Redemptive Genetic Counseling

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Now that completion of the sequencing stage of the human genome project has been announced, our knowledge of human genetics and our ability to use and manipulate that knowledge is growing very rapidly. As we gain a greater and greater understanding of how the human body functions and controls itself on a genetic level many questions arise. Among others, questions concerning genetic diseases develop as the causes of more and more disorders become apparent and methods of testing for them become more and more common. Questions such as, can genetic cures be found, can treatments be discovered, and how early and with what certainty can diseases be tested for, are intricately woven into this issue.

However, even more than these pragmatic questions, the true meaning of humanity itself begins to be reconsidered. Shall people expressing severe genetic disorders be denied the right to live based on the fact that their quality of life would be very diminished? How would a severe case be defined, since genetic disorders manifest themselves in a range of severities from harmless to life threatening? Finally, what effect would this devaluing of certain types of humanity have upon our attitude towards others, such as the elderly manifesting dementia? These questions and others concerning our treatment of humanity must be addressed in order to avoid a radical devaluing of all human life.

Genetic counseling is a relatively new field that, despite its youth, is intimately connected with addressing these issues. The issues and questions surrounding the growth of knowledge in the field of genetics bring into question the possibility of the existence of a Christian, redemptively minded genetic counseling clinic. By discussing the relevant background information and these current issues in the context of genetic counseling this paper will provide justification for the existence of a Christian genetic counseling clinic. Lastly, by examining
these issues a model for the creed and operation of a Christian genetic counseling clinic will be constructed.

**Background into the field of genetic counseling**

**History**

Genetic counseling is a relatively new field, and it is appropriate to begin with a short history. The study of genetics began in the mid-19th century with Gregor Mendel. He studied inheritance in pea plants, but his results were not recognized until his work was rediscovered in 1900 by Carl Correns and Hugo deVries. In the intervening years Lamarck and Charles Darwin had both put forth theories of inheritance. The rediscovery of Mendel’s work led to the ability to predict the risk of occurrence of inherited genetic conditions. This ability allowed genetic advising to begin taking place in its earliest forms in the United States in 1906 (Baker, Schuette, and Uhlmann 3).

Following this early genetic advising were tragic results. That genes controlled all behavior became a commonplace belief. This belief resulted in a collection of state laws referred to as the Sterilization Laws of 1907 to 1937 (Zallen 73). During this time states enacted laws that provided for the sterilization of people containing undesired hereditary disorders. For example, the following comments were contained in a United States Supreme Court opinion in 1927, which upheld a Virginia statute surrounding the sterilization of patients in state supported mental institutions:

“experience has shown that heredity plays an important part in the transmission of insanity, imbecility, &c. The statute then enacts that, whenever the superintendent of certain institutions, including the above-named State Colony, shall be of opinion that it is for the best interests of the patients and of society that an inmate under his care should be sexually sterilized, he may have the operation performed upon any patient afflicted with hereditary forms of insanity, imbecility…It would be strange if [public welfare] could not call upon those who already sap the strength of the State for these lesser sacrifices” (Buck v. Bell).
Furthermore, discrimination by nationality against people not from Great Britain or northwestern Europe occurred with the United States’ Immigration Act of 1924 that restricted immigration of the undesired people.

Around this same time involuntary sterilization was the result of directed genetic counseling in Germany and Sweden (Multer-Hill 136-139). In Germany during the mid-1930’s the Nazis advocated mandatory sterilization for those expressing undesirable characteristics, such as schizophrenia or alcoholism. People were sentenced to sterilization based on a mock trial composed of two medical doctors and one judge, in which the patient and lawyer typically did not know the diagnosis (Multer-Hill 137). The sterilization of all colored people, most gypsies, and all with at least one Jewish grandparent resulted in 62,463 people being sterilized in 1934, 71,760 in 1935, and 64,646 in 1936, which is roughly 0.1 percent of the German population per year. In Sweden 62,888 people, mostly women, were sterilized between 1935 and 1975, when the law legalizing sterilization was revoked. Between 1935 and 1948 most of the women were sterilized for eugenic reasons on the grounds that they were part gypsy, but after 1948 most occurred for medical reasons. All of these sterilizations occurred under a law prohibiting involuntary sterilizations, but the people were badly informed and mildly coerced (Multer-Hill 139). Through history in our own country and others the potential danger from the misuse of the results of genetic counseling is clearly seen.

Genetic counseling has continued to grow and develop from these tragic beginnings. The first early genetic counseling clinics in the United States were opened in Michigan in 1940 and Minnesota in 1941 (Harper 4). However, the term genetic counseling was coined by Sheldon Reed in 1947, and in the late 1950’s came the development of a wealth of genetic disorder tests,
with the first fetal chromosomal anomaly diagnosis being reported by Jacobson and Barter in 1967 (Baker, Schuette, and Uhlmann 4).

Over the three decades following this diagnosis, genetic counseling as a profession has greatly developed. The first masters program in genetic counseling was started by Sarah Lawrence College in 1969, with the first graduates graduating in 1971. Between 1969 and 1992 15 more programs developed and two professional organizations were started. The National Society of Genetic Counselors was established in 1978, and in 1992 the American Society of Genetic Counselors had over 1000 members (Bosk 156). In December of 1971 it became apparent that some guidelines for genetic screening needed to be established. A group of geneticists and ethicists led by Marc Lappe met to establish guidelines to curtail abuses by genetic screening institutions brought to light by past screening programs. The established guidelines and requirements included the need for screening to be voluntary, all tests to involve informed consent, free access for the participant into the information found, counseling programs to explain the results, and absolute secrecy of information gathered (Harsanyi and Hutton 253). Genetic counseling as a profession now covers all of the areas touched on by these guidelines.

Today the majority of genetic counselors are not physicians but counselors with master’s degrees in genetic counseling. There is also a great need for more genetic counselors, as “it is widely recognized that there are too few trained genetic counselors, and that those who are trained and employed are simply overwhelmed by the case load they are expected to carry. This situation will likely become more severe as more genetic tests become available” (Bosk 36). With the completion of the sequencing phase of the human genome project more and more tests for genetic disorders will soon become available and the prospects for gene therapy will broaden.
This will cause a greater need for genetic counselors as more people desire to know their risks for producing a child with a genetic disorder.

**What is Genetic Counseling?**

It is difficult to develop a concise definition or description of genetic counseling. Overall, genetic counseling has been defined as “the communication of information to individuals and families concerning an existing or potential birth defect or genetic condition” (Genetic Testing for Cystic Fibrosis 10). This simple definition does not do justice to the wealth of complicated questions surrounding genetic testing and counseling, but it will stand for now. Testing may include tests of adults for disorders that may not have become symptomatic yet, such as Huntington’s disease, which typically does not show symptoms until middle age. However, the scope of this paper will be narrowed to a treatment of issues surrounding prenatal testing for genetic disorders in an unborn child and the testing of a couple considering pregnancy in order to evaluate their risks of having an affected child.

The dominant portrayal of genetic counseling in the literature is as an information gathering process. Genetic counselors are seen as information bearers whose job it is to communicate test results and risks to their patients in a way that is easily understood. The National Society of Genetic Counselors has adopted the following statement as part of their definition of a genetic counselor.

> “Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They identify families at risk, investigate the problem present in the family, interpret information about the disorder, analyze inheritance patterns and risks of recurrence and review available options with the family…They serve as educators and resource people for other health care professionals and the general public.” (NSCG Home Page)
This description reveals the emphasis on a genetic counselor as an information provider. A greater framework must exist for the treatment of patients of genetic counselors, as genetic counselors must have previous information concerning patients before they can offer a valid risk-assessment.

This process of genetic counseling has been described by many, but Beth Lincoln-Boyce and Robert Cefalo reduce the process to four main parts. The first is information gathering. During this stage of counseling the genetic counselor gathers medical records and lab results and attempts to put together a pedigree. A pedigree is a family history of the couple seeking counseling that includes all genetic or health disorders that family members have expressed so that risks for future family members can be established. Second in the process of genetic counseling comes risk assessment. This involves the counselor meeting with the patients and making an estimate of the likelihood that their children will express a genetic disorder present in the pedigree or the parents’ genotypes. Thirdly, the genetic counselor communicates all other relevant information and the parents decide on a course of action. This may include further genetic testing of the parents or an unborn child and the communication of those test results and how they affect previous risk statements. Genetic counselors also provide parents with their current options for action, given the test results, and allow them to make a supported decision. Lastly, the genetic counselor must follow-up with the patients. This may include a copy of test results and a letter containing a summary of the information contained in the counseling session so that information forgotten can be reviewed. (19-22)

This outline of genetic counseling provides a basic description of the counseling process. However, each of the stages needs greater explanation. First, referral to a genetic counselor occurs for a number of reasons. These include advanced maternal age, an abnormal result
following a standard prenatal screen such as ultrasound, parental history of multiple miscarriages or infertility, family history of a genetic disorder, maternal health problems such as diabetes, maternal exposure to teratogens such as alcohol or drugs, ethnic background, consanguinity, or parental anxiety concerning the possibility of genetic disorders (Pouncey). All of these are possible reasons for a patient to seek prenatal genetic counseling, and the counselor must first obtain any necessary medical records, test results, or other information concerning the reason for referral before the first counseling session in order to be prepared to offer initial suggestions.

Based on these initial findings the genetic counselor can make preliminary risk assessments. These estimations are based on family histories and other contributing factors such as advanced maternal age. Family histories provide probabilities that the parents are carriers for a genetic disease. These probabilities are then multiplied to determine the likelihood of the unborn child expressing the genetic disorder. For example, Tay-Sach’s disease is a recessive disease caused by genetic mutation. Since it is recessive, both copies of the gene in a person must contain the mutation in order to express the disease. Two carriers of the disease, having only one copy each, have a one in four chance of having a child that expresses the disease. In this case the probabilities of the parents being carriers, determined from their parents’ carrier status, is multiplied by one fourth to obtain the probability of having an affected child. These are the types of risk analyses that the genetic counselor can provide based on initial findings and information gathering.

Once initial risks have been established more conclusive tests may be desired. It is the job of the genetic counselor to advise the parents as to what tests are available and which are recommended in their situation. Types of tests include prenatal screening for disorders expressed by an unborn child, carrier testing to establish the carrier status of potential parents,
and susceptibility tests to establish a person’s greater susceptibility to a disease, such as testing for two genetic mutations which indicate a greater chance of contracting breast cancer (Zallen 44-45). Many prenatal tests for various genetic disorders in an unborn child exist at this point in time, and the number is growing constantly with the completion of sequencing the human genome. Some common ones include ultrasound, amniocentesis, chorionic villus sampling, testing for alpha-fetoprotein, and the triple screen, which includes tests for HCG levels, estriol, and alpha-fetoprotein (Pouncey). Results of each of these prenatal tests increase or decrease the initial risk estimates. For example, high levels of alpha-fetoprotein in a sample of maternal blood serum can indicate the presence of neural tube defects such as spina bifida, in the unborn child. Also, high levels of HCG and low levels of estriol in the maternal blood serum increase the possibility that the unborn child has Down’s syndrome.

The results of these tests have different possible meanings. No test result is a completely certain indicator for genetic disease. False positives or negatives occur during testing. For example, many mutations can cause cystic fibrosis, and the current genetic test for cystic fibrosis identifies 85 percent of Caucasian carriers, meaning that fifteen percent of people testing negative actually carry a cystic fibrosis gene mutation (Marshall 71). This kind of testing error is caused by the fact that multiple mutations can cause the same genetic disease. Likewise, recombination among genes causes error to be introduced into test results (Drlica 62). Also, test results can differ between ethnic populations because different ethnic populations are more susceptible to certain diseases. For example, the Scotch and English tend to be more susceptible to cystic fibrosis, Irish and Polish to phenylketonuria, Eastern European Jews to Tay-Sach’s, and Africans to sickle-cell anemia (Drlica 148). These few examples indicate that genetic testing is not completely certain. In general the genetic counselor must pull together many different
factors to produce one risk assessment for a genetic disease, and “if risks are falsely assessed, the genetic counseling undermines the rational choice and patient autonomy the service was intended to promote” (Bosk 45).

It is seen that based on the probabilities given them by the genetic counselor a couple must make a reproductive decision. The picture of genetic counselors as information givers restricts their participation in this area. Genetic counselors are referred to as non-directive. This means it is the responsibility of the genetic counselor to provide patients with accurate information regarding their risks of having a child with a genetic disease, a proper explanation and description of each of the conditions tested for, a discussion about the effects this will have upon the family, a discussion about all reproductive options, and an explanation of the possibility of other family members carrying this trait (National Academy of Sciences 175). Once this discussion has taken place, it is the job of the genetic counselor to allow the parents to make their own, informed reproductive decision. Non-directive refers to this withdrawing on the part of the genetic counselor out of the decision-making process and the genetic counselor’s practice of not imposing their values on their patients. The emphasis in genetic counseling is on allowing patients to find decisions right for their circumstances, not decisions right for the genetic counselor’s personal morality.

At this point in time there are very few possible decisions parents can make following genetic counseling. Some genetic conditions have symptoms that can be treated if they are detected soon enough. One example is phenylketonuria, which is a metabolic disorder causing severe mental retardation and death that can be treated by a diet very low in phenylalanine. Other conditions can be treated by fetal surgery, such as spina bifida where the open neural tube defect can be covered up to stop nerve exposure. The vast majority of genetic conditions can
not, however, be treated before or after birth. Should a genetic disorder be detected in an unborn child the parents typically have only two options, to keep the child or to abort the child. In light of this fact some authors hold that testing should not occur until there is an adequate treatment for a disorder. The authors of *Christian Faith, Health, and Medical Practice* state,

“Where there is a safe and accurate test for a condition and where that test is related to available and effective treatment, we celebrate this new power to diagnose newborns, children, and adults. Where such conditions are not met, we are more cautious than celebratory, and we are particularly concerned about the sort of mentality that would routinely screen for conditions for which there are neither accurate tests nor effective therapy.” (Hessel et al 245)

This question of when it becomes appropriate to begin testing for a disorder in light of the possible treatments and therapies available is an issue in genetic counseling that will be discussed later in the paper.

Once a couple has discovered that their unborn child has a genetic disorder and they have determined to keep the child different resources are available to them. Various organizations have resources for parents that are specific to a condition. For example, the March of Dimes produces Public Health Education Information Sheets on various genetic disorders, and these sheets contain references to more specific organizations, such as the Spina Bifida Association of America. These organizations provide information to parents and sometimes have support services as well. Some states have support programs as well. The state of Tennessee supports a program called Parents Encouraging Parents which concentrates on one on one support for parents of children with genetic disorders and connects parents with local or national services and resources. Support groups and other resources are also available on a disorder by disorder basis. One example of a disorder specific support service is that available for parents of children with Down’s syndrome in the state of Tennessee. The state of Tennessee provides support services and support groups from the time of diagnosis. At the age of three, the school system
takes responsibility for the child and provides general family support and education systems. State agencies and social workers further assist the family in raising a child with and dealing with the effects of Down’s Syndrome (Pouncey). All of these services, combined with information databases and education programs comprise parental resources following diagnosis of a genetic disorder.

The genetic counselor’s responsibilities do not typically end following diagnosis. Genetic counseling usually entails follow-up procedures as well. Initially this consists of a letter from the genetic counselor detailing everything discussed in the counseling sessions because the shock of a positive result often inhibits the parents’ ability to comprehend the session (Lincoln-Boyea and Cefalo 22). Furthermore, genetic counselors often serve as a resource for parents if they have further questions or need more information. Lastly, the follow-up procedures, such as monitoring the diet of a child with phenylketonuria, are usually performed by a separate facility. “It is vital that a close relationship exist between the screening authority and the follow-up facility” (National Academy of Sciences 263). In this way children diagnosed with disorders are treated properly and quickly in accordance with their condition.

The process of genetic counseling has now been described. Genetic counselors advise patients as to their risk or the risk of their children to express a genetic disorder according to their family histories or genetic tests performed. As a result of this risk assessment a couple is left to choose from among their limited options according to their own opinions and circumstances. Throughout this entire process many questions and issues arise concerning the practice and perception of genetic counseling. The most prominent of these issues will now be addressed.
Issues in Genetic Counseling
To Test or Not to Test?

The first question in genetic counseling is whether or not to engage in testing. Most conditions do not currently have adequate treatments or cures, causing the purpose of prenatal testing to become unclear. At this point prenatal testing is for one of three reasons. First, it can be to prepare the prospective parents for living and dealing with a child with a genetic disorder. Second, in rare cases, such as some open neural tube defects or some metabolic disorders such as phenylketonuria, the condition can be corrected or treated. Thirdly, a child found to have a genetic disorder can be aborted and the associated troubles avoided. The first two are acceptable from a Christian perspective, but the third is not. Prenatal genetic testing cannot be seen as a search and destroy mission for children with unwanted genetic disorders.

Other factors also play into the decision to test or not. Typically these factors surround details of the suspected condition and the emotions of the parents. The decision to test usually includes an analysis of the specifics of the condition tested for. This includes life expectancy, quality of life, possible range of symptoms from severe to nominal, and the strain it would place upon the resources, financial and emotional, of the child’s family (Pouncey). Whether or not incurable and untreatable disorders should be tested for at all is a large issue. Anxiety levels in the parents often factor into their decision to test. Parents often are seeking to allay their fears concerning their unborn child and often it is to ease these anxieties that prenatal testing is conducted.

Finally the decision to test is based upon the test itself. Whether or not a given test can predict results with a considerable amount of accuracy comes into the discussion. If a test is highly inaccurate, then there seems little reason to use it to test for a genetic condition. Many tests also pose risks to the mother and unborn child. For example, amniocentesis involves
introducing a long needle into the amniotic fluid to obtain a sample. There is danger of penetrating the fetus and a percentage of the procedures performed result in miscarriage (Pope John XXIII Center 18). However, the use of sonography in guiding the needle’s placement has increased the safety of this procedure. More difficulty arises when the sole beneficiary of genetic testing is the parents. Testing often eases the fear of parents, but “the procedures of antenatal diagnosis usually appear to offer no hope of benefit for the unborn. It is this fact that poses a problem concerning the moral justifiability of many of the antenatal diagnostic procedures” (Pope John XXIII Center 19). When there are no clear benefits for the fetus, prenatal testing often can not be justified given the risk to the unborn child.

All of these issues and questions come into play when considering the question of whether or not to engage in prenatal testing for genetic disorders. Once the decision to engage in testing has been decided further issues in the area of genetic counseling are revealed. These surround questions of availability and confidentiality and they will now be addressed.

Availability of testing and payment
Even if the decision has been made to engage in prenatal genetic testing the ability to test is not always available to a patient. Tests are very costly and coverage by insurance varies. The costly nature of these tests results in an unequal availability to potential patients. “Extensive, expensive, high-technology care is available to the pregnant middle-class woman, while the most rudimentary care is often not provided to the least-privileged members of the society. What is a fundamental right for those with private health insurance is denied to those whose health care is contingent on public funds” (Bosk 140). Genetic counseling becomes one more dividing factor between the rich and poor.
Insurance coverage for tests varies by plan and state. Most private insurance covers test costs fairly well because there are good reasons for testing, such as a history of multiple miscarriages leading to a test for chromosomal translocations in both parents. However, they often do not see the point of testing the father in this situation because his role in the miscarriage is not seen by the insurer. Often genetic tests are treated like lab test fees. In the state of Tennessee the state sometimes helps with the funding for genetic tests. However, Tenn Care insurance has poor coverage (Pouncey). Medicaid has similar poor coverage. Overall it is often the more expensive tests that are not covered by insurance.

If insurance covers the costs of a genetic test, questions of confidentiality result. Often insurance companies could benefit by knowing the test results. Coverage could be granted or denied to the child based on the test results. Does payment for the test grant the insurance company access to the test results? This and further questions of confidentiality will now be considered.

**Confidentiality**

Medical records are protected by confidentiality laws due to the fact that they could be harmful to the person if made public. Similar principles apply to the results of genetic testing. These results could be even more harmful because they speak to the unchangeable genetic makeup of a person. There is no easy way to determine who should have access to a person’s genetic test results.

Different parties could benefit from this knowledge. First, other family members often have a right to know the results if the patient carries a gene that they also have a possibility of carrying. Second, insurance companies and employers would benefit from knowledge concerning the life expectancy and work life of their insured or employees. This would allow
them to make decisions concerning coverage and employment based on the results of their genetic tests. Insurance companies often request access in return for funding for tests, and this provides them with a wealth of power concerning health insurance coverage. This begins to allow others to have control over the patient’s life.

Autonomy of patients is an important idea when discussing confidentiality. As more and more people have access to the results of genetic tests, a person has less and less control over their own life because others would dictate their life situations to a great degree based on those results. It is important that a person maintains control over their own decisions, and this control begins to be taken away as soon as the limits of confidentiality are expanded.

Typically the list of parties allowed access to the results of genetic tests is rather short. One example of a common list of parties having access to the results of genetic testing would include the patients, the referring physician, the genetic counselor and their private chart, and if the clinic is within a hospital, the person’s hospital chart typically maintains a copy (Pouncey). A problem arises when other family members would like to know the results. Many times it is because they themselves could be carrying the gene or disorder tested for. “In general, it is properly the decision of the person whose truth it is, not the decision of the genetic counselor, whether or not to make that truth known to others” (Hessel et al 253). This question also includes access to test results following a patient’s death. Many do not want their results released even after death, and in New York one clinic’s “ethics committee is now revising its consent forms to require all patients tested to specify which family members should have access to the results after their death” (Lewin 3).

In the above situations the patient is given total control over who receives access to test results. However, there are cases when serious harm to others may be avoided if they are
informed as to the test results. “In cases where the risk of harm and the magnitude of the possible harm are great to others, … the genetic counselor may and must break the confidence” (Hessel et al 254). Thus, there are situations in which the genetic counselor may break patient confidentiality. However, the patient controls confidentiality in all other situations.

Genetic counselors often have to counsel patients as to who should have access to test results. The counselor can press the fact that other family members’ lives could be affected and helped by the knowledge. This typically is seen as directive counseling because the counselor is trying to change the opinion of the patient and bring them round to their own point of view. Typically, being directive in this capacity is acceptable, however, when it comes to reproductive decisions the counselor is typically seen as non-directive. The issue of non-directiveness and value neutrality will now be addressed.

**Nondirectiveness and Value Neutrality**

Another way of safeguarding patient autonomy is by holding to a philosophy of non-directiveness. Under this philosophy genetic counselors seek to allow their patients to make reproductive decisions that are right for the couple. Typically this involves providing all the needed information concerning the disorder in question and the risks associated with it, discussing possible options with the parents, and then allowing the to make their own decision. “Their goal is to present genetic information in clear and accurate terms, but without recommendations about choices” (Cole-Turner and Waters 39). In this way counselors can not be accused of supporting one course of action. For example, in the middle of the abortion debate they cannot be accused of supporting one side or the other.

Central to the idea of non-directiveness is the conception that a genetic counselor only provides factual information and remains value neutral in all discussions. However, it is doubtful that a genetic counselor can be value neutral as “the tone of voice and body language of
the counselor who is telling couples about a genetic condition subtly reveal evaluations” (Hessel et al 253). The actions of the counselor will invariable serve as a directive force in a counseling session. Due to the fact that non-directiveness is unattainable, directiveness should be explicit on the part of the counselor, otherwise it becomes manipulative (Clarke 19).

Also crucial to the idea of nondirectiveness is the belief that there is no one right decision for every patient. Each couple is different and has a different set of circumstances, which means that one answer will not be right for each couple. A common theme is, “It is particularly important that couples realize that in general there is no ‘right’ or ‘wrong’ decision to be made, but that the decision should be the right one for their own particular situation” (Harper 15). When faced with the reality of making this decision, couples often ask questions of the genetic counselor, seeking help in making their decision. However, the

“commitment to a nondirective style leads counselors to respond to the question, ‘What should we do?’ with a didactic lecture about how only the couple can know what is right for them, and to respond to the follow-up question, ‘What do others in our situation do?’ by dismissing the relevance of the question because each individual couple is in its own unique situation” (Bosk 39). Many times this leaves patients and couples feeling alienated and uncertain. “The dark side of patient autonomy [is] patient abandonment” (Bosk 158).

This idea of nondirectiveness is now starting to be questioned. It is apparent that it is impossible for counselors to remain completely value neutral and nondirective while counseling patients about their choices and decisions. The basis of value neutrality has traditionally been that facts and values are separate, and therefore facts can be presented by the genetic counselor without imposing their own values upon them. However, the separation of facts and values is being questioned, along with whether they can be presented separately (Cole-Turner and Waters 40).
Currently, however, genetic counseling is still treated as nondirective and value neutral. In light of this treatment genetic counselors must provide a discussion of all possible options for the patient. This includes providing information about selective abortions. Following is a brief discussion concerning the issue of selective abortions.

Abortion

The issue of abortion is intimately tied to the field of genetic counseling. In a nondirective setting abortion must be presented as one of the viable options for dealing with an unborn child that has a genetic disorder. Problems arise when the genetic counselor is personally opposed to abortion. “Presenting abortion as one of the possible alternatives, as though it were morally indifferent or morally on par with carrying a child to term, seems to do violence to such a counselor’s conscience” (Pope John XXIII Center 28). However, due to the legal nature of abortion until the 24th week of pregnancy, a genetic counselor could face civil liability charges for not advising a patient of their abortion options (Pope John XXIII Center 28). In light of these considerations a genetic counselor may feel very torn over the issue of abortion.

One way of dealing with this on the part of the genetic counselor is to separate counseling from the patient’s decision. The decision is seen as the parents’ and the genetic counselor has no part in it. In this scenario the level and quality of the counseling are the important items to focus on and not whether children were carried to term (Bosk 124). This attempts to remove all values from the genetic counselor in regard to a patient’s decision to abort.

Total autonomy on the side of the parents fails to take into account the emotional and psychological effects that abortion could have upon the mother and father. Often times the child is wanted and the parents engaged in testing thinking the result would turn out fine, therefore, the abortion is of a wanted child. “In contrast to the mostly positive reactions of women after an
abortion for psychosocial indications, many authors have observed the opposite following a
termination of pregnancy for fetal abnormality” (Clark 116). Thus, abortion following genetic
testing is often more traumatic than abortion of an unwanted child. Also, grief is more profound
when the parents’ personal loss is considered. The abortion of a child for genetic reasons
deprives the parents of their life with the child, and the grief is even greater because “in losing a
pregnancy we lose a part of our own future” (Cole-Turner and Waters 131). Nondirective
explanation of abortion options does not take these larger issues into account.

Another side to this issue is the question of when a patient decides to abort and what the
factors involved in the decision are. First, abortions following the 24th week of pregnancy are
almost always illegal, with certain states permitting them in the case of lethal conditions, but
then a doctor willing to do the procedure must be found (Pouncey). Before the 24th week of
pregnancy questions concerning quality of life often determine the patient’s decision. Typically
“reproductive decisions are strongly influenced by the parents’ sense of the burden imposed by
the disease upon an afflicted child and upon themselves” (National Academy of Sciences 177).
Factors considered are often the projected life span of the affected child, the severity of the
symptoms, such as mental retardation or physical deformity, the emotional effect the parents
perceive it will have on themselves and the family, and the financial ability to provide for
available treatment. These considerations are taken into account when parents are deciding
whether to carry a child to term.

Further debate occurs over when it is appropriate to view abortion as a viable option.
This is the question of “selective” abortion. The issue surrounds the question of whether it is
morally right for parents to abort unborn children for whatever reason they choose. Many
authors support abortion in the cases where the prognosis is so dismal that the life of the child
would almost be no life at all, but this often depends on the ability to accurately test and
diagnose the genetic condition (Hessel et al 248). Decisions to abort in these cases begins to
divide between people with lives worth living and those lives that should be avoided. “Yet the
very project of genetic counseling is built upon the premise that at least some clients believe that
it is better to avoid some types of life” (Montgomery 218). This is a very dangerous area to
venture into. When people begin to make decisions regarding the quality of others’ lives,
dehumanization can easily begin to occur. The last issue surrounding genetic counseling to be
touched on will be this tendency to dehumanize and discriminate against children with genetic
disorders.

**Dehumanization of People with Genetic Disorders**

One of the dangers in the cycle of genetic testing followed by abortion is a tendency to
devolve certain types of human life based on their genetic makeup. Another danger is the
tendency to view children as products or as consumer objects. These perspectives have a great
influence on the way in which children in our society are treated, especially children with genetic
disorders.

The first tendency, to reduce people to the genetic disorders they express, leads to
discrimination and stigmatization. Unborn children with genetic disorders are often aborted
because it is felt that their future quality of life would be so low that their lives would not be
worth living. This in effect says that people living with those same genetic disorders should not
have been allowed to be born, do not deserve to live, and that their lives are a mistake. In
addition to this message, genetic counselors often “emphasize how most fetuses with an
abnormality abort spontaneously during pregnancy, are ‘naturally selected,’ as it were, and how
prenatal testing is merely an improvement on nature” (Lippman 160). Thus, the message that
children with genetic abnormalities are somehow unnatural is also given. This only serves to reinforce a societal stigmatization of children with genetic disorders.

An example of the discrimination that can result from genetic testing was seen in the village of Orchemenos. This small village had a high percentage of people carrying and expressing genes for sickle cell anemia, a genetic disorder causing shriveled red blood cells and death in those with two copies of the mutated gene. A group of researchers engaged in village wide screening programs for the sickle cell gene and then counseled the villagers concerning marriage to prevent two carriers producing children. After leaving the village isolated for some time, the researchers returned to find that people carrying the sickle cell gene had been discriminated against and the village had essentially been cut in half based on their genetic makeup (Harsanyi and Hutton 243). In our society “maximizing the medical benefits of genome research would require a social environment in which health care consumers were protected from discrimination and stigmatization based on their genetic makeup” (Hudson 392).

The second danger is that of turning children into consumer objects. With the power of genetic testing parents can almost choose any quality they desire their children to have. “Prenatal diagnosis does approach children as consumer objects subject to quality control. This is implicit in the general assumption that induced abortion will follow the diagnosis of fetal abnormality” (Lippman 146). Making this assumption turns children into products whose termination can be justified by any trait that society feels makes them of a lower quality than normal life or makes them too expensive to support. “The tendency we must resist is allowing the decision to terminate a pregnancy to become largely one of accountancy, with the expectation that if the projected financial cost is too high, the decision to abort will be administrative and routine” (Cole-Turner and Waters 139). If this happens children will no
longer be seen as humans or gifts of God but as another product that needs quality control during its production.

All of these issues are central to the field of genetic counseling. Discussions on these topics have filled entire books individually; here they have only been touched upon. However, based on these controversial issues and questions various perspectives on how to address these issues in the practice of genetic counseling will now be presented in an attempt to discover what aspects are at the heart of the definition of genetic counseling. By doing this a Christian, redemptive model of genetic counseling can be produced from those aspects.

**Perspectives on Genetic Counseling**

**The National Society of Genetic Counselors**
The National Society of Genetic Counselors (NSGC) holds what appears to be the typical societal viewpoint of genetic counseling. They are “an organization that furthers the professional interests of genetic counselors, promotes a network of communication within the profession, and deals with issues relevant to human genetics” (Code of ethics). Adherence to the NSGC’s Code of Ethics is required for membership in the organization, and the NSGC has also put out position statements on many of the issues surrounding genetic counseling. They provide a contemporary perspective on genetic counseling.

In general the NSGC is careful to safeguard the patient. They promote equal access for all people to genetic counseling services and advocate health care reform, which would guarantee universal coverage for genetic testing, prenatal care, and abortions (Code of Ethics). “The NSGC, as an organization, publicly supports a woman’s right to reproductive freedom, including her right to prenatal diagnosis and access to safe and legal abortion” (Code of Ethics). This safeguard necessarily implies that genetic counseling must be nondirective, presenting all...
needed information, correct risk assessments, and all possible reproductive options with no greater emphasis given to one over another. The NSGC presents genetic counseling as a value neutral, nondirective genetic testing service.

Safeguarding the patient also extends into confidentiality and discrimination. The NSGC holds that the limits of confidentiality are to be set by the patient, as they are to dictate who receives access to their test results. In light of this perception of confidentiality, the NSGC holds that genetic counselors are to work to prevent discrimination in society based on the results of genetic tests.

Overall the NSGC views genetic counseling as a value neutral information service that provides accurate risk assessments and information concerning reproductive options to concerned parents or potential parents. This view is the typical perspective encountered in the literature concerning genetic counseling.

**A Practicing Genetic Counselor**

A practicing genetic counselor offers a somewhat similar view of genetic counseling. She presents genetic counseling as an information-giving process that is often meant to correct the misinformation that people sometimes believe. The overall purpose of genetic counseling is portrayed as providing information in an understandable form so that patients can make informed decisions (Pouncey). Throughout the entire process the idea of patient autonomy is projected.

However, a practicing genetic counselor offers a slightly different perspective on nondirectiveness than the NSGC. Value neutrality is not seen as an easily accomplished ideal, such as it appears in the writings of the NSGC. Rather, the personal beliefs of the genetic counselor make nondirectiveness difficult because all options must be presented despite the moral convictions of the counselor. Some genetic counselors have changed fields rather than deal with this difficulty. However, the longer a counselor is in the field, the easier value
neutrality becomes and direction comes to be seen as hurting the job of genetic counseling (Pouncey). In summation, a practicing genetic counselor educates and gives options, letting the patient make their own decision, despite the moral opinions of the genetic counselor.

**A Secular Ethnographer**

Charles Bosk offers a different perspective in his book *All God’s Mistakes*. He offers a sociological perspective on genetic counseling. Bosk spent almost three years observing the work of genetic counselors in a large, pediatric hospital. Unlike typical genetic counseling programs the genetic counselors in this clinic were all physicians. As physicians “they had an obligation to act, to help the patient; but to satisfy this obligation, they had to refrain from taking charge of decision making. They had to act, but not decisively” (Bosk 27). This served as a point of tension for the physicians acting as genetic counselors.

In general Bosk views genetic counseling as a nondirective, information service. However, the major difference from the other perspectives is that he views nondirectiveness as grounds for patient abandonment. He writes, “Genetic counseling as a service is generally a matter of transferring information to individuals who request it, and then leaving those individuals alone to make the tragic choices based on that information. This concern for individual privacy is an important part of the work ideology of genetic counselors” (Bosk intro. xix). Patient autonomy is seen as an important part of genetic counseling. However, it is also seen as leading to patient abandonment (Bosk 158) because physicians offer moral advice only in the form of impersonal risk assessments (Bosk 152). Genetic counseling abandons parents and leaves them to make whatever decision they will, with little support, under the concept of nondirectiveness.
Abortion is seen as the primary method of making genetic counseling useful. “For while genetic counseling does not remedy many problems, it does, through therapeutic abortions, save some individuals from the burdens and pains of raising offspring with devastating and overwhelming problems” (Bosk intro. xxiv). Thus, genetic counseling is seen as only relieving potential pain or anxiety but not as curing any real problems.

Lastly, the most fearful element of genetic counseling is viewed as its unobjectionable, ordinariness. Genetic counseling is used every day and is applied in many situations. Yet it is never challenged and rarely questioned.

“The mapping of the human genome, the prenatal screening of fetuses for genetic fitness, the therapeutic manipulation of our genetic make-up—all of these are audacious exercises…I cannot tell which is the greater hubris, that we try to do all these things, that we do them with so few second thoughts, or that we do them despite the magnitude of second thoughts” (Bosk intro. xviii). Genetic counseling is seen as the ordinary vehicle for these actions. Bosk’s perspective challenges this everydayness of genetic counseling and the use of genetics.

**The Catholic Church**

In 1973 the Catholic Church founded the Pope John XXIII Medical-Moral Research and Education Center “to provide the Church with carefully documented research studies dealing with the long-range ethical implications of modern medicine and their significance in relation to biotechnological advances” (Pope John XXIII Center preface xv). This center published a set of documents in 1980 that deals with the issue of genetic counseling and genetic testing. Essays contained in this work were written by the Task Force on Genetic Diagnosis and Counseling, and conclusions have been decided based on their “compatibility with the teaching of the Church’s Magisterium as judged by the editors” (Pope John XXIII Center preface xvi).

The Catholic Church, through this publication, has issued a perspective on genetic counseling and has addressed many of the issues brought forward in this paper. Abortion was by
far the issue addressed most strongly, and this issue is also tied to the issue of contraception in the Catholic Church. Contraception, sterilization as a method of contraception, and abortion are held to be inappropriate and immoral in all circumstances. In this light the issue of abortion ceases to concern when abortion is appropriate but begins to concern how a counselor deals with a patient when one or the other or both hold this belief. Furthermore, it causes already existing tensions concerning the moral beliefs of the counselor and patient to be amplified (Pope John XXIII Center 51).

Given the belief that abortion is wrong and the tensions that it amplifies, the other major attribute of the Catholic Church’s perspective is its treatment of nondirectiveness. This issue is two-fold. It first concerns the counselor and what information and options they must present to their patients in counseling settings. In the counseling setting the Catholic Church finds a place for information and moral counseling.

“Respect for the moral autonomy of the client and for the primary responsibility of individuals to make their own decisions in matters of reproduction would seem to require that the counselor answer any questions straightforwardly and in a manner comprehensible to the client. Thus, it would appear that the counselor has a moral (and legal) responsibility to discuss, but not promote, even immoral alternatives (e.g., the use of contraception or abortion) with his client if they bear any reasonable relationship to the client’s purposes and goals” (Pope John XXIII Center 135).

It is seen that in the Church’s perspective it is important to give all possible options, despite the moral beliefs of the counselor. However, “to provide only this type of data is to render only a partial service” (Pope John XXIII Center 137). In this way genetic counseling is seen as incomplete if it is viewed as no more than a neutral information service.

The other aspect of genetic counseling, moral counseling, composes the second half of the issue of nondirectiveness. The issue concerns the counselor’s responsibility as a member of the Catholic Church and their moral and spiritual obligations as a follower of Christ. As a
follower of Christ and a member of the Catholic Church, a Catholic genetic counselor has an obligation to present their values to their patients and guide them with moral counseling. To “discuss alternatives without presenting the counselor’s values and even once raising moral questions is hardly consistent with the responsibility to impress the divine law on the affairs of the secular city” (Pope John XXIII Center 136). However, the job of the genetic counselor is not seen as compelling patients to make a certain decision, but the responsibilities of a Christian in the genetic counseling profession will not be carried out if they merely conduct themselves as information bearers (Pope John XXIII Center 137).

Overall the Catholic Church holds that abortion, sterilization, and contraception are immoral, even when they can be used by parents facing children with genetic disorders. In light of this belief they hold that genetic counselors are not non-directive information givers that merely present all the options for patients to make their choice. Genetic counselors have a duty to provide moral counseling so that the patient can find a decision that follows the will of God. Although counselors can not make the ultimate decision for parents, leaving moral values out of the counseling session does not fulfill the Christian responsibilities of the counselor.

**Redemptive Genetic Counseling
Is it Possible?**

Given the contemporary societal view of genetic counseling as presented by the National Society of Genetic Counselors and a practicing genetic counselor it initially seems as though a Christian, redemptive model for genetic counseling would not be possible. As described above, genetic counseling becomes closely intertwined with a safeguard of parental choice and rights as regards all reproductive decisions. The rights of the unborn child seldom, if ever, enter into the discussion. Value neutrality is heralded as the pinnacle of counseling skills, and therapeutic
abortions for the reason of ending genetic disorders are supported. Obviously, there are many ways in which a Christian could object to this model of genetic counseling.

The key to determining whether or not a Christian model of genetic counseling is possible is deciding whether or not genetic counseling must necessarily take this form. In other words, are there core items that define genetic counseling that do not necessarily imply these features? If there are defining points of genetic counseling that could be practiced under a different model or framework, then a Christian model could be proposed. For the field of genetic counseling there are defining points that can be shaped by a greater model and framework, such that a Christian model could be proposed.

At the very center of genetic counseling is the ability to develop and use tests for genetic disorders. The field of genetic counseling could not exist without these tests, which makes their existence crucial to developing a foundation for genetic counseling. By themselves the tests are value neutral. However, a counselor or patient who necessarily holds to values and a belief system must use the test results. It is this use of genetic test results that involves differing purposes and models. Thus, before value judgements are placed upon test results, they serve as a defining factor for any genetic counseling model.

In addition to tests and test results, a person skilled in the meaning of these test results is central to genetic counseling. However, this directly introduces the issue of nondirectiveness. A counselor who is responsible for interpreting test results cannot be completely value neutral when giving the interpretation of the results to patients. At this point each model of genetic counseling must differ. In each framework the genetic counselor will hold to a slightly different set of beliefs and those beliefs will enter into the counseling sessions to different extents. A Christian model of genetic counseling must include Christian genetic counselors, for example,
and their values on abortion will enter into a discussion of reproductive options to a greater or lesser extent. Thus, the presence of someone skilled in interpreting test results is central to genetic counseling, but how they involve their personal beliefs will differ between models.

Along these same lines, an exchange of information is necessary for genetic counseling. Thorough information concerning patients’ family histories and genetic conditions in question must be provided. Likewise, a counselor is responsible for giving exact information regarding a genetic condition, such as inheritance, symptoms, onset, and treatments. Also, they must provide information concerning the probability of a couple giving birth to an affected child based on family histories and genetic tests. However, just as values and beliefs are integral to the identity of a counselor, so the method of information exchange inherently contains values. To some extent counselors will present their beliefs. It may be subtle, in an attempt to remain non-directive, or it may be blatant in an attempt to manipulate a patient’s decision. Each different model of genetic counseling will involve the voicing of values to some extent.

Also central to genetic counseling is the realization that the parent makes the ultimate reproductive decision. Genetic counseling must remain a type of counseling and place the final responsibility for decision making in the hands of the patient. If this decision-making capacity is removed from the hands of the patient, then the genetic counselor has control over who lives, dies, or is never born. It takes on the form of genocide rather than counseling, where people are chosen based on an established set of characteristics. Thus, every model of genetic counseling must affirm the fact that ultimately the patient makes the final decision.

These are all elements that essentially define the core of genetic counseling. Each model of genetic counseling must utilize these factors, because without any one of them genetic counseling would no longer be possible. Through the brief discussion of these factors it is seen
that certain elements of society’s conception of genetic counseling are not necessary to the existence of genetic counseling. For example, a non-directive style is not essential to the definition of genetic counseling, provided that the counseling still affirms the patient’s ability to make the final decision. The elevation of abortion as a cure to genetic disorders is also not necessary for the practice of genetic counseling. At its heart genetic counseling requires genetic tests, a knowledgeable counselor, an exchange of information regarding test results, and an affirmation of the patient’s ability to make the final decision.

It is seen that a Christian model for genetic counseling can be developed based on these basic requirements. Beyond these requirements a Christian model of genetic counseling quickly begins to diverge from the common societal conception. For the purposes of this paper these will be the only two models addressed in an attempt to define and describe a Christian model. The two conceptions of genetic counseling differ in their foundations and purposes. The National Society of Genetic Counselors operates under a model of genetic counseling in which testing is conducted to some extent with the expectation that if an abnormality is found abortion will follow. This model gives into the temptation of “allowing the decision to terminate a pregnancy to become largely one of accountancy, with the expectation that if the projected financial cost is too high, the decision to abort will be administrative and routine” (Cole-Turner and Waters 139). Thus, genetic counseling is used as a means of reducing the abnormalities in the human gene pool and reducing the financial costs of supporting people with those abnormalities.

However, in a Christian model of genetic counseling this attitude must be avoided. The idea that genetic science can be used to test and abort children in order to improve the human gene pool “is an assault upon the dignity of the fetus and the meaning of humanity” (Cole-Turner
and Waters 108). Genetic science and counseling can and should be used to treat and safeguard unborn children from genetic disorders and can be used to prevent the birth of children to parents with high risks of genetic diseases through contraception and sterilization. However, the tendency to devalue persons with genetic disorders must be avoided, because this attitude sinfully denies people the dignity and respect they deserve from being made in the image of God.

Christians are called to avoid sin in order to be found blameless in the eyes of God. However, the world is a fallen place, where unfortunately, it is very difficult to distinguish between the person and the disorder because “the only way to prevent the condition is to prevent the birth of the person with the condition” (Cole-Turner and Waters 138). Even so, it is possible for Christians to live in a redemptive manner, actively pursuing the paths of God in this world while still acknowledging that a broken environment for their actions always exists. Living redemptively involves considering the safety of the unborn child and affirming its integrity, even when the fallen world would rather not accept the child. Thus, in a Christian model of genetic counseling a pro-life philosophy must result to prevent the temptation to therapeutically abort all children carrying any kind of defect that the parent finds undesirable. In this way contemporary genetic counseling begins with a foundation that genetic disorders should be prevented at the expense of unborn children, whereas, a Christian model affirms the integrity of the unborn child and seeks to acknowledge the effects of sin in the world, while always seeking to avoid them.

Building on these foundations the two models have different operational methods. A contemporary model of genetic counseling upholds a non-directive style in which the counselor seeks to allow the patient autonomy in decision making by not providing any value judgements on options. A Christian model could not allow for this abandonment of patients, resulting in
greater turmoil and pain. Christian genetic counseling must provide for moral counseling so that the patient does not feel abandoned and alone in their decision.

Overall, a Christian genetic counseling model is possible by building on the central elements of genetic counseling. This model differs significantly from the contemporary societal conception in foundation and purpose. Where the societal model upholds a non-directive counseling style that offers significant support for therapeutic abortions in an attempt to eliminate unwanted genes, the Christian model upholds the integrity of the unborn child through moral counseling and a pro-life philosophy. The paper now concludes with a discussion of the creed and operational appearance of a genetic counseling clinic that seeks to enact a Christian genetic counseling model.

A Model of a Christian Genetic Counseling Clinic
Its Creed
Each model of genetic counseling is built upon a set of values and beliefs that compose its creed. This set of beliefs serves as the foundation upon which clinics operate. Following is a list of values, which a model of Christian genetic counseling holds to be true and uses as its foundation.

Dignity of man, including children—Central to the Christian faith, and therefore to a genetic counseling model built upon it, is the dignity of all men. Genesis 1:27a says, “So God created man in his own image” (The Holy Bible, NIV) This implies that each man, woman, and child has been created to exhibit qualities of God such as holiness and righteousness. More generally, man is a rational and moral being who exhibits to a limited extent the attributes of God. Exhibition of these traits as they were intended occurred before the Fall of man, meaning after the Fall they are exhibited imperfectly. However, the possession by man of the image of God entitles each person to respect and dignity in the eyes of fellow men.
This dignity extends to children. Christ’s care for children is obvious when He commanded the disciples to let the children come to His side because the kingdom of heaven belonged to them (The Holy Bible, NIV Matthew 19:14). Furthermore, the Psalmist writes of the wondrous ways in which God knew him even before his birth and put him together inside of his mother’s womb (The Holy Bible, NIV Psalm 139:13). Through this it is seen that children are deserving of respect and dignity as well. This belief extends to unborn children as seen in the words of the Psalmist, which implies the necessity of a pro-life philosophy for a Christian genetic counseling clinic. A Christian genetic counseling clinic must be careful to safeguard the dignity of unborn children who could easily be thought of as defective due to genetic disorders that society holds as imperfect. The dignity of man and children makes a pro-life philosophy in which abortion is not treated as a viable option crucial to the operation of a genetic counseling clinic.

*Man rules over creation*—Man was also created to subdue and rule over all of creation, including creatures and all the earth (The Holy Bible, NIV Genesis 1:26, 28). Included in this creation is its genetic composition. The genetic composition of creation was also created and mandated by God, and therefore, it is included in the mandate to rule over all creation. Through this the use of genetics and genetic science can be seen as fulfilling part of the creation mandate. Just as using antibiotics such as penicillin can be seen as fulfilling the creation mandate to subdue creation in order to combat effects of the fall, such as disease, this gives man a foundation for using genetic counseling to help prevent the spread of genetic disease.

However, man is also seen as a steward of creation. Man has not been given the freedom to maliciously or haphazardly use creation for his own devices at any time. Implicit in the creation mandate is the command to care for creation and use it for the will of God, not the will
of men. Genetic counseling finds a basis in the creation mandate to rule over creation, including genetics, but also finds a caution to not use it haphazardly and with little thought for the sole purposes of men.

*Creation is fallen and must be redeemed*—Man’s command to rule over creation led to the fall of creation as a result of the Fall of man. Genesis 3:17b-18 says, “Cursed is the ground because of you; through painful toil you will eat of it all the days of your life. It will produce thorns and thistles for you, and you will eat the plants of the field” (The Holy Bible, NIV). Creation is seen to be directly affected by the Fall of man. Human genetic composition and our manipulation of those genes, as a part of creation, must be included in the Fall. The attributes of human genes on the pre-Fall earth, in the context of genetic diseases, can not be listed with any certainty. Certainly though, a strong case can be made for painful, life-threatening diseases being caused by the Fall, and therefore, not existing in the original creation. If the suffering caused by genetic diseases is a direct result of the Fall of man, Christian genetic counseling clinics have a duty to treat it as such and seek its prevention. However, gene therapy and genetic solutions must not be seen as a perfect remedy to all the problems of disease and without fault in all their applications. Rather, genetic diseases become another result of the fallen creation in need of redemption.

Man is clearly meant to preach the redemption of creation in the final days. Christ commands His disciples to preach the good news to all of creation (The Holy Bible, NIV Mark 16:15). Creation is described as groaning as in the pains of childbirth in anticipation and longing for the final days of redemption (The Holy Bible, NIV Romans 8:22-23). All things in heaven and on earth will be brought under the headship of Christ at the fulfillment of time (The Holy Bible, NIV Ephesians 1:10). Finally, Christ brings peace and reconciliation to all things on earth
through the shedding of His blood (The Holy Bible, NIV Colossians 1:20). Until He returns Christians are called to redeem the earth for Christ.

Due to the effects of the Fall, creation is not currently manifested as God intended it to be. It is permeated with the results of sin. Man’s act of working for the redemption of creation involves trying to reverse these effects, because redemption involves becoming more like something was created to be. In the context of genetic diseases, this involves working to prevent the spread of disease and to find cures for genetic conditions, so that humans can once more be free of the suffering that genetic diseases cause, i.e. as it was in the original creation. For Christian genetic counselors this means claiming the practices of genetic sciences for the purposes of God in creation. A Christian genetic counseling clinic must realize the sinful effects of the Fall upon creation and be committed to making creation be as it was intended to be, namely, free of suffering.

However, perfect redemption in this life is not possible. It is only through the work of Christ that man and creation are ultimately redeemed. Only at the Second Coming of Christ, with the manifestation of the new earth, will creation finally return to its original state (The Holy Bible, NIV Rev. 21: 1-4). Thus, a Christian genetic counseling clinic must work to reverse the effects of sin upon the creation in the context of genetic diseases, while realizing that only through the work of Christ will ultimate redemption occur, and they should appropriately look towards that day with anticipation and joy.

*God as the source of values*—Man is created in the image of God, although until the moment of glorification he is fallen. However, Christians must still find the character and nature of God to be the source of their moral values. “No one is good—except God alone,” reads Mark 10:18 (The Holy Bible, NIV). The creation of man is pronounced as very good by God because
he has been made in the image of God (The Holy Bible, NIV Genesis 1:27, 31). Creation as a work of God is good, as pronounced by God (The Holy Bible, NIV Genesis 1:10, 12, 18, 21, 25, 31). However, creation finds its goodness in the identity of God with goodness as seen in Mark. Thus, no value in creation is seen as independent of the nature and character of God. For example, God describes the nation of Israel by saying, “You are holy to me because I, the Lord, am holy” (The Holy Bible, NIV Leviticus 20:26). The holiness of Israel finds its source in the nature of God’s holiness.

Therefore, Christian genetic counseling must seek God as the source of its moral values. Man cannot ascribe moral value to something apart from the will and nature of God. For example, genetic counseling guards the sacredness of life because God regards human life as His sacred image. A Christian genetic counseling clinic must examine its practices in the light of the character of God and His values. This paper will now conclude with a description of a model for the operation of a Christian genetic counseling clinic.

**Its Operation**

From the beginning it is imperative that Christianity not be separated from the genetic counseling clinic. Christ greatly chastises the Pharisees and teachers of the law because they separate the kingdom of God and their duties as followers of God to things such as justice, mercy, and faithfulness from their daily tasks and duties (The Holy Bible, NIV Matthew 23). Therefore, it is imperative that the work of Christ be directly evident in the operation of a genetic counseling clinic. By applying the above principles and beliefs to the operation of and issues surrounding a clinic this can be accomplished. The best way to approach this description is to briefly describe the treatment and counseling of a patient from the beginning of their encounters.
This format will entail dealing with the issues brought out in this paper and detailing the components unique to a Christian genetic counseling clinic.

Before a patient enters the genetic counseling clinic they must be aware of the pro-life philosophy of the clinic. Therefore, a Christian genetic counseling clinic must not hide its creed in an attempt to draw clients in but must openly advertise its commitment to preserving human life. In this way a patient will not be confused or deluded as to what the clinic believes, but can find the clinic to be a safe haven where abortion will not be assumed or pushed.

Once the patient has entered the clinic a support network must be established. This includes the counseling staff of the clinic first of all. Patients must be treated with dignity and respect in accordance with the belief that they are made in the image of God. One patient’s situation must not be placed above another for any reason and discrimination must not occur, but rather the clinic staff must treat each patient equally and fully. Another vital and unique element in the support network at a Christian genetic counseling clinic is the presence of clergy. Clergy must be seen as aiding the genetic counseling process by providing support and theological counseling for a patient. By having a basic grasp of genetics clergy can help patients to understand and interpret results more carefully (Cole-Turner and Waters 15). Likewise, with the consent of the patient, clergy play a helpful role in the counseling session itself by helping the patient or couple to remember details and later to review them. Also, a pastor could help to ask questions that clarify confusing elements of the testing process or results (Cole-Turner and Waters 34). In this way clergy are seen to provide very helpful support in the process of genetic counseling.

It is not appropriate for a Christian genetic counselor to remain nondirective. It is also not appropriate, however, for a Christian genetic counselor to force courses of action upon
patients despite the strength of the counselor’s feelings. It has already been stated that a Christian genetic counseling clinic cannot support abortion as a viable course of action when unwanted genetic conditions are detected. In light of this a Christian genetic counselor can and should counsel a couple away from abortion and towards other options. The traumatic effects that abortions can cause, especially in the context of fetal anomaly, should be explained. Then an explanation of the Christian commitment to the dignity of man and the integrity of the unborn should follow. In this way the creed of the clinic bears directly upon its operation. One way to support this method is to use the presence of clergy. Clergy can help to more fully explain doctrines of man, creation, the Fall, and redemption, and how reproductive decisions are concerned with these doctrines. By providing another source of directive counseling in the form of clergy the philosophy of the clinic can be further safeguarded. A Catholic model even proposes requiring moral counseling by clergy of all patients (Pope John XXIII Center 148). Thus, a Christian genetic counseling clinic must not uphold nondirectiveness in light of their creed, but must still affirm that final decision-making ability resides with the patient.

Even before the question of nondirectiveness arises, the question of testing must be addressed. Ideally, couples would attend genetic counseling sessions before attempting pregnancy if the need is felt, such as in the case of a family history of a genetic disorder. In this case extensive family histories and pedigree analyses can be used to assess the risk of the couple giving birth to an affected child. The risks can then be weighed and a decision concerning pregnancy can be made, avoiding the issue of abortion. However, many couples or single patients come to the genetic counseling clinic already in the midst of a pregnancy. In this case the decision to test or not arises.
At this point in time there are very few genetic conditions that can be cured or treated. However, when this is the case testing is beneficial and should be performed in order to preserve the life of the child. Also, in the case of some genetic disorders miscarriage is almost inevitable, and genetic testing allows the parents to come to terms with this reality, but the bulk of disorders still have no treatment or decisive symptoms. Many disorders can have a range of symptoms from virtually undetectable to severe, and the expression level can not be determined with a genetic test. In this case the decision to test becomes very difficult. Positive results may be useful for preparing the parents for a child with a genetic disorder, however, many could choose abortion as an easy solution. At a Christian genetic counseling center the clergy play an important role in this decision by providing counseling and support for parents about to make difficult testing decisions. Ultimately, a “theological understanding of human personhood and parenthood is consistent with a cautious and limited use of prenatal genetic technology” (Cole-Turner and Waters 65). Testing should be encouraged when the unborn child can benefit from the results in the form of treatment or knowledge or parental preparation. However, a proper view of subduing and redeeming creation in the form of genetics is not consistent with an attempt to abort all children containing genes held to be undesirable or tainted. This issue is unavoidably cloudy because the decision to test must lie with the patient, and parental motives and decisions can not always be fully known by the counselor at the time of testing.

Contained in the question of testing lies the issues of availability and confidentiality. A proper view of man prevents discrimination in treatment, including testing, on any basis. Thus, a Christian clinic must provide testing to all people equally. Likewise, a Christian genetic counseling clinic must attempt to preserve the confidentiality of results. Discrimination on the basis of test results is not consistent with a proper view of man deserving dignity and respect
because he is in the image of God. Thus, by safeguarding the confidentiality of their patients a clinic will help to prevent improper discrimination by society.

The question of breaking confidentiality for the purposes of alerting family members that are possibly affected is similar to the previous discussion on this issue. A patient must be allowed control over the release of test results, because widespread release begins to allow others to have control over a patient’s life and infringes upon their autonomy. However, in the case where serious harm would come to another family member if results were to be withheld the counselor may break confidentiality. The patient must always be alerted to this fact, preferably before testing occurs.

Once the decision to test has been made the question of abortion quickly arises. It has been clearly stated that a Christian genetic counseling clinic must be openly pro-life, promoting the life and rights of the unborn child. This can often be aided through directive and pastoral counseling as described above that directly encourages a course of action. Thus, in most cases abortion is not supported by the clinic as a viable option. However, a case can be made for abortion in certain situations. Some genetic disorders have nearly one hundred percent miscarriage rate. Others will result in death within a few months or a few years of life in which symptoms severely decrease the child’s quality of life. In these situations, when the quality life is drastically affected some authors make a case for abortion as a way of preventing the child’s and the parents’ pain (Cole-Turner and Waters 135). This decision is a very dangerous one to make because over time the line between conditions making abortion acceptable and those condemning abortions become hard to discern. It would be easy to constantly redefine what determines an undesirable quality of life for each situation. In light of these concerns a Christian genetic counseling clinic is not justified in supporting abortions for any reason. Rather, support
in the form of further counseling can be provided for parents of a child prenataly diagnosed with a fatal genetic disorder.

The last issue raised by the question of abortion is the dehumanization of people with genetic disorders. It is obvious from a Biblical view of man as created in the image of God and as sacred in His sight that all men are of value. This includes every person with a genetic disorder. Christian genetic counseling clinics must be careful to safeguard this aspect. This is done by promoting a pro-life philosophy. It can also be done through actions as simple as referring to people as people, such as by their names, and not by the disorders they express. Labeling people with genetic disorders by referring to them by what disorder they have is a very easy way to dehumanize a patient. Counselors must be careful to safeguard the humanity of a patient both in the clinic and without by promoting a greater knowledge and awareness of people with genetic disorders and concerning the disorders themselves. In this way dehumanization by society can be addressed and overcome. It is crucial that the person be separated from and seen as more than the disorder.

This description covers the basic treatment, issues, and decisions surrounding genetic counseling of a patient in a Christian clinic. The creed of a Christian genetic counseling clinic is visible through its operation and treatment of issues in the field. Ultimately, Christian genetic counseling seeks to reclaim the practice of genetics for the work of Christ in the world by promoting the knowledge of genetic disorders and preventing the dehumanization of people expressing those disorders.

A wealth of questions arise concerning the nature and definition of humanity as a result of the human genome project and its recent accompanying wealth of genetic information. The
The field of genetic counseling is intimately tied to these issues, because it daily deals with questions surrounding the value of human life, both born and unborn. The typical societal presentation of genetic counseling in no way tries to uphold the dignity of the unborn, and can easily lead to dehumanization of people expressing genetic disorders. In response to this aspect of the broken, sinful world, Christians are called to reclaim the practices of genetics for Christ and His work in the world. This involves examining the field of genetic counseling and creating a Christian foundation and model for a genetic counseling clinic.

This paper has performed that function. The field of genetic counseling as it currently exists has been presented. This includes a discussion of central issues and various perspectives on the field. From this springs the argument for the existence of a Christian genetic counseling clinic and a description of the beliefs such a clinic must hold. Out of these beliefs grows a model for the operation of a Christian clinic. By developing and utilizing a Christian model for genetic counseling, Christians are actively participating in the redemption of creation until the final return of Christ. By working within the field of genetic counseling the practice of genetics can be redeemed for God’s purposes in the world.
Works Consulted


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