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Department of Paediatrics and Adolescent Medicine  
Queen Mary Hospital

## Prenatal Genetic Screening/Testing: Some Ethical Considerations

EC Hui\*

### Definitions

GENETIC SCREENING (GS) refers to a widespread testing of populations or groups of asymptomatic individuals to define the prevalence of a specific genetic disease or trait, regardless of the likelihood of the development of the disease. Genetic screening is usually performed in newborns, and has been used to detect conditions such as phenylketonuria, hypothyroidism and some hemoglobinopathies. It is also useful to identify carriers of Tay-Sachs disease, cystic fibrosis, thalassemia and sickle cell anemia. GS is usually more sensitive than it is specific, and one has to allow for a higher incidence of false positive results. GENETIC TESTING (GT) on the other hand is required to be both sensitive and specific, because it is intended to be a diagnostic tool, and it is expected to be able to identify all who have the genetic defect being tested and exclude all who are normal. PRENATAL GENETIC SCREENING and/or TESTING (PGS/T) refer to the application of these testing concepts to the pregnant women in order to identify genetically affected fetuses rather than newborns or grown-ups. Examples of genetic defects identified by PGS/T include Rh factor incompatibility, chromosomal diseases such as Down syndrome, familial

genetic disorders such as Duchenne's muscular dystrophy, familial polyposis coli, hemochromatosis, polycystic kidney disease, and Huntington's disease. With the advent of in vitro fertilization technique to produce embryos ex utero, PREIMPLANTATION GENETIC TESTING (PiGT) has become another option to detect the presence of potential genetic defects in the embryos before they are being transferred to the womb. In a sense, PiGT may be considered as a form of PGS/T.

### Methods of Prenatal Genetic Testing/Screening

- 1) Indirect screening of potential genetic defects in the fetus by testing blood samples of the pregnant woman e.g. maternal serum alpha-fetoprotein level.
- 2) Direct genetic testing of fetal cells obtained in early pregnancy by separating fetal cells from the maternal blood sample.
- 3) Direct sampling of fetal tissues by amniocentesis and chorionic villi sampling (CVS) to determine the presence of conditions such as neural tube defects, Tay-Sachs disease or Down syndrome.
- 4) Pre-implantation embryo biopsy and genetic analysis. Embryos conceived in vitro are allowed to grow to the 8-cell stage when one of the early totipotent cells is removed for genetic testing to determine the presence of defective genes that give rise to conditions such as cystic fibrosis, Tay-Sachs disease, hemophilia A, B, beta-thalassemia, sickle cell disease, Lesch-Nyhan syndrome and others.

\*Professor E Hui, Professor of Biomedical Ethics, University of British Columbia, Vancouver, Canada

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## Medical Benefits and Moral Risks of PGT/S

In general, prenatal genetic testing is believed to be beneficial for the parents, their prospective children and the society as a whole. This general conclusion is supported by reports which indicate that in a country such as the United States, genetic disorders account for as much as 50% of all pediatric admissions and 20% of infant deaths.<sup>1</sup> Specifically, prenatal testing is extremely helpful to allay the fear and anxiety of the prospective parents when test result is negative, and alternatively to prepare them psychologically and materially in the event that they decide to continue with the pregnancy even when the test result is positive. The option to abort the affected fetus is currently the most acclaimed benefit to prospective parents who do not want to carry such a pregnancy to term. Prenatal testing thus enhances the reproductive autonomy and liberty of the pregnant woman and prevents the defective gene from being passed to the next generation. Likewise, the society benefits most when positive testing is followed by an abortion, thereby reducing the financial burden of caring for a genetically handicapped future citizen. This may be understood as an ultimate form of preventive medicine by "birth prevention". In addition, members of the society who have been born and are living with genetic handicaps may also potentially be benefited by the resources thus saved. However, this is only true if and when the spared scarce medical resources are actually re-allocated and directed to their care and support.

On the other hand, the medical benefit of genetic testing to the prospective child is much less obvious. Before reliable and cost-effective therapy for genetic disorders becomes available, there will always be a significant and almost intolerable gap between what medical scientists can diagnose and what physicians can cure, giving rise to what I will call a "diagnostic-therapeutic gap". To illustrate this point, let us consider Huntington's disease (HD), a diagnosable genetic disease which has a symptom-manifestation latency period of 30-40 years, and for which there is no known medical cure. If the knowledge of having a HD gene is made known early on in life through PGT, the affected person may be subject to anxiety and depression for more than half of his or her life when he or she could have lived normally and happily in ignorance of this information. This perhaps explains why by the end of last century, only about 300 suspected individuals have voluntarily tested for the genetic disorder, and suggests that genetic testing for an untreatable disease does not stimulate a lot of enthusiasm, and may not be morally justified with

ease. In the foreseeable future, as the Human Genome Project (HGP) provides the medical community with more information about multi-factorial and polygenic genetic diseases, medical scientists will be even more likely to identify persons at risk of developing a genetic disease much sooner than they have a way to either prevent or treat the disease.

As mentioned above, because prenatal genetic testing offers the option of terminating the affected fetus or rejecting the affected embryo for transfer when the test result is positive, they cannot be said to be morally neutral procedures, and the medical community has long recognized that they should only be performed with great moral caution. In what is to follow, I will identify and comment on some of the more important moral concerns raised by this branch of medical technology, with the hope that this important and potentially beneficent medical innovation may be employed by physicians with a sharpened moral consciousness, in order that the technology may truly benefit the patients it seeks to help.

## Ethical Issues and Analysis

- 1) The first medico-ethical principle "prima non nocere" (first do no harm) compels us to identify the various ways prenatal testing may harm the fetuses being tested. Direct fetal tissue sampling by either amniocentesis or CVS is associated with an increased rate of spontaneous abortion, approximately 1.6% and 3.2% respectively. CVS is also known to be associated with an increased incidence of physical defects and mental retardation. For PiGT, sufficient data are not available for us to know for sure how well the embryos will do after they have been tested to be free of genetic defects and transferred to the human womb for gestation, but given the known risks associated with children conceived by the IVF technique,<sup>2</sup> we have reason to exercise great caution before these testing procedures are recommended to parents. Besides, after the supposedly unaffected embryos have been transferred and allowed to grow to the first trimester, these fetuses are routinely subjected to amniocentesis or CVS to confirm the original negative findings of PiGT, thus subject the fetuses to additional risks from these diagnostic interventions. Naturally, when prenatal genetic testing is positive, and the pregnant woman decides to terminate the pregnancy, or the scientist decides to reject the embryo for transfer, the harm to the nascent life is fatal. Since termination

of a nascent human life is the commonest and often the only outcome, prenatal genetic testing must be viewed as morally weighty diagnostic procedures. This consideration brings into sharp focus the first moral dilemma that confronts every physician before he or she orders a PGT: "Which genetic condition should be tested, and on what criteria and by whom should that decision be made?"

- 2) Which genetic disorders are physicians morally justified to test? If treatment for genetic disorders is not readily available, and abortion is the most viable "therapeutic" option when genetic testing is positive, the selection and justification of genetic disorders for screening and testing becomes the most important and the first ethical question that confronts the physician and the pregnant woman. According to Wilson & Jungner,<sup>3</sup> one of the principles for genetic screening and testing is that the condition sought must be highly prevalent and has serious consequence for the individual or society as a whole. These authors suggest that three aspects of a genetic disease should be considered in the determination of its severity.

First, the probability of disease manifestation must be reasonably high. We now recognize that there is likely a genetic component to most, if not all, human diseases. Some "abnormal" genes directly cause diseases, but some may only predispose but not necessarily cause the affected persons to have the diseases. Where a direct causal link between genotype and disease manifestation is known, and that there is a good likelihood that the disease will be manifested, the justification for testing the condition is strong. For genes that only render a person susceptible to diseases, and there are other non-genetic factors which determine the disease manifestation, the justification for genetic testing is greatly reduced, and many believe that testing for genetic predispositions to diseases should be treated in the same way as testing for non-disease characteristics which are disallowed.

Second, the time of onset of disease manifestation is a critical factor, and the earlier the onset of symptoms the more justified it is to test for the disease. The need to establish an acceptable "latent period" between genetic diagnosis and onset of symptoms is due to the concern that if the latent period is too long, the test does not actually confer any therapeutic benefit to the patient,

but increases the chance for personal anxiety, social discrimination and stigmatization. For example, it is very doubtful if prenatal testing for late onset disorders such as familial Alzheimer's disease can easily be justified. On similar sort of reasoning, some countries discourage testing for the Huntington's disease until the age of adulthood even at the price of foregoing the opportunity of identifying the carrier state at an early age.

Third, the degree of harm to health when the genetic disease manifests should be considerable. People who embrace a high view of the nascent life generally believe that prenatal testing should be restricted to the most severe conditions with manifestations of profound retardation, extreme physical handicap and/or prolong suffering, because fetuses tested positive for these conditions almost always end up in their being aborted. Others who put more moral weight on the reproductive freedom of parents hold that no genetic disease is too "minor" to justify prenatal testing, and no genetic disease is too "trivial" to justify an abortion. They hold the view that reproductive choices are intimately personal decisions that should be left to the parents as part of their right of autonomy. We believe that an intermediate position can be adopted whereby some mildly or moderately harmful genetic conditions may be tested, with the proviso that parents are counseled to consider the option not to abort those fetuses that have remediable or manageable genetic defects.

In light of the ever increasing number of human "genetic abnormalities" identified by the HGP, many medical professionals rightly believe that the most serious moral challenge in the practice of prenatal genetic testing is to establish moral criteria of testing for the inclusion or exclusion of conditions that do not satisfy the above three criteria of severity, and to develop a reasonable and just approach to deal with the prospective parents' request for testing of these conditions when they intend to abort any affected fetus even if it is only minimally affected. Clearly, what is trivial or minor is a matter of subjective value. Is low stature trivial? Or low intelligence, morbid obesity or mental illness? The question as to what constitutes a desirable, normal and healthy fetus is not entirely answered by scientific and objective data, but also significantly influenced by one's values, perspectives, beliefs and cultural traditions. Hence, what genetic disorders people are to test, and which affected fetus people are to abort, are to a very

large extent subjective and value-laden choices. In particular, the choice to abort a fetus with a "minor" genetic condition is shaped by one's belief in the moral status of the fetus, understood along a continuum of positions from strict fetal right to life on one end to unrestrictive reproductive liberty on the other. To strike a just balance between respecting the fetus' right to life and honoring the parents' right to reproductive choices is never a simple but always a necessary moral task for physicians in this practice. We believe that genetic testing can be morally justified only for conditions that satisfy the three criteria of severity, and for which the termination of the nascent life is viewed as a real moral possibility or necessity. Testing for non-disease characteristics, susceptibilities to diseases, diseases generally recognized to be "minor", and late-onset diseases should be excluded, and to abort a fetus for these reasons is to attach little or no value to a developing human life. To the extent that the whole purpose of prenatal testing is aimed at the betterment of the human life, it is a contradiction to allow the employment of the same technology to depreciate the value of human life by unnecessarily aborting fetuses whose prospect for a flourishing life is only minimally compromised.

Before we leave the question as to which genetic conditions physicians should test, we need to discuss one last interesting moral dilemma: "Should treatable genetic conditions be tested?" Wilson and Jungner list the ability to treat the genetic condition as the most important criterion for its testing. The advantages of prenatal testing of treatable genetic diseases are primarily directed to the prospective parents who may be psychologically and materially more prepared to deal with the birth of a child with an unfortunate but nonetheless treatable genetic disorder. Furthermore, this knowledge will enable the parents to take the necessary precautions for their future reproductive plans in a more timely fashion. The affected child essentially has nothing to gain by being tested before birth, but is exposed to the risk of being harmed or aborted. For example, one may question the moral basis to recommend prenatal genetic testing for the condition of phenylketonuria, the only common genetic disease that can be effectively treated. Similarly, with increase sophistication in the management of patients with cystic fibrosis (CF), many patients are able to retain fairly decent functional capacities. One group reports that in U.K., over 50% of patients 16 years and older with

known CF are in salaried employment.<sup>4</sup> In the future when gene therapy becomes more successful, to justify prenatal testing of many treatable genetic conditions will be even more problematic. We believe that when reliable and effective treatment for a genetic disorder is available, prenatal testing for that condition is largely rendered redundant. It is neither necessary nor justifiable. But some people insist that a pregnant woman should be allowed to test the fetus with the intention to abort the affected fetus because it is her autonomous right to do so, even when effective treatment for the affected fetus is available. This leads to the next question as to the extent and limit, if any, of parental autonomy.

- 3) What is the extent and limit of the parents' right to autonomous choices of genetic testing and abortion? It is now generally agreed that for parents to request PGT for the sole purpose of gender selection of the future child, and to abort the fetus with an unwanted gender is morally unacceptable. However, this moral judgment against abortion is based on the underlying sexual discrimination which is considered to be morally repugnant, rather than on the intrinsic moral value of the fetus. On the other hand, most people would not protest the abortion of a fetus diagnosed to be homozygous for Tay-Sachs disease. This is based on the best interest of the future child who is doomed not only to a short lifespan of not more than 2 years, but also to a life experience of nothing but misery, suffering, pain, progressive deterioration and death. But if the PGT shows the presence of trisomy 21 in the fetus, indicating that the future child will have Down syndrome, would termination of the pregnancy be as ethically justified as in the case of the Tay-Sachs disease? Here we are not sure how severe the genetic defect will manifest in the child, and so an abortion cannot be justified on the basis of the future child's best interest, which is a criterion reserved only for a handful of severe genetic disorders. What if the social circumstances and financial situation of the family simply cannot afford to take care of a child with Down syndrome? Is the right of the affected fetus to be born sufficiently strong to override the parents' desire? Current ethical thinking generally favors parental autonomy over fetal rights, and if it is not the parents' wish to have a defective child, their decision is to be honored as part of their reproductive freedom and choice. We are of the opinion that such a decision is made with considerable moral risk on two counts. In

the first place, the fetal right to life is not given its due moral weight, and secondly the disvalue inflicted on the fetus (death) far exceeds the value gained by the parents (reproductive liberty). In short, the principles of justice and of proportionality, both considered indispensable in ethical decision-making, seem to have been entirely ignored.

Yet there are other examples of genetic selection and abortion which cannot be justified ethically even in the name of parental autonomy. For example, it has been reported that couples with congenital deafness frequently request genetic testing with the intention to identify and abort "normal" hearing fetuses and to selectively reproduce children with the same congenital condition. Similar requests have been made by people afflicted with dwarfism.<sup>5</sup> These examples suggest that it is both appropriate and necessary to draw boundaries of parental autonomy in the decision-making process regarding PGT, and it is within the physicians' autonomy not to provide any testing which may produce an effect that is, in the physician's opinion, contrary to the intention of genetic testing.

With the ever increasing number of "disease" genes made known through the HGP, it is conceivable that in the future some parents may want to exercise their autonomous right by refusing to undergo prenatal genetic testing for a particular disease, when the general public believe that to give birth to an untested and genetically defective child is morally irresponsible and creates an unnecessary and avoidable burden for the society.<sup>6</sup> In other words, should genetic testing be ever mandated by the government, or should they always be offered as a voluntary informed choice? This may become a pressing ethical issue in the near future. Presumably, when the risks and benefits of prenatal genetic testing is clearly in favor of testing, and parental voluntary choice is not sufficiently favorable to protect the welfare of the future child, then mandated genetic testing may have to be implemented. But when we assess risks and benefits of mandatory genetic testing, we must avoid defining the benefit in terms of the savings achieved by termination of pregnancy. This is ethically unacceptable because it amounts to making it an obligation for parents to prevent the birth of a child once the fetus is found to be genetically challenged. Rather, risks and benefits of mandatory testing ought to be judged in terms of the number of pregnancies being

"spared" of termination as a result of finding them to be normal. In all cases, there should always be extensive sufficient public debate on the matter before any genetic testing is mandated. In the U.S., for example, so far only the state of Colorado has mandatory genetic testing for cystic fibrosis, and it is in the form of a screening test for the newborns. Finally, a mandatory genetic testing does not waive the requirement of an informed consent. In the event of an adamant refusal of a mandated test, education and persuasion rather than coercion are the preferred approach to convince the parents that the best interest of the fetus and other parties are not served by their refusal. This leads us to consider the nature of an informed consent in the context of prenatal genetic testing.

- 4) What is a fully voluntary, un-coerced informed consent for prenatal genetic testing? Even if we assume that parents have the absolute right to decide on behalf of their offspring in matters of genetic testing and abortion, physicians still have to ascertain that parents, and particularly the pregnant woman, have agreed to undergo genetic testing with full informed consent and without coercion. This is not always achieved. An informed consent in the context of PGT requires that (a) the pregnant woman understand the nature and risks of the surgical intervention i.e. amniocentesis, CVS or pre-implantation genetic testing of the embryo; (b) the nature of the genetic tests to be performed, and the choice not to undergo PGT; (c) the implication of a positive test and the probable consequence of an abortion if the genetic condition diagnosed is sufficiently severe. All three components would have to be explained, preferably in the same setting, before it can be accepted as a fully informed consent. Studies have shown that tests are often presented to the pregnant woman as a routine procedure, with up to 50% of pregnant women tested having no idea that a positive test it may entail the termination of the pregnancy.

Coercion in PGT is more common than most people realize, and there are several sources of coercive forces directed towards the pregnant women which can be very subtle. Obstetricians may provide directive advice in favor of testing for fear of malpractice law-suit, in the event that an abnormal child is born without testing. Public opinion is another source of pressure. Singer reports that 39% of Americans believe that all

pregnancies should be tested for any serious genetic defects, and 10% believe that abortion should be mandatory if such defects are found.<sup>6</sup> Pharmaceutical companies are also applying pressure to the pregnant women to submit to testing, first by intimidation, taking advantage of the fact that women are usually blamed for adverse pregnancy outcomes; and second by commercialization, presenting PGT not as a medical procedure but as a health-related merchandise for popular consumption and taking advantage of modern consumers' herd mentality: "If everyone is getting PGT, I don't want to be left out by not getting it." Health insurers may also apply not-so-subtle pressure by threatening not to provide health care benefits for conditions that can be diagnosed by PGT. The insurance company is obviously presuming that once the condition is diagnosed, it can be prevented, and the only sure way to avoid the financial expenses of a diagnosed condition is to abort the fetus. It has been reported that an insurance carrier in the U.S. makes similar threats when a non-lethal genetic condition has been diagnosed but the parents decide to continue the pregnancy.<sup>7</sup> Given that consent is not always fully informed and coercive influences are not always excluded, we recommend that genetic counseling should be a mandatory part of prenatal genetic testing, both before and after the testing.

- 5) How to prevent prenatal genetic testing from becoming a form of eugenics? In the near future, we may expect an increasing number of parents to exercise their reproductive autonomy through PGT to select what traditionally are seen as desirable genes for their offspring, such as elegant physical features, high intelligence and so on, and to eliminate the opposite features. If this trend is allowed to develop, many fear that PGT will become nothing more than a eugenic movement in disguise. While this concern is not ungrounded, the matter hinges again on what genetic conditions are considered legitimate targets for screening, testing and elimination either by rejection for implantation or termination of pregnancy. In general, most medical communities agree that "eugenically" motivated PGT for superior physical and intellectual traits is ethically unacceptable. However, it should be noted that even when physicians confine themselves to the sort of genetic conditions that can be legitimately tested, they may continue to harbor a feeling that PGT is nonetheless part of a "eugenic" act. It is, indeed! This is so because most prenatal testing will unavoidably

produce a eugenic effect whether it is intended or not; once it is agreed that it is legitimate to test, correct and/or eliminate the target genotype, the goal will be to reduce the prevalence of that "undesirable" genotype, and the net effect is essentially eugenic.

We need to point out that the term "eugenic" does not necessarily entail evil acts, but it has had a bad press because of the heinous acts committed in its name in Europe and the U.S. in the first half of the last century. In order that prenatal genetic testing not to acquire a similar pejorative connotation, it must be carried out voluntarily with un-coerced informed consent from prospective parents and without discrimination against the genetically affected nascent lives. How successful any society will meet the second requirement is always a major moral challenge, because prenatal genetic testing, especially when followed by abortion, never seems to fail to convey a discriminatory message to those in the society who have to live with physical and/or mental disabilities, to the effect that their lives are not worth living and they are better off dead. Studies on disabled people have invariably shown that they feel more disabled by social discriminations than by their own handicaps. It is possible that our society's tolerance for congenital malformations is inversely proportional to our capacity to diagnose genetic disorders followed by their elimination. But the presence of genetic defects does not imply that the affected person's future life is thereby totally ruined, and the prevalence of physical/mental disabilities is not entirely determined by the human genome, and the handicap will always be found in our society even if all genetic causes can be eliminated. To believe otherwise was the root cause of the eugenic crimes committed in the last century, and to provide full factual information through non-directive and un-coercive counseling is the safeguard that eugenic crimes will not be repeated in the days to come.

- 6) How do we ethically manage the genetic information obtained through genetic testing? How to keep genetic information in strict confidence in order to protect the privacy of the patient has become one of the most pressing moral issues arising from genetic testing. Who should have access to the genetic information? Are schools, health care providers, adoption agency personnel, employers, insurers, or law enforcement agencies entitled to this information? As medical records are computerized and genetic registries are being

created, regulation of the use of these databases and their protection from breach of privacy will become a formidable task. Any unwarranted disclosure of sensitive genetic data may lead to a life-time of discrimination and stigmatization. Unless the rule of medical confidentiality is strictly abided by, affected people will not feel secure enough to seek medical care and counseling. This indirectly infringes on their right to have access to medical care, and directly compromises their health status which has been jeopardized by the genetic disorder in the first place.

Furthermore, genetic disorders, by definition, are inherently family-related problems. For example, the diagnosis of a genetic condition in one family member automatically leads to a host of unwelcome questions: "Who else is affected?" and "Who is culpable of bringing the gene into the family?" The diagnosis of a genetic disorder in a family invariably causes severe strain within that family. For example, when a family member is found to have Huntington's Disease, automatically, one of the parents of the affected person must be a carrier. They are then confronted with the dilemma of having to find out who is the "guilty" parent. The siblings of the affected person, and their children, if any, will face similar dilemmas to identify any other victims. This raises a rather peculiar moral question: Do potentially affected people have the right not to know? Some argue that they do, on the basis that people with known HD have a high risk for committing suicide, and patient refusal to testing may literally become life-saving. Others insist that those who are suspected to be carriers are obligated to be tested in order to have better reproductive planning. This raises the issue of the proper limit of respecting one's autonomy in face of communal and family interests, as well as other issues of family ethics. In a society which emphasizes the value of family solidarity over the value of individual autonomy, individual interests will often be sacrificed.

For example, some parents automatically assume that they have the right to insist on testing their children who are minors. They argue that if parents have the obligation to look after the welfare of their children, then to the extent that the identification of a defective gene may help the parents to plan better for the future of their affected children, they should have the right to insist on the genetic testing, either prenatal or postnatal.

On the other hand, others argue that to allow parents to identify genetic defects of their children interferes with the potentially independent individuals' rights to decide whether they want to know of their genetic status. Hence, parents should defer the testing until after their children reach the age of majority. For the same reason, the Huntington Disease Society of America excludes anyone under the age of eighteen to be tested, although this age limit is not universally accepted. Testing for unwilling minor children may be justified if the test offers possibility of prevention or treatment of symptoms e.g. familial hypercholesterolemia, improves reproductive planning e.g. HD, and identifies carrier state for recessive conditions e.g. cystic fibrosis. Testing for unwilling minors and disclosure of the genetic information for the sole benefit of other family members are ethically questionable, if not unacceptable, practices. In summary, we recommend that as part of the ethical assessment of a request for genetic testing, the protection of the "genetic privacy" of the potentially affected minor (which includes the fetus) must be carefully considered, discussed and guaranteed by all the parties involved (parents, family, physicians, and hospital) prior to the performance of genetic testing. It is the minor who has to face a life-time of potential harassment, discrimination and stigmatization if his or her genetic status is not confidentially guarded at all cost.

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