THE DEVELOPMENT AND VALIDATION OF THE ATTITUDES TOWARD GENETIC PREDICTIVE TESTING QUESTIONNAIRE

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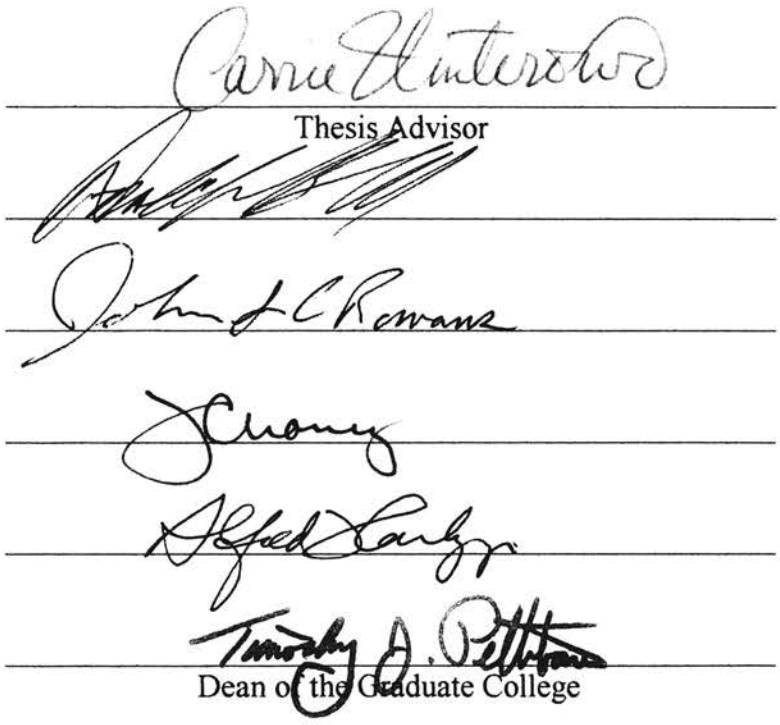

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CHAPTER ONE

INTRODUCTION

Genetic predictive testing gained momentum with the advent of the Human Genome Project (Garver & Garver, 1994). Presently, this project has contributed to our knowledge of single gene disorders such as cystic fibrosis, Duchenne muscular dystrophy, myotonic dystrophy, and Huntington disease. As more single gene disorders are mapped and sequenced, more specific diagnostic tests and treatment strategies will likely become possible (Garver & Garver, 1994). One of the greatest contributions of the Human Genome Project will be an understanding and perhaps even treatment of the multifactorial inherited diseases, such as some forms of cancer, coronary artery disease, hypertension, and diabetes mellitus (Garver & Garver, 1994). The goals of genetic predictive testing and genetic counseling (e.g., learning, understanding, choosing, and coping with regard to genetic disease/disorders), as well as the sensitive nature of the information delivered, clearly indicates a need for psychotherapeutic intervention for some patients seeking these genetic services. In many cases, geneticists and genetic counselors are not trained to deal with the emotional consequences resulting from the genetic predictive testing findings. In fact, there is a current call for psychologists to become involved in genetic counseling (Shiloh, 1996).

Research has primarily focused on attitudes toward genetic predictive testing given a single genetic disorder (e.g., breast cancer, Tay-Sachs disease) rather than on general attitudes toward genetic predictive testing (e.g., Heimler & Zanko, 1995; Lafayette, Abuelo, Passero, & Trantravahi, 1999; Lerman, Audrain & Croyle, 1994; and Meryash, 1992). To date, no robust measure of general attitudes toward genetic

predictive testing has been developed. One of the purposes of this study is to develop a measure of general attitudes toward genetic predictive testing. Such a measure could aid physicians, genetic counselors, researchers, as well as psychologists to prepare for the future medical/psychological needs of individuals who are offered genetic testing by understanding their attitudes that may affect genetic predictive testing decisions.

Demographic Characteristics and Attitudes Toward Genetic Predictive Testing

Research on attitudes toward genetic predictive testing as well as studies of actual utilization of genetic testing services show clear differences based on criteria such as ethnicity, socio-economic status (SES), gender, and age. Some studies have addressed the relationship between demographic characteristics of individuals and their attitudes toward genetic predictive testing for specific genetic disorders (Singer, 1991; Sharma, Phadke, & Agarwal, 1994; Cassel, 1997; Davison, Macintyre & Smith, 1994; Rapp, 1993; Brensinger & Laxova, 1995; Lippman, 1994; Press & Browner, 1997; and Becker et al, 1975). In general, research has shown that white individuals demonstrate more favorable attitudes toward genetic testing for specific genetic disorders (e.g., cystic fibrosis, breast cancer) than ethnic minority individuals. However, African American individuals are more likely to want prenatal testing for themselves compared to white individuals (Singer, 1991).

Groups which are better educated and more affluent are likely to be more familiar with the potential benefits of genetic testing/counseling and prenatal testing, and are better able to afford them as compared to groups with less education and from lower socioeconomic backgrounds (Singer, 1991).

With regard to gender, both men and women tend to respond in favor of genetic testing for a single genetic disease/disorder. Men are more likely to respond positively to statements such as "everyone should undergo testing" and "poor people should have an abortion in case of fetal defect" (Singer, 1991). Women are more likely than men to undergo genetic predictive testing as it has become common practice to perform prenatal genetic testing (Lippman, 1994).

Few researchers have explored age differences in attitudes toward genetic predictive testing for a single genetic disease/disorder. It has been demonstrated that participants in younger cohorts are more likely to accept the technology of genetic testing for specific genetic disorders (e.g., cystic fibrosis and breast cancer) and advocate its use for others as compared to participants in older age cohorts (Singer, 1991; Becker et al, 1975).

Although some researchers have explored racial/cultural, gender, SES, and/or age differences in attitudes toward genetic predictive testing for specific genetic diseases/disorders, more research is needed in this area. Unlike other studies that focus primarily on one demographic characteristic, this study will attempt to explore the relationship of a variety of demographic characteristics with general attitudes toward genetic predictive testing.

Health Belief Model

The Health Belief Model (HBM) has been one of the most widely used and researched conceptual frameworks in the health behavior field since its development in the 1950's. The model includes four basic dimensions: perceived susceptibility to illness, anticipated severity of the consequences of illness, beliefs concerning the benefits or

efficacy of a recommended health behavior, and beliefs concerning the cost of or barriers to enacting the health behavior (Rosenstock, 1966). Each of these dimensions can have a significant impact on the likelihood of seeking preventive or remedial interventions for their health and well being. For example, people who believe they are more susceptible to an illness or disease, who anticipate severe health consequences, who believe in the benefits of specific health behaviors, and who perceive fewer barriers to specific health behaviors may be more likely to pursue health behaviors such as self-care practices, preventive interventions and/or screenings for illness/disease.

The HBM has been employed in research investigating a variety of health behaviors including HIV needle risk practices (Falck, Siegal, Wang, & Carlson, 1995), decision making with regard to amniocentesis (French, Kurczynski, Weaver, & Pituch, 1992), mammography usage (Stein, Fox, Murata, & Morisky, 1992; Fischera & Frank, 1994), breast self-examination (Calnan & Rutter, 1986; Millar, 1997; Rutter & Calnan, 1987), Thomas, Fox, Leake, & Roetzheim, 1996), attendance at medical health checks (Norman, 1995) and medication compliance among psychiatric outpatients (Kelly, Mamon & Scott, 1987; Ludwig, Huber, Schmidt, Bender, & Greil, 1990). Critical reviews (Janz & Becker, 1984; Harrison, Mullen, & Green, 1992) have concluded that there is substantial empirical support for the HBM.

To date, only three studies have examined the relationship between the health belief model and genetic predictive testing (Becker, Kaback & Rosenstock, 1975; Hoogewerf, Hislop, Morrison, Burns, & Stizo, 1990; O'Connor & Cappelli, 1999). All three of these studies examined the HBM in relation to one genetic disease/disorder including Tay-Sachs disease, faecal occult blood and Cystic Fibrosis. Two of the studies

supported the use of the HBM in predicting who may be more likely to use genetic predictive testing (Becker, Kaback & Rosenstock, 1975; O'Connor & Cappelli, 1999). In the third study, the researchers were unable to conclude whether health beliefs were related to compliance behavior due to difficulties in the operationalization of the HBM (Hoogewerf et al, 1990). No study to date has investigated the relationship between the HBM and attitudes toward genetic predictive testing in general.

The HBM model may be helpful in understanding attitudes toward genetic predictive testing. The model has been used to research utilization of a number of medical services and provides a conceptual formulation for understanding why individuals do and do not choose to engage in a variety of health related actions based upon the four dimensions of the model (susceptibility, severity, benefits and barriers). Using this model in relation to attitudes toward genetic predictive testing could help medical and psychological service providers better understand individuals' health beliefs that might influence their likelihood to pursue genetic predictive testing in general.

Purposes of the Study

The purposes of this study are to 1) explore the factor structure of the Attitudes Toward Genetic Predictive Testing Questionnaire, and 2) to explore the relationship of demographic variables with general attitudes toward genetic predictive testing.

Significance of Study

This study will attempt to fill a gap in current literature on genetic predictive testing in several ways. First, the development of an adequate measure of attitudes toward genetic predictive testing is necessary because research to date has employed measures which only include a few questions and which tend to be aimed toward genetic

predictive testing for one particular genetic disorder (e.g. breast cancer, cystic fibrosis). The field of genetic predictive testing is rapidly expanding not only in the number of specific genes being located, but also in the number of genetic predictive tests available.

This study will be significant in that general attitudes toward genetic predictive testing will be explored, unlike former studies. An increased understanding of attitudes toward genetic predictive testing and its correlates will educate psychologists and other practitioners who may see clients who are considering genetic predictive testing procedures. This study can aid psychologists' understanding of general attitudes toward genetic predictive testing including individuals' perceptions of the susceptibility of having a genetic disease/disorder, perceived severity of carrying a gene for a genetic disease/disorder, as well as the perceived benefits and barriers of genetic predictive testing. In addition, the findings of this study will hopefully provide medical doctors, genetic counselors, and psychologists with more information about the characteristics of people who might have positive and negative attitudes toward genetic predictive testing. This information will guide these professionals in providing adequate prevention and intervention services to clients.

Research Questions

1) What is the component structure of the Attitudes Toward Genetic Predictive Testing Questionnaire?

2) What is the relationship of demographic variables (e.g. age, race, gender, income level, educational level, number of family medical/psychiatric conditions in the participant's history and the presence or absence of a genetic disease/disorder in the

participant) with the component scores of the Attitudes Toward Genetic Predictive Testing Questionnaire?

3) What is the internal consistency reliability of the Attitudes Toward Genetic Predictive Testing Questionnaire and component scores?

Research Hypotheses

1) It is hypothesized that a significant and meaningful factor structure of the Attitudes Toward Genetic Testing Questionnaire will emerge using a principle components analysis with oblimin rotation.

2) It is hypothesized that certain demographic variables will be significant predictors of attitudes toward genetic predictive testing, component scores, in particular age, race, gender, income level, educational level, number of family medical conditions in the participant's history and the presence or absence of a genetic disease/disorder in the participant. It is predicted that positive attitudes toward genetic predictive testing will be associated with the following demographic characteristics: young, Caucasian, women, from higher educational backgrounds and family income level, who have family histories of medical/psychiatric conditions and who report that they suffer from a genetic disease/disorder.

Assumptions

1) The data collected in this study will be generalizable to the general public.

2) Participants will complete surveys based on their own knowledge and attitudes of genetic predictive testing.

3) Participants will complete surveys in an honest and open manner.

4) Survey research is a valid way to measure attitudes.

5) The instrument will measure the construct it purports to measure.

6) Components of the Attitudes Toward Genetic Predictive Testing Questionnaire will be correlated.

Definition of Terms

Genetic predictive testing: Genetic predictive testing is the study of a group or individual for the purpose of finding an inherited disease (Glanze, Anderson, & Anderson, 1985). Examples of such tests include blood tests (sample of blood drawn for use in genetic analysis) and amniocentesis (removal of less than one ounce of amniotic fluid from a woman's womb using a needle attached to a syringe).

Genetic Counseling: Genetic counseling represents a clinical application of new genetic knowledge. It is defined as a communication process meant to help an individual or family with the following: (1) comprehend their medical diagnosis, (2) understand heredity's contribution to the diagnosis and the risk of recurrence in relatives, (3) review risks and family goals and choose the best option with regard to treatment or reproduction, (4) adjust to a diagnosis of oneself or a family member, and (5) cope with the risk of recurrence of the disorder (Shiloh, 1996).

Genetic disorder: Genetic disorder is defined as any disease or condition that is genetically determined. Also known as inherited disorder or hereditary disorder (Glanze et al., 1985).

Genetic disease: Genetic disease is defined as any disease that is genetically determined (Glanze et al., 1985).

Attitudes toward genetic predictive testing: (1) In the research literature, attitudes toward genetic predictive testing refers to participants' views on issues relating to the

practice of genetic predictive testing for themselves personally. (2) These attitudes were measured by the Attitudes Toward Genetic Predictive Testing Questionnaire developed for use in this study. (3) The items were developed to address the four basic dimensions of the Health Belief Model: perceived susceptibility to having a genetic disorder, perceived severity of developing a genetic disorder, and benefits and risks for pursuing genetic predictive testing.

Health Belief Model (HBM): A model of health behavior initially developed in the 1950's by Rosenstock. The model includes four basic dimensions: susceptibility, severity, benefits and barriers.

Susceptibility: A dimension of the Health Belief Model that refers to an individual's perception of vulnerability to an illness. Susceptibility includes acceptance of a diagnosis as well as perceived risk of illness in general. This study investigated participants' perceptions of vulnerability to genetic disease/disorders in general.

Severity: A dimension of the Health Belief Model which refers to an individual's perception of the seriousness of contracting an illness, including the medical (e.g., death, disability, and pain) as well as the social (e.g., effects on work, family life and social relations) effects. This study investigated participants' perceptions of the seriousness of developing a genetic disease/disorder and his/her perceptions of the medical and social consequences of developing a genetic disease/disorder.

Benefits: A dimension of the Health Belief Model which refers to an individual's perception or belief that a medical treatment or procedure will reduce the disease threat or that the health action is "potentially efficacious" (Stretcher, Champion & Rosenstock,

1997, p. 74). This study investigated participants' perceptions of the benefits of genetic predictive testing.

Barriers: A dimension of the Health Belief Model that refers to an individual's perceptions of the potential negative aspects of a particular health action. The barriers may interfere with an individual's willingness to participate in a health action. This study investigated participants' perceptions of the barriers to seeking genetic predictive testing.

Demographic Variables: The following demographic characteristics were studied: age, race, sex, income level, educational level, family history of medical conditions, and presence/absence of a gene for a genetic disease/disorder.

Age: Age refers to the current age of the participant. Age was measured by a self-report item on the Demographic Questionnaire.

Race: Race refers to the racial group from which a participant originates. Race was be measured by a self-report item on the Demographic Questionnaire which included the following categories: African American/Black, American Indian/Native American, Asian/Asian American, Caucasian, Hispanic/Latino(a) and Other.

Sex: Sex refers to whether the participant is male or female. Sex was measured by a self-report item on the Demographic Questionnaire.

Income level: Participants' income level was measured by one item on the Demographic Questionnaire. They were asked to report their annual family income level given the income range options provided (e.g., less then $10,000/year, $10,001-15,000/year).

Educational level: Participants' educational level was measured by one item on the Demographic Questionnaire. They were asked to report the total number of years of education they have completed (e.g., 12=completed high school, 13=1 year of college).

Family history of medical conditions: Family history refers to whether a participant has a history of medical or psychiatric conditions in his/her family background (e.g., breast cancer, heart disease, Alzheimer's Disease). Family history of medical/psychiatric conditions was measured by a self-report item on the Demographic Questionnaire and scored according to number of conditions reported by the participant.

Gene: Gene refers to whether a participant has knowledge that he/she carries the gene for a genetic disease/disorder. Gene was measured by a self-report item on the Demographic Questionnaire. They were asked to respond "yes" or "no".

CHAPTER TWO

History of Genetic Predictive Testing

The first use of genetic knowledge can be traced to the 7th century BC. During this time, the Babylonian soothsayers used the birth of children with congenital malformations to counsel the nation about its future (Neel, 1973). The concept of heredity is also clearly stated in various books of the Bible. During Biblical times, the concept that "both the good and bad characteristics of an individual are in large part a biologic legacy from his ancestors was perhaps then more explicitly accepted than it is now" (Reed, 1980, p. 1). In fact, throughout history, it has been accepted in nearly every culture that some traits are familial and that children frequently show the same deficits as some of their relatives (Reed, 1974). Genetic predictive testing, has to some degree been practiced since the development of language (Reed, 1949).

Genetic predictive testing was developed in order to identify people who are at risk for genetic disorders. In past centuries, the inheritance of a genetic disorder depended upon the general cultural concepts of heredity. It was the discovery of Mendel's laws that put the discipline of heredity on an acceptable scientific basis (Reed, 1974). Mendel's classic studies of the garden pea demonstrated that an inherited trait could not be recognized unless one or more alternate forms of that particular trait are present (Cann, 1968). Mendel (1865) writes that:

> there appear among the differentiating characters at the same time dominant characters, which are transmitted entirely or nearly unchanged to the hybrids, then in terms of the developmental series that one of the two original parents which

possesses the majority of dominant characters must always be predominant (p. 34).

Mendel's principles of heredity were important to genetic predictive testing for two reasons. First, the principles showed us the precise rules of how heredity works (Reed, 1980). Also, it became possible to assign precise probabilities to hereditary situations (Neel, 1973).

Although genetic predictive testing could not have developed without the help of Gregor Mendel, it seems as though Sir Francis Galton played a larger role in its creation. Galton was the first to study, in an adequate way, the contributions of heredity and environment in the development of human traits (Reed, 1974). He compared identical and fraternal twins without the insight of Mendel's laws; however, he arrived at a reasonable concept of the fundamental basis of heredity in the development of human behavior. Galton tended to overestimate the importance of heredity which reflected the attitudes of the Victorian era regarding race and class (Reed, 1974). Galton was primarily concerned with the eugenics movement – from which genetic counseling evolved. This affiliation is apparent in the first publication of Sir Francis Galton in 1865.

The term "eugenics" was first used in 1883 by Francis Galton (Galton, 1865). He defined it as "the study of the agencies under social control that may improve or impair the racial qualities of future generations, either physically or mentally" (p. 319). Garver & Garver (1994) state that a more recent definition would be "the science that deals with all influences that improve the inborn quality of the human race, particularly through the control of hereditary factors" (p. 1109).

One of the earliest eugenicists, not a professional geneticist, was a physician by the name of Charles F. Dight. Dight's work and interest centered on the application of Mendel's laws of heredity to the welfare of mankind (Reed, 1980). Dr. Dight realized that practically every family had problems resulting from their particular heredity and that many of the problems could be solved if there were a center where the family could get the facts about human genetics. This idea caught the attention of others, and well over 3,500 families or individuals have received education and consequent understanding of problems due to their heredity at the Dight Institute for Human Genetics of the University of Minnesota (Reed, 1980).

During the 1940's, a new profession began to emerge from the growing amount of genetic predictive testing being conducted. It became necessary to train professionals who could relay genetic predictive testing results to individuals and families. These professionals became known as genetic counselors. Originally based in research biology and genetics, the first genetic counselors provided information rather than counseling (Eunpu, 1997). The majority of those practicing genetic counseling were nonphysicians, mostly biologists (Eunpu, 1997).

Having no generally accepted name, at the time the sharing of genetic information to individuals and families was called genetic hygiene, genetic consultation, and/or genetic advice (Reed, 1974). This "genetic advice" was to be delivered in a neutral manner and had become linked to the eugenic movement in many minds (Wolff & Jung, 1995). On December 2, 1947, in an effort to distinguish genetic predictive testing from a movement toward a perfect race, Reed introduced the expression "genetic counseling" to the Dight Institute Advisory Committee (Reed, 1974). Genetic counseling was viewed as

a kind of "genetic social work" and Sheldon Reed hoped to expand genetic counseling to include the psychosocial aspects and envisioned genetic counseling to be a separate branch of medicine (Wolff & Jung, 1995).

The term was changed from "Counseling" to "Medical" in 1955 to soothe the physicians working in the genetic field. This change was anticipated in the Dight Institute Bulletin Number 6 from the following quotation: "The function of a counselor in human genetics has been inherited mainly by the physician, which is as it should be, for the problems are very often medical as well as genetic" (Reed, 1949, p. 8).

The field of counseling genetics continued to grow over the next few years. The Dight Institute Bulletin Number 7 listed ten genetic counseling centers in the United States. One such center was located in Norman, Oklahoma (Reed, 1951). Others were located in California, Utah, Texas, Minnesota, Michigan, Ohio, North Carolina, and New York (Reed, 1951).

In 1959, an important discovery was made by Lejeune and associates (Reed, 1974). These researchers found that children with Down's Syndrome had three members of the 21st pair of chromosomes. This was the event that finally brought human genetics to the attention of ordinary physicians (Reed, 1974). Also in 1959, L. R. Dice wrote a book entitled Hereditary Counseling which was prophetic for its time. Dice wrote:

> Human heredity actually is a phase of public health. The heredity of the population should be of at least as much concern to each commonwealth as are infectious diseases. I look forward to the time when heredity counseling will be available in every large center of the population. Such a development, however, is

not likely to be achieved in the near future (p. 63).

Books by Haldane (1954) and Harris (1959) on human biochemistry were also of great significance for genetic counseling. These texts revealed that the practice of biochemical techniques rest upon the detection of persons who carry a recessive gene in a concealed state and in the detection of homozygous conditions before and after birth (Reed, 1974).

Genetic predictive testing/counseling gained momentum again in the 1960's and 1970's with the advent of the prenatal diagnosis of chromosomal and metabolic diseases early in pregnancy, coupled with the possibility of selective abortion (Neel, 1973). At that time, genetic counseling gained attention in the medical realm, and was almost exclusively offered through academic medical centers (Eunpu, 1997). Genetic counselors became concerned with not only providing medical or genetic information, but also with caring for the family seeking information.

The first master's level genetic counseling program was established at Sarah Lawrence College in 1969. Seventeen other master's programs followed by 1989 (Burke & Kolker, 1994). Genetic counseling was defined broadly as " a communication process which deals with human problems associated with a genetic disorder" (Eunpu, 1997, p. 2). Furthermore, Reed (1974) stated that genetic counseling should be:

> (a) a social service carried out entirely for the benefit of the family involved, (b) consultation should be free of charge so there is no financial barrier, and (c) its availability should be universal (p. 337).

A history of the genetic predictive testing/counseling movement would be incomplete without a mention of the Human Genome Project. Watson (1990) wrote "the

possibility of knowing our complete set of genetic instructions seemed an undreamable scientific objective in 1953 when Francis Crick and I found the double helical structure of DNA" (p. 44). The first serious proposal to start sequencing the human genome occurred at a meeting held in May 1985. Robert Sinsheimer, then chancellor the University of California at Santa Cruz, brought together a small group of scientists with the hope that the project might be taken seriously (Watson, 1990). One member of that group, Renato Dulbecco, sensed the challenge and proposed the movement in 1986 in an editorial in Science. He suggested that the fundamental problem of cancer could be studied by determining the sequence of the entire human genome (Green & Waterston, 1991).

The Human Genome Project became a worldwide effort that included scientists from the United States, Canada, Great Britain, Europe, Russia, and Japan. The goal was to map and sequence all of the estimated 3 billion bp that make up the human genome. The project hoped to yield information on the entire DNA contained in a human being, not only of the protein coding genes (exons) but also the genetic material between these genes (introns). In June 2000, the scientists involved in the Human Genome Project announced the virtual completion of the sequencing of the human genome (Hamel, 2001). The estimated cost of this project was $3 billion (Garver & Garver, 1994).

Presently, this project has contributed to our knowledge of single gene disorders such as cystic fibrosis, Duchenne muscular dystrophy, myotonic dystrophy, and Huntington disease (Garver & Garver, 1994). As more single gene disorders are mapped and sequenced, more specific diagnostic tests and treatment strategies will likely become possible. One of the greatest contributions of the Human Genome Project will be an understanding and perhaps even treatment of the multifactorial inherited diseases, such as

some forms of cancer, coronary artery disease, hypertension, and diabetes mellitus (Garver & Garver, 1994). Thus, society at large could benefit from the knowledge produced by the Project regarding some of the serious genetically based diseases that are currently present in our society. Hoffman (1994) writes that "the day of the personal DNA profile provided at birth, complete with calculated risks of various cancers (e.g., breast or colon), heart disease, alcoholism, and many other conditions, could be an actuality" (p. 130). Thus, the potential impact of the Human Genome Project on length and quality of life and on health care is tremendous.

The Human Genome Project has had an enormous impact on the field of genetic predictive testing. Since the advent of the Human Genome Project, the field of genetic testing and counseling has gained incredible momentum. Genetic predictive tests are currently available for a number of genetic diseases, such as breast cancer. Furthermore, by the year 2010, it is expected that genetic predictive tests will be available for dozens of common conditions such as colon cancer (Collins & McKusick, 2001). These new genetic predictive tests will allow individuals to seek targeted preventive efforts and may prevent premature deaths. By 2020, it is predicted that every category of cancer tumor will have an identified molecular fingerprint, allowing for targeted and individualized treatment of specific forms of cancer (Collins & McKusick, 2001).

Although genetics is still considered within the medical realm of services, the genetic counselor refrains from recommending a course of action unlike most medical counseling. Therefore, the decision and the responsibility for the outcome fall to the counselee. This attitude represents the historical development of genetic counseling, shifting away from eugenics toward a client-oriented paradigm (Shiloh, 1996).

Furthermore, we now know that many chronic diseases such as diabetes, cancer, hypertension, and schizophrenia have a genetic component. Also, advances in genetic diagnostic technologies are dramatically expanding the possibilities for genetic screening and prenatal diagnosis. At one time, pregnancies were assumed to be normal until proven otherwise. Today, pregnancies are increasingly becoming viewed as risky and fraught with abnormalities until potential defects are ruled out by genetic tests (Shiloh, 1996).

Despite the fact that the goals of genetic predictive testing and genetic counseling as well as the sensitive nature of the information delivered clearly indicates a need for psychotherapeutic intervention; there has been much hesitancy on the part of genetic counselors to deliver such services. In a recent survey of members of the National Society of Genetic Counselors, only 79 of 1346 members identified an interest in psychotherapy (Eunpu, 1997). It is for this reason that there is a current call for psychologists to become involved in genetic counseling (Shiloh, 1996). Interdisciplinary training is now available in an attempt to promote collaborative relationships between genetic counselors, psychotherapists and physicians in providing psychosocial services for families with genetic conditions (Peters, Djurdjinovic & Baker, 1999). Even Reed wrote in 1968 that a genetic counselor must "have the qualities of sympathy, compassion and willingness to listen to the client" (p. 105). These qualities seem to be attributes of a humanistic psychotherapist.

Controversy

The field of genetic predictive testing is not without controversy. In many cases, the development of genetic capability has exceeded lawmakers and the general public's ability to prepare. In some cases, clients are receiving news of carrying sometimes

terminal diseases, yet treatment is not the focus and many times not even possible. With today's genetic testing capability, clients can be tested and informed of carrying diseases years before any symptomology is present (Sharma, Phadke & Agarwal, 1994). This leads some consumers to wonder whether genetic predictive testing is helpful. Geneticists argue that such information is helpful as, with informed consent, diagnosed individuals may enter experimental treatment trials. A good example of such a genetic diagnosis is Alzheimer's Disease. A client can now be informed that he/she carries the gene for the disease, there is no treatment available, and they can not be told with certainty whether or not they will develop the disease because other factors must also be present (Collins & McKusick, 2001).

Genetic predictive testing deals with human problems associated with the occurrence or risk of a genetic disease/disorder in a family, not with the disease/disorder itself. Often, curing the disease is not the goal of genetic predictive testing, and treatment or prevention may not be possible (Shiloh, 1996). In fact, genetic counselors' goals are learning, understanding, choosing and coping (Shiloh, 1996).

Genetic testing developed from the eugenic movement. It has been argued that geneticists utilize negative eugenics or the prevention or treatment of disease. However, others argue that genetic testing will likely lead to positive eugenics or working toward improving the race. It is this argument that has led to much of the public fear surrounding genetic predictive testing.

Liability is also becoming an issue in genetic predictive testing, especially with regard to prenatal diagnoses. In an article by Schroeder (1991), she points out that parents who give birth to a deformed child who had tested negative for such deformities

are now filing "wrongful birth" suits against geneticists and genetic counselors. The parents are not claiming that the physician or counselor caused the deformity, but rather their lack of advice or information precluded any parental decision regarding the birth of the child .

Another concern relating to prenatal diagnosis is that of testing children or minors. Essentially, genetic testing conducted on a fetus is done without his/her consent. If the child is carried to term, he/she may have a diagnosis for which symptoms will not occur for years, if ever (Bird & Bennett, 1995). What will be the consequences on these individuals who live their entire lives just waiting to become ill? If the parents withhold the medical diagnosis from the child to spare them harm, this brings new meaning to "family secrets". Today, most centers will not perform genetic predictive tests for adult-onset diseases/disorders on asymptomatic children prior to the age of 18 (legal adulthood) (Bird & Bennett, 1995).

A fundamental controversy with regard to genetic counseling is that the information on heredity and risk is largely probabilistic (Shiloh, 1996). Thus, individuals, couples, and families are faced with emotional reactions such as grief and anxiety based upon probability of developing a disease/disorder.

An equally controversial issue in genetic predictive testing is whether to fully disclose test results to clients. There are many genetic predictive tests available today that can produce by-products or reveal diagnoses in addition to the individual being tested. The question lies in whether physicians should reveal all findings to the client (even if psychologically harmful) or only reveal the results of the test they were given

consent to conduct. In the United States, physicians have made it common practice to reveal all results in order to avoid lawsuits (Wertz, 1992).

Many genetic predictive test results also identify relatives who are at risk or are carriers for a genetic disease/disorder. This raises the issue of disclosure to relatives at genetic risk. Should confidentiality be maintained in all cases, or is there a duty to warn relatives in harms way? In one sense, genetic diseases/disorders could be considered infectious diseases in that they can be transmitted to other generations. Thus, physicians face a dilemma between the duty to maintain client confidentiality and the duty to warn third parties of potential harm. There is currently no consensus among health care professionals with regard to this dilemma (Wertz, 1992). A study by Benkendorf, Callanan, Grobstein, Schmerler, & Fitzgerald (1994) illustrates this dilemma with a case example of an individual with Fragile-X Syndrome. The woman wishes to determine which of her parents was a carrier in order to alert the appropriate relatives about the potential genetic risk and the availability of genetic predictive testing. However, she does not want to inform the parents involved as they are in their 80's and the news would likely cause distress and guilt. Should the procedure be conducted without the knowledge or consent of the parents being tested (Meryash, 1992)? An article by Evers-Kiebooms (1995) also illustrates this point. If an asymptomatic grandchild undergoes genetic predictive testing and receives news that he or she is a carrier of the gene for a genetic disease/disorder, he/she has automatically and inadvertently also established the intervening parent as a carrier of the genetic disease/disorder.

Probably the largest controversy relating to genetic predictive testing involves the privacy of genetic information from employers and insurers. It is now possible to see an

individual's genotype (molecular genetic make-up) independently of the phenotype (visible characteristics). Thus, new genetics reveal asymptomatic conditions that may remain forever asymptomatic or that may manifest themselves in mid-life or in old age. The new genetic predictive testing capabilities also reveal susceptibilities or risks for developing common diseases such as breast cancer or diabetes. These are risks, not certainties. At this time, insurance companies in the United States continue to regard genetic information in the same category as other types of medical information that insurers may legally require as a condition of insurance. A few health insurers in the United States presently use genetic predictive testing or plan to use it in the future in making coverage and rate decisions. Insurance companies routinely request medical records before coverage is granted, and genetic predictive testing (if conducted) is part of an individual's medical record (Wertz, 1992). Thus, in the future this disclosure of genetic information may lead to genetic discrimination. That is, there is a legitimate concern that individuals who test positive for a gene linked to genetic disease/disorder could be denied health, life, or disability insurance as well as employment opportunities. The fear is substantiated as genetic disorders could fall in the "preexisting condition" clause of insurance applications (Bird & Bennett, 1995). According to Roy, Johnson, Breese, & Hagerman (1995), Colorado is currently the only state to have passed a law (Senate Bill 58) to protect families from genetic discrimination by limiting the transmission of information regarding genetic diagnoses to insurance companies.

Individuals in prisons, courts of law, and military services are often required to undergo genetic predictive testing for various reasons (Bird & Bennett, 1995). This raises the question of informed consent. Geneticists in most nations believe that genetic

predictive testing should be voluntary rather than mandatory (Wertz, 1992). The President's Commission argued that the only use of mandatory screening should be for newborns, "if early diagnosis and early treatment directly benefited the newborn" (Wertz, 1992, p. 501). However, should mandatory screening be used in cases where partial treatment is available such as with sickle cell anemia and cystic fibrosis (Wertz, 1992)?

One final controversy in genetic predictive testing is with regard to the emotional and psychological consequences of such information. To date, it seems that society has not prepared itself for the emotional backlash that could arise from mass genetic predictive testing. Mental health professionals should prepare for treating individuals, couples and families who have undergone genetic predictive testing.

Demographic Characteristics Associated with Attitudes Toward Genetic Predictive Testing and Utilization of Such Services

Understanding the historical context of genetic predictive testing is important as it demonstrates the rapid growth of such testing. To date, the research has primarily focused on demographic characteristics toward genetic predictive testing given a single genetic disorder (e.g., breast cancer, Tay-Sachs disease) rather than on demographic characteristics with regard to general attitudes toward genetic predictive testing. However, studies of attitudes toward such testing as well as studies of actual utilization of genetic testing services show clear differences based on criteria such as ethnicity, socio-economic status (SES), gender, and age. These differences could have a powerful impact as mass screening programs for genetic diseases appears likely in the near future (Becker et al, 1975). These studies will be discussed by the significant demographic variables or

groups previously associated with utilization and/or attitudes toward genetic predictive testing.

Race/Culture. In general, white individuals demonstrate more favorable attitudes toward genetic testing in general when compared to other racial groups. However, African-Americans are more likely to desire prenatal testing for themselves as compared to Whites (Singer, 1991). Previous studies have also demonstrated race/culture differences in attitudes toward abortion when a fetal abnormality is detected using genetic predictive testing. White males are somewhat more likely than African-American men to want their partner to have an abortion in case of fetal defect. However, African-American women are much more likely than white women to want an abortion for themselves (Singer, 1991). African-Americans are also more likely to respond positively to the statement "everyone whose test indicates the presence of a fetal defect should undergo an abortion" when compared to white individuals (Singer, 1991, p. 240).

In some cultures, genetic testing results could have lasting negative effects. For example, abnormal genetic information can be grounds for divorce or second marriage in middle eastern cultures. Thus, the information obtained from the genetic testing can be used to victimize the female partner (Sharma, Phadke, & Agarwal, 1994).

Differences also exist in the individual's reason for submitting to genetic predictive testing based upon their culture. For example, in some countries (e.g., India) female children are not typically wanted or valued. In fact, prenatal diagnosis is being widely used in India as a sex-selection technique, resulting in selective abortion of female fetuses (Cassel, 1997). There is currently no law in the United States against this practice.

Jewish communities have large numbers of individuals with Tay-Sachs disease. Arranged marriages are commonplace amongst some Ashkenazy Jewish communities in the United States. Therefore, when a member of a family tests positive for Tay-Sachs disease, their entire family may be stigmatized as having "tainted blood" (Davison, Macintyre & Smith, 1994). This stigmatization may range from difficulty in finding partners with whom to arrange marriages to being shunned by one's community (Davison et al, 1994). It is easy to understand why some Jewish individuals would be hesitant to submit to genetic testing.

A study by Brensinger & Laxova (1995) found that the majority of the Amish families they interviewed were never offered genetic services. This may have been due to preconceived ideas by the physicians that the women would deny genetic testing or that it would not affect their reproductive decisions. The researchers found that the Amish families were interested in understanding the cause of their children's problems and recurrence risks.

Socio-Economic Status. Equal access to services is another problem in the field of genetic predictive testing. Almost everywhere, even in countries with national health insurance, people with more education and higher SES are more likely than others to take advantage of genetic services. Groups which are better educated and more affluent are likely to be more familiar with the potential benefits of genetic counseling and prenatal testing, as well as better able to afford them compared to groups with less education and of lower socioeconomic status (Singer, 1991). Poor women might be denied access to genetic technologies, resulting in more low-income women with children having a variety

of genetic diseases than women who are not poor and who do have the option of genetic diagnosis and treatment (Cassel, 1997).

Currently, there is a movement to reach underserved populations. For instance, the Prenatal Diagnosis Laboratory (PDL) was set up by the Health Department of New York City in 1978 to provide outreach to the urban poor. This is the largest cytogenetics lab attached to a public health facility in the United States. The center analyzes amniotic fluids for 24 hospitals and serves primarily the African-Americans and Hispanics (Rapp, 1993).

Gender. Both men and women tend to respond in favor of genetic testing. However, men are more likely to respond positively to statements such as "everyone should undergo testing" and "poor people should have an abortion in case of fetal defect". Men are also more likely to favor genetic testing for sex selection, but do not respond in favor of aborting fetuses based on their sex (Singer, 1991).

Recently, it has become possible to test women for the BRCA1 gene, a breast cancer susceptibility gene (Lerman, Schwartz, Lin, Hughes, Narod, & Lynch, 1997). In a study conducted by Lerman, et al. (1997), only 58% of subjects requested their BRCA1 test results. This suggests that science has exceeded the curiosity of humans. Tests such as this one may cause undue stress, as other factors must be present for the breast cancer to develop – a gene alone is not sufficient (Lerman, Audrain, & Croyle, 1994). Today, many women who test positive for this gene are opting to have total mastectomies before any symptomology is present.

With regard to genetic predictive testing, women are more likely than men to undergo testing as it has become common practice to perform prenatal genetic testing

(Lippman, 1994). In fact, more than 50% of pregnancies in the United States now undergo some form of screening (Press & Browner, 1997). With this increased knowledge about their pregnancies, women face an increasing pressure to do as much as is technologically possible to ensure the birth of children without genetic disease/disorders (Rothenberg, 1997).

One study (Press and Browner, 1997), demonstrated that women are not properly informed about the potential impact of genetic screening, nor are they given the option to decline. In 1986, the state of California passed a law stating that physicians must offer the maternal serum alpha-fetoprotein test (MSAFP) to all pregnant women. The MSAFP is a genetic predictive test designed to detect neural tube defects and other developmental disabilities. However, their study revealed that nurses would *tell* pregnant women that they would be given two follow-up appointments: one for a diabetes test and one for the MSAFP. Many women interviewed did not even know the purpose of the MSAFP test and certainly did not feel that they could refuse the test. Women typically responded that they thought that the test could somehow ensure their baby's health and that the knowledge gained through such testing should not be refused (Press & Browner, 1997). When genetic testing is perceived by the patient as routine and mandatory or just another blood test, women may be likely to overlook the possibility that the results may require a deliberate patient decision.

Age. Few researchers have explored age differences in attitudes toward genetic testing. Singer (1991), found that participants in younger cohorts were more likely to accept the technology of genetic testing and advocate its use for others as compared to

participants in older age cohorts. In addition, the acceptance of genetic testing was higher among married couples of childbearing age than among single individuals.

Another study also found that younger age cohorts were most likely to participate in genetic predictive testing older age cohorts (Becker et al, 1975). Their study consisted of offering Tay-Sachs disease testing to 1,000 Jewish members of a community. Seventy-five percent of those individuals who consented to be tested were between the ages of 18 and 34.

Summary. More research is needed to better understand how attitudes toward and utilization of genetic predictive testing are related to the demographic characteristics of individuals. Research to date has focused primarily on attitudes toward genetic predictive testing toward a single genetic disorder (e.g., breast cancer or Tay-Sachs disease) rather than on general attitudes toward genetic predictive testing. In addition, few studies have addressed the relationship between demographic variables of individuals and their attitudes toward genetic predictive testing (Singer, 1991; Sharma, Phadke, & Agarwal, 1994; Cassel, 1997; Davison, Macintyre & Smith, 1994; Rapp, 1993; Brensinger & Laxova, 1995; Lippman, 1994, Press & Browner, 1997; and Becker et al, 1975). The research summarized in this review suggests that individuals with positive attitudes toward genetic predictive testing are generally young, Caucasian, from high SES, and have an interest in having children of their own.

Health Belief Model

The Health Belief Model may be useful in understanding attitudes toward genetic predictive testing. This model has been one of the most widely used conceptual frameworks in the health behavior field since its development in the 1950's. The HBM

has been used as a conceptual formulation for understanding why individuals do and do not choose to participate in a wide variety of health related actions. The HBM was initially developed by a group of social psychologists in the U.S. Public Health Service in an attempt to explain the widespread failure of people to participate in programs designed to prevent or detect disease (Rosenstock, 1966). Janz and Becker (1984) point out that while there are many other models of health-related behaviors, none approach the Health Belief Model in terms of research attention and/or corroboration.

The HBM is a value-expectancy theory. Thus, in the context of health-related behavior, the model involves the following: (1) the desire to avoid illness or to get well (value) and (2) the belief that a specific health action available to an individual would prevent (or ameliorate) illness (expectation; Stretcher, Champion, & Rosenstock, 1997). The expectancy portion of the original theory was divided in terms of the individual's estimate of personal susceptibility to and the perceived severity of the illness and the individual's perceived severity of the illness.

Originally, the HBM model included four basic concepts: perceived susceptibility to illness or health breakdown, anticipated severity of the consequences of illness or health breakdown, beliefs concerning the benefits or efficacy of a recommended health behavior and beliefs concerning the cost of or barriers to enacting the health behavior (Rosenstock, 1966). Perceived susceptibility has been defined as "the individual's belief of being vulnerable to an illness or condition" (French et al, 1992, p. 178). Perceived severity has been defined as an individual's "perception of the seriousness of the illness or condition . . . may be influenced by whether or not the concern is permanent or temporary, acute or chronic, or potentially fatal" (French et al, 1992, p. 178). Perceived

benefit has been defined as "the belief by the individual that the prescribed medical treatment or procedure will reduce the severity of occurrence or recurrence of the health situation" (French et al, 1992, p. 178). Perceived barriers have been defined as "costs or negative components, such as pain, expense, or inconvenience, which may interfere with a recommended health activity being undertaken" (French et al, 1992, p. 178). The definition of the constructs of the health belief model was left open to debate at the model's conception (Sheeran & Abraham, 1993). Rosenstock (1974) and Becker, Haefner & Maiman (1975) illustrate how various researchers have operationalized each of the constructs somewhat differently. A meta-analysis of HBM studies concluded that this lack of operational homogeneity continues to weaken the HBM's status as a "coherent psychological model of the prerequisites of health behavior (Harrison, Mullen, & Green, 1992, p. 114). However, despite this lack of homogeneity in the defining the dimensions of the HBM, a series of studies have shown that the various operationalizations allowed identification of beliefs correlated with health behavior (Janz & Becker, 1984).

Hockbaum (1958) included a fifth dimension in his early HBM study (which predates the actual origin of the HBM), namely "cues to action". This dimension refers to factors that instigate action in the patient or participant. These cues may be bodily events (such as a sneeze) or environmental (such as the perception of a media event or perception of a poster). The cue to action dimension has been considered an important addition to the model, but is generally viewed as difficult to study and is therefore not included in most HBM research (Stretcher, Champion & Rosenstock, 1997). Furthermore, the cues to action dimension has not been systematically studied (Stretcher

et al, 1997). An individual's general health motivation or "readiness to be concerned about health matters" has also been included as a dimension of the HBM model (e.g., Becker, Haefner, & Maiman, 1977).

The Health Belief Model views preventive health action as likely to be performed by individuals who (1) feel threatened by a disease (perceive themselves susceptible to the disease and perceive its consequences to be severe and (2) perceive the benefits of preventive health behavior to outweigh the costs or barriers (Rosenstock, 1966). Thus, an individual will likely participate in health preventive behavior to ward off, screen for, or to control ill-health conditions if (1) they perceive themselves as susceptible to the disease/disorder, (2) they believe the disease/disorder will have serious consequences (on health, work, social life, etc.), (3) they believe that a course of action available to them will be beneficial in either reducing their susceptibility to the disease/disorder or will reduce the severity of the disease/disorder and (4) they believe that the benefits of the preventive action outweigh the perceived barriers/costs. Rosenstock (1966) noted, "the combined levels of susceptibility and severity provided the energy or force to act and the perception of benefits (less barriers) provided a preferred path of action" (p. 120).

Rosenstock (1974) attributes the first health belief model (HBM) research to Hochbaum's (1958) studies of the uptake of tuberculosis X-ray screening. In this study, Hockbaum found that perceived susceptibility to tuberculosis and the belief that people with the disease could be asymptomatic (thus, screening could be beneficial) distinguished between patients who had and had not undergone chest X-rays. Later, Haefner and Kirscht (1970) demonstrated that a health education intervention designed to increase participants' perceived susceptibility, perceived severity and anticipated benefits

resulted in a greater number of check-up visits with a doctor as compared to a control group over an eight month period (Stretcher, Champion & Rosenstock, 1997).

"The HBM has received greater research attention and has been applied to a broader range of health behaviors and subject populations than any other social cognitive model (Sheeran & Abraham, 1993, p. 26). Sheeran & Abraham (1993) identified three broad areas of HBM research including (a) preventive health behaviors including both health-promoting (e.g., diet and exercise) and health-risk (e.g., smoking), (b) sick role behaviors (e.g., compliance with recommended medical regimens), and (c) clinic use (e.g., physician visits for a variety of reasons). More specifically, the HBM has been employed in researching health behavior such as HIV needle risk practices among injection drug users (Falck, Siegal, Wang, & Carlson, 1995), decision making regarding amniocentesis in women of advanced maternal age (French, Kurczynski, Weaver, & Pituch, 1992), mammography usage (Stein, Fox, Murata, & Morisky, 1992; Fischera & Frank, 1994), breast self-examination practices (Calnan & Rutter, 1986; Millar, 1997; Rutter & Calnan, 1987; Thomas, Fox, Leake, & Roetzheim, 1996), attendance for prenatal care (Zweig, Lefevre, & Kruse, 1988), attendance at health checks in general practice (Norman, 1995) and medication compliance among psychiatric outpatients (Kelly, Mamon & Scott, 1987; Ludwig, Huber, Schmidt, Bender, & Greil, 1990). Sheeran & Abraham (1993) provide a comprehensive overview of the applications of the HBM in research. In addition, two quantitative reviews of research using the HBM with adults have been published (Janz & Becker, 1984; Harrison, Mullen, & Green, 1992).

Of particular interest to this study is the fact that only three studies have used the HBM in investigating genetic disease. Becker, Kaback and Rosenstock (1975) were the

first investigators to link the HBM with genetic screening. Becker et al. (1975) examined the ability of health beliefs to distinguish participants from nonparticipants in a screening program for Tay-Sachs disease. Perceived susceptibility was measured by the participant's estimate of the likelihood that he/she could carry the gene for Tay-Sachs and transmit this gene to his/her progeny. Perceived severity was interpreted and the participant's view of the potential impact of learning that he/she was a carrier of the disease. Benefits and barriers were measured in terms of a personal evaluation of how much good it would do the potential carrier to be screened for the disease and the potential psychosocial costs of knowing that he/she carried the gene for the disease. The investigators found that more participants than nonparticipants in the screening felt they were susceptible to the illness. The investigators found a negative relationship between perceived severity and participation in the genetic screening. No significant relationships were found with relation to perceived benefits and barrier and participation in the genetic screening.

The second study to link the HBM and genetic disease was conducted in 1990 and examined compliance with genetic screening for faecal occult blood (Hoogewerf et al, 1990). The researchers were unable to conclude whether health beliefs were related to compliance behavior in this study.

More recently, O'Connor & Cappelli (1999) investigated health beliefs and the intent to use predictive genetic testing for cystic fibrosis carrier status. The authors concluded that their study provided support for the HBM in predicting who may be more likely to use genetic predictive testing for cystic fibrosis. They stated that the model

accounted for 20% of the between groups variability, with one-half of this variability directly attributable to the HBM variables.

Despite its utility and popularity, the HBM is not without criticism. The HBM has suffered from a number of conceptual problems. The model has been criticized for placing too much emphasis on decision making variables and virtually ignoring social and personality variables (Lai, Hamid, & Cheng, 1999). The HBM model has also been referred to as simplistic. Furthermore, the universality of the HBM across cultures has not been systematically tested (Lai et al., 1999).

Despite the criticism, summary results of the HBM research to date has provided substantial empirical support for the model (Stretcher et al, 1997). Overall, perceived barriers has been the most powerful single predictor of the HBM dimensions across all studies and behaviors. Furthermore, perceived susceptibility and perceived benefits have been shown to be greater predictors of preventive health behavior than perceived benefits. In general, perceived severity has been the least powerful predictor (Stretcher et al, 1997). Janz & Becker (1984) point out that the four major dimensions of the HBM (susceptibility, severity, benefits and barriers) contributed independently to prediction of different health-related behaviors or decisions.

Relevance of Genetic Predictive Testing/Counseling to Psychologists

Despite the obvious psychological consequences of obtaining genetic predictive test results, this type of testing has been primarily handled by physicians called medical geneticists or by genetic counselors who have an academic background in genetics plus training in genetic counseling (Shiloh, 1996). There is a growing movement for genetic counselors to provide services that meet the psychological needs of clients, especially

with regard to predictive genetic testing of late-onset diseases (e.g., Alzheimer's Disease). As genetic counselors are not fully trained to handle the realm of possible psychological reactions to the delivery of genetic predictive testing results, psychologists should be prepared to intervene. According to Shiloh (1996), "it is inevitable that psychologists will become increasingly involved in the process" (p. 476).

Despite the fact that the goals of genetic counseling and the sensitive nature of the information delivered clearly indicates a need for psychotherapeutic goals, there has been much hesitancy on the part of genetic counselors to deliver such services. In a recent survey of members of the National Society of Genetic Counselors, only 79 of 1346 (5.9%) of members identified an interest in providing psychotherapy (Eunpu, 1997). There are several possible reasons for this hesitancy. First, genetic counseling occurs primarily in major medical centers and operates within the medical mode. They may also feel uncertain about the appropriateness of claiming psychotherapy as a part of their professional definition. Third, they do not have extensive training in psychotherapeutic techniques. Another hypothesized explanation is that there simply is not enough time for genetic counselors to incorporate psychotherapy into their sessions (Eunpu, 1997). In fact, according to one source, the need for genetic counseling services is growing faster than the ability of general clinicians to provide the services (Chapple, May, & Campion, 1995).

Individuals who undergo genetic predictive testing may experience a variety of psychological consequences including emotions such as shame, guilt, and suicidal ideation. These individuals may also display extreme behavioral consequences such as preventative surgery (e.g., mastectomy) or the act of suicide. Some common emotions

that surface in clients who seek genetic predictive testing/counseling are shame and guilt. Chapple, May, and Campion (1995) found that a majority of the respondents felt that genetic conditions were stigmatizing. In another study, a majority of respondents viewed their individual behavior as the main cause of disease and perceived heredity as negligible (Blaxter, 1984 as cited in Chapple et al, 1995). This study also found that older people were more likely to blame heredity for a condition. It seems as though younger people have accepted the idea that one's lifestyle is responsible for disease development. In the United Kingdom, lifestyle is considered the main reason for disease development and is promoted by health education policy. Therefore, it is easy to understand how individuals could blame themselves for possessing genetic abnormalities or for passing them to future generations. "Genetic disorders strike to the heart of a person's self system since much of our self-image and self-esteem is bound up in our capacity for health and for producing healthy progeny" (Evers-Kiebooms, 1995, p. 24).

According to Peters (1994), the prevalence of suicide issues in genetic predictive testing/counseling contexts is unknown and reports of suicidal ideation in the genetic literature are rare. It seems logical that with the grave psychological consequences of terminal genetic diagnoses, suicidality must be considered a potential psychological consequence of genetic predictive testing.

It has been said that in the future, genetic counseling will become "routinized and primary health care practitioners will conduct much of this counseling" (Kenen & Smith, 1995, p. 120). The authors contend that master's level genetic counselors will handle the more complex cases and will be responsible for training other health care professionals such as nurses, social workers, and family practitioners who will "shoulder the majority

of the straightforward counseling interactions" (Kenen & Smith, 1995, p. 123). In the event that the information is delivered in a straightforward manner, it is likely that psychotherapy will be necessary in many cases. Psychologists need to become involved so that volatile, potentially life-altering information is delivered with care to the psychological well-being of the client.

Often, clients of genetic counselors do not fully understand the genetic information they receive (Chapple, May & Campion, 1995). Therefore, families may be making important decisions without a full understanding of the implications of their diagnoses and information (Begleiter & Rogers, 1994). Psychologists could either aid families in understanding genetic information or train genetic counselors in basic counseling and empathy skills so they can recognize when a client does not understand genetic information. A study by Leonard, Bartholomew, Swank, and Parcel (1995) found that clients' understanding of cystic fibrosis increased with the use of a brochure and a role model story. Psychologists could aid in the development of such techniques.

Chapple, May and Campion (1995) calls for caution before embarking on a large-scale population-screening program. "Unless such screening has clear benefits, it would place an impossible and unjustified burden on an already overstretched genetic counseling service. Appointment times would get shorter rather than longer, and social and psychological aspects of counseling would suffer further" (Chapple, May & Campion, 1995, p. 288-89). This illustrates the importance of psychologists being prepared and willing to participate in counseling clients with genetic issues.

Although genetic counseling will remain the task of medical professionals, who have the expertise to diagnose and analyze hereditary and health consequences of genetic

disorders and risks, a psychologist on the genetic counseling team seems essential (Shiloh, 1996). Psychologists are equipped with the knowledge to assess individual differences among clients in terms of psychological status, needs, expectations, etc., which may lead to more personalized counseling opportunities. Psychologists may also be better able to identify clients at risk for psychosocial stressors who will likely need additional counseling and support. Psychologists can also intervene in crisis situations, provide family and supportive counseling, and help resolve personal and interpersonal problems raised by the genetic predictive testing/counseling (Shiloh, 1996).

It is also possible that family problems could surface over a disagreement about how to proceed after genetic information has been obtained. One study found that in 55% of cases, each partner sought genetic predictive testing for different reasons, and in 33-45% of cases, the partners differed in their perceptions of the seriousness of emotional, marital, social, and financial problems that might result from the birth of a child with a genetic disorder. Furthermore, about 25% differed about whether they intended to have a child in the next 2 years (Wertz, 1994). Psychologists, who are generally trained in family and marriage counseling, could help families cope and compromise.

It is also known that genetic predictive testing/counseling personnel work under a great amount of pressure. Many popular topics such as abortion may be against a genetic professional's own value system. This could lead to even more daily stress, anxiety, guilt, etc. Thus, a psychologist in a consulting role could help alleviate some of the genetic counselors' burdens. "Psychologists can provide support, help clarify counselor's

values, and encourage open discussion of feelings and stresses by the genetic team" (Shiloh, 1996, p. 483).

There is currently a call for genetic professionals to begin providing teratogen (environmental agents that may contribute to genetic malformations or disease) counseling in order to prevent birth defects (Stein, Fine & Pergament, 1994). As psychologists, counseling psychologists in particular, have a preventative and wellness approach to counseling and psychotherapy, it seems natural that psychologists could easily get involved in teaching clients how to live health life-styles and potentially decrease their chances of having a child with birth defects due to teratogen effects.

Several researchers are calling for more multicultural training in genetic counseling (Wang, 1994; Weil & Mittman, 1993; Sharma, Phadke,& Agarwal, 1994; & Rapp, 1993). It is estimated that by the year 2040, Whites will comprise only 62% of the total population (Weil & Mittman, 1993). In cities such as Los Angeles and San Francisco, ethnic minority groups have already reached majority status. Furthermore, prenatal data from San Francisco shows that 75% of births in that city are to non-Caucasian women (Weil & Mittman, 1993). Ethnic minority groups face many barriers with regard to health care services. These barriers include: poverty, language, lack of recognition of genetic risk, and cultural differences involving health beliefs and practices (Weil & Mittman, 1993). Despite these startling statistics, no formal training of cross-cultural genetic counseling exists. Instead, genetic counselors and their programs have based their cultural competency upon culture specific information provided by speakers from different cultural groups (Wang, 1994). Many psychologists are qualified to fill this training gap.

Shiloh (1996) reports that of 9,000 articles that appeared in the major genetic and obstetric journals from 1985 to 1989, only 45 presented data dealing with psychological, social, and ethical issues of genetic counseling. This represents a call for psychologists to get involved and conduct research on human reactions and behavior related to genetic predictive testing/counseling. Genetic predictive testing/counseling provides a real-life laboratory to test issues such as risk perception, decision making, interpersonal communication, stress and coping, and family dynamics (Shiloh, 1996).

Obviously, more client support will be needed in the future as more genes are identified with regard to terminal diseases which may or may not develop in the clients' lifetimes (Chronister, 1995). One prime example of this notion is the recent identification of BRCA1, a breast cancer susceptibility gene (Lerman et al, 1997). In a study conducted by Lerman, et al. (1997), only 58% of subjects requested their BRCA1 test results at the conclusion of the study. This suggests that science has exceeded the curiosity of humans. Tests such as this one may cause undue stress as other factors must be present for breast cancer to develop – a gene alone is not sufficient (Lerman, Audrain, & Croyle, 1994). In fact, many women who test positive for the BRCA1 gene are opting to have total mastectomies before any symptomology is present (Lerman, Audrain, & Croyle, 1994). Psychologists could provide the support likely needed by women who are tested for the BRCA1 gene.

Other genetic tests now have the capability to confirm diagnoses rather than predict. One example of this is Huntington's Disease. The guidelines for testing recommended by the Huntington Disease Society of America clearly include psychological components. The guidelines require psychological intervention to

determine the individual's voluntary and informed consent for testing, emotional stability, support network, and personal readiness. The guidelines also stipulate post-test counseling for at least two years (Heimler & Zanko, 1995). Psychologists could provide this post-test counseling.

Prenatal genetic predictive testing is on the rise. With increasing numbers of couples on a quest for the perfect child, abortion numbers are likely to increase as well. This will lead to a need for increased support for post-abortion counseling (Kolker & Burke, 1993; Suslak, Scherer, & Rodriguez, 1995; Meryash, 1992). It is likely that the necessary support will be sought from psychologists. One study of genetic counselors found that less than one-third included a discussion of abortion as an option and a description of abortion procedures in their sessions. The genetic counselors cited personal and client discomfort as the reason for not including abortion-related discussions with clients (Burke & Kolker, 1994). This lack of information will likely cause higher incidence of shame and guilt when individuals choose to have an abortion. Another article includes a letter written to a genetic counselor from a former client. The woman writes about her abortion; "I desperately wanted someone to ask, 'Why are you crying?' so I could say, 'Because this is a wanted pregnancy,' but no one did" (Green, 1992). This is clearly a place for psychologists to intervene or become involved.

Conclusion

Research conducted on genetic predictive testing has previously been limited to the study of attitudes toward or utilization of genetic predictive testing for one genetic disorder (e.g., breast cancer). No research to date has investigated the relationship of demographic variables with attitudes toward genetic predictive testing in general. Genetic

predictive testing could be viewed in the preventive care realm. Individuals who pursue genetic predictive testing could obtain information about their likelihood of developing a genetic disease/disorder and could receive early treatment, gather information about life-style changes to ward off the disease, and/or undergo preventive surgery. Furthermore, it has been shown that the HBM is useful in predicting health care behavior. Thus, the development of the Attitudes Toward Genetic Predictive Testing Questionnaire incorporating the dimensions of the HBM could be a useful tool in understanding individuals' attitudes toward genetic predictive testing. This information will guide health care professionals in providing adequate prevention and intervention services to clients. In addition, this information could be useful in the development of educational programs designed to promote genetic predictive testing services.

CHAPTER THREE

METHODS AND PROCEDURES

Participants

Two hundred forty-seven college students in undergraduate courses (e.g. World of Work, Total Wellness, dance and engineering classes) and graduate courses (e.g., counseling psychology and school psychology classes) at Oklahoma State University were recruited for voluntary participation in this study. The sample included 118 females (47.8%) and 129 males (52.2%). Marital status among those sampled included, 213 single (86.2%), 22 married (8.9%), 9 divorced (3.6%), 1 widowed (.4%), and 1 other (.4%). Forty-nine students (19.8%) were in their first year of college, 48 (19.4%) were in their second year, 38 (15.4%) were in their third year, 50 (20.2%) were in their fourth year, and 25 (10.1%) were graduate students. In addition, 37 participants (15%) did not complete this item on the demographic questionnaire. Race among the sample participants was reported as, 7 African-American (2.8%), 12 American Indian (4.9%), 4 Asian American (1.6%), 197 Caucasian (79.8%), 2 Hispanic (.8%) and 23 Biracial/Multiracial (9.3%). Two (.8%) did not report their race. The ages of the participants ranged from 18 years to 50 years (M=22.41, SD=5.17). Most of the participants (n = 181, 73.3%) were in the traditional college age range of 18-22 years.

Measures

Participants in this study were asked to complete the following measures: a demographic questionnaire and the Attitudes Toward Genetic Predictive Testing Questionnaire.

Demographic Questionnaire. A demographic questionnaire was used to collect information regarding age, race, sex, marital status, occupation, family income level, education level, family history of medical conditions, religious preference and practices, and current number of children. (See Appendix D.)

Attitudes Toward Genetic Predictive Testing Questionnaire. This questionnaire was developed for use in this study (See Appendix E). This 37-item questionnaire is designed to measure participants' general attitudes toward genetic predictive testing. The items address attitudes toward genetic predictive testing across the four dimensions of the Health Belief Model: susceptibility, severity, benefits and barriers. Participants respond to each item using a 7-point Likert scale (1 = Strongly Disagree, 7 = Strongly Agree). Sample items include "I would not be willing to undergo a genetic predictive test to detect a genetic disease or disorder for which there is no current cure," and "I would undergo a genetic predictive test if I was at risk for a genetic disease/disorder."

Currently, no established general measure of health beliefs exists (O'Connor & Cappelli, 1999). However, several investigators have developed measures tailored to specific genetic diseases/disorders such as mammography compliance, Cystic Fibrosis, and Huntington's Disease (e.g., Aiken et al., 1994; Champion, 1995; Hyman & Baker, 1992). Items for the Attitudes Toward Genetic Testing Questionnaire were derived through an extensive review of the related literature (on health beliefs and specific diseases/disorders) and included adaptations of items published in other studies (Teltscher & Polgar, 1981; Jacobsen et al., 1997). These items include a series of face-valid questions, covering the major motivational determinants of preventive health behavior as postulated by the Health Belief Model (Rosenstock, 1966; Becker et al,

1975). These questions assess perceived susceptibility to genetic disorder/disease, severity of disease, benefits of intervention and barriers to intervention. The items were tailored to address attitudes toward genetic predictive testing for genetic disorders/disease in general.

For determination of content validity, the list of 39 items included in the original version (See Appendix F) was distributed to five raters: one faculty and four doctoral students who were trained in the Health Belief Model by the principal investigator. Each rater was given the conceptual definition of each of the four dimensions (susceptibility, severity, benefits and barriers) to aid in identification of the dimensions. The raters coded one set of 16 sample items (4 items per dimension, but randomly ordered) to test their ability to code accurately. Any rater that incorrectly rated more than two items was to rate a second set of sample items. None of the five raters used for this study was required to complete the second sample set. Each of the five raters was then asked to independently classify each item of the Attitudes Toward Genetic Predictive Testing Questionnaire (presented in random order) into one of the four dimensions provided (See Appendix F for the Conceptual Definitions of the Dimensions of the Health Belief Model form, Summary of the Health Belief Model form and the Sample Items for Raters form). Items were selected for inclusion on the Attitudes Toward Genetic Predictive Testing Questionnaire if four of the five (80%) raters coded the same dimension for that item (See Appendix F for copy of the Item List for Raters to code). Only two items were deleted (80% rater agreement was not met): "My concerns about developing a certain genetic disorder would be reduced if I knew I did not carry the gene for that disorder" (60%) and "I feel that I already know my chances of having a genetically transmitted

disease or disorder, so I wouldn't learn anything more by being tested" (40%). The final questionnaire included the 37 remaining items.

Procedures

To recruit individuals for this study, the primary investigator made contact with instructors of undergraduate and graduate courses at Oklahoma State University to establish a time when their classes could be solicited for participation in this study. Those students who voluntarily agree to participate received a packet to complete in class, which took approximately 20 minutes to complete. The packet included an informed consent form (See Appendix C), the Demographic Questionnaire (See Appendix D) and The Attitudes Toward Genetic Predictive Testing Questionnaire (See Appendix E). Participants signed the informed consent form that explained the purpose of the study, the potential benefits and risks of participation in the study, and their right to withdraw from this study at any time without penalty. At the time of data collection, the informed consent form was collected separately from the packet to ensure confidentiality of responses. No incentives for participation in the study were provided.

CHAPTER FOUR

RESULTS

The results presented in this chapter are organized by the research questions for this study. Descriptive statistics, the principle components analyses of the Attitudes Toward Genetic Predictive Testing Questionnaire, and the series of forward multiple regressions results will be presented.

Descriptive Statistics

The means and standard deviations for the items of the Attitudes Toward Genetic Predictive Testing Questionnaire for the total sample are presented in Table 5. In visually inspecting the means and standard deviations for these items, these participants, on average, agreed that they were healthy (item 1). On average, the participants somewhat agreed that: they would undergo genetic predictive testing if they were at risk of a genetic disease/disorder (item 3); if the test was safe and simple (item 12), and if the test was 100% certain in detecting the gene (item 14). Participants, on average, strongly agreed that they would not be willing to undergo a genetic predictive test if the test was potentially dangerous to their health (item19). On average, participants agreed that knowing whether or not they carry the gene for a genetic disease/disorder would motivate them to practice preventive health measures (item 25), and knowing that they carry the gene for a genetic disease/disorder would cause them to worry more about other family members who could be carriers (item 26). Furthermore, participants somewhat agreed, on average, that knowing whether or not they carry the gene for a genetic disease/disorder would help them make important life decisions (item 27). On average,

these participants were not very concerned about developing a genetic disease/disorder and its impact.

Research Question #1:

" What is the factor structure of the Attitudes Toward Genetic Predictive Testing Questionnaire?"

A principal components analysis with oblimin rotation was conducted to explore the component structure for the Attitudes Toward Genetic Predictive Testing Questionnaire. The oblimin rotation was used given the assumption that the components would be related. Examination of the component correlation matrix confirmed this assumption (See Table 6).

Kaiser (1960) suggested that only those factors whose eigenvalues are greater than one should be retained when conducting a factor analysis. This study produced four factors with eigenvalues greater than one, which was one indicator that a four-factor model would best fit this data.

The Scree test is a graphical method where eigenvalues are plotted against their ordinal numbers. It is appropriate to retain all components whose eigenvalues are in the steep descent before the first component on the line where the components start to level off. When applied to the results of this data set, this rule suggested four factors should be retained (See Appendix B, Figure 1). Thus, based on the Kaiser rule (eigenvalues greater than 1) and an examination of the scree plot, a four component solution emerged.

The four component model, rotated using Oblimin rotation with Kaiser normalization produced the most interpretable components (See Table 7 for item loadings by component, Table 8 for the structure matrix and Table 9 for the pattern matrix). Items

with loadings .40 or higher were included in the components. This four component solution was fairly consistent with the four component structure of the Health Belief Model described in the original research. The four components accounted for 47.51% of the total variance, and were named the Severity and Susceptibility Component (Component 1), the Benefits Component (Component 2), the Barriers Component (Component 3), and the Self Benefits Despite Barriers Component (Component 4).

The Severity and Susceptibility component described the participants' perception of the risk of contracting a genetic disease/disorder and perceptions of the severity of such a disease/disorder. This component uniquely accounted for 22.02% of the total variance. Examples of items from the Severity and Susceptibility factor were, "I believe that I am at risk for developing a genetic disease/disorder" and "I am concerned that I will develop a genetic disease/disorder that will have a negative impact on my work".

The Benefits component consists of items which refer to potential benefits of undergoing genetic predictive testing. This component uniquely accounted for 11.72% of the total variance. An example of the Benefits component was, "Knowing whether or not I carry the gene for a genetic disease/disorder would improve my quality of life".

The Barriers component includes items which refer to the potential barriers of undergoing genetic predictive testing. This component uniquely accounted for 7.60% of the total variance. An example of the Barriers factor was, "I believe that genetic predictive testing would be emotionally upsetting to me."

The Self Benefits Despite Barriers component includes items which were originally coded by raters as benefits and barriers. This component uniquely accounted for 6.16% of the total variance. An example of the Self Benefits Despite Barrier

component was, "I would be willing to undergo a genetic predictive test if a predictive test was expensive." A summary of the four rotated components is reported in Appendix A, Table 7.

Five items loaded on more than one component in this analysis. The following four items loaded on components 2 (Benefits) and 4 (Self-benefits Despite Barriers): "Knowing whether or not I carry the gene for a genetic disease/disorder would improve how I feel about myself", "Knowing whether or not I carry the gene for a genetic disease/disorder would help me make important life decisions", "Knowing whether or not I carry the gene for a genetic disease/disorder would improve my quality of life" and "I believe that genetic predictive testing could reduce my risk of having a genetic disease/disorder". "Knowing that I carry the gene for a genetic disease/disorder would lead to marital or family problems" loaded on component 3 (Barriers) and 4 (Self-benefits despite barriers). Three items did not load on any of the four components: "I believe that I am a healthy person", "I would not be willing to undergo a genetic predictive test if the test was less than 100% certain in detecting a gene responsible for a genetic disease/disorder," and "I would not be willing to undergo a genetic predictive test if the test was potentially dangerous to my health" (See Table 7 for factor loadings).

Research Question #2:

"Is there a relationship between demographic variables (i.e., age, race, gender, income level, educational level, number of family medical/psychiatric conditions in the participant's history and the presence or absence of a genetic disease/disorder in the participant) and attitudes toward genetic predictive testing component scores?"

A series of forward multiple regression analyses were conducted to investigate the relationships between demographic variables and the four components extracted from the Attitudes Toward Genetic Predictive Testing Questionnaire. The predictor or independent variables were age (continuous variable), race (0 = non-white, 1 = white), sex (0 = female, 1 = male), income level (1 = less than $10,000/year, 2 = $10,001-15,000/year, etc.), educational level (continuous variable), number of family medical conditions in the participant's history (continuous variable), and the presence or absence of a genetic disease/disorder in the participant (0 = no, 1 = yes). Each of the four component (factor) scores served as the dependent variables.

In the first multiple regression analysis, component one (Severity and Susceptibility) was the dependent variable. Three variables significantly entered the equation ($F(3,232) = 13.67$, $p<.01$). These variables accounted for a total of 15% of the variance in component one scores. Sex entered the equation first and uniquely accounted for 9.3% of the variance. Income entered the equation second and uniquely accounted for 3.6% of the variance. Finally, gene entered the equation and uniquely accounted for an additional 2.1% of the variance. (See Table 10).

In the second multiple regression analysis, component two (Benefits) was the dependent variable. Three variables significantly entered the equation, ($F(3,232) = 18.553$, $p<.01$). These variables accounted for a total of 19.3% of the variance in factor two scores. Gene entered the equation first and uniquely accounted for 10.4% of the variance. The number of medical conditions in the participant's history entered the equation next and uniquely accounted for 6.2% of the variance. Sex (male or female) accounted for an additional 2.7% of the variance in component two. (See Table 11).

In the third multiple regression analysis, component three (Barriers) served as the dependent variable. One variable significantly entered the equation ($F(2,232) = 4.373$, $p<.01$). Gene entered the equation and uniquely accounted for 1.8% of the variance in component three. (See Table 12).

In the fourth multiple regression analysis, component four (Self Benefits Despite Barriers) served as the dependent variable. No variables significantly entered this equation.

Pearson correlation analyses were conducted for the demographic variables (used for the multiple regression analyses) and the four component scores. See Appendix A, Table 13 for the correlation matrix of these variables. There was a significant relationship between sex and component one ($r = -.30$, $p<.01$), and sex and component two ($r = .19$, $p<.01$). Women were more likely to perceive themselves as more susceptible to genetic disease in general with more severity compared to men. However, women were less likely to perceive the benefits of genetic predictive testing as compared to men. There was also a significant relationship between income level and factor one ($r = .19$, $p<.01$). Individuals with higher income levels were more likely to perceive themselves as more susceptible, with more severity, to genetic diseases/disorders as compared to individuals with lower income levels. A significant relationship was also found between gene (whether and individual carries the gene for a genetic disease/disorder) and component one ($r = -.18$, $p<.01$), component two ($r = -.32$, $p<.01$) and component three ($r = .13$, $p<.05$). Individuals who believe they carry the gene for a genetic disease/disorder perceive themselves are less susceptible to genetic diseases/disorders with less severity, perceive fewer benefits to genetic predictive testing

and perceive more barriers to genetic predictive testing than individuals who do not carry the gene for a genetic disease/disorder. A significant relationship was also found between the number of medical conditions in an individual's family history and component two ($r = -.32$, $p<.01$). In this study, participants were asked to report whether or not they have a family history of several genetic conditions by responding "yes" (positive for family history of condition) or "no" (no known family history of the condition). Forty eight participants reported a family history of heart disease. Other conditions reported included Breast Cancer (42), Alzheimer's Disease (30), Schizophrenia (5), Down's Syndrome (4), Cystic Fibrosis (4), and Other Disease/Disorder (50 including conditions such as Diabetes and Lung Cancer). Individuals with a higher number of medical conditions in their family history were less likely to perceive benefits of genetic predictive testing than individuals with a lower number of medical conditions in their family history.

Research Question #3:

"What is the internal consistency reliability of the Attitudes Toward Genetic Predictive Testing Questionnaire and component scores?"

Cronbach alphas were computed for the component scores and the overall scale score. The results indicated that the four components and the overall measure had good internal consistency: Component one, Severity and Susceptibility, Cronbach alpha = .92; Benefits, Cronbach alpha = .87; Barriers, Cronbach alpha = .70; Self-benefits Despite Barriers, Cronbach alpha = .81; Overall score, Cronbach alpha = .87.

CHAPTER FIVE

DISCUSSION

A summary of major findings with discussion of results, clinical implications, limitations, recommendations for future research, and conclusions are presented in this chapter.

Attitudes Toward Genetic Predictive Testing Questionnaire Factors

Severity and Susceptibility, Benefits, Barriers and Self Benefits Despite Benefits were the four components that emerged from the Attitudes Toward Genetic Predictive Testing Questionnaire using principal components analysis with oblimin rotation. One of the original objectives of this study was to create a measure of general attitudes toward genetic predictive testing based upon the four components of the Health Belief Model. The Health Belief Model involves four basis concepts: perceived susceptibility to illness or health breakdown, anticipated severity of the consequences of illness or health breakdown, beliefs concerning the benefits or efficacy of a recommended health behavior and beliefs concerning the cost of or barriers to enacting the health behavior (Rosenstock, 1966).

The four components obtained in this study are similar to the factors of the Health Belief Model, with some alteration. First, the components of Susceptibility and Severity seem to be related rather than separate components with regard to general attitudes toward genetic predictive testing. If people believe that they are susceptible to a genetic disease/disorder in general, they will also perceive the genetic disease/disorder as severe in some nature (e.g., negative impact on work, family life, social relationships). Having a family history of genetic disease/disorders in their family was related to susceptibility

(those participants with more medical conditions reported in their family history perceived themselves as more susceptible to genetic disease/disorder).

Two components found in this study, Benefits and Barriers, are the same as found in the Health Belief Model. Some of the benefits of a genetic predictive test in general included increase of sense of personal control, improvement of how individuals feel about themselves, and helping to make important life decisions. Some of the barriers of the genetic predictive testing in general included pain, admittance to the hospital for a short period of time, and marital or family problems.

Component four includes some items originally coded by item raters as benefits and barriers. Further examination of these items suggest that this component involves perceived benefits (e.g., personal control), despite some of the side effects of genetic predictive testing (unpleasantness, expense, time involved, and negative side effects).

The HBM has been employed in research investigating a variety of health behaviors including HIV needle risk practices (Falck et al, 1995), decision making with regard to amniocentesis (French et al, 1992), mammography usage (Stein et al, 1992; Fischera & Frank, 1994), breast self-examination (Calnan & Rutter, 1986; Millar, 1997; Rutter & Calnan, 1987), Thomas et al, 1996), attendance at medical health checks (Norman, 1995) and medication compliance among psychiatric outpatients (Kelly, Mamon & Scott, 1987; Ludwig et al, 1990). Critical reviews (Janz & Becker, 1984; Harrison, Mullen, & Green, 1992) have concluded that there is substantial empirical support for the HBM.

The HBM model may be helpful in understanding general attitudes toward genetic predictive testing. The model has been used in researching utilization of a

number of medical services and provides a conceptual formulation for understanding why individuals do and do not choose to engage in a variety of health related actions based upon the four dimensions of the model (susceptibility, severity, benefits and barriers). Understanding general attitudes toward genetic predictive testing could help medical and psychological service providers better understand individuals' health beliefs that might influence their likelihood to pursue genetic predictive testing.

Three previous studies have examined the relationship between the health belief model and genetic predictive testing for one specific genetic disease/disorder, including Tay-Sachs disease, faecal occult blood and Cystic Fibrosis (Becker et al, 1975; Hoogewerf et al, 1990; O'Connor & Cappelli, 1999). Two of the studies supported the use of the HBM in predicting who may be more likely to use genetic predictive testing (Becker et al, 1975; O'Connor & Cappelli, 1999). This is the first study of its kind to explore the health beliefs toward developing a genetic disease/disorder in general and attitudes toward genetic predictive testing in general.

In one study, a negative relationship was found between perceived severity and participation in Tay-Sachs genetic screening (Becker et al, 1975). No significant relationships were found with relation to perceived benefits and barriers and participation in the genetic screening. O'Connor & Cappelli (1999) provided support for the HBM in predicting who may be more likely to use genetic predictive testing for cystic fibrosis. The model accounted for 20% of the between groups variability, with one-half of this variability directly attributable to the HBM variables. In the third study, the researchers were unable to conclude whether health beliefs were related to compliance behavior with genetic screening for faecal occult blood due to difficulties in the operationalization of

the HBM (Hoogewerf et al, 1990). While this study did not directly test the HBM with genetic testing behaviors, further research is needed to confirm the relationship of health beliefs with genetic screening/testing behaviors in general.

Some studies have addressed the relationship between the demographic characteristics of individuals with their attitudes toward genetic predictive testing regarding a specific genetic disease/disorder (Singer, 1991; Sharma, Phadke, & Agarwal, 1994; Cassel, 1997; Davison, Macintyre & Smith, 1994; Rapp, 1993; Brensinger & Laxova, 1995; Lippman, 1994, Press & Browner, 1997; and Becker et al, 1975). Overall, previous research suggested that individuals with positive attitudes toward genetic predictive testing were generally young, Caucasian, from high SES, and had an interest in having children of their own.

In a previous study, groups which were better educated and more affluent were likely to be more familiar with the potential benefits of genetic counseling and prenatal testing, as well as better able to afford them compared to groups with less education and of lower socioeconomic status (Singer, 1991). Individuals in this study with higher income levels were more likely to perceive themselves as more susceptible with more severity to genetic diseases/disorders as compared to individuals with lower income levels. However, income level was not related to benefits or barriers of genetic predictive testing.

In another study, women were more likely than men to undergo genetic predictive testing as it has become common practice to perform prenatal genetic testing (Lippman, 1994). In this study, women were more likely to perceive themselves as more susceptible with more severity, yet they were less likely to perceive the benefits of genetic predictive

testing as compared to men. Women may perceive fewer benefits to genetic predictive testing because they may already be aware of their health concerns. Another possible explanation is that men may be less fearful of the results and feel that the results will be more beneficial as compared to women. Still another explanation is that women may be accepting of not wanting to know the results of genetic predictive testing. It is important to note that this study measured attitudes and attitudes do not equal action. Thus, an individual may see the value of genetic predictive testing, but not seek genetic predictive testing.

Few researchers have explored age differences in attitudes toward genetic testing. Singer (1991) found that participants in younger cohorts were more likely to accept the technology of genetic testing and advocate its use for others as compared to participants in older age cohorts. In addition, the acceptance of genetic testing was higher among married couples of childbearing age than among single individuals. Another study also found that younger age cohorts were most likely to participate in genetic predictive testing older age cohorts (Becker et al, 1975). In this study, no significant relationships were found between age and the components of the ATGPTQ (severity and susceptibility, benefits, barriers and self-benefits despite barriers). However, the participants were all college students and most were between the ages of 18 and 22, making it difficult to draw conclusions regarding age differences in attitudes toward genetic predictive testing in the general population.

In this study, individuals who reported carrying the gene for a genetic disease/disorder perceived themselves as less susceptible to genetic diseases/disorders with more severity, perceived fewer benefits to genetic predictive testing and perceived

more barriers to genetic predictive testing than individuals who did not report carrying the gene for a genetic disease/disorder. This result could be due to the fact that these individuals have already been diagnosed with a genetic disease/disorder, thus genetic predictive testing would be futile. These individuals may simply be less interested in genetic predictive testing. However, it is unclear why these individuals would perceive themselves as less susceptible to genetic diseases/disorders. Other family members may have carried a gene for a genetic disease/disorder without necessarily developing the genetic disease/disorder, therefore reducing perceived vulnerability to harm or illness. It is possible that individuals who carry a gene for a genetic disease/disorder may be in denial about their susceptibility to illness and the level of severity. These individuals may not be concerned about or care about their level of susceptibility or the level of severity related to genetic disease/disorders.

Study participants with a higher number of medical conditions in their family history were less likely to perceive benefits of genetic predictive testing than individuals with a lower number of medical conditions in their family history. This finding is inconsistent with the hypothesis of this study. Furthermore, individuals who reported a high number of medical/psychiatric conditions in their family history were less likely to perceive genetic disease/disorders as severe. It is possible that individuals with a strong family history of medical/psychiatric conditions may have substantial information about their risks of developing a genetic disease/disorder, thus genetic predictive testing may not reveal significantly new information to these individuals. Another explanation may be that individuals with strong family histories of medical/psychiatric disorders may be in denial about their susceptibility to illness and the severity of genetic diseases/disorders.

More research is needed on how family history and the presence or absence of a gene for a genetic disease/disorder influences genetic predictive testing decisions and preventive health behavior.

Clinical Implications

One of the practical implications of this research is that the promotion of genetic predictive testing services will likely require an increased understanding of participants' decision making process which appears to involve considering their perceived risk, otherwise known as their susceptibility to developing a genetic disorder, the severity of their genetic disorder if they have one, and the benefits and barriers to undergoing genetic predictive testing. Previous research has focused on participants' attitudes toward a specific genetic disease/disorder. However, with the completion of the Human Genome Project and a growing number of genetic predictive tests becoming available, a general measure of attitudes toward genetic predictive testing seems warranted.

The field of genetic predictive testing is rapidly expanding not only in the number of specific genes being located, but also in the number of genetic predictive tests available. A general measure will allow clinicians/physicians to gain understanding of individuals' general attitudes toward genetic predictive testing for the wide range of genetic diseases/disorders for which genes have been identified. Furthermore, an increasing number of individuals may seek genetic predictive testing as these genes are identified. This information will help guide health care professionals in providing adequate prevention and intervention services to clients. In addition, this information could be useful in the development of educational programs designed to promote genetic predictive testing services.

The Health Belief Model suggests that individuals' are more likely to pursue preventive health actions if they (1) feel susceptible to disease and (2) perceive the benefits of a preventive health behavior to outweigh the costs. Subscale scores of the four factors of this measure could aid in predicting the likelihood that an individual will pursue the preventive health action of genetic predictive testing. Furthermore, subscale scores could be used to identify individuals who have an interest in seeking genetic predictive testing services as well as in identifying barriers or reasons why individuals are not seeking such services.

In this study, some demographics in this sample were related to susceptibility, severity, benefits and barriers of genetic predictive testing, including sex, presence or absence of a gene for a genetic disorder, income, and number of medical/psychiatric conditions in family history. These findings suggest that demographic characteristics of the clients served must be considered when developing educational and preventive screening interventions for genetic diseases/disorders. Simply because a person believes that they carry a gene or they have a family history of medical/psychiatric conditions may not necessarily motivate someone to seek genetic predictive testing. In fact, the findings of the study suggest the exact opposite. Therefore, education may be key in motivating individuals to pursue genetic predictive testing, particularly when there is a family history of a genetic disease/disorder.

Furthermore, these findings suggest that while women may perceive themselves as more susceptible to genetic disease/disorders, women were less likely to perceive the benefits of genetic predictive testing as compared to men. Therefore, educational efforts and future research should attempts to better understand the decision making process of

men versus women. Efforts should also address possible socioeconomic concerns with regard to access to genetic predictive testing procedures. The current reality is that individuals will likely need to pay for genetic predictive testing out of pocket rather than such services being covered by insurance policies. Furthermore, many individuals in this country do not have insurance coverage. Thus, genetic predictive testing may only be utilized by those with financial resources.

Limitations

The Attitudes Toward Genetic Predictive Testing Questionnaire was created for this study. While the component structure as well as the internal consistency of this instrument was examined in this study, more research is needed to validate this instrument with other samples.

Like all research, the results of this study must be considered in the context of the conceptual and methodological framework chosen to answer the research questions. Problems common to research in general as well as elements particular to the design and implementation of this study are reviewed here to maintain healthy caution about the validity of the findings.

First, the sample was relatively homogeneous. The mean age of those participating was 22.40 years, the majority of whom were between the ages of 18 and 22 years. In addition, most of the participants were white (79.8%), single (86.2%), and had no children (90.3%). Homogeneous and non-random samples often restrict the range of the results. This sample was not a random sample, but rather a convenience sample. Therefore, the homogeneous, non-random nature of the sample does not reflect the greater variance in the population with regard to ethnicity, age or socioeconomic status.

The component structure derived might be different from what would be extracted from a more heterogeneous and random sample. Consequently, the generalizability of the results may be limited.

This study is limited in that participants were asked whether or not they carried the gene for a genetic disease/disorder rather than asking whether individuals have been diagnosed with a genetic disease/disorder. A larger sample including participants of a clinical nature (i.e., patients undergoing genetic testing) would have been highly desirable in terms of better understanding the phenomenon examined here.

Additionally, in a study using participant self-report, the assumption has to be made that the students answered the questionnaire honestly and that their answers reflected their true perception about the subject matter surveyed. This method of data collection can be subject to a number of response sets which could lead to spurious results.

Another limitation of this study is that the items were derived from and validated from Western culture. Cross-cultural analyses were not possible due to the homogeneity of the sample. Furthermore, the results of this study have not been cross-validated yet, indicating that these results and any subsequent implications need to be interpreted with caution.

Furthermore, analogue methodology was employed in that the participants were asked to hypothesize about whether or not they would undergo genetic predictive testing in the future. These results may not be generalizable to their actual genetic predictive testing practices, thus potentially threatening the ecological validity of the results of this study.

Recommendations for Future Research

In this study, the Attitudes Toward Genetic Testing Questionnaire was developed and analyzed using principle components analysis. Further research is needed to refine and improve the measure. Further research is also needed to explore the validity of this instrument.

While certain demographic characteristics accounted for some of the variance in the components of the Attitudes Toward Genetic Predictive Testing Questionnaire, much of the variance in these components is still unexplained. Thus, there may be important contributors which have not been studied to date. Further research is needed to explore significant predictors of attitudes toward genetic predictive testing.

Validating this measure with clinical populations and with more ethnic and racially diverse individuals is clearly indicated. It is also recommended that qualitative methods be used in future studies to better understand the various factors that affect attitudes toward genetic predictive testing.

REFERENCES

Aiken, L., West, S., Woodward, C., & Reno, R. (1994). Health beliefs and compliance with mammography: Screening recommendations in asymptomatic women. Health Psychology, 13, 122-129.

Becker, M., Haefner, D., & Maiman, L. (1977). The Health Belief Model in the prediction of dietary compliance: a field experiment. Journal of Health and Social Behavior, 18, 348-366.

Becker, M., Kaback, M., Rosenstock, I., & Ruth, M. (1975). Some influences on public participation in a genetic screening program. Journal of Community Health, 1 (1), 3-14.

Begleiter, M., & Roger, J. (1994). Genetic counseling for a family with two distinct anomalies: A case report of a neural tube defect and 5p-syndrome in a fetus. Journal of Genetic Counseling, 3 (2), 87-93.

Bird, T., & Bennett, R. (1995). Why do DNA testing? Practical and ethical implications of new neurogenetic tests. Annals of Neurology, 38 (2), 141-146.

Brensinger, J., & Laxova, R. (1995). The Amish: Perceptions of genetic disorders and services. Journal of Genetic Counseling, 4 (1),27-47.

Burke, B., & Kolker, A. (1994). Variation in content in prenatal genetic counseling interviews. Journal of Genetic Counseling, 3 (1), 23-37.

Calnan, M., & Rutter, D. (1986). Do health beliefs predict health behaviour? An analysis of breast self-examination. Social Science Medicine, 22 (6), 673-678.

Cann, H. (1968). Principles of human inheritance. Birth Defects: Original Article Series, IV (6), 5-19.

Cassel, C. (1997). Policy implications of the Human Genome Project for women. Women's Health Issues, 7 (4), 225-229.

Chapple, A., May, C., & Campion, P. (1995). Parental guilt: The part played by the clinical geneticist. Journal of Genetic Counseling, 4 (3), 179-191.

Chapple, A., May, C., & Campion, P. (1995). Lay understanding of genetic disease: A British study of families attending a genetic counseling service. Journal of Genetic Counseling, 4 (4), 281-300.

Chronister, A. (1995). Genetic counseling issues. Developmental Brain Dysfunction, 8 (4-6), 353-358.

Collins, F. & McKusick, V. (2001). Implications of the Human Genome Project for Medical Science. Journal of the American Medical Association, 285 (5), 540-544.

Davison, C., Macintyre, S., & Smith, G. (1994). The potential social impact of predictive genetic testing for susceptibility to common chronic diseases: A review and proposed research agenda. Sociology of Health and Illness, 16 (3), 340-371.

Dice, L. (1959). The structure of heredity counseling services. In: H. Hammons (Ed.), Heredity counseling (pp. 60-64). New York: Hoeber-Harper.

Eunpu, D. (1997). Systemically-based psychotherapeutic techniques in genetic counseling. Journal of Genetic Counseling, 6 (1), 1-20.

Evers-Kiebooms, G. (1995). Risk communication in genetic counselling and genetic risk perception. Special issue: Risk communication. European Review of Applied Psychology, 45 (1), 23-28.

Falck, R., Siegal, H., Wang, J., & Carlson, R. (1995). Usefulness of the health belief model in predicting HIV needle risk practices among injection drug users. AIDS Education and Prevention, 7 (6), 523-533.

Fischera, S., & Frank, D. (1994). The Health Belief Model as a predictor of mammography screening. Health Values, 18 (4), 3-9.

French, B., Kurczynski, T., Weaver, M., & Pituch, M. (1992). Evaluation of the Health Belief Model and decision making regarding amniocentesis in women of advanced maternal age. Health Education Quarterly, 19 (2), 177-186.

Galton, F. (1865). Hereditary talent and character. Macmillan, 12, 157-166, 318-327.

Garver, K., & Garver, B. (1994). The Human Genome Project and eugenic concerns. American Journal of Human Genetics, 54, 148-158.

Glanze, W., Anderson, K., Anderson, L. (Eds.). (1985). The Mosby Medical Encyclopedia. New York: Plume.

Green, R. (1992). Letter to a genetic counselor. Journal of Genetic Counseling, 1 (1), 55-70.

Green, E., & Waterston, R. (1991). The Human Genome Project: Prospects and implications for clinical medicine. Journal of the American Medical Association, 266 (14), 1966-1975.

Haldane, J. (1954). The biochemistry of genetics. London: George Allen & Unwin Ltd.

Hamel, R. (2001). Genetics and ethics: Issues and implications of the Human Genome Project. Health Progress, March-April, 22-23.

Harris, H. (1959). Human biochemical genetics. New York: American Elsevier Publishing Company, Inc.

Harrison, J., Mullen, P., & Green, L. (1992). A meta-analysis of studies of the Health Belief Model with adults. Health Education Quarterly, 7 (1), 107-116.

Heimler, A., & Zanko, A. (1995). Huntington disease: A case study describing the complexities and nuances of predictive testing of monozygotic twins. Journal of Genetic Counseling, 4 (2), 125-137.

Hoffman, E. (1994). The evolving genome project: Current and future impact. American Journal of Human Genetics, 54, 129-136.

Hoogewerf, P., Hislop, T., Morrison, B., Burns, S., & Sitzo, R. (1990). Health belief and compliance with screening for faecal occult blood. Social Science and Medicine, 30, 721-726.

Jacobsen, P., Valdimarsdottir, H., Brown, K. & Offit, K. (1997). Decision making about genetic testing among women at familial risk for breast cancer. Psychosomatic Medicine, 59, 459-466.

Janz, N., & Becker, M. (1984). The Health Belief Model: A decade later. Health Education Quarterly, 11 (1), 1-47.

Kelly, G., Mamon, J., & Scott, J. (1987). Utility of the Health Belief Model in examining medication compliance among psychiatric outpatients. Social Science Medicine, 25 (11), 1205-1211.

Kenen, R., & Smith, A. (1995). Genetic counseling for the next 25 years: Models for the future. Journal of Genetic Counseling, 4 (2), 115-124.

Kolker, A., & Burke, B. (1993). Grieving the wanted child: Ramifications of abortion after prenatal diagnosis of abnormality. Health Care for Women International, 14 (6), 513-526.

Lafayette, D., Abuelo, D., Passero, M., & Tantravahi, U. (1999). Attitudes toward cystic fibrosis carrier and prenatal testing and utilization of carrier testing among relatives of individuals with cystic fibrosis. Journal of Genetic Counseling, 8 (1), 17-36.

Lai, J., Hamid, P., & Cheng, S. (1999). Health beliefs, optimism, and preventive health decisions in Hong Kong Chinese. Journal of Social Behavior and Personality, 14 (1), 147-158.

Leonard, K., Bartholomew, L., Swank, P., & Parcel, G. (1995). A comparison of two approaches to education about carrier testing for cystic fibrosis. Journal of Genetic Counseling, 4 (2), 97-113.

Lerman, C., Audrain, J., & Croyle, R. (1994). DNA-testing for heritable breast cancer risks: Lessons from traditional genetic counseling. Mini-series: Advances in behavioral medicine research on breast cancer. Annals of Behavioral Medicine, 16 (4), 327-333.

Lerman, Schwartz, Lin, Hughes, Narod & Lynch (1997). The influence of psychological distress on use of genetic testing for cancer risk.

Lippman, A. (1994). In: K. Rothenberg & E. Thomson (Eds.), Women and prenatal testing: Facing the challenges of genetic technology. Ohio State Press: Columbus, OH.

Ludwig, W., Huber, D., Schmidt, S., Bender, W., & Greil, W. (1990). Assessment of compliance-related attitudes in psychiatry. Social Psychiatry Psychiatric Epidemiology, 25, 298-303.

Mendel, G. (1948). Experiments in Plant Hybridisation. Cambridge: Harvard University Press. (Originally read at the meetings of the 8th of February and 8th of March, 1865).

Meryash, D. (1992). Characteristics of fragile X relatives with different attitudes toward terminating an affected pregnancy. American Journal on Mental Retardation, 96 (5), 528-535.

Millar, M. (1997). The effects of emotion on breast self-examination: Another look at the Health Belief Model. Social Behavior and Personality, 25 (3), 223-232.

Neel, J. (1973). The coming of age of genetic counseling. Birth Defects: Original Article Series, IX (4), 1-4.

Neel, J. (1973). Social and scientific priorities in the use of genetic knowledge. In: B. Hilton, D. Callahan, M. Harris, P. Condliffe, & B. Berkley (Eds.), Ethical issues in human genetics: Genetic counseling and the use of genetic knowledge (pp. 353-368). New York: Plenum Press.

Norman, P. (1995). Applying the Health Belief Model to the prediction of attendance at health checks in general practice. British Journal of Clinical Psychology, 34, 461-470.

O'Connor, B., & Cappelli, M. (1999). Health beliefs and the intent to use predictive genetic testing for cystic fibrosis carrier status. Psychology, Health & Medicine, 4 (2), 157-168.

Peters, J. (1994). Suicide prevention in the genetic counseling context. Journal of Genetic Counseling, 3 (3), 199-213.

Peters, J., Djurdjinovic, L., & Baker, D. (1999). The genetic self: The Human Genome Project, genetic counseling, and family therapy. Families, Systems & Health, 17 (1), 5-25.

Post, S. (1994). Genetics, ethics, and Alzheimer disease. Journal of the American Geriatrics Society, 42 (7), 782-786.

Press, N., & Browner, C. (1997). Why women say yes to prenatal diagnosis. Social Science and Medicine, 45 (7), 979-989.

Rapp, R. (1993). Amniocentesis in sociocultural perspective. Journal of Genetic Counseling, 2 (3), 183-196.

Reed, S. (1949). Counseling in human genetics. Bulletin of the Dight Institute, 6, 1-21.

Reed, S. (1951). Counseling in human genetics, part II. Bulletin of the Dight Institute, 7, 1-17.

Reed, S. (1974). A short history of genetic counseling. Social Biology, 21 (4), 332-339.

Reed, S. (1980). Counseling in medical genetics: Third edition. New York: Alan R. Liss, Inc.

Rosenstock, I. (1966). Why people use health services. Milbank Memorial Fund Quarterly, Q44 (3), 94-127.

Rothenberg, K. (1997). Genetic accountability and pregnant women. Women's Health Issues: Official Publication of the Jacobs Institute of Women's Health, 7 (4), 215-219.

Roy, J., Johnsen, J., Breese, K., & Hagerman, R. (1995). Fragile X syndrome: What is the impact of diagnosis on families? Developmental Brain Dysfunction, 8 (4-6), 327-335.

Rutter, D., & Calnan, M. (1987). Do health beliefs predict health behaviour? A further analysis of breast self-examination. In: H. Dent (Ed.), Clinical Psychology: Research and Developments (pp. 35-41). London: Croom Helm.

Schroeder, L. (1991). Social work and genetic services: Legal roadblocks on the road less traveled. International Social Work, 34 (1), 97-108.

Sharma, A., Phadke, S., & Agarwal, S. (1994). Sociocultural and ethical dilemmas of genetic counseling: A suggested working approach. Journal of Genetic Counseling, 3 (1), 81-83.

Sheeran, P., & Abraham, C. (1993). The Health Belief Model. In: M. Conner & P. Norman (Eds.) Predicting Health Behavior: Research and practice with social cognition models (pp. 23-61). New York: Plenum Press.

Shiloh, S. (1996). Genetic counseling: A developing area of interest for psychologists. Professional Psychology Research and Practice, 27 (5), 475-486.

Singer, E. (1991). Public attitudes toward genetic testing. Population Research and Policy Review, 10, 235-255.

Stein, A., Fine, B., & Pergament, E. (1994). Training genetic counselors to provide teratogen counseling. Journal of Genetic Counseling, 3 (2), 133-140.

Stein, J., Fox, S., Murata, P., & Morisky, D. (1992). Mammography usage and the Health Belief Model. Health Education Quarterly, 19 (4), 447-462.

Stretcher, V., Champion, V., & Rosenstock, I. (1997). The Health Belief Model and health behavior. In: D. Gochman (Ed.) Handbook of Health Behavior Research I: Personal and Social Determinants (pp. 71-91). New York: Plenum Press.

Suslak, L., Scherer, A., & Rodriguez, G. (1995). A support group for couples who have terminated a pregnancy after prenatal diagnosis: Recurrent themes and observations. Journal of Genetic Counseling, 4 (3), 169-178.

Teltscher, B. & Polgar, S. (1981). Objective knowledge about Huntington's disease and attitudes towards predictive tests of persons at risk. Journal of Medical Genetics, 18, 31-39.

Thomas, L., Fox, S., Leake, B., & Roetzheim, R. (1996). The effects of health beliefs on screening mammography utilization among a diverse sample of older women. Women and Health, 24 (3), 77-94.

Wang, V. (1994). Cultural competency in genetic counseling. Journal of Genetic Counseling, 3 (4), 267-277.

Watson, J. (1990). The human genome project: past, present, and future. Science, 248, 44-51.

Weil, J., & Mittman, I. (1993). A teaching framework for cross-cultural genetic counseling. Journal of Genetic Counseling, 2 (3), 159-169.

Wertz, D. (1992). Ethical and legal implications of the new genetics: Issues for discussion. Social Science and Medicine, 35 (4), 495-505.

Wertz, D. (1994). Provider gender and moral reasoning: The politics of an "ethics of care." Journal of Genetic Counseling, 3 (2), 95-112.

Wolff, G., & Jung, C. (1995). Nondirectiveness and genetic counseling. Journal of Genetic Counseling, 4 (1), 3-25.

Zweig, S., LeFevre, M., & Kruse, J. (1988). The Health Belief Model and attendance for prenatal care. Family Practice Research Journal, 8 (1), 32-41.

APPENDIX A

DATA TABLES

Table 1

Results of Items Coded into the Health Belief Model

Item	Factor
1) I believe that I am a healthy person.	Susceptibility
2) I believe that I am at risk for developing a genetic disease/disorder.	Susceptibility
3) I would undergo a genetic predictive test if I was at risk for a genetic disease/disorder.	Benefits
4) I would not be willing to undergo a genetic predictive test to detect a genetic disease or disorder for which there is no current cure.	Barriers
5) I am concerned that I will develop a genetic disease/disorder that will have a negative impact on my work.	Severity
6) I am concerned that I will develop a genetic disease/disorder that will have a negative impact on my family life.	Severity
7) I am concerned that I will develop a genetic disease/disorder that will have a negative impact on my social relationships with others.	Severity
8) I am concerned that I will develop a genetic disease/disorder that will result in pain.	Severity
9) I am concerned that I will develop a genetic disease/disorder that will result in disability.	Severity
10) I am concerned that I will develop a genetic disease/disorder that will result in death.	Severity
11) I would not be willing to undergo a genetic predictive test if the test was less than 100% certain in detecting a gene responsible for a genetic disease/disorder.	Barriers
12) I would be willing to undergo a genetic predictive test if the test was safe and simple.	Benefits
13) I would be willing to undergo a genetic predictive test if a predictive test was expensive.	Barriers
14) I would be willing to undergo a genetic predictive test if the test was 100% certain in detecting a gene responsible for a genetic disease/disorder.	Benefits
15) I would not be willing to undergo a genetic predictive test if the test involved painful procedures.	Barriers
16) I would not be willing to undergo a genetic predictive test if the test involved admittance to the hospital for a period of time.	Barriers
17) I would be willing to undergo a genetic predictive test if the test was time consuming.	Barriers
18) I would be willing to undergo a genetic predictive test if the test was unpleasant.	Barriers

Table 1 continued

Results of Items Coded into the Health Belief Model

Item	Factor
19) I would not be willing to undergo a genetic predictive test if the test was potentially dangerous to my health.	Barriers
20) I would be willing to undergo a genetic predictive test if the test resulted in negative side effects.	Barriers
21) Knowing whether or not I carry the gene for a genetic disease/disorder would increase my sense of personal control.	Benefits
22) Knowing that I carry the gene for a genetic disease/disorder would leave me in a state of hopelessness and despair.	Barriers
23) Knowing whether or not I carry the gene for a genetic disease/disorder would improve how I feel about myself.	Benefits
24) If I had a genetic disease/disorder, it would cause others to view me negatively.	Severity
25) Knowing whether or not I carry the gene for a genetic disease/disorder would motivate me to practice preventive health measures (e.g., self-exams, regular physician check-ups).	Benefits
26) Knowing that I carry the gene for a genetic disease/disorder would cause me to worry more about other family members who could be carriers (e.g., mother, father, sisters, brothers).	Barriers
27) Knowing whether or not I carry the gene for a genetic disease/disorder would help me make important life decisions.	Benefits
28) Knowing that I carry the gene for a genetic disease/disorder would lead to marital or family problems.	Barriers
29) Knowing whether or not I carry the gene for a genetic disease/disorder would improve my quality of life.	Benefits
30) Knowing whether or not I carry the gene for a genetic disease/disorder could save my life.	Benefits
31) I am fearful that genetic predictive test results could negatively affect my ability to maintain/obtain insurance coverage.	Barriers
32) There is a history of genetic diseases/disorders in my family.	Susceptibility
33) I believe that genetic predictive testing would do more good than harm.	Benefits
34) I believe that genetic predictive testing would be emotionally upsetting to me.	Susceptibility
35) I believe that genetic predictive testing could reduce my risk of having a genetic disease/disorder.	Benefits
36) I am fearful that my genetic predictive test results could be released to others without my consent.	Barriers
37) I believe that I have a genetic disease/disorder.	Susceptibility

Table 2

Results of Raters Codes for Items

	Raters				
Item	1	2	3	4	5
1	1	1	1	1	1
2	1	1	1	1	1
3	3	3	3	3	1
4	4	4	4	3	4
5	2	2	2	1	2
6	2	2	2	2	2
7	2	2	2	2	2
8	2	2	2	2	2
9	2	2	2	2	2
10	2	2	2	2	2
11	4	4	4	4	4
12	3	3	3	4	3
13	4	4	3	4	4
14	3	3	3	4	3
15	4	4	4	4	4
16	4	4	4	4	4
17	4	4	3	4	4
18	4	4	3	4	4
19	4	4	4	4	4

Table 2 continued

Results of Raters Codes for Items

	Raters				
Item	1	2	3	4	5
20	4	4	3	4	4
21	3	3	3	3	3
22	4	4	4	2	4
23	3	3	3	3	3
24	2	2	2	2	4
25	3	3	3	3	3
26	4	4	4	4	4
27	3	3	3	3	3
28	4	4	4	4	4
29	3	3	3	3	3
30	3	3	3	3	3
31	4	4	2	4	4
32	1	1	1	1	1
33	3	3	3	3	3
34	4	4	2	4	4
35	3	3	3	3	3
36	4	4	2	4	4
37	1	1	1	1	1

Note: 1 = Susceptibility, 2 = Severity, 3 = Benefits, 4 = Barriers

Table 3

Demographics of Study Participants

Variable	Response	N	Percent
Sex	Male	129	52.2 %
	Female	118	47.8 %
Marital Status	Single	213	86.6 %
	Married	22	8.9 %
	Divorced	9	3.7 %
	Widowed	1	.4 %
	Other	1	.4 %
Race	African American	7	2.9 %
	American Indian	12	4.9 %
	Asian American	4	1.6 %
	Caucasian	197	80.4 %
	Hispanic	2	.8 %
	Biracial/Multiracial	23	9.4 %
Community	Urban	52	27.1 %
	Suburban	34	17.7 %
	Rural	106	52.2 %

Table 3 continued

Demographics of Study Participants

Variable	Response	N	Percent
Income	<$10,000/year	25	10.2 %
	$10,001-15,000/year	13	5.3 %
	$15,001-20,000/year	9	3.7 %
	$20,001-25,000/year	11	4.5 %
	$25,001-30,000/year	10	4.1 %
	$30,001-40,000/year	12	4.9 %
	$40,001-50,000/year	18	7.3 %
	$50,001-60,000/year	20	8.2 %
	$60,001-70,000/year	21	8.6 %
	$70,001-80,000/year	29	11.8 %
	$80,001-90,000/year	22	9.0 %
	>$90,000/year	55	22.4 %
Year in College	Freshman	49	23.3 %
	Sophomore	48	22.9 %
	Junior	38	18.1 %
	Senior	50	23.8 %
	Graduate Student	25	11.9 %
Children	Yes	24	9.7 %
	No	223	90.3 %

Table 3 continued

Demographics of Study Participants

Variable	Response	N	Percent
Family History of:			
Breast Cancer	Yes	42	17 %
	No	205	83 %
Huntington's Disease	Yes	1	.4 %
	No	246	99.6 %
Schizophrenia	Yes	5	2 %
	No	242	98 %
Heart Disease	Yes	48	19.4 %
	No	199	80.6 %
Down's Syndrome	Yes	4	1.6 %
	No	243	98.4 %
Alzheimer's Disease	Yes	30	12.1 %
	No	217	87.9 %
Cystic Fibrosis	Yes	4	1.6 %
	No	243	98.4 %
Other Disease/Disorder	Yes	50	20.2 %
	No	97	79.8 %

Table 3 continued

Demographics of Study Participants

Variable	Response	N	Percent
Known History of Gene	Yes	16	6.5 %
	No	230	96.4 %
Previous Genetic Testing	Yes	2	.8 %
	No	243	98.4 %

Table 4

Continuous Demographic Variables of Participants

Variable	M	SD
Age	22.41	5.17
Years of Education	14.89	2.36
Number of Medical/Psychiatric Conditions	.74	1.04

Table 5

Means and Standard Deviations of Attitudes Toward Genetic Predictive Testing Questionnaire Items

Items	M	SD
1. I believe that I am a healthy person.	6.00	1.07
2. I believe that I am at risk for developing a genetic disease/disorder.	3.36	1.76
3. I would undergo a genetic predictive test if I was at risk for a genetic disease/disorder.	5.20	1.58
4. I would not be willing to undergo a genetic predictive test to detect a genetic disease or disorder for which there is no current cure.	3.33	1.83
5. I am concerned that I will develop a genetic disease/ disorder that will have a negative impact on my work.	2.85	1.62
6. I am concerned that I will develop a genetic disease/ disorder that will have a negative impact on my family life.	3.06	1.77
7. I am concerned that I will develop a genetic disease/ disorder that will have a negative impact on my social relationships with others.	2.84	1.65
8. I am concerned that I will develop a genetic disease/ disorder that will result in pain.	3.17	1.79
9. I am concerned that I will develop a genetic disease/ disorder that will result in disability.	3.03	1.75
10. I am concerned that I will develop a genetic disease/ disorder that will result in death.	3.09	1.86
11. I would not be willing to undergo a genetic predictive test if the test was less than 100% certain in detecting a gene responsible for a genetic disease/disorder.	3.45	1.71
12. I would be willing to undergo a genetic predictive test if the test was safe and simple.	5.47	1.48
13. I would be willing to undergo a genetic predictive test if a predictive test was expensive.	3.45	1.62
14. I would be willing to undergo a genetic predictive test if the test was 100% certain in detecting a gene responsible for a genetic disease/disorder.	5.40	1.58
15. I would not be willing to undergo a genetic predictive test if the test involved painful procedures.	4.44	1.68

Table 5 continued

Means and Standard Deviations of Attitudes Toward Genetic Predictive Testing Questionnaire Items

Items	M	SD
16. I would not be willing to undergo a genetic predictive test if the test involved admittance to the hospital for a period of time.	4.41	1.75
17. I would be willing to undergo a genetic predictive test if the test was time consuming.	3.81	1.64
18. I would be willing to undergo a genetic predictive test if the test was unpleasant.	3.49	1.63
19. I would not be willing to undergo a genetic predictive test if the test was potentially dangerous to my health.	5.23	2.00
20. I would be willing to undergo a genetic predictive test if the test resulted in negative side effects.	2.79	1.77
21. Knowing whether or not I carry the gene for a genetic disease/disorder would increase my sense of personal control.	3.96	1.78
22. Knowing that I carry the gene for a genetic disease/ disorder would leave me in a state of hopelessness and despair.	2.92	1.63
23. Knowing that I carry the gene for a genetic disease/ disorder would improve how I feel about myself.	3.20	1.52
24. If I had a genetic disease/disorder, it would cause others to view me negatively.	2.97	1.61
25. Knowing whether or not I carry the gene for genetic disease/disorder would motivate me to practice preventive health measures (e.g., self-exams, regular physician check-ups).	5.41	1.52
26. Knowing that I carry the gene for a genetic disease/ disorder would cause me to worry more about other family members who could be carriers (e.g., mother, father, sister, brothers).	5.29	1.49
27. Knowing whether or not I carry the gene for a genetic disease/disorder would help me make important life decisions.	4.59	1.71
28. Knowing that I carry the gene for a genetic disease/ disorder would lead to marital or family problems.	2.87	1.47
29. Knowing whether or not I carry the gene for a genetic disease/disorder would improve my quality of life.	3.43	1.51

Table 5 continued

Means and Standard Deviations of Attitudes Toward Genetic Predictive Testing Questionnaire Items

Items	M	SD
30. Knowing whether or not I carry the gene for a genetic disease/disorder could save my life.	4.87	1.74
31. I am fearful that genetic predictive test results could negatively affect my ability to maintain/obtain insurance coverage.	4.23	1.73
32. There is a history of genetic disease/disorders in my family.	3.44	1.94
33. I believe that genetic predictive testing would do more good than harm.	4.40	1.61
34. I believe that genetic predictive testing would be emotionally upsetting to me.	3.52	1.59
35. I believe that genetic predictive testing could reduce my risk of having a genetic disease/ disorder.	3.63	1.81
36. I am fearful that my genetic predictive test results could be released to others without my consent.	3.25	1.94
37. I believe that I have a genetic disease/disorder.	2.33	1.61

Possible score range: 1 to 7

1=strongly disagree, 2=disagree, 3=somewhat disagree, 4=unsure, 5=somewhat agree, 6=agree, 7=strongly agree

Table 6

Component Correlation Matrix

	Components			
Component	1	2	3	4
1	1.000	-.159	.204	-.256
2	-.159	1.000	.082	.224
3	.204	-.082	1.000	-.045
4	-.256	.224	-.045	1.000

Component 1 = Severity and Susceptibility
Component 2 = Benefits
Component 3 = Barriers
Component 4 = Self-Benefits Despite Barriers

Table 7

Principle Factor Analysis Item Loadings for the Attitudes Toward Genetic Predictive Testing Questionnaire (Based on Structure Matrix)

Component 1: Susceptibility and Severity

Item #	Item	Loading
2	I believe that I am at risk for developing a genetic disease/disorder.	.65
5	I am concerned that I will develop a genetic disease/disorder that will have a negative impact on my work.	.88
6	I am concerned that I will develop a genetic disease/disorder that will have a negative impact on my family life.	.92
7	I am concerned that I will develop a genetic disease/disorder that will have a negative impact on my social relationships with others.	.85
8	I am concerned that I will develop a genetic disease/disorder that will result in pain.	.91
9	I am concerned that I will develop a genetic disease/disorder that will result in disability.	.89
10	I am concerned that I will develop a genetic disease/disorder that will result in death.	.87
32	There is a history of genetic diseases/disorders in my family.	.57
37	I believe that I have a genetic disease/disorder.	.52

Table 7 continued

Principle Components Analysis Item Loadings for the Attitudes Toward Genetic Predictive Testing Questionnaire (Based on Structure Matrix)

Component 2: Benefits

Item #	Item	Loading
3	I would undergo a genetic predictive test if I was at risk for a genetic disease/disorder.	.64
12	I would be willing to undergo a genetic predictive test if the test was safe and simple.	.73
14	I would be willing to undergo a genetic predictive test if the test was 100% certain in detecting a gene responsible for a genetic disease/disorder.	.78
21	Knowing whether or not I carry the gene for a genetic disease/disorder would increase my sense of personal control.	.60
23	Knowing whether or not I carry the gene for a genetic disease/disorder would improve how I feel about myself.	.42
25	Knowing whether or not I carry the gene for a genetic disease/disorder would motivate me to practice preventive health measures (e.g., self-exams, regular physician check-ups).	.74
26	Knowing that I carry the gene for a genetic disease/disorder would cause me to worry more about other family members who could be carriers (e.g., mother, father, sister, brothers).	.65
27	Knowing whether or not I carry the gene for a genetic disease/disorder would help me me make important life decisions.	.65
29	Knowing whether or not I carry the gene for a genetic disease/disorder would improve my quality of life.	.49
30	Knowing whether or not I carry the gene for a genetic disease/disorder could save my life.	.70
33	I believe that genetic predictive testing would do more good than harm.	.52
35	I believe that genetic predictive testing could reduce my risk of having a genetic disease/disorder.	.45

Table 7 continued

Principle Components Analysis Item Loadings for the Attitudes Toward Genetic Predictive Testing Questionnaire (Based on Structure Matrix)

Component 3: Barriers

Item #	Item	Loading
4	I would not be willing to undergo a genetic predictive test to detect a genetic disease or disorder for which there is no current cure.	.47
15	I would not be willing to undergo a genetic predictive test if the test involved painful procedures.	.51
16	I would not be willing to undergo a genetic predictive test if the test involved admittance to the hospital for a period of time.	.53
22	Knowing that I carry the gene for a genetic disease/disorder would leave me in a state of hopelessness and despair.	.61
24	If I had a genetic disease/disorder, it would cause others to view me negatively.	.57
28	Knowing that I carry the gene for a genetic disease/disorder would lead to marital or family problems.	.47
31	I am fearful that genetic predictive test results could negatively affect my ability to maintain/obtain insurance coverage.	.51
34	I believe that genetic predictive testing would be emotionally upsetting to me.	.47
36	I am fearful that my genetic predictive test results could be released to others without my consent.	.58

Table 7 continued

Principle Components Analysis Item Loadings for the Attitudes Toward Genetic Predictive Testing Questionnaire (Based on Structure Matrix)

Component 4: Self Benefits Despite Barriers

Item #	Item	Loading
13	I would be willing to undergo a genetic predictive test if a predictive test was expensive.	.53
17	I would be willing to undergo a genetic predictive test if the test was time consuming.	.69
18	I would be willing to undergo a genetic predictive test if the test was unpleasant.	.68
20	I would be willing to undergo a genetic predictive test if the test resulted in negative side effects.	.65
21	Knowing whether or not I carry the gene for a genetic disease/disorder would increase my sense of personal control.	.42
23	Knowing whether or not I carry the gene for a genetic disease/disorder would improve how I feel about myself.	.53
27	Knowing whether or not I carry the gene for a genetic disease/disorder would help me make important life decisions.	.41
28	Knowing that I carry the gene for a genetic disease/disorder would lead to marital or family problems.	.45
29	Knowing whether or not I carry the gene for a genetic disease/disorder would improve my quality of life.	.59
35	I believe that genetic predictive testing could reduce my risk of having a genetic disease/disorder.	.44

Items that did not Load on 4 Components

Item #	Item
1	I believe that I am a healthy person.
11	I would not be willing to undergo a genetic predictive test if the test was less than 100% certain in detecting a gene responsible for a genetic disease/disorder.
19	I would not be willing to undergo a genetic predictive test if the test was potentially dangerous to my health.

Table 8

Structure Matrix of the Attitudes Toward Genetic Predictive Testing Questionnaire

Items	Factor Loadings			
	1	2	3	4
1. I believe that I am a healthy person. *	-.18	.15	-.08	.17
2. I believe that I am at risk for developing a genetic disease/disorder.	**.65**	-.05	.13	-.12
3. I would undergo a genetic predictive test if I was at risk for a genetic disease/disorder.	.05	**-.64**	-.29	-.17
4. I would not be willing to undergo a genetic predictive test to detect a genetic disease or disorder for which there is no current cure.	-.05	.35	**.47**	.15
5. I am concerned that I will develop a genetic disease/ disorder that will have a negative impact on my work.	**.88**	-.07	.06	-.22
6. I am concerned that I will develop a genetic disease/ disorder that will have a negative impact on my family life.	**.92**	-.17	.08	-.17
7. I am concerned that I will develop a genetic disease/ disorder that will have a negative impact on my social relationships with others.	**.85**	-.10	.09	-.21
8. I am concerned that I will develop a genetic disease/ disorder that will result in pain.	**.91**	-.26	.20	-.16
9. I am concerned that I will develop a genetic disease/ disorder that will result in disability.	**.89**	-.20	.21	-.18
10. I am concerned that I will develop a genetic disease/ disorder that will result in death.	**.88**	-.20	.17	-.15
11. I would not be willing to undergo a genetic predictive test if the test was less than 100% certain in detecting a gene responsible for a genetic disease/disorder.	.07	.31	.29	.04
12. I would be willing to undergo a genetic predictive test if the test was safe and simple.	.05	**-.73**	-.18	-.15
13. I would be willing to undergo a genetic predictive test if a predictive test was expensive. *	-.10	.18	.01	**.53**
14. I would be willing to undergo a genetic predictive test if the test was 100% certain in detecting a gene responsible for a genetic disease/disorder.	.08	**-.78**	-.10	-.19
15. I would not be willing to undergo a genetic predictive test if the test involved painful procedures.	-.05	.02	**.51**	.37

Table 8 continued

Structure Matrix of the Attitudes Toward Genetic Predictive Testing Questionnaire

Items	Factor Loadings			
	1	2	3	4
16. I would not be willing to undergo a genetic predictive test if the test involved admittance to the hospital for a period of time.	-.05	-.06	**.53**	.38
17. I would be willing to undergo a genetic predictive test if the test was time consuming. *	-.15	.19	-.04	**.69**
18. I would be willing to undergo a genetic predictive test if the test was unpleasant. *	-.18	.20	-.03	**.68**
19. I would not be willing to undergo a genetic predictive test if the test was potentially dangerous to my health.	.04	-.34	.34	.24
20. I would be willing to undergo a genetic predictive test if the test resulted in negative side effects.	-.25	.08	-.06	**.65**
21. Knowing whether or not I carry the gene for a genetic disease/disorder would increase my sense of personal control. *	.33	**-.60**	.21	**-.42**
22. Knowing that I carry the gene for a genetic disease/ disorder would leave me in a state of hopelessness and despair.	.22	-.15	**.61**	-.29
23. Knowing that I carry the gene for a genetic disease/ disorder would improve how I feel about myself.	.27	**-.42**	.27	**.53**
24. If I had a genetic disease/disorder, it would cause others to view me negatively.	.24	-.09	**.57**	-.27
25. Knowing whether or not I carry the gene for genetic disease/disorder would motivate me to practice preventive health measures (e.g., self-exams, regular physician check-ups).	.10	**-.74**	.13	-.11
26. Knowing that I carry the gene for a genetic disease/ disorder would cause me to worry more about other family members who could be carriers (e.g., mother, father, sister, brothers).	.16	**-.65**	.25	-.12
27. Knowing whether or not I carry the gene for a genetic disease/disorder would help me make important life decisions.	.29	**-.65**	.29	**-.41**
28. Knowing that I carry the gene for a genetic disease/ disorder would lead to marital or family problems.	.19	-.22	**.47**	**-.45**
29. Knowing whether or not I carry the gene for a genetic disease/disorder would improve my quality of life.	.26	**-.49**	.17	**-.59**

Table 8 continued

Structure Matrix of the Attitudes Toward Genetic Predictive Testing Questionnaire

Items	Factor Loadings			
	1	2	3	4
30. Knowing whether or not I carry the gene for a genetic disease/disorder could save my life.	.22	**-.70**	.16	-.30
31. I am fearful that genetic predictive test results could negatively affect my ability to maintain/obtain insurance coverage.	.34	-.31	**.51**	-.13
32. There is a history of genetic disease/disorders in my family.	**.57**	-.10	.32	-.16
33. I believe that genetic predictive testing would do more good than harm.	.24	**-.52**	.16	-.22
34. I believe that genetic predictive testing would be emotionally upsetting to me.	.17	-.11	**.47**	-.17
35. I believe that genetic predictive testing could reduce my risk of having a genetic disease/ disorder.	.17	**-.45**	.15	**-.44**
36. I am fearful that my genetic predictive test results could be released to others without my consent.	.25	.03	**.58**	.01
37. I believe that I have a genetic disease/disorder.	**.52**	.08	.13	-.27

Note: principal axis factoring, oblimin rotation, Kaiser normalization
Significant item loadings are in bold print.
* These items were reverse scored.

Table 9

Pattern Matrix for the Component Analysis

ATGPTQ	Components			
Items	1	2	3	4
1	-.131	.096	-.044	.112
2	.668	.051	.020	.036
3	.032	-.659	-.346	-.033
4	-.082	.360	.522	.072
5	.909	.063	-.119	-.039
6	.953	-.048	-.113	.079
7	.875	.029	-.090	.090
8	.914	-.138	.011	.110
9	.890	-.072	.024	.070
10	.892	-.075	-.012	.094
11	.057	.343	.309	-.070
12	-.021	-.748	-.238	-.024
13	.040	.073	.023	.518
14	-.020	-.790	-.161	-.027
15	-.062	-.036	.536	.389

Table 9 continued

Pattern Matrix for the Component Analysis

ATGPTQ	Components			
Items	1	2	3	4
16	-.074	-.119	.555	.410
17	.032	.040	-.011	.693
18	.069	.055	.032	.664
19	-.046	-.385	.323	.336
20	-.089	-.079	-.017	.645
21	.160	-.502	.122	-.259
22	.033	-.036	.590	-.244
23	.065	-.292	.211	-.440
24	.074	.016	.544	-.232
25	-.021	-.747	.073	.056
26	.023	-.642	.191	.034
27	.087	-.556	.214	-.257
28	-.019	-.090	.446	-.413
29	.057	-.358	.102	-.491
30	.068	-.648	.089	-.135
31	.209	-.241	.451	-.053
32	.524	-.026	.208	-.015

Table 9 continued

Pattern Matrix for the Component Analysis

ATGPTQ	Components			
Items	1	2	3	4
33	.120	-.479	.092	-.081
34	.035	-.034	.457	-.136
35	-.044	-.362	.100	-.355
36	.168	.088	.559	.059
37	.496	.207	.042	-.186

Note: principal axis factoring, oblimin rotation, Kaiser normalization

Component 1 = Severity and Susceptibility
Component 2 = Benefits
Component 3 = Barriers
Component 4 = Self-Benefits Despite Barriers

Table 10

Multiple Regression of Demographic Variables on ATGPTQ Component One, Severity and Susceptibility

Predictors	R	Rsq	F(eqn)	RsqCh	F(Ch)	r
Sex	.31	.093	23.98**	.093	23.98	-.31**
Income	.36	.129	17.33**	.036	9.79	.19**
Gene	.39	.150	13.67**	.021	5.65	-.18**

* $p<.05$

** $p<.01$

r = Pearson product moment correlation

Table 11

Multiple Regression of Demographic Variables on ATGPTQ Component Two, Benefits

Predictors	R	Rsq	F(eqn)	RsqCh	F(Ch)	r
Gene	.32	.104	27.24**	.104	27.24	-.32**
Nummed	.41	.165	23.20**	.062	17.27	-.32**
Sex	.44	.193	18.55**	.027	7.90	.19**

* $p<.05$

** $p<.01$

r = Pearson product moment correlation

Table 12

Multiple Regression of Demographic Variables on ATGPTQ Component Three, Barriers

Predictors	R	Rsq	F(eqn)	RsqCh	F(Ch)	r
Gene	.14	.018	.02*	-.018	4.37	.13*

* $p<.05$

** $p<.01$

r = Pearson product moment correlation

Table 13

Correlation Matrix of Demographic Variables and Component Scores (One-Tailed)

Variable	Age	Sex	Income	Educate	Gene	Nummed	Race	F1	F2	F3	F4
Age	1.000										
Sex	-.01	1.000									
Income	-.26**	.01	1.000								
Educate	.66**	.07	-.34**	1.000							
Gene	-.06	.02	-.17**	-.08	1.000						
Nummed	.21**	-.17**	-.22**	.29**	.22**	1.000					
Race	.10	.02	.09	.06	.05	-.08	1.000				
F1	-.07	-.31**	.19**	-.09	-.18**	-.08	-.04	1.000			
F2	.02	.19**	.07	.01	-.32**	-.32**	.09	-.13*	1.000		
F3	.02	-.12	.03	.05	.13*	.07	-.06	.14*	-.34**	1 .000	
F4	.06	.07	-.02	.09	-.11	.05	-.11	-.09	.02	.09	1.000

*p<.05, **P<.01

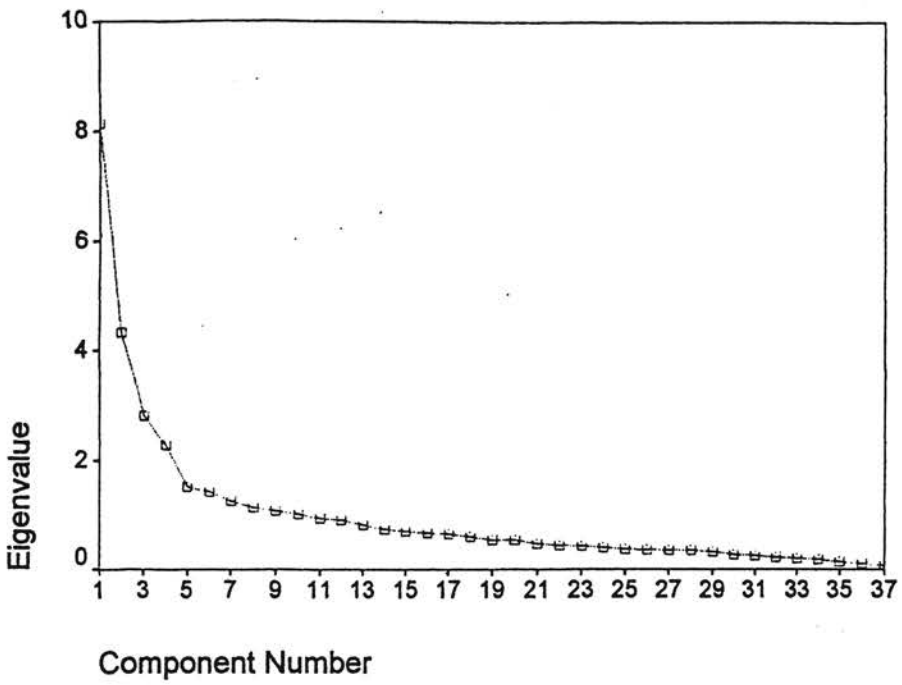
F1 = Susceptibility and Severity
F2 = Benefits
F3 = Barriers
F4 = Self Benefits Despite Barriers

APPENDIX B

FIGURES

Figure 1

Scree Plot



APPENDIX C

INFORMED CONSENT

INFORMED CONSENT

You are invited to participate in a research study exploring attitudes toward genetic predictive testing. Participation in this study involves completing a demographic sheet and one questionnaire.

Completing this questionnaire will take no longer than 20 minutes. Possible benefits of participating in this study include increased awareness of your attitudes toward genetic predictive testing. We hope the results of this study will provide important information on this topic. There are no foreseeable risks of participating in this study, and your participation is voluntary. You are free to withdraw your consent and participation at any time without penalty. **If you choose to participate, please complete the demographic sheet and questionnaire in this packet.** By signing this form, you are giving your informed consent to participate in this study.

To maintain the confidentiality of your participation, we will collect this sheet separately from the questionnaire. Please do not write your name on any of the questionnaires other than this consent form. **All of the information you provide is strictly confidential, and no individual participants will be identified. Your confidentiality will be strictly maintained.**

I understand that participation is voluntary, that there is no penalty for refusal to participate, and that I am free to withdraw my consent and participation from this study at any time.

I may contact either Stephanie Porterfield, M.S. or Carrie Winterowd, Ph.D. at Oklahoma State University, (405) 744-6040, or Sharon Bacher at the Institutional Review Board at (405) 744-5700 should I wish further information about this study. Thank you for your interest and participation in this project.

I have read and fully understand the consent form. I sign it freely and voluntarily.

Date: _____

Signed: _____

APPENDIX D

THE DEMOGRAPHIC QUESTIONNAIRE

Demographic Information

Directions: Please answer each question by filling in the blank or circling the letter that best describes you.

1) Age _____ 2) Gender: Female ❒ Male ❒

3) Marital Status: Single ❒ Married ❒ Divorced ❒ Widowed ❒ Other ❒

4) Occupation: _____

5) Race (check all that apply):

a) ❒ African American/Black
b) ❒ American Indian/Native American
c) ❒ Asian/Asian American
d) ❒ Caucasian
e) ❒ Hispanic/Latino(a)
f) ❒ Other (please explain): _____

6) In what type of community did you grow up?

a) ❒ Urban (city of more than 50,000)
b) ❒ Suburban (town or area next to a city of 50,000 or more
c) ❒ Rural (town of 50,000 or less not next to an urban area

7) Current annual family income (Check One):

a) ❒ less than $10,000/year
b) ❒ $10,001 – 15,000/year
c) ❒ $15,001 – 20,000/year
d) ❒ $20,001 – 25,000/year
e) ❒ $25,001 – 30,000/year
f) ❒ $30,001 – 40,000/year
g) ❒ $40,001 – 50,000/year
h) ❒ $50,001 – 60,000/year
i) ❒ $60,001 – 70,000/year
j) ❒ $70,001 – 80,000/year
k) ❒ $80,001 – 90,000/year
l)) ❒ $90,001 or more/year

8) Year in college (Check One):

a) ❒ Freshman
b) ❒ Sophomore
c) ❒ Junior
d) ❒ Senior
e) ❒ Graduate Student
f) ❒ Other _____

9) Education (# of years completed): _____ (e.g., 7 = completed 7th grade, 13 = completed one year of college training)

10) Do you have any children ❒ yes ❒ no If yes, how many children do you have? _____

11) Does any member of your family suffer from any of the following medical/psychiatric conditions? (check all that apply) Add any other significant conditions in your family that are not listed below.

❒ Breast Cancer ❒ Heart Disease ❒ Alzheimer's Disease
❒ Huntington's Disease ❒ Down's Syndrome ❒ Cystic Fibrosis
❒ Schizophrenia ❒ Other _____ ❒ Other _____

12) To your knowledge, do you suffer from or carry the gene for any genetic disorder? ❒ yes ❒ no
If yes, for what genetic disorder(s)? _____

13) Have you sought out genetic predictive testing to rule out inherited genes for genetic disorders?
❒ Yes If yes, for what purposes? _____
❒ No

14) What is your religious affiliation? _____

15) How strongly do you agree with the beliefs of your religion? (check one)

❒ Strongly agree ❒ Agree ❒ Agree somewhat
❒ Strongly disagree ❒ Disagree ❒ Disagree somewhat

16) How many times per month do you attend religious activities/services? _____ per month.

APPENDIX E

THE ATTITUDES TOWARD GENETIC PREDICTIVE TESTING QUESTIONNAIRE

Attitudes Toward Genetic Predictive Testing Questionnaire

Tests for detecting the presence of genes responsible for numerous disorders/diseases (predictive tests) are now in use. Examples of such disorders/diseases include, but are not limited to, Down's Syndrome, Huntington's Chorea, Alzheimer's Disease, Breast Cancer, Cystic Fibrosis, Schizophrenia and Tay-Sachs Disease. **We would like to know your attitudes toward such predictive tests in general.**

INSTRUCTIONS: For the following items, please circle the number that best describes your view. There are no right or wrong answers. Do not skip any items if you can avoid it.

1=Strongly Disagree, 2=Disagree, 3=Somewhat Disagree, 4=Unsure, 5=Somewhat Agree, 6=Agree, 7=Strongly Agree

1) I believe that I am a healthy person.	1 2 3 4 5 6 7
2) I believe that I am at risk for developing a genetic disease/disorder.	1 2 3 4 5 6 7
3) I would undergo a genetic predictive test if I was at risk for a genetic disease/disorder.	1 2 3 4 5 6 7
4) I would not be willing to undergo a genetic predictive test to detect a genetic disease or disorder for which there is no current cure.	1 2 3 4 5 6 7
5) I am concerned that I will develop a genetic disease/disorder that will have a negative impact on my work.	1 2 3 4 5 6 7
7) I am concerned that I will develop a genetic disease/disorder that will have a negative impact on my family life.	1 2 3 4 5 6 7
8) I am concerned that I will develop a genetic disease/disorder that will have a negative impact on my social relationships with others.	1 2 3 4 5 6 7
9) I am concerned that I will develop a genetic disease/disorder that will result in pain.	1 2 3 4 5 6 7
10) I am concerned that I will develop a genetic disease/disorder that will result in disability.	1 2 3 4 5 6 7
11) I am concerned that I will develop a genetic disease/disorder that will result in death.	1 2 3 4 5 6 7
12) I would not be willing to undergo a genetic predictive test if the test was less than 100% certain in detecting a gene responsible for a genetic disease/disorder.	1 2 3 4 5 6 7
13) I would be willing to undergo a genetic predictive test if the test was safe and simple.	1 2 3 4 5 6 7
14) I would be willing to undergo a genetic predictive test if a predictive test was expensive.	1 2 3 4 5 6 7
15) I would be willing to undergo a genetic predictive test if the test was 100% certain in detecting a gene responsible for a genetic disease/disorder.	1 2 3 4 5 6 7
16) I would not be willing to undergo a genetic predictive test if the test involved painful procedures.	1 2 3 4 5 6 7
17) I would not be willing to undergo a genetic predictive test if the test involved admittance to the hospital for a period of time.	1 2 3 4 5 6 7
18) I would be willing to undergo a genetic predictive test if the test was time consuming.	1 2 3 4 5 6 7

1=Strongly Disagree, 2=Disagree, 3=Somewhat Disagree, 4=Unsure, 5=Somewhat Agree, 6=Agree, 7=Strongly Agree

18) I would be willing to undergo a genetic predictive test if the test was unpleasant.	1 2 3 4 5 6 7
19) I would not be willing to undergo a genetic predictive test if the test was potentially dangerous to my health.	1 2 3 4 5 6 7
20) I would be willing to undergo a genetic predictive test if the test resulted in negative side effects.	1 2 3 4 5 6 7
21) Knowing whether or not I carry the gene for a genetic disease/disorder would increase my sense of personal control.	1 2 3 4 5 6 7
22) Knowing that I carry the gene for a genetic disease/disorder would leave me in a state of hopelessness and despair.	1 2 3 4 5 6 7
23) Knowing whether or not I carry the gene for a genetic disease/disorder would improve how I feel about myself.	1 2 3 4 5 6 7
24) If I had a genetic disease/disorder, it would cause others to view me negatively.	1 2 3 4 5 6 7
25) Knowing whether or not I carry the gene for a genetic disease/disorder would motivate me to practice preventive health measures (e.g., self-exams, regular physician check-ups).	1 2 3 4 5 6 7
26) Knowing that I carry the gene for a genetic disease/disorder would cause me to worry more about other family members who could be carriers (e.g., mother, father, sisters, brothers).	1 2 3 4 5 6 7
27) Knowing whether or not I carry the gene for a genetic disease/disorder would help me make important life decisions.	1 2 3 4 5 6 7
28) Knowing that I carry the gene for a genetic disease/disorder would lead to marital or family problems.	1 2 3 4 5 6 7
29) Knowing whether or not I carry the gene for a genetic disease/disorder would improve my quality of life.	1 2 3 4 5 6 7
30) Knowing whether or not I carry the gene for a genetic disease/disorder could save my life.	1 2 3 4 5 6 7
31) I am fearful that genetic predictive test results could negatively affect my ability to maintain/obtain insurance coverage.	1 2 3 4 5 6 7
32) There is a history of genetic diseases/disorders in my family.	1 2 3 4 5 6 7
33) I believe that genetic predictive testing would do more good than harm.	1 2 3 4 5 6 7
34) I believe that genetic predictive testing would be emotionally upsetting to me.	1 2 3 4 5 6 7
35) I believe that genetic predictive testing could reduce my risk of having a genetic disease/disorder.	1 2 3 4 5 6 7
36) I am fearful that my genetic predictive test results could be released to others without my consent.	1 2 3 4 5 6 7
37) I believe that I have a genetic disease/disorder.	1 2 3 4 5 6 7

APPENDIX F

RATER TRAINING AND CODING FORMS

CONCEPTUAL DEFINITIONS OF THE DIMENSIONS OF THE HEALTH BELIEF MODEL

Perceived Susceptibility (1)

This dimension refers to one's subjective perception of the risk of contracting an illness. Includes acceptance of the diagnosis, personal estimates of resusceptibility, and susceptibility to illness in general.

Perceived Severity (2)

This dimension refers to one's feelings concerning the seriousness of contracting an illness or of leaving it untreated. Perceived severity includes evaluations of both medical and clinical consequences (e.g., death, disability, and pain) and possible social consequences (such as the effects of the conditions on work, family life, and social relations).

Perceived Benefits (3)

This dimension concerns one's beliefs regarding the effectiveness of the various available actions in reducing the disease threat, termed the perceived benefits of taking health action. Examples include medical testing or procedures to prevent and/or detect medical diagnoses, which could reduce the severity of the occurrence of the diagnosis.

Perceived Barriers (4)

This dimension refers to one's beliefs regarding the potential negative aspects of a particular health action or those aspects which may act as impediments to undertaking the health behavior. Examples include expense, dangerousness, time-consuming, unpleasantness, inconvenience, etc.

SUMMARY OF THE HEALTH BELIEF MODEL

The Health Belief Model relates a socio-psychologic theory of decision making to individual health-related behaviors. According to the Health Belief Model, individuals' readiness to take action for a health condition (prevention and/or treatment of a known medical condition) depends upon their perception of four dimensions.

Perceived susceptibility: Refers to an individual's subjective perception of the risk of contracting an illness. Includes acceptance of the diagnosis, susceptibility to illness in general as well as personal estimates of resusceptibility (chances of getting a medical condition again).

Perceived severity: Refers to an individual's feelings concerning the seriousness of contracting an illness or of leaving the illness untreated. This dimension includes evaluations of medical and clinical consequences (e.g., death, disability and pain) as well as possible social consequences (e.g., effects of the illness on work, family life and social relations).

Perceived benefits: Refers to an individual's beliefs regarding the effectiveness of a particular health action(s) available in reducing the disease threat. That is, the individual decides whether the prescribed medical treatment or procedure will reduce the severity of occurrence or recurrence of the illness.

Perceived barriers: Refers to an individual's perception of the potential negative aspects of a particular health action which may act as impediments to undertaking the recommended health behavior. Individuals are thought to use a kind of cost-benefit analysis in which the individual weighs the effectiveness of an action against the costs of such an action including that it may be expensive, dangerous (e.g., side effects, harm to unborn children), unpleasant (e.g., painful, difficult, upsetting), inconvenient, time-consuming, etc. Thus, the cost part of the cost-benefit analysis is related to perceived barriers.

The first two dimensions (susceptibility and severity) refer to the diagnosis or disease. The third and fourth dimensions (benefits and barriers) refer to the health action. Health actions include medical examinations, medical testing, preventive measures (e.g., stop drinking, self-breast examinations), etc.

The model proposes that "the combined levels of susceptibility and severity provide the energy or force to act and the perception of benefits (less barriers) provides a preferred path of action". The model has proven useful in estimating the probability that an individual will engage in preventive health care activities.

References:

French, B., Kurczynski, T., Weaver, M., & Pituch, M. (1992). Evaluation of the Health Belief Model and decision making regarding amniocentesis in women of advanced maternal age. Health Education Quarterly, 19 (2), 177-186.

Harrison, J., Mullen, P., & Green, L. (1992). A meta-analysis of studies of the Health Belief Model with adults. Health Education Quarterly, 7 (1), 107-116.

Sheeran, P., & Abraham, C. (1993). The Health Belief Model. In: M. Conner & P. Norman (Eds.) Predicting Health Behavior: Research and practice with social cognition models (pp. 23-61). New York: Plenum Press.

Sample Items for Raters

INSTRUCTIONS: For each item, please circle the number that best describes the Health Belief Model dimension it represents

1 = Perceived Susceptibility
2 = Perceived Severity
3 = Perceived Benefits
4 = Perceived Barriers

I am concerned that I will develop lung cancer.	1 2 3 4
Lung cancer would be painful.	1 2 3 4
A chest x-ray would be expensive.	1 2 3 4
I would stop smoking if that action could prevent lung cancer.	1 2 3 4
My fears about developing lung cancer would be reduced if I would undergo a chest x-ray	1 2 3 4
I feel generally healthy	1 2 3 4
Having a chest x-ray would require too much time.	1 2 3 4
If I develop lung cancer, I fear I would die.	1 2 3 4
Knowing that I do not have lung cancer would improve how I feel about life.	1 2 3 4
I do not have a family history of lung cancer.	1 2 3 4
If I develop lung cancer, I may be unable to work.	1 2 3 4
A chest x-ray would be unpleasant.	1 2 3 4
Lung cancer would have a negative impact on my family life.	1 2 3 4
The radiation of undergoing a chest x-ray could be dangerous to my health.	1 2 3 4
I believe that individuals with lung cancer cough frequently and I do not have a frequent cough.	1 2 3 4
Knowing that I have not developed lung cancer might motivate me to take preventative measures such as to stop smoking.	1 2 3 4

Sample Items for Raters – Form Two

INSTRUCTIONS: For each time, please circle the number that best describes the Health Belief Model dimension it represents.

1 = Perceived Susceptibility
2 = Perceived Severity
3 = Perceived Benefits
4 = Perceived Barriers

Knowing that I do not have breast cancer might motivate me to take preventative measures such as performing monthly self-breast exams.	1 2 3 4
I believe that individuals with breast cancer have disfiguration and I am not disfigured, so I do not have breast cancer.	1 2 3 4
The radiation of undergoing a mammogram could be dangerous to my health.	1 2 3 4
Breast cancer would have a negative impact on my social life.	1 2 3 4
A mammogram would be unpleasant.	1 2 3 4
If I develop breast cancer, I may be unable to fulfill my school obligations.	1 2 3 4
I do not have a family history of breast cancer, therefore I will not develop breast cancer.	1 2 3 4
Knowing that I do not have breast cancer would improve how I feel about life.	1 2 3 4
If I develop breast cancer, I will die from the disease.	1 2 3 4
Having yearly mammograms would require too much time.	1 2 3 4
I have already undergone chemotherapy for breast cancer, therefore it is impossible for me to develop breast cancer again.	1 2 3 4
My fears about developing breast cancer would be reduced if I would undergo a mammogram.	1 2 3 4
I would eat healthy and exercise if I believed that would prevent breast cancer.	1 2 3 4
A mammogram would be painful.	1 2 3 4
I fear that if I develop breast cancer, it would be unbearable.	1 2 3 4
I am concerned that I will develop breast cancer.	1 2 3 4

Item List for Raters to Code

INSTRUCTIONS: For each item, please circle the number that best describes the Health Belief Model dimension it represents.

1 = Perceived Susceptibility
2 = Perceived Severity
3 = Perceived Benefits
4 = Perceived Barriers

I believe that I am at risk for developing a genetic disease/disorder.	1 2 3 4
I would undergo a genetic predictive test if I was at risk for a genetic disease/disorder.	1 2 3 4
I would be willing to undergo a genetic predictive test if the test was time consuming.	1 2 3 4
I would not be willing to undergo a genetic predictive test to detect a genetic disease or disorder for which there is no current cure.	1 2 3 4
I am concerned that I will develop a genetic disease/disorder that will have a negative impact on my social relationships with others.	1 2 3 4
I am concerned that I will develop a genetic disease/disorder that will result in pain.	1 2 3 4
I believe that genetic predictive testing would do more good than harm.	1 2 3 4
I am concerned that I will develop a genetic disease/disorder that will result in death.	1 2 3 4
My concerns about developing a certain genetic disorder would be reduced if I knew I did not carry the gene for that disorder.	1 2 3 4
I would not be willing to undergo a genetic predictive test if the test was less than 100% certain in detecting a gene responsible for a genetic disease/disorder.	1 2 3 4
I would be willing to undergo a genetic predictive test if the test was safe and simple.	1 2 3 4
I am concerned that I will develop a genetic disease/disorder that will have a negative impact on my work.	1 2 3 4
I would be willing to undergo a genetic predictive test if the test was expensive.	1 2 3 4
I would be willing to undergo a genetic predictive test if the test was 100% certain in detecting a gene responsible for a genetic disease/disorder.	1 2 3 4

Item List for Raters to Code continued

I would not be willing to undergo a genetic predictive test if the test involved painful procedures.	1 2 3 4
I believe that I am a healthy person.	1 2 3 4
I am concerned that I will develop a genetic disease/disorder that will result in disability.	1 2 3 4
I would not be willing to undergo a genetic predictive test if the test involved admittance to the hospital for a period of time.	1 2 3 4
I would be willing to undergo a genetic predictive test if the test was unpleasant.	1 2 3 4
I am concerned that I will develop a genetic disease/disorder that will have a negative impact on my family life.	1 2 3 4
I would not be willing to undergo a genetic predictive test if the test was potentially dangerous to my health.	1 2 3 4
I would be willing to undergo a genetic predictive test if the test resulted in negative side effects.	1 2 3 4
I feel that I already know my chances of having a genetically transmitted disease or disorder, so I wouldn't learn anything more by being tested.	1 2 3 4
Knowing whether or not I carry the gene for a genetic disease/disorder would increase my sense of personal control.	1 2 3 4
Knowing that I carry the gene for a genetic disease/disorder would leave me in a state of hopelessness and despair.	1 2 3 4
Knowing whether or not I carry the gene for a genetic disease/disorder would improve how I feel about myself.	1 2 3 4
If I had a genetic disease/disorder, it would cause others to view me negatively.	1 2 3 4
Knowing whether or not I carry the gene for a genetic disease/disorder would motivate me to practice preventive health measures (e.g., self-exams, regular physician check-ups).	1 2 3 4
Knowing that I carry the gene for a genetic disease/disorder would cause me to worry more about other family members who could be carriers (e.g., mother, father, sisters, brothers).	1 2 3 4
Knowing whether or not I carry the gene for a genetic disease/disorder would help me make important life decisions.	1 2 3 4
Knowing that I carry the gene for a genetic disease/disorder would lead to marital or family problems.	1 2 3 4
Knowing whether or not I carry the gene for a genetic disease/disorder would improve my quality of life.	1 2 3 4

Item List for Raters to Code continued

Knowing whether or not I carry the gene for a genetic disease/disorder could save my life.	1 2 3 4
I believe that genetic predictive testing could reduce my risk of having a genetic disease/disorder.	1 2 3 4
There is a history of genetic diseases/disorders in my family.	1 2 3 4
I am fearful that genetic predictive test results could negatively effect my ability to maintain/obtain insurance coverage.	1 2 3 4
I believe that I have a genetic disease/disorder.	1 2 3 4
I believe that genetic predictive testing would be emotionally upsetting to me.	1 2 3 4
I am fearful that my genetic predictive test results could be released to others without my consent.	1 2 3 4

APPENDIX G

IRB APPROVAL

Oklahoma State University
Institutional Review Board

Protocol Expires: 5/5/01

Date : Friday, May 05, 2000 IRB Application No: ED00261

Proposal Title: THE DEVELOPMENT AND VALIDATION OF THE ATTITUDES TOWARD GENETIC PREDICTIVE TESTING QUESIONNAIRE

Principal Investigator(s) :

Stephanie Porterfield
2126 W. Arrowheard Dr.
Stillwater, OK 74074

Carrie Winterowd
434 Willard
Stillwater, OK 74078

Reviewed and Processed as: Exempt

Approval Status Recommended by Reviewer(s) : Approved

Signature : Carol Olson

Carol Olson, Director of University Research Compliance

Friday, May 05, 2000
Date

Approvals are valid for one calendar year, after which time a request for continuation must be submitted. Any modifications to the research project approved by the IRB must be submitted for approval with the advisor's signature. The IRB office MUST be notified in writing when a project is complete. Approved projects are subject to monitoring by the IRB. Expedited and exempt projects may be reviewed by the full Institutional Review Board.

Oklahoma State University
Institutional Review Board

Protocol Expires: 4/8/02

Date : Monday, April 09, 2001 IRB Application No ED00261

Proposal Title: THE DEVELOPMENT AND VALIDATION OF THE ATTITUDES TOWARD GENETIC PREDICTIVE TESTING QUESIONNAIRE

Principal Investigator(s) :

Stephanie Porterfield
2126 W. Arrowhead Dr.
Stillwater, OK 74074

Carrie Winterowd
434 Willard
Stillwater, OK 74078

Reviewed and Exempt **Continuation**

Approval Status Recommended by Reviewer(s) : Approved

Signature : Carol Olson

Carol Olson, Director of University Research Complian

Monday, April 09, 2001
Date

Approvals are valid for one calendar year, after which time a request for continuation must be submitted. Any modifications to the research project approved by the IRB must be submitted for approval with the advisor's signature. The IRB office MUST be notified in writing when a project is complete. Approved projects are subject to monitoring by the IRB. Expedited and exempt projects may be reviewed by the full Institutional Review Board.

VITA

Stephanie L. Porterfield

Candidate for the Degree of

Doctor of Philosophy

Thesis: THE DEVELOPMENT AND VALIDATION OF THE ATTITUDES TOWARD GENETIC PREDICTIVE TESTING QUESTIONNAIRE

Major Field: Educational Psychology

Specialization: Counseling Psychology

Biographical:

Personal Data: Born in Tulsa, Oklahoma on September 28, 1969 daughter of John Lingenfelter and LaTrenda Deem.

Education: Graduated from Claremore High School, Claremore, Oklahoma in 1987. Graduated from the University of Tulsa in 1995 with a Bachelor of Arts in Psychology. Graduated from the University of Kansas in 1998 with a Master of Science in Counseling Psychology. Completed the requirements for the degree of Doctor of Philosophy at Oklahoma State University in December 2001.

Experience: Completed a 2000 hour Pre-doctoral Internship at the Oklahoma Health Consortium. Rotations included the University of Oklahoma Counseling and Testing Center, Norman Child Guidance Clinic and Bethesda Alternative, Inc.

Professional Membership: American Psychological Association Student Affiliate