Invasive prenatal genetic testing: A Catholic healthcare provider's perspective

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Invasive prenatal testing is performed for a variety of reasons, but the most common indication is for genetic testing of the fetus. Although many times the information obtained from this type of testing results in selective termination of fetuses with genetic diagnoses, the information itself may be morally neutral. Should a Catholic healthcare provider be willing to perform invasive prenatal testing in the setting of uncertainty with respect to the patient's plans following a diagnosis of a genetic abnormality?

Keywords: Invasive prenatal testing, Amniocentesis, Chorionic villus sampling, Catholic bioethics

A BRIEF HISTORY OF INVASIVE TESTING FOR FETAL GENETIC ABNORMALITIES

There may be no more ideal way to illustrate the importance of invasive prenatal testing to prenatal diagnosis than to understand its history. Its history illustrates not only how long this technology has been in existence, but also the many uses of this technology. From its beginning, one of the intended uses included the diagnosis of genetic diseases in the fetus. I will focus only on the amniocentesis, rather than the chorionic villus sampling (CVS), for the sake of brevity as the history of amniocentesis will allow the reader to understand the intended use of this technology as it developed.

In 1877, Prochownick described a transabdominal amniocentesis in the third trimester (Prochownick 1877). Henkel, in 1919, reported the use of an amniocentesis for the treatment of polyhydramnios (Henkel 1919). It was not until 1952

when Bevis and Mane (1952) published an article using amniocentesis to predict the severity of hemolytic disease in the fetus that amniocentesis became more widespread.

One of the first reported uses of this test for genetic testing came in 1956. Fuchs and Riis (1956) performed an amniocentesis to determine the fetal sex by identifying the Barr body. This allowed the possibility of physicians being able to offer a diagnosis to parents who had a family history of a sex-linked disorder, such as hemophilia A and Duchenne muscular dystrophy.

Steele and Breg reported on the ability to culture amniotic fluid cells that were suitable for karyotyping in 1966 (Steele and Breg 1966). This was shortly followed by one of the first reports using cultured fetal cells for the diagnosis of not only Down syndrome, but galactosemia and mucopolysaccharidosis (Nadler 1968). Brock and Sutcliffe (1972) reported on

elevated amounts of alpha-fetoprotein in the amniotic fluid in fetuses with neural tube defects. Milunsky and Littlefield in 1972, published an article looking at the prenatal diagnosis of inborn errors of metabolism (Milunsky and Littlefield 1972).

Nadler and Gerbie published a manuscript in *The New England Journal of Medicine* in 1970 assessing the role of amniocentesis in the detection of genetic disorders. They performed 162 amniocenteses between the 13th and 18th weeks of gestation in “high risk” pregnancies (Nadler and Gerbie 1970). They were able to diagnose Down syndrome, Pompe’s disease, lysosomal acid phosphatase deficiency, and metachromatic leukodystrophy. They stated,

Cultivation of amniotic-fluid cells obtained by transabdominal amniocentesis early in the second trimester of pregnancy provides a method that enables parents at “high risk” for having offspring with certain serious genetic disorders to have children without risk of such a defect. (Nadler and Gerbie 1970, 912)

This paper was a spring board that allowed the amniocentesis to become more prevalent in the diagnosis of genetic disease in the fetus, while affirming the association of this testing with selective abortion of fetuses with genetic defects based on parental desire.

Not always used for the detection of genetic defects or congenital anomalies, amniocentesis was used for the detection of fetal lung maturity. In 1973, Gluck et al. found that the ratio of lecithin to sphingomyelin was predictive of respiratory distress syndrome (Gluck and Kulovich 1973).

Other modalities for invasive testing include fetal umbilical cord blood sampling and CVS. Today, CVS and amniocentesis are the tests most

commonly used for invasive prenatal testing for fetal genetic disease.

DESCRIPTION AND RISKS OF AMNIOCENTESIS AND CVS

A genetic amniocentesis involves the insertion of a 20- or 22-gauge needle into the amniotic fluid under ultrasound guidance. This procedure is performed traditionally between 15 and 20 weeks gestation (ACOG Practice Bulletin 2007a). The use of ultrasound is necessary in order to prevent any harm to the fetus during the procedure. Approximately 20–30 cc of amniotic fluid is obtained with this procedure. This procedure can also be performed in pregnancies with multiple gestations (twins and triplets).

A CVS is performed between 10 and 13 weeks gestation. This procedure can be performed by either the transabdominal or transcervical technique, depending on placental location and operator experience. Both of these techniques are done under ultrasound guidance so as to avoid injury to the fetus.

The most feared risk from both of these invasive testing modalities is pregnancy loss. Overall, the risk of a complication that would lead to the loss of the pregnancy ranges from 1 in 300 to 1 in 500 for both of these procedures (ACOG Practice Bulletin 2007a). This loss rate may be lower in experienced hands. The majority of the cases of pregnancy loss after a mid-trimester amniocentesis (62%) occur within two weeks following the procedure (Eddleman et al. 2006). The benefit of the CVS over the amniocentesis is that the fetal diagnosis is made earlier in pregnancy. This may lead to earlier reassurance for the patient, as well as earlier and safer methods of termination for the patient if the results are abnormal (ACOG Practice Bulletin 2007a). The

American College of Obstetricians and Gynecologists does state that invasive testing does provide benefits for the patient that does not desire pregnancy termination. The diagnosis prior to birth allows for planning ahead and allowing the patient to develop a management plan for both the remainder of the pregnancy and following delivery (ACOG Practice Bulletin 2007a). These benefits and risks are to be kept in mind as we explore the proportionality of this testing within the context of Catholic teaching. Ultimately, like any other medical procedure, the risks of the procedure have to be weighed against the benefits of the procedure.

INDICATIONS AND COUNSELING FOR INVASIVE PRENATAL TESTING

Pre- and post-test counseling are very important for the patient who is considering invasive testing. The pre-test counseling should include the risks, burdens, and benefits of the procedure, as well as a discussion of the alternatives to the procedure, such as screening tests. Screening tests for fetal aneuploidy involve minimal risk to the patient and no risk to the fetus, but do not allow for a definitive diagnosis. Counseling should also include understanding the natural history of individuals with a genetic defect. Also, the patient should be offered counseling with a genetic counselor or physician who has experience in taking care of these individuals. While the post-test counseling after a positive result obtained from invasive testing is complex and not the focus of this review, a comment should be made here. The Catholic physician should have the opportunity to provide this post-test counseling because the content of the counseling would be able to dispel any misperceptions of what it is like to raise a child with a genetic defect such as Down

syndrome. Correcting these misperceptions may incline women to avoid abortion.

The American College of Obstetricians and Gynecologists states that everyone, regardless of age, should be offered invasive testing prior to 20 weeks gestation (ACOG Practice Bulletin 2007b). Prior to development of this guideline, women under the age of 35 were offered screening for fetal aneuploidy. If this screening was positive, then they were offered invasive testing after a thorough counseling session.

The risk for fetal aneuploidy is determined primarily by the maternal age at time of delivery. There are certain other conditions that carry an increased risk for fetal aneuploidy. These include a previous fetus with an autosomal trisomy, a fetus with a structural abnormality on ultrasound, a previous child with a sex chromosomal abnormality, a parental carrier of a chromosomal translocation or chromosomal inversion, and a parent with aneuploidy or mosaicism for aneuploidy (ACOG Practice Bulletin 2007b).

CATHOLIC GUIDANCE WITH REGARD TO INVASIVE PRENATAL TESTING

Catholic healthcare providers, acting in accord with Catholic principles, should assume that abortion is always morally wrong. The aim of this article is to discuss how Catholic healthcare providers should think about prenatal testing in light of Catholic teaching on this subject, especially when the patient is unclear about her plans for what she will do with an abnormal result.

Catholic physicians are faced with potentially challenging scenarios surrounding prenatal testing. These scenarios mainly pivot on not only what the patient will do with the information once she

receives it, but also how strongly she feels about her potential course of action. The challenges have to do with the clinical and ethical significance of information obtained from invasive testing for both the physician and patient. This information is morally neutral, yet it can lead to selective termination of fetuses with genetic defects if it is used improperly. It can be very difficult for a woman to accurately predict what she will do with this information once it is obtained. This uncertainty presents a moral challenge for the physician who is considering performing the procedure.

This level of uncertainty as to what to do with an abnormal result is difficult to reduce, even with adequate pretest counseling. Many times, patients are not able to adequately predict what they would do with a positive result after a thorough post-test counseling session. Even if pregnancy termination is not brought up in the pre-test counseling session, patients are aware that this option exists.

For the patient who has received a result indicating some type of genetic defect in the fetus, there are three options. She can elect to continue the pregnancy, have a pregnancy termination, or give the child up for adoption after birth.

As a Catholic physician who provides invasive prenatal testing, it is sometimes difficult to accurately gauge where the patient is concerning what she would do with the abnormal results, even after they have been given to her. Knowing what the patient would do with the abnormal results may allow the physician a better understanding as to the bioethical implications involved with performing these procedures (although many times, this is not possible).

Here are three scenarios that one may find oneself in while counseling for invasive prenatal testing:

1. The patient that states prior to the testing that under *no* circumstances

would she consider pregnancy termination for an abnormal test result.

2. The patient *unequivocally* states that she would have a pregnancy termination if the results are abnormal. She may or may not already have plans in place for a termination.
3. The patient that is *uncertain* as to what she would do with the results if they are abnormal. She may or may not terminate the pregnancy and is unable to make this decision until the results are available to her. It is in my experience that the most common scenario is this last one.

These examples allow us to analyze the scenario-responsive nature of invasive testing. The first scenario should allow the Catholic physician to perform the procedure. The second scenario may require the Catholic physician who embraces the teaching of the Magisterium to invoke his conscience and not perform the invasive testing. The third scenario presents challenges to our conscience as healthcare providers due to the uncertainty as to what the patient will do with the information once it is obtained.

PAPAL ENCYCLICALS AND INSTRUCTIONS FROM THE CONGREGATION FOR THE DOCTRINE OF THE FAITH

The Congregation for the Doctrine of the Faith's instruction *Donum vitae* was written due to concerns expressed by theologians, bishops, doctors, and scientists with regard to,

Biomedical techniques which make it possible to intervene in the initial phase of the life of a human being and in the very processes of creation and their conformity with the principles of Catholic morality. (Foreword)

This instruction makes it very clear that the human being as a person must be respected starting at the moment of conception (*Donum vitae*). It quotes Vatican II's *Gaudium et spes* in saying that "Life once conceived, must be protected with the utmost care; abortion and infanticide are abominable crimes" (Section 51). This statement leaves absolutely no doubt as to the seriousness of abortion and the respect that is due to the human embryo.

It addresses specifically the question of whether prenatal diagnosis is morally licit or bad. While it clearly states that if the procedure is done respecting the integrity and life of the human fetus, then prenatal diagnosis is morally licit or good, it further states that it can be done if the risks are not disproportionate to the life and integrity of both the embryo and mother. With the pregnancy loss rate in invasive testing to be 1 in 300 to 1 in 500, one could argue that any risk of total loss of life for the embryo is disproportionate to its life and integrity in all cases of invasive prenatal testing. Unlike many complications from surgery that can be repaired or mediated by further surgery or medication, the risk with invasive prenatal diagnosis is almost always complete loss of the fetus. There is currently no treatment for a complication from invasive prenatal testing.

This argument is strengthened if one considers that there currently is no *in utero* treatment for fetal aneuploidy. For example, if a diagnosis of Down syndrome or some other fetal trisomy is received, there is no therapy that can be given *in utero* to improve the outcome for that individual. There may be benefit to allowing the patient to come to an acceptance of this diagnosis prior to birth, as well as allowing her time to prepare for the arrival of this child, but this would not result in any lessening of the severity of the diagnosis or improvement in the outcome of the child.

The instruction further states,

But this diagnosis is gravely opposed to the moral law when it is done with the thought of possibly inducing an abortion depending upon the results: a diagnosis which shows the existence of a malformation or a hereditary illness must not be the equivalent of a death-sentence. (Section 2)

Here the word "diagnosis" seems to mean the act of invasive prenatal testing. Therefore, if the act of invasive prenatal testing is done with a thought of possibly inducing an abortion, then the act is morally illicit or bad.

An example may indicate the confusion that can arise from the interpretation of this passage. During counseling for invasive prenatal testing, a patient states that she is not sure if she would terminate the pregnancy if the results were to come back as abnormal. By stating this, she is implying, at the very least, a thought of possibly inducing an abortion if the results were to come back as abnormal. For the Catholic healthcare provider in this example, performing the act of invasive testing could be considered morally illicit or bad. In my experience, many times a patient will not be able to say for certain what she would do with the results if they were to come back as abnormal. What is needed here is a more precise formulation of this moral teaching.

In the second scenario proposed above, offering prenatal testing would be morally illicit due to the certainty of pregnancy termination. With regard to the third scenario, because the patient is unsure whether she will terminate the pregnancy, offering prenatal testing might be morally illicit because the possibility for abortion exists. As we will see later, this differs slightly from Elio Sgreccia's approach to this bioethical dilemma.

The Congregation for the Doctrine of the Faith prepared the instruction *Dignitas*

personae (*On Certain Bioethical Questions*) in order to bring up to date the information found in *Donum Vitae*. It states that the teachings found in *Donum vitae* are still valid, but more questions have come about with the use of new biotechnologies (*Dignitas personae*).

While not addressing traditional prenatal diagnosis specifically as did *Donum Vitae*, it does address the issue of preimplantation genetic diagnosis (PGD). Although this is not like traditional invasive prenatal testing, I will take a moment and address this particular type of prenatal diagnosis as it does involve invasive prenatal testing on a human embryo. PGD is a form of prenatal diagnosis done on an embryo that was created through *in vitro* fertilization. This embryo can be tested for genetic abnormalities prior to placing it into the uterus for implantation. If the embryo is found to have the genetic abnormality in question, this embryo is then destroyed. *Dignitas personae* states that this type of prenatal diagnosis is different than traditional prenatal diagnosis that is discussed above. Unlike traditional prenatal diagnosis,

in which the diagnostic phase is clearly separated from any possible later elimination and which provide therefore a period in which a couple would be free to accept a child with medical problems, in this case, the diagnosis before implantation is immediately followed by the elimination of an embryo suspected of having genetic or chromosomal defects, or not having the sex desired, or having other qualities that are not wanted. (Section 22)

This type of prenatal diagnosis is always morally illicit. Furthermore, it discussed PGD in the context of a eugenic mentality that “accepts selective abortion in order to prevent the birth of children affected by various types of anomalies” (Section 22).

In any case, one can assume that PGD is morally illicit.

On March 25, 1995, Pope John Paul II warned of the special attention that must be given to the morality of prenatal testing (*Evangelium vitae*). *Evangelium vitae* specifically recognized that this testing has risks associated with it. It states that if these risks are not disproportionate for the child and mother, then invasive testing can be performed. It also acknowledges a benefit of invasive testing in that it may provide for a “serene and informed acceptance of the child” (Section 63). This may represent an evolution in thought in that there is not only an acceptance of a risk associated with invasive testing, but also an acknowledgment of the benefit of serene acceptance of this child. As clinicians, it is easier for us to understand a risk if it is balanced by a benefit. This process of accepting a child with a genetic defect can begin *in utero* for both the mother and the father.

Now, when discussing the risks and benefits of invasive testing with a patient, the “serene and informed acceptance” of the diagnosis as a benefit may tip the scales so that the procedure is morally licit for both the patient and the physician. However, it further warns, rightfully so, that these techniques can be used with a eugenic intention which accepts selective abortion of fetuses with genetic defects. Selective abortion can even lead to accepting infanticide and euthanasia.

ETHICAL AND RELIGIOUS DIRECTIVES FOR CATHOLIC HEALTH CARE SERVICES

The issue of invasive prenatal diagnosis is specifically addressed in the *Ethical and Religious Directives for Catholic Health Care Services* (2009). Not surprisingly, this document discusses the inherent dignity of

every human life and the concept that life begins at conception.

In addressing prenatal diagnosis, it states in directive 50:

Prenatal diagnosis is permitted when the procedure does not threaten the life or physical integrity of the unborn child or the mother and does not subject them to disproportionate risks; when the diagnosis can provide information to guide preventative care for the mother or pre- or postnatal care for the child; and when the parents, or at least the mother, give free and informed consent. Prenatal diagnosis is not permitted when undertaken with the intention of aborting an unborn child with a serious defect.

Again, the concept of risks from the procedure to the unborn child is used to determine whether or not this invasive testing is morally licit. Currently there is no test available that can accurately give the diagnosis of fetal aneuploidy and does not carry with it some risk of pregnancy loss. Therefore, any type of invasive prenatal testing includes some risk of loss of life for the fetus. Could it be that from a strict interpretation of this paragraph, no procedure currently available for prenatal diagnosis is allowed due to there always being a risk of loss of life under any circumstances where invasive prenatal testing is performed? It is not clear as to whether the authors intend for this paragraph to be taken in a strict literal sense.

Furthermore, if one acknowledges the risks to the unborn child with this testing and the discussion of disproportionality, then one should also acknowledge the presence of benefits. With no benefits to the testing, all risks would be disproportionate, regardless of how small they are. Therefore, if we assume that the benefit is the “serene and informed acceptance of the child” as in *Evangelium vitae*, then the risk of pregnancy loss may not be always

considered disproportionate. On the contrary, the risk of loss of life to the embryo will always override the “serene and informed acceptance of the child.”

This document again reiterates that prenatal testing is morally illicit if it is done with the intention of pregnancy termination.

The above examples of Catholic teaching are either incomplete or excessively restrictive with respect to how the Catholic healthcare provider should act when confronted with invasive prenatal testing in a patient who is not sure what she will do if the results are abnormal. The two examples below may provide better guidance for the Catholic healthcare provider due to the fact that they deal with either an instance where there is a direct benefit to the fetus for invasive prenatal testing or they deal with the uncertainty that patients face in dealing with the information obtained from the testing in terms of continuing or ending the pregnancy.

MAKING SENSE OUT OF BIOETHICS

Father Tad Pacholczyk expands upon the morality of prenatal testing from a real-life view in an article in his series “Making Sense Out of Bioethics” (Pacholczyk 2006). This example illustrates a direct benefit for invasive testing that does not exist when it is done for the detection of Down syndrome or other fetal aneuploidies. This benefit that he illustrates may be able to balance out the risk of loss of life to the fetus from the invasive testing with respect to proportionality. As was discussed from the magisterial documents above, he states that performing invasive testing when the patient knows that she will have an abortion if the results are abnormal is morally illicit. Next, he brings up the scenario in which fetal testing for a disease like Krabbe’s leukodystrophy is

performed so that the family can initiate a search for a bone marrow transplant while the patient is still pregnant. Here, invasive testing may improve the outcome for the child by allowing time to find a bone marrow transplant match prior to birth. This benefit may either improve the quality of life for the child or even increase the chance of survival for the child by attempting to find a match for a bone marrow transplant more quickly because done prenatally. To contrast this with invasive prenatal testing for Down syndrome, a prenatal diagnosis of Down syndrome will not increase the chance of survival of the child compared with a postnatal diagnosis. Although this is a great example of a case with definitive benefit to the fetus, this example is extremely rare and not one that the healthcare provider will likely ever face.

He also speaks of allowing prenatal testing in order for the parents to come to an acceptance of a child with a genetic defect prior to birth. If invasive prenatal testing allows a family to better prepare for a child with a disability, then this testing can be done. He states,

Children with special needs certainly bring difficulties and challenges, but they also bring great graces, opening our eyes to deep and important truths about life and the meaning of unconditional love.

Here also, we see recognition of the benefit of prenatal testing being an acceptance of a child with a genetic defect. This provides the patient with a potential benefit to the testing so that the risk can be examined in proportion to this benefit.

It is important that Fr. Pacholczyk points out this benefit. As providers, we tend to focus on the diagnosis and many of the negatives associated with a prenatal diagnosis, regardless of what the diagnosis specifically is. We are reminded here that, we need to focus also on the graces that these children bring to couples and to

discuss this with our patients. The more we accurately focus on these benefits, the more the scales tip in the favor of the patient continuing the pregnancy once a positive result is obtained. It is through giving the patient the entire spectrum of outcomes associated with the diagnosis that we help the patient to make a truly informed decision.

As providers, we need to focus not only on the negative aspects of individuals with a genetic disease (as these do need to be discussed), but also on the positive aspects of these individuals. These individuals can bring unique experiences to parents and families, a benefit that is sometimes left out of postnatal counseling, as Fr. Pacholczyk points out very accurately. This is because as providers, we see individuals with any type of disability/genetic disease through the lenses of our own experiences. This vision allows us to make a prejudicial quality of life determination for these individuals that is not accurate.

PERSONALIST BIOETHICS

Perhaps the best approach to the bioethics of invasive prenatal testing (in my opinion) was written by Elio Sgreccia in his book titled, *Personalist Bioethics* (2012). He clearly states that if the test is being performed and it were known to be certain that it would be a preparatory act for an abortion, then it would be wrongful to perform the invasive testing for the patient.

If there is a prearranged and pre-established directive for an abortion if the test result comes back as indicative of a genetic defect and the patient has accepted this prior to the procedure, then the invasive testing is morally wrong. Although he does not clearly define the terms “pre-arranged” and “pre-established,” the implication is that it involves some concrete

plan of action already put into place by the patient that will go into effect once the diagnosis comes back as abnormal. In my experience, this is not very common in prenatal testing.

His approach to prenatal testing differs from the above Catholic sources in one major way. He tackles the uncertainty that patients have when confronted not with the question of whether or not to perform invasive prenatal testing, *but the question as to what to do with the information once the information is received*. Many times, the patient is unable to accurately determine what she would do if the test would come back as abnormal at the time she is considering the test. In reality, the decision is not as black and white as one might think. Here is the most common example that a provider will see in doing prenatal testing.

Rarely does a patient have a definitive plan in place prior to receiving the results of the testing. Some women will simply state that they will not terminate if the results are abnormal. Even in this circumstance, many women will not be 100 percent sure when they make this statement as it is difficult to determine this without the actual diagnosis. Most women simply do not know and this is where the confusion arises for the provider. Sgreccia tackles this issue with clarity of thought, while trying to be in line with Catholic bioethical teaching. He confronts the uncertainty with compassion and care. He does not imply that the Catholic health-care provider should not do the procedure. Rather, he argues that the best person to be in this position is the Catholic health-care provider.

Sgreccia acknowledges that a woman's plan of action after the procedure many times cannot be predicted with any certainty prior to the procedure. He even states that it is impossible to ask the woman ahead of time what her future action will be. Furthermore, he states that

due to the anxiety surrounding the procedure, she most likely does not have a definitive plan of action and that even a plan of action that has as one of its consequences termination should not be considered unalterable:

Finally, from the objective viewpoint, the diagnostic action is not directly connected with the abortion outcome: the woman, particularly if assisted, could always accept the unborn child even if the child is deformed, and the abortion outcome does not necessarily follow from the diagnosis. Asking the woman what her attitude would be in the event of an unfavorable result does not prove to be a practicable course of action because it could lead to a hypocritical position and, moreover, it is difficult to predict a state of mind when the real conditions are lacking. (Personalist Bioethics, 362)

I like the way that he brings to life the situation where a woman's conduct after the results are received cannot be predicted prior to the testing. In fact, he further states that this is the most common situation into which the provider is placed and I agree. He gives advice to the physician who may be confronted with a patient who has received an abnormal result and is contemplating a termination. He states that the provider should make the patient aware that the fetus is a human being and can be helped. This includes discussing medical resources, as well as financial and social resources, that are available to the child and family.

Many times, patients may feel pressured to terminate the pregnancy upon an abnormal result from prenatal testing. In fact, most women that undergo prenatal testing and receive a diagnosis of Down syndrome chose to terminate their pregnancy (Peller, Westgate, and Holmes 2004; Stoll et al. 2002). If the patient is leaning toward termination and the physician does not do his or her due diligence

in counseling the patient correctly, this inadequate counseling may tip the scales in favor of termination. Allowing the Catholic physician to perform invasive testing when the patient still has not made a choice as to termination allows the Catholic physician the opportunity to be there for the patient when the result does come back as abnormal. In my very humble opinion, this is frequently overlooked in the above Catholic sources for guidance in invasive prenatal testing.

One may think that I am proposing that the provider should offer directive, rather than non-directive counseling. This is not what I am proposing. What I am proposing is for the Catholic healthcare provider to be present to discuss what the empirical data show regarding families and individuals living with genetic problems. Take for example Down syndrome. How many patients are told at the time of prenatal diagnosis of Down syndrome that 99 percent of individuals living with Down syndrome are happy with their lives and that 97 percent of these individuals like how they look? (Skotko, Levine, and Goldstein 2011a). Are they ever told that 97 percent of parents who have children with Down syndrome are proud of their son or daughter with Down syndrome? Are they told that 99 percent of parents who have children with Down syndrome report that they love their child with Down syndrome? Finally, are they told that only 4 percent of parents that have a child with Down syndrome report regret in having that child with Down syndrome? (Skotko, Levine, and Goldstein 2011b).

What I am proposing is that Catholic care providers should be there in order to provide the patient with accurate information that is backed by empirical research. This is necessary so that societal misperceptions of Down syndrome can be corrected. Women that act upon incorrect data based on their own misperceptions of

a genetic disease are not making an informed decision.

Looking back at *Donum vitae*, we can see some potential discrepancy. If interpreting *Donum vitae* literally, the Catholic physician would have to remove him- or herself completely from the situation if there was any thought of a termination if the results showed fetal aneuploidy. This could have potential detrimental effects if the results do return as indicating fetal aneuploidy in that the Catholic physician would not be there to adequately counsel her regarding what Father Tad spoke about in “Temptations in Prenatal Testing.” There may not be any discussion of the “serene acceptance” of this child, nor any discussion of the graces that can be bestowed on a family when choosing to take care of a child with a genetic defect.

CONCLUSION

As one can see, there is some discrepancy among certain Catholic sources that pertain to this specific issue of offering invasive diagnosis for fetal aneuploidy. One may assume that for the patient who has concrete plans in place for termination if the diagnosis is fetal aneuploidy, it would be morally illicit to offer invasive prenatal testing. There seems to be no disagreement among the Catholic sources with this scenario.

One could argue that because of a very real risk of a complication with invasive prenatal diagnosis that could lead to loss of the pregnancy, this would preclude offering invasive prenatal testing at all. It does appear that there has been some evolution of thought in acknowledging that invasive testing carries with it not only a risk of pregnancy loss as expressed by Blessed John Paul II in *Evangelium vitae*, but also a benefit in accepting a child with a genetic defect prior to birth.

If this is the case, then it may be agreed upon that it is morally licit in performing invasive testing if the patient has absolutely no plans of termination if the results indicate fetal aneuploidy.

Discrepancy arises when the patient cannot articulate what she would do with the information. It may be difficult for the practicing physician to accurately determine whether or not the patient would proceed with termination following the diagnosis of fetal aneuploidy at the conclusion of the pre-test counseling session. In reality, these counseling sessions tend to be brief due to lack of time on the provider's part. Little time is spent actually discussing what it is like raising a child with a genetic defect such as Down syndrome. It may be difficult, if not impossible in the time permitted, to actually give the patient as much information as would be necessary for her to accurately predict with certainty what she would do with the information that is obtained from the testing. To those reading that are not involved in direct patient care, this may seem disconcerting, but it is the environment in which one practices today.

During the post-test counseling session, a large part would be devoted to telling the patient what it would be like to raise a child with aneuploidy. As well, the patient may meet with healthcare providers that specialize in the care of individuals with the particular genetic abnormality.

One could easily envision a scenario where a patient would have thought that she would have terminated the pregnancy at the end of the pre-test counseling session and prior to the diagnosis, yet, after a thorough post-test counseling session, she would change her mind and elect to continue the pregnancy. If a Catholic physician is there to help her during this counseling session, it in no way guarantees that she will not proceed with the termination of pregnancy, but it

may be of benefit in reducing the risk of this happening by providing accurate information that is obtained from empirical research.

Making strict guidelines that disallow a Catholic physician from participating in invasive testing if there is even a hint of pregnancy termination may be dangerous. It does not allow for a real discussion centered upon the personhood of the fetus and the idea that these children do give great joy to their parents, even though they may come with unique challenges.

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BIOGRAPHICAL NOTE

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