarding the use of PGD for example in theme ‘play God’, ‘perfectionism’ and ‘freedom of choice’, thus indicate one of the major finding in this study. It also highlights the main factor that influences their perceptions; their expertise in the field of reproductive and genetic technology, which they use to analyse their responses toward the issues discussed.

2) What are the potential PGD users’ perceptions on ethical and clinical issues posed by PGD?

This study shows that most potential PGD users’ perceptions on PGD are based on their personal experiences with genetic disorders, where it is highlighted in theme play God’, ‘perfectionism’ and ‘freedom of choice’. For example, in theme ‘perfectionism’, most potential PGD users viewed PGD as alternative to their medical situation, where it can help them to conceive healthy children. Their desire to have healthy children which is

genetically related to them is due to the fact that they had suffered themselves or witnessed enough suffering on their previous children that are afflicted with genetic disease.

With the emergence of PGD, it is bring relief to them, thus view PGD as medical miracle that they needed, and to be able to provide their future children with the best quality of life as possible. They do not view parents or couples who choose to go for PGD as trying to play God or purposely used it to create their own ‘designer babies’.

This is also witnessed in theme ‘play God’ and ‘freedom of choice’ where potential PGD users highlighted their own personal experiences and relate it with their perception on PGD; they believe parents or couple with personal experience with genetic diseases will view PGD more as medical alternatives rather than technology that they can use to manipulate and lead to the creation of ‘super child or designer babies’.

This finding concur with the previous studies of Palomba et al. (1994), Chamayou et al. (1998) and Hui et al. (2002), which draw attention to the influence of personal reproductive histories or personal experiences with genetic diseases to one’s perception on PGD. PGD is viewed as an option for parents to avoid the birth of genetically disabled children in particularly for parents or couples who previously has children with genetic disability (Chamayou et al. 1998).

Also this finding is in accordance with the observation made by Roberts and Franklin (2004) where PGD is viewed as a technology to avoid future pain and suffering by the couple and their offspring, in particularly for couples who are raising a chronically or terminally ill child. This is also in line with Kalfoglou et al (2005) where the benefit of PGD for ‘at risk’ couples lead to the perception that PGD is a medical intervention used to avoid the suffering of their children.

However, this study also highlighted that some of the potential PGD users’ perception on PGD is based on their faith in God. For example, in theme ‘play God’ and

‘perfectionism’, they view PGD as trying to play God because it enables parents to select their children based on the genetic characteristic that they desire instead of just accepting it as ‘gift’ from God.

They preferred to leave the faith of their child at the hand of God than taking matter in their own hands, as they believe that all the things that happen in their life is part of God’s will and plan. Changing or creating your child as your heart desire is like not being grateful of what God has given into your life and not believing in God’ plan for your life. This finding concur with the studies by Genetic and Public Policy Center (2004) [GPPC], which draw the attention that people who think about genetic technology in term of its religious or moral implications are much more likely to say they feel very strongly about ethical issues related to it than those who oriented by health and safety related to the technology.

The same study also highlighted that most people with a religious or moral orientation worry that PGD is too much like playing God. It is hard to understand why some people are afflicted with genetic diseases but they believe that it is a part of God’s divine plan. This perspective contributes to their views that PGD is trying to play God. However, as a whole, it was found that potential PGD users’ perceptions in this study mainly expressed, based on their personal experiences with genetic diseases as compare to those who expressed their perception on PGD as trying to play God based on religious term.

This finding differ from the studies that were conducted by GPPC (2004) and Kalfoglou et al (2005) on the notion of playing God through PGD, in which most of the perception on PGD as trying to play God were expressed in religious or secular rationales; either that we used the technology that God has given us and use it wisely or it should not be use because it is unnatural and view as against the will’s of God. The logical

explanation of this is that one's personal struggle or experiences with genetic disease, might lead to the changes in term of their perception on certain technology that is related to their medical conditions.

3) What are the religious representatives' perceptions on ethical issues posed by PGD?

The study shows that religious representatives' perceptions on PGD are varied. For example, the Christian principles of the sanctity of human life contribute to their perception on themes 'sanctity of life', 'play God', 'perfectionism' and 'freedom of choice'. Christianity believe in the sanctity of human life where embryo is viewed as a human life, thus against any action that consequence in the destruction of human embryo.

Based on this perspective, human embryo does have right to live just as a born human baby, resulted in the limitation of parental reproductive rights. This finding concur with the Tang (2008) and Doolin and Motion (2010) which draw attention to the limitation of parental rights to final decision-making in regard to PGD as compare to a secular believe that parent has the sole right to make the final decision as they are the guardian of the child. It is for the same reason that they viewed PGD as trying to play God by deciding who get to be born and who does not; a task, which only God allowed to do.

This differs with the Muslim representatives' perceptions on PGD, where PGD is viewed as medical technology and knowledge that comes from God. It is a technology that is used to treat or cure genetic diseases. Therefore, parent who used it for medical purposes is not seen as trying to play God or purposely trying to change the genetic combination of their child, but merely, their effort to save the child.

For example in theme 'perfectionism', finding shows that Muslim representatives stated that the use of PGD to eliminate genetic diseases is encourage in Islam as it is view as parent's effort to make sure that the children is healthy and avoid passing inherited

genetic diseases into the family line. This finding concurs with previous articles by Fadel (2007) and Islam et al. (2007), which draw attention to the notion that God created diseases and treatment to cure the diseases.

Buddhist representatives' perceptions on all the themes are basically due to the fact that PGD provide parents with an option to avoid the suffering of their children, particularly for those who previous had children afflicted with genetic diseases. Although prohibiting the action of deliberately destroyed human embryo, Buddhism allow the act if the intention is to save lives and to avoid the suffering of others, and subsequently give happiness to the child and the whole family.

Buddhist sees this as parent's determination and love toward their child. This is in line with Harvey (2008) articles, which draw attention to Buddhist dictum mandates that any choice be exercised with greatest compassion for all involved. Adding that if the psychological or spiritual damage caused by caring for a severely disabled child outweighs the negative aspect of letting surplus embryos die then PGD may be morally acceptable.

4) What are the factors that influence participants' perception on PGD?

There are several factors that influence participants' perception on PGD, which are highlighted in this study. The factors are include; medical knowledge in reproductive and genetic field that influence the medical professionals' perception on PGD; the role of suffering for both the parent and child; having ultimate faith in God's plan; personal values on life; having the power to decide life and death; Islamic Law; and religious teaching on good intention, has become the main factors in shaping the religious representative's perception on PGD.

Having a vast knowledge in the medical field, in particular, the field of reproductive and genetic technology, they tends to use their expert knowledge on the field when face with

ethical issues, which arise from the use of medical technology. This is observed in this study where their perception on the themes, in which they described that due to lack of knowledge in PGD, member of the public tends to have negative perception on PGD, thus discourage the use of it, either by themselves or others. At the same time, their medical understanding of embryo status also influences the views on embryo status; embryo is an accumulation of cell that has no moral status, but deserves respect.

Potential PGD users' perceptions on PGD are evidently influence by two factors; the role of suffering for the parent and child and strong faith in God. For some participants, enduring and going through the burden and suffering of taking care of children with genetic diseases or a person living with genetic diseases, have an impact in their future reproductive choices; PGD provides them with such choices. Having strong faith in God and His plan in their life becomes the main reason why some of the potential PGD users prefer to leave the matter of procreation to Him. For these participants, religious faith becomes the pillar of strength in their struggle in taking care of their genetically or physically disabled child.

The idea that human has the authority to decide who get to lives and who dies, becomes the main factor to influence Christian representatives' perceptions on PGD, which is observed in their perspective on the sanctity of human life. This is because embryo is considered as a human life; according to Christianity, life begins when conception happens.

Since PGD involved the selection of embryo, whether to be implant or discarded, they view it as an act of human taking over the work of God; only God has the right to decide who get to live and dies or who will be born healthy and who will not. As for Muslim representatives, their perception on PGD is adhere to the Islamic Law where their perspective on life and how one should live their life to ensure peace, contentment and

wellbeing may fill the world, is through the codification of divine revelations to Prophet Muhammad (Islam et al., 2007).

For Buddhist representative, the Buddhist teaching on good intention influences his perception on PGD. Buddhist forbid any act that destroy any kind of life including plants, animal and human but in the case of PGD, the destruction of embryo is the consequences of parent's effort to avoid suffering to their future children by avoiding the transfer of genetic diseases.

5) Do their perceptions affect their final decision-making on PGD?

The findings in this study showed that participants' perceptions on PGD are ambiguous where participants displayed a range of perspectives, which are influence by several factors that subsequently might lead to their final decision on PGD. The study shows that participants' decision-making are categorized into several aspects; medical evaluation, potential or actual sensations of pain and suffering and religious education.

This finding concurred with the studies of Hershberger and Pierce (2010), which draw attention to the decision- making process concerning PGD; it is cognitively demanding and complex, always involved a lot of emotion and involve some moral judgment regarding ethical issues associated with it.

Participants from the medical field evaluated their final decision on PGD based on the medical conditions that the parents are facing. They need to evaluated medical situation on a case-by-case basis before providing PGD to their patients. These include the severity of the disease by those seeking treatment and the significant risk presented by the genetic conditions in the embryo and psychological aspect of the parent. At the same time, highlight the need to respect parent's right to decide.

This finding is accordance with the observation made by Williams et al (2007), which draw attention to the view of staff working in one of the PGD unit in the UK and their opinions on the widening scope of PGD. Although stating that besides the seriousness and the significant risk posed by the medical conditions to the child, they still emphasizing on the notion of reproductive choice.

This finding showed that the potential PGD users' perceptions on PGD do influence their final decision-making. For potential PGD users who prefer to leave their faith to God, they preferred not to engage in PGD services. They will leave the decision to God and will just accept His decision as their life destiny. They prefer not to interfere with the natural process of procreation. This is not a surprise because according to Zawawi (2003) the maintenance of religious beliefs and a strong sense of respect to rich Asian cultures is a strong influence to reproductive choices in Malaysia.

At the same time, they felt that their condition is treatable unlike other diseases with no options for prevention or treatment. This finding concur with studies of Quinn et al. (2009) which draw attention to the advantage of a treatable diseases as compare to a more serious genetic diseases that lack or no cure or treatment. Thus, indicate they're unfavourable toward the use of PGD for their medical conditions.

However, for some potential PGD users, religious conviction in regards of PGD is equally important as other factors when making their final decision on PGD; the cost involved, safety and quality issues, success rate, risks and spousal opinions on PGD. They do not place religious opinions on PGD as higher than any of these factors but as equally important as the factors mentioned when making their reproductive choices.

They showed that although religious opinions are important, it is also equally important for them to include other aspects related to the technology, particularly, aspects that might has impact on them or their child either physically, emotionally or

psychologically. This finding indicates that the strong influence of religion to reproductive choices in Malaysia (Zawawi, M. 2003) could not be generalized because there are other factors that might have a stronger influence on individual reproductive choices.

Another aspect that influence the final decision making on PGD among potential PGD users is the notion that PGD can avoid the birth of children with genetic disabilities and able to avoid the suffering of the child. Personal experience with genetic diseases and witnessing the suffering of someone with genetic disease, who are also close to them, do influence their evaluation on PGD.

This is concurred with the study of Quinn et al (2009) where some participants expressed their decision to favour PGD due to personal experience with genetic diseases. The finding in this study supported previous study by Van Rij et al (2011) and Hershberger and Pierce (2010) where potential PGD users indicate that their personal experiences with PGD do contribute to their decision making on PGD.

However, the finding highlight new information in which, the finding also show that there is a link between participant's personal experience with genetic disorder and their belief about the appropriateness of individual decision making on PGD. This is notably one of the most important finding because frequently presentations on personal experience with genetic disorder are generally associated with their own decision-making or motive to use PGD but not as a contributing factor to support the appropriateness of individual decision-making on PGD for others.

It is expected from this study that religious representatives will use religious teachings and rulings of their respective religion when making decision on PGD. Since Christianity against technology that involved the destruction of human embryo, PGD is not permitted among Christian couples or parents. This differ in Islam where PGD is allowed because of its significant potential benefit in various medical situations, thus, explained the decision

of Muslim representatives in this study to permit the use of PGD among Muslim couples or parents as long as it is use for medical purpose.

Buddhist views on the good intention of the parents to avoid suffering to their child and to provide them a healthy life, lead to their final decision on PGD; allow the use of PGD. These findings are accordance with the observation made by Fadel (2007), Motion and Doolin (2010), Roberts (2009) and Tang (2006) which draw attention to the influence of their religious perceptions on PGD toward their decision-making in regard to the technology.

6) What are the ethical implications of PGD in Malaysia?

The finding shows that there are several ethical implications of PGD in Malaysia as expressed by the participants. These include; 1) the possibility of further discrimination and stigmatization toward people with genetic disabilities and their parents, 2) Further change in human relationship as individuals are judge on their physical feature as well as their genetic combinations. PGD can also lead to the changes in parent-children relationship, as the expectation on children is higher and sometimes can be unrealistic, 3) the notion of parenthood is no longer an occasion of joy but an occasion of conveniences; couples will have children if the children are born healthy, 4) might have long term consequences on the sanctity of marriage particularly when sperm or egg donation from third party is involve and 5) increasing parental reproductive rights might lead to the possible misuse of the technology, which refer to the 'slippery slope' of PGD.

5.3 Implications for future practice

This study also highlights participants' concerns on the possible misuse of PGD if it is used without restriction. In their concerns, participants highlighted the need for proper regulation and policy concerning the use of PGD, as well as increasing control and proper monitoring of the use of PGD. The outcome of this study can provide useful information to policy makers on genetic technology, which indicated the important to include multi-disciplinary participants when conducting study in regards to policy formulation of new reproductive technologies including PGD.

This is because it is important to know and respect the views and opinions of people from various related field in regards to PGD. Proper regulations on the use of PGD in the country would lead to stringent requirements for PGD providers where they might be required to have a special license before being allowed to offer their services as in the UK where PGD providers have to obtain a license from the HFEA (Human Fertilization and Embryology Authority) [2005]. Such a measure according to most medical professionals can help to prevent PGD from being misused by individuals or organisations that use it without considering societal and ethical factors to gain personal benefits.

5.4 Recommendation for future research

Future research on this area could involve more participants from other focus group, which are not included in this study. Groups that should be considered in future research on this study including, (1) individuals who have used PGD previously, (2) representatives from government agencies involved in policy making, (3) representatives from other religions besides Islam, Christian & Buddhist and (4) medical staff that work in fertility

clinics that provide PGD services. This would give the researcher a wider spectrum of opinions and views on the use of PGD in Malaysia.

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APPENDIX A

Distribution of data		Sanctity of Life (SL)		Play God (PG)		Perfectionism (P)		Freedom of Choice (FC)	
Themes	Yes/No	Why	Yes/No	Why	Yes/No	Why	Yes/No	Why	
Contentious Views									
Group 1									
Participant 1	✓	embryo has limited right	✓	helping parents patients medically	✓	elimination of genetic diseases	✓	giving the autonomy to parent to decide	
Participant 2	✓	anomaly	✓	a matter of individual's choice	✓	prevention of genetic diseases	✓	parental rights	
Participant 3	✓	embryo has limited moral status & rights	✓	it is the parent's decision	✓	helping parents to have healthy kid	✓	up to the parents to decide	
Participant 4	✓	accumulation of cell	✓	parent has the right to decide	✓	producing healthy child, not perfect	✓	my duty to make sure parent free to decide	
Participant 5	✓	depending on each individual	✓	medical advancement	✓	medical intervention	✓	parental rights	
Participant 6	✓	limited moral status compare to born child	✓	it really is a matter of individual choice	✓	prevention of genetic diseases	✓	autonomous right of the parents	
Participant 7	✓	depend on one definition of life	✓	medical advancement	✓	help parent to have healthy child	✓	decision should be given to the parents	
Participant 8	✓	depending on each person's belief	✓	parent's decision	✓	prevention of genetic diseases	✓	rights of the parents	
Group 2									
Participant 9	✓	depending on what my religion say	✓	do not want to judge	✓	just want a healthy child	✓	responsibility to give the best to the child	
Participant 10	✓	embryo is embryo, it is not human life	✓	individual's choice	✓	medical tool to assist those who need	✓	responsible to give a child a good life	
Participant 11	✓	will refer to religious leader	✓	we should accept the child as it is	✓	we should 'redia'	✓	I will choose not to go but for others, up to them	
Participant 12	✓	prefer to seek advice from religious org.	✓	it's a gift from God	✓	leave it to God	✓	yes	
Participant 13	✓	prefer to seek advice from religious org.	✓	I think it is more toward medical needs	✓	placing their priority on having healthy children	✓	if there is a choice, why not	
Participant 14	✓	prefer to seek advice from religious org.	✓	it's a choice that everyone has the right to choose	✓	depend on one definition of perfect	✓	individual choice	
Participant 15	✓	will refer to religious leader	✓	it doesn't matter if one really want a child	✓	nope	✓	yes	
Group 3									
Participant 16	✓	potential life	✓	yes, we should be perseverance	✓	perfection is more than physical; it is also spiritual	✓	choose base on christian values	
Participant 17	✓	potential life	✓	child is a gift, no matter how sick they are	✓	God is in control of everything	✓	choose with conscious christian mind	
Participant 18	✓	life itself	✓	we are trying to take over the work of God	✓	no matter what, human can never be perfect	✓	no justice to the unborn child	
Participant 19	✓	no soul yet	✓	God permit us to use tech. to heal	✓	medical technology that has the ability to heal children	✓	yes but must be within the frame of religion	
Participant 20	✓	no soul yet	✓	God allow us to make sure our lineage is healthy	✓	parent's determination in making sure their children are healthy	✓	must be based on religious teaching	
Participant 21	✓	everything has a soul	✓	whatever that make the family happy	✓	what important is that the child is healthy	✓	parents have the rights to decide what best for their child	

Questions

Part A: Interview Particular

1. Name/Designation
2. Organisation
3. Time & venue
4. Length of interview session

Part B: On PGD

6. Have you heard of PGD?
7. As medical practitioners/scientists, what do you think of this technology?
8. Do you think parents/couple who decided or who had used PGD as someone trying to play with nature or playing God? Why?
9. What are your views on issues pertaining to the moral status of the embryo?
10. What do you think on PGD and the issues of human perfection? Why?
11. Do you think that PGD would have an impact on the societies regarding their view on genetic diseases?
12. If you were to make clinical decision on PGD, what would it base on and why?
13. Do you think PGD is the new eugenics? Why?

*Questions were not asked according to sequences written above & some pertinent questions may arise during the course of the interview.

Questions

Part A: Interview Particular

1. Name/Designation
2. Organisation
3. Time & venue
4. Length of interview session

Part B: On PGD

6. Have you heard of PGD?
7. What do you think of PGD?
8. What do you think about parents/couple who decided or who used PGD? Do you think they are trying to play with nature?
9. What are your views on issues pertaining to the status of the embryo?
10. What do you think on PGD and the ethical issue of perfection?
11. As parents with children who are diagnosed with genetic disorder/individuals who has genetic disorder, describe how you feel about PGD and what it capable off?
12. Do you think parents/individuals should be given the freedom to decide whether to use PGD or not? Why?
13. Would you consider using PGD? Why?

*Questions were not asked according to sequences written above

Questions

Part A: Interview Particular

1. Name/Designation
2. Organisation
3. Time & venue
4. Length of interview session

Part B: On PGD

6. Have you heard of PGD?
7. What do you think of PGD? Why?
8. What do you think about parents/couple who decided or who used PGD?
Please explain.
9. What are your opinions on the issues of reproductive right of the parent in PGD?
10. What is your view on the status of embryo? Why?
11. Do you think that on the issues of perfection and PGD? Why?
12. Do you think that it will change society perception and acceptance on people who has genetic disorders or some kind of disabilities? Why?
13. What do you think on issue of using PGD for sibling donors?
14. Base on your religious understanding, what should be considered when making decision regarding whether to use or not to use PGD?
15. What would be the possible impact of PGD to the Malaysian society in the future?

*Questions were not asked according to sequences written above

Appendix E

Ethical Implications of Preimplantation Genetic Diagnosis (PGD) in Malaysia

Participant Consent Form

I, (participant's name) with IC no....., confirm the following;

I confirm that I understand the Research overview which has been explained to me. I also understand that I may ask any question related to the Project if I do not understand any part of it and the researcher will be available to answer it.

I understand that my participation is voluntary and that I can withdraw from this study at any stage without giving any reason.

I understand that this project has been approved by the Department of Science and Technology Studies, Faculty of Science, University of Malaya, Kuala Lumpur.

I understand that the information from the interview is confidential. I understand that the data gathered within this study will be used only for scientific purposes and that the information may be written for inclusion in a book or scientific journal. I understand that my name will not be used in a book or journal articles that are published from this study.

I agree to take part in this interview on(date)
at(place of interview).

Participant's signature:.....
Time of interview:.....

I, hereby confirm that I have explained to the participant the nature and purpose of the above – mentioned research.

Date & time.....

Signature.....(Interviewer)

Ethical Implications of Preimplantation Genetic Diagnosis (PGD) in Malaysia

Borang izin peserta

Saya, dengan No. IC....., mengesahkan yang berikut;

Saya mengesahkan bahawa saya memahami kandungan ringkasan projek tersebut seperti yang telah diterangkan. Saya juga faham bahawa saya boleh menanya soalan yang berkaitan dengan projek tersebut jika ada persoalan yang timbul.

Saya faham bahawa penyertaan saya adalah sukarela dan saya boleh menarik diri dari kajian ini pada bila-bila masa tanpa memberi sebarang sebab.

Saya faham bahawa projek ini telah diluluskan oleh Jabatan Sains & Teknologi, Fakulti Sains, Universiti Malaya, Kuala Lumpur.

Saya faham bahawa semua maklumat yang diperolehi semasa temubual adalah rahsia. Saya faham bahawa semua maklumat yang dikumpulkan dari kajian ini akan digunakan untuk kegunaan saintifik sahaja dan juga terbitan buku atau journal saintifik. Saya juga faham bahawa nama saya tidak akan dipaparkan di dalam mana-mana terbitan yang melibatkan kajian ini.

Saya bersetuju untuk mengambil bahagian di dalam kajian ini pada.....(tarikh)
di.....(tempat temubual).

Tandatangan peserta:.....

Masa temubual:.....

Saya sahkan bahawa saya telah menerangkan kepada peserta sifat dan tujuan penyelidikan tersebut di atas.

Tarikh & masa Tandatangan.....(penemubual)

Appendix F

To Whom It May Concern,

Via. Associate Professor Dr. Siti Nurani Mohd Nor
The Head of Department
Department of Science & Technology Studies
Faculty of Science
University of Malaya, Kuala Lumpur.

Dear Sir,

SEEKING APPROVAL TO CONDUCT AN INTERVIEW WITHIN YOUR ORGANISATION TO FACILITATE DOCTORAL RESEARCH.

With reference to the above, I am here by writing to seek approval from your goodself to collect information and conduct interviews within your organisation to facilitate my research. My name is Angelina Patrick Olesen and I am a PhD student from the Department of Science and Technology, Faculty of Science, University of Malaya. I am currently doing research on Pre-implantation Genetic Diagnosis Research entitled as follows;

“Ethical Implication of Pre-implantation Genetic Diagnosis (PGD) in Malaysia”

I have attached a brief introduction about my research and the pre-constructure question that I will ask during the interview.

I would like to assure you that all information gathered from your institution will be kept strictly confidential unless I am given permission by you to disclose parts that may require me to do so.

Your co-operation and due assistance very much appreciated in ensuring the success of this research. Thank you.

Your sincerely,

Angelina Patrick Olesen (SHB090003)